***Dancing with Agency*: How rehabilitation nurses seek to promote and preserve personhood following traumatic brain injury**

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A thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy

Faculty of Medicine and Health

The University of Sydney

2026

Statement of Originality

This is to certify that to the best of my knowledge, the content of this thesis is my own work. This thesis has not been submitted for any degree or other purposes.

I certify that the intellectual content of this thesis is the product of my own work and that all the assistance received in preparing this thesis and sources have been acknowledged. I have not used artificial intelligence in the creation of this thesis.

Stephen Joshua Kivunja

Date: December 31, 2025

Acknowledgements

First of all, I would like to offer my deepest appreciation to my three supervisors, Associate Professor Janice Gullick, Clinical Associate Professor Julie Pryor, and Associate Professor Jo River, for their unwavering commitment that has guided me through my doctoral studies that have culminated in the compilation of this thesis. I appreciate the diverse expertise, insights, professional critique, and feedback that each one of you brought to my research study. This doctoral journey has been a marathon, and I appreciate that you came along and stuck with me despite the ups, downs, and challenges that I experienced along the way. I shall forever remember the meetings and discussions that we had which always elevated my work. I am grateful for your words of wisdom that guided me from a novice to a competent researcher.

I would also like to thank Associate Professor Sandra West and Associate Professor Tom Buckley for warmly welcoming me when I first approached the School for the opportunity to pursue doctoral studies and making arrangements to find the appropriate principal supervisor for me. In Associate Professor Janice Gullick, I have had the best principal supervisor for my research work. Janice, thanks for your excellent support, I am very proud to be a student of yours. Thanks to my fellow student colleagues with whom I often had discussions during this doctoral journey in higher degree by research workshops and online writing sessions.

I would like to acknowledge The Westmead Charitable Trust (Western Sydney Local Health District) for offering me the research grant that financially supported the conduct of my doctoral study. Stephen Schibeci, thank you for coordinating my

correspondence with The Trust. I would like to thank Kylee Macaulay and Professor Rochelle Wynee for recommending my application for PhD research funding within the Local Health District. My appreciation also goes out to my clinical managers, Sharon Rogers and Danijela Klanac who facilitated my study leave that enabled me to focus on my research as I balanced the challenges of clinical work and studies. My gratitude also go out to Duncan McKechnie, Jhoven De Jesus, Shilpa Bassi and Emilija Puric for the contribution towards facilitating my field access. To all the patients, families and nurses that participated in the study, thanks for sharing your insights, that have contributed to the development of this theoretical work.

My thanks also go out to my family members who have seen me manoeuvre through this research journey. To my dad, Dr Charles Kivunja, thank you for the frequent discussions we had about doctoral research that elevated my motivation to push on. To my mum Elizabeth Kivunja, brothers Charles Kivunja and Richard Kivunja, sisters Diana Kivunja and Eva Garnaut, nephews and nieces, and Georgia Kivunja thank you for the patience and well wishes that allowed me to concentrate on my studies. To my dear sisters, Rosemary Kivunja and Caroline Kivunja Stevenson, grandma-Jajja Zeulesi Wotali and grandma-Jajja Roza: you are not here with us to celebrate this milestone with me, but our thoughts and memories as the entire family are with you. Accomplishing a project of this magnitude can only be possible with input from many supports, and I am thankful to members of my extended family and friends. I wish to acknowledge Dr David Harris for undertaking the professional editing services associated with this thesis. The research reported in this thesis was supported by the award of a Research Training Program scholarship to the PhD Candidate.

Authorship Attribution Statements

Chapter Two of this thesis has been published as

(1) Kivunja, S., River, J., & Gullick, J. (2018). Experiences of giving and receiving care in traumatic brain injury: An integrative review. *Journal of Clinical Nursing, 27*(7–8), 1304 -1328. https://doi.org/10.1111/jocn.14283

(2) Kivunja, S., Pryor, J., River, J., & Gullick, J. (2024). Conceptualising personhood in nursing care for people with altered consciousness, cognition and behaviours: A discussion paper. *Nursing Philosophy, 25*(3), e12490-n/a. https://doi.org/10.1111/nup.12490

Chapter Three of this thesis has been published as:

(3) Kivunja, S., Pryor, J., River, J., & Gullick, J. (2022). Navigating the role of clinician-researcher: Insights from a constructivist grounded theory study in traumatic brain injury. *The Australasian Journal of Neuroscience, 32*(2), 6–17. https://doi.org/10.21307/ajon-2021-008

I designed the study, analysed the data and wrote the drafts of the manuscript.

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Lead Supervisor name: Associate Professor Janice Gullick

Signature: Date: 13.12.2025

Generative AI Attribution Statement

No content produced by generative AI tools has been used in the preparation of this thesis.

Australian Government Support Statement

This research was supported by an Australian Government Research Training Program (RTP) Scholarship.

Conference and Symposium Presentations

Kivunja, S., Pryor, J., River, J., & Gullick, J. (2024, April 16). *Insights from a nurse-led project in traumatic brain injury care: A doctoral nurse-clinician researcher's journey* [Symposium presentation]. WSLHD Nursing & Midwifery Research Information Symposium, Westmead Hospital, New South Wales, Australia

Kivunja, S., Pryor, J., River, J., & Gullick, J. (2023, November 9-10). *Examining agency: Reporting on analytical insights from a Constructivist Grounded Theory study of social processes that promote personhood in traumatic brain injury care* [Conference presentation]. Australasian Neuroscience Nurses' Association Annual Conference, Perth, Australia

Kivunja, S., Gullick, J., Pryor, J., River, J. (2023, September 27-29). *Exploring 'Personhood' as the basis for understanding social processes in traumatic brain injury care* [Conference presentation]. The 26th International Nursing Philosophy Conference in association with IPONS: Re-imagining a nursing ecosystem in an uncertain world, Sydney, New South Wales, Australia. https://doi.org/10.1111/nup.12495

Kivunja, S., Pryor, J., River, J., & Gullick, J. (2023, September 06). *A doctoral researcher's journey: Insights from a nurse-led project in traumatic brain injury care* [Symposium presentation]. WSLHD Nursing and Midwifery HDR Symposium 2023, Westmead Hospital, New South Wales, Australia

Kivunja, S., Pryor, J., River, J., & Gullick, J. (2022, November 10-11). *Social processes that promote and preserve personhood in traumatic brain injury nursing care: Exploring lines of inquiry* [Conference presentation].

Australasian Neuroscience Nurses' Association Annual Conference 2022, Melbourne, Australia

Kivunja, S., Pryor, J., River, J., & Gullick, J. (2022, July 20). *Social processes that promote and preserve personhood in traumatic brain injury nursing care* [Conference presentation]. Faculty of Medicine and Health, Higher Degree Research Conference 2022, The University of Sydney, Sydney, Australia

Kivunja, S., Pryor, J., River, J., & Gullick, J. (2021, November 11-12). *Navigating the role of a clinician and a researcher: Insights from a Constructivist Grounded Theory study in Traumatic Brain Injury* [Conference presentation]. Australasian Neuroscience Nurses' Association Annual Virtual Conference 2021, Melbourne, Australia

Kivunja, S., Pryor, J., River, J., & Gullick, J. (2021, June 9-11). *Ethical research design for vulnerable populations-Social processes that promote and preserve personhood in traumatic brain injury nursing care* [Symposium presentation]. International Collaboration of Nurse Scholars (ICoNS), International PhD Summer School, Virtual Workshop, The University of Sydney, Sydney, Australia

Kivunja, S., Pryor, J., River, J., & Gullick, J. (2019, October 17-18). *Constructing the meaning of personhood for people with traumatic brain injury* [Conference presentation]. Australasian Neuroscience Nurses' Association Annual Conference, Wellington, New Zealand

Kivunja, S., River, J., & Gullick, J. (2019, May 1-3). Navigating participant access and field observations in a Grounded Theory Study [Conference

presentation]. International Institute for Qualitative Methods (IIQM) Conference, Brisbane, Australia

Kivunja, S., River, J., & Gullick, J. (2018, April 30 - May 03). *Constructivist Grounded Theory: It's appropriateness to understanding care in traumatic brain injury*. [Conference presentation]. International Institute for Qualitative Methods (IIQM) Conference, Banff, Alberta, Canada

Kivunja, S., River, J., & Gullick, J. (2018, August 29-31). *Experiences of giving and receiving care in Traumatic brain injury* [Symposium presentation]. Westmead Hospital Research Week, New South Wales, Australia

Kivunja, S., & Gullick, J. (2017, June 2-7). *Understanding of ethical issues, theoretical and methodological framework, and international research positioning as a PhD researcher* [Symposium presentation]. International Collaboration of Nurse Scholars PhD Summer School, University of Lleida, Catalonia, Spain

The Scholarships, grants and awards associated with this thesis

This thesis was supported by the following funding sources:

- The Australian Government Research Training Stipend (RTP) Scholarship
- The University of Sydney Postgraduate Research Support Scheme (PRSS)
- The Westmead Charitable Trust (Western Sydney Local Health District) PhD Research Grant.

Abstract

Traumatic Brain Injury (TBI) can alter consciousness, cognition and behaviours, threatening traditional understandings, recognition and expression of personhood during rehabilitation nursing care. This thesis presents a substantive theoretical understanding of the social processes that rehabilitation nurses engage in to promote and preserve personhood during inpatient TBI rehabilitation. Using purposive and theoretical sampling, 16 patients, 12 family members, and 39 nurses from three Australian TBI rehabilitation units were engaged in semi structured interviews, supported by field observations. Analysis followed Constructivist Grounded Theory methods, guided by symbolic interactionism and social constructionism.

Findings indicated that nurses' main concern when aiming to promote and preserve personhood is their need to engage with multiple and demanding decision-makers encountered in their everyday practice. The subsequent Basic Social Process of Dancing with Agency explains how nurses select strategies and interact with the agency of others in delivering their care. The theory of Dancing with Agency has three components. First, as nurses are protecting the body of the person, physiological integrity takes priority over promoting a patient's personal agency, while a nurse's autonomy is constrained by policies, procedures, and organisational guidelines. Second, nurses actively engage the person who is the patient to understand their personhood, promote their agency, and to find in-the-moment opportunities to encourage participation in self-care activities. Third, in pursuit of some sense of normality, nurses hand over the baton, gradually ceding their own

agency and expertise to support the person, family, and carers to take-back control and decision-making. Contextual factors that influence this Dance include rigid, and at times ineffective, team practices, the locked rehabilitation environment and use of restraints, and the values, beliefs and experience of the individual nurse. Rehabilitation nurses' nuanced Dance with the Agency of multiple and demanding decision-making players has implications for the personhood of their patients and the enactment of their own clinical judgement in supporting rehabilitation goals.

Table of Contents

1 CHAPTER ONE: Introduction 11
1.1 Chapter Introduction 11
1.2 Background to the study 12
1.2.1 Traumatic Brain Injury 12
1.2.2 An overview of systems of care for TBI in Australia 14
1.2.3 Support schemes for people with TBI 17
1.2.4 Rehabilitation 19
1.2.5 Rehabilitation nursing 20
1.2.5.1 Rehabilitation nurse competencies 21
1.2.6 Brief overview of challenges faced by patients with TBI, families and nurses 23
1.2.7 Elements of personhood and person-centred nursing care 24
1.3 Aim of the study and research question 25
1.4 Significance of the study 25
1.5 Structure of this thesis 26
1.6 Chapter summary 28
2 CHAPTER TWO: Literature Review 29
2.1 Chapter introduction 29
2.2 Use of literature in this study 29
2.3 Experiences of giving and receiving care in traumatic brain injury: an integrative review 33
2.4 Conceptualising personhood in nursing care for people with altered consciousness, cognition and behaviours: a discussion paper 60
2.5 Chapter summary 68
3 CHAPTER THREE: Methodology and Methods 70
3.1 Introduction 70
3.2 Research methodology 70
3.2.1 The research focus 70
3.2.2 The research paradigm – Social Constructionism 71
3.2.3 Symbolic interactionism 72
3.2.4 Historical development of Grounded Theory 74
3.2.5 Constructivist Grounded Theory 76
3.3 Research methods 77
3.3.1 The research setting 78
3.3.2 The research team 78

3.3.3 The impacts of the COVID-19 pandemic on the study ... 78
3.3.4 Ethics approval ... 80
3.3.5 Reflexivity ... 81
3.3.6 Ethical design ... 82
3.3.6.1 Addressing ethics standards and my role as a clinician -researcher ... 82
3.3.6.2 Reflection on this publication ... 96
3.3.7 Recruitment and sampling ... 96
3.3.7.1 Inclusion and exclusion criteria ... 97
3.3.7.2 Recruitment of people with TBI ... 99
3.3.7.3 Recruitment of family members ... 100
3.3.7.4 Recruitment of nurses ... 101
3.3.7.5 Number of participants ... 102
3.3.7.6 Sample description and characteristics ... 105
3.4 Data collection ... 107
3.4.1 Data collection methods ... 107
3.4.2 Participant interviews ... 108
3.4.3 Field observations ... 111
3.4.4 Documents as a form of data ... 112
3.4.5 Data management ... 112
3.5 Data analysis ... 114
3.5.1 Data coding approach ... 116
3.5.1.1 Initial coding ... 116
3.5.1.2 Focused coding ... 118
3.5.1.3 Axial coding ... 120
3.5.1.4 Theoretical coding ... 120
3.5.1.5 Constant comparative methods ... 121
3.5.1.6 Applying symbolic interactionism ... 122
3.5.1.7 Theoretical sampling ... 122
3.5.1.8 Theoretical saturation ... 123
3.6 Memo writing and diagramming ... 124
3.7 The storyline ... 128
3.8 Identification of the main concern ... 128
3.9 Criteria for evaluating this Grounded Theory study ... 129
3.9.1 Credibility, Originality, Resonance, Usefulness ... 129
3.9.2 Enhancing rigour using the COREQ Framework ... 133

3.10 Chapter summary 133
4 CHAPTER FOUR: Findings 134
4.1 Introduction 134
4.2 The main concern: Multiple and demanding decision-makers 137
4.3 The basic social process: *Nurses Dancing with Agency in TBI rehabilitation care* 141
4.4 Defining *The Dance* 142
4.4.1 Properties of *The Dance* 143
4.4.2 Purpose of *The Dance* 143
4.4.2.1 Regaining functional capacity 144
4.4.2.2 Promoting the person's independence and quality of life 144
4.4.2.3 Getting the person home 146
4.5 Three components of *The Dance* 149
4.5.1 Component 1: Protecting the body of the person 149
4.5.1.1 Introduction: Definition of component 149
4.5.1.2 Nurse activities protecting the body of the person 150
4.5.1.3 Accepting clock-driven practice routines 154
4.5.1.4 Collaborating with allied health to protect the body of the person 160
4.5.1.5 Collaborating with the patient and family to protect the body of the person 162
4.5.2 Component 2: Engaging the patient as a person 176
4.5.2.1 Introduction: Definition of component 176
4.5.2.2 Understanding the capacity of the patient 177
4.5.2.3 Understanding the personhood of the patient through the family 179
4.5.2.4 Understanding the personhood of the patient through personal items 180
4.5.2.5 Prioritising intentional communication with the patient 186
4.5.2.6 Knowing the person and personalising care 191
4.5.3 Component 3: Handing over the baton 197
4.5.3.1 Introduction: Definition of component 197
4.5.3.2 The actions of individual nurses 198
4.5.3.2.1 Taking in-the-moment opportunities to promote self-care 198
4.5.3.2.2 Acknowledging and addressing discharge anxiety 201
4.5.3.3 Structured organisational practices 203
4.5.3.3.1 Engaging substitute decision-makers 204
4.5.3.3.2 Enabling care transitions through structured organisational practices 206
4.5.3.3.3 Structured training programs for patients, family and professional carers 209
4.5.3.3.4 Discharge planning structures 213

4.5.3.4 Celebrating handing over the baton 215
4.5.4 Contextual factors that influence *Dancing with Agency* 216
4.5.4.1 Introduction: Definition of contextual factors 216
4.5.4.2 Rigid and ineffective team practices 216
4.5.4.2.1 Rigidity of the decision-making actors 216
4.5.4.2.2 Ineffective communication and teamwork 223
4.5.4.3 Restrictive environment and practice 227
4.5.4.4 Nurses' values, beliefs and experience 238
4.5.4.5 Nurse staffing profile and skill mix 240
4.5.4.6 Nurses feeling mentally and physically drained 241
4.6 Chapter summary 243
5 CHAPTER FIVE: Discussion 244
5.1 Introduction 244
5.2 Discussion of key findings 245
5.2.1 Multiple and demanding decision-making actors as the main concern 245
5.2.2 Ineffective team practices influence protecting the body of the person and handing over the baton 247
5.2.3 Protecting the body of the person and personhood 251
5.2.3.1 The impact of schedules and routines on personhood 252
5.2.3.2 Collaborating with patients and families in body protection 255
5.2.3.3 Restrictive practices, protecting the body of the person and personhood 259
5.2.4 Engaging the patient as a person and personhood 263
5.2.4.1 Understanding the capacity of the person 264
5.2.4.2 Understanding the personhood of the patient 265
5.2.4.3 Prioritising intentional communication 266
5.2.4.4 Knowing the person and personalising care 267
5.2.5 Handing over the baton 269
5.2.5.1 Taking-in-the moment opportunities to promote self-care 269
5.2.5.2 Acknowledging and addressing discharge anxiety 271
5.2.5.3 Considerations for personhood when preparing for discharge 272
5.3 Strengths of the study 273
5.3.1 A strong application of symbolic interactionism 273
5.3.2 Multicentre study with multiple data sources 276
5.4 Limitations of the study 277
5.5 Recommendations to promote personhood through nursing practice, education, policy, and research 278

5.5.1 Recommendation 1: Promote interdisciplinary team practices 278
5.5.2 Recommendation 2: Facilitate early family engagement in rehabilitation 279
5.5.3 Recommendation 3: Support least restrictive practice 280
5.5.4 Recommendation 4: Research recommendations.. 282
5.6 Conclusion 283
6 References 286
7 APPENDICES 328
7.1 Appendix 1: ETHICS DOCUMENTS.. 328
7.1.1 Appendix 1.1A: Initial HREC Approval 328
7.1.2 Appendix 1.1B : Revised HREC Approval.. 331
7.1.3 Appendix 1.1C: Addition of new sites & removal of two sites.................................. 334
7.1.4 Appendix 1.1D: Change of site Principal Investigator 336
7.1.5 Appendix 1.1E: Extension of HREC Approval 337
7.2 Appendix 2: SITE APPROVAL LETTERS 339
7.2.1 Appendix 2.1: Research Site 1 -SSA authorisation letter 339
7.2.2 Appendix 2.2: Research Site 2 -SSA authorisation letter 342
7.2.3 Appendix 2.3: Research Site 3 -SSA authorisation letter 344
7.3 Appendix 3: DOCUMENTS COMMON ACROSS ALL THREE SITES 346
7.3.1 Appendix 3.1: Guide to determine capacity for consent & participation.................. 346
7.3.2 Appendix 3.2: Master Patient Consent Form.. 347
7.3.3 Appendix 3.3: Master Family Consent Form... 348
7.3.4 Appendix 3.4: Master Nurse Consent Form.. 349
7.3.5 Appendix 3.5: Master Data collection form -patients 350
7.3.6 Appendix 3.6: Master Data collection form Nurses.. 351
7.3.7 Appendix 3.7: Master Family flyer 352
7.3.8 Appendix 3.8: Master Nurses flyer 353
7.3.9 Appendix 3.9: Participant Distress Protocol 354
7.3.10 Appendix 3.10: Framework for Field Observations 355
7.3.11 Appendix 3.11a: Introduction letter -Patients... 357
7.3.12 Appendix 3.11b: Introduction letter -Family 358
7.3.13 Appendix 3.11c: Introduction letter – Nurses.. 359
7.3.14 Appendix 3.12a: Participant Information Statement -Patients 360
7.3.15 Appendix 3.12b: Participant Information Statement -Family................................... 364
7.3.16 Appendix 3.12c: Participant Information Statement -Nurses................................... 368
7.4 Appendix 4: INTERVIEW GUIDES USED IN PHASE ONE 372

7.4.1 Appendix 4.1: Phase 1- Interview guide -patients 372
7.4.2 Appendix 4.2: Phase 1- Interview guide - family members 374
7.4.3 Appendix 4.3: Phase 1- Interview guide -nurses..... 376
7.5 Appendix 5: INTERVIEW GUIDES USED IN PHASE TWO 379
7.5.1 Appendix 5.1: Phase 2-Interview guide -patients, family members and nurses 379
7.6 Appendix 6: Research Data Management Plan 386
7.7 Appendix 7: Example of Navigation pane snippet 395
7.8 Appendix 8: Post-it-notes 396
7.9 Appendix 9: Examples of memos 397
7.10 Appendix 10: Storyline - early draft 401
7.11 Appendix 11: Presentations at conferences, symposiums and workshops 422
7.12 Appendix 12: PERMISSIONS TO USE PUBLISHED MANUSCRIPTS 424
7.12.1 Appendix 12.1: Publication 1 -Journal of Clinical Nursing 424
7.12.2 Appendix 12.2: Publication 2- Nursing Philosophy 425
7.12.3 Appendix 12.3: Publication 3 – Australasian Journal of Neuroscience Nursing 426
7.13 Appendix 13: The Consolidated criteria for reporting qualitative research (COREQ) checklist 428

List of Tables

Table 1: Key Insurance supports that facilitate TBI rehabilitation in the state of New South Wales, Australia. 18
Table 2: Inclusion /exclusion criteria. 97
Table 3: Number of study participants providing data in each phase of the data collection. 103
Table 4: Total interviews showing range and mean. 110
Table 5: Example of initial coding of an interview. 118
Table 6: Example of focused coding. 119
Table 7: Criteria for the Constructivist Grounded Theory in this study as adapted from Charmaz (2014, p.337) 130

List of Figures

Figure 1: Genealogy of Grounded Theory (Adapted from Morse et al., 2016, p.17). 75
Figure 2: Study participants providing data in each phase of the data collection by site. 104
Figure 3: Visual representation of the Grounded Theory process followed (adapted from Charmaz, 2014, p.18) 115
Figure 4: Example of a memo. 121
Figure 5: Example of memo written during data analysis. 125
Figure 6: Example of early diagramming of properties and dimensions of the core category. 126
Figure 7:Theory of Dancing with Agency (early conceptual thinking). 127

Key to transcripts

A unique code convention was used while presenting the data from participant interviews and field observations. The following descriptions provide brief explanations of the various codes represented to guide the reader of the thesis

Participant codes:

RN14: Registered Nurse (the number 14 represents position in recruitment count).

EN8: Enrolled Nurse (the number 8 indicates position in recruitment count).

P6: Patient participant (the number 6 indicates position in recruitment count).

F9: Family member (the number 9 indicates position in recruitment count).

Field observation data codes:

Field Note, N185 : Field note is a documented participant observation. The number, e.g., N185, represents the accumulative count for the field note.

List of abbreviations

ACI	Agency for Clinical Innovation
ADLs	Activities of Daily Living
AIHW	Australian Institute of Health and Welfare
APN	Advanced Practice Nurse
ARNA	Australasian Rehabilitation Nurses' Association
BIRU	Brain Injury Rehabilitation Unit
CGT	Constructivist Grounded Theory
ComPacks	Community Packages
COREQ	Consolidated criteria for reporting qualitative research
CT	Computed Tomography
CTP	Compulsory Third Party vehicle insurance
CNC	Clinical Nurse Consultant
CNE	Clinical Nurse Educator
CNS	Clinical Nurse Specialist
EN	Enrolled Nurse
FN	Field Note
GT	Grounded Theory
HREC	Human Research Ethics Committee
IPONS	International Philosophy of Nursing Society
ICU	Intensive Care Unit
IDC	Indwelling Urinary Catheter
iCare	Insurance and Care services
MDT	Multi-disciplinary Team
NGT	Nasal-Gastric Tube
NUM	Nurse Unit Manager

NDIS	National Disability Scheme
NHMRC	National Health and Medical Research Council
OT	Occupational Therapist
PEG	Percutaneous Endoscopic Gastronomy tube
PPE	Personal Protective Equipment
PTA	Post Traumatic Amnesia
RN	Registered Nurse
TBI	Traumatic Brain Injury
WHO	World Health Organisation

1 CHAPTER ONE: Introduction

1.1 Chapter Introduction

In this chapter, I first provide a personal statement clarifying my motivation for conducting this research. Second, I provide an overview of traumatic brain injury (TBI) as a major healthcare problem in Australia and globally. I provide an overview of the systems of care for TBI in Australia and of the wider Australian Healthcare system. The principles of rehabilitation and models of care delivery are discussed, followed by an orientation to Australian nursing roles and nurses' educational preparation. The focus then narrows to consider rehabilitation nursing and the Australian rehabilitation competency standards that address personhood. Finally, I explicate the aim and significance of the study underpinning this thesis and conclude the chapter by explaining the overall thesis structure.

My interest in pursuing a substantive research project in the field of TBI stems from my current role as a Clinical Nurse Specialist in the Neurosciences Unit at a major tertiary hospital in Australia. In my role, I provide expert clinical nursing care to people presenting with TBI, and I interact with their family members and serve as part of the multidisciplinary team that collectively manages inpatient and care transition processes.

Having worked in this clinical setting for over 13 years, I have become familiar with systems of care for people with TBI and how they are supported during the recovery phase. I observed that patients with TBI and their families seemed to experience several challenges as a consequence of the physical and physiological impacts resulting from injury, the need to adjust to loss, and a new sense of self, while fitting

in with the complexities of institutionalised healthcare. I also noticed the challenges that neuroscience nurses faced as they interacted with patients in ways that promoted respect and dignity, particularly when managing behaviours that nurses and others found challenging. I then began to ponder how patients with TBI could be better assisted during their hospital admission and later during the rehabilitation phase. I decided that this was an area where I could advance my theoretical knowledge, inform clinical nursing practice, and improve TBI care. I had a strong conviction that the completion of this Grounded Theory study would enable the development of novel understandings and contribute new theoretical knowledge that could support the provision of quality person-centred care for people living with TBI in rehabilitation settings.

1.2 Background to the study

1.2.1 Traumatic Brain Injury

TBI describes an acquired injury to the brain as a result of an external force which may result in cognitive or physical impairments, the ramifications of which are dependent on the severity and location of injury (Australian Institute of Health and Welfare [AIHW], 2023). Throughout the world, TBI remains a major cause of hospitalisation, disability, and death (Brazinova et al., 2021; Hiskens et al., 2023; Roozenbeek et al., 2013; Shen et al., 2025; Yan et al., 2025). TBI severity can be assessed using the Glasgow Coma Scale which evaluates level of consciousness (GCS), the Post Traumatic Amnesia (PTA) duration in days and the Westmead PTA scale (Tenovo et al., 2021). The spectrum of TBI severity can be mild (GCS 13-15), moderate (GCS 9-12), or severe (GCS 3-8) (Pugh et al., 2021; Saatman et al., 2008). PTA represents a period of cognitive impairment which occurs following TBI

where the affected person may experience disorientation, confusion, and difficulty memorising information (Schacter & Crovitz, 1977). People who sustain moderate to severe TBI present with a spectrum of enduring impairments. These impairments may affect cognition, memory, sleep, behaviour, attention, judgement, speech, and psychosocial, physical and motor functioning (Arciniegas et al., 2002). In turn, these effects may impact a person's ability to perform daily living activities, engagement with others, participation in recreation activities, employment and require the person to rely on significant others, carers, and long-term rehabilitation support (Barman et al., 2016; Yan et al., 2025). People with mild TBI regain baseline cognitive functioning within three months of injury, while for those with moderate to severe TBI, cognition may not be attained even beyond a period of two years post injury (Arciniegas et al., 2002).

The WHO designated TBI as a worldwide public health problem due to its high socioeconomic impacts and incidences, with the global burden of TBI estimated to range from 50 to 74 million cases annually (Shen et al., 2025; Zhong et al., 2025). In Australia, the incidence of hospitalisation for TBI remains under-reported. The most recent nation-wide report estimates that between 2015 and 2020, 16,582 people were hospitalised with moderate to severe TBI, and most of these people had further injuries in other anatomic regions (AIHW, 2023). During the two years 2020 and 2021, there were 2,400 deaths from TBI (9.3 per 100, 000 population) (AIHW,2023). For those who survive, the estimated lifetime cost is AUD$2.5 million to AUD$4.8 million per injured person (AIHW, 2023; Hunt, 2019). This incidence of an injury that carries high levels of trauma and disability is of concern to nurses working in this

specialty, and to administrators who manage the human and economic resources related to TBI care.

Most incidences of TBI among Australian adults are due to motor vehicle accidents and falls, with additional causes including physical assaults and sports-related accidents (AIHW, 2023). Most people with TBI are male (AIHW, 2007). About one-quarter of injuries occur within the age range of 15 to 24 years (AIHW, 2021), while one third are sustained by people aged 65 or older (AIHW, 2023). This demographic and epidemiology data is consistent with registry reports from the United States of America (USA) (Centres for Disease Control and Prevention (CDCP), 2024), United Kingdom (UK) (Lawrence et al., 2016; Quintard, et al., 2021), and Europe (Brazinova et al., 2021). In Australia, Aboriginal and Torres Strait Islander people are over-represented in TBI statistics, and this over-representation is similar for indigenous people worldwide (Golding, et al 2025).

1.2.2 An overview of systems of care for TBI in Australia

The Australian health system ranks amongst the best in the world and contains both public and private healthcare providers (Australian Government Department of Health, Disability and Ageing (AGDHDA, 2025). Public hospitals are jointly funded by the central or Commonwealth Government and the state or territory governments. These hospitals are run by state and territory governments and provide free healthcare services, including inpatient brain injury rehabilitation. There are also private providers, such as general practitioners (GPs), medical specialists, urgent medical centres, allied health professionals, and nurses who provide healthcare services to the public for a fee (AGDHDA, 2025). In the private hospital system, a

patient must have private health insurance to receive treatment. While those with private health insurance can also use their private health cover benefits within the public hospital system, having private insurance is not a precondition for admission into public hospital care system. The Australian health system faces multiple challenges relating to the increased demand for services generally (AGDHDA, 2025).

Many people begin their inpatient TBI care journey in an Intensive Care Unit (ICU). In Australia and New Zealand (2013-2022), acute brain injuries (inclusive of TBI) account for 14% of unplanned admissions to ICU. Compared to other ICU patients, people admitted with an acute brain injury are more likely to receive mechanical ventilation, have higher ICU and hospital length of stay, and higher 90-day and 180-day mortality. They also have a greater likelihood of discharge to either a rehabilitation facility, a chronic care facility, or a nursing home (Golding, et al., 2025).

Upon discharge from ICU, acute inpatient care is then provided in specialist neuroscience units with specific medical, nursing, and Allied Health expertise. Australia is a geographically challenging landscape for acute and chronic injury management with most of the population and therefore, medical services, concentrated in coastal regions (AIHW, 2023). While people living in major cities have immediate access to care for acute and chronic injury, those in less urban regions are disproportionately affected by brain injury and experience a lack of access to trauma services that can offer immediate medical treatment. People living in very remote regions are more than three times more likely to experience brain injury (AIHW, 2023). People and their families affected by serious TBI, and

accessing either critical care, acute care, or inpatient injury rehabilitation, are often a long way from home and sources of support (AIHW, 2023). Australian TBI registry data revealed an independent increase in the odds of in-hospital death when injury occurred in remote areas, and reduced odds of dying in hospital for the higher density states of NSW and Victoria (O'Reilly, et al. 2025). Other factors impacting outcomes post TBI have been reported as access to support structures that facilitate treatment and recovery, ethnicity, social-economic status, sex, and statuses relating to education, employment and insurance (Berwick et al., 2022; Ponsford, 2013).

The level of GCS has been reported as a valid predictor of inpatient mortality post TBI with a score of eight or less linked to mortality (Chi et al., 2006). Having longer duration of PTA and lower GCS are predictive of poorer functional outcomes and less chances for employment post TBI (Ansari et al., 2025; Avesani et al., 2005). Among older adults, moderate to severe TBI is associated with higher mortality (Chi et al., 2006; Khan et al., 2017). However, individuals with TBI aged over 65 years may handle personal emotions better and have a lower risk for psychiatric morbidity than those aged 18-65 (Deb & Burns, 2007; Ponsford, 2013).

Pre-injury education level is associated with higher employment and integration into the community post injury (Wood & Rutherford, 2006). A lack of social support is associated with poor social and psychological well-being for people with TBI (McCarthy et al., 2006). The pattern of family functioning pre-injury determines how family members adjust post TBI with better outcomes present for the family where pre-injury family functioning levels are high (Always et al., 2012; Downing et al., 2021). From an Australian context, individuals with TBI from culturally and

linguistically diverse (CALD) backgrounds were found to have lower levels of employment and social integration when compared to those who were native English speakers (Ponsford et al., 2020: Saltapidas & Ponsford, 2008).This suggests that ethnicity, cultural beliefs, practices, traditions of coping can influence outcomes post TBI.

1.2.3 Support schemes for people with TBI

A variety of schemes support health expenses and professional carers for people living with TBI after discharge. Table 1 provides an overview of some of the key schemes that offer support services.

Scheme	Description	Eligibility	What is covered
National Disability Insurance Scheme (NDIS)	A national scheme that provides funding for support and services directly to people with disability (NDIS, 2025)	Eligibility criteria requires a person to: -be an Australian citizen, permanent resident or a protected special category visa holder living in Australia -have a disability as a result of permanent impairment -be in need of disability-specific supports to accomplish activities of daily living (NDIS, 2025)	Funding is provided for services, items, and equipment that support the person living with a disability caused by a permanent impairment that is intellectual, cognitive, neurological, sensory, physical, or psychosocial (NDIS, 2025)
Compulsory Third Party (CTP) Insurance	A News South Wales (NSW) based personal injury insurance policy which protects the driver of the motor vehicle from liability if they were to injure or cause the death of a person or people in a motor accident. It covers the cost of injuries caused by your vehicle to the people involved in an accident, including the driver (State Insurance Regulatory Authority, SIRA, 2024.) CTP in NSW is covered by 6 insurers.	The driver of a vehicle and all third parties involved, including drivers, pedestrians, passengers, cyclists and motorcyclists, regardless of fault (unless you are charged with a serious driving offence) (SIRA, 2024)	All injured people, regardless of fault, can claim up for up to 6-12 months. If one is not at fault and their injuries are more serious, they may be able to claim benefits beyond this period. Those who have been severely injured may also be eligible for the Lifetime Care & Support Scheme. (SIRA, n.d.) which also covers treatment and care expenses post motor vehicle accident, personal injury benefits, and income support (SIRA, 2024)
Insurance and Care services (iCare)	Provides insurance and care services that covers long-term care for injuries resulting from roads or workplace incidences in NSW (iCare, 2025)	Specific eligibility criteria require the injury to have occurred at work, in the state of NSW, and where the employer has a workers' insurance policy (iCare, 2025)	Covers anyone injured at work through workers' compensation. Support amount and duration is dependent on type, nature and severity of injury sustained while at work. Covers workplace injury which may be psychological or physical such as brain injury, spinal cord injury, amputations, and burns (iCare, 2025)

Table 1: Key Insurance supports that facilitate TBI rehabilitation in the state of New South Wales, Australia.

1.2.4 Rehabilitation

Rehabilitation is a whole of person approach that seeks to maximise function, across physical, social, psychological, and work domains for an individual experiencing disability, and it may include modifying the person's environment (Agency for Clinical Innovation [ACI], 2021). Typically, rehabilitation focusses on goals considered meaningful to the person (ACI, 2021).

Rehabilitation in Australia is provided through three areas: 1) in-reach services, where specialist multi-disciplinary teams provide early rehabilitation interventions during acute hospitalisation; 2) inpatient rehabilitation facilities that may be co-located with hospitals or are stand-alone facilities; and 3) outreach rehabilitation, a consultative hub and spoke model whereby a larger specialist rehabilitation service supports a smaller health setting (ACI, 2019). Ambulatory care programs are an important tier of rehabilitation, and they are delivered through outpatient, day hospital, or home-based programs. The scope of these programs means that a person's rehabilitation needs are met by diverse health disciplines, services, and external agencies (National Health Service, 2016).

In NSW, the Brain Injury Rehabilitation Network (within the NSW Agency for Clinical Innovation – one of four pillars of NSW Health) monitors the State's TBI model of care, promotes equity and access to services, incorporates consumer and family perspectives in development and evaluation of services, develops education resources and training opportunities, and supports strategies to translate brain injury rehabilitation research into practice. The Network incorporates 15 Brain Injury Rehabilitation Programs across NSW (ACI, 2021).

1.2.5 Rehabilitation nursing

Rehabilitation nursing facilitates the attainment of optimal outcomes for people receiving care in rehabilitation settings (Australian College of Nursing, 2022). Rehabilitation nurses are best able to meet a person's needs when they have appropriate education and training to deliver effective care that facilitates the attainment of rehabilitation goals (Pryor & Smith, 2002). The Australasian Rehabilitation Nurses' Association (ARNA, 2023) is the peak body that informs education and training for rehabilitation nurses. Rehabilitation nurses are required to conform to a specific set of competencies (ARNA, 2023) and align with the general scope of practice classifications found in a range of specialties in NSW (NSW Health, 2023).

There are two categories of nurses in Australia: Registered Nurses (RNs) and Enrolled Nurses (ENs). The educational preparation of these two categories of nurses follows a number of pathways. While RNs typically undergo three years education at the University level, ENs are educated in the Technical and Further Education (TAFE) institutions, whose curricula span 1.5 years. RNs and ENs have a different scope of practice and, at all times, ENs work under the supervision of RNs. In NSW, advanced practice classifications of RNs include Clinical Nurse Specialist (CNS), Clinical Nurse Educator (CNE), Clinical Nurse Consultant (CNC), and Nurse Practitioner (NP). These roles usually require postgraduate qualifications, and recognition of professional expertise and leadership (NSW Health, 2023).

1.2.5.1 Rehabilitation nurse competencies

The Australasian Rehabilitation Nurses' Association (ARNA) Rehabilitation Nursing Competency Standards for Registered Nurses (2023), and the Rehabilitation Practice Guideline for Enrolled Nurses, offer guidance that informs the practice of rehabilitation nursing. The ARNA (2023, p.26) Rehabilitation Nursing Competency Standards have seven domains and those that directly relate to promoting and preserving personhood for the person receiving rehabilitative care are summarised below:

(1) The rehabilitation approach:

- Seek to actively know each person as an individual in "their context and possess a sense of their personhood" (Competency Element 1.2, ARNA, 2023, p.11).

(2) Teaching and coaching:

- Support "the development of knowledge and skills in significant others and formal carers through teaching and coaching" (Competency Element 2.4, ARNA, 2023, p.12).

(3) Observation, assessment and interpretation:

- Incorporate these three elements within their daily routines as "core activities for getting to know the person and planning their response" (Competency Element 3, ARNA, 2023, p.16).
- Base "the choice of intervention, timing, duration, frequency and approach for the nursing response upon the assessment of the person in their context at that point in time, being mindful of the long term and short term goals" (Competency Element 3.2, ARNA, 2023, p.16).

4) Administering and monitoring therapeutic interventions.

- Promote “the person’s self-determination, the attainment of goals and maximisation of safety” (Competency Element 4.5, ARNA, 2023, p.19).
- Nurses contribute to “the person’s rehabilitation through active participation in allied health and medical interventions, including collaborative assessment, planning, implementation and evaluation of interventions with the person, significant others and/or formal and informal carers and the rehabilitation team” (Competency Element 4.6, ARNA, 2023, p.19).

(5) Managing rapidly changing situations:

- Use a “repertoire of skills to effectively manage a variety of rapidly changing situations, that may be related to physiological, psychological, social or spiritual dimensions of the person, significant others, formal and informal carers and/or the rehabilitation team” (Competency Element 5.5, ARNA, 2023, p.22).

(6) Management, advocacy and co-ordination:

- Liaise “with significant others and/or formal and informal carers to support the achievement of the person’s goals” (Competency Element 6.5, ARNA, 2023, p.23).

The Competency Standards are a living document and are subject to periodic review to ensure currency. Rehabilitation nurses work around the clock and target the achievement of set goals across the person’s rehabilitation world. The rehabilitation nurses are considered an integral member of the interdisciplinary care team, and they are well positioned to provide collaborative leadership as they navigate complex pathways and discharge plans (ARNA, 2023).

1.2.6 Brief overview of challenges faced by patients with TBI, families and nurses

Challenges faced by patients with TBI encompass difficulty living with impairments (e.g. self-awareness, physical, cognitive and emotional), along with behavioural and mental health challenges (Di Somma & Fleming, 2024). Patients with TBI experience varying levels of self-awareness and apathy that affect motivation to participate in rehabilitation (Bivona et al., 2019; Geytenbeek et al., 2017; McCabe et al., 2024). Impaired self-awareness in patients with TBI can lead to difficulty with social adjustment, and an inability to determine personal limitations and their consequences (Dromer et al., 2021; English et al., 2016).

Families of patients with TBI face multiple challenges arising from changed emotions and behaviours such as aggression, anxiety, distress, frustration, and irritability. These could lead to changes in family member roles, family ways of living and a destabilisation of family dynamics (Whiffin et al., 2021). Making life adjustments in the context of TBI care can also be difficult for family members (Oyesanya, 2017).

Family members are faced with a sense of isolation, and with fear and helplessness brought about by the person's injury. Families may struggle to find answers that are not readily available and may become frustrated if health professionals ignore or do not engage with them in the assessment and delivery of care (Whiffin et al., 2021). This lack of engagement between families and professionals leads to a lack of congruence in patient and family expectations, particularly in relation to TBI prognosis and recovery (Oyesanya et al., 2021). Families' intense grief and emotions can last for years, generating overwhelming and complex reactions that are challenging to deal with (Whiffin et al., 2021).

Nurses who care for patients with TBI have described the negative impacts of organisational resource limitations on the quality of TBI nursing care (Nayeri et al., 2022). They have also reported a lack of guidelines, education and clinical knowledge, particularly related to care modifications and interventions for patients with residual cognitive impairment (Oyesanya et al., 2018).

1.2.7 Elements of personhood and person-centred nursing care

Personhood can be understood as “a state or experience of being recognised as a person” (Derakhshan et al., 2025 ,p.127). Literature suggests that personhood is a multifaceted concept, with no universally recognised definition (Derakhshan et al., 2025; Kivunja et al., 2024). However, several domains have proposed including moral personhood (moral worth of humans), natural personhood (accorded to all humans) and legal personhood (as an entity entitled to rights) (Derakhshan et al., 2025). Personhood is relational in that an individual is connected to others with whom meanings are shared and conveyed (Derakhshan et al., 2025).

Person-centred nursing care encompasses application of nursing strategies that are respectful and empowering for the person receiving care while acknowledging therapeutic humility (Chochinov et al., 2023). In enabling nursing care that addresses personhood, McCance and McCormack (2025) propose a mid-range theory (the Person-Centred Nursing Framework). Important domains are 1) *the attributes of the nurse* (professional competence and commitment, interpersonal skills, clarity of beliefs and values, and self-awareness); 2) *the care environment* (adequate skill mix, systems that promote shared decision-making and shared power, effective staff relationships and organisational systems, suitable physical environment, and the enabling of innovation and risk-taking); 3) *person-centred nursing processes*

(working with people's beliefs and values, having a sympathetic presence, engaging authentically, sharing power and providing holistic care); and 4) *outcomes of effective person-centred care* (a good care experience for patients, their families, and nurses).

1.3 Aim of the study and research question

The aim of this study is to develop a substantive explanatory theory of the social processes that promote[1] and preserve[2] personhood in TBI nursing care within rehabilitation settings from the perspectives of patients, family members and nurses. This study was guided by the following research question:

> What are the social processes that promote and preserve personhood in TBI nursing care?

1.4 Significance of the study

This thesis provides a theoretical explanation of human interactions in TBI rehabilitation. Older research suggests people who have experienced TBI face disruption to their ways of thinking, moving, and being in the world (Kneafsey & Gawthorpe, 2004). During rehabilitation care, they are challenged to relearn tasks that were once taken for granted. Their head injury may change their perceptions of people and the world, and in turn, their behaviours. They may not remember important people and past activities. These changes mean that people may be vulnerable to threats to their personhood, while family members may be struggling

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[1] My use of the phrase to "promote personhood" refers to an extension beyond the current recognition and expression of personhood.
[2] My use of the phrase to "preserve personhood" refers to avoiding a loss of the current recognition and expression of personhood.

with a sense of loss of the person they knew, and important relationships need to be redefined (Kneafsey & Gawthorpe, 2004).

Nurses and others use various mediums of interaction when providing care which has implications for personhood (Oyesanya et al., 2017). Elements of personhood that are inherent (for example, one's culture, one's web of relations, and one's rights) may be recognised and preserved, while elements of personhood that need to be redefined or regained following injury (such as self-expression, agency, autonomy, freedom of movement, and capacity for self-care) may require targeted care plans and nursing approaches (Oyesanya et al., 2017) that promote lost expressions of personhood. This thesis may challenge nurses to evaluate practices that are potentially distressing to patients, families, and carers, and to prioritise person-centred strategies that may be of more value.

1.5 Structure of this thesis

Chapter 1 presents the introduction and background for the study, overview of systems of care for TBI in Australia, explains the concept of rehabilitation and rehabilitation nursing in Australia. Rehabilitation nurse competences are illustrated including the support schemes for people with TBI. The chapter also provides a background to the challenges that patients, families and nurses experience as a result of TBI, and presents the aim of the study, the significance of the study and structure of the Thesis.

Chapter 2 discusses the role of literature review within Grounded Theory studies. A discussion about the positioning of literature review in the methodology of Grounded Theory, and its application in this thesis is provided. A peer reviewed integrative

review on the giving and receiving of care in TBI is embedded. A published discussion paper focused on the conceptualisation of personhood for people with altered cognition is also presented.

Chapter 3 explains the research methodology and the methods used to operationalise the study. The research focus, research paradigm, symbolic interactionism and historical development of Grounded Theory are explained. Constructivist Grounded Theory, informed by Charmaz (2006, 2014, 2025), is justified as the guiding methodology for the study underpinning this thesis.
The research methods are explained, including the research setting, research team, and impacts of COVID-19 pandemic on the study. Aspects pertaining to ethics approval, researcher reflexivity, ethical design, and recruitment and sampling are presented. A published discussion paper explores the pertinent ethical issues associated with navigating the role of clinician researcher, and strategies to enhance the ethicality of TBI research design is embedded. The methods used for data collection and data analysis are explained. The use of memos, diagramming, Storyline and the identification of the main concern are presented. There is a clarification of the criteria used to evaluate the Grounded Theory developed in this study and how rigour was enhanced using the COREQ Framework.

Chapter 4 explores the main concern and the basic social process pertaining to the study. The substantive theory *of Dancing with Agency* is explained through three non-linear components: *protecting the body of the person*; *engaging the person who is the patient;* and *handing over the baton*. The contextual factors that influence this *Dancing with Agency*, are presented.

Chapter 5 summarises and discusses the key elements and contributions of the substantive Constructivist Grounded Theory of *Dancing with Agency*. The strengths and limitations of the study underpinning this thesis are considered, and the findings are synthesised and compared with the wider global literature. Recommendations are made for nursing practice, education, policy and further research. Conclusions are then drawn.

1.6 Chapter summary

In this chapter, I have provided an overview of TBI as a healthcare problem in Australia and worldwide, and the systems of care that support people recovering from TBI. The general aims and principles of rehabilitation are summarised, along with the models of care delivery. The educational preparation of nurses in Australia was explained, and the competency standards for rehabilitation nurses were noted as they relate to ideas of personhood. The aim and significance of the study underpinning this thesis were expounded, and the structure of this thesis was outlined. In the next chapter, I provide details of the literature reviewed before and during this study.

2 CHAPTER TWO: Literature Review

2.1 Chapter introduction

In this chapter, I explore the use of literature in Grounded Theory studies. I present the personal circumstances that situate me in relation to this literature review, as a neuroscience nurse and doctoral student, and I clarify my approach to navigating literature during the study. This chapter includes two published peer-reviewed papers: the first is an integrative review exploring experiences of giving and receiving care in TBI (Kivunja et al., 2018); and the second is a discussion paper that conceptualises *personhood* in nursing care for people with altered consciousness, cognition, and behaviours (Kivunja et al., 2024).

2.2 Use of literature in this study

In contemplating the position of literature in this study, I am aware that the timing of literature review in Grounded Theory is contested among theorists of this methodology (Charmaz, 2025; Corbin & Strauss, 2008; Dunne, 2011; Flick, 2018; Glaser, 1978). Glaser and Strauss (1967) advised against undertaking an initial review of the literature around the area of substantive interest. Glaser (1978) later recommended that researchers delay reviewing literature. The rationale is that delaying reference to literature prevents the possibility of researchers developing theoretical preconceptions that could unduly influence the study findings (Deering & Williams, 2020). However, thinking about the role of literature in Grounded Theory studies has evolved over time. Strauss and Corbin (1998) recommend the use of literature in combination with a reflective rather than a blank mind. Alternatively, Charmaz (2014) sees exclusion of pre-existing knowledge as impractical, given that

research proposals, including those for grants and higher degree research candidature, require a sophisticated knowledge of leading theories and research in the field. Extant theories, literature and prior knowledge are valuable ingredients that can be used when constructing grounded theories (Charmaz, 2014; Clarke et al., 2018). There is a suggestion that the debate and consensus is now centred upon when and how an extensive literature review should be conducted, rather than on whether one should be conducted prior to analysis (Dunne, 2011).

As a Clinical Nurse Specialist caring for people with TBI, I have pre-existing knowledge of patient and family characteristics, person-centred care needs, and a body of literature that supports evidence-based care. Equipped with this pre-acquired clinical knowledge I could not enter the field as 'blank slate'. Rather, Grounded Theory researchers should take a critical and reflective approach to literature. For Charmaz (2014), these perspectives and knowledge strengthen the researchers' theoretical sensitivity and, consequently, earlier reference to literature is considered beneficial for constructing theories that are grounded in data. I embraced this position and incorporated the two literature reviews undertaken while conducting this study (Kivunja et al., 2018; Kivunja et al., 2024) to inform the development of the substantive theory of nurses *Dancing with Agency*.

The first included paper is an integrative review of experiences of giving and receiving care in TBI (Kivunja et al., 2018). The paper synthesises findings from studies that included either patient, family members, or nurse experiences. This early scoping work allowed me to avoid 'reinventing the wheel', while finding an opportunity to fill a knowledge gap. The most influential finding for the development

of this study was that ‘seeking personhood’ (of the person with TBI) was an important cross-cutting theme that explained experiences across my three participant groups. Personhood then provided the focus for my study. This review also clarified that no single study incorporates the views of patients, family members, and nurses. Furthermore, in this literature, there appeared to be a mismatch in experiences of person-centred care across these cohorts. This insight influenced my study design to engage with the experiences of people with TBI, their family members, and nurses.

In an early informal review of the construct of *personhood*, I used literature initially to define my use of the term as a foundational theoretical construct and to help the development of an interview guide. A working definition of personhood also helped me to describe the purpose of my study to participants, given that personhood may be an unfamiliar or abstract concept to some people. Later in the research, after initial interviews and field observations, I returned to the personhood literature in greater depth to enhance my theoretical sensitivity and to consider further lines of enquiry in my subsequent data collection (Charmaz, 2014). I developed the second included paper: “Conceptualising personhood in nursing care for people with altered consciousness, cognition and behaviours” (Kivunja, et al., 2024). This work opened my mind to the different ways in which *personhood* is expressed across cultures, and how it might be either threatened or promoted by a range of conditions that, like TBI, could alter consciousness, cognition, and behaviours. This broader focus was adopted because of the limited literature that directly explored personhood in TBI care. In particular, this work helped to support my theoretical understanding of the body as integral to personhood and how personhood is sustained through a web of

relations, including the family members and significant others. Engagement with this literature supported greater critical thinking about the developing analysis (Birks & Mills, 2023; Bryant & Charmaz, 2007; Thornberg, 2012).

Charmaz (2014, p.307) advises that the "researcher should tailor the final version of the literature review to fit the specific purpose and argument of his or her research report". As a researcher engaged with this literature, I constantly reflected on how prior knowledge from the literature might either impede or impose upon my interpretation of the phenomena during the study and to consider how such impacts could be minimised (Flick, 2018).

2.3 Experiences of giving and receiving care in traumatic brain injury: an integrative review

Author attribution statement

This manuscript has been published as:

Kivunja, S., River, J., & Gullick, J. (2018). Experiences of giving and receiving care in traumatic brain injury: An integrative review. *Journal of Clinical Nursing, 27(7–8),* 1304–1328. https://doi.org/10.1111/jocn.14283

I co-designed the search strategy with my supervisors who are co-authors (A/Prof Jo River and A/Prof Janice Gullick). I conducted the systematic literature search and data extraction. I synthesised the literature using an integrative review methodology, I wrote the original manuscript and revised it with critical input from my co-authors. I prepared responses to reviewer feedback with further input from co-authors and submitted the manuscript.

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Signature **Date:** 29 September, 2025

As supervisor for the candidature upon which this thesis is based, I can confirm that the authorship attribution statement above is correct.

Lead supervisor name*:* A/Prof Janice Gullick

Signature **Date:** 29 September, 2025

Permission to include the published manuscript in this thesis is attached (see Appendix 12.1)

Accepted: 21 January 2018
DOI: 10.1111/jocn.14283

REVIEW

WILEY Journal of Clinical Nursing

Experiences of giving and receiving care in traumatic brain injury: An integrative review

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Aims and objectives: To synthesise the literature on the experiences of giving or receiving care for traumatic brain injury for people with traumatic brain injury, their family members and nurses in hospital and rehabilitation settings.

Background: Traumatic brain injury represents a major source of physical, social and economic burden. In the hospital setting, people with traumatic brain injury feel excluded from decision-making processes and perceive impatient care. Families describe inadequate information and support for psychological distress. Nurses find the care of people with traumatic brain injury challenging particularly when experiencing heavy workloads. To date, a contemporary synthesis of the literature on people with traumatic brain injury, family and nurse experiences of traumatic brain injury care has not been conducted.

Design: Integrative literature review.

Methods: A systematic search strategy guided by the PRISMA statement was conducted in CINAHL, PubMed, Proquest, EMBASE and Google Scholar. Whittemore and Knafl's (*Journal of Advanced Nursing*, 52, 2005, 546) integrative review framework guided data reduction, data display, data comparison and conclusion verification.

Results: Across the three participant categories (people with traumatic brain injury/family members/nurses) and sixteen subcategories, six cross-cutting themes emerged: seeking personhood, navigating challenging behaviour, valuing skills and competence, struggling with changed family responsibilities, maintaining productive partnerships and reflecting on workplace culture.

Conclusions: Traumatic brain injury creates changes in physical, cognitive and emotional function that challenge known ways of being in the world for people. This alters relationship dynamics within families and requires a specific skill set among nurses.

Relevance to clinical practice: Recommendations include the following: (i) formal inclusion of people with traumatic brain injury and families in care planning, (ii) routine risk screening for falls and challenging behaviour to ensure that controls are based on accurate assessment, (iii) formal orientation and training for novice nurses in the management of challenging behaviour, (iv) professional case management to guide access to services and funding and (v) personal skill development to optimise family functioning.

KEYWORDS
carers, experiences, families, integrative review, nurses, nursing care, patients, traumatic brain injury

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1 | INTRODUCTION

In Australia and worldwide, traumatic brain injury (TBI) represents a major public health problem (Langois, Rutland-Brown, & Wald, 2006). TBI is an injury to the brain that results from an external impact or force and can lead to disruption of normal cognitive function (Centers for Disease Control and Prevention (CDCP, 2014). People with TBI experience varying levels of emotional, behavioural and physical changes including physical disabilities which may impact on their quality of life and social functioning (Centers for Disease Control and Prevention, 2014).

In Australian hospitals, and in clinical settings worldwide, the everyday care needs of people with TBI are primarily provided by nurses working within multidisciplinary healthcare teams. The setting for this care includes emergency departments (ED), intensive care units (ICU), specialist brain injury units (BIU), general ward environments and community outreach services. The clinical care tasks of nurses will vary according to the individual person's needs, and whether they present with mild, moderate or severe TBI. Effective nursing care also relies on a therapeutic relationship with family members to maximise positive care outcomes (Fleming, Sampson, Cornwell, Turner, & Griffin, 2012).

An initial review of the literature indicates the experience of both receiving and providing care for TBI is complex. People hospitalised with TBI can experience challenges to care, describing multiple examples of feeling disempowered (Chamberlain, 2005; Coco, Tossavainen, Jääskeläinen, & Turunen, 2011; Fleming et al., 2012; Jumisko, Lexell, & Söderberg, 2007; Webster, Taylor, & Balchin, 2015). The physical and psychological impact of TBI can be distressing for the entire family, who commonly describe a combination of insufficient information and an overwhelming care burden (Family Caregiver Alliance, 2017). Nurses may struggle to meet the care needs of people with TBI, particularly when they exhibit challenging behaviour (Chen, Davis, Davis, Pan, & Daraiseh, 2010). While individual studies of people with TBI, family and nurse experiences offer insights into the challenges of managing TBI, it is still unclear how common such experiences are across various healthcare settings. It is thus timely to synthesise literature related to giving and receiving care in TBI, particularly given that the experiences of care are based on interpersonal understandings and interchanges between people with TBI, and professional and informal caregivers.

For the purpose of this integrative review, the term "care" refers to the provision of services necessary for the maintenance of the physical, social and psychological welfare of people with TBI, their family members and primary nurse carers. The term "experiences" refers to events or incidences a person encounters during the course of giving or receiving care within a TBI care environment.

This review was guided by the following research question: "What are the experiences of giving and receiving care in traumatic brain injury from the perspectives of people with TBI, their family members and nurses in hospital or rehabilitative care settings?"

What does this paper contribute to the wider global community?

- There is a mismatch in perceptions of person-centred care between people with traumatic brain injury (TBI) and nurses. People with TBI feel controlled and constrained, and TBI puts significant stress on family dynamics. Underskilled nurses are overwhelmed by their caring role.
- People with TBI and families need a partnered approach to care planning, case management for service access and personal skill development to optimise family functioning.
- Nurses need evidence-based protocols and training to manage challenging behaviour, and a structured orientation for novice nurses to the TBI environment is essential.

2 | BACKGROUND

Australian epidemiological data indicate that over 22,000 people (around one per thousand) were hospitalised due to TBI between 2004 and 2005 (Brain Injury Australia, 2016). Similarly, in the United States of America (USA), TBI remains a major health problem with approximately 2.5 million people hospitalised each year and up to 52,000 deaths annually (CDCP, 2014). Children under 4 years, adolescents between 15 and 19 years and adults 65 years or older are most likely to experience TBI, with males having a higher incidence (59%) (Faul, Xu, Wald, & Coronado, 2010). In Europe, the overall TBI incidence is estimated at 262 per 100,000 people per year (Peeters et al., 2015). The leading causes of TBI are falls (35.2%), motor vehicle accidents (17.3%) and physical assaults (10%). Among young adults, TBI is most often due to road accidents, whereas among the youngest and oldest, falls are the main causes (Faul et al., 2010).

Traumatic brain injury can be devastating to the people affected as it may lead to physical disabilities such as limb weakness, and psychological changes such as memory and cognition impairment, stress and sensory limitations. The long-term effects of TBI may include epilepsy and/or depression depending on the extent of the injury (Langois et al., 2006). Physical and cognitive difficulty can limit a person's ability to return to work impacting their capacity to be self-reliant and often leading to welfare dependency (Hooson, Coetzer, Stew, & Moore, 2013).

While experiences of people with TBI remain understudied, findings indicate that people feel excluded from decision-making, receive conflicting information regarding treatment and feel mistreated by professional caregivers who fail to listen or who give care impatiently (Chamberlain, 2005; Coco et al., 2011; Fleming et al., 2012; Jumisko et al., 2007; Webster et al., 2015).

Traumatic brain injury has impacts beyond the injured person because of the intensity of their daily care needs. Family caregivers of people with moderate-to-severe brain injury report dissatisfaction with many aspects of caregiving, particularly related to the burden

of care and their own perceived level of mastery over caregiving skills (Jumisko et al., 2007). Families also report anxiety, depression, fatigue, distress, anger, strain to family dynamics and significant changes to their way of life (Family Caregiver Alliance, 2017; Kao & Stuifbergen, 2004). The limited literature examining the experience of family members records a lack of appropriate education, information and support for psychological stress (Coco et al., 2011). The distress of people with TBI and their families impacts on professional staff, with nurses encountering physical assaults from people with TBI and aggression from family members. To add to the burden for nurses, inadequate staffing ratios can at times lead to heavy workloads (Chen et al., 2010).

A more comprehensive understanding through a synthesis of TBI care research from multiple perspectives is now required. This will contribute to deeper understanding of how therapeutic interactions are experienced and the enablers and challenges to person and family-focused care.

3 | AIM

The aim of this integrative review was to synthesise literature related to the experiences of giving and receiving TBI care from the perspectives of people with TBI, their family members and nurses interacting with hospital or rehabilitation services to provide direction for improvement in nursing care provision and further research. The experience of receiving care will be considered from the perspectives of both people with TBI and family members, while caregiving will be explored from the perspectives of both family members and nurses.

4 | METHODS

The framework outlined by Whittemore and Knafl (2005) guided this integrative review. This approach allows researchers to review primary sources that use multiple research methodologies. When well-conducted, this framework also provides a view of a phenomenon from multiple perspectives, which can inform, and guide practice in clinical nursing (Whittemore & Knafl, 2005). Whittemore and Knafl's six-stage strategy for rigour enhanced the quality of the review. This included problem identification, literature search, data evaluation, data analysis and data presentation. Table 1 illustrates the decisions and issues associated with the integrative review process.

Additionally, Whittemore and Knafl's ten elements of data analysis were used to ensure that a robust evaluation was performed, including accurate identification of patterns and themes across the literature. The ten elements of data analysis included; noting patterns and themes, seeing plausibility, clustering, counting, making contrasts and comparisons, discerning common and unusual patterns, submitting particulars into the general, noting relations between variability, finding intervening factors and building a logical chain of evidence. These elements are presented in Table 2.

The databases of CINAHL, PubMed, Proquest, EMBASE and Google Scholar were searched between January 2017–April 2017 according to predetermined inclusion and exclusion criteria (See Table 3). Because there was very limited research that focused solely on the family members, we placed a generous time limit (from 1995) to capture these experiences. The key words used included the following: traumatic brain injury, nurses, patients, families, experiences, nursing care, hospital and rehabilitation. Medical Subject Headings (MeSH) included the following: brain injuries, right hemisphere injuries, left hemisphere injuries, inpatients, practical nurses and caregivers. The key words were also searched in combination using Boolean operators "OR" and "AND." Table 4 gives further details of the search strategy.

During the literature search, reference was made to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement and a PRISMA flow diagram was developed (See Figure 1) (Moher, Liberati, Tetzlaff, & Altman, 2009). The initial search resulted in a large number of papers (n = 3,510), and additional papers were also identified via a manual search of reference lists (n = 18), resulting in a total of 3,528 papers. Duplicate articles and nonprimary research abstracts were removed (n = 3,309). The abstracts of the final 219 papers were screened, and of these, 111 papers clearly did not meet the inclusion criteria and were removed (See Figure 1). Four papers that examined acquired brain injury (ABI) were included because a percentage of participants had acquired a brain injury due to TBI (Erikson, Karlsson, Borell, & Tham, 2007; Gebhardt, McGehee, Grindel & Testani-Dufour, 2011; Pryor, 2005; Turner et al., 2007). The texts of the remaining articles (n = 108) were read in full. A further 77 papers were removed following application of the exclusion criteria. In total, 31 papers were considered at a level that was satisfactory for inclusion in this review.

Each paper was independently assessed and systematically appraised for methodological rigour using the McGill Mixed Methods Appraisal Tool (MMAT-Version 2011) (Pluye et al., 2011). This tool-guided assessment with specific criteria for qualitative studies, descriptive quantitative surveys and mixed methods studies included in this review. The quality appraisal items included clarity of the research question and aims, appropriateness of methodology and analysis, relationship between the findings and the research setting and relationship between researchers and participants. For quantitative surveys, it included the validity of the measurement instrument and response rates. For mixed methods, it considered the integration of qualitative and quantitative components. Studies with a qualitative appraisal measurement of <50% were excluded. Quality appraisal details appear in Table 5.

Traumatic brain injury can create particular ethical challenges regarding capacity for consent. All included studies had Human Research Ethics Committee approval, their processes seemed reasonable, and all their participants provided written consent.

TABLE 1 Six stages of the integrative review process (Whittemore & Knafl, 2005)

Stage of review	Explanation of methodological process
Problem identification	TBI remains a major health problem worldwide that affects individuals, families and communities. Traumatic brain injury (TBI) care settings are dynamic clinical environments that necessitate the therapeutic interaction between people with TBI, families and nurses. These three subgroups of persons, experience issues and challenges arising from physical disability including limb weakness and sensory limitations, and psychological changes such as memory and cognitive impairment and psychological responses to stress. The long-term effects of TBI can also include epilepsy and depression and difficulty returning to the workforce can have a negative impact on the person's self-reliance and can increase their reliance on welfare support. While there are numerous studies on the experience of TBI, the notion of "care" in response to this injury remains understudied. An integrative literature review of pertinent sources to synthesise and evaluate what is known about the topic of giving and receiving care in TBI will generate deeper understanding of the experiences and the contexts in which such care is provided and will inform recommendations for practice and future research
Literature search	A research question was used to focus and guide the search for literature. Key databases included CINAHL, PubMed, Proquest, EMBASE and Google Scholar. There were no limits set on date of publication to provide access to the best evidence available about the topic of review. The inclusion and exclusion criteria were predefined and applied. The focus of the search was primary research articles. However, as an integrative review considers both empirical and theoretical sources, the inclusion of theoretical papers that provided key data to the review was facilitated by our research strategy (although none were identified). Nonprimary review papers that addressed issues related to the topic were used to inform our background and discussion. The final review process resulted in 31 research papers
Data evaluation	Primary research papers varied in methodological approach: phenomenology, descriptive qualitative, grounded theory, mixed methods and descriptive structured questionnaires. All papers were evaluated for rigour using the McGill Mixed Methods Appraisal Tool (Pluye et al., 2011), specific to the relevant methodology. Manuscript quality was determined using a two-point scale that considered both methodological/theoretical rigour and relevance of the findings (high or low). While this did not result in exclusion of papers, those reports with low levels of rigour were given less weight during analysis
Data analysis	A summary table was developed which listed the characteristics of the papers considered for review (Table 5). The extraction of data from primary sources was on the basis of relevance to the topic of review. The findings from all the reviewed papers were conceptualised and synthesised into three categories: people with TBI experiences, family members' experiences and nurses' experiences (Table 6). Within these categories, themes that emerged from the synthesis of findings from various sources were cross-checked with the primary sources for accuracy and congruence. Whittemore and Knafl (2005) propose Miles & Huberman's (1994) approach which involves (i) Data reduction—Classifying data into preliminary groups (people with TBI, family members and nurses); (ii) data display—Table 6 assembles data for the 3 participant groups to see patterns and relationships; (iii) data comparison—this is where our cross-cutting themes were developed by seeing relationships of ideas across groups; (iv) conclusion drawing and verification—a narrative explanation of findings was prepared by the first author and was followed by a robust and iterative process of debate and review of findings within the team
Presentation	There was a systematic presentation of findings and analytic discussion of results. A summarised table of synthesis of themes that emerged from the analysis and conceptualisation of findings appears in Table 6

TBI, traumatic brain injury.

5 | RESULTS

The 31 papers that met the inclusion/exclusion criteria are summarised in Table 5.

The papers presented data from studies conducted in 13 countries: Six papers from the USA, five from Australia, four from France, three from the United Kingdom, three from Sweden, two from Canada, and one each from Thailand, Denmark, New Zealand, Botswana, South Africa, Finland and Japan. Two papers combined data from France and Canada. The review included 16 generic qualitative studies (Damkliang, Considine, Kent, & Street, 2015; Fleming et al., 2012; Freeman, Adams, & Ashworth, 2015; Gebhardt, McGehee, Grindel, & Testani-Dufour, 2011; Hammond, Davis, Cook, Philbrick, & Hirsch, 2016; Holm, Schönberger, Poulsen, & Caetano, 2009; Jumisko et al., 2007; Keenan & Joseph, 2010; Lefebvre & Levert, 2012; Lefebvre, Pelchat, Swaine, Gelinas, & Levert, 2005; Mbakile-Mahlanza, Manderson, & Ponsford, 2015; Pryor, 2005; Saban, Hogan, Hogan, & Pape, 2015; Searby & Maude, 2014; Soreny, 2009; Webster et al., 2015). Eight of the qualitative papers applied a phenomenological approach: six used descriptive phenomenology (Erikson et al., 2007; Hooson et al., 2013; Howes, Benton, & Edwards, 2005; Kao & Stuifbergen, 2004; Turner et al., 2007; Wongvatunyu & Porter, 2005), and two used hermeneutic phenomenology (Johnson, 1995; Jumisko, Lexell, & Söderberg, 2009). Two studies used grounded theory (Nochi, 1998; Villaneuva, 1999), and one used participatory research (Hammond et al., 2016) and two used mixed methods (Chamberlain, 2005; O'Callaghan, McAllister, & Wilson, 2011). Finally, three used cross-sectional surveys (Coco, Tossavainen, Jääskeläinen, & Turunen, 2013; Jaimes, Thompson, Landis, & Warms, 2015; Oyesanya, Thomas, Brown, & Turkstra, 2016).

All papers examined the experience of giving and/or receiving care for TBI. Data from the articles were categorised under participant groups, and the following categories and subcategories emerged: (i) people with TBI experiences—experiencing challenge to self-identity, feeling different, experiencing a changed body, behaviour and emotions, needing practical help, experiencing personal growth and regaining personal control; and (ii) family members' experiences—seeking support, seeking partnership with health

TABLE 2 Elements of data analysis (Whittemore & Knafl, 2005)

Elements
Noting patterns and themes: An iterative process was applied and data from primary sources were compared to identify relationships, patterns and themes
Seeing plausibility: All themes that emerged were considered against this element in terms of being credible, acceptable, trustworthy or reasonable. Our critical stance began with quality review of the primary ideas and research methods in the included papers and their relationship to our research question. Initial coding was conducted by the first author and presented in tabular form. The initial coding was debated within the team as to the "fit" of the data within themes. The first author then narratively described the review findings. This narrative was then subject to rigorous discussions between team members as to the strengths and weaknesses of the conclusions drawn. This involved an iterative process whereby we returned repeatedly to the original sources to confirm meaning and test the strength of our synthesis
Clustering: Themes identified as patterns of similar data extracted from primary sources were clustered under three subgroups; people with TBI experiences, family members' experiences and nurses' experiences
Counting: Phases that represented experiences of giving and receiving care were identified in the findings of reviewed sources and their occurrences were counted. The phase with the most count ranked first in the presentation of subthemes during the review process and themes needed to be richly described and noted to have reached data saturation within their primary sources
Making contrasts and comparisons: Reporting of the findings was critically presented with examples provided to enable contrasts and comparisons to be drawn, including negative case examples.
Discerning common and unusual patterns: The themes were verified with primary data sources to confirm accuracy in the reporting of patterns that were identified in the findings. Negative case examples were considered and described
Subsuming particulars into general: Subthemes were identified in the data extracted from the primary sources. These subthemes were further merged into larger subgroups that formed the main themes
Noting relations between variability: Possible explanations for variability between studies and groups were explored
Finding intervening factors: Factors such as gender, injury severity, caring or care recipient role and time since injury were considered during analysis
Building a logical chain of evidence: Themes were grouped under three headings that represented people with TBI, family members and nurses. The analytical presentation of findings and discussion of results followed a logical sequence with primary sources referenced to themes.

TBI, traumatic brain injury.

TABLE 3 Inclusion and exclusion criteria

Inclusion criteria
• Primary study published in peer-reviewed journal • Focus of paper is on experiences of providing care to people with TBI/or people with TBIs' experiences of receiving care following TBI/or family members experiences of providing care for a person affected by TBI or receiving support for their care of a person with TBI
Exclusion criteria
• Papers published in a language other than English • Review articles and grey literature • Studies that did not include details of time spent in the hospital setting

TBI, traumatic brain injury.

professionals, making sense of the TBI, pursuing positive coping and dealing with new family responsibilities); and (iii) nurses' experiences —providing advocacy and support, monitoring physiological response, maintaining personal safety, providing a therapeutic environment, entering the person's world, the importance of beliefs, competence in providing nursing care and managing challenging behaviour. These subcategories are further described in Table 6.

5.1 | Cross-cutting themes

The categories and subcategories in Table 6 were systematically analysed and synthesised, and six major cross-cutting themes were identified in relation to people with TBI, family members' and nurses' experiences of giving and receiving care in TBI. These themes comprised: (1) seeking personhood, (2) navigating challenging behaviour, (3) valuing skills and competence, (4) struggling with changed family responsibilities, (5) maintaining productive partnerships and (6) reflecting on workplace culture.

5.1.1 | Seeking personhood

Seeking personhood was a theme that resonated across the experiences of people with TBI, their families and nurses. People with TBI described *seeking personhood* by trying to overcome feelings of regret and grief for lost independence (Howes et al., 2005; Turner et al., 2007). Their *personhood* was challenged by personal costs and lost abilities, for example, failure to regain pre-TBI elements of identity such as employment status (Hooson et al., 2013). A major challenge to *personhood* was carrying guilt where, for example, they worried about other victims of the traumatic event that led to their present state (Johnson, 1995). While in receipt of hospital care, people with TBI's sense of *personhood* seemed to be eroded if they experienced insensitivity, impatience and mistreatment from care providers (Chamberlain, 2005; Jumisko et al., 2007, 2009; Webster et al., 2015).

A further threat to *personhood* for people with TBI was their sense of feeling different. This sense of abnormality was reinforced where they did not take part in, or had minimal input into planning their inpatient care, and when they were excluded from planning for

TABLE 4 The Search strategy

Database	Concepts	Subject headings	Search terms	Combinations
CINAHL	1. Traumatic brain injury	Brain injuries Right hemisphere injuries Left hemisphere injuries	Traumatic brain injury OR Brain injuries OR Right hemisphere injuries OR Left hemisphere injuries OR Brain injur* OR Head Injur* OR	"OR"; "AND" Boolean/ Phrase
	2. Hospital setting	Inpatients Clinical laboratories Hospitals, Public Hospitals, Veterans Hospitals Military	Inpatients Public hospitals Acute care settings	
	3. Nurses	Nurses or practical nurses	Nurses or practical nurses or Nurs*	
	4. Patients	Patients or caregivers	Patients or caregivers	
	5. Families	Families	Families or famil*	
	6. Nursing care	Nursing care or nursing care delivery systems or critical care nursing	Nursing care or nursing care giving caregiving	
	7. Rehabilitation settings	Rehabilitation settings	Rehabilitation settings	
PubMed	Traumatic brain injury, nursing care, nurses, patients, families, hospital settings, rehabilitation settings	Brain injuries, traumatic Inpatients or patients Nurses, families Hospital, rehabilitation settings	Traumatic brain injuries OR Brain AND injuries AND traumatic Giving care OR receiving care OR Nurses, patients, families, hospital, rehabilitation settings	"OR"; "AND"
Proquest	Traumatic brain injury, nursing care, nurses, patients, families, hospital settings, rehabilitation settings	Brain injuries, traumatic Hospitals, Public Rehabilitation settings	Traumatic brain injury, nursing care, nurses, patients, families, hospital settings, rehabilitation settings	"OR"; "AND"
EMBASE	Traumatic brain injury, nursing care, nurses, patients, families, hospital settings, rehabilitation settings	Traumatic brain injury or head injury or brain injury Nurses or nursing Patients, families, hospitals Rehabilitation settings	Traumatic brain injury or head injury or brain injury Nurses or nursing Patients, families, hospitals Rehabilitation settings	"OR"; "AND"
Google Scholar	Traumatic brain injury, nursing care, nurses, patients, families, hospital settings, rehabilitation settings	Keywords and full sentences focusing on the review topic were used in the search process		

their discharge from acute care settings (Freeman et al., 2015; Jumisko et al., 2007; Kao & Stuifbergen, 2004; Nochi, 1998).

There was also notable threat to *personhood* in rehabilitative care settings and people with TBI described these as restrictive environments. Professional caregivers were perceived as authoritative and people had minimal or no input into their own personal rehabilitation care (Fleming et al., 2012; Keenan & Joseph, 2010). As a result of their injury, people with TBI had limited ability to communicate their own views to professional caregivers and became irritable, engaged in self-criticism and had minimal social interactions during rehabilitation (Freeman et al., 2015; Webster et al., 2015). Also, negative perceptions of self hindered the persons' progression towards regaining personal control and participating in rehabilitative efforts instituted by professional caregivers (Hooson et al., 2013). People with TBI described professional care that often lacked empathy, generated psychological distress, and they longed to return home or to their families (Johnson, 1995). However, family caregivers' negative comments, criticisms and family dynamics could also heighten peoples' irritability (Hammond et al., 2016; Howes et al., 2005). This sequence of narratives suggests that the lack of perceived compassionate care generated negative perceptions of self among individuals with TBI, devaluing their sense of *personhood.*

People with TBI experienced stigma and discrimination which negatively impacted on social interaction and changed the way they valued life (Howes et al., 2005; Jumisko et al., 2007; Nochi, 1998). They perceived a lack of control over their personal lives, were in receipt of unfamiliar care and found it difficult to rely on other people for assistance with personal tasks (Chamberlain, 2005; Erikson et al., 2007). Feelings of powerlessness and desperation were particularly severe for people who had no community support, and who expressed feeling stranded in the hospital (Villaneuva, 1999).

More positive aspects of *seeking personhood* were also noted. People with TBI experienced personal growth through participating in meaningful activities and managing their personal time, and involvement in, or interaction with, community support groups (Turner et al., 2007). People with TBI also sought to regain personal control by maintaining their physical and psychological well-being, mastering unfamiliar situations and achieving new ways of doing

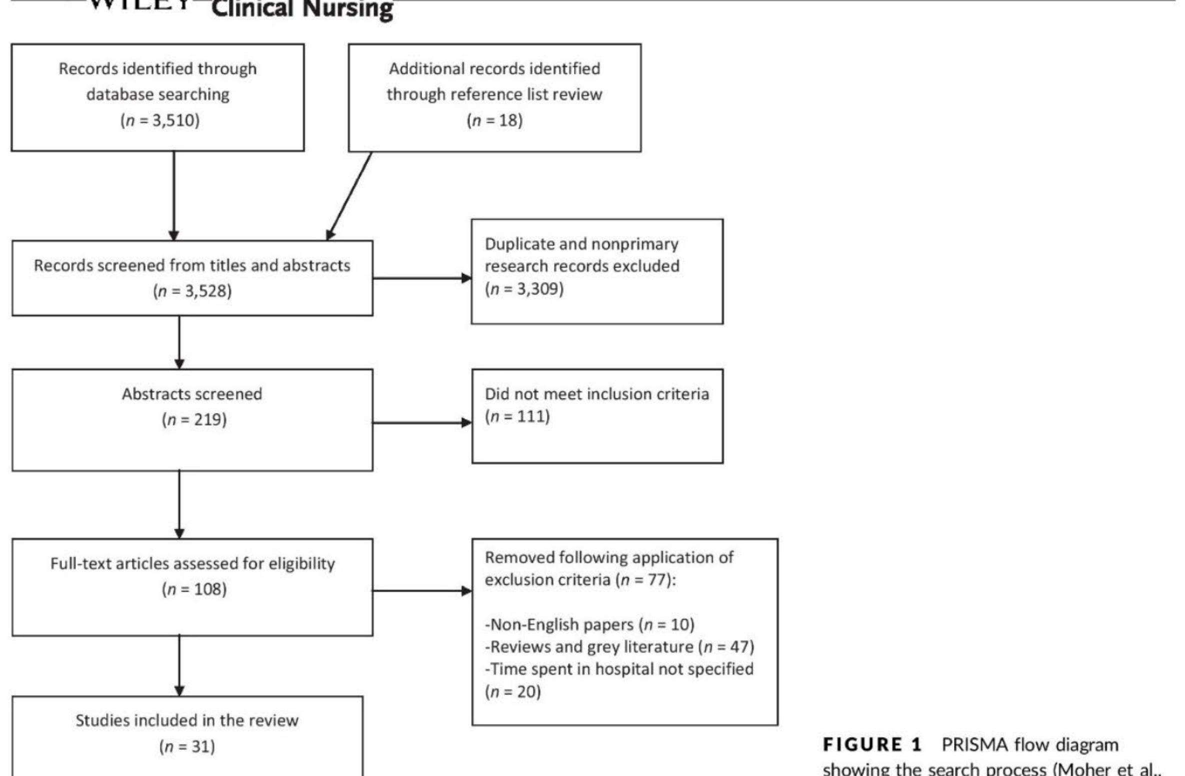

FIGURE 1 PRISMA flow diagram showing the search process (Moher et al., 2009)

things (Erikson et al., 2007; Turner et al., 2007). For some, regaining personal control over their everyday lives was dependent upon their ability to adapt and accept changes resulting from TBI as well as their personal interpretation of the traumatic events leading to their injury (Johnson, 1995; Jumisko et al., 2009; Turner et al., 2007).

Family members contributed to personalising their loved one's experience by offering supportive care to the best of their abilities (Kao & Stuifbergen, 2004; Oyesanya et al., 2016). This often necessitated negotiating their own personal circumstances to accommodate the care needs of the person with TBI (Kao & Stuifbergen, 2004).

Nurses endeavoured to attend to personhood and person-centred care by instituting meaningful partnerships with people with TBI to improve health and well-being (Coco et al., 2011). Nurses also tried to understand the person's worldview and described how they considered the whole person's physical, emotional and social needs and aimed to provide care in a nonjudgemental way (Mbakile-Mahlanza et al., 2015; Villaneuva, 1999). This whole-of-person care included considering the person's cultural background. Nurses reflected on how their personal culture and values influenced their response to people with TBI and their views about care (Mbakile-Mahlanza et al., 2015). Developing rapport with people with TBI and providing them with meaningful clinical information was considered a key obligation for nurses. However, according to people with TBI, nurses selectively observed or rarely upheld this responsibility when providing person-centred care. For example, nurses at times concentrated on providing physical care and neglected the importance of engaging with them interactively (Villaneuva, 1999).

5.1.2 | Navigating challenging behaviour

People with TBI expressed living in a changed body along with altered behaviour and emotions. *Challenging behaviours* included increased irritability, changed physical and emotional behaviours as well as having to do things slower than they did before (Hammond et al., 2016; Holm et al., 2009; Mbakile-Mahlanza et al., 2015; Nochi, 1998). People with TBI experienced anxiety when professional caregivers made changes to their daily routines, and they were also troubled by memory loss, confusion and mental health changes (Hammond et al., 2016; Holm et al., 2009; Mbakile-Mahlanza et al., 2015).

Family members' descriptions of the experiences of managing challenging behaviour while in hospital or rehabilitation were absent and this was primarily due to the fact that such duty of care rested with the nurses.

Challenging behaviour hindered the provision of quality care and required the implementation of proactive nursing strategies to maintain safety for both people with TBI and nurses. Nurses had to watch for, and identify, triggers for people with TBIs' aggression and expressed being fearful for their personal safety (Pryor, 2005; Searby & Maude, 2014; Villaneuva, 1999). Providing care for people with

TABLE 5 Characteristics of included studies

SN	Author	Study design	Aim	Setting	Sample	Methods	Quality appraisal score (MMAT)	Findings
1	Chamberlain (2005)	Mixed Methods study—Descriptive qualitative study and extended Glasgow Outcome Score	To describe the experience of surviving traumatic brain injury (TBI) as narrated by patients 1 year after injury	Public Hospitals-Australia	Convenience sample of 60 people within 1 year of TBI	Unstructured Interviews audio-recorded & transcribed verbatim. Data analysed using qualitative content analysis	100%	People with TBI reported insensitive professional care that lacked empathy. They received incongruent information and advice which caused them distress. People felt left to "float away" when they called for help without a caregiver response. The perceived insensitivity of clinicians diminished peoples' hope of recovery. People with TBI without community support felt stranded in hospital
2	Coco et al. (2013)	Structured nonvalidated questionnaire	(i) To see how frequently neurosurgical ward nurses provided practical support to TBI family and perceived required level of competence (ii) To seek correlations between nurse characteristics, family interventions provided and perceived level of nurse competence to facilitate emotional support	Neurosurgical wards-Finland	Population sample of 115 registered and nonregistered nurses	Structured nonvalidated questionnaire. Descriptive statistics were used to determine how often nurses provided emotional support to family members of patients with TBI	100%	Nurses' level of education and length of work experience affected the practical support they provided to family. Teaching family members how to assist activities of daily living and how to deal with mood swings needed advanced nursing competence. Nurses saw supporting family members with breaks, recreation and planning persons' hospital discharge as basic competencies and were the most commonly undertaken nursing activity. Effective practical family support required multidimensional practical nurse competencies
3	Damkliang et al. (2015)	Descriptive qualitative study	To describe nurses' perceptions of an evidence-based care bundle for initial nursing management of patients with severe TBI	ED in a rural hospital-Thailand	Convenience sample of 15 nurses working in the ED	Semi-structured interviews during and after roll-out of care bundle audio-recorded and transcribed verbatim and analysed using thematic analysis and these were descriptively described	100%	Nurses felt the evidence-based care bundle for people with TBI increased their awareness, knowledge, skills, confidence and understanding of TBI care. It enhanced people' safety, team work and communication among clinicians in the ED. Nurses felt that agitated people with TBI were a major challenge to care for

(Continues)

TABLE 5 (Continued)

SN	Author	Study design	Aim	Setting	Sample	Methods	Quality appraisal score (MMAT)	Findings
4	Erikson et al. (2007)	Longitudinal descriptive phenomenological study	To describe the lived experience of memory impairment in daily occupations during the first year after acquired brain injury (ABI)	Rehabilitation clinic-Sweden	Purposive sample of 4 participants with acquired brain injury (ABI) (1 TBI participant)	Interviews (four times over 12 months after TBI) were audio-recorded and transcribed verbatim. Data analysed using Empirical Phenomenological Psychological method (Karlsson 1993)	100%	People with TBI experienced a chaotic life-world where they received care that was unfamiliar to them. They described a loss of personal control as a result of dependence on caregivers to perform personal tasks. Learning new ways of doing things was challenging and caused symptoms such as headache and stress
5	Fleming et al. (2012)	Descriptive qualitative study	To describe and interpret the inpatient brain injury rehabilitation experience from the perspective of patients and their care givers	Brain injury rehabilitation unit in a tertiary hospital-Australia	Purposive sample of 20 patients with ABI (16 had TBI) and 18 caregivers	Semi-structured interviews were conducted and tape recorded. An interview guide was used, data were transcribed verbatim and data were analysed using content analysis	100%	People with TBI perceived the TBI rehabilitation environment as restrictive and likened it to prison. There was lack of privacy and space and a concern for security of personal belongings. People with TBI described recurrent mistreatment and disrespect from staff. In-house activities created boredom and therapy was considered unstructured. People with TBI reported a positive experience if they were visited by family or friends. Families felt the environment impacted on the people's well-being and motivation towards rehabilitation. Families needed further information regarding TBI, the rehabilitation process, treatment goals and outcomes and counselling services
6	Freeman et al. (2015)	Descriptive qualitative study	To provide an understanding of the individuals' sense of self and sources of emotional distress and growth following TBI	Neuropsychological rehabilitation centre-UK	Purposive sample of 9 male participants 17 – 21 months since TBI	Semi-structured interviews were audio-recorded and transcribed verbatim. Data were analysed using thematic analysis	100%	Men experienced changes in self-awareness and a sense of abnormality and were ashamed or embarrassed about their head injury. Participants expressed regret when they compared the present state to their preinjury state. They also felt that that people treated them differently; engaged in self-criticism (sense of guilt); they longed to be as others wanted them to be and withdrew from social contacts

(Continues)

TABLE 5 (Continued)

SN	Author	Study design	Aim	Setting	Sample	Methods	Quality appraisal score (MMAT)	Findings
7	Gebhardt et al. (2011)	Descriptive qualitative study	To (i) explore the caregiver's hope for recovery from ABI, (ii) compare the nurse's and carers hopes for recovery and (iii) identify what caregivers and nurses do to maintain hope for recovery during rehabilitation	Major catastrophic care hospital-USA	Purposive sample of 42 participants, that is, Caregivers of patients with ABI (n = 21) and Nurses (n = 14)	Semi-structured interviews were conducted, audio-taped, transcribed & coded. Data were analysed using thematic analysis.	100%	Nurses and caregivers maintained hope for recovery from TBI by allowing the involvement of family; getting to know the people with TBI better; having spiritual strength; and encouraging family members to take people with TBI recovery 1 day at a time
8	Hammond et al. (2016)	Participatory qualitative study	To (i) describe the experience of irritability from the perspectives of multiple people living with or affected by TBI and (ii) develop a conceptual model of irritability	Tertiary hospital setting-USA	Convenience sample of 44 stakeholders including: individuals with a history of TBI (n = 16), family members (n = 10), community professionals (n = 8), healthcare providers (n = 7) and researchers (n = 3)	Using five focus groups, sessions were video and audio-taped and transcribed verbatim. The constant comparison method was used and data were coded using grounded theory coding methods. Time since TBI ranged from 2 to 16 years	100%	People experienced five dimensions of irritability triggers; (i) affective triggers (related to moodiness and feelings); (ii) behavioural triggers (self-regulation, impulse control and poor time management); (ii) cognitive perceptual triggers (ways of seeing the world); including negative self-talk, not letting go of thoughts, blaming others, negative social comparisons, resentment about the cause of TBI, having rigid expectations of self (iv) relational triggers (interpersonal and family dynamics); not accepting the limitations of TBI, having family take over tasks, criticism, negative comments, caregiver's tone of voice (perceived or real). Family struggled with self-disclosure regarding feelings, opinions about the injury (v) environmental triggers (environmental stimuli, disruption to routine, cultural expectations); noise, crowds, distraction, sudden change in routine, societal expectations

(Continues)

TABLE 5 (Continued)

SN	Author	Study design	Aim	Setting	Sample	Methods	Quality appraisal score (MMAT)	Findings
9	Holm et al. (2009)	Descriptive qualitative study	To (i) identify most frequently reported difficulties for patients/families after severe TBI at hospital discharge, (ii) compare patients' and relatives' reports of patient difficulties and (iii) explore the role of injury severity, disability and other factors on subjective experience	Brain injury unit (BIU)-Denmark	Purposive sample of 52 patients with TBI and 50 relatives of patients with TBI	Validated questionnaire on discharge from the Brain Injury Unit. Data were analysed using Statistical Package for Social Sciences (SPSS 13.0)	100%	People with TBIs' self-reported somatic and cognitive difficulties included trouble remembering things, having to do things slowly, trouble concentrating and lacking energy. Families reported that people with TBI had difficulty finding things and were at times confused. A discrepancy existed between people with TBIs' view of the difficulties they faced compared to healthcare professionals and family members
10	Hooson et al. (2013)	Interpretative Phenomenological Analysis (IPA)	To understand positive contributors to work (RTW) rehabilitation for people with multiple TBI impairments and disabilities	Brain injury rehabilitation unit-UK	Purposive sample of 10 patients 3–9 years after TBI	Semi-structured interviews audio-recorded and transcribed verbatim. Field notes and data were analysed using IPA techniques	100%	The RTW experience was difficult and painful and caused a grief reaction. People with TBI reported loss self, loss of being part of a team and change to future occupational dreams. They preferred to return to previous employment rather than volunteering/retraining. Rehabilitation was influenced by change in physical abilities, emotions and therapeutic relations. RTW rehabilitation was influenced by a supportive work environment, the individual's personal perspective and the support of family and friends.
11	Howes et al. (2005)	Interpretative Phenomenological Analysis (IPA)	To investigate the experience of TBI from the perspective of TBI patients	General hospital setting-UK	Convenience sample of six women with TBI	Semi-structured interviews were audio-recorded and transcribed verbatim. Analysis occurred using IPA techniques	100%	Participants described changes to cognition, physical perception and function and decreased social interaction. Intense emotional reactions such as anger, anxiety, psychological distress, panic attacks were sometimes directed towards caregivers. They struggled to make sense of their new situation and felt insecure. People with TBI gradually

(Continues)

TABLE 5 (Continued)

SN	Author	Study design	Aim	Setting	Sample	Methods	Quality appraisal score (MMAT)	Findings
								adapted to and accepted changes in life
12	Jaimes et al. (2015)	Cross-sectional study using a validated survey	To survey nurses' knowledge of pain management for patients with combat-related TBIs	Two TBI rehabilitation units-France	Convenience sample of 25 nurses from 2 TBI rehabilitation units	Electronic survey. Quantitative data analysed using SPSS. Qualitative responses analysed using thematic analysis	75% (response rate of 52%)	Nurses' understanding of TBI pain management was challenged by misconceptions about who was the best judge of pain (nurses or people with TBI). Nurses felt that people with TBI over reported pain. The combination of mental health problems and TBI made pain management complex for people with combat-related TBI
13	Johnson (1995)	Descriptive Phenomenological study	To describe the lived experience of one family with TBI	Acute care hospital settings and outpatient rehabilitation settings-USA	Purposive sample of 7 family members (parents and siblings) of 1 person with TBI	Interviews with family audio-recorded & transcribed verbatim. Data were analysed using hermeneutic analysis	100%	Family members described overwhelming helplessness, valued honest answers from clinicians and wanted to be involved in care provision. Families were emotionally affected by the presence of an endotracheal tube. The person with TBI described longing to return home, having concern for others and needing to understand the events that led to the TBI
14	Jumisko et al. (2007)	Descriptive qualitative study	To describe how people with moderate or severe TBI and their close relatives are treated/perceived by others in their world	Tertiary hospital setting-USA	Purposive sample of 12 people with TBI and 8 family members	Semi-structured interviews audio-recorded & transcribed verbatim, data were analysed using thematic content analysis	100%	People with TBI described being excluded (being avoided, being ruled by the authorities, searching for answers); missing confirmation (being met with distrustfulness and being misjudged); longing for the right kind of help (appreciated people who listened, believed, tried to understand or help)
15	Jumisko et al. (2009)	Interpretative phenomenological study	To elucidate the meaning of feeling well for people with moderate or severe TBI	Community-USA	Purposive sample of 8 participants with moderate or severe TBI	Semi-structured interviews audio-recorded & transcribed verbatim. Data were analysed	100%	Feeling well for participants with TBI was that the unfamiliar life gradually became familiar. Feeling well also required finding strength; regaining control over everyday life; being close to someone and being good to others

(Continues)

TABLE 5 (Continued)

SN	Author	Study design	Aim	Setting	Sample	Methods	Quality appraisal score (MMAT)	Findings
						using hermeneutic analysis		
16	Kao and Stuifbergen (2004)	Descriptive Phenomenological study	To describe the meaning of the experience of the relationship between young adult TBI survivors and their mothers using a phenomenological approach	Participants were recruited via a Brain Injury Association-Sweden	Purposive sample of 9 males and 3 females (aged 18–25 years) and their mothers (n = 12)	Semi-structured interviews audio-recorded & transcribed verbatim. Data were analysed using Colaizzi's (1978) phenomenological method	100%	TBI survivors' felt abnormal: they did not meet family/society's expectations and withdrew from society. Mothers experienced prolonged uncertainty and needed acceptance and support. Mother–child relationships became strained (overprotection vs. independence); marital complications occurred and marital life habits were renegotiated. Internal and external stressors increased strain to family relations
17	Keenan and Joseph (2010)	Descriptive qualitative study	To identify the needs of individual family members of a relative who sustained a severe TBI and to determine if these needs changed over time	Major trauma academic health institution-Sweden	Purposive sample of 25 family members of people with TBI	Semi-structured interviews were conducted upon discharge from ICU and discharge from hospital, audio-recorded & transcribed verbatim. Data were analysed using thematic analysis	100%	Family members' needed to be involved in TBI care. They wanted meaningful updates about health status, guidance in making sense of the TBI news, help in dealing with uncertainty and in receiving community support. Family members identified good listening, getting to know the family, demonstrating knowledge and competence in caring for the traumatic brain-injured relative as important nurse competencies
18	Lefebvre et al. (2005)	Descriptive qualitative study	To investigate the experience of individuals who had sustained a TBI, their families and the physicians and health professionals involved, from critical care episodes and subsequent rehabilitation	Tertiary trauma centre, two rehabilitation centres, a paramedic organisation and an association of people with TBI – Canada	Purposive sample of eight people with TBI, 14 family members, 22 health professionals, nine physicians	Semi-structured interviews audio-recorded and transcribed verbatim. Data were thematically analysed with assistance of QSR NUDIST software	100%	People with TBI and families had difficulty grasping the significance of TBI, were uncertain about the future, wanted to be involved in care planning/decision-making and expected to be listened to. Transfer between facilities was destabilising, created disorientation and generated stress. People with TBI experienced social isolation and stigma. Clinicians were uncertain about effects of care interventions and prognosis; they discussed key TBI matters with colleagues but not with families, withholding true facts; high family expectations and conflicting family

(Continues)

TABLE 5 (Continued)

SN	Author	Study design	Aim	Setting	Sample	Methods	Quality appraisal score (MMAT)	Findings
								dynamics affected TBI care delivery. Lack of resources affected quality of care with work overload and exhaustion being the main barriers; poor handover between acute/ rehabilitation facilities affected continuity of care. Clinicians felt unprepared for breaking the news about TBI to families. Positive relationships between families and clinicians supported adaptation, while disagreements were hurtful and detrimental to trust. The role, habits and activities of family were shaken up and questioned. Families desired people with TBI to reintegrate into social/community life and participate in meaningful work. Lack of resources for social integration resulted in social withdrawal and marginalisation
19	Lefebvre and Levert (2012)	Exploratory, descriptive qualitative study	To explore the needs of individuals with TBIs and their loved ones throughout the continuum of care and services	Acute hospital settings-Canada and France	Purposive sample of 150 participants (people with TBI, their family and clinicians)	18 focus groups: patients (n = 56), family (n = 34), clinicians (n = 60) were audio-recorded, transcribed verbatim and analysed using content analysis	75% (nonvalidated questionnaire)	People with TBI wanted accurate information about progress, treatment options and test results. Families needed support and reassurance from clinicians and wanted to be involved in proving care. Collaborative relationships with clinicians were vital. Professionalism, respect for privacy, empathy, sensitivity and maintaining a stable healthcare team enhanced quality of TBI care
20	Mbakile-Mahlanza et al. (2015)	Descriptive qualitative study	To explore the experiences of people with TBI, their family carers and clinicians in Botswana	Two public rural hospitals-Botswana	Purposive sample of 21 patients with TBI, 18 carers & 25 clinicians	Semi-structured interviews in the local language or English were audio-recorded and transcribed verbatim. Data analysed using thematic analysis	100%	TBI-related changes were physical, sensory, cognitive, emotional and behavioural. Beliefs about the cause of TBI were associated with supernatural causes, superstitions, bad luck, witch craft, or God's will. Family members showed love and devotion but communication with clinicians was limited. Carers described inadequate information, resources (e.g., computers, Internet, staff) and language barriers

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TABLE 5 (Continued)

SN	Author	Study design	Aim	Setting	Sample	Methods	Quality appraisal score (MMAT)	Findings
21	Nochi (1998)	Grounded theory study	To examine the various experiences of self that people with traumatic brain injuries (TBI) have in their daily lives	Community setting-New Zealand	Theoretical sample of 10 people with TBI	Semi-structured interviews audio-recorded and transcribed verbatim; data analysed using constant comparative method in grounded theory framework	100%	People with TBI experienced loss of clear self-knowledge, (memory loss); loss of self by comparison (feeling different); loss of self in the eyes of others (label placed by society)
22	O'Callaghan et al. (2011)	Mixed methods Descriptive study	To identify the current experiences of health care and needs of carers of adults with TBI in Victoria, Australia	Postal survey and individual interviews-Australia	Purposive sample of 184 carers of people with TBI	Validated postal questionnaire and semi-structured interviews. Survey data analysed using SPSS. Qualitative data – QRS NVIVO 7 and analysed using thematic analysis	100%	Carers experienced a reduction in supportive services following discharge. The information received while transitioning through the healthcare journey was inadequate and progressively declined, while the responsibility for caring increased. When planning and providing rehabilitative services for people with TBI, carers' needs were not adequately advocated for
23	Oyesanya et al. (2016)	Cross-sectional validated survey study	To investigate nurses' beliefs and learning preferences about caring for patients with moderate/ severe TBI	Major trauma hospital-Botswana	Purposive sample of 513 nurses caring for people with TBI	Electronic survey, data analysed using latent class analysis	100%	There was diversity among the surveyed nurses in terms of: their perceived level of knowledge about TBI care, recovery and treatment options; their beliefs about prognosis, consequences of TBI & nursing role; and their learning preferences and ways of accessing sources of knowledge
24	Pryor (2005)	Descriptive qualitative study using Critical Decision Method	To identify the cues that nurses use to predict aggression in people with ABI	10 hospital brain injury units-Australia	Purposive sample of 28 nurses from 10 different brain injury units	Interviews audio-recorded, transcribed verbatim, thematic analysis in Critical Decision Method framework	100%	When seeking cues for aggression, nurses listen to the person's' speech content (talking, verbalising, threatening); changes in voice (tone, volume, speed); changes in facial expression and in behaviour (wandering, pacing, striding, fidgeting)

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TABLE 5 (Continued)

SN	Author	Study design	Aim	Setting	Sample	Methods	Quality appraisal score (MMAT)	Findings
								and in described emotions (anxiety, frustration, being scared, desperation)
25	Saban et al. (2015)	Descriptive qualitative study	To describe the experience of family caregivers providing care to veterans with TBI	Hospital setting-Australia	Purposive sample of 7 female family caregivers	Telephone interviews audio-recorded and transcribed verbatim. Data analysed using content analysis	100%	Families described becoming aware of disabilities; observing troubling symptoms; dealing with memory loss; being fearful of the person's anger; sensing the person with TBI's loneliness; acknowledging the effects on the family unit; and coping with the situation at hand
26	Searby and Maude (2014)	Descriptive qualitative study	To describe the experiences of newly registered Australian graduate nurses providing care for patients with post-traumatic amnesia following TBI	Tertiary trauma hospital-Australia	Purposive sample of six graduate nurses caring for people with TBI	Semi-structured interviews audio-recorded and transcribe verbatim, analysed fusing thematic and inductive processes	100%	Nurses found people with TBIs' behaviour to be distressing and described conflicting methods of managing difficult behaviour. Nurses felt unprepared and were fearful of assault. They perceived wandering people with TBI to be at risk of harming other persons and staff. Nurses sought external support (calling for security response); used containment processes (use of restraints); and advocated for people's safety
27	Soreny (2009)	Descriptive qualitative study	To gain an understanding of registered nurses' experiences of caring for patients with challenging behaviours	Neuroscience hospital department-USA	Purposive sample of 4 registered nurses caring for people with TBI	Semi-structured interviews, audio-recorded and transcribed verbatim, data analysed using thematic analysis	100%	Nurses felt the neuroscience environment was challenging but was a beneficial place to stay and develop professionally. Understanding challenging behaviour required an understanding of the causes and impact of behaviour. Tactics and strategies varied (common sense tactics, restraints, neuroscience strategies). Nurses sought additional ward-based, or additional mental health staff support.
28	Turner et al. (2007)	Descriptive Phenomenological study	To explore the transition experiences from hospital to home of a purposive sample of individuals with ABI	Hospital outpatient unit and community ABI case management service-Australia	Purposive sample of 13 people with ABI (TBI, $n = 6$) and 11 caregivers	Semi-structured interviews were audio- recorded and transcribed verbatim, Inductive analysis supported by NVIVO software	100%	The hospital experience involved uncertainty, disbelief, shock, sadness, anger, grief and frustration and other life changes. Family caregivers provided a range of supports. There was need for strengthened postdischarge follow-up, case management, and links to support

(Continues)

TABLE 5 (Continued)

SN	Author	Study design	Aim	Setting	Sample	Methods	Quality appraisal score (MMAT)	Findings
								groups. Building friendship networks and community involvement were beneficial as were engaging in meaningful activities and maintaining psychological well-being
29	Villaneuva (1999)	Grounded theory study	To explore the experiences of critical care nurses caring for patients who were unable to respond due to a TBI or receiving neuromuscular blocking agents	Teaching hospital-USA	Purposive sample of 16 ICU nurses caring for people with TBI	Interviews were audio-recorded and transcribed verbatim. Data analysed using constant comparison method and grounded theory coding	100%	Nurses described learning about the person with TBI, maintaining and monitoring (haemodynamic stability); talking to the person with TBI, working with families; struggling with dilemmas and personalising the care experience
30	Webster et al. (2015)	Exploratory, descriptive qualitative study	To (i) examine key challenges for TBI patients and families (ii) create tools to guide families and staff to cope with consequences of TBI in underresourced settings	Acute care hospital and outpatient support clinics-South Africa	Purposive sample of 354 TBI survivors & 175 family members	In-depth interviews of individuals & focus groups audio-recorded & transcribed verbatim. Phase 1 interviews to develop tools, Phase 2 to evaluate. Data analysed using thematic analysis.	75% (inadequate description of data analysis)	Families described poor communication from physicians, receiving complex information and lack of guidance for coping with cognitive impairment, personality changes and TBI behavioural issues. Families' mental health and well-being were affected by stress, frustration, fatigue and burnout. Need was expressed for further information on rehabilitation and access to support services after discharge. People with TBI felt that caregivers became impatient, did not listen and were frustrated because carers did not understand personal needs/problems; desired a more meaningful way of life and well-being
31	Wongvatunyu and Porter (2005)	Longitudinal, descriptive phenomenological study	To describe mothers' experience of helping young adults with TBI	Support groups of mothers with young adults with TBI-USA	Convenience sample of 7 mothers of people with TBI	3 longitudinal interviews using interview guide were audio-recorded & transcribed verbatim. Descriptive phenomenological analysis	100%	Mothers described reconnecting with their child's brain; considering their child's safety; making their lives as normal as possible; dealing with their biggest problem; and advocating for their child

ABI, acquired brain injury; ED, emergency department; IPA, interpretative phenomenological analysis; RTW, return to work; TBI, traumatic brain injury; MMAT, Mixed Methods Appraisal Tool score.

TABLE 6 Clustering of themes within the three categories

Main categories	Categories	Subcategories
People with TBI experiences	Experiencing challenges to self-identity	Regretting and grieving for lost independence[11,28] Having concern for personal cost to life in terms of lost abilities[10] Worrying about others involved/affected by the traumatic event[13] Experiencing insensitivity of health professionals[1] Being unable to communicate own views to caregivers[30] Receiving mistreatment from caregiving staff[15,14] Coping with impatience of caregivers[30] Engaging in self-criticism and social withdrawal[6] Struggling to manage irritability triggers: negative comments, criticisms, family dynamics[7] Pondering how to overcome authoritative rule and having input into personal care[5,17] Learning to live in a restrictive care environment[5] Receiving care that lacked empathy generating psychological distress[11] Longing to return to home or family[13]
	Feeling different	Experiencing a sense of abnormality[6,16,21] Being excluded from care planning[14] Experiencing stigma and discrimination[14,21] Having decreased social interaction and valuing life differently[11] The difficulty of having to rely on carers for assistance[1] Being in receipt of unfamiliar care[4] Lacking control over personal life[4] Feeling powerless and desperate[29] Feeling stranded in hospital where community support was not available[29]
	Experiencing a changed body, behaviour and emotions	Experiencing increased irritability post-TBI[7] Having somatic and cognitive difficulties[9,20] Having physical, emotional and behavioural changes[21] Experiencing anxiety from changes to routine[7] Experiencing difficulty living with memory loss, confusion and mental changes[9,20] Having to do things slower than before[9]
	Needing practical help	Needing follow-up services postdischarge from hospital[28] Longing for the right kind of help[14,19] Needing practical support from close friends[15,19] Wanting collaborative relationship with healthcare professionals[19] Inadequacy of organisational resources hindered practical help[18] Needing factual information from nurses[23]
	Experiencing personal growth	Growing through involvement in community support groups[28] Undertaking meaningful activities and managing personal time[28]
	Regaining personal control	Maintaining physical and psychological well-being[28] Mastering unfamiliar situations[4] Achieving new ways of doing things[4] Adapting to and accepting changes post-TBI[11] Making sense of the situation[13,28] Regaining control over every day life[15] Engagement with rehabilitation affected by personal perspectives post-TBI[18]
Family members' experiences	Seeking support	Wanting culturally appropriate support from caregivers[20] Needing information to support understanding of TBI care[17,20] Longing for emotional and practical support[2,13,17] Seeking strategies to manage feelings of helplessness[13] Engaging strategies to offer encouragement and coping[16]
	Seeking partnership with health professionals	Wanting family involvement in care delivery[8] Needing to be informed of care provision options[13] Expecting to be listened to[17,18] Wanting support for the person and carers upon discharge[22] Advocating for the family members with TBI[31] Desiring honest and clear information about care being given[8] Wanting to be involved in decision-making[18] Feeling unsupported by healthcare professionals[18] Feeling that the information being provided about a loved one's TBI was insufficient[18]

(Continues)

TABLE 6 (Continued)

Main categories	Categories	Subcategories
	Making Sense of TBI	Having difficulty grasping the significance of TBI[18] Getting the news and making sense of it[17] Grasping the person with TBI's disabilities[25] The value of meaningful information about prognosis[23] Understanding that cultural and religious beliefs affect TBI care[20] Finding coping strategies to manage personal circumstances[25,31]
	Pursuing positive coping	Engaging ways to maintain hope[8] Having spiritual strength[25] Taking 1 day at a time[8] Holding on to hope and moving on[8,17]
	Dealing with new family responsibility	Experiencing altered family dynamics[16] Feeling of "dealing with the biggest family problem"[31] Recognising the psychological impact TBI has on every member of the family[18] Experiencing family strain due to balancing family commitments with TBI care[16] Experiencing uncertainty about TBI progression and prognosis[18] Sharing the responsibility of family care[20] Feeling fearful and unprepared with how to deal with a TBI family member when discharged from hospital[20]
Nurses' experiences	Providing advocacy and support	Assessing people with TBIs' and families' care needs and addressing them effectively[29] Supporting family members with decision-making and accessing welfare[2] Working collaboratively with family when planning people's discharges to ensure adequate support is provided for[2,29] Educating family members in TBI care[2] Aiming not to give families false hopes about prognosis[18]
	Monitoring physiological response	Knowing the baselines[29] Knowing the person's responses to procedures and medications[29] Reading subtle cues[29] Monitoring, assessing and making clinical judgement[29]
	Maintaining personal safety	Enhancing personal safety and quality of care through creating a safe care environment[3,26,27] Using evidence-based guidelines[3] Identifying people's aggression triggers[24] Watching out for people with TBI[29] Using nurse call button to alert other staff members for help[26] Questioning whether the use of restraints and containment for personal safety were ethical nursing practices[26] Advocating for the use of one-to-one nurse assistants to observe and ensure safety for people with TBI[26] Experiencing fear for personal safety[26]
	Providing a therapeutic environment	Managing noise from alarms and beeps[29] Managing light[29] Maintaining regular repositioning of people with TBI for comfort[29] Promoting light music and quiet moments[29] Providing person-centred care by individualising the person with TBI's care experience[29] Experiencing barriers to providing care such as inadequate staffing, which hindered delivery of quality care [18,20] Provision of care was hindered by organisational factors such as lack of resources and trained staff[20] The use of care bundles improved nurses' knowledge and quality of personal care[3] Lack of adequate equipment hindered performance of nursing tasks[3] Feeling inadequately prepared to manage pain for people with combat-related TBI[12] Deciding whether talking/not talking to the person with TBI depending on the level of person's acuity, comprehension, family dynamics and context of TBI[2]
	Entering the person's world	The need to familiarise self with the person, family or carers [29] Viewing people with TBI as best judges of personal pain[12] Learning about the person from family or significant others[29] Striving to understand the person with TBI's word[20] Offering reassurance and explanation of procedures[29] Orientating the person[29]

(Continues)

TABLE 6 (Continued)

Main categories	Categories	Subcategories
		Being nonjudgemental about the person with TBI [29] Establishing therapeutic relationships with person's families[2] Considering the person as an object of care and not as a whole[18]
	The importance of beliefs and competence in providing nursing care	Identifying personal beliefs related to the presenting nature of TBI[23] Perceiving level of competence and knowledge regarding TBI[23] Facing a dilemma as to what information should be communicated to family about a loved one's TBI [18] Novice nurses feel overwhelmed and intimidated[29] Caring for people with severe TBI was considered as being complex[3] Needing more specialised training the care for people with TBI[23]
	Managing challenging behaviour	Experiencing caregiving as complicated when mental health problems were combined with TBI[12] Needing more mental health skills training[27] Understanding how own perceptions of challenging behaviour can affect care[26] Predicting aggression using cues from people with TBI and calling for support[31] Experiencing distress of TBI care for newly graduated nurses[26] Dealing with conflicting ways of managing challenging behaviour[26] Seeking support from other allied health professionals, for example, psychiatrists[26,27] Using restraints for safety[29] Being a target for personal aggression—physical or verbal[27] Experiencing stress as a result of caring for people with TBI presenting with aggressive behaviour[26] Experiencing competing needs around timing of medication for people with TBI[26] Feeling angry and considering resignation in response to difficulty coping with continuous challenging personal behaviour[26] Avoiding caring for people with TBI presenting with challenging behaviour[27]

Superscript numbers denote article reference number in Table 5

both TBI and mental health problems required a special skill set; recommendations for specialised training have been made to allow nurses to navigate challenging behaviour in a more effective manner (Jaimes et al., 2015).

Nurses expressed being a target for both verbal and physical forms of aggression while providing care for people with TBI (Searby & Maude, 2014; Soreny, 2009). To provide effective care for people with TBI exhibiting challenging behaviour such as aggression, nurses needed to understand their own perceptions of challenging behaviour and how these perceptions might impact their care choices (Searby & Maude, 2014). There were conflicting ways of managing aggressive people with TBI; while some nurses relied on restraints and containment, others did not, out of concern for personal safety. Less restrictive nursing strategies included monitoring for predictable cues such as the person's facial expressions and tone of voice (Wongvatunyu & Porter, 2005).

In some circumstances, nurses sought support from allied health professionals conversant in navigating challenging behaviour or mental illness (Searby & Maude, 2014; Soreny, 2009). Nurses also experienced competing needs around timing of medication for people with TBI who presented with challenging behaviour, especially when their expectations, and/or medical officers' expectations differed from what nurses felt needed to happen (Searby & Maude, 2014). Nurses often found the conflicting approaches to *challenging behaviour* difficult to navigate; this was especially so for newly qualified nurses who were unfamiliar with the care needs of people with TBI (Searby & Maude, 2014; Villaneuva, 1999). Nurses expressed a sense of frustration and some considered resigning or changing clinical specialty as a result of being unable to cope with continuously strenuous problems of *managing challenging behaviour* (Soreny, 2009).

5.1.3 | Valuing skills and competence

The cross-cutting theme of *valuing skills and competence* resonated primarily within the category of nurses' experiences. Nurses needed appropriate clinical *skills and competence* to understand and address the care needs for both people with TBI and families. For example, nurses needed observational skills to understand the person with TBI's usual response to procedures and medications, to manage the environmental stimuli such as noise and light, to read subtle cues from the person and to monitor, assess and make clinical judgements (Villaneuva, 1999). The communication *skills and competence* of the nurses were also considered as essential for the provision of effective care. Nurses had to make constant decisions about whether to discuss aspects of care with people with TBI and families, depending on the level of the person's acuity and comprehension, family dynamics and the context of care. Nurses required advanced communication and education skills to prepare family members for their changed situation and caring role (Coco et al., 2013; Villaneuva, 1999).

Caring for people with severe TBI was considered a complex task that required specialised nursing *skills and competence* and novice nurses were at times overwhelmed and intimidated while providing

person-centred care (Damkliang et al., 2015; Oyesanya et al., 2016; Villaneuva, 1999). For example, nurses felt inadequately prepared to manage pain for people with combat-related TBI, and this was an area where further training would be valuable (Jaimes et al., 2015). Nurses' beliefs about the nature and causative factors of TBI, along with beliefs about their own level of *skills and competence*, influenced the approach they used to provide care (Oyesanya et al., 2016).

5.1.4 | Struggling with changed family responsibilities

There were notable changes in the lives of family members who often struggled with *changed family responsibilities* and dynamics. Families experienced difficulty receiving the news about the person affected by TBI, grasping the significance of the TBI situation and making sense of it (Keenan & Joseph, 2010; Lefebvre et al., 2005). Families particularly struggled to come to terms with the person's disabilities and expressed the need to receive meaningful information from healthcare professionals about care and prognosis (Oyesanya et al., 2016; Saban et al., 2015). Families also found it difficult to navigate their personal circumstances in order to accommodate the care needs of the person with TBI, which might include sharing care responsibilities as a family (Kao & Stuifbergen, 2004). Accommodating the care demands of a person with TBI could lead to alterations in family living arrangements or work commitments (Kao & Stuifbergen, 2004). Culture and religious beliefs influenced how families adjusted to TBI. For some families, coping strategies included maintaining hope, having spiritual strength, taking 1 day at a time and thinking positively (Gebhardt et al., 2011; Keenan & Joseph, 2010; Mbakile-Mahlanza et al., 2015; Saban et al., 2015; Wongvatunyu & Porter, 2005).

5.1.5 | Maintaining productive partnerships

People with TBI preferred *productive partnerships* with health professionals to better manage the burden of TBI and actively sought collaborative approaches to care (Lefebvre & Levert, 2012; Lefebvre et al., 2005). People with TBI sought *productive partnerships* that provided factual information about TBI care, provided appropriate support from posthospital follow-up services, which engendered support among family and friends (Jumisko et al., 2007, 2009; Lefebvre et al., 2005; Oyesanya et al., 2016; Villaneuva, 1999). However, people with TBI also described a lack of organisational resources which impacted negatively on the quality of support they received from clinical partnerships.

Families also preferred to work in *productive partnerships* with health professionals. In such partnerships, family members wanted honest, clear and timely information, to be fully involved in care provision, to be listened to and to be consulted about important decisions (Gebhardt et al., 2011; Keenan & Joseph, 2010; Lefebvre et al., 2005; Wongvatunyu & Porter, 2005). In some situations, healthcare professionals selectively disclosed information to family members and this practice was detrimental to *maintaining productive partnerships* (Mbakile-Mahlanza et al., 2015).

Family members longed for culturally appropriate partnerships with healthcare professionals that allowed the right kind of emotional and practical support (Johnson, 1995; Keenan & Joseph, 2010). This included providing culturally appropriate information to enable a deeper understanding of TBI care (Mbakile-Mahlanza et al., 2015). Families also expressed the need for pragmatic support and interventional strategies to help manage feelings of helplessness and to promote coping (Johnson, 1995; Kao & Stuifbergen, 2004).

Nurses described working closely with families in establishing and maintaining *productive working partnerships* and in learning more about the person with TBI (Coco et al., 2013). This *productive partnership* approach was important when planning discharge for people with TBI to ensure that adequate support was provided (Coco et al., 2013; Villaneuva, 1999). To achieve a *productive partnership*, nurses described entering the person with TBIs' world, to know the details of the person's life and care needs, and familiarising themselves with the family or other carers. Nurses sought *productive partnerships* through viewing people with TBI as the best judges of their personal pain, offering reassurance, routinely orientating them to place or time and by explaining the care being delivered (Jaimes et al., 2015; Villaneuva, 1999). Nurses also sought *productive partnerships* with families by providing information to guide decision-making and by supporting them to access welfare services (Coco et al., 2013).

5.1.6 | Reflecting on workplace culture

Family members saw the provision of culturally appropriate care not just as a partnership issue with individual nurses, but also as a *workplace culture* issue. When *workplace culture* did not support or value cultural competence, families' cultural preferences were overlooked and they felt misunderstood (Mbakile-Mahlanza et al., 2015).

Nurses' beliefs and actions were influenced by their *workplace culture*. Although nurses used guideline-based care which they believed supported them in the provision of more effective, safe, high-quality TBI care (Damkliang et al., 2015; Searby & Maude, 2014; Soreny, 2009), the use of restraints was described being dependent on *workplace culture*. Some nurses questioned whether the practice of restraints was ethical and advocated for the use of one-to-one nursing to enhance the safety and dignity of people with TBI (Searby & Maude, 2014). Nurses also experienced organisational barriers to the provision of high-quality TBI care, including inadequate staffing, lack of appropriately trained nursing staff and inadequate equipment to perform certain nursing tasks (Damkliang et al., 2015; Lefebvre et al., 2005; Mbakile-Mahlanza et al., 2015).

6 | DISCUSSION

This paper reports on an integrative review, which examined the experiences of giving and receiving care in TBI from the perspectives of people with TBI, their family members and nurses in hospital and

rehabilitation settings. The broad aim of the review was to collate and analyse the diverse literature base in order to provide direction for improving care for people with TBI and their families. Information generated may serve as a resource for health professionals to guide TBI care provision.

The most striking finding is the mismatch in perceptions of person-centred care between people with TBI and nurses. Although both groups identified *seeking personhood* as a key concern, and nurses described their careful attention to the people with TBIs' physical, emotional and social needs, this was incongruent with people's reports of poor nursing care, which could be experienced as impatient, uncaring and restrictive. This review draws on multiple sources, and it is acknowledged that people with TBI in some TBI settings may receive high-quality nursing care. However, this review indicates that the nursing care may not be as person-centred as nursing staff believe. This finding is consistent with research outside of TBI settings, which suggests nursing staff may be unaware of how task-focused their care is, or how visible their attitudes, skills and competence are to people with TBI (Morris, Payne, & Lambert, 2007). Other researchers have attributed the mismatch in the perception of person-centred care between people with TBI and nurses to inadequate nurse staffing, task-focussed care and time constraints that reduce nurses' capacity to individualise care and engage with people with TBI (Hunter, Hadjistavropoulos, & Kaasalainen, 2016).

Cultural beliefs are also bound to contribute to the mismatch in perceptions of care between people with TBI and nurses as such beliefs may shape interpretations of person-centred care (Mbakile-Mahlanza et al., 2015). Clearly, the mismatch in perceptions of care is a major barrier to *productive partnerships* which necessarily encompass physical, emotional and social aspects of skilled and competent care.

Second, nursing management of *challenging behaviour* was described by people with TBI as overly restrictive and was detrimental to their efforts to regain *personhood*. Restrictions on free movement in TBI care may reduce unfavourable outcomes such as falls or harm to others, and workers are required by law to provide and maintain a work environment which ensures that there is no risk to health and safety (News South Wales Government, 2011). It is likely, therefore, that restrictive nursing care in TBI settings is an attempt to meet both safety and legal obligations and prevent foreseeable injury. Nursing staff were, however, clearly conflicted in regard to best practice for managing *challenging behaviours*. The provision of skilled and competent nursing care was often influenced by *workplace culture*, which conflicted with nurses' values regarding care. For example, the routine use of restraints to manage *challenging behaviour* was seen by some nurses as unethical. This is because of the heightened risk of physical and psychological harm to people with TBI and may contribute to nurses being emotionally affected after caring for restrained people with TBI (Lach, Leach, & Butcher, 2016). This review found that some nurses felt overwhelmed by their caring role and unable to cope with managing *challenging behaviour*. Novice nurses particularly struggled to institute rational, remedial nursing interventions.

In contrast, this review suggests that less restrictive measures for managing challenging behaviour in TBI care are achievable, with nurses describing careful assessment and monitoring to avoid escalation. Restraint-free care environments are possible, with nurses encouraged to target and address the contributing factors, and this has been linked to increased satisfaction with care (Lach et al., 2016). It is also the case that healthy *workplace culture* can empower nurses to question clinical practices irrespective of the level of seniority. The risks and benefits of free movement of the person with TBI care needs to be carefully considered and decided on an individual basis. To maintain well-being for people with TBI and promote *personhood*, as well as reducing the distress for nurses providing care, we would suggest that restraints in TBI are considered as a last resort, and that staff be provided with sufficient training, protocols and resources for alternative interventions.

Finally, this review suggests that TBI care put significant strain on family members and alters family dynamics. People with TBI felt inadequately supported by their families or informal caregivers (Chamberlain, 2005; Erikson et al., 2007; Freeman et al., 2015; Jumisko et al., 2007; Kao & Stuifbergen, 2004; Saban et al., 2015; Webster et al., 2015). Families struggled to adjust to their caring responsibilities and required tailored support. Although nurses tried to maintain *productive partnerships* by encouraging families to engage in personal care and by providing detailed and meaningful information about the nature of, and reasons for care, there was once again a mismatch in perceptions: families still perceived a lack of support from health professionals and reported unmet information and care needs.

It is unclear whether a lack of support from nursing staff impacted on the capacity of families to provide helpful care to their relative with TBI. Struggling to come to terms with altered family relationships and a TBI diagnosis, families may require support services beyond those offered by health professionals, such as financial support or respite care. Disability support services and respite services, along with many other forms of practical, funded assistance can reduce care burden for families (Coco et al., 2011). An example of such support is Australia's new National Disability Insurance Scheme (NDIS) which provides a more flexible funding model to maximise the affected individual's independence, community involvement, education, employment, health and well-being (NDIS, 2016). While the form of support required varies from person to person, the NDIS seeks to fund support that enhances a person's ability to take care of their daily living requirements, such as mobility equipment, professional therapies, employment support or modifications to increase the safety of home living environments (NDIS, 2016). Nevertheless, it should be acknowledged that not all families are well positioned to assume or maintain a carer role, due to commitments, other caring responsibilities, existing health issues or the physical and psychological consequences of carer-stress (Fleming et al., 2012). The concomitant care of young children compounds the complexity of family caring with likely consequences for family well-being. People with TBI face decreased participation in parenting, leaving an unequal

distribution of family responsibilities such as raising children (Maestas & Sander, n.d.).

6.1 | Limitations of this review

The first limitation for this review is that only papers published in English were included. Therefore, pertinent papers from diverse cultural settings, which could have informed further discussion, were not reviewed. Also, many of the papers included in the review were qualitative, and hence context bound in time, place and culture. Therefore, when transferring these results, they should be considered in the light of the reader's own context. For example, some studies were published prior to 2000 (Johnson, 1995; Nochi, 1998 & Villaneuva, 1999). It may be that both TBI care and workplace culture have shifted significantly.

Additionally, the included studies frequently researched people with TBI, families and clinicians separately, and again, possibly across different contexts. It is therefore conceivable that some of the mismatch we discovered between people with TBI and nurses' perceptions of care could be explained by this. Finally, as all reviews are dependent on the strength of the search strategy, there is a possibility that the search terms used may have excluded some studies that investigated certain aspects of TBI care.

7 | RELEVANCE TO CLINICAL PRACTICE

1. A greater emphasis on involvement of the people with TBI and their family in the designing of care plans can minimise the gap between consumers' and nurses' perceptions of person-centred care. Collaboratively identifying care challenges and setting realistic goals can support *productive partnerships* and acknowledge *personhood* through a reciprocal understanding between people with TBI and nurses (Lefebvre & Levert, 2012). Furthermore, cultural competence training may reveal diverse customs and beliefs which can then contribute to a deeper understanding of personal care needs and other factors that support the framing of culturally congruent health care (Roscigno, 2013).
2. To reduce people with TBIs' sense of being restrained and controlled, routine formal falls risk screening may identify risks that are actual and individualised, rather than inferred through a restrictive blanket approach (Spoelstra, Given, & Given, 2012). Similarly, aggression risk or violence risk screening may enable early identification of challenging *behaviour* and support the timely enactment of individualised preventative measures which are more humane.
3. Novice nurses need to be well-orientated to the TBI care environment. Structured training may equip them with proven strategies for managing agitation or aggression including de-escalation actions, making early requests for assistance and engaging input from allied health professionals with mental health skills (Lach et al., 2016). Specific training in managing aggressive behaviour is known to be effective in developing clinical skills and enhancing nurse's confidence to practice (Soreny, 2009). Rigorous specialty orientation programs and transition to specialty practice programs can enhance skill acquisition, standardise practice and improve the delivery of nursing care.
4. TBI rehabilitation care should promote family functioning by developing the person's sense of their strengths, encouraging people to accept help, building organisational skills and encouraging family therapy where relevant (Maestas & Sander, n.d.). People with TBI and their families should also be referred for professional guidance to maximise their access to available services and funding.

8 | CONCLUSION

There is often a mismatch in the perception of person-centred care provided in TBI between people with TBI, family members and nurses. Strategies that enhance inclusive collaboration of people with TBI and families into care planning should be encouraged. This requires structured reframing of communication and care planning processes to enable the time, space and communication skills to enhance input and inclusion of people with TBI and their families. People with TBI may present with challenging behaviour and nurses need proper training and skills to navigate this complex field. Greater support for novice neurological nurses and a consistent, evidence-based approach to behavioural de-escalation and use of restraints is likely to improve staff competence and ensure the delivery of quality TBI care. Support for families caring for a people with TBI should be an integral part of care provision to relieve care burden. It is important for people with TBI, their families and nurses, to establish and maintain productive partnerships that foster mutual understanding and encourage information sharing.

ACKNOWLEDGEMENTS

None.

CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

CONTRIBUTIONS

Study design: SK, JR, JG; data collection and analysis: SK, JR, JG; and manuscript preparation: SK, JR, JG.

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How to cite this article: Kivunja S, River J, Gullick J. Experiences of giving and receiving care in traumatic brain injury: An integrative review. *J Clin Nurs*. 2018;27:1304–1328. https://doi.org/10.1111/jocn.14283

Reflection on publication

This was my first publication as a novice researcher and introduced me to the rigorous design and conduct of literature reviews. I acquired invaluable knowledge and skills that then formed the foundation of the next two publications included in this thesis.

This integrative review revealed that there was limited understanding of what patients and families/carers perceived as important contributions to TBI care. Also, healthcare providers do not know what challenges, enables or inspires nurses to give the best possible TBI care. This integrative review identified a clear mismatch between patients', families' and nurses' care expectations that relate to personhood in TBI nursing care. However, most papers in the integrative review studied patients, family carers or nurses as a standalone cohort at different locations. Therefore, it is unclear whether these mismatches were due to differences in the research contexts, including country, historical placing and level of acuity. It remains unclear what kind of nursing care promotes personhood for people with TBI and promotes partnership between families/carers and nurses. To date, there is no published research that integrates patient, family and nurse experiences of TBI care and the social processes that promote personhood and collaboration in care. This Constructivist grounded theory study aims to address this gap in the literature.

2.4 Conceptualising personhood in nursing care for people with altered consciousness, cognition and behaviours: a discussion paper

Published peer reviewed paper: Kivunja, S., Pryor, J., River, J., & Gullick, J. (2024). Conceptualising personhood in nursing care for people with altered consciousness, cognition and behaviours: A discussion paper. *Nursing Philosophy, 25*(3), e12490-n/a. https://doi.org/10.1111/nup.12490

Author attribution statement

This manuscript has been published as:

Kivunja S, Pryor, J., River J, Gullick J. (2024). Conceptualising personhood in nursing care for people with altered consciousness, cognition and behaviours: A discussion paper. Nursing Philosophy, 25(3):e12490. https://doi.org/10.1111/nup.12490

I conducted the literature search and data extraction. I synthesised the literature thematically, I wrote the original manuscript draft and revised it with critical input from my co-authors (A/Prof Julie Pryor, A/Prof Jo River and A/Prof Janice Gullick). I prepared responses to reviewer feedback with further input from co-authors and submitted the manuscript.

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Signature **Date:** 29 September, 2025

As supervisor for the candidature upon which this thesis is based, I can confirm that the authorship attribution statement above is correct.

Lead supervisor name*:* A/Prof Janice Gullick

Signature **Date:** 29 September, 2025

Permission to include the published manuscript in this thesis is attached (see Appendix 12.2)

Received: 29 February 2024 | Accepted: 18 June 2024
DOI: 10.1111/nup.12490

DIALOGUE CONTRIBUTION

WILEY

Conceptualising personhood in nursing care for people with altered consciousness, cognition and behaviours: A discussion paper

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Funding information
Stephen Kivunja is a recipient of research grant funding from Western Sydney Local Health District Westmead Charitable Trust, Grant/Award Number: WSLHD-WCT-2021

Abstract

The aim of this discussion paper is to explore factors and contexts that influence how nurses might conceptualise and assign personhood for people with altered consciousness, cognition and behaviours. While a biomedical framing is founded upon a dichotomy between the body and self, such that the body can be subjected to a medical and objectifying gaze, relational theories of self, multiculturalism and technological advances for life-sustaining interventions present new dilemmas which necessitate discussion about what constitutes personhood. The concept of personhood is dynamic and evolving: where historical constructs of rationality, agency, autonomy and a conscious mind once formed the basis for personhood, these ideas have been challenged to encompass embodied, relational, social and cultural paradigms of selfhood. Themes in this discussion include: the right to personhood, mind–body dualism versus the embodied self; personhood as consciousness, rationality and narratives of self; social relational contexts of personhood and cultural contexts of personhood. Patricia Benner's and Christine Tanner's clinical judgement model is then applied to consider the implications for nursing care that seeks to reflexively incorporate personhood. Nurse clinicians are able to move between conceptions of personhood and act to support the body, as well as presumed autonomy and relational, social and cultural personhood. In doing so, they use analytical, intuitive and narrative reasoning which prioritises autonomous constructions of self. They also incorporate relational and social contexts of the person receiving care within the possibilities of technological advances and constraints of contextual resources.

Institutional affiliation where the work was conducted: Susan Wakil School of Nursing and Midwifery (Sydney Nursing School), Faculty of Medicine and Health, The University of Sydney, Sydney, New South Wales 2006, Australia.

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KEYWORDS
behaviours, cognition, conceptualisation, conscious disorders, nursing, personhood

1 | INTRODUCTION

Definitions and constructs of personhood in healthcare are contextual, and often depend on culture, beliefs and the medical conditions that affect a person, including impacts on their rationality, self-determination and capacity to interact with their social world (Garthoff, 2019; Penner & Hull, 2008; Scharmer, 2018; Walker & Lovat, 2015). Consequently, what encompasses nursing care for people with altered consciousness, cognition and behaviours is bound to be influenced by the value and understandings that nurses assign to personhood (Blain-Moraes et al., 2018). In many healthcare settings, and in health literature, notions of personhood are founded upon the existence of a biological being with unique personal attributes, who possesses autonomy (which may be either personal or relational), with most constructs of personhood incorporating both the body and society (Berenbaum et al., 2017; Kong et al., 2017; Playford & Playford, 2018; Walker & Lovat, 2015). This discussion paper draws on literature addressing both personhood and its relationship to care for people with altered consciousness, cognition and behaviours, including people with dementia (Berenbaum et al., 2017; Higgs & Gilleard, 2016; Milte et al., 2016; Palmer, 2013; Smebye & Kirkevold, 2013; Vukov, 2017), people in intensive care units (ICU) (Koksvik, 2016; Walker & Lovat, 2015) and older adults in residential care homes at end-of-life (Kong et al., 2017). It also examines research on the personhood of people with lived experience of mental health challenges (McTighe, 2015) and people in a neurologically nonresponsive state following severe traumatic brain injury (TBI) (Playford & Playford, 2018; Young, 2019).

2 | THE RIGHT TO PERSONHOOD, MIND–BODY DUALISM VERSUS THE EMBODIED SELF

There are complex and ethically, legally and politically fraught debates about what it means to be a person, including whether a person with diminished capacity or a nonresponsive patient is conceived of as a full person (Blain-Moraes et al., 2018; Koksvik, 2016; Penner & Hull, 2008; Playford & Playford, 2018). For example, in relation to the acknowledgement of humanness, the American philosopher Jeff McMahon argued:

> How a being ought to be treated depends, to some significant extent, on its [sic] intrinsic properties—in particular, its psychological properties and capacities. With respect to this dimension of morality, there is nothing to distinguish the cognitively impaired from comparably endowed nonhuman animals. (1996, as cited in Playford & Playford, 2018, p. 1409)

Tristram Engelhardt also questioned the automatic right to personhood among people with significant impairment: 'If the significantly neurologically or physically damaged human being no longer has the attributes necessary to 'rationality', then that human being no longer enjoys a claim to personhood' (1996, as cited in Walker & Lovat, 2015, p. 311). Furthermore, James Walter proposed that a lack of particular capacities not only has implications for personhood, but also for access to clinical care: 'When the properties that define humanhood are absent, the patient is not considered a moral subject who possesses any rights to healthcare' (2004, as cited in Walker & Lovat, 2015, p. 311). While these ideas are quoted from the 1990s and early 2000s, even recent literature referred to people who are unresponsive as being in a 'vegetative state' (Playford & Playford, 2018); language that suggests that the unresponsive person becomes a nonperson when they are unable to interact with or respond to their world.

In medicine, the dichotomous construct of mind–body dualism has been central to conceptions of personhood, where the physical body as a vessel for life is seen as distinctly separate to the nonphysical, subjective and rational self (Descartes, 1641/1996). This Cartesian dualism reduces human beings to body organs or parts, separate from mind, emotions and sense of identity (White, 2013). Historically, as the care of living bodies moved from the home to hospitals, further study, comparison, classification and statistical evaluation of the physical body was made possible and has been referred to as a *medical gaze* over a *machine-body* (Foucault, 2003). The dehumanising impacts of this separation of the body from the person's identity, and the material and intellectual frameworks that maintain the *medical gaze*, have been described as 'infused' with power (Foucault, 2003). This is, particularly, relevant to the power of medicine to name, describe and control. The dehumanising impact of the Cartesian view of the body, and its consequence (the medical gaze) in objectifying the body, sees nothing in it that is intrinsic to personhood (White, 2013).

In contrast, personhood has been understood through the idea of the *lived body*, which has emerged to theorise a unified and embodied human existence (Koksvik, 2016). There is an intertwining of the physical (habitual, biological, organic) body with the existential (personal, spontaneous, individual) body that is constantly transformed by the situations people find themselves in, as they perceive their world and express themselves through their body (Merleau-Ponty, 1962, 1968).

3 | PERSONHOOD AS CONSCIOUSNESS, RATIONALITY AND NARRATIVES OF SELF

Central to the historical and philosophical positioning described, most definitions of personhood encompass the notion that a range of psychological and intellectual capacities impact on a person's

perception of the world, such as self-consciousness, rationality, cognition, moral agency, autonomy, linguistic ability and the ability to have goals and make plans (Penner & Hull, 2008; Playford & Playford, 2018; Walker & Lovat, 2015). This is, however, challenged by stages of human development and comparisons with nonhuman beings; for example, the notion that newborn babies have lesser cognitive abilities than adult chimpanzees (Premack 2007, in Playford & Playford, 2018).

While rationality and intellect develop over a lifetime, when they become a focus for perceived personhood, this can lead to the denial of the recognition of the human rights of individuals where intellectual capacity is lost due to disability, illness, injury or age-related degeneration (Lefebvre & Levert, 2012; Playford & Playford, 2018). In response to this denial, personhood has been reconceptualised in some settings. A study exploring how personhood was perceived by carers of people living in the community with dementia described personhood as having three dimensions that were not contingent on cognition, including: biologic, individual and sociologic (Berenbaum et al., 2017). For example, *biologic personhood* considers an individual as a biological being where the focus of care is on fulfilling biological needs, such as relief from pain; *individual personhood* encompasses lived experiences, values and past roles (which may be understood vicariously via other significant persons) and *sociologic personhood* includes how society perceives and interacts with the person (Berenbaum et al., 2017).

Personhood has also been reconceptualised in relation to stigma. Mental health challenges, and, particularly, those involving altered states of mind (e.g., psychosis) are an example of a state where a person's sense of reality can be altered (Matthews, 2016). In such a state, the person's behaviours may be deemed socially unacceptable or uninterpretable and respect for personhood may be diminished as behaviour is stigmatised: examples may include a person hearing voices or expressing ideas that are outside of consensus reality or a person threatening harm to self or others. In such cases, medical interventions are often instituted irrespective of the person's will, as capacity is determined to be diminished. While involuntary treatments may be perceived (by some) as appropriate for relieving the person's distress, they have come under heavy criticism from people with lived experience of mental health challenges, and those who advocate for their rights. Criticisms include clinicians overriding people's rights and engaging in care and interactions that are dehumanising and undermine personhood (Matthews, 2016). In such circumstances, recognition of the capacity of a person receiving care to create a meaningful narrative, intelligible to others, is not the basis of personhood (McTighe, 2015). Rather, the impacts of the social and political environment are taken seriously, given they are implicated in traumatising individuals and disrupting personal narratives. Consequently, the person with mental health challenges, who is experiencing distress and altered states, is understood as seeking to make sense of self within this disordered sociological context (McTighe, 2015).

4 | SOCIAL RELATIONAL CONTEXTS OF PERSONHOOD

Literature further examines the social and relational contexts of personhood. In relational personhood, the possibility of exercising autonomy in the world is viewed as essential (Walker & Lovat, 2015). While autonomy is usually viewed as the individual's capacity for self-determination, it is also intimately linked to the relationships individuals have with others, who may respond to requests or act as advocates based on their knowing of the person (Sofronas et al., 2018; White, 2013; Young, 2019). As embodied cultural creatures, we are dependent upon intersubjective bonds that are derived from our understanding as *beings-in-the-world* (Svenaeus, 2014). For example, in a discussion paper exploring withdrawal of life-sustaining treatment decisions in the ICU, the concept of personhood and autonomy was revised to incorporate social relationships with relatives, ICU staff and salient others in the community. These people were presumed to perceive the person's best interests and act as an advocate for them, and thereby bring into reality the idea, that 'our identities exist within the context of relationships' (Walker & Lovat, 2015, p. 311). However, one dilemma lies in the example of a hypothetical patient who might have valued unlimited medical intervention. In such a case, ongoing technical support would be considered justified without consideration of cost, resource availability or indeed, if that intervention was futile in sustaining meaningful life. However, this egoistic approach, which gives the individual primacy, not only requires positioning 'in the world of others, but rather in the world as it actually *is*' (Walker & Lovat, 2015, p. 312). An authentic account of autonomy necessarily connects with the person's real-world and temporal situation with others, including their future quality of life in that world, as 'the lived body is not a thing, it is a situation' (Beauvior, 2011, as cited in Walker & Lovat, 2015, p. 312). As such, while personhood may persist through lived relationships despite serious neurological damage, this does not negate a decision to withdraw life-sustaining treatment (Walker & Lovat, 2015). Rather, the responsibility of upholding relational personhood within the world of a new future would be taken up by nurses, doctors, family and significant others to act, serve and advocate for the unresponsive person, with ongoing discussions about treatment at multiple time points, and with multiple viewpoints, based on evolving status and contexts (Playford & Playford, 2018).

Relational personhood was described in a Norwegian study as enacted, being both done and undone for ICU patients who were unresponsive, unconscious or with impaired lucidity (Koksvik, 2016). Relational personhood was undone where an ICU patient was unable to speak, and their words were replaced by the sounds of their monitored organs which conversed with the outside environment (e.g., cardiac rhythm alarms and the sound of the mechanical ventilator). In this way, machinery becomes an integral part of the person who is the patient, and part of a network between the person and their clinicians. However, in this work, only when the nurse turns from the machine to the person who is the patient, are relational

faculties taken into account and relational personhood enacted. While treatment in the ICU is founded on 'doing what has to be done', possibly without regard for the person who is the patient, relational personhood is negotiated between several factors that emerge as vital when the person's capacities for expression are inhibited (Koksvik, 2016, p. 140). Examples of 'doing personhood' in this context included covering the body to respect modesty and speaking to the person, whether or not they were perceived to hear and understand. 'Undoing personhood' was exemplified by speaking over the patient as if they were not present, or speaking for the patient, ignoring signs of distress or signs of care preferences (Koksvik, 2016). Furthermore, this study found that what a clinician viewed and valued also influenced how relational personhood was supported, or negated, in the doing and undoing of personhood. Some behaviours of the person who is the patient, even involuntary behaviours (like convulsions), could be labelled as deviant and therefore attributed a moral value, even when unrelated to a person's intentions, rationality, agency, autonomy or awareness (Koksvik, 2016). Such an approach to behavioural evaluation, contributes to the undoing of personhood. This supports Kitwood's notion that personhood is a 'standing or status bestowed upon one person by others, and in the context of social being' (Kitwood, 1997, p. 8).

5 | CULTURAL CONTEXTS OF PERSONHOOD

The meaning of personhood in healthcare has also been discussed from the perspective of culture with divergent meanings described between some Western and non-Western cultures (Koksvik, 2016; Kong et al., 2017; Playford & Playford, 2018). While in some Western cultures, personhood is promoted as dependent on a conscious and self-aware individual with agency and a right to individual choice, some non-Western cultures have prioritised relational personhood which may be denied, attenuated, withdrawn by others or lost (Conklin & Morgan, 1996; Koksvik, 2016; Playford & Playford, 2018).

These diverse cultural interpretations have also been found to shape nursing practice and patient experiences. For example, among the Tallensi ethnic group of Ghana, personhood has been described as being earned and is bestowed only upon those members of the community who demonstrate long periods of service to the community (Koksvik, 2016). In Botswana, aspects of personhood following unfavourable life events such as TBI, are traditionally understood as enhanced or diminished in the context of mystical powers, misfortune or interaction with ancestors (Mbakile-Mahlanza et al., 2015). In Hong Kong, a Western model of dignity was determined as overly individualistic and culturally irrelevant to Chinese people where consideration of collective family and community groups was more highly valued and where the interdependent self and familial connectedness took precedence in understanding personhood (Kong et al., 2017). However, it is an important consideration that in low-income countries, with severe resource constraints, access to highly technical life-saving interventions may depend more upon access to resources and care, than on cultural considerations about life, death and personhood.

6 | DISCUSSION

This discussion paper aimed to explore conditions and factors that influence how nurses might conceptualise and assign personhood for people with altered consciousness, cognition and behaviours. As the paper puts forward, not all elements of current definitions of personhood, are applicable to people who have diminished intellectual or psychological capacity. Indeed, there is an appreciation of the experiences and values of a person before their altered state, and the relationships with significant others, clinicians and the social world that sustain personhood. For example, autonomy does not merely reside within the individual, rather, relational autonomy exists and is supported by persons of significance, including strangers in the clinical context who engage with and interact with machines that 'speak' for the person. Within this discussion, recognition of the inequity and stigma and the tendency to withdraw personhood on this basis, is paramount. This discussion also suggests that personhood has a cultural context, informed by cultural expectations, beliefs, traditions and resources, which impact on notions and options to recognise personhood. These elements combined become part of a nurses' clinical assessment to inform nursing clinical judgement. However, it also requires the nurse to understand and challenge their own ideas about personhood, and how that may inform appropriate care.

In a reflection on practice within biomedical settings, dualistic perspectives of personhood and separation of mind and body may dominate, with a resulting impact on decision-making about a person's body that may be misaligned with the person's sense of self. Attribution of personhood also has a basis in morality. Ethical dilemmas may arise from how people and healthcare workers view life and death, and how diverse religious or spiritual beliefs may complicate decision-making in life-threatening situations. It also seems that society places great value on intellectual capacity, self-determination and intelligible narratives of self, meaning we are challenged to value people with cognitive impairment, reduced capacity or altered states of mind when providing medical intervention and person-centred care. Alterations in consciousness may also make it hard for people receiving care to express preferences, putting the emphasis on clinicians, including nurses, to promote personhood by understanding what they may have wanted or may wish to communicate. Finally, altered perceptions of reality and unusual behaviours, in, for example, those with mental health challenges, can make it challenging to connect with people. This is, particularly, so in highly controlled hospital environments where rights are withdrawn, and it is harder to manage behaviours in a way that does not dehumanise and reduce dignity (Cutler et al., 2021).

In wrestling with the ramifications of reflections on personhood, nurses might consider the seminal works of Patricia Benner and Chrstine Tanner. Tanner (2006) proposes that nurses interpret the

person's needs through three patterns of reasoning: *analytic reasoning*, which draws on the systematic use of objective clinical data to breakdown a situation and generate a range of possible responses. This type of reasoning may utilise observation charts and trends, care plans and pathways, guidelines and algorithms and speaks mainly to biologic personhood or the body of the person. *Intuitive reasoning* informs an immediate grasp of a situation based on experience of similar previous situations and pattern recognition, including past interactions with a patient, or with people from similar backgrounds or illness states (Benner, 1984; Benner & Tanner, 1987; Benner et al., 1996). *Narrative reasoning* involves clinicians making sense of a person's illness experience and explaining what one sees through having knowledge of their biopsychosocial lives, including relational aspects (Tanner, 2006). This may provide insight into the illness experience and meanings, ways of coping and both the patient's history and sense of future possibilities as well as relational knowledge of the person (Barkwell, 1991). These insights may not, however, be directly accessible from the person at the centre of care. Detailed nursing assessments in relation to these three types of reasoning support biologic, relational and cultural personhood for people receiving nursing care.

Before a nurse can pursue this reasoning pattern, they must notice phenomena that will set up their expectations about a person's situation. These phenomena occur within the *context* of care, the *background* to the current situation, and the existing *relationships* that underpin care (Tanner, 2006). When Tanner's clinical judgement model was used in a study of pain assessment for severely burned ICU patients (Taggart et al., 2021), *context* incorporated the severity of injury and phase of recovery, patient responsiveness and cognition, the presence of emotional trauma, medical devices that inhibit communication, relevant language proficiency and context of the unit culture. The *background* incorporated the culture, beliefs, values and experience of the ICU clinicians. Professional and therapeutic *relationships* were shaped by concepts drawn from Benner et al. (2009): the nurses' intentions to humanise and personalise care, knowing the patient as a person, knowing the patient's usual pattern of responses and the relationships between patients and clinicians (Taggart et al., 2021). These elements contribute to nurses' noticing salient phenomena that set up expectations and an initial grasp of the situation. What a nurse notices may determine their attention to personhood, which reasoning patterns they select and how they prioritise subsequent nursing interventions.

In contemporary clinical practice, the concept of personhood remains dynamic and continues to challenge and move away from the historical constructs of the possession of rationality, agency, autonomy and a conscious and intelligible mind. Technological advances for life-sustaining interventions, along with growing multiculturalism, present new dilemmas which necessitate an evolving discussion about the constitution of personhood (Koksvik, 2016). The insights provided seem to argue for the promotion of care that supports people to maximise their existing capacities, to limit the harm that could occur to them due to their limited abilities, and to value personhood as an inherent quality sustained through lived relationships (Higgs & Gilleard, 2016; Vukov, 2017). Nursing strategies with positive impacts on personhood can promote comfort and dignity, provide access to meaningful activities, promote independence, communicate a person's value and support connections with family and friends (Kong et al., 2017; Milte et al., 2016; Palmer, 2013; Smebye & Kirkevold, 2013). For people with mental health challenges, research suggests that sociologic personhood and sense of psychological safety are enhanced when nurses actively seek ways to promote personhood through empowering the individual, collaborating with them and respecting equality and personal choice (Cutler et al., 2021). Such care demonstrates respect for the person's beliefs, emotions, values and lived experiences (Palmer, 2013). On the other hand, nursing approaches that construct personhood-inhibiting experiences can lead to a sense of losing oneself (Cutler et al., 2021). This is when people are unable to express their personal qualities and interests, where they are uprooted from environments that support personal expression, or where their voices and choices are marginalised, and when priority is placed on task-centred over person-centred interventions (Cutler et al., 2021; Kong et al., 2017; Smebye & Kirkevold, 2013).

7 | CONCLUSION

The purpose of this discussion paper was to explore conditions and factors that influence how nurses might conceptualise and assign personhood for people with altered consciousness, cognition and behaviours. The primacy and inherency of rationality and individual autonomy to personhood when assessing and providing person-centred care for some populations has been questioned. The importance of sociorelational and cultural elements may be of greater importance. What nurses bring to a situation, the context of care and important interpersonal relationships may influence what they notice about a clinical situation and how that may support their assessment, clinical judgement and enactment of personhood. A clinical judgement model by Patricia Benner and Christine Tanner was used to highlight how nurses may use analytical, intuitive and narrative reasoning to support consideration of personhood, including biologic, sociological, relational and cultural personhood. Nurses might also consider individual, social and cultural contexts of care and how these impact on their considerations. These differences render challenges for nurse clinicians in promoting personhood and require reflexivity, understanding both one's own position towards people in one's care and the will to explore the person's lived relationships with significant others.

ACKNOWLEDGEMENTS

The authors would like to acknowledge the Western Sydney Local Health District Westmead Charitable Trust. Open access publishing facilitated by The University of Sydney, as part of the Wiley - The University of Sydney agreement via the Council of Australian University Librarians.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no data sets were generated or analysed during the current study.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

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How to cite this article: Kivunja, S., Pryor, J., River, J., & Gullick, J. (2024). Conceptualising personhood in nursing care for people with altered consciousness, cognition and behaviours: A discussion paper. *Nursing Philosophy* *25*, e12490. https://doi.org/10.1111/nup.12490

Reflection on the publication:

My aim for undertaking this discussion paper was to explore conditions and factors that influence how nurses might conceptualise and assign personhood for people with altered consciousness, cognition and behaviours. I took this broad focus as there was limited literature specific to people with TBI. There was, however, published work about how personhood was constructed across fields such as dementia care, intensive care, mental health care and end-of-life care. Some people giving and receiving this care also experienced challenges related to altered consciousness, cognition and behaviours.

I was intrigued that the concept of personhood had such diverse meanings attributed to it including legal, political, religious, spiritual, biological, cultural, social and relational domains. This understanding has implications for nursing practice, given that one's personhood encompasses multiple constructs within a person's lived world. I found that using framings of clinical judgement from Patricia Benner and Christine Tanner was useful in bridging the gap between the understanding of personhood in one's assessment, and how that feeds into nurses' decision-making for person-centred care.

2.5 Chapter summary

This chapter has explained and justified the use of literature in this Grounded Theory study and presented two published literature reviews that I used to achieve two objectives: first, to understand experiences of giving and receiving care in TBI, to identify a gap in literature and to position my study within the field; and second, to open my mind to different ways of thinking about *personhood.* In the next chapter, I

discuss the research methodology of Constructivist Grounded Theory and the methods used to conduct the study.

3 CHAPTER THREE: Methodology and Methods

3.1 Introduction

The first part of this chapter justifies Constructivist Grounded Theory (CGT) (Charmaz, 2014) as the best-fit research methodology for this study, due to its relevance and ontological congruence with the study aims. I explain the research paradigm and theoretical underpinnings of the study, and I present a brief discussion of the key historical developments in Grounded Theory.

The second part of this chapter presents the methods that I have used to operationalise the methodology. The research design is a multicentre, qualitative study using CGT (Charmaz, 2014), with iterative data collection using semi-structured interviews and field observations (Creswell, 2003; Denzin & Lincoln, 2005). The first section presents the research setting and research team, and the impact of COVID-19 on the study design. The ethical design of the project is described in a peer reviewed publication. Finally, I discuss the recruitment and sampling, data collection and analysis, and the criteria for rigour.

3.2 Research methodology

3.2.1 The research focus

I sought to understand the social processes relating to the phenomena under study, and constructed a grounded interpretation from the research participants' point of view (Charmaz, 2014). I chose a paradigm that then framed the ontology (nature of reality), the epistemology (nature of knowledge), and axiology (moral and ethical implications), and a theoretical framework that enabled me to explore how social

interactions occur, and the meanings that can be drawn from the symbolism such interactions convey (Denzin & Lincoln, 2005; Guba & Lincoln, 2005).

My focus was guided by the aim of the study which intended to develop a substantive explanatory theory of the social processes that promote and preserve personhood in TBI nursing care within rehabilitation settings from the perspectives of patients, family members and nurses. My thoughts where anchored by the research question - What are the social processes that promote and preserve personhood in TBI nursing care?'

3.2.2 The research paradigm – Social Constructionism

The research paradigm represents the researcher's worldview and describes a set of beliefs that guides their actions and dictates how meanings are constructed from research data (Denzin & Lincoln, 2005; Guba & Lincoln, 2005; Kivunja & Kuyini, 2017).

In this study, I adopted a *social constructivist* research paradigm, whereby subjective reality, knowledge and truth are constructed through cultural norms and practices and collective human interactions (Andrews, 2012; Creswell & Poth, 2018). This paradigm in turn requires a relativist ontology and a subjectivist and socially constructed epistemology, whereby I recognise the existence of multiple constructions of reality (Guba & Lincoln, 2005). I believe that the researcher brings their own epistemological lens to the reality being studied (Rieger, 2019). Congruent with the methodological approach of CGT, knowledge is further co-created between the researcher and the research participants within a subjectivist epistemological

position to develop theory founded upon participants' understanding of their lived social world (Charmaz, 2014; Galbin, 2014; Hall et al., 2013).

My focus as a social constructionist researcher was firstly on understanding the social practices of rehabilitation nurses during their everyday interactions with people with TBI and their families and, secondly, on understanding how the nurses constructed personal meanings from these interactions (Andrews, 2012; Charmaz, 2014). I sought to make interpretations in light of social contexts and interactions that shaped elements of personhood in TBI care. This work meant challenging my own understandings by elevating the understandings of participants in a process of co-creation.

3.2.3 Symbolic interactionism

Symbolic interactionism constituted a theoretical perspective, via which a researcher understands how people construct meanings about feelings, and thoughts about self, social lives, and reality (Charmaz et al., 2019). American philosopher, George Herbert Mead (1863-1931) is credited with initiating the concept of symbolic interactionism (Benzies & Allen, 2001; Liamputtong, 2020). However, the term 'symbolic interactionism' was later coined by Herbert Blumer in 1969, based on Mead's 1934 theoretical works (posthumously collected), which were concerned with how individuals related with society (Carter & Fuller, 2016). Symbolic interactionism "refers to the peculiar and distinctive character of interaction as it takes place between human beings" (Blumer, 1962, p.180). Blumer contended that patterns of human behaviour should be studied as *actions*, and human's social lives should be analysed according to what people do together in *units* (Carter & Fuller 2016).

Symbolic interactionism sees human society as comprised of acting units and activities that are observable in society arise from such units (Blumer, 1962). Acting units may be comprised of organisations or individual people and they act toward situations. Actions are developed, and occur, in relation to the interpretation of specific situations. The acting units have to "identify the things that they have to be mindful of, such as tasks, opportunities, obstacles, means, demands, discomforts, and dangers" (Blumer, 1962, p.187). The acting units have to assess these elements and make rational decisions as individual persons, collective groups, or agents of other entities (Blumer, 1962). Acting units are responsible for defining and structuring group life. Through repeated interactions, people in society are able to develop a common understanding and act alike. From a symbolic interactionist stance, social organisation can be conceptualised as a collection of acting units that independently construct their own actions under conditions that may be set by social roles, social systems, culture, or social stratification (Blumer, 1962).

Blumer refers to Mead's "triadic nature of meaning", whereby symbols, in particular gestures, are communicated as a social process. The meaning of a gesture signifies: 1) what the person reading the gesture is directed to do; 2) what the person who sends the gesture is planning; and 3) what combined action results from these exchanges of meaning. Any misunderstanding about any stage of the three lines of action can lead to ineffective communication, a slowing of the interactive process, and the establishment of a barrier to the creation of an effective joint action (Blumer, 2003, p. 142).

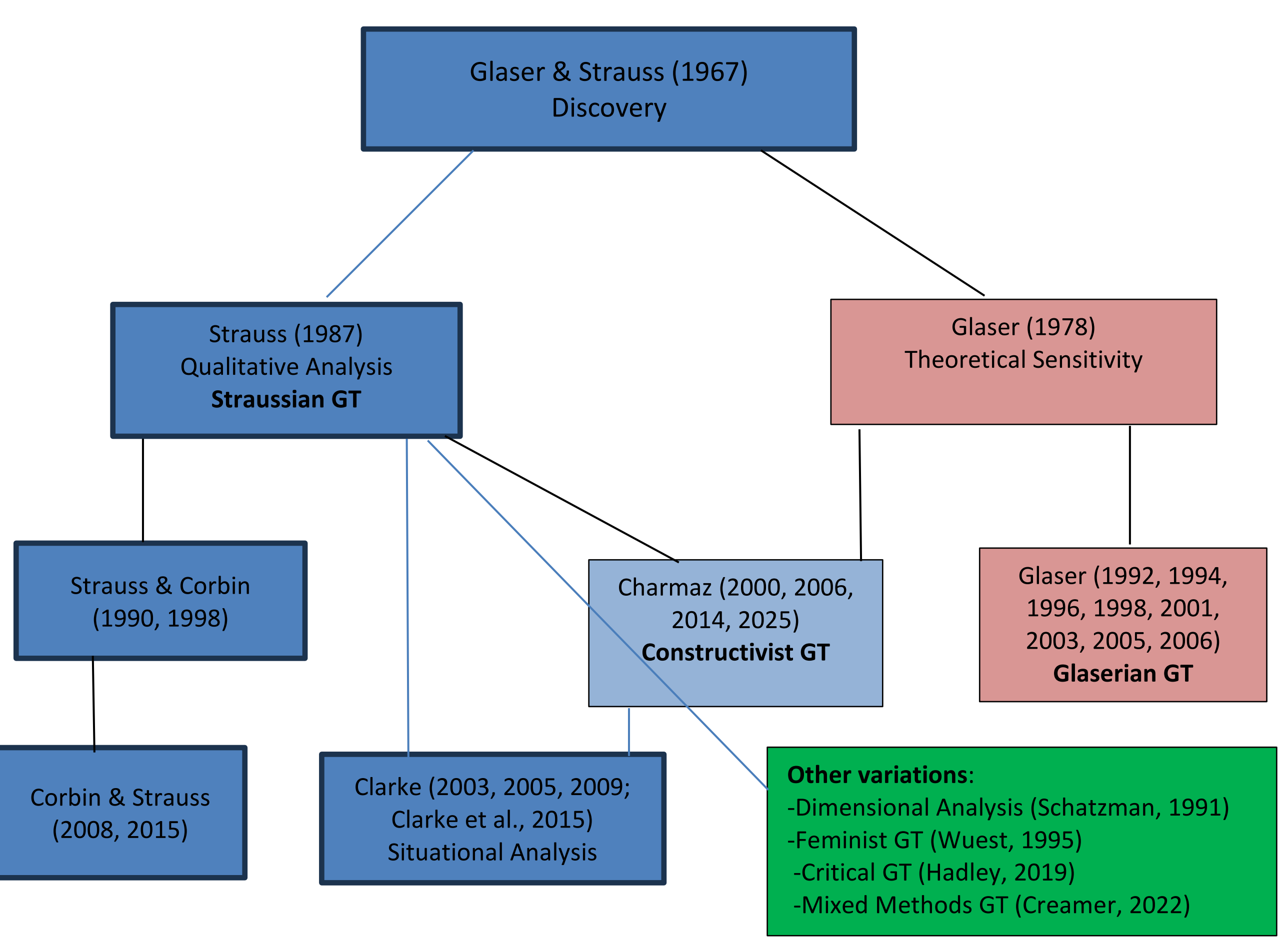
Finally, Blumer sees social processes as underpinned by the idea of *agency*: each *acting unit* can regulate their responses as autonomous contributions so that a group as a whole can achieve goals under a range of circumstances. This view assumes that the agent has some freedom and flexibility in their role and that they act of their own accord without structural influences (Carter & Fuller 2016). In the application of symbolic interactionism during analysis, Hewitt et al (2022, p.7) suggest considering throughout the analysis: "Who and what are the actors in this situation? What is meaningful to the actors in this situation and why? and, How do actors' individual lines of action interact in this situation?" These insights into symbolic interactions were integral to the general approach to theoretical construction in my study, given that the participants were social actors. By gaining a deeper familiarity with the symbolism in the participants' interactions, I was able to derive meanings from their point of view that contributed to constructions of a substantive theoretical understanding (Salvini, 2019).

3.2.4 Historical development of Grounded Theory

Grounded Theory methodology was developed by sociologists Barney Glaser and Anselm Strauss (1967, p.1) as a method of generating "theory from data systematically obtained from social research". The aim of Grounded Theory is to develop theory that is grounded in data rather than from extant theories (Corbin & Strauss, 2015; Glaser, 1978; Glaser & Strauss, 1967). This methodology was initially popular in nursing and social health research and gradually spread into other areas, such as education, business management, and psychology, and remains widely used by many researchers worldwide (Oktay, 2012; Strauss & Corbin, 1997).

Conceptual differences arose between Glaser and Strauss (Creswell & Poth, 2018) leading to further development of the methodology along different lines of thought (Glaser 1978; Strauss,1987; Strauss & Corbin, 1990). Further remodelling of the methodology occurred with other proponents adapting the ways in which Grounded Theory is characterised, theorised, and applied (Charmaz, 2014, 2025; Clarke, 2005; Corbin & Strauss, 2015; Creamer, 2022; Birks & Mills, 2023; De Chesnay, 2014; Morse et al., 2016; Stern & Porr, 2011). These diverse formulations of Grounded Theory are at times referred to as families, approaches, versions, or traditions. Figure 1 illustrates the genealogy of Grounded Theory (Morse et al., 2016).

Figure 1: Genealogy of Grounded Theory (Adapted from Morse et al., 2016, p.17).



3.2.5 Constructivist Grounded Theory

Constructivist Grounded Theory (CGT) was conceptualised by Kathy Charmaz (1930-2020), who was influenced by both Barney Glaser and Anselm Strauss. Charmaz attended multiple graduate seminars conducted by Glaser while completing her sociology doctoral studies at the University of California, San Francisco. Charmaz also had a close student-mentor relationship with Strauss, who reviewed and provided academic feedback on her work until his passing in 1996 (Charmaz, 2014). Charmaz positions her approach to GT within the constructivist paradigm, which acknowledges reality as “the world made real in the minds and through the words and actions of its members” (Charmaz, 2000, p. 523). Charmaz (2014, p.17) argues that “neither data nor theories are discovered either as given in data or the analysis”. Researchers are part of the world that they study, the data they collect, and the analyses they produce (Charmaz, 2014). The resultant theories created through CGT studies are the researchers’ construction of reality and comprise participants’ implied meanings and pragmatic perspectives (Charmaz, 2014).

CGT “offers a set of general principles, guidelines, and strategies rather than formulaic prescriptions” (Charmaz, 2014, p.3), with systematically gathered data forming the foundation for analysis and theory construction. This approach encourages the use of analytic processes from other Grounded Theorists where they seem appropriate to the emerging analysis (Rieger, 2019). Through this flexibility, emphasis is placed on study participants’ views, values, beliefs, feelings, assumptions, and ideologies (Creswell & Poth, 2018).

Although there are multiple variations of Grounded Theory, some essential elements define the approach (Birks & Mills, 2023; Charmaz, 2006, 2014). In general, Grounded Theory researchers begin with purposive recruitment of participants, and collect data via interviews and observations (Charmaz, 2014; Glaser, 1978; Glaser & Strauss, 1967; Corbin & Strauss, 2015; Strauss & Corbin, 1990). Data analysis requires a systematic approach to coding, with data are sorted into segments that allow for constant data comparisons (Birks & Mills, 2023; Glaser & Strauss, 1967; Glaser, 1992). Data collection and data analysis occur simultaneously. The constant comparisons of data are supported by analytical memos that facilitate the development of categories. Then, using theoretical sampling, additional data are collected to address any gaps observed in the tentatively developed categories. The researcher goes back and forth between field and study to iteratively compare tentative theoretical understandings or interpretations with previous data (Charmaz, 2014). This constant comparison of data allows for the construction of a substantive theory that provides systematic understanding of a primary research problem that is experienced as a social process (Bryant & Charmaz, 2007; Charmaz, 2014).

3.3 Research methods

The research design is a theory-building, multicentre qualitative research study, using iterative collection of in-depth interviews with people with TBI, family members and nurses experiencing inpatient TBI rehabilitation, and field observations of TBI rehabilitation nursing care (Charmaz, 2014; Creswell & Poth, 2018; Denzin & Lincoln, 2005).

3.3.1 The research setting

I conducted the study at three specialist inpatient brain injury rehabilitation units in Australia. All three research sites had 16 beds. One site was located in a stand-alone rehabilitation facility, while two were located within major tertiary hospitals. By using three research sites, I considered the study findings more likely to be transferrable.

In preparation for recruitment, I visited key people at each site to communicate the aims and design of the project and the support I would need from each unit. Before each visit to recruit and/or collect data, I contacted the key personnel at each site via email and/or phone to clarify the times and dates when I planned to visit the site for research purposes. It was mutually understood that, sometimes, local clinical circumstances or staffing might change these arrangements at short notice.

3.3.2 The research team

The research team included me as the primary researcher (a PhD student and neuroscience Clinical Nurse Specialist). The supervision team were three senior nurse and public health academics with PhD credentials and qualitative research expertise in health service, rehabilitation, population health, critical, acute and chronic care nursing, rehabilitation nursing, and mental health nursing.

3.3.3 The impacts of the COVID-19 pandemic on the study

This study was severely impacted by the coronavirus (COVID-19) pandemic that affected Australia and nations worldwide between December 2019 and 2021 (Chang et al., 2020; Moore et al., 2021). To limit the spread of COVID-19, various

restrictions were put in place to regulate how both clinical care and research were conducted. These restrictions included a mandated pause of all research-related work in clinical settings when COVID-19 was at its highest peak (Australian Government Department of Health and Aged Care, 2020). These restrictions required adjustments to the overall timeline for this study.

When progressive containment of the disease meant that clinical sites were opened for research purposes, social distancing precautions and the mandated use of Personal Protective Equipment (PPE) remained. These mandates meant that I had to adjust my research approach, and obtain further approvals from the Human Research Ethics Committee (HREC):

i) Changes to the scope of the study

The original study included settings that incorporated broader components of TBI care, including Intensive Care Units (ICUs), acute care wards at two public hospitals, and two TBI rehabilitation units. Due to restrictions on access to many acute sites, the study design was revised to focus on rehabilitation settings only.

ii) Changes to research protocol

Changes to the original research protocol were made to address mandatory COVID-19 directives. New provisions were added to the research protocol, including social distancing, wearing of PPE, routine screening at site entrance, and checking in with local clinical staff in case nurses' workload (often impacted by staff sick leave) meant that research activities would present an unacceptable burden on that day.

iii) Changes to research methods

The use of videoconferencing was included as an alternative to face-to face interviews for nurse participants. This change was supported by evidence that participants find video conferencing a highly viable and acceptable tool for qualitative data collection (Archibald et al., 2019).

3.3.4 Ethics approval

The main ethics approval was obtained in Australia from the Sydney Local Health District Human Research Ethics Committee - Concord Rehabilitation General Hospital (Ref: 2019/ETH13511, Appendices 1.1A &1.1B). Site specific assessment authorisations were then received from all three sites: (1)-2019/PID15131(Appendix 2.1); (2)-2022/STE00094 (Appendix 2.2); (3)-2022/STE00093 (Appendix 2.3). Due to the impacts of COVID-19, the healthcare regulations at the time did not make it possible to conduct recruitment from the ICU and acute care setting. Consequently, a change was made to the study scope to recruit participants from rehabilitation settings. Two sites were removed from the study scope and two new sites were added as per ethics approval (Appendix 1.1C). At one site, there was a condition that only a nurse clinician who was a fulltime staff member could act as the principal investigator. In response, I made an amendment to reflect this requirement (Appendix 1.1D). There was an extension to the duration of study due to impacts of COVID-19 interruptions and ethics approval was obtained for this extension (Appendix 1.1E).

3.3.5 Reflexivity

As a CGT researcher, I did not have to set aside my knowledge gained through personal experience and literature. However, to avoid forcing such preconceived ideologies on data, I engaged in reflexivity as a practice congruent with this research approach (Charmaz, 2014). My assumptions about the research aim before I started were documented in a journal.

After 13 years of experience as a clinical neuroscience nurse in an acute care setting, my view of nurses as givers of care required a shift of perspective to incorporate nurses as a facilitators of self-care. My academic supervisors have challenged my thinking, while reflection on my experiences as a clinician, and memo writing about emerging ideas in the data have increased my theoretical sensitivity.

Furthermore, as a male of African cultural background, I bear understandings of personhood as predominantly relational and consider all human beings as persons: one is a person for as long as they exist in the world. This understanding contrasts with Western constructions of personhood characterised by, for example, individualism, rationality, and capacity. Awareness of my cultural positioning sensitised my own conceptualisation of personhood, particularly when I reviewed literature by authors who purposefully presented concepts of personhood in ways that were culturally positioned. I was reflective in my application of personhood as a construct, so as to accommodate views that contrasted with my own cultural beliefs. I was sensitive to theoretical ideas that I encountered when preparing for publications, and presentations at conferences, symposiums and workshops (Appendix 11).

3.3.6 Ethical design

3.3.6.1 Addressing ethics standards and my role as a clinician -researcher

People with TBI may be vulnerable to research processes that do not accommodate alterations in consciousness, cognition and behaviours, nor recognise the power imbalance between the researcher and the participant. Family participants who may be advocates for the person with TBI themselves have lived through the traumatic event. Workplace research where nurse participants are part of a small, connected community raises further ethical risks. Referring to national ethical guidelines in the design of my study enabled me to strengthen my reflexivity and my sensitivity to participant safety and autonomy using targeted research strategies.

Aspects pertaining to ethics in this study were framed around the National Health and Medical Research Council (NHMRC, 2018a) National Statement on Ethical Conduct in Human Research in Australia. The third peer reviewed publication included in this thesis (Kivunja et al., 2022) explores the key ethical aspects that I addressed in the study. This publication describes how my study addressed research merit and integrity, justice, beneficence, and respect. It led me to examine specific groups that require particular ethical attention, such as people with cognitive impairment and people in unequal and dependent relationships. The publication also explores the challenges that I might encounter when functioning in the role of clinician researcher, which brings its own power dynamic to the researcher-participant relationship. Furthermore, as a neuroscience nurse clinician working in the acute setting, I have extensive familiarity with people with TBI, their characteristics and experiences, and recognise that this familiarity may colour my understanding of what I see and hear in the field.

Following this ethical examination, I developed a range of research strategies to support participant inclusion, informed consent, and participant confidentiality, to avoid participant distress, and to examine my own positioning as a clinician working in the research field.

Author attribution statement

This manuscript has been published as:

Kivunja, S., Pryor, J., River, J., & Gullick, J. (2022). Navigating the role of clinician-researcher: Insights from a constructivist grounded theory study in traumatic brain injury. Australasian Journal of Neuroscience, 32(2), 6–17. https://doi.org/10.21307/ajon-2021-008

I co-designed approach to literature review with my supervisors who are co-authors (A/Prof Jo River and A/Prof Janice Gullick). I conducted the literature search and data extraction. I synthesised the literature. I wrote the original manuscript draft and revised it with critical input from my co-authors. I prepared responses to reviewer feedback with further input from co-authors and submitted the manuscript.

Student name : Stephen Kivunja

Signature **Date:** 29 September, 2025

As supervisor for the candidature upon which this thesis is based, I can confirm that the authorship attribution statement above is correct.

Lead supervisor name*:* A/Prof Janice Gullick

Signature **Date:** 29 September, 2025

Permission to include the published manuscript in this thesis is attached (see Appendix 12.3)

Navigating the role of clinician-researcher: Insights from a Constructivist Grounded Theory study in traumatic brain injury

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Abstract

Using the case of traumatic brain injury, this paper explores 1) challenges to academic and ethical integrity when in the role of clinician-researcher, and 2) potential strategies to enhance ethical qualitative research involving people with possible physical and/or emotional trauma and temporary or permanent cognitive disruption. When undertaking qualitative research with patients, families, and/ or health professionals, a researcher's clinical background may stimulate insightful and relevant research questions, interviews, and/or field observations of care to inform meaningful and translatable practice improvements. However, there may be tension between clinician versus researcher values, and these priorities affect what the clinician sees and interprets in the field. A clinician's ingrained values and professional socialisation can make it difficult to hold their professional assumptions about various phenomena at bay. The principles of human research merit and integrity, justice, beneficence, and respect, along with methodological clarity, can provide a rigorous foundation for discussion of ethical research in traumatic brain injury.

This paper discusses challenges and strategies through: 1) examining clinical assumptions; 2) determining capacity for consent; 3) considering dependent or unequal power relationships; 4) determining the scope for field observations; 5) responding to unprofessional practice; 6) discriminating between research interviews and clinical conversations; and 7) critically reflecting on research data. Implications for clinical research are evident: seeing past one's own construct of understanding is challenging for clinician-researchers aiming to illuminate both patient and family experiences of care, and nuanced clinical skills. Careful ethical and methodological planning can protect participants while illuminating elements of specialist practice.

Keywords: Nurses, brain injury, clinician, researcher, ethics, grounded theory

Introduction

Care of people with traumatic brain injury (TBI) is complex and challenging as, depending on the severity of the head injury, TBI patients may struggle with injury-related outcomes such as physical disabilities, cognitive impairment, emotional, psychiatric, and behavioural changes, as well as social isolation (Diaz-Arrastia et al., 2017; Gould et al., 2019; Salas et al., 2018). Neuroscience nurses may, therefore, provide care to patients with reduced self-awareness and capacity to understand or follow instructions, a heightened propensity for distress, anger, and risky or challenging behaviours, and relational conflict. People with TBI may struggle to find new ways of managing activities of daily living or to reconstruct personal identity in the face of often multiple personal losses, disability, and invisibility (Oyesanya et al., 2018; Stenberg et al., 2022). To provide quality patient care that addresses these unique challenges to recovery, neuroscience nurses increasingly seek to engage in research to understand how TBI care can be shaped in ways that improve clinical practice, systems of care and patient outcomes (Smith et at., 2018).

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DOI: 10.21307/ajon-2021-008

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However, this specialist knowledge can also present both ethical and methodological challenges.

These include: 1) assumptions stemming from extensive clinical knowledge that may constrain critical openness toward new understandings during data collection and analysis; 2) determining capacity for consent; 3) recruiting people in dependent or unequal relationships; 4) what should (or should not) contribute to field observation data; 5) responding to unprofessional practice; 6) discriminating between research interviews and a clinical conversation; and 7) critically reflecting on research data in ways that allows for innovation (versus generating solutions only from one's current therapeutic repertoire). The systematic application of ethical and methodological strategies may help to manage the tension between the clinician-researcher's pre-existing knowledge and assumptions and the phenomenon being studied so that new understandings are enhanced by subjectivity, rather than being skewed by bias.

This paper explores ways of managing these challenges through careful ethical and methodological design. A study of social processes that promote and preserve personhood for people receiving rehabilitation care is used as a vehicle for this discussion. Reflexivity is an important basis for examining the clinician-researcher role. The primary researcher (SK) is a Clinical Nurse Specialist (CNS) in an acute neuroscience ward at a major tertiary teaching hospital, caring for people with a range of neurological conditions including TBI. Such care extends to the support of family members, providing updates, support and education about ongoing care and treatment. This doctoral research project arose from the clinician-researcher's curiosity about the lived experience of TBI and its intersection with nursing care.

Background

The multi-centre research study that provides context for this discussion paper uses Constructivist Grounded Theory (CGT) (Charmaz, 2014). Human Research Ethics Committee approval was received (Ref:2019/ETH13511) to investigate the social processes that promote and preserve personhood in TBI nursing care across three brain injury inpatient rehabilitation units in Sydney, Australia. Participants are people with TBI, family members, and nurses working in TBI inpatient rehabilitation care settings. The data collection involves either single or longitudinal one-to-one semi-structured interviews with all participant groups, and field observations of nursing care. Data collection and data analysis occur concurrently where data coding is undertaken using the constant comparative method, a central component of CGT (Charmaz,2014). The study addresses a gap in our understanding about giving and receiving care for TBI identified in an earlier integrative review that informed the design of this study (Kivunja et al, 2018).

Aim

The aim of this paper is to explore 1) challenges to academic and ethical integrity when in the role of clinician-researcher, and 2) potential strategies to enhance ethical qualitative research design involving people with possible physical and/or emotional trauma and temporary or permanent cognitive disruption using the case of TBI.

Methods

Framework for the discussion

In Australia, the guiding ethical framework is the "National Statement on Ethical Conduct in Human Research" from the National Health and Medical Research Council (NHMRC, 2018a). It provides guidelines for the ethical design, conduct and dissemination of results of human research. The National Statement builds upon the Declaration of Helsinki (World Medical Association, 2018) and stipulates four principles that guide ethical conduct of research: research merit and integrity, justice, beneficence, and respect (NHMRC, 2018a). These principles, along with ethical considerations specific to particular participant groups (for example, people in dependant or unequal relationships, and people with cognitive impairment), and methodological processes aligned to CGT were useful in identifying, examining, and developing strategies to facilitate navigation of the clinician-researcher role.

Discussion of challenges and strategies

There were seven challenges encountered in designing and implementing this research, and the following discussion is inclusive of research design strategies.

Challenge 1: Examining assumptions stemming from extensive clinical knowledge

The clinician-researcher (SK) is both an experienced neuroscience nurse and a doctoral researcher, with prior theoretical and clinical knowledge. He has a Masters degree in neu-

roscience nursing and has published an integrative literature review on the experiences of receiving and giving care in TBI settings (Authors blinded, 2018). His clinical experience within this field spans over ten years and equips him with a bank of clinical experiences that are related to the research topic. To a certain extent, these clinical experiences were a major challenge to the role of researcher. For example, they had potential to influence how the interview questions for people with TBI were phrased, what terminologies were chosen for participant information statements and patient and family interviews, what aspects of nursing care were chosen to observe during field data collection, and how the observed patient-nurse interactions were interpreted and reported. He navigated this challenge using the following three strategies:

Strategy 1.1 - Building ethical knowledge: As a novice, the clinician-researcher familiarised himself with the National Statement on Ethical Conduct in Human Research (NHMRC, 2018a), the Australian Code for Responsible Conduct of Research (NHMRC, 2018b) and Good Research Practice (GRP) by attending specific GRP training, and Emotional-First Aid training.

Strategy 1.2 - Clarifying the philosophical stance: An early determination of the chosen philosophical stance secured the assumptions under which data were to be viewed (Charmaz, 2014; Weaver & Olson, 2005). A detailed documentation of the choice of paradigm (constructivist), ontology (the multiple nature of reality), epistemology (the subjective nature of knowledge), and methodology (CGT) (Charmaz, 2014) was compiled. These choices clarify that the aim is to construct a theory that will explain a social process, that there are multiple realities reflecting multiple truths for participants, and that this knowledge is co-constructed according to apriori social understandings. Communicating these elements is fundamental to the conception and conduct of a robust study (Howes, 2017; Guba & Lincoln, 1994) and provides a solid foundation for a rigorous constructivist grounded theory investigation (Charmaz, 2014).

Strategy 1.3 - Being open minded and reflexive: Charmaz (2014) advises that a researcher using CGT should approach their study, not as a blank slate, but as a knowledge-laden individual with an open mind. The clinician-researcher's values, priorities and positions can affect what they see and interpret in the field, and nurses' ingrained values and intensive professional socialisation can make it difficult to hold their professional assumptions about phenomena at bay (Charmaz, 2014; Hay-Smith et al., 2016). Seeking an open mind can assist nurse-researchers in examining and alleviating such embedded philosophies or practices (Berthelsen & Hølge-Hazelton, 2017; English et al., 2022). Another strategy to maintain an open mind is working within a team with varied clinical backgrounds. Approaching analysis as a team allows team members to challenge assumptions about the data with analysis becoming more insightful due to these multiple perspectives.

To put this doctrine into practice, the clinician -researcher applied a reflexive approach, documenting an early reflexive statement as the basis for a research decision trail, or reflexive journal (Berger, 2015; Koch, 1994). This evidence documents the initial potential influences and biases arising from experiences as a nurse working in an acute neuroscience ward, and associated disciplinary idiosyncrasies (Hay-Smith et al., 2016). It also records any research related decision-making that resulted in a change in process or an emerging ethical issue (Davis, 2020; Mortari, 2015). Examples of reflective journal entries include ethical and method-related changes resulting from the SARS-CoV-2 (COVID-19) pandemic, including changes in study scope, and safe access to participants. The journal was, for example, a useful and readily accessible resource to inform the process for an interview with a participant deemed a close contact of a person with suspected COVID-19. The reflexive journal remains a dynamic document that captures the various approaches to participant recruitment, interviews, field observations, data analysis, coding, developing categories and interpretations as the study progresses. A position of reflexivity is aligned with CGT methodology to facilitate a transparent and open discussion of how a researcher is situated, relative to their data and participants (Charmaz, 2014; Davis, 2020; McGhee et al., 2007; Peddle, 2021) and is considered a criterion for rigour in qualitative reporting generally (Tong et al., 2007).

Challenge 2: Determining capacity for consent

The clinician-researcher works in a taken-for-granted way in their clinical role with vulnerable patients. They develop methods to communicate, determining preferences and including families, with a focus on safe care and recovery from an acute injury. However,

the approach required to addressing the vulnerabilities of these people as research participants required a different lens. Some of the potential patient participants would have cognitive impairment (Gorgoraptis et al., 2019; Haarbauer-Krupa et al., 2021). This required an ethical process for informed consent, given that participants were at the rehabilitation phase of care, and the dynamics of the study settings were unknown to the research team. As a measure of respect for participants, the clinician-researcher had to re-examine his clinical assumptions about cognitive impairment as a barrier to participation in scholarly activities. The strategies employed to address this challenge are as follows:

Strategy 2.1 - Redefining capacity for consent: Considering the ethical principle of justice, the National Statement principles hold that people with cognitive impairment are entitled to be included as participants in research studies that are of benefit to them (NHMRC, 2018a). An assessment form, 'Guide to determining capacity for consent and suitability of participation' (Supplementary file 1), was developed and used for this purpose. The tool enabled identification of candidates who may be cognitively impaired but could express their wishes about things that affect them in their day-to-day life, including things they do not want to do, could participate in a simple conversation about recent events and were less likely to be distressed if a researcher sat at their bedside observing their care, or asked questions about events that led to their TBI. In line with the principle of research merit and integrity (NHMRC, 2018a; Section 4.5.1), the clinician-researcher deliberated on how the capacity for patient participation would be addressed from the perspective of a researcher, rather than that of a nurse clinician. Participant information statements clarified that consent could be withdrawn at any time and refusal to participate was respected and would not impact researcher or clinician relationships (NHMRC, 2018a; Sections 4.5.9 and 4.5.11). Ongoing consent was further confirmed during interviews: a handheld 'Stop sign' that could be raised by the participant to stop the interview or field observation was created in the understanding that it may be easy to assent to elements of participation, but harder to withdraw that consent during data collection.

Strategy 2.2 - Witnessing the consent process: Beneficence refers to the benefits of research outweighing the risks, but cognitive impairment may hinder a person's decisions about their own best interests (Xu et al.,2020). Consent for participation in the study was sought from participants individually (NHMRC, 2018a; Section 4.5.5), but due to issues of cognitive impairment in people with TBI, the research team determined a need for a designated patient advocate, who was external to the research team and acting in line with the patient's best interests. An advocate was considered a person with the capacity to understand the merits, risks and procedures of the research, who was independent of the research team and, where possible, knew the participant and was familiar with their condition (NHMRC, 2018a; Section 4.5.8). They may be, for example, a family member, or a clinical staff member involved in their care. In this study, the advocate, with reference to the 'Guide to determining capacity for consent and suitability of participation' (Supplementary file 1), signed the consent form (under the patient's signature) to confirm that they also had considered the potential harms arising from the patient's participation and that the patient understood enough about their participation to make a decision in their best interest.

Challenge 3: Considering dependent or unequal relationships

Navigating the role of clinician-researcher required critical examination and management of unequal relationships or perceived coercion to participate. Unequal relationships were foreseen firstly between patients and the clinician-researcher (Franco & Yang, 2021; Mauthner, 2019), who had extensive TBI nursing experience and advanced training in research, in a world where clinical knowledge is often privileged over other ways of knowing (Foucault, 1980; Eide & Kahn, 2008). Clinical knowledge is a form of 'biopower' which aligns behaviour as either normal or deviant, creating pressure for patients to conform to normative social behaviours, which may include perceived pressure to take part in research (Foucault, 1980). This power imbalance can be intensified for people with TBI who may present with a degree of cognitive impairment (Bashir, 2020; Gorgoraptis et al., 2019; Oyesanya et al. 2019; Stålnacke et al., 2019). A second form of potential power imbalance was between local senior nurse clinicians who assisted with nurse participant screening, nurse unit managers who supported the research, and potential nurse and patient participants. Nurses represent a form of power in brain injury settings, as depending on the nature of the facility and the stage of the person's recovery, they may organise almost every element of the person's day and operationalise

restrictive approaches to care. The strategies used to navigate unequal relationships are as follows:

Strategy 3.1 - Collaboration with local stakeholders: Several meetings between the research team and local senior nurses who were key contacts at each site clarified key aspects of the study to promote voluntary participation. The clinician-researcher collaborated with site senior nurses who disseminated recruitment flyers and identified potential participants (Kraft et al., 2020a). These senior nurses, who were not in supervisory roles, explained the purpose and activities related to the research. The clinician-researcher then spoke to potential participants about the study and provided them with written participant information statements. Participants were given as much time as they wished to consider participation and the clinician-researcher then returned at a negotiated date to finalise consent. The recruitment and timing of consent was negotiated with specific nurse clinicians at each site to secure the most convenient time for potential participants, and to minimise disruption to unit workflow (NHMRC, 2018a; Section 4.5.6). Only people with no previous relationship to the clinician-researcher, either professional or personal, were recruited. Purposive sampling was initially used to recruit the most suitable participants to provide data that would help answer the research questions, then as lines of inquiry emerged from the data, theoretical sampling was used to target participants who could address important parts of the developing theory, or to revisit and reinterview existing participants (Fletcher, 2019).

Strategy 3.2 - Communicating research merit and integrity (NHMRC,2018a; Section 4.3.3): A supervisory team with expertise in CGT methodology, rehabilitation nursing and care of vulnerable populations supported development of a sound research protocol. Researcher qualifications and academic roles were listed on participant information statements. Letters of invitation to patient and family participants were signed by the Nurse Unit Manager, communicating the clinical oversight of the study by local healthcare professionals with the best interest of patients at heart. Letters inviting nurse participants were signed by the principal university research supervisor supporting an arm's length approach (Chiang et al., 2001), independent of hierarchical hospital structures.

Strategy 3.3 - Simplifying participant information: A simplified participant information statement was designed for patient participants with possible cognitive impairment, and for patients and families, interview questions were phrased using lay terms (for example, the term 'head injury' instead of 'traumatic brain injury' or 'TBI').

Challenge 4: Determining the scope for field observation data

Another challenge for the clinician-researcher was deciding what constituted data in field observations; what to observe and what to omit for methodological, ethical and privacy reasons. One fundamental property of grounded theory is the doctrine that all is data (Glaser & Strauss, 1967); everything encountered in the field has potential to contribute data. However, early observations demonstrated a tendency to only see clinical issues that underpinned clinician practice, and privacy implications presented further constraints.

Strategy 4.1 - Developing a field observation tool: A 'Framework for field observations' was developed to allow for a structured approach to gathering observable data in the field (Lapid et al., 2021). These included the observable care needs of patients, emotional needs, things patients could either do or needed help with, how patients communicated their needs to family and nurses, how nurses communicated with patients, and what nurses/families did to support personhood. The participant information sheet noted that observations would not include personal care such as showering or toileting. Participants could request the clinician-researcher to leave if they did not wish something to be observed, and all participants had the choice to participate in interviews only.

Challenge 5: Responding to unprofessional practice

A potential ethical challenge was responding to any observed unprofessional nursing practice during field observations. This might include unsafe clinical practice, non-adherence to policies and procedures, imminent medication errors or lack of consideration for patients or family members. Although not yet encountered, the following strategies are in place:

Strategy 5.1 - Following mandatory reporting guidelines: Mandatory notification guidelines for healthcare professionals in relation to unprofessional practice that endangers the health, safety, and wellbeing of patients are stipulated by the Australian

Health Practitioner Regulation Agency (AHPRA, 2020). One benefit of being a clinician-researcher is that they can interrupt poor and potentially dangerous practice. In recognising both notifiable behaviour, but also unprofessional practice that would not meet the threshold for mandatory notification, the following statement was included in the nurse participant information sheet:

"If during an observation, the researcher notes an imminent safety issue such as a likely fall or medication error, he would raise this immediately with you so you could respond to the safety issue yourself. If the researcher observes something that constitutes "Notifiable behaviour… (e.g., intoxication, sexual misconduct, or significant departure from accepted professional standards that has placed the public at risk)" he would seek advice before making any notification. Behaviour that is unprofessional in some way but not unsafe would be considered part of the confidential research data. In all cases, the researcher would aim to manage the situation in a respectful and just way"

Challenge 6: Discriminating between a research interview and a clinical conversation

A challenge for the clinician-researcher in the interview phase was to recognise how a qualitative research interview differs in purpose and structure from a clinically focused conversation with a patient. This required careful construction of an interview guide, and careful consideration of choice of terminologies, the location and duration of interviews, and how to manage moments of distress (DeJonckheere et al., 2019; DiCicco-Bloom & Crabtree, 2006; Josselson, 2013). The following strategies addressed this challenge:

Strategy 6.1 – Drawing on prior knowledge, clinical experience and consumer engagement: The initial interview guide was informed by the clinician-researcher's clinical expertise in TBI, findings of the team's integrative review and feedback from consumer engagement (a patient and spouse with lived experience of TBI). Consumer input was valuable for incorporating TBI consumer-related concepts into the interview guide (Australian Clinical Trials Alliance, 2018; Brett et al., 2014; Kraft et al., 2020b; Miller et al., 2017) and drew attention to clinical jargon in interview and recruitment documents. Acknowledging respect for participants' intrinsic value (NHMRC, 2018a), interview questions explored participants' beliefs, customs, and cultural heritage.

Strategy 6.2 - Performing pilot interviews: Two pilot interview sessions with neuroscience nurse colleagues were conducted using the draft interview guide and these verbatim transcripts were critiqued by members of the research team. Pilot interviews with peers give insight into clarity of questions, language, and active listening skills prior to commencing data collection (McGrath et al., 2019). They can sensitise the interviewer to effective use of prompts, following up on key topics, and pausing to allow participants space to consider their thoughts and answers. Reflection of content and feelings helped to check for understanding and communicate active listening. In CGT, interview guides evolve according to the researcher's developing theoretical sensitivity, as they follow emerging lines of inquiry from previous interviews (Charmaz, 2014; Colon et al., 2015). Interview guides are continuously reviewed and updated so that emerging lines of inquiry inform theoretical sampling (subsequent participants are sought to explore specific emergent issues for examination) (Charmaz, 2014).

Strategy 6.3 - Being mindful of interview duration: TBI can impact a person's capacity for concentration (Stålnacke et al., 2019). Though the anticipated duration was 30-60 minutes, there was provision for pausing, stopping, and rescheduling interviews where needed. The clinician-researcher's experience made him attuned to subtle patient cues of tiredness or inattention. Interview schedules were negotiated and planned for periods when patients were less likely to be tired, such as before exercises, physiotherapy or energetic recreational activities (NHMRC 2018a; Section 4.4.5; Sigstad et al., 2014).

Strategy 6.4 - Preparing to manage distress: Given the potential for discomfort or distress during interviews that involve recollection of traumatic events (NHMRC, 2018a; Section 4.5.2; Sander et al., 2013) a 'Participant Distress Protocol' was developed (Supplementary file 2) to guide actions in response to either a self-limiting or extended period of distress.

Challenge 7 - Critically reflecting on research data

A final challenge for the clinician-researcher was to critically reflect on research data, using the lens of a researcher rather than that

of a nurse clinician. The following strategies helped to overcome this challenge:

Strategy 7.1 - Memoing: Memo writing is a key strategy in CGT; it prompts and supports researchers to construct codes and categories earlier in the research process to support the abstraction of novel theoretical ideas (Charmaz, 2014). Memos can be documented in the reflexive journal (Bowen, 2009; Charmaz, 2014).

Strategy 7.2 - Analysing data in a team environment: The clinician-researcher regularly engaged with the research supervisors through collaborative analysis and team dialogue. This enabled refinement of codes and critical feedback on the developing categories. When early codes were interpreted through the nurse-clinician eyes, the supervisors continually challenged this narrow perspective, to encourage routine critical questioning of clinician assumptions, so as to remain open and theoretically sensitive to the unfolding theory (Berger, 2015; Charmaz,2014; Glaser, 1978). This researcher triangulation brings multiple perspectives to data analysis, which is a strength in qualitative research.

Conclusion

Neuroscience nurses who function in the role of clinician-researcher can face several ethical and methodological challenges. Use of the National Statement on Ethical Conduct in Human Research helps to embed the values and principles of ethical conduct: respect for human beings, research merit and integrity, justice and beneficence to develop research practices underpinned by trust, accountability and ethical equality (NHMRC, 2018a). In the study discussed here, ethical considerations specific to patients with TBI, their family members and/or nurses who care for them included people in unequal or dependent relationships, and people with cognitive impairment. Elements of CGT, such as openness, reflexivity and memoing supported the clinician-researcher to challenge previous clinical assumptions and move from concrete clinical thinking to abstraction of novel theoretical ideas.

Acknowledgements

We would like to acknowledge the Westmead Charitable Trust Nursing and Midwifery Career Development Scheme for the research grant that is supporting the primary study.

The authors report no conflict of interest related to this manuscript

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Supplementary file 1

Guide to determining capacity for consent and suitability for participation

Title of the research:

Social processes that promote and preserve personhood in traumatic brain injury nursing care

Participation in field observations of care with proxy consent

- Is this person likely to be easily distressed if a researcher is sitting in proximity to the bed space observing their care?

Participation in field observations and / or interviews (patient consent)

- Is this person likely to be easily distressed if a researcher is sitting in proximity to the bed space observing their care?
- Is this person likely to be easily distressed if a researcher asks them questions about their injury and nursing care?
- Can this person express their wishes about things that affect them in their day-to-day life? E.g., things they don't want to do
- Can this person conduct a simple conversation about recent events in their life?

Supplementary file 2

PARTICIPANT DISTRESS PROTOCOL

RESEARCH PROJECT

Social processes that promote and preserve personhood in TBI Nursing Care

A guide for management in the case of a participant's emotional distress during or after the interview.

1. It is recognised that research participants discussing emotive topics in in-depth interviews may become emotionally distressed. In such instances the following management will occur.

Scenario	Action
The participant has a short, self-limiting period of emotion in response to a difficult topic	1. Pause the interview 2. Ask the participant if they would like to take a break or stop the interview completely 3. If the participant expresses a wish to continue the interview and is able to do so without undue distress, allow them to do so 4. If the participant wishes to stop the interview, ask if they would like to continue the interview at a later time or date or withdraw from the study. 5. At the end of the interview, explore the five elements of psychological first-aid (safety, calm, connectedness, self/group - efficacy and hope) 6. Offer to refer them to the counselling support programme at the site Hospital.
The participant has an extended period of emotional distress.	1. Stop the interview 2. Ask if they would like you to call a support person 3. Stay with the participant until they are calm. 4. Explore the five elements of psychological first-aid (safety, calm, connectedness, self/group -efficacy and hope) 5. Refer them, with their permission, to the 'Employee Assistance Program (staff participants) or to the social worker or psychologist for the TBI Unit (patient and family participants). 6. In the case of a patient participant, significant distress will trigger immediate cessation of the interview or observation. We will thank the participant for their time and will destroy any data collected and withdraw the participant from the study. 7. Call the next day to check on their well being 8. Offer them the option to withdraw from the study. 9. Report to the ethics committee as an adverse event.

3.3.6.2 Reflection on this publication

While I was an experienced neuroscience nurse clinician in the early stages of my research study, I was still a novice CGT researcher. I tended to view my work using a clinician's lens rather than a researcher's lens. For example, during my open coding for the initial set of interviews, I used categories comprised of clinical terminologies as opposed to conceptualising the content of human interactions. Generating theory grounded in data without clinician preconceptions was a primary goal for my developing research skills. First, writing this paper better positioned me to collect and analyse data, and to critically interpret what I saw as grounded theoretical concepts that exemplified the social process under investigation (Charmaz, 2014). Second, writing this paper enhanced my theoretical sensitivity and empowered me to be more aware and responsive to the assumptions that I brought to my study as an experienced nurse clinician. Third, I needed to enhance my ability to conduct this study in a manner that demonstrated adherence to ethical practices, given the potential vulnerabilities of people with TBI and their families taking part in the research. Aligning my research design and associated strategies to the National Statement on Ethical Conduct in Human Research (NHMRC, 2018a) strengthened my understanding of the specific implications for ethical research design and conduct, particularly in preparation for recruitment of study participants and data collection in the field.

3.3.7 Recruitment and sampling

Three groups of study participants were recruited: people with a lived experience of TBI (patients with TBI); the family or people of significance to the first group; and rehabilitation nurses. The recruitment of participants was initially purposive and then

theoretical, and some processes were unique for each research site due to local clinical practices, routines, protocols, and nursing staffing levels, which at times influenced how research activities were to be undertaken.

3.3.7.1 Inclusion and exclusion criteria

Table 2: Inclusion /exclusion criteria.

Participant groups	**Inclusion criteria**	**Exclusion criteria**
Rehabilitation nurses	ENs or RNs currently providing care for adults whose primary reason for inpatient rehabilitation was a TBI.	Casual nursing staff. Nursing students. Assistants in nursing or personal care attendants.
People with TBI	People 18-years or over who were inpatients in a rehabilitation setting and their primary reason for hospitalisation was TBI.	People who were not fluent in English (due to the need for semiotic interpretation of interview data). People who were non-verbal. People with significant cognitive deficit (i.e., advised by nursing staff that the patient is likely unable to provide informed consent, or unable to tell their story). *This exclusion criteria applied to interview participation only. These people would, however, be suitable as participants in field observations with the proxy consent of their family. This strategy supported the ethical domain of justice, whereby all people should have the opportunity to participate in research as advocated for by the National Health and Medical Research Council (NHMRC, 2018a).*

Family and significant others	People 18-years or over, who were either a close family member or another person of significance, who provided close care and support for a person with TBI. *Patient and family members did not need to be dyads (i.e. related to one another). This rule provided a window into the experiences of, for example, critically injured non-verbal or non-English-speaking participants via their carer, and patient participants who did not have a close family carer.*	People who are not fluent in English. People with cognitive impairment.

I recruited participants over two temporal phases of fieldwork:

- **Phase One sampling:** Phase One, conducted between June 2021 and March 2022, involved initial data collection to support the construction of tentative categories (Charmaz, 2014). In this first phase, I used purposive sampling to identify participants who were best able to inform the research aims. I sought a sample of participants who were broadly representative of the age and gender of TBI patients, and of nursing staff with a range of skills, experience, classification of registration, training, and years of practice (e.g., ENs versus RNs). In phase one, I was unable to recruit family participants from site 1 and site 3, or patient participants from site 3 due to the impacts of NSW Health COVID-19 regulations that restricted research activities and interrupted my access to the field. These omissions were addressed in phase two sampling.

- **Phase Two sampling:** Phase Two was undertaken during November and December, 2024, following the development of tentative categories in the data. This theoretical sampling engaged, or re-engaged, with participants who were most likely to confirm or challenge emerging categories in the evolving theory (Charmaz, 2014; Holton & Walsh, 2017). 'Holes' in the evolving theory guided this sampling phase. For example, the number of family participants needed to be expanded to bring greater confidence to the analysis, and nurse participants needed to be re-engaged to confirm the assumed power of allied health guidelines across sites. The final sample size was guided by a process of theoretical sufficiency, whereby participants were recruited until the categories developed were robust, and the relationships within and between categories had been defined, confirmed, and explained (Charmaz 2014).

In preparation for recruitment across participant groups, I held confidential meetings with the key site clinical contacts who were knowledgeable about the potential study participants in their units. The key site clinical contacts introduced me to prospective patient, family member, and nurse participants. I did not have any relationship with potential participants. I conducted all recruitment processes in a private space to maintain confidentiality for research participants. All recruitment documents and processes were HREC approved.

3.3.7.2 Recruitment of people with TBI

Screening of people with TBI: I discussed the Guide to Determining Capacity for Consent and Suitability for Participation (Appendix 3.1) so the key contacts were

aware of the selection criteria and could recommend potential candidates to approach for recruitment.

Providing participant information to people with TBI: The key site clinical contacts introduced me to prospective patient participants at the patient's bedside or in a private space within the BIRU. I provided each potential patient participant with an introduction letter (Appendix 3.11a), which formally invited them to participate in the study, and the Patient Participant Information Statement (Appendix 3.12a).

Consenting of people with TBI: If the person with TBI was deemed to have capacity, they provided informed written consent. If the person could not provide consent (e.g., the person was non-verbal), I sought advice from clinical staff about approaching their next of kin to provide proxy consent for participant observations. Patient participants signed the Consent Form (Appendix 3.2), which was witnessed by another person who was able to ascertain that: (i) the participation was voluntary; (ii) consent could be withdrawn at any time without any consequences of the participant, (iii) the person had capacity to consent. People with TBI are considered a vulnerable population, therefore, I aligned their recruitment with section 4.5 of the NHMRC (2018a) guideline, which addresses conducting research involving people with cognitive impairment.

3.3.7.3 Recruitment of family members

This participant group could include a TBI patient's immediate family member, non-professional carer, or a significant other. When the person with TBI had capacity to consent, I also asked for their permission to invite a close family member or support

person to participate, and I was guided by their suggestion as to the most appropriate person. Otherwise, the key site contacts identified and recommended family members who were regular visitors to the rehabilitation settings.

Providing information to family members: The key contact clinician at each site introduced me to the potential candidates at each candidate's bedside and usually in the presence of the person with TBI. I provided potential family participants with a Family flyer (Appendix 3.7), an Introduction letter (Appendix 3.11a) and Participant Information Statement (Appendix 3.12b), and I provided them with opportunities to ask questions and receive answers to those questions.

Consenting of family members: I obtained informed consent from those who agreed to participate in the study (an Informed Consent-Family Form was also signed (Appendix 3.3)).

3.3.7.4 Recruitment of nurses

Key site contacts who were clinical nurses identified potential nurse participants. The key site contacts were not the supervisors of the nurses they identified.

Providing information to nurses: I provided copies of the Nurse flyer (Appendix 3.8) to the key site contacts to display in the nursing staff room, and on education notice boards. Copies were also emailed to nursing staff by the key contacts. I discussed with the key contacts what nursing staff participation would entail, such as time away from the clinical space, and the formalities of how I and the nurses would meet. The key clinical nurse contacts then organised days and times when I could provide study information to potential nurse participants. I provided an introduction letter

(Appendix 3.11c) and the Participant Information Statement - Nurses (Appendix 3.12c) to those identified as potential study participants and provided opportunities for questions and answers.

Consenting of nurses: Written consent was given by all nurse participants using the Consent Form-Nurses (Appendix 3.4).

3.3.7.5 Number of participants

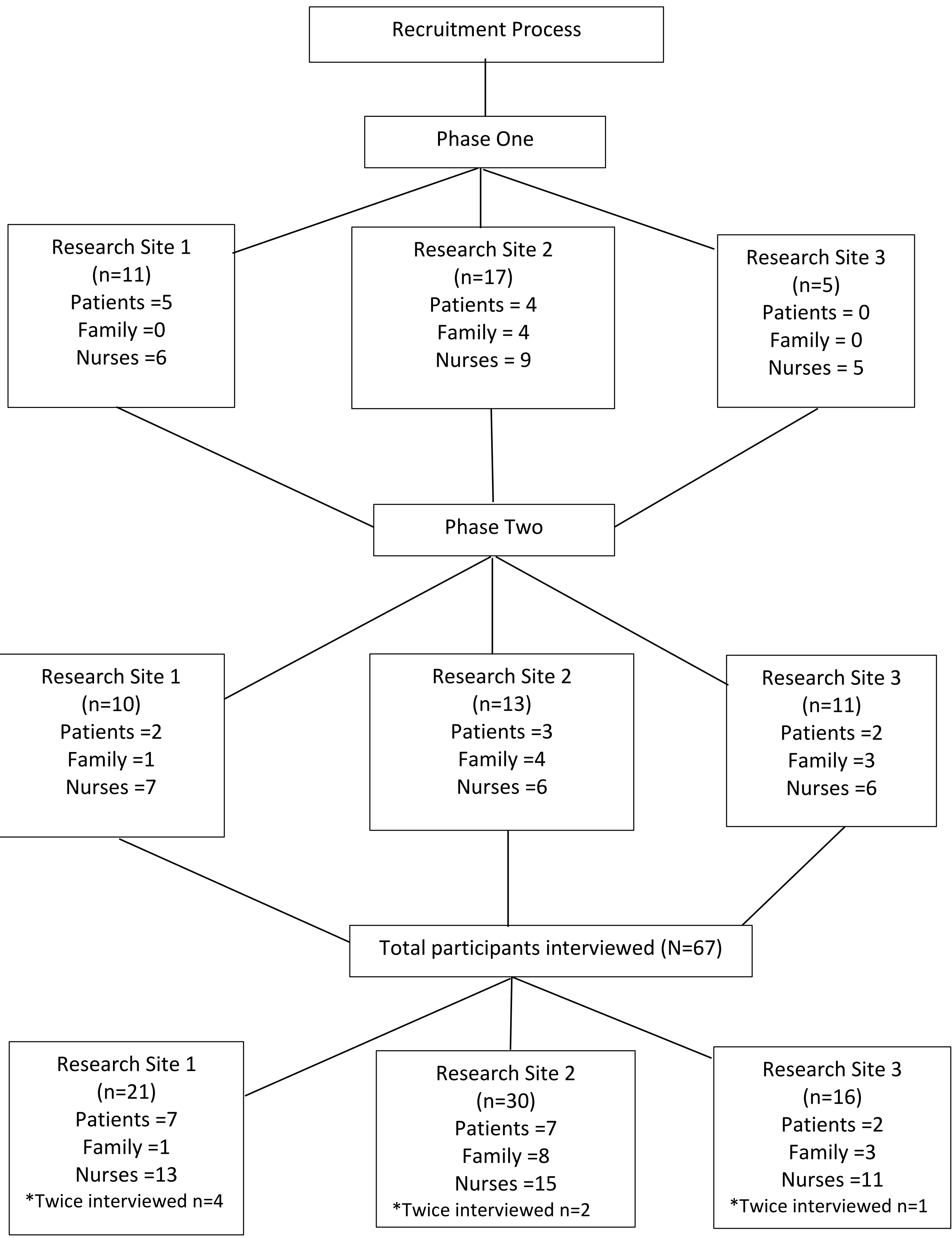
Sample size in Grounded Theory studies is determined by theoretical saturation, rather than by a sample calculation (Charmaz, 2014; Foley & Timonen, 2015). However, I estimated that a target sample size of 15 to 20 people with TBI, 15 to 20 family members, and 20 to 25 nurses spread across the three study sites would provide a point at which I could assess for data sufficiency/theoretical saturation (estimated total 50 to 65). As the focus of the inquiry was on how nurses preserve and promote personhood, it was intended that nurses made up the bulk of participants, with patient and family participants providing further perspective as *acting units* participating in social processes.

The final sample (n=67) included 16 people with TBI (23.9%), 12 family members (17.9%) and 39 nurses (58.2%). Seven nurses (n=7) participated in both Phase One and Phase Two interviews. Table 3 presents the number of participants contributing data in each phase of data collection, while Figure 2 presents the participants who provided data by site.

Table 3: Number of study participants providing data in each phase of the data collection.

Participants interviewed	**Phase One**	**Phase Two**
Patients	9	7
Family members	4	8
Nurses	20	19
Total	33	34

Figure 2: Study participants providing data in each phase of the data collection by site.



3.3.7.6 Sample description and characteristics

In a study that centres on personhood, it would seem appropriate to refer to participants by pseudonym name rather than by code. However, the brain injury care community in the state of New South Wales, Australia is small and connected. The ratio of male to female nurses means male nurses could become identifiable through the use of a gender specific names, or use of gendered pronouns. I have therefore chosen to refer to participants by code only. I have also not referred to study sites in data labelling, even in deidentified form, because of similar confidentiality concerns. While detailed reporting of sample characteristics is considered an element of study rigour, participant confidentiality should have priority, particularly in qualitative studies that create particular challenges (Damianakis & Woodford, 2012). Demographic data are pooled.

Characteristics for patient participants

Of the 16 patients recruited for the study, four (25%) were female and 12 (75%) were male. This mix is typical of the gender representation in TBI (Gupte et al., 2019). The participants' ages ranged between 16 and 65 years (median 34 years). Seven (43.8%) patients had sustained TBI due to motor bike accident (MBA) or motor vehicle accident (MVA) and nine (56.3%) had suffered falls. Three patients had multi-trauma (18.8%). Given that all patient participants were recruited after their acute hospitalisation, severity of TBI and GCS at time of injury were frequently missing. However, the GCS for eight (50%) of the patients was available and was in the range of 3-8, indicating severe TBI. All patient participants (n=16, 100%) had a Glasgow Coma Scale GCS of 15/15 at the time of recruitment. Post Traumatic Amnesia Testing (PTA) was performed on five patient participants (n=5, 31.3%). The

patient cohort was multicultural and identified as South East Asian (n=6, 37.5%), Australian (n=3, 18.8%), British (n=2, 12.5%), Continental European (n=2, 12.5%), Middle Eastern (n=2,12.5%), and South Asian (n=1, 6.25%). All patient participants (n=16, 100%) were able to sit out of bed (SOOB), four (n=4, 25%) were ambulant independently, nine (n=9, 56.3%) required assistance from one person to mobilise, and five (n=5, 31.3%) required assistance from two persons to mobilise. The length of stay for all patients (n=16,100%) on the acute ward ranged from nine days to seven months, while the length of stay in TBI rehabilitation ranged from nine days to 15 months at time of recruitment. Six (n=6, 37.5%) patients had TBI managed conservatively (i.e., without surgery), while 10 (n=10, 62.5%) underwent surgical interventions to manage TBI.

Characteristics of family participants

Of the 12 family participants, eight (66.7%) were female and four (33.3%) male. The age range was 23 to 64 years (median 51.5 years). The relationships between family members and the patients were distributed between four mothers (33.3%), three fathers (25.0%), one sister (8.3%), one brother (8.3%), one daughter (8.3%) and two wives (16.7%). Five family participants (41.7%) were part of a patient/family dyad and comprised of South East Asian (n=1, 8.3%), Continental European (n=2, 12.5%), and Middle Eastern (n=2,12.5%) backgrounds. Available data indicated that the TBI severity of patients matched to family participants was severe (GCS 3-9, for three patients (25%)) at time of injury, and 15 (n=5, 41.7%) at time of recruitment. Two fathers (16.7%), three mothers (25%) and one wife (8.3%) were recruited independently without recruitment of their relative with TBI.

Characteristics of nurse participants

Of the 39 nurse participants, 29 (74.4%) were female and 10 (25.6%) were male. The age of nurse participants ranged from 21 years to greater than 70 years. The total years of nursing experience ranged from three months to 49 years (median 14 years). The total years of neuroscience (TBI rehabilitation) nursing experience ranged from three months to 20 years (median 7.5 years). Among nurse participants there were six ENs (15.4%), 27 RNs (69.2%), and six Advanced Practice Nurses (APNs) (15.4%)[3], one of whom was a Nurse Unit Manager (NUM). Regarding highest qualification, three nurses (7.6%) held a nursing certificate only, four (10.3%) held a diploma, 23 (58.9%) held a bachelor's degree, and nine (23.1%) had a post graduate qualification.

3.4 Data collection

3.4.1 Data collection methods

I collected all data during Phases One and Two using semi-structured interviews, field observations of participant social interactions, and field notes. Demographic data were collected from patient and nurse participants at the interview stage using the patient data collection form (Appendix 3.5) and the nurse data collection form (Appendix 3.6).

Some participants were happy to be interviewed immediately after recruitment. For others, I made an appointment to return to the site and interview them at a convenient time, such as when patient participants did not have any rehabilitative

[3] Advanced Practice Nurses (APNs) are nurse clinicians usually requiring postgraduate qualifications including CNSs, CNCs. and CNEs with specialty expertise.

therapy sessions to attend, or when nurse participants were able to be covered for their clinical load.

3.4.2 Participant interviews

a) Development and testing of interview guides:

Interviews guides helped to structure and focus the interview process (Appendix 4.1; Appendix 4.2; Appendix 4.3). Phase One interviews were informed by my initial literature review (Kivunja et al., 2018), clinical experience, and the research expertise of the supervision team. A person with lived experience of TBI and their spouse were also consulted for their input and opinion to ensure that questions and terminologies used were congruent with, sensitive to, and respectful of, the patient participant cohort. The Phase Two interview guides (Appendix 5.1) allowed me to undertake theoretical sampling, test the evolving theory, and progress toward achieving theoretical sufficiency (Charmaz, 2014).

The Phase One nurse interview guide was tested in two pilot interviews with two nursing colleagues with experience caring for people with TBI. The two practice interviews enabled me to understand what to expect when I entered the field. Recording and transcription of these interviews facilitated feedback from my supervisors to develop my interview skills. For example, I obtained useful tips on how to use open-ended questions, prompts, pause strategically to allow the participant to provide information-rich responses, and pace myself to manage the interview timeframe. The Phase one patient and family interview guides were not piloted. By this time, I had gained confidence in my interview skills and the guide was based on a solid literature review. In Grounded theory, the interview guide evolves

as new lines of inquiry open and so they are considered a dynamic document, with the researcher as the instrument. Charmaz (2014, p.82) suggests thinking about the interview as a "reflexive progression" where the participants views are received through conversation, and the interview is co-constructed between the researcher and participant).

a) **Interview strategy**: I conducted all interviews face-to-face or via telephone using a semi-structured method. All interviews were conducted in a private room, with exceptions made when participants preferred or requested to be interviewed in other inpatient areas or via telephone. The main approach was to conduct patient and family member interviews separately. However, this strategy was flexible to accommodate for participants who chose to be interviewed jointly. I estimated that the duration for each interview would be between 30 to 60 minutes. However, the actual duration varied depending on the clinical time that nurse participants could have in the context of staffing shortages or skill mix, patients' preferences for shorter sessions, and family members' availability in the context of family commitments. As the theoretical sampling approach meant returning to the field to clarify elements of the developing theory, the full interview guide was not used for repeat or later interviews (particularly when theoretical saturation had been reached). As such, some interviews were shorter, being more focused to clarify an emerging theoretical line of inquiry. Table 4 summarises the particulars relating to range and mean of interviews for each group of participants:

Table 4: Total interviews showing range and mean.

Item	Nurses (N=39)	Patients (N=16)	Family (N=12)
Range	10.17 mins - 66.01 mins	16.05 mins - 90 mins	17.06 mins - 88.10 mins
Mean	45.17 mins	43.52 mins	49.85 mins

c) *Protocol for maintaining confidentiality:* Before commencing recording, I provided a unique code for each interview to support participant confidentiality. I verbalised this code so that it was captured in the audio recording. I recorded all interviews using a digital recorder, which were transcribed verbatim using a confidential, professional transcription service provider based in Australia. I examined transcriptions against the audio files for accuracy. Words that could threaten privacy were edited. For example, I used pseudonyms where a person's name (e.g., family member, nurse, doctor, or staff member) was identified in an exemplar. I labelled all transcripts and audio files using unique codes to allow data de-identification prior to conducting data analysis. The digital master file linking the study participants' names to their unique identifier was stored in the University of Sydney research data repository folder specifically set-up for the study. I carefully examined data that, through its uniqueness, could make a person identifiable, before including it in any report of findings (Damianakis & Woodford, 2012).

d) *Participant Distress Protocol:* This protocol, described and tabled in the previously included publication (Kivunja et al., 2022), specified the actions I would take in a situation where a participant became emotional during the interview. Possible actions included pausing or stopping the interview, rescheduling the interview for a later date, and exploring options for psychological first aid. If the participant experienced emotional distress for an extended period, the interviewed would be

stopped, I would ask if the participant would like a support person to be called, stay with the participant until they were calm, and make referral to appropriate assistance or services. I evoked part of the provisions in the distress protocol on three occasions when interviewing family members, when family participants became emotional when talking about the events leading up to their loved one's accident.

3.4.3 Field observations

I developed a Framework for Field Observations (Appendix 3.10) based on personal clinician-research experiences and my supervisors' inputs. This framework offered a flexible guide rather than a prescriptive list of inclusions and exclusions. For example, it guided observation of patients' physical and emotional needs, how patients communicated their personal care needs to others, and the symbols used by study participants to communicate between others. By focusing my gaze on the key elements of interest, the guide eliminated what Charmaz (2014, p.41) describes as "seeing data everywhere, and gathering everything and nothing". I undertook several sessions of field observations of caring and social interactions of participants across morning and afternoon shifts. I conducted a total of 41,580 minutes of field observations over a period of 99 days. The field observation sessions ranged from 60 to 420 minutes per field visit, and I kept a written record that served as data for subsequent coding.

While drafting field notes, I followed the CGT strategy to "seek data, describe the observed events, answer fundamental questions about what was happening and then develop theoretical categories" (Charmaz, 2014, p.42). This strategy helped to

move my thinking towards theoretical conceptualisation of observed social phenomena.

3.4.4 Documents as a form of data

I referred to other documents for context when undertaking this study: patient timetables that were displayed in patient rooms (e.g., schedules for therapies or activities); clinical policies, guidelines (e.g., data about patient transfers, how to perform prescribed personal care, and management of people with behaviours that others find challenging); and patient medical records (e.g., details about the person with TBI, causes, and management). This work was approved by the HREC. All three sites utilised different electronic medical systems, and my access to study specific data both in print and electronic form was facilitated by the site key contacts.

3.4.5 Data management

Prior to the commencement of the study, I developed a detailed Research Data Management Plan (RDMP) (Appendix 6) (Sydney Local Health District, 2020) which specified how data were to be managed in line with the Australian Code for the Responsible Conduct of Research (NHMRC, 2018b). The HREC-approved RDMP included details about type of data to be produced, data collection methods and tools, software to be used, file formats, data documentation and metadata, data storage and security, ethical considerations, access, sharing and reuse of data, data retention and disposal, preservation and archiving (Sydney Local Health District, RDMP Template, 2020).

Data for this study were digital audio recordings of participant interviews, Microsoft Word transcriptions of interviews, and observation field notes. I stored the digital files in a password protected data repository maintained by the University of Sydney Information and Communication Technology Department. I kept all research data secure as per the University of Sydney Research Data Management Policy (USRDMP, 2014). I scanned, and stored digitally, all consent forms and data collection forms used to gather information relating to participants on a password protected computer. The hard copies along with other non-digital data (e.g., observation field notes and physical documents) were stored in a secure and locked cabinet at my residence. I ensured that all patient, family, and nurse participants consent forms (Appendix 3.2; Appendix 3.3 ; Appendix 3.4) and patient and nurse data collection forms (Appendix 3.5; Appendix 3.6) were deidentified using unique codes. I stored these forms separately to ensure the privacy and confidentiality of participants. The master file linking the study participants' names to their unique identifier was stored in the University of Sydney digital data repository that is only accessible via a unique password on campus or via Virtual Private Network (VPN) when accessed off campus by me.

The digital data were accessible by me, as the primary student researcher, via a secure password protected University of Sydney computer with a two-step-factor authentication feature. My three research supervisors also had access to all research data. Access research data off campus was via a Virtual Protected Network (VPN) as an additional layer of data security. After completion of the study, data will be stored for five years in the password protected data repository at the University of Sydney and will be destroyed thereafter following guidelines stipulated by the

USRDMP (2014). The main software packages used to manage data in this study were MS Word, MS Excel, and EndNote. However, NVivo Version 13 (Lumivero, 2020) was used to explore sample interview data, and this use enabled the exploration of various aspects of the evolving theory. This work took place during the phase when I was contemplating whether to use manual coding or computer-assisted coding.

3.5 Data analysis

Data collection and data analysis were undertaken concurrently according to methodological convention (Charmaz, 2014, Birks & Mills, 2015; Glaser & Strauss, 1967). Data analysis began immediately after the first interview. Figure 3 illustrates the data analysis process that I used.

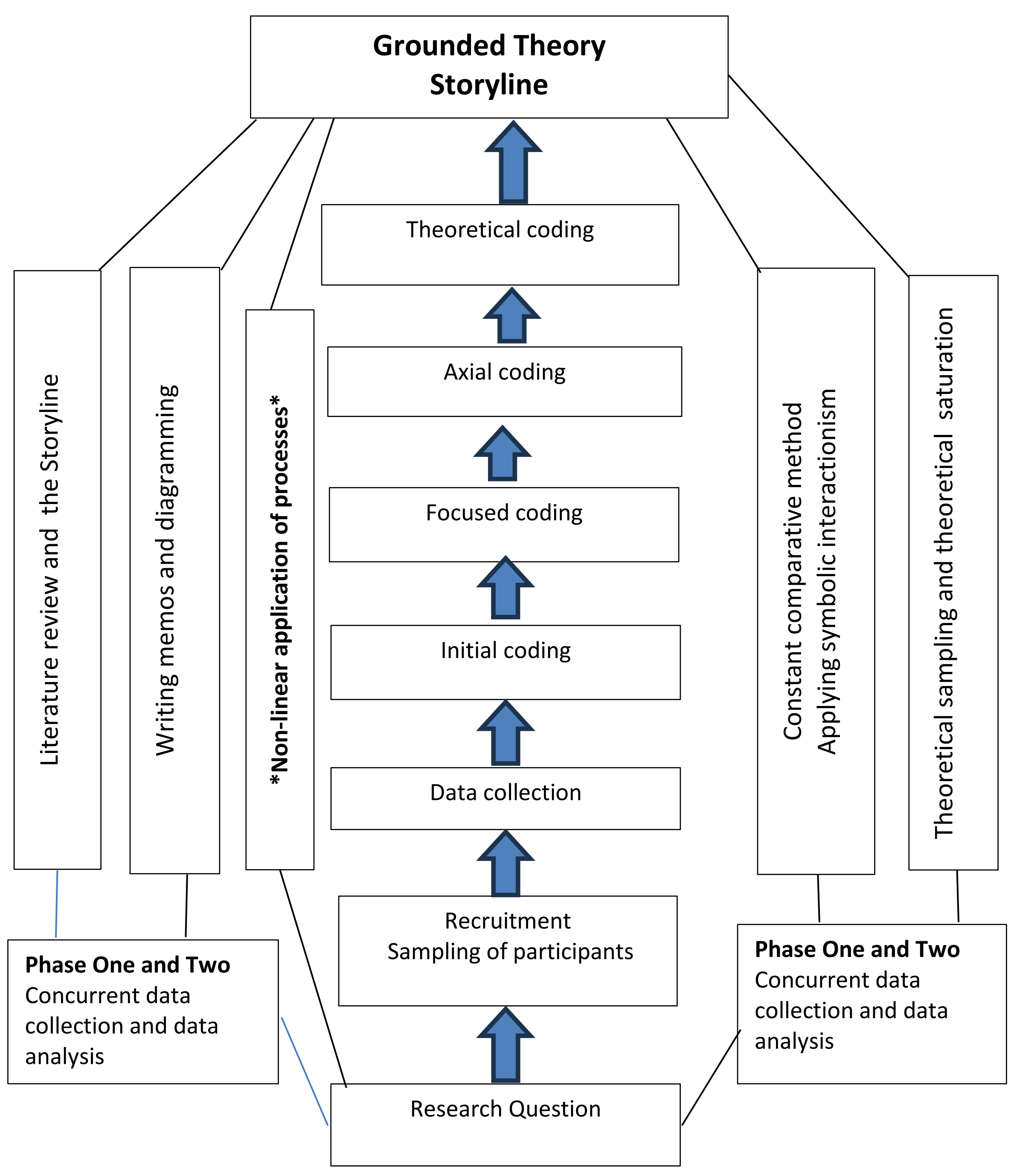


Figure 3: Visual representation of the Grounded Theory process followed (adapted from Charmaz, 2014, p.18)

3.5.1 Data coding approach

I used manual coding for this study. The coding was informed by symbolic interactionism with a constructivist GT approach (Charmaz, 2014). I scrutinised all data gathered from interviews and field observations one instance at a time. I was interested in establishing the nature of the interaction, the symbols and language used and their meaning, and the contextual factors. I conceptualised tentative categories that were a personal interpretation of the symbolism derived from the data. The coding was an iterative process (Charmaz, 2014) undertaken over many months, comprising periods during which I coded alone followed by intensive discussions with supervisors.

3.5.1.1 Initial coding

The flexibility of CGT allows the use of all sources of GT to construct theoretical abstractions (Charmaz, 2014). Initial coding involved summarising a section of interview data with a category consisting of a brief label or heading (Birks & Mills, 2023; Charmaz, 2014; Corbin & Strauss, 2008, Glaser, 1978). Initial coding involved analysing interview transcripts and filed notes word-by-word, then line-by-line, segment-by-segment, and incident-by-incident (Charmaz, 2014). This approach broke the data down into segments and allowed me a closer analytical understanding of what was transpiring in the data (Charmaz, 2014). I was interested in the social processes that were occurring, how participants acted, thought, and felt, including when, why, and how, the process seemed to change according to the individuals and context (Charmaz, 2014). I examined what the data was suggestive of, what was left unsaid, whose perspective was being represented, and what categories could be theoretically constructed from the data (Charmaz, 2014). I aimed

as much as possible to code data using words that depicted action (gerunds) rather than topics (see Table 5) and this aim allowed me to stay open to what was occurring in the data and emerging in the analysis (Charmaz, 2014). I was aware that, as a Neurosciences Clinical Nurse Specialist, I held preconceived ideas about caring for people with TBI. This personal characteristic demanded reflexivity and bringing an open mind (rather than an empty head) to coding to see what I could learn and theoretically develop (Charmaz, 2014). While coding, I was mindful that the initial codes were grounded in data and provisional, and I remained open to multiple possible conceptualisations and kept in mind that I could revisit these for revision or rewording to strengthen fittingness with data (Charmaz, 2014).

My initial coding was discussed with my supervisors as a group to evaluate the fit (Charmaz, 2014). When GT researchers code as a group, different codes are bound to be constructed because each researcher brings a varied “perspective, social location, personal and professional experiences” (Charmaz, 2014, p.118). This approach meant that codes were critically evaluated, and differences in code conceptualisation were accommodated rather than dismissed (Charmaz, 2014). These group coding sessions contributed to the construction of nuanced theoretical interpretations and insights (Charmaz, 2014).

I followed Charmaz’s advice (2014, p.120) to “make your codes fit the data rather than forcing the data to fit” the emerging theory, and I did so by “remaining open, staying close to the data, keeping codes simple and precise, constructing short codes, preserving actions, comparing data with data and moving quickly through data”. Initial coding facilitated the separation of data, the visualisation of developing

social processes, and the identification of new lines of inquiry, which I pursued through subsequent data collection (Charmaz, 2014). Table 5 presents examples of early initial codes.

Table 5: Example of initial coding of an interview.

Interview text	Initial codes
You get to know the patient but try not to talk too much, too loud. And just sort of sometimes talk about what you know their interest is and sometimes that will calm them down	Creating a calm environment
You can sort of have a way of making them [patients] agree with you. That they think they've made it up. They haven't really	Reaching agreement
So we swap around. If we see they're playing up for one nurse, we'll go over and we'll talk to them and that nurse will walk away, and the person usually calms down.	Working in teams to promote calmness
You usually let them talk about what they want to talk about. And agree with them. That's sometimes if you don't agree, you've got to be careful about how you agree and disagree with them because sometimes that could trigger them, so you just sort of play along and act a little bit dumb and they... Even one of them likes playing Solitaire. So you let him think he's teaching you how to play it. So he goes, "Okay, you have a go now. You might have worked that out"	Playing along

3.5.1.2 Focused coding

During focused coding, I compared initial codes and revised them for further analysis (Charmaz, 2014). The initial codes were sorted and synthesised to create condensed and explanatory codes that progressed the analytical work toward theoretical construction (Charmaz, 2014). I first examined how initial codes formed patterns, then decided which initial codes best explained what was happening, and finally determined whether these codes revealed any gaps in the data that needed strengthening (Charmaz, 2014). Focused coding allowed me to use a number of

initial codes to advance data analysis by treating such codes as the basis upon which to direct the evolving theory (Charmaz, 2014). This work, moving from initial coding to focused coding, was often a back-and-forth process.

Focused coding suggested that the basic social process was driven by nurses deciding when to prioritise physical safety and physiological integrity, when to prioritise engagement with the patient as a person, and when to prioritise the person's autonomy in caring episodes during rehabilitation. Focused coding moved the analysis toward understanding some of the important social process (see Table 6).

Table 6: Example of focused coding.

Interview text	**Initial coding**	**Focused codes**
…talking to the patient . I mean, yes, it's your patient but realising that this person is a human and they did have a life before they were stuck in a bed. I think reminding the nursing staff, hey, these are humans, and these are people who need conversation, they need interaction	Talking to the patient who is the person	Talking to the person
They (Family) probably are our number one go-to source to understand their (Patients) personhood the most… if our patients can't communicate effectively to us, we go to their family members, who have spent the most time with them and would have known them best.	Referring to family to understand the person	Talking to the family
The goals are mainly set by the family and the patient; we just help them out... We don't set the goals for the patients. Because it's what the patient wants. So the patient and the family set the goals, and we help them with the goals.	Facilitating goal setting by patients and family	Enabling patient focused goal setting
If they have the capacity to respond to questions, asking them what they need, asking them what works for them. Something as simple as, "Which side is stronger? Where do you roll better, to your left or to your right?" helps me help them. It makes me understand what I need to do to care for them.	Ascertaining the care needs of the person	Seeking to understand how to help the patient

3.5.1.3 Axial coding

Using axial coding, I explored multiple ways to put data back together (Charmaz, 2014; Strauss & Corbin, 1990). This work facilitated the identification of patterns and relationships in codes and informed the construction of categories. Tentative categories were developed through grouping of codes and writing memos about these conceptualisations (Birks & Mills, 2023). I identified conceptual patterns with explanatory power in relation to the social process. Through axial coding, properties (characteristics) of categories and subcategories were developed from the data and explained to bring about conceptual depth (Birks & Mills, 2023; Charmaz, 2014).

3.5.1.4 Theoretical coding

To enable the theorisation of data, I used theoretical coding to conceptualise how focused codes related to each other (Charmaz, 2014). Theoretical coding involved scrutinising categories generated by focused coding to present an explanation of how "categories and their subcategories integrate together to form an abstract grounded theory" (Birks & Mills, 2023, p.179). At this stage I used the navigation pane (Appendix 7), a MS Word feature, to visualise and organise my findings into categories and subcategories (Monaro et al., 2022).

I navigated this stage by strategically following Charmaz' (2014) advice of using concepts from other fields instead. One useful concept that I found to be quite handy was Denzin's (2001) strategy for exploring data for interactions, symbols and languages, contextual factors and meaning (Callaghan et al., 2018; Denzin, 2001). An example of a memo that I wrote while using this strategy during data analysis is presented below (Figure 4):

Figure 4: Example of a memo.

Memo: 18/10/2024: Delivering patient care in pairs

Nurses deliver the care for patients who have a history of exhibiting concerning behaviours in pairs so that they are ready to respond or call for help in case a challenging situation rises. Items such as chairs of tables are introduced into the patients rooms only if required as during meal times. A nurse participant describes this approach as follows:

> *"So that's why we don't keep the light chair or we removed the table out. So, when we go give him food, we just bring the table in, like the side table. We had an incident, we left the table there, when the blood lady went to take his blood, he just grabbed the trolley or the chair she was using and hit her. Unfortunately. So, we have to be careful. And two nursing staff to attend him, you don't go by yourself. It's important, especially, in a locked room. You go two people. Just in case, emergency, you just exit and call for help."*

Interaction: removing harmful objects from patient's immediate environment, introducing furniture in patient's room, drawing on previous knowledge of patient behaviour, delivering nursing care in pairs

Symbol & language: history of this patient grabbing objects and hitting other people using objects symbolises potential danger to staff, furniture in this patient's room symbolises potential danger to staff, locked room symbolises potential danger to staff, nurses delivering care in pairs symbolises nurses' agency to protect self

Contextual factor: nurses having awareness that physical danger to themselves is real in the TBI rehab setting

Meaning: The nurses prioritise their personal safety in response to particular cues, but they still provide care, they do not walk away from it

3.5.1.5 Constant comparative methods

Constant comparisons were made throughout the analysis to explore similarities and differences between data (Charmaz, 2014; Glaser & Strauss, 1967). I noted incidents, then compared these with other incidents in the same interview and between interviews. I compared what happened during field observations of participants' social interactions during care routines across days of the week, times

of day, and study sites. I went backwards and forwards during interview coding to compare what participants said and what I had observed in the field. Throughout all stages of this analysis, I made constant comparisons between data and data, data and codes, and between categories and categories, to identify analytical cues that aided the construction of properties and dimension (Charmaz, 2014). This iterative approach contributed to the advancement and transformation of the analytical understandings of the social processes that constituted the phenomena under study.

3.5.1.6 Applying symbolic interactionism

I constantly applied symbolic interactionism in the analysis of field observation data. I took note of gestures and non-verbal cues that were used by patient and nurse participants in relation to what was being said, done, or described, and what meanings may have been conveyed. For example, I observed that a non-verbal patient would move their head away as a signal that they did not want to have any more food from the nurse assisting them with feeding. When the nurse responded by stopping their action, this was analysed and interpreted as an approach to personalising care that respected the person's agency and self-determination, hence contributing to promoting and preserving personhood.

3.5.1.7 Theoretical sampling

I used a theoretical sampling approach, which in Grounded Theory refers to a systematic and strategic process, whereby a grounded theorist gathers additional data to explore, illustrate, and reshape the developing theory (Charmaz, 2014; Holton & Walsh, 2017). I performed this task during Phase Two, when I had developed "tentative categories and emerging but incomplete" theoretical

conceptualisations within Phase One (Charmaz, 2014, p.193). I had developed a tentative core category (Dancing with Agency), its properties and its dimensions (range of variations). While this core category was promising, it was not yet a firm abstraction upon which analytical rendering could be rested (Charmaz, 2014). I ventured back into the field for more data collection with the specific goal of saturating the properties of this substantive category of *Dancing with Agency*. During this process, I followed lines of inquiry that included: *Why do nurses have the dance? What does the dance require? What are the contextual factors that influence the dance that the nurse is having with agency? What contextual factors influence dancing with agency? What symbols and language do participants use when interacting? and, what do such symbols and languages mean?*

3.5.1.8 Theoretical saturation

I continued the analysis until I reached a point where I felt I could claim theoretical saturation, whereby categories were robustly supported by data. Generally, this stage is achieved when no new theoretical insights seem to arise from new data, and there is no rationale for further data collection (Charmaz, 2006, 2014; Rieger, 2019). A major challenge faced by Grounded Theory researchers is the difficulty in ascertaining when codes are saturated and when the theory is adequately developed (Creswell & Poth, 2018; Glaser, 1978; Low, 2019). I acknowledge that I experienced this challenge. However, in my study, theoretical saturation was facilitated by the pursuit of specific lines of inquiry and by the exploration of specific, rather than general, questions with participants during Phase Two data collection (Birks & Mills, 2023; Charmaz, 2014).

Mindful of the varying views on theoretical saturation (Low, 2019) and theoretical sufficiency (Dey, 1999), I was guided by the following advice offered to constructivist grounded theorists by Charmaz:

> Be open to what is happening in the field and be willing to grapple with it. When you get stuck, go back and recode earlier data and see if you define new leads. Use grounded theory guidelines to give you a handle on the material, not a machine that does the work for you. (2014, p. 215)

3.6 Memo writing and diagramming

Memos were used to record my thoughts, deliberations, directions and questions throughout the analysis. These memos allowed me to converse with myself about the data, my ideas, my thoughts, and my plans of action, and to document my journey and growth as a researcher (Charmaz, 2014). These memos included personal reflections, analytical thoughts about codes, how categories were interconnected with each other, developing lines of inquiry, and probable theoretical categorisations (Bryant & Charmaz, 2007; Holton, 2007; Kenny & Fourie, 2014).

Theoretical memos comprised my written considerations of several of the theoretical explanations developed from my data (Charmaz, 2014). Theoretical memoing involved sorting categories prepared by hand – on the floor and a wall in my home office – to build an integrated theoretical statement (Charmaz, 2014). Coloured post-it-notes helped me to visualise all the codes as a collective, including how they related to each other (Appendix 8). This work allowed me to start visualising the developing theory at an abstract level, including where the links were between the core category, properties, dimensions, phases, outcomes, and contextual factors.

Though presented separately in this thesis, the process of theoretical sorting occurred at the same time as theoretical sampling (Charmaz, 2014). Figure 5 presents an example of the memos that I wrote during the data analysis.

Figure 5: Example of memo written during data analysis.

Memo: Thoughts from face-to-face-team meeting discussion 05/06/2023
This content describes what the 3 non-linear processes or parts (i.e. 1a,1b & 1c) represent/mean in relation to data analysis in this intermediary phase:

1(A) Monitoring and maintaining physiologic integrity
This section consists of categories that symbolise that nurses are monitoring and maintaining physiologic integrity for patients. Nurses do not have (agency)/power as to determine what needs to be done. Policies, directives, organisational guidelines appear to direct how care is delivered
- The nurse's agency is constrained by policies, directives, or organisational guidelines and physiological integrity takes priority over the promotion of personal agency.

1(B) Engaging the person who is the patient
- Nurses are engaging the person who is the patient and activate their own agency and clinical expertise to promote the agency or the person, finding in-the-moment opportunities to encourage participation in self-care activities.
-Here the nurses have agency and determine what needs to be done for patients

1 (C) No name yet for this code/category (Advancing independence of the person who is the patient)
I am still considering what this is :
- ? Nurses giving agency to the patient, families, cares, community relationships
-The nurses are enabling the patient to take the lead regarding their care
- Nurses are advancing independence of the person who is the patient and use their own agency and expertise to support the person, family, and carers to take-back control and decision-making about daily activities.

To compliment memo writing, diagramming aided my visualisation of the developing theoretical categories, properties, dimensions, contextual factors, and outcomes (Birks & Mills, 2023; Charmaz, 2014). Diagramming allowed me to identify gaps in the Phase One data analysis, and I explored these gaps in the Phase Two theoretical sampling (Birks & Mills, 2023; Charmaz, 2014). These diagrams, stored as dated and labelled files, allowed me to track the development of my thoughts and

the analysis over time, and they supported accurate record keeping and an audit trail. Figures 6 and 7 present examples of diagrams.

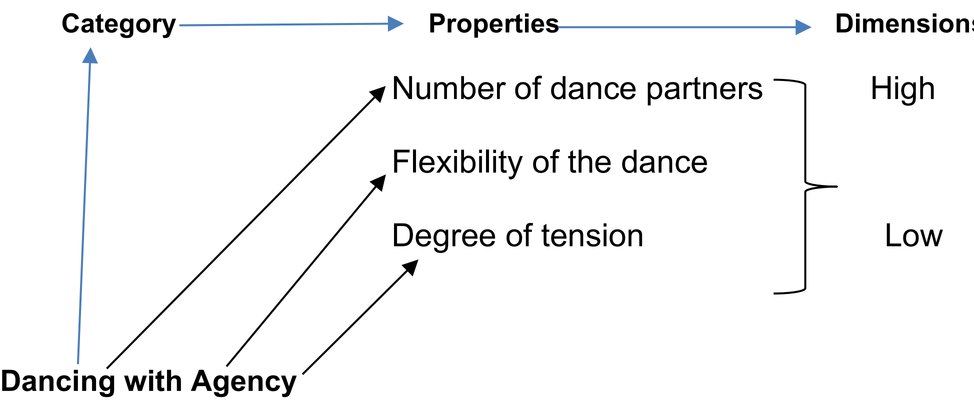


Figure 6: Example of early diagramming of properties and dimensions of the core category.

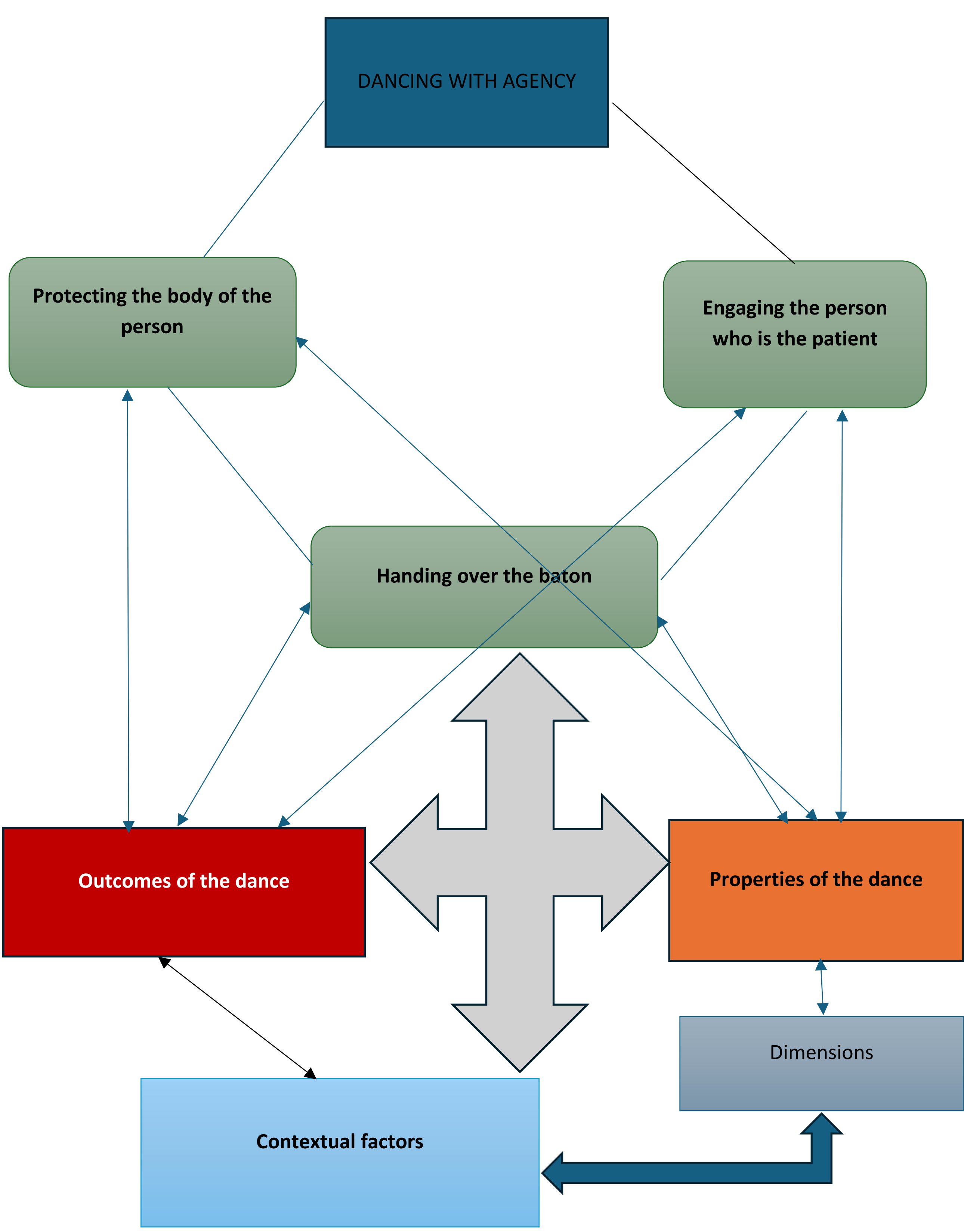


Figure 7:Theory of Dancing with Agency (early conceptual thinking).

3.7 The storyline

I applied "Storyline" – an advanced Grounded Theory tool – to move from analysis to theorisation (Birks & Mills, 2023, p.198). The guiding principles I utilised to construct a storyline were aligned with Birks and Mills (2023, p.199) acronym 'TALES':

T: Theory takes precedence (as the final product of data analysis)

A: Allows for variation (an abstraction of theory that makes room for multiple dimensions and negative cases)

L: Limits gaps (weaknesses in the developing theory are identified for the purpose of informing further data collection/analysis)

E: Evidence is grounded (while an abstraction, the storyline is accurate and valid in drawing together analytical relationships), and

S: Style is appropriate (in this case, the style is framed by this document being a tool for the research team to structure and critique the theory)

Writing a storyline for this study required multiple drafts, and the theoretical constructs evolved with the incorporation of the Phase Two data. Appendix 10 contains an earlier draft of the storyline as a tool for theoretical coding.

3.8 Identification of the main concern

My understanding of Grounded Theory studies is that the main concern represents the problem or issue that is shared by the participants and that this main concern is generated from the data through constant comparative analysis (Holton & Walsh, 2017).The main concern highlights "the issue or problem that occupies much of the action and attention in the research setting" (Holton & Walsh, 2017, p.88). The main

concern was not known at the onset of this study; it was generated later, during the open coding, and as data analysis advanced. While identifying the main concern is not a prerequisite for CGT studies, specifying the main concern supported the conceptualisation of the basic social process and substantive Grounded Theory reported in this study (Charmaz, 2025). The main concern in this study is that a shared end goal of rehabilitation is to promote and preserve the patient's personhood. However, there are multiple, demanding, decision-making actors in inpatient TBI rehabilitation who nurses encounter in their everyday practice. Consideration of, and engagement with, these actors influences the ways in which nurses promote and preserve their patient's personhood. The main concern is revisited later in the findings chapter.

3.9 Criteria for evaluating this Grounded Theory study

3.9.1 Credibility, Originality, Resonance, Usefulness

I am aware that an evaluation of a Grounded Theory is essential upon the completion of a study. This evaluation enables the researcher to reach a formal judgement as to whether "quality has been achieved" in line with the "criteria" specific for the variation of methodology used (Birks & Mills, 2023, p.52). The criteria for evaluating any qualitative study vary according to the audience, the purpose for which the criteria are developed, and the author who forms those criteria (Charmaz, 2014). The criteria that I adopted for this Constructivist GT study assessed for credibility, originality, resonance, and usefulness (Charmaz, 2014; Charmaz & Thornberg, 2021). Table 7 explains the application of these criteria.

Table 7: Criteria for the Constructivist Grounded Theory in this study as adapted from Charmaz (2014, p.337)

Criteria for rigour	How criteria are demonstrated in the study
Credibility	This criterion evaluates the Grounded Theory for conceptual grounding and application of logical thought (Charmaz, 2014). Credibility was demonstrated by: • Intimate familiarity with the setting and topic by spending prolonged periods of field observation across three research sites (a total of 80 hours of field observation) to gather field data. • A total of 67participants were recruited and interview duration totalled 44.4 hours. I gathered sufficient data upon which systematic scrutiny and comparisons were undertaken throughout the study (Charmaz & Thornberg, 2021). • My assumptions as a researcher were made clear at the onset of the study. I was always conscious of my approach, knowing that I believe in multiple realities, and that truth is a co-construction between researcher and participants (Charmaz, 2014). • I engaged in constant reflexivity and memo writing during the research so that data collection and analysis reflected my assumptions and participants' positions, worldviews, and social conditions (Rantung et al., 2024; Wertz et al., 2011). • Observation data were captured in field notes and these data were integrated with participant interview data to compare both types of data in relation to categories, properties, and dimensions. • The substantive category along with the three phases, properties, and dimensions, are explored using a wide range of data from field observations and participant interviews. • Analysis is supported by logical links that are systematically derived from data.

Criteria for rigour	How criteria are demonstrated in the study
	• Claims made in the study are supported with a wide range of evidence drawn from field notes, interview data and memos. • The research team met regularly to refine and challenge data analysis (Rantung et al., 2024).
Originality	This criterion evaluates whether a study offers new insights, grounded conceptualisation of a primary research topic area, and establishes the significance of the theory constructed from the analysis (Charmaz & Thornberg, 2021): • No previous study offers insights and theoretical conceptualisations of the social processes through which nurses promote and preserve personhood for people in this context. • While previous researchers have explored the experiences of TBI (Chamberlain, 2005; Erikson et al., 2007; Fleming et al., 2012; Freeman et al., 2015; Gebhardt et al., 2011; Hammond et al., 2016; Holm et al., 2009; Jaimes et al, 2015; Jumisko et al., 2009; Kivunja et al., 2018), this study focuses on addressing a gap in literature that demonstrated the existence of a mismatch between patients', carers' and nurses' understandings of care that promotes personhood for people receiving rehabilitative care for TBI.
Resonance	This criterion "demonstrates that the researchers have constructed concepts that not only represent their research participants' experience, but also provide insight to others"(Charmaz & Thornberg, 2021, p.316): • The theoretical constructs are presented, with supporting text from participant interviews, to exemplify that the understanding of the perspectives explored are grounded in data.

Criteria for rigour	How criteria are demonstrated in the study
	• References were made to other research during the review of literature and this provided access to insights from other studies that explored closely relatable topic areas. The application of theoretical sensitivity enabled deeper scrutiny of the categories, properties, and dimensions that were developed for this study. • The interim results have been presented at national and international conferences and recognised with awards.
Usefulness	This criterion involves "clarifying research participants' understanding of their everyday lives, forming a foundation for policy and practice applications, contributing to creating new lines of research, as well as revealing pervasive processes and practices" (Charmaz & Thornberg, 2021, p.316): • The substantive theory developed is useful in its mapping of how nurses navigate the complexities of providing care that advances personhood for people who have complex trauma, may have cognitive and behavioural changes, and must conform or negotiate elements of prescribed rehabilitation over the stages of recovery, and with reference to a person's preferences and relationships. • The theoretical understandings offer new insights that can inform professional development activities that can guide the delivery of person-centred social interactions during TBI nursing care in rehabilitation settings. • The substantive social process of *Dancing with Agency*, along with its three phases, exemplifies a grounded theoretical conceptualisation that is attained through robust exploration of multicentred data collection and analysis. The findings transcend the three TBI care settings and may be applicable in similar contexts, locally and internationally.

3.9.2 Enhancing rigour using the COREQ Framework

To guide the presentation of the reported data, I used the qualitative reporting framework known as the “Consolidated criteria for reporting qualitative research (COREQ)” 32-item checklist (Tong et al., 2007, p.349) (Appendix 13). The COREQ tool enabled me to report several important aspects of my research study, including: members of the research tea; methods used; study setting; and how data were analysed and interpreted (Tong et al., 2007). COREQ is useful to refer to when designing a study because many academic journals require inclusion of this checklist on article submission. However, I omitted COREQ elements, such as member checking, that were not relevant to my Grounded Theory study.

3.10 Chapter summary

This first part of this chapter described the research paradigm, the guiding social theories of symbolic interactionism and social constructivism, and the historical development of Grounded Theory. A rationale was provided for the use CGT, along with a description of the general features of this methodology. The second part of this chapter described and justified the practical ‘doing’ of this CGT study, and explained the research settings, the recruitment and sampling procedures, and the use of semi-structured interviews and participant observations as the main data collection methods. The complex stages of constant, comparative, Constructivist GT analysis were described, including theoretical sampling, theoretical sensitivity, and theoretical saturation to enable the realisation of a substantive theory that explains the social processes that promote and preserve personhood for people with TBI in rehabilitation settings. Next, Chapter Four presents the study findings.

4 CHAPTER FOUR: Findings

4.1 Introduction

In this chapter, I present the research findings for this Constructivist Grounded Theory study as illustrated in Figure 8. I describe the main concern, which is “the issue or problem that occupies much of the action and attention in the research setting” (Holton & Walsh, 2017, p.88). I then describe how this informs the basic social process, which “explains how that concern or problem is managed, processed, or resolved” (Holton & Walsh, 2017, p.88).

The main concern expressed by nurses is one of dealing with multiple and demanding decision-makers when providing rehabilitation care to the person with TBI. Arising from this main concern is the basic social process, which I theorise as ‘*Nurses Dancing with Agency in TBI Rehabilitation Care’* or in short (*The Dance*). I also describe contextual factors and examine these in relation to their influence on the *basic social process*. To support the emerging theory, I incorporate excerpts from participants’ interviews and field notes documenting participant observations.

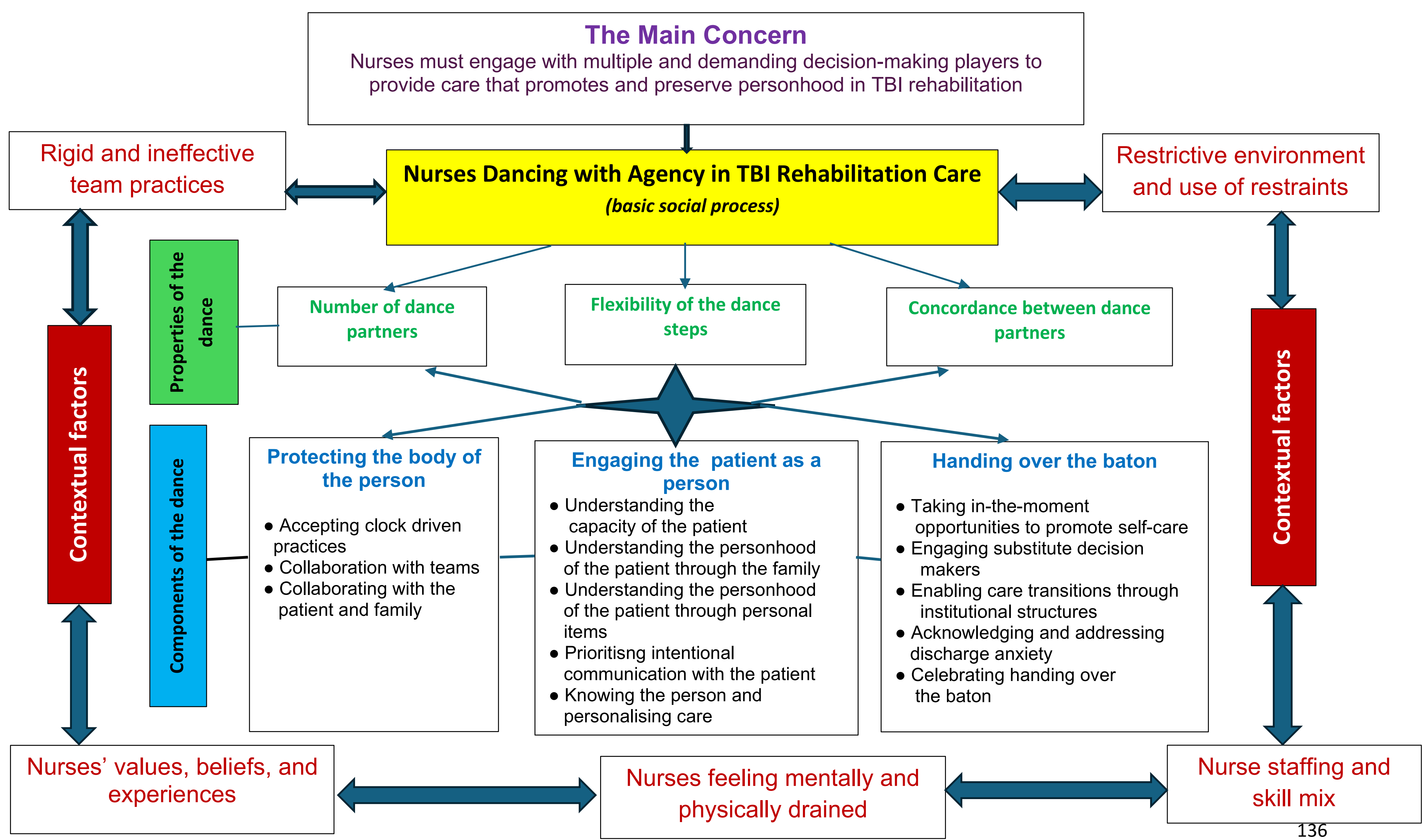
Introductory notes to Figure 8:

In Figure 8, I illustrate the *Theory of Nurses Dancing with Agency in Traumatic Brain Injury Rehabilitation Care*. The main concern for nurses and the basic social process are listed. *The Dance* has three properties that impact the agency of nurses and others: *Number of dance partners; Flexibility of the dance steps;* and *Concordance between dance partners*.

The Dance is made up of three components that encompass as subthemes, the specific strategies that nurses use to promote and preserve personhood in TBI rehabilitation. 1) *Protecting the body of the person* [with subthemes: accepting clock driven practices; collaboration with teams; and collaboration with the patient and family); 2) *Engaging the patient as a person* (with subthemes: understanding the capacity of the patient; understanding the personhood of the patient through the family; understanding the personhood of the patient through personal items; prioritising intentional communication with the patient; knowing the person and personalising care; and 3) *Handing over the baton* (with subthemes: taking in-the-moment opportunities to promote self-care; engaging substitute decision makers; enabling care transitions through institutional structures; acknowledging and addressing discharge anxiety; and celebrating handing over the baton).

Four contextual factors influence *The Dance*: Rigid and ineffective team practices; Restrictive environment and use of restraints; Nurses' values, beliefs, and experiences; Nurses feeling mentally and physically drained; and Nurse staffing and skill mix. All these aspects of *The Dance* are presented with exemplars in this chapter.

Figure 8: The Theory of Nurses Dancing with Agency in TBI Rehabilitation Care: A diagrammatic representation



4.2 The main concern: Multiple and demanding decision-makers

The main concern of nurses in this study related to their engagement with the **multiple and demanding decision-making actors** in TBI rehabilitation, who they encountered in their everyday practice when delivering care that might preserve and promote personhood. The nurse participants, in the main, used their own agency to protect the agency and personhood of the patients. Nurses engaged with multiple decision-making actors, including patients, family members, carers, the rehabilitation team (e.g., allied health, medical, case managers, nursing colleagues), the organisation, and external agencies.

Each decision-making actor brought their own agency to interactions with the nurse participants, and these interactions influenced how the person with TBI's rehabilitative care was structured, delivered, or promoted. Engaging with multiple decision-making actors was demanding for these nurses because it required continuous negotiation and re-negotiation of agency.

Nurse participants also had to engage with a high number of diverse professional decision-making actors, with different scopes of practice and responsibilities, who brought their specific disciplinary lens to influence and shape TBI rehabilitative care. A nurse participant described this situation:

> *…we have the physios, OTs, speechies, neuropsych, clinical psych[ology], psychiatry, medical, recreational therapists, social work, dieticians, case managers. We have orthoptists who look at eyes. (EN8, Line 268, p.12)*

The needs of people with TBI were dynamic and required an agile decision-making process. However, the effectiveness of communication and teamwork between patients, families, and decision-making actors was variable. When social processes between these diverse decision-makers worked well, nurses could undertake their work efficiently, communicate and exercise their clinical judgement confidently, and negotiate an approach to care that promoted and preserved personhood. However, some decision-making actors could be inflexible, and their clinical priorities could conflict with a nurse's clinical judgement. A nurse's agency in responding was dependent on a number of factors, including: the proportion of nurses compared to allied health workers; interdisciplinary hierarchies and communication practices; guidelines driving care; and patient capabilities.

In general, more decision-making actors led to more complexity in the nurses' social interactions, while fewer decision-making actors (e.g. a two-way interaction) meant that the nurse needed to navigate fewer perspectives. Fewer actors could make it easier to determine whose agency was to be privileged, and to negotiate divergent perspectives and clinical priorities. Nurses were particularly equipped to negotiate if they were comfortable with their knowledge, experience, and scope of practice. However, when there were many decision-making actors, the nurses' abilities to effectively contribute to decision-making depended on the various actors' appetites for collaboration and their willingness to seek agreement in working relationships, as well as their having shared knowledge of the situation and rehabilitation goals.

The perceived power between decision-making actors also influenced social interactions. The most dominant decision-making actors in TBI rehabilitation were allied health professionals. As a team, allied health professionals appeared to perceive themselves as having higher authority in shaping rehabilitative care for patients and informing or dictating nursing practice. As the nursing team often formed a small part of the healthcare team, the sheer numbers of allied health professionals could eclipse the presence of nurses. One nurse participant reported that “there is actually more allied health employed on the unit than nursing at the moment in our brain injury unit… nursing is one small bit of a very large team here… (RN1, Line 70, p.3). Another nurse participant concurred: “[Of] all the therapists in our ward – there’s more Allied Health therapists than nurses… every single Allied Health therapist... category is on staff” (RN1, Line 268, p.12).

The large number of allied health decision-making actors in some settings meant that nurses had to negotiate the collective demands of allied health professionals and their scripted guidelines. When the allied health professionals who wrote the guidelines were not physically present, the guidelines themselves became acting units that sought to direct nursing practice and patient engagement in care. Nonetheless, the nurses still used their own agency to determine and navigate their response to those scripted directions, often with a view to achieving the joint goal of patient safety and rehabilitation progress. However, when the nurse was also engaged in a social process with the person who is the patient, this process became a three-way interaction when the power of the guidelines had such prominence. In these situations, the person with TBI seemed to have the least power and the nurses

had to choose whether to be advocates in the face of allied health power. A nurse participant explained:

> *If a patient can communicate to any extent that they prefer things a certain way… I give them that option as much as possible… You're fighting against what you're supposed to do based on all the guidelines that you're supposed to follow, and what your patient wants to have done for them, so you have to meet those two in the middle…. So… the nurses here do try to skirt around certain guidelines, just so we can at least provide our patients … the basic things that they like. Because… we have these very rigid guidelines… and yet we're supposed to provide holistic care*. (*EN29, Line 294, p.13)*

Patient and family member decision-making actors were also prominent in shaping nurses' practice, and they often held different knowledges and interests in relation to clinical care. It is noted that patients and families are in dependent relationships with nurses and other clinicians.

Families knew the person with TBI in contexts beyond the clinical environment and they brought knowledge that was vital to decision-making. Families were also a source of knowledge to understand the patient's personhood and often took over elements of care after discharge. Family members had the opportunity to bring such knowledge and opinions to clinicians, and described varying experiences of feeling considered or heard.

However, patients, families, and other decision-making actors could find negotiations challenging. People who are patients, their families, and significant others, added to

the number of decision-making actors, and all actors had knowledge and opinions about care that did not always align with each other, or with those of the care providers. An aim of TBI rehabilitation is to acknowledge and respond to dependency, while also returning as much autonomy and independence as possible to the person who is the patient. However, a skill of rehabilitation nurses is to facilitate the safe transfer of that autonomy and independence. Therefore, nurses had to make decisions *for* patients in some circumstances to maintain safety, while, at other times, nurses sought to support autonomy by enabling the person to make their own decisions. This negotiation was made more complex through the inclusion of patients and families in decision-making as a central feature of person-centred practice, as well as by the patients' and the families' diverse and sometimes divergent knowledges and opinions. As one nurse participant stated:

> *One of my patients, she hates having her hair washed every single day, she doesn't enjoy it, but family want it to be done every single day, and it's like why? We're supposed to be advocating for our patients and yet you're telling us this is what the family wants so we have to follow it? But we're not advocating for family, we're advocating for our patient. (EN29, Line 294, p.13)*

4.3 The basic social process: *Nurses Dancing with Agency in TBI rehabilitation care*

In Grounded Theory studies, a basic social process (also referred to as core category) is a researcher's interpretation of what shapes understandings and actions of participants in the field (Charmaz, 2006; 2014; 2025) and it encompasses the researcher's constructed categories and subcategories (Birks & Mills, 2023, p.178). The basic social process in this study is theorised as *Nurses Dancing with Agency in*

TBI rehabilitation care (In short hereafter, 'Dancing with Agency'). Agency – an important concept in the guiding theory of Symbolic Interactionism – refers to "the feeling of control over actions and their consequences" (Moore, 2016, p.1). Even where structures would seem to dictate a person's responses to a situation, in symbolic interactionism, actors have in-the-moment opportunities to respond to another's direction with their own agency (Blumer, 1962).

The theory of *Dancing with Agency* depicts the basic social process expressed through: 1) language (e.g., the words one chooses, whether written or verbal); and 2) symbols that create meaning in interactions (examples could include: symbols of authority, such as job titles, published policies, clinical procedures, and uniforms; symbols that convey meaning about an environment; and body language and actions that carry meaning for the observer). The language and symbols that support this *Dance with Agency* are also influenced by personal and professional constructions of self, social worlds, and society.

4.4 Defining *The Dance*

The substantive theory of *Dancing with Agency* explains how nurses select (or neglect) strategies and interact with the agency of other actors to navigate the intricacies of promoting and preserving personhood for people with TBI in inpatient rehabilitation. Some of these other actors are people working in care-related roles (e.g., personal care assistants, doctors, allied health staff, families, patients, local managers) and some are structures (e.g., professional bodies, government bodies, and institutions) that nonetheless are part of the social process, and interact with nurse agency because of the power they exert. There is a relationship between

these parties, with each person or entity (e.g., structure or organisation) bringing their own agency and power to interactions. At times, these people or entities compete for priority. While, ideally, all actors have the patient as the focus of their concern, the outcome of *The Dance* sometimes results in the promotion of personhood and, at other times, *The Dance* results in the promotion of other priorities.

4.4.1 Properties of *The Dance*

Dancing *with Agency* appeared to have three key properties that impacted care that promoted personhood: 1) the *number of dance partners* (other decision-making actors) whose agency the nurse had to consider; 2) the *flexibility of the dance steps*, or the extent to which nurses could leverage their clinical judgement and negotiate or overrule an existing plan for care in either the patient's best interest, or in response to the current state of the operating care environment; and 3) the *concordance between dance partners*, or whether dance partners were *in-* or *out-of-step* with each other regarding judgements about the best plan of care to support personhood.

4.4.2 Purpose of *The Dance*

In the context of competing demands of people and agencies, the purpose of nurses' *Dancing with Agency* was to promote the goals of rehabilitation. However, in some instances, nurses would simply comply with other decision-making actors' rules. Nurse participants reported that the goals of TBI rehabilitation include: facilitating the regaining of functional capacity; promoting the person's independence and quality of life, and getting the person home.

4.4.2.1 Regaining functional capacity

Maximising function was a primary goal of rehabilitation. A nurse participant (RN33), explained this goal as incremental and contingent on the level of injury:

> *Our role here is to get them functioning as much as they can, in terms of what they can do for themselves… patients will come in, [requiring a hoist], two assist, in an almost vegetative state. Being able to move from there, to at least moving one side of their body, being able to brush their own teeth, being able to call for help and stuff like that is already a big improvement. (RN33*, Line 579, p.25)

A mother/family member (F11) was aspirational in their hope for their son regaining functional capacity through a continued progression towards the pre-injury self: "to give him more capacity to do things…. His brain isn't fully formed… so rehabilitation should be to get him to the best position possible, and it will be ongoing even if after he leaves the hospital" (*F11*, Line 560, p.25).

4.4.2.2 Promoting the person's independence and quality of life

While advancing the person's functional capacity was a key rehabilitation goal, nurses also sought to promote the person's independence in activities of daily living (ADLs). ADLs – such as hygiene, feeding, transfers and supporting mobility – include the type of care that nurses commonly provide to people in hospital when they have reduced function. In TBI care, independence with ADLs was framed as a precursor to quality of life, perhaps representing a *symbol* of dignity and personhood. A nurse participant (RN33) explained that they were "trying to get them being able to be slightly independent so that they can have some sort of quality of life and they don't

have to rely on nursing staff constantly is my goal for the Brain Injury Unit" (RN33, Line 579, p.25).

There seemed to be *concordance* in *The Dance* between nurses and family members in relation to rehabilitation goals. Family members clearly linked greater independence to quality of life. The mother of a person with TBI explained the links between a level of independence, enjoyment, and self-expression, as elements of quality of life:

> *The goal of rehab is…Number one, whatever his abilities are, that there's a quality of life with that. That it enables him to enjoy whatever he can at whatever functional state he's in. And to be able to [speak]… and to have an ability to express his needs. I can see his frustration in that some days. (F7*, Line 55, p.2)

While the nurses' *Dance with Agency* was usually in *concordance* with patient and or family priorities, patient participants often had very specific goals for function and independence that were linked to their own personal priorities. For example, one patient participant prioritised both mobility and speech, which she perceived as returning to her 'normal' self: "Right now [my rehabilitation goal is] walking and speech…. I can walk by myself, but really slow. [Walking and speech] is still a little bit different from a normal person's" *(P15, Line 219, p. 8)*

Another family member linked the idea of seeking maximum function to independence (which may be construed as an element of personhood), and to quality of life: "it's pretty much getting him functioning to his best ability, so he can go

outside and be independent. Be able to do things on his own. Hopefully get back to work and back to living a normal life again, not having to be dependent on people" (F8, Line 46, p.3).

Other patient participants also framed rehabilitation as "getting better" and, again, as moving towards their own perception of "normal" functioning. Thinking beyond the rehabilitation unit, another patient participant referred to several elements of life that were lost to them that, perhaps, constituted their personhood, and they expressed a desire to return to their personal 'normal': "I just want to get back to work and start driving again. I can't drive for a year… it's all I want, so I can get better. I just want everything back to normal" (P14, Line 203, p.11).

4.4.2.3 Getting the person home

Getting the person home was the final goal for rehabilitation. An experienced nurse participant linked independence and quality of life to the idea of *getting them home*. Home was not necessarily the place where the person had always lived. Home was not just a structure, or a place where physical needs might be met. Home was also somewhere that a person might experience something that contributed to their quality of life and their sense of personhood; perhaps, through a feeling of familiarity or belonging that they had lost to the injury:

> *From my perspective, the goal of rehab is to get [patients] home, or get them in a place where they can feel at home… give them... their independence back as much as possible…. Sometimes for that patient, it's not possible, but at least giving them a quality of life… just giving them their life back. (RN33*, Line 579, p.25)

Return to normality did not always mean a full functional recovery. As a nurse participant explained, a common goal of rehabilitation involved not only going 'home' as a measure of perceived normality, but also returning the person to their social world – even with residual disability – in a way that afforded them dignity and choice:

> *Everyone acknowledges that when it comes to a patient or each patient that they are involved with, there is a common goal. There is an end goal… rehab them to the point where they can exist in the community comfortably, where they have got dignity, a certain level of agency, where we can return them to as close to normal as we possibly can pre-injury…. Close to normal because it's never going to be what it was. There is always going to be something that's not quite right . (EN9, Line 230, p.10)*

While nurses aimed for the person to go home, this needed to be prepared for in a way that was supportive of family, thereby extending consideration of the patient's personhood to encompass the relationship they had with their family: "[we] make sure the family is happy as well. We do not want the family to be stressed when they go home… we want them [patients] to go home comfortably" (RN11, Line 566, p.25).

One family member emphasised that family preparation was contingent on family involvement, given their intimate understanding of the person:

> *I think the goal of rehabilitation [is to] involve the family much more. I've been with [Tom] 46 years… doctors and nurses have been with him just for a few months. A partner knows this person; a parent would know their child. They know what they can do, what their ability [is for] doing. Involve the family more*

into all these activities … my husband's going to a nursing home, but I'm going to be still there nearly every day… I want to be [involved]. (F12, Line 408, p.18)

In synthesising these ideas about the goals of rehabilitation, the idea of giving the 'person their life back' suggests that the purpose of the *Dance with Agency* for nurses is to hand over independent function, self-expression, and capacities to the person, to make the person feel closer to their 'normal' pre-injury self, while acknowledging that residual disability may remain. This handing over prepared the person for their return to family and community, which required input from, and collaboration with, the person and family members.

Nurses' *Dancing with Agency* involved facilitating the advancement of rehabilitation goals that were ideally set by patients and their families. When the goal of rehabilitation was given primacy, nurses prioritised patient's agency and promoted independence with ADLs. In doing so, the role of nurses in rehabilitation was to engage patients in self-care and not 'to do it all' for them. This role required the agency of health care actors to focus on maximising personal capacities and encouraging patient participation toward attainment of specific personal goals. *The Dance* also involved nurses continuously exploring the extent to which patients were mindful of their rehabilitation goals. At other times, the goals of rehabilitation meant that the agency of health professionals was privileged over that of patients and family.

4.5 Three components of *The Dance*

The basic social process of *Dancing with Agency* comprises three components: (1) *protecting the body of the person*; (2*) engaging the patient as a person*; and (3) *handing over the baton*. These components are clearly differentiated by practice intentions, and are non-sequential, often happening concurrently during the nurse-patient encounters.

4.5.1 Component 1: Protecting the body of the person

4.5.1.1 Introduction: Definition of component

The body is the vessel for personhood, and a TBI patient's capacity for self-monitoring and self-protection may be compromised by impairments of the brain, and potentially other body parts. *Protecting the body of the person* describes a collection of strategies employed by nurse participants to monitor and maintain integrity of the body and protect the person from physiological derangement and physical harm. Protection from such harm was not only perceived as necessary for the attainment of rehabilitation goals; it was also seen as inherent to nursing practice more generally. In the context of *protecting the body of the person*, nurse agency was usually privileged over patient and family agency. Nurse agency was underpinned by the privileging of nursing knowledge and clinical reasoning, and it was applied at a time when the person was less physiologically stable and less functionally able. There was also an organisational expectation that nurses fulfil these functions, which is a part of the workplace socialisation of nurses. However, *The Dance* required to protect the body of the person was not always straightforward.

4.5.1.2 Nurse activities protecting the body of the person

Nurses were the primary decision-making actors in monitoring and maintaining physiological integrity and physical safety to avoid further injury. Nursing strategies to monitor for physiological integrity included: assessing vital signs; blood glucose monitoring; observing for swallowing difficulties, nutritional adequacy, patterns of elimination, emotional status, and mental status; and assessing for skin integrity. Nursing strategies used to maintain physiological integrity included: assisting patients with feeding and fluid intake (oral intake or enteral feeds), periodic patient repositioning, medication administration, and request for medical review. Physiological integrity and physical safety were described as vital for the promotion of personhood in TBI rehabilitation nursing because a patient's ability to participate in any form of therapy was dependent on the stability of their physiological and physical state. A patient's physiological deficits were viewed as potential sources of specific physiological risks such as aspiration, infection, malnutrition, mental health challenges, and multi-organ failure (e.g., in the case of sepsis). Nurses also monitored physiological integrity to facilitate early intervention in response to signs of deterioration.

Described assessments nurses used to monitor physical safety included: assessment for falls risk,; assessing for patency and security of clinical or assistive devices; monitoring patient emotional cues (e.g. for aggression) and risk of absconding; and monitoring the patient's immediate environment and its appropriateness. Nursing strategies used for maintaining physical safety included: increased nursing supervision; one-to-one nursing allocation; use of specially designed (Hi-Lo) beds; use of seatbelts when *at risk* patients sat out of bed; and use

of medical and mechanical restraints and seclusion as last resorts for patients with behaviours that others find challenging or potentially harmful.

Nurses were the main decision-making actors in *protecting the body of the person* who is the patient. Descriptions of these social processes suggest that nurses control the direction of protecting the body of the person. While the person who is the patient receives protection in a way that is either passive or, perhaps, reflects their agency in concordance with nurses: they often shared the joint goal of maintaining a safe body. A nurse participant explained that the pivotal function of nurses in rehabilitation was observing, assessing, coordinating, and critiquing elements of physiological care.

> *We play a role in literally every single aspect of the therapy. We are watching them [patients] swallow, we are making sure they don't aspirate. We're also making sure that they're getting the correct diet … getting patients up and down ready for therapy. We're also involved in the therapy … dependent on the level of what the patient can do… everything from oral hygiene to body hygiene… nutrition, so how they're fed, how they eat, or if they're eating through a tube. (RN33, Line 15, p.1)*

Another nurse participant also explained the link between physiological care and maintaining comfort and dignity by supporting body care that a person cannot do themselves: "patients… with their incontinence… cannot do anything for it, so we have to clean them up, we have to wash them and change them and make them comfortable" (RN21, Line 38, p.2).

Protecting the body of the person was complex, with multiple considerations that required the nurse to know the person and their care needs intimately. When patients had a multiplicity of physical safety needs, their care often required inputs from a range of multidisciplinary actors, including prescribing supportive clinical devices and their application, safe transfer requirements, and physical limitations to consider prior to mobilisation. Some of these interventions were sources of patient discomfort and/or required patient input and cooperation to fulfil. In achieving the joint goal of protecting the body of the person, nurse participant (RN14) suggested that social processes needed to be directed towards understanding the person's body protection needs:

> *You have to be very mindful of each person's different deficits... for instance, for one of our patients... we have to make sure... we have a helmet in situ whenever we're transferring. We've also got to make sure she's got splints on her lower legs. We've got to make sure that we're supporting this side. There's a lot of things to take into account, and if you're not familiar with the patients, it would make it a lot harder on you to just get into that rhythm of knowing what each patient needs. They've got a lot of different requirements. (RN14, Line 444, p.19)*

Patients also recognised the vital role that nurses played in monitoring and maintaining their physiological integrity. A young patient participant described a range of nurse driven initiatives, and they seemed to understand the rationale for those initiatives and responded with acquiescence, given the joint goal of physiological stability:

Nurses… remind me to take the pills, they measure my blood pressure and occasionally, they come in to ask if I wear my stockings because the stockings help with blood clots and also, they give me injections every single day for… making the blood thinner. (P8, Line 135, p.7)

Nurses often delegated, or enabled family members to contribute to, the monitoring and maintaining of physiological integrity. Family members responded by performing certain tasks to protect the body of the person, including assisting the person with showering, oral care, feeding, transfers, and exercises. At times, family members also cleaned patients after episodes of incontinence. A family participant described their response to the delegated care role they played in the rehabilitation of their son: "[we] help with showering, transferring him from bed to wheelchair. Take him to his physio, help the physios as much as we can. He can feed himself now, but originally [we] had to help with feed" (F4, Line 116, p.6).

Nurses also had to operationalise elements of safety mandated by the organisation. For example, the locked nature of the TBI care unit restricted personal freedom of movement. Movement in and out of the unit had to be authorised by nurses, which constrained patient agency. While nurses might understand and rationalise this rigid policy (a lack of *flexibility in the dance*), they also had to negotiate patient agency and subsequent patient frustration. Some patients resorted to creative means of exercising personal agency, such as leaving the unit without seeking nurse or organisational approval, which meant that the purpose of the organisation's action was not achieved. An experienced nurse participant explained:

> *… we do have a lot of absconding patients... Because this is a locked ward, they have to get permission to go out and in… even if they are cleared to go out for the therapy and everything, they have to come and ask the nurses to open the door for them. That might be frustrating. They say that they are locked up here… They just want to get out of here. (RN20, Line 379, p.17)*

4.5.1.3 Accepting clock-driven practice routines

Nurses were socialised in healthcare settings to attend to routine tasks in ways that were often clock driven. The purpose of routine was often to formalise the processes to protect the body of the person, and to promote physiological integrity and physical safety. Completing routines for protecting the body of the person often required nurses to *dance with the agency* of a high number of decision-making actors to, for example, gain the permission of patients, the engagement of families, and meet the priorities of other staff and the organisation. The focus on the timing of tasks had numerous imperatives, including clinical imperatives (e.g., blood glucose monitoring before meals), workflow imperatives (e.g., having patients showered before their physical therapy sessions) and organisational safety imperatives (e.g., hourly rounding). Nurses are socialised to value these clock-driven routines and their imperatives. Perhaps therefore, even when the routines were demanding, nurses were usually willing to organise their practice in line with the workplace, being the decision-making player that holds these expectations.

In enacting these routines, nurses prioritised things like a clean body, the support of nutrition, and the formal assessment and management of risk, as key elements of physiological integrity. A nurse participant explained:

> *Once we receive the handover, we start with daily routine of showering the patients and then dressing them and setting them up in the chair and getting them ready for the meals. Most of our patients need help with feeding and they're on modified diets and fluids… making sure their environment is risk-free; doing an environmental risk assessment, also the patient risk assessment to make sure they're safe… making sure there is a call buzzer in reach…. And then… medication rounding and doing the pressure area care rounds according to the patient care plan. (RN18, Line 77, p.4)*

The routine nature of clinical rounding (a routine of checking and documenting attendance to specific nursing activities) was performed as and when clinically indicated. In one setting, rounding was mandated by decision-making actors high up in the healthcare hierarchy, such as unit managers, who exerted control over nursing work. Nurse participants explained that contributing toward monitoring and maintaining physiological integrity and physical safety was a routine but purposeful nursing practice. Despite the rigidity of rounding as an expected practice, it appeared to be non-controversial because of the clinical rationale understood by the nurse participants: "regular rounding, pad checks for the patients who are incontinent; we do those every two hours. Once the patients are asleep, we do regular hourly rounding just to make sure they're okay and they're breathing" (RN17, Line 133, p.6).

Assessment and management of skin integrity was another important practice routine because many patients were unable to protect their bodies from unrelieved pressure. Although the agency regarding patient safety largely rested with the organisation, the nurses were receptive to this because of the level of patient need

and patient safety gains. Decision-making actors in such contexts were other nurses, Personal Services Assistants (PSAs), and patients. The routine nature of nurses initiating these processes presupposed input from other decision-making actors. This *concordance between dance partners* was assumed, given the joint goals of the nurse and the organisation in body protection. The *low flexibility in the dance* (driven by clock time) was normalised and accepted. One nurse participant explained this constellation of *The Dance* and their pride in the results of this body protection:

> *Some people need two people to assist full care, so we have to… make sure that the pads are regularly checked and changed, or… they'll end up with sore bottom. So we do the pressure areas at 10 o'clock, 2 o'clock and 6 o'clock, every fourth hour… because of the constant repositioning and constant changing of pads, we don't have many cases of [pressure] injuries. (RN15, Line 387, p.17)*

Another nurse participant described how rounding was enacted and adjusted according to patient need. This participant provided a sophisticated rationale, based on an environmental and patient assessment. This rationale informed a strategy that met the requirements for safety monitoring and management while maximising patient agency and dignity:

> *Monitoring is different, because you use your environment first. So depending on the level of falls risk … we may need incidental supervision like nurse rounding every 15 minutes. Or… this guy … in room 10, is closer to the nurses' station, and it's in a main thoroughfare. So, the way we're nursing him – because he's a high falls risk – we're not restraining him at all, but the bed [is lowered] to the floor, there's a mattress on the floor, and he just rolls out of*

bed, and he rolls around on the floor. And every time we go past him, we can see what he's up to. So it's about [utilising] least restraint. (RN7, Line 250, p.11)

Monitoring and maintaining physiological integrity necessitated working within a pre-planned daily routine or sequence, which required nurses to consider the time for patients to engage with other clinical decision-making actors, who supported the attainment of rehabilitation goals. One nurse participant suggested that their patients were socialised to this routine, and were aware of the schedule for the day. This shared socialisation supported *concordance between dance partners*, with agency shared through acceptable routines: "whatever nursing involves … that's the routine, and then they go to physio, because they've got a plan for the day, so the patient knows this is the time they have to be up and ready for the therapy" (RN19, Line 461, p.20).

In delivering routine care to protect the body of the person, concordance between nurse and patient agency during interactions was achieved when the patient saw the routine as a reflection of a nurse's thoroughness, competence, and consistency, that made the patient feel valued and safe. Also, while there was a lack of flexibility in this routine, several patient participants seemed to appreciate the predictability:

The nurses have been fantastic, very thorough. Like even this morning, before breakfast they've done my blood sugar, they've done my blood pressure, my temperature, my heart rate gets checked before every meal …. It's 15 minutes before the food's due to come, they'll be here any moment and they do it

> *every time and they're really good and they're always polite about it and it happens. (P11, Line 378, p.17)*

Concordance between nurse and patient dance partners was more likely when patient comfort was a focus of the nurse's routine, due to the prioritisation of personhood. A nurse participant described this routine: "we do personal care… we get them out of their day clothes and put them into more loungewear or pyjamas; just get them relaxed for the afternoon" (RN17, Line 133, p.6). This comfort care routine might have been either standard unit practice, and or a value of the individual nurse. Comfort, as a priority, may be engrained in varying degrees in the clinical duty of care that individual nurses have toward the promotion of personhood.

During interactions between the nurse and a potentially irritable patient, when the nurse prioritised patient agency and gave opportunities for flexibility in routine practice, concordance was promoted. Nurse participant (RN14) explained their role in monitoring the person's readiness to engage with nursing interventions, and their own level of flexibility when negotiating task timing with the patient. Sometimes this role required negotiating with multiple decision-making actors. However, when all decision-making actors recognised the value of managing the patient's emotional state – and the shared goals of rehabilitation were given priority – the nurse perceived the patient's personhood as being promoted:

> *Maybe with these patients, there's different times of the day where they are more compliant or more happy or not as combative. For instance, our patient just wants to sleep until 10:00 in the morning and doesn't want to wake up for the 8:00 medications - tends to become aggressive at these times when you*

wake them up to take their medications. You would just wait until they wake up… you don't want to get them agitated for a reason like a medication that can be postponed if you consult with the doctors, with the team, and you know that it's safe to postpone…. Maybe before the traumatic brain injury they used to wake up at 10:00 all the time, and they don't like this new thing of being woken up at 8:00. That's fine as well. We want to get them back into how they used to do things, because it's rehabilitation... that's something about their personhood…. If they like to start their mornings at 10:00... We'll promote that with them. We'll help them do that. (RN14, Line 400, p.18)

While collaboration with the patient to achieve body-protection goals would be preferrable for promoting personhood, there were examples of nurses choosing not to negotiate, or insisting on performing tasks in a certain way despite a patient's reasonable argument. These actions usually occurred when the nurse perceived a threat to patient safety and prioritised *protecting the body of the person* over the person's autonomy. In one encounter, there was poor concordance between the nurse and the person with TBI – the actors were *out-of-step* with each other. In this case, the nurse's agency was privileged over that of the patient. While the joint goal of safety might have been met, it seems that the goal of promoting personhood (through autonomy, dignity and comfort) was not met. This outcome occurred due to a lack of *flexibility in the dance steps* and the power of the nurse to exert control over the patient in what was already an unequal power relationship. A patient participant explained their perception of an experienced nurse who exerted the power of their agency over them. As the account shows, the patient discursively reasserted their

own agency by asserting that the nurse’s actions were not reasonable and that the nurse was set in their ways:

> *I was being transferred over to a chair to be in the shower… I wanted them [nurses] to take the hoist off because I can move. I can wiggle around and get the hoist out. And the nurse is like ‘No, you have to have it in the shower’ and I said, ‘But then it’s going to be wet, just take it off.’ She was like ‘No, you’re wearing this hoist in the shower’... Every other shower I have had when that nurse hasn’t been there, guess what they do? They take the hoist off… Because then when they lift you in the hoist, you’re wet and you get cold and yucky because the hoist is all wet and then… they have to put three towels on the bed… and you’re all wet… so that one I didn’t win… I just gave up in the end... A senior nurse… just stuck in her ways. This is how it’s done, and … there’s no [other way]. (P6, Line 345, p.15)*

4.5.1.4 Collaborating with allied health to protect the body of the person

Allied health guidelines were symbols of external agency that could subsume nurse agency. These dynamic, patient-specific prescriptions stipulated equipment, people, and processes to be followed during a person’s rehabilitation. At two research sites, nurses’ adherence to the guidelines was mandated, while at another site they were considered a guide, and much more open to nursing input and co-revision. Nurses often perceived the allied health guidelines as advantageous when they needed the expertise of others to inform a practice problem, when they needed to support continuity of care between nurses, and when patient safety could be compromised if guideline-oriented care was not followed. For example, if the patient had difficulty

swallowing, a speech pathologist might prescribe a procedure for assisting feeding safety. In such a situation, a nurse participant explained their willingness to cede agency to allied health decision-making actors in order to protect the body of the person during mealtimes:

> *Some [patients] can hold the ordinary spoon. Some of them can't. So, [OT] make a big grip... Some… spoons are crooked so they can put in their mouth. It's all different… That's the OT's job… they give a guideline, so we follow that. (RN30, Line 326, p.15)*

Nurses also perceived another allied health prescription to be advantageous: the communication tools designed by speech pathologists. These tools enhanced nurses' communication with non-verbal patients. Nurses valued this aspect of collaborative allied health engagement because it facilitated personalised care in an otherwise one-way, nurse-led interaction with patients with communication impairments. In this instance, the nurse was often willing to delegate agency to the speech pathologist to enhance the person's capacity for communication, enable more flexible nursing care, and support patient choices and expression. This collaboration in turn supported the nurses', allied health staffs', and patients' joint goal of promoting the patient's personhood by facilitating expression of preferences. A nurse participant explained:

> *The speech pathologists are quite good with developing their own communication guidelines, so when a patient can't verbally communicate, we have something called an AAC [Augmentative and Alternative Communication]… it's basically like a flip chart that [patients] point 'yes' or 'no' to. One of our patients has a really big one where it's more than just 'yes' or*

> *'no', there's things that she likes to do, or if she wants to communicate that she wanted, a certain hairstyle, she can point at it. And we ask them questions. We talk to them like they're normal human beings, there shouldn't be any difference… in the way that you talk to them, but instead of… a verbal response they'll point. (RN33, Line 50, p.3)*

Another nurse participant described how they appreciated the presence and expertise of allied health workers, who they saw as enhancing their own professional development and practice. The nurse participant initiated social interactions with the allied health team as a way of enhancing their own capacity for protecting the body of the person, and as a way to support the joint goals of rehabilitation and nursing practice:

> *The fact that Allied Health is so closely tied to this place is really helpful to nurses, because they can learn a lot… I'm always asking, when the patients are being mobilised, taken to therapy by the OTs, 'Is there anything you wanted us to do? Is there anything we should keep an eye on?'… But that doesn't make it harder, that just makes us better… personally, I think it's just an avenue for learning. (EN24, Line 229, p.11)*

4.5.1.5 Collaborating with the patient and family to protect the body of the person

The patient who is the person could also initiate and direct social interactions with the goal of protecting their own body and promoting comfort. The following field note exemplifies purposeful collaboration between the nurse and the patient to protect the body and how this contributed to the personalisation of care and the promotion of patient agency (FN6). The interaction followed a sequence: the patient initiated the

interaction; the nurse called for a second dance partner, presumably to enhance safety; the nurse checked in to accommodate patient preferences during the encounter; and on completion, the nurse asked whether the joint goal had been met. As the nurse described:

> *The patient calls out for nurse assistance with repositioning while resting in bed. The nurse responds and notifies the patient that there will be two nurses needed to perform the task. A second nurse is called and the two nurses work together to reposition the patient. Nurses ask the patient which side he prefers to be turned, how he would like the pillows to be placed and this ends with the patient thanking the nurses for their work. (Field note, FN6)*

Monitoring for patients' physical safety was also a focus of the nurse's collaboration with family members and other support people. When working collaboratively, nurses frequently brought family members into the work of *protecting the body of the person* by including them in care activities. Even though this action increased the number of decision-making actors, when nurses sought concordance with patients and family, the dance partners were more likely to be *in-step* and achieve meaningful joint outcomes including protecting body integrity. This inclusion usually took the form of a family member assisting with personal body care tasks (such as personal grooming, bathing, feeding, cleaning the person after incontinence, and observing and supervising the patient). Giving family members the agency to take over some elements of body care seemed acceptable to family members, particularly when it increased their sense of connection with the patient and contribution to their comfort, or when the work was framed as preparing the family member to support the person's care after discharge. Nonetheless, most families seemed willing to

participate in assisting their loved one with care and safety: “I don’t know if it’s just this ward, but a lot of the people here, they’re all willing to help when they can. They rarely refuse helping their family members” (EN24, Line 83, p.4).

Family members seemed comfortable initiating a conversation with nurses when they had concerns about *protecting the body of the person*. When nurses responded openly to family members, the joint goals of protecting the body of the person and comfort could be achieved:

> *They’re involved. Mainly they’re the ones that … start it [the idea] and we [consider it] – because it’s their loved one, so they’re noticing the changes… It could be a transfer [or]… a chair that they’re not happy with. We could be happy with it because we’re not sitting it, in the end. So, the family can raise concerns and then we work together as a team to find a solution to it. (RN28, Line 143, p.7)*

Acknowledging *concordance between dance partners*, a patient’s father explained how nurses identified his presence as a trigger for them to share care activities with him. The nurses and family member seemed to be *in-step* with this arrangement because it helped to protect the body of the person, while also allowing the father to express his fathering role:

> *The… wife… does do caring, like nails… but only on the weekend… I come every day, I shave him, I assist the nurses and staff… Well… you’ve only got so many nurses. And if one is off, that means the others have to pick it up. So, they’ll go, ‘Oh, Roy’s[4] okay, his dad’s here’… So I end up doing a fair bit of*

[4] pseudonym

nursing, cleaning the teeth, exercises... It's all right, I don't mind being hands on with it, because it's my kid. (F3, Line 22, p.2)

A patient's wife seemed to suggest that the act of bathing her husband was both promoting his personhood and therapeutic for her because it promoted their relational bond:

> *My thing is if he feels clean and fresh, he'll rehabilitate better. Would you go to sleep without a shower if you've been running around all day? No… So, when I come here for an evening and bathe him… it's beautiful, it's what we do, have a shower before we go to bed instead of having one shower in the morning with three nurses and then that's your day. So, that's the humane part… The nurse can help you, but the human part is very personal and it's a bond that you have with your partner and only that bond can give you [hope]. (F2, Line 693-702, p.33-34)*

Another patient participant also described this delegation of care to family members when nurses were diverted by other tasks. The role of agency was not entirely clear in this instance. While the nurses seemed to hand over agency to the family members (through their absence), it was not clear how the family members were prepared to receive and enact this agency. The patient explained:

> *… the nurses are very busy… so when they see my family come here, they are very happy to see them… When my parents come, nurses … leave away from us so in the daytime my parents will do anything they can do. (P15, Line 109, p. 4)*

It is difficult to understand from the above examples whether these nurses shared the responsibility for *protecting the* body of the person as a means of pro-active collaboration that prepared a family unit for discharge, or to make space for family time, or whether this was simply a way of delegating tasks from an already crowded clinical schedule. A nurse participant explained one rationale for sharing the responsibility of monitoring for patient safety with the family, with the purpose of *protecting the body of the person*:

> *Nancy, she's quite impulsive at the moment, and she's missing part of her skull… so if she falls she's at risk of a bleed. So informing her family [that], 'If she's in the chair, make sure she's not trying to get out of it; if she is, let us know and we'll move her back to bed'… that's just patient safety… Unless specified, we can't physically stand there and watch them the entire time. So… that's an instance where we would involve the family. (EN24, Line 83, p.4)*

Requesting family members to 'keep an eye out' for their loved one was *in-step* with shared goals when the family member had a sense that the request increased their family member's safety, was part of shared agency (through the granting of permission), and was a shared strategy for care. The following field note illustrates the concordance between a nurse and a family member, and the family member's contribution as a dance partner in monitoring and maintaining the physical safety of his son:

> *Patient's father (F3) called nursing staff upon noticing that Jack [the patient] was becoming short of breath. Nursing staff attend to Jack, applied supplementary oxygen… and called for a medical review. Jack had a*

tracheostomy removed… but sputum kept oozing out of the tracheotomy surgical hole. Nursing staff kept applying tape over the tracheotomy… but the tape kept falling off… Jack's father stated that his stay at Jack's bed side allowed him to call for help from nurses early and prevented any negative consequences for Jack. (Field note, FN185)

Family members were key decision-making actors and patient advocates, who could alert nurses when subtle signs of pain or discomfort were observed. It seems that this patient's father was comfortable assuming and directing his agency to protect the body of his son, and that this action was met with acceptance by nurses and others. A field note illustrated the father's contribution:

Sometimes physios require splints to be applied for four hours on and off. The new splints cause pain [for the patient] at times. The patient's father is able to convey these patient concerns to the nurses and other clinicians who are willing to make adjustments in care. (Field note, FN32)

A nurse participant also described a nuanced *Dance with Agency* between the patient and family members as *dance partners*. During this dance, the collaboration was used as a teaching moment to increase patient safety and prepare the family members to support the person at home. Even though these interactions aimed to reduce variability (and therefore, flexibility, for safety reasons), they also provided an example of attention to personhood because the nurse checked in on the patient's level of comfort. This strategy was also modelled to the family members:

… integrating them [the family] into your care – if they're present… say, 'This is why I'm doing this. I'm doing this because it's dangerous if we do it this way,

and this is just a safer and more comfortable way for the patient.' We'll ask the patient as well, 'Is this more comfortable for you?' And then the family member being there and being exposed to all these answers being provided can… get that insight, and then they can provide that same care to them [the patient] that we're giving. (RN14, Line 110, p.5)

On rare occasions, when they felt that the family members were *out-of-step* with the goals of protecting the body of the person, and that their interactions with the patient were unsafe, nurses took more extreme measures. Where patient safety was threatened, this lack of *concordance between dance partners* necessitated nurses taking actions like restricting family presence within the rehabilitation environment. Nurses rationalised that these actions safeguarded patient safety. However, at times, the family members resisted aligning with nurses' directions:

We've had situations where… family members… hinder the process and the progress that the patient makes… especially if they don't agree with why we do what we do. We've had a few… who we've had to actually bar from coming in because… you tell family members you cannot feed patients this type of food because they have dysphagia, they're not able to swallow properly. It's really dangerous, they could end up choking on it and aspirating. And despite explaining this to them, they will give them chips, water, things like that… sometimes you don't know what goes through their minds… especially when you tell them, 'You can't bring in cigarettes, you can't bring in drugs [medications]… and give it to a patient'. (EN29, Line 436, p.19)

While family member involvement was mostly valued and appreciated, there were clear boundaries to family members' agency set by the organisation, or perhaps by the allied health team, that privileged specialist knowledge and clinical judgement. Strict allied health guidelines required family members to be trained in care provision before they could take part in care and limited the ways in which family members could contribute to personal care for the person. This constraint on family agency, while not designed by nurses, had to be enforced through nursing agency. A mother described how she was told by a nurse that she could not attend to personal care for her teenage daughter because of unit guidelines. The meaning for the mother in this interaction was that she wanted to care for and nurture her child. This restriction put the mother *out-of-step* with the nurse and left her frustrated and powerless:

> *I was actually showering [Jackie(pseudonym)] at [another hospital]… When we got here, I was made to feel… like it was something I wasn't allowed to do. It was a nurse that was really making me feel [frustrated]. She told me that we've got different guidelines… here compared to where I've come from… We were her parents… She's a little bit underage… She's 17… but then the nurses were very [strict] – 'You haven't been trained to do this'… But it's hard to be told when I was participating in the care of her and feeding of her… to be told you can't do any of that because you're not trained… I think they were referring to whether the therapists had trained me to do it. Which the therapists don't, but I wasn't really sure where that training was meant to come from. But I didn't ask because we've always just tried to assist the nurses with whatever they wanted… I understand… because if she was dropped on the floor… or if something happened and then you've got to answer, well why did this happen? (F10, Line 275, p. 12)*

Sometimes, poor *concordance between dance partners* could arise when an agreed level of family involvement was not communicated across the nursing team. The incongruence of information across multiple nurse dance partners made things difficult for families. A family participant explained how they were disrespectfully brushed-off by an officious nurse, which diminished any sense of collaboration in the provision of care:

> *[The unit manager] mentioned that they [nurses] were going to be possibly short [staffed], and so I said to her, 'Well, we'll come in at 8:30' … But when we came in they had [enough] nurses, and they were putting her in the shower. And a different nurse snapped at us and said, 'You're here too early.' Then I said, 'Well, we were told that possibly they were going to be short on nurses, so we came in to assist [with showering].' Then she was just like, 'No, no, no. Out you go!' (F10, Line 275, p. 12)*

Other examples of nurses constraining family members' agency arose when nurses' perceived that family members were overstepping accepted boundaries, and when nurses perceived that nursing agency should be privileged and families should respect their specialist knowledge. These occasions were described by nurses as the 'over involvement' of family members. Participants noted that such 'over involvement' could occur when families held strong beliefs about what constituted proper care influenced by previous clinical encounters or knowledge of the person. This 'over-involvement' meant that nurses *Danced with Agency* of the family, in the hope that they would 'step back'. Several examples of 'over involvement' were

conveyed across participating sites. A nurse participant described the lack of concordance in encounters with a particular family, with both parties clearly having the patient's best interests at heart. The patient's family was brought back in step with the clinicians' directives when more dance partners joined the interactions to communicate the shared goals:

> *I think sometimes [family] over-involvement is not very useful… they obviously know their loved ones better than us, but we know what works clinically for the patient, and a lot of the times we are overruled by the family because they want this done a certain way. That's when it gets in the way of person [centred] care. An example was a patient came in with a certain IDC [indwelling catheter) bag. We wanted to change it because it does not fit our guidelines, and when they go to physiotherapy that's not going to work... So when they came in... we changed the bag straight away... Even when we tried to educate the family on why we changed the bag, they were very adamant that this bag will cause the bladder to explode. We had to educate them over and over again, and they weren't listening to the nursing staff. We tried everyone… our seniors… our CNC… they wouldn't listen to anyone. They were very overly involved... It wasn't until we had a family meeting with all the seniors in this place, and our consultant, when they finally understood, 'We need to step back a bit'… But sometimes they [family] don't listen… and we are put down … sometimes it does get too much. (RN33, Line 442, p.20)*

While the extent of family 'over-involvement' in their loved one's care arose from positive motives to protect the body, nurses still found the scrutiny of their practice uncomfortable at times:

… the majority of the time it's not the patient, it's the family members that create that conflict between the nurses and the patient. The patient is fine, but it's just that particular family member because they're too involved with the… care and they start to pick on everything that you do. They always say, "Oh, you're not doing that the right way. It has to be this [or] that." At the same time, I feel like… if that's their child, it's understandable. They're just looking out for them. But sometimes, it gets a bit too much. It affects how we look after the patient… you're just trying to do your work, but then if there's too many eyes watching you, it creates that pressure in the working environment. (RN11, Line 416, p.18)

Sometimes protecting the body of the person was delegated to family members in ways that were overwhelming. Family members were pivotal decision-making actors in the patient's rehabilitation and nurse agency was also gradually delegated to families as a way to facilitate the patients' independence. While this pattern in *The Dance* increased the number of decision-making actors in a positive way, it required both the flexibility and parameters – flexibility to allow others into the caring circle, and parameters to that flexibility to avoid a patient's dependence on a well-meaning family. When there was *flexibility in the dance steps* that enabled family involvement, nurses used this flexibility as an opportunity to offer education and advance families' understanding of TBI rehabilitation, its therapeutic intricacies, and its dynamics. A nurse participant explained:

I think it is good to get family involved because eventually, they're going to go home. That's the goal. And to start training the family early will give them more knowledge as to how to look after this patient holistically'... because…

when you're a family member of a loved one that's sick you just want to do everything, and that is not something that we promote. We try to promote independence... Educating the family early on and getting them involved allows them to understand… how to get involved appropriately, instead of overdoing it for the patients and the patients relying on the family. (RN33, Line 245, p.11)

In some ways, the family members were an extension of the patient who is a person through their relational personhood. Nurses utilised this knowledge to delegate (handover) certain patient care tasks to families as decision-making actors. A patient's sister gave an extended example of the tension between giving family-informed care and having to do something to ensure safe care, or to avoid missed care. This participant described initiating their care interactions with the patient to enhance their comfort and safety. This would compensate for the nurses' care being reduced because of their clinical obligations, and contribute to promoting and preserving personhood:

To be honest, we're a unique family. We do everything. Because we have found that the family doing it … was safer… with [the patient] avoiding any misunderstanding that's sometimes that's happening with the nurses… Even the medicines… We take it from the nurses and give it to him. We [put the splints on], we prepare his food. We have our way to make the things the way that [the patient] wants, because he's a family member, so we know what he likes and what he doesn't. It's hard for the nurse to be with each patient, to do these small details. So the family is important…. [they] know exactly what he

needs. Like doing the room the way he likes … be with the family or watching TV, or getting him up. (F6, Line 54, p. 2)

However, some nurses seemed to manage these interactions through their unnegotiated absence, which placed undue burden on the family and often caused frustration. In such cases, nurses used their agency to resist the family's needs. A family member explained the family's frustration with these actions:

> *… they [nurses] just depend on us because they know that we do everything. So this [puts] us under pressure sometimes. Not all the nurses… But It makes us feel that we have to come… That we can't leave him, because we know if we left him, the nurses won't do [things] the way that we [do]. So, it's hard for us. It's either my mum and I, or it's my mum… from 8.00 to 8.00 every day… We're overwhelmed [with the] care and his needs. (F6, Line 87, p. 2)*

This same family participant explained how the nurses' delegation of care to the family members created tension in their interactions with the person they cared for. The patient felt uncomfortable with this delegation of caring tasks to his family because he was uncomfortable with his level of dependence on them:

> *So basically, he [person with TBI] knows that we know how [things should] be done. So, he has more trust with us. But he also has the other perspective that he doesn't want us to do the things that the nurses should do… So sometimes he gets angry that 'No, it's not your job. The nurses should do it.' So, he keeps buzzing… because he just doesn't feel comfortable that we do everything. (F6, Line 152, p. 7)*

Another family participant described how this overwhelming sense of responsibility for care led to the loss of their previously known life:

We don't go anywhere, we don't do anything, I'm here at the hospital every single day… for the last 19 months, just to be with him and help him. My husband comes directly after work every day. My daughter… has to work. …but come[s] up at weekends. We don't really have a life anymore. Our life is Jimmy [pseudonym]. That's our main concern. (F9, Line 42, p.2)

This reliance on family members for care provision seemed to be a structural factor in the resources of these rehabilitation units. One nurse participant described how they relied on the family to achieve good care, given that the nurses were stretched by the mismatch between their resources and their workload:

…sometimes [when] the family comes it's a big relief for us – because we know they[patients] are in good hands, they'll care for them. The families are there… so we can do our medication, other stuff. Whereas if the families are not there… that was a bit hard for us. (RN15, Line 536, p.23)

A family participant provided an example of failure for protecting the body of the person when care was delegated to the family. They were distraught and distressed with the perceived poor clinical care. There seemed to be an abdication of responsibility by the nurses:

…when he [patient] had to go down and get x-rays… I'd always go. There usually was someone [a nurse] with him but at one stage there wasn't and that was quite a horrible situation … He had a [feeding] tube blockage and - three, four times a day he was going down for scans… Normally a nurse

[escort] comes with us or one of the orderlies comes with us but for some reason they weren't there… So they took him and brought him back and he was crying… he had vomited everywhere and obviously had almost choked. It was just me there, I was devastated. The nurses down there were useless, they weren't even going to clean his bed. I was trying to clean his bed but because I was in a state they started to help… it was quite horrific… I complained when I came up. I said "he always needs someone with him"… after that they always send someone with him. I don't know why that day they hadn't because they're required to … he can't communicate. (F11, Line 268, p. 12)

4.5.2 Component 2: Engaging the patient as a person

4.5.2.1 Introduction: Definition of component

Component Two of *Dancing with Agency* is constructed as *engaging the patient as a person*. Nurses used various strategies during their social interactions to engage with the *patient as a person*, understand their personhood, and facilitate expression of that personhood. Because of the purpose of rehabilitation, it was imperative to engage the *patient* as a person in their own care and recovery. Nursing strategies that were used to engage *the person who is the patient* included: understanding the capacity of the patient; understanding the personhood of the patient through the family; understanding the personhood of the patient through personal items; prioritising intentional communication with the patient, and knowing the person and personalising care.

4.5.2.2 Understanding the capacity of the patient

To establish patient capacity (needs, strengths, and weaknesses in the context of TBI), nurses *Danced with the Agency* of patients and the agency of others (in the form of supplemental clinical assessment and judgement). Purposeful interactions between nurses and patients enabled the collation of information that guided nurses' decisions relating to optimal personal care choices. Nurse agency was supplemented by specialised input from many diverse categories of allied health professionals, and medical officers as dance partners. Contextual factors were the capacity of patients to voice their needs, their physical strengths and functional deficits, and the dominance of allied health in rehabilitation.

A nurse participant explained that the strategy of understanding the capacity of the patient involved encouraging their agency and asking specific questions about their capacity. These actions were followed by graduated collaborative input from allied health as other partners in *The Dance*. Allied health agency was at hand and supported nurse agency in the following example of a social process with multiple dance partners. The dance partners were *in-step* with each other and this *concordance* enabled the joint goal of shared decisions about care:

> *If they [patients] have the capacity to respond to questions, asking them what they need, asking them what works for them. Something as simple as, "Which side is stronger? Where do you roll better, to your left or to your right?" helps me help them. It makes me understand what I need to do to care for them. And then, obviously we work closely with allied health, they help fill in the gaps. And then, hopefully with all this information, I can have a full picture and start adding myself into it. (RN22, Line 36, p.2)*

Nurses frequently performed formal assessment using clinical tools to objectify cognitive capacity prior to allowing patient agency. The patient's cognitive capacity then formed the foundation upon which the nurse-patient interaction was based. Nurses considered a patients' agency and took the lead when cognitive impairment impacted perceived autonomy of the person for 'rational' decision-making. The nurses *Danced with Agency* in the social process of listening to patient preferences during personal care, and in deciding when to either allow patient input or disregard their requests. Varying degrees of tension arose when dance partners were *out-of-step* and could not harmonise patient preferences and the nurse's prioritised clinical options. For the nurse, the heightened tension was created by the potential for something to go wrong, which could lead to physical harm to the patient. One nurse participant described their *Dance with Agency*:

> *I will not listen to the patient if he's very confused. I will assess... if they pass the PTA [post-traumatic assessment]… Basically that means they're OK, they can decide. They think well… But, if I know he's confused and disordered, disoriented, then I have to lead… One young [patient] came from [another hospital]... He wanted to go out and he can't yet… He's walking around, I know he's good in here, but he wants to go to the toilet by himself without [nurses] for safety or without physio clearance. I will just say 'No. I will have somebody walk with you.' I will not listen… You have to know what kind of patient you have before you let them decide what they want to do. (RN31, Line 297, p.13)*

4.5.2.3 Understanding the personhood of the patient through the family

Nurses sought to understand the personhood of *the patient as a person* by understanding the patient's routines and preferences and enabling patient focused goal setting. To understand the person's previous construction of personhood, nurses had to make a conscious decision to access information by initiating interactions with several dance partners. The patient was prioritised as the source of understanding of personhood and the patient's family was a further source of understanding when severity of TBI impeded patient input. The family members contributed as both a part of the person's relational personhood and as independent actors who offered a wealth of information that informed personal care based on their longer relationships, and their knowledge of the person.

Nurse participant, Bailey explained the family's value in their knowledge of the person:

> *They [family] probably are our number one go-to source to understand their [patients'] personhood… if they [patients] have severe traumatic brain injury…if our patients can't communicate effectively to us, we go to their family members, who obviously would have spent the most time with them and would have known them best. They would help a lot. (RN14, Line 205, p.9)*

One family member expressed that it was important for clinicians to understand the nuance of her daughter's injury, perhaps because they felt it would reduce judgement and optimise how nursing staff would construct their daughter's

personhood. This person's mother initiated interactions that clarified the mechanism of injury with an apparent goal of framing their daughter's personhood:

> *They know it's from a car accident, which I understand that's how you'd sum it up. But that's… the problem. They're being summed up in a couple of sentences… I find that if I tell the nurses what's actually happened to her they seem to have a different perspective on her. That's what I do sometimes. I'll just tell them what's happened… because I feel like if you have a greater understanding… that's what happens in the… handover. You get summarised, you get told about the medicines mainly… how the person was injured is just summarised in a sentence or two. Car accident, hit a tree, fat embolism… they've got to get the medicine right. I know, but to me, the personal touch is not there. It gets missed a little bit. (F10, Line 653, p.28)*

Nurses generally sought *flexibility in the dance steps* they used to promote the personhood of the patient by being open to the person's preferences. However, sometimes the availability of resources constrained their ability to meet those preferences: "We [nurses] like to ask family…What kind of foods they [patients] preferred. Sometimes it's not possible to give them those foods, but at least we have an idea of what they like to eat" (EN29, Line 421, p.18).

4.5.2.4 Understanding the personhood of the patient through personal items

As well as seeking to understand the person's previous construction of personhood for nurses' relational work, nurses also had strategies to reconnect that person to their sense of personhood. Again, pursuing these strategies required the nurses to

increase the number of decision-making actors (in this case, family and friends) to gain access to personal items. For example, the use of personal photos in patients' rooms was a routine nursing strategy to elevate personhood in rehabilitation care. This personalising of the rehabilitation space provided a means for the person who is the patient to develop familiarity with their previous world. These items could create a space with imbued meaning and familiarity. Nurse participant, RN17, explained how this personalisation process helped to provide a conceptual bridge between the rehabilitation unit and the person's future life in their community:

> *….definitely [photos] help provide [patients] that sense of familiarity, so they're not in just a bleak, blank hospital room. Seeing something familiar, I think, really helps them – provides a sense of security for them, that this is not just a hospital room, this is rehab, this is the next step out towards the community, and that's what they [patients] have to look forward to. (RN17, Line 175, p.8)*

Valuing the family members as decision-making actors in their social processes gave nurses access to multiple elements of the person's socially constructed world. This *Dance with Agency* between the nurse and the person's significant others was usually based on shared goals. In particular, family members appreciated the familiarity of the patient's rehabilitation space and displayed personal artifacts to inspire hope and support patients' recovery. One nurse participant explained how reminders of diverse elements of a person's social world contributed to the promotion of personhood through evidence of individual meanings that symbolised the previously known self and a sense of status. This nurse used these visual cues to initiate conversations about personhood:

*So, let's say there's photos of cats, dogs, photos of their friends, photos of them at parties with all their family members, nieces, nephews… We have a patient who used to be a chef. He has lots of photos of meals that he's cooked … and in his chef's outfit. It's just to show them, 'This was all your life, and this is what – who you are.' Just a reminder of what they've been. (*RN14*, Line 219, p.10)*

Another nurse participant described how engaging significant others as dance partners supported identity and status recollection for the person. By personalising their patient's environment and celebrating elements of their identity, recovery was supported through positive messaging:

*We had an athlete who was preparing himself to go to Olympics, then he had this accident, and he was recovering, so you can see the encouraging words written everywhere, his achievements, his photographs… I feel like that may fall under person-centred [care] as well. You are creating an environment where the patient feels like he is in his own home or own set up. (*RN20*, Line 85, p.4)*

Pictures on the wall were often carefully chosen to enhance the person's connection with their lived world and increase their desire to get back elements of that life. A patient's wife described the importance of intricate personal details captured in photographs, which made visible the person's choices and positive memories that might support recovery through meaning-making. She used photographs to initiate interactions with her husband about their shared life experiences:

It [picture on the wall] shows him what our life was like before. Gives him some drive to want to get back to doing what we were doing before. There's some restaurant photos. There's photos of him… That's our pizza… behind you, with the muscles and the clams on it.. On top of it is [our] pasta. (F2, Line 629, p.28)

Using other items from home as symbols of personhood enabled the person to rebuild personal memories, and to reconnect with their pre-injury lives and their old selves. One nurse participant (RN33) described a range of objects that could be considered personally meaningful and so contribute to personhood:

We try to get the family to bring as many things as they can in that the patient connects with. It could just be a little doll, or even a soccer ball… and we put them in their line of vision just so that looking at it, it reminds them of the person that they used to be and they can get their old self back. (RN33, Line 181, p.8)

Another nurse participant explained the importance of personal clothing as symbols of identify and homeliness that also promoted comfort:

We like to encourage them [patients] having as much home items as possible. So, we're always dressing them in their [own] pyjamas… We change them into their day clothes during the day... We put on their shoes… we encourage them to have home blankets to make them more comfortable. Just to try to make the room look as much as it would [with] more familiar items in it. (RN14, Line 224, p.10)

Dressing the person in their own clothes was used to promote flexibility and familiarity and to act as a discriminator between a sick person and a 'normal person'. This type of empowerment potentially supported the person's sense of agency, personhood, and identity. A family member explained:

> *You've got to be very positive in here… they [nurses] are positive, they don't let you be in your hospital clothes, they want you in clothes, so that you're not feeling sick or looking sick… you at least look okay, like you're working or visiting, whatever … It gives it a sense of normality. (F3, Line 152, p.7)*

Nurse participants also explained that the use of personal items was therapeutic for family members because it allowed them to feel that they were amplifying elements of personhood for their loved one. It was also suggested that this use of personal items could be therapeutic for nurses when their ability to make a substantial difference to a person's quality of life felt limited:

> *…we [nurses] say, 'Feel free to... make this wall whatever you want it to be', to… remind them of the people that love them too, and support them, and will be there for them. It's a very deep thing for the family members If they [nurses] feel like they can't give the patient what they need … with their nursing … then that's something that they can do for them … showing them photos and providing that kind of support. Sometimes it's the most that they can do…. That's the collaboration between us and the families. (RN32, Line 468, p.21)*

By incorporating photos and personal items brought in by family, nurses were able to solicit cues about a person's interests that could inform person-centred conversations:

> *We'll be able to pick up the photos and be like, 'Your kids are beautiful. Your daughter, I think she's going to come in today' and you start to communicate in that way, something the patient would love to hear… So that's how we let them [family members] make it a home feel for the patient. So that's personalising [of] care that we give. (RN32, Line 468, p.21)*

Nurses also asked family members directly about the person's interests to enable person-centred conversations. Family members were a source of understanding of personhood:

> *We like to ask family what topics of conversation or what interests do they have so that we can bring that up in our topics of conversations. What kind of foods they preferred…. And just generally communicating with family when they're around just to see what they were like prior to our patients having the brain injury. (EN29, Line 421, p.18)*

At one research site, nurses utilised a creative strategy to understand the personhood of the patient. The strategy involved collating the patient's lived world in a booklet that aimed to reorientate them to their previous world and the present rehabilitation environment. This strategy allowed the patient to make sense who they were before and also provided them a sense of continuity to their present self:

> *One formal thing that we do is a 'Book-about-me'… a book from premorbid stuff, to the accident, and afterwards. So… your kids, your work history, your*

parents... It's like an orientation thing premorbid. Now that you have had your accident, some have a picture of them in ICU... And then what's happening now… We try as much as we can through environmental stimulus to orientate themselves to the self. We orientate the patient to who they are. So hopefully, from that it comes out with where they are and why. (RN1, Line 306, p.14)

4.5.2.5 Prioritising intentional communication with the patient

Patients valued nursing care that was preceded by clear nurse explanations about what was happening. The *Dance with Agency* was shaped by how nurses constructed and conveyed explanations to patients, while accommodating the impacts of TBI such as cognitive impairment. The effectiveness of these explanations may also depend on the clinical expertise and experience of the nurse. The nurse's initial social interactions with the patient, the structure of their conversation, the tone of their conversation, and the nurse's body language, facilitated the foundation for establishment of a meaningful therapeutic relationship. Prioritising meaningful interactions laid the foundation for exploring personhood.

The incorporation of family members' input was helpful where the person engaged in behaviours that nurses found challenging. A nurse participant highlighted this social process:

That initial communication… the initial interaction with them for the day. They might not remember who you are previous to this, so that's really important. And the way you speak to them, depending on the way they talk and the way they are, it needs to be direct to them and personalised. So you start off with

the introductions and the normal kind of, 'How was your morning, how was your night, have you slept well, is it a good day?' Sometimes the family … bring in cards or things that you can integrate into building that rapport for the day... that can be a really good strategy to use, especially for somebody who is quite agitated normally. (RN31,Line 262, p.12)

A patient participant expressed the importance of nurses' explanations, and demonstrated how a poor *concordance between dance partners* was likely when nurses offered no meaningful rationale for their actions. On the other hand, being treated as a person with agency and capacity seemed to promote a sense of dignity in the patient:

I think because they [nurses] now realised that explaining stuff to me does make sense, because all those parts of the brain are now working, that they do explain it really well and quite accurately and I can go 'okay, that makes sense'. It's quite nice to have things explained to you properly when they realise that you do actually understand it and you can converse about it, and I will accept it. Just telling me, 'No, you can't do it', is not going to work because I'm going to rebel against it, but if you actually explain it to me... I agree. (P11, Line 141, p.7)

The nurse's *Dance with Agency* took various shapes as elements of the patient as a person changed by the day. The dynamic nature of the patient's situation (cognition, behaviour, sense of personal agency) could provoke a change in the nurse's approach to nurse-patient interactions. When nurses made a conscious choice to initiate nurse-patient conversations around topics of interest to the patient, this

complimented the delivery of personalised care. A nurse participant highlighted this point:

> *...essentially just asking them [patients], 'Do you like this? Do you like that? Is this how you like it? Is this the temperature of water that you like?'… not just assume that because this is what they said one day that it's going to be the same thing the next day. So it's always keeping your patients in the loop with what you're doing so that you can tweak your care from day to day. (EN29, Line 336, p.15)*

Not prioritising a patient's agency and not valuing and facilitating their personal expression of needs appeared to have poor outcomes for the patient's sense of personhood. A patient participant explained how he and a nurse were *out-of-step* with each other when the nurse was focused on tasks and did not recognise the symbol of the buzzer as a tool for communicating and expressing patient agency:

> *I didn't have the buzzer. The nurse was there, next to me and I said, 'Nurse, can you give me the buzzer please?' 'I'll finish this and I'll give you the buzzer. Don't worry, don't worry.' I asked for the buzzer four times. 'Don't worry. Let me finish, let me finish.'... At the end, she left without giving me the buzzer and I had to scream. It's the only thing that allows me to communicate. Or I need something heavy to throw through the window, smash the window off to get their attention. That's the only thing left to me… I was attached to a machine. I unplugged the machine. The machine started to beep, so when they hear the machine, they came straight away. What can you do?… Sometimes they don't get it. (P10, Line 538, p.26)*

At one site, clinical tools – in the form of colour-coded (yellow or white) timetables – were 'acting agents' that informed the ways in which nurses communicated with patients. These tools were devised by allied health dance partners, and at times could constrain nurse and patient agency. 'Yellow coloured timetables' had low or no flexibility because they dictated how patient care was structured. 'White timetables' allowed for *flexibility in the dance steps* because nurse agency could be exercised based on the application of clinical judgment to advance patient agency, self-determination, and choices about personal care. The *Dance with Agency* involved the nurse constantly navigating the bi-dimensional tools that shaped the patients' rehabilitation world. The key contextual factors were site specific practice and the assumed or sanctioned power of allied health at this particular facility. This nurse participant explained:

> *If a patient is able to communicate their needs, and they're more alert and orientated and able to tell me what they want, I usually ask them, 'Hey, would you like to have a shower now?' Especially the timetable differences, so if it's a yellow timetable that means it's a bit more strict and they need these certain therapies, they need to get up at this certain time, they need to go back to bed at a certain time. That could just be because they've been fatiguing quite a lot. But if it's a patient that's on a white timetable where it's free-flowing and they're also able to make decisions themselves, then I always like to ask them, like, 'Would you like to have breakfast now?'… I would let them know that this is what's booked in for now, but how do you feel about going now? Do you want more rest, or would you like to wait a bit and do it later, what do you think? (RN33, Line 112, p.5)*

Social interactions between clinicians and patients were not always successful, making it difficult to achieve joint goals. Sometimes communication tools were not patient-centred and excluded patients from knowledge about their care plan. For example, timetables at one site were often prepared by allied health professionals without input from the person with TBI or their family members, making it difficult for dance partners to achieve concordance – these parties were out-of-step when trying to achieve their goals. These practices distanced the person from their care planning, and signalled that their input was of low value. For example, at one site, the timetable was placed outside the door where members of allied health could view it but the person with TBI could not, making that person's situation even more complex. This impersonal practice impeded the provision of person-centred care and attenuated patient personhood. One patient participant was unaware of what care was planned for the day and expressed feeling confused:

> *[The] Timetable [is] organised by therapist and the physio together... I don't organise... I'm okay. But [if I know beforehand], I can prepare a lot of things, because I don't have [any] idea till my father takes a photo of my timetable. So every Monday morning I don't… know what's going on. Sometimes [I am] very confused so I will ask a nurse [and]… they will tell me… Maybe before [they] stick [the timetable] on my door, maybe show me first? (P16, Line 165, p.6)*

Patient agency was also augmented by the use of electronic digital devices to enhance communication. Personhood was promoted when patients were able to convey their needs effectively using technology. This nurse participant explained:

There've been times that we've used iPads, so if their hand dexterity's a bit better… we have had patients who are able to type out their needs and tell us what they need, or even have a conversation with just typing in the iPad. (RN33, Line 50, p.3)

The person may have difficulty expressing their care needs and may require family members, carers, or significant others, to convey these needs to nurses or other actors. A family member exemplified a person-centred approach to initiating interactions with her son about their care needs. The goal seemed to be promoting and preserving personhood and advancing agency for the person:

I always … speak to him like I would otherwise. For example, yesterday after his blood pressure dropped and had a little bit of a seizure, I asked him, 'Are you feeling worried, are you feeling sad, are you feeling, okay?' Or other days I would ask him, 'How can I do everything right, the way you want them to. I hope I'm explaining things to you and giving you a chance.' I'm saying, 'I'm giving you the options to say yes or no.' I ask him every day, 'I hope I'm doing this right for you, Jake.'[5] (F7, Line 328, p.15)

4.5.2.6 Knowing the person and personalising care

Knowing the person and personalising their care contributed positively toward building rapport. This further supported an understanding of the person's own rehabilitation goals, which are ideally set by the person, if they are to be meaningful. While engaging *the person who is the patient*, nurses functioned as facilitators of rehabilitation goal setting by encouraging patients and families to take the lead.

[5] pseudonym

There was *flexibility in the dance steps* when family members as partners were able to freely exercise their agency in collaborating in setting the person's rehabilitation goals. Nurses engaged in *The Dance* as they assessed goal feasibility, made alternative recommendations, or provided further support to enable the person's goal realisation. Potential high-tension situations were mitigated when the nurse realised that strategies might need in-the-moment modifications:

> *The goals are mainly set by the family and the patient; we just help them out… we don't set the goals… because it's what the patient wants…. If the patient wants to drink themselves, we help them out. If the patient doesn't want to be fed, they just want us to set up, we are happy for that. And then we encourage independence for the patient as much as possible. And sometimes we come to a stage where the patient is tired, fatigued and can't feed themselves, then we feed them. (RN15, Line 300, p.13)*

There was a fluctuation in the intention of nurse agency; nurses could either seek to personalise care, or to control and dominate the person. This pattern of interaction was dependent on whether either setting clear boundaries for the person, or accommodating their preferences, was considered more likely to attain rehabilitation goals. Both of these actions required the exertion of agency, although the former reduced patient agency. Nurses strategically applied a highly flexible and tactical, rather than a robotic, approach to the shaping and delivery of patient care because no person was alike. *Flexibility in the dance steps* had to be limited for some patients where a clinical requirement, patient safety, or rehabilitation therapy had to be prioritised. . The level of tension in social interactions depended on various contextual factors, such as the nurse's level of experience, the nurse's patient load,

the severity of the TBI, the patient's capacities, competing resources, and local protocols. A nurse participant suggested that nurses needed to be flexible to get the best out of the patient:

> *Not every strategy… or every management style for a patient's care is going to work. Some might need a little bit of… not tough love… but a bit more restriction and a bit more boundary setting, whereas others might need… more empathy… a softer care towards them. So it just really depends on what style works for them, and what you see [as] getting the best out of the patient, and reaching their rehab goals… because we're all so individualised… also given their trauma throughout their life or what their [past] experiences have been… if you provide the same kind of care for everybody you just become a robot… you're never going to provide… a rapport with that person because they're just going to see you as this person that comes in, does their job, goes away… So it's really important… to have that encouragement and that rapport to really find how the patient can recover to the best of their ability. (RN32, Line 115, p.6)*

Nurses frequently chose to oblige patients' and family members' requests, while knowing that some essential aspects such as medications could not be overly delayed for safety reasons. This recognition and accommodation of patient and family agency acknowledged the role of autonomy as an element of personhood and rehabilitation. This nurse participant explained the back-and-forth negotiation of agency to achieve the joint goals of the interaction:

> *…this morning I had a patient who was due for 8 o'clock meds but he was in the bed until 10 o'clock. I went there a couple of times, wife was there, she*

said, '[He's] sleeping, don't bother.' So I [adjusted] to do the medications at 10 when the patient woke up. Because that's what they want – we [nurses] can't force people. It's their life, but… we can't leave them [in bed] the full day. We'll give them some time, and then we [approach them] …say 'you [have] a long day, you've got therapies, you've got to get up now.' (RN15, Line 315, p.14)

When the nurse failed in knowing the person, and using this knowledge to personalise the rehabilitation environment, this could lead to patient distress. A patient participant explained a tense interaction, when the nurse did not understand their needs:

When you are lying in bed, the [lights] are bright, they sting, it actually hurts your eyes…. most nurses know that I don't like the lights because I complain... I am quite light sensitive… So… I am not always ready for, the bright lights going on. One of the nurses when I did a wee in the middle of the night turned on all the lights and I'm like 'You don't need to see that much… It's not a poo that you are wiping up'. (P6, Line 503, p.22)

Remembering details about a person's injury and considering this during care interactions was necessary to promote the person's comfort during therapeutic interactions. Patient participant P6 also expressed lack of concordance in *The Dance*, when a nurse did not remember important details about their body and care needs:

There is only one nurse at the moment… I have an… injury on this particular arm and as you can see I have quite a deep scar and this causes pain just by being [touched]... Sometimes when she [nurse] rolls me over… she grabs a

bit too firmly and it actually causes me quite some pain. So I have spoken to her about it twice and I think she just forgets. I know she's not doing it on purpose, she is not trying to hurt me, but she has been a little bit rough… I don't like [it]. (P6, Line 52, p.3)

Knowing the person and personalising their care was crucial. Patients might refuse to participate in therapy if they perceived that nurses were not familiar with their personal strengths or weaknesses. Nurses who were new to TBI rehabilitation, or those that were casual or temporary, were perhaps more likely to experience tensions in *The Dance*. One nurse participant gave an example of this failure to know the person and the consequences for their rehabilitation:

…we have one patient… we've learned to use the [communication] board with him and figure out what he wants. We know him, we know his likes and his dislikes. If a.. casual or a temporary person came in… it has [happened] in the past, where the patient has refused to get out of bed… because he was very upset that the nurse couldn't understand him and… didn't know all the little details about him, how he likes his legs stretched, what he doesn't like and how he wants to get up at a particular time and, when he's positioned into the wheelchair, how he wants to be faced. These are all the little things that you can't just add all of that into the nursing handover... Really you need to know this person… or he [won't] let them do therapy. (RN27, Line 276, p.13)

Nurses were flexible, allowing the patient to direct an interaction when they perceived an opportunity for patient agency to be safely exercised. This was the case even when such actions had no clinical rationale but contributed to promoting

the person's agency. A nurse participant exemplified this social process that resulted in low tension:

> *I was showering someone this morning who has sensitivity in his right foot. So, he likes to have a (taped) mat to his left foot when he stands. To me that is a no brainer… You don't even have to think about it … for me this is about personhood… And it is the small things…he was very happy. (RN1, Line 51, p.3)*

There were other examples of nurses allowing patients to take the lead in everyday elements of life in the rehabilitation unit, representing a gradual transference of control from the nurses to the person. The actors in this social interaction had the shared goal of promoting the person's agency, personhood, and rehabilitation. An EN participant explained:

> *We have one patient… who is progressing really well, so I think we'll come to a point … where we give very minimal prompts and we allow him to do what he needs to do, obviously within boundaries and making sure that he's as safe as possible. So sometimes he'll say, 'I just want to sit here in the loungeroom and watch television', because that's what he enjoys. So… at the moment we're just allowing him… to lead us… I don't think we need to police everything… which is great because he's happy, and… it's allowing him to progress in his rehab. (EN29, Line 468, p.20)*

4.5.3 Component 3: Handing over the baton

4.5.3.1 Introduction: Definition of component

The component *handing over the baton* involved the nurses privileging and harnessing the agency of *the patient as a person*, by relinquishing nurse control over the things that patients could do for themselves. Nurses prioritised the agency of the patient by finding in-the-moment opportunities to encourage patient participation in self-care activities, and they promoted personhood by fostering a sense that the patient was moving towards their new normal. The main outcomes that nurses working in TBI rehabilitation sought were to get the person ready to go home, get them as close to normal as possible, help them regain functional capacity, and maximise their independence within the confines of the person's ability.

Handing over the baton required high *flexibility in the dance steps*; nurses were willing to step in and assist the person with accomplishing tasks, while also foreseeing how the person might stretch themselves further. This pattern of nurse agency, which involved both pushing forward and pulling back as required, advanced patients' self-reliance and autonomy as they transitioned towards discharge. This process helped the person to redefine their own sense of personhood. The baton was also handed over to the paid carers, families, or significant others who would go on to support patient agency.

The nursing strategies for *handing over the baton* are categorised under two distinctively different classifications relating to: (i) the actions of individual nurses; and (ii) structured organisational practices.

4.5.3.2 The actions of individual nurses

Individual nursing strategies that were used to *hand over the baton* included: taking in-the-moment opportunities to promote self-care; and acknowledging and addressing discharge anxiety.

4.5.3.2.1 Taking in-the-moment opportunities to promote self-care

Early in a person's rehabilitation journey, there is a constant process of assessing the person's capacities and limitations. At the same time, nurses encourage them to try new elements of self-care in ways that allow for, and sensitively accommodate, little 'failures'. For example, an EN participant explained:

> *You try and see if they can do it first. Say, if you're undressing them. You say, 'Oh, do you want to see if you can do it for me ?' They'll try and then get flustered, 'I can't.' You say, 'Oh, well, I'll help you.' So you sort of do it that way. So you try and help them and say, 'Okay, I've got your shirt off, how about your socks, do you want to try and get them off?' They might get them off so you [say], 'Oh … Wow, you got them off!' So just sort of praise them up for what they're doing…" (EN2, Line 345, p.19)*

Offering graduated nursing care in the context of the person's physical capabilities allowed for the promotion of autonomy, which was a vital aspect of personhood. One nurse participant clarified this strategic approach for providing rehabilitative care

> *… and even [when in] the showers... sometimes if they're able to move the limbs say, 'Okay, here is a washer, you wash yourself, and you dry yourself.' So really involve them in the care and try to maintain their independence. Because if you always help, they're not going to improve. (RN15, Line 334, p.15)*

A nurse participant (RN32) noted that nurses used confidence-building strategies as a social process to push patients beyond their comfort zone, albeit in ways that felt emotionally safe for the patient:

> *If they [patients] take the initiative to complete a task, I'll provide assistance, but sometimes they do need a little bit of a push because they're frightened. And it might be as simple as putting on their own shoes. They've had people doing it for them so much… they're like, 'Oh I can't do that' and you're like, 'actually no, give it a go, I'll help you if you can't.' So you stand back and let them do what they can, and you'll know a point when you need to step in, but for the most part they can do more than they think… What you realise in this work is that recovery [from TBI] does require a… push … and it's usually [that patients] just fear that they might fail at the task. (RN32, Line134, p.6)*

Patients generally responded well to this gradual handing over of self-care, particularly when there was *flexibility in the dance steps*. A patient participant appreciated how agency was handed back by nurses in seemingly small ways in line with their current capacities*:*

> *… if the nurses put the toothbrush and the toothpaste and the cup there for me… I can brush my own teeth… I can feed myself… I can almost brush my hair by myself, but I need to be handed the hairbrush… Sometimes I need help opening some things. There's a little plastic fruit cup and I struggle to get the lid off, but I can feed myself as well… But the nurses are getting out of the habit of opening it for me… giving me an opportunity too. Sometimes it takes me a good two minutes, which doesn't seem like a long time but when you're*

thirsty two minutes is a long time. So… loosening the water bottle but then letting me unscrew it and open it. (P6, Line 446-465, p.19-20)

Mostly family members knew that rehabilitation involved letting the person do things for themselves rather than having others do things for them. In promoting independence and the perceived 'normal' self for the person, nurses encouraged family members to *hand over the baton* where possible. A family member described how they promoted the normal self and a sense of dignity for their brother:

He very much likes to be independent… Sometimes I offer to help him with something, but he doesn't want me to help him. Before, he had a bit of trouble putting his shoes on, but now he's much better at doing that on his own, so now … I'll just tie his laces … but he'll put the shoe on himself. Or before I'd help him get changed… Or going to the toilet… but now … he wants independence, so he'll say, 'Okay, you don't need to help me.' … Because he wants to function on the outside… push himself to be independent. (F8, Line 27, p. 2)

One patients' wife expressed being happy when decision-making actors gave a number of options for activities that might engage her husband, and when they privileged his agency if he did not wish to engage. However, the wife did acknowledge that they would sometimes have preferred the patient's agency to be further challenged to aid the attainment of rehabilitation goals:

… they're doing one thing and he goes… 'I don't want to play cards', 'Okay, we'll go on the bike.' 'I don't want to do that.' They have more than one option for him. And then, if he keeps refusing all of them, they say, 'Okay, we'll leave

it for today.' Because he's never forced into doing something; he's always asked… I'm really happy.. And I say [to the staff], 'Sometimes you might have to push him a bit harder'… I always say, '[Peter(pseudonym)], you have to do it. You're not going to get better if you do don't do it.' But if he doesn't want to do it, you can't make him. (F12, Line 248, p.12)

Nurses found ways to incorporate work towards the important rehabilitation goal of independent mobility into the person's day. One patient participant explained that the "[nurses] make me walk to my appointments by myself" (P14, Line 36, p.2). During the promotion of independent mobility, patients were closely observed by various decision-making actors who were ready to intervene in case the person experienced difficulty. Another patient participant explained:

I wear the belt [when walking independently]. If I fall or I'm about to fall, my companion, be it nurses or anyone else, can grab hold of that belt and stop that from happening…I like it … because it makes you safer. (P16, Line 80, p.5)

4.5.3.2.2 Acknowledging and addressing discharge anxiety

As the moment for discharge from rehabilitation approached, some patients became anxious about leaving the rehabilitation unit because they anticipated what awaited them in the community upon discharge. Nurses were pivotal in initiating timely interventions from relevant dance partners and mitigating anxiety. A nurse participant explained:

Some patients can become very fearful about what's going to happen… 'How am I going to cope?' And that may present in different ways. Anxiety -

sometimes we see patients blowing up from time-to-time, and that can create… on-the-spot tension. But usually when you get to the root problem and problem solve, or you bring in supports from allied health or whoever's involved with the discharge, those things become less anxiety-provoking or fearsome, and patients tend to recover from that pretty quickly. And we're a pretty tough species, us nurses. We don't bruise too easily. (RN10, Line 469, p.20)

Sometime anxiety about discharge led to delays in discharge as the patient and family members tried to grasp the 'shock' of having to face the outside world without the input of dance partners that they had been used to seeing in rehabilitation. A nurse participant exemplified this type of tension:

I think it [anxiety] happens because … sometimes even though they want to be discharged, at the same time they feel like they're not ready to be discharged… they're going to meet different people from care agencies… It's confronting and scary… Sometimes they tend to create a problem so they can delay their discharge… It makes it a bit tricky. (RN11, Line 209, p.9)

The family members could also feel emotionally unprepared for discharge if the *concordance* between clinicians' and the family dance partners' expectations were *out-of-step*. One nurse participant attributed the family members' reluctance to accept the *handing over of the baton* to their continuing grief for the loss of the person's agency or autonomy as a consequence of the TBI:

Maybe sometimes the family is not happy when the patients get discharged too early, because I guess the family is not ready emotionally and physically…

They've still got a lot of expectations, but then the patient's been here for so long, and the prognosis and the outcome, it's not changed. The family might not be able to accept that. They're still grieving. Sometimes, we get the family to speak to psychologists or a social worker… to accept that this is what it is... They have to go, somehow. And they can still have therapies in the community. It's not the end. (RN12, Line 454, p.20)

Another nurse participant used skilled therapeutic conversation to prepare people for the discharge environment:

I always say, 'I know it's never going to be the same when you go home, you'll feel like you're by yourself. It's not going to be smooth sailing, it's going to be a lot of adjustment. Everything's going to be new, especially if you're here for a long time'… They might have sleepless nights for the first week or two... a lot of adjustment, but they just have to remember that it's not going to be permanent. They will find their way again eventually, … build a relationship with their new carers and be more comfortable… I usually say, 'It's not going to be easy, but eventually you get there.' (RN11, Line 241, p.11)

4.5.3.3 Structured organisational practices

Social processes that nurses use when *handing over the baton* were often framed by structured organisational practices. These included: engaging substitute decision makers; enabling care transitions through structured organisational practices; structured training programs for patients, family members and professional carers; structured training for the patient; and discharge planning structures.

While working within structured organisational practices, nurses sought and *danced with the agency* of other dance partners as they *handed over the baton*. The person's return to the social world at times necessitated modifications to their home environments to facilitate ease of mobility and performance of ADLs. The major dance partners in this process were iCare and the National Disability Insurance Scheme (NDIS) – government bodies that provide financial facilitation for people with disability to enable necessary and reasonable supports that align with their personal goals.

4.5.3.3.1 Engaging substitute decision-makers

Some nurses with recognised organisational authority met formally with other members of the multidisciplinary team, patients and family members. They worked collaboratively to enhance the personhood of the person through the transfer of agency. Decision-making actors, such as carers or their next of kin, were particularly important in these social interactions when the person did not have capacity for decision-making. RN27 provided an example:

> *We do have… MDT [multi-disciplinary team] meetings, follow-up progress meetings, where the family member is heavily involved with decision-making. We're collaborating with them all... But if the person can make decisions themselves, we try to encourage [their input] to see what they want… and inform the carer, because it's about the person… we try to empower the patient… But if the sole decision-making sits with the next-of-kin… of course we empower them. (RN27, Line 63, p.3)*

The personhood of patients was affected when they did not have family members available to make decisions for them during discharge from rehabilitation. Elements of personhood, such as personal preferences, cultural needs, or choices may not have been adequately accommodated. RN25 explained the difficulty of promoting personhood under these circumstances:

> *It does affect their personhood because they cannot make the decision for themselves, and they have no one who can make the decision on their behalf. The care that they get… might not be what they want it to be and their… cultural needs might not be [taken into perspective]… [personal care] might not meet their preferences or choices. (RN25, Line 270, p. 13)*

Decision-making *for* patients who lacked the capacity to exercise their own agency required dancing with many partners. The multiplicity of dance partners included nursing, medical, and allied health partners, and family members. Many dance partners were engaged to ensure that the best-fit decisions were made in a way that privileged the patient's best interests. One nurse participant elaborated upon this form of *handing over the baton* when the extent of residual TBI related incapacity was high, and they seemed to acknowledge the inevitable attenuation of personhood:

> *Because being in brain injury… rehab, not everyone… goes back to that capacity of making decisions for themselves. So, there is always a family member or a public guardian having to make decisions for them. They're incorporated in the decision, but there's so little that they can input for themselves. Because some of them go home… still [severely impacted by]*

traumatic brain injury. They can't really say much or put any input [in personal decision-making]… (RN28, Line 185, 9.8)

Family members appreciated the opportunity to participate in a multidisciplinary team meeting because this gave them access to the rationale for care, provided an update on the person's progress, and provided a forum in which they could ask questions about their loved one's rehabilitation. This then informed the family's decision-making. One family participant explained the benefit of such meetings (although, in this instance, there was only one meeting, which limited the opportunities for meaningful interactions):

> *…we had the meeting with all the team members who look after him, and the doctors, nurse, and everybody tell what they have done to look after Tim [pseudonym of person with TBI] from [their] different perspective… That meeting's really good because we can ask our question and we can understand what they're doing now, what stage Tim is in... But unfortunately, there's only one meeting… If they can do [weekly or two-weekly] meetings that would be… a very good way for [us to] understand… the future plan for him...Tim can also ask questions. (F1, Line 288, p.13)*

4.5.3.3.2 Enabling care transitions through structured organisational practices

Facilitating home stays

One strategy of *handing over the baton* was using institutional protocols that granted patients planned periods away from the rehabilitation environment. These periods promoted a sense of return to the 'normal lived world' for the person. Families

reported varying outcomes when patients had time away from rehabilitation for home stay or visits. Positive outcomes were associated with a smooth transition from rehabilitation. RN33 explained:

> *It depended on how the gate pass [period away from rehabilitation] went. Sometimes it doesn't go to plan, but… usually the family members are also very happy that they [patient and family] were able to go home and to be surrounded by people they love. They [family members] always give us a little handover of how things went and… usually they're very supportive and happy about sending them [the patient] home again, and they're very excited for the next [home visit]. (RN33, Line 634, p.27)*

The brief breaks from rehabilitation routines allowed for connection with loved ones which uplifted patient spirits and enhanced their drive to participate in activities. The breaks seemed to provide more meaning to the rehabilitation tasks because the person with TBI then understood that these tasks would bring them closer to discharge. Consequently, they seemed to become more engaged in social interactions about their care:

> *One person that I'm talking about… goes [on a home stay] with all the equipment. I find that they're so much more alert… because they did have this break from just routine, routine, routine, and seeing strangers' faces. When they go home they'd be surrounded by their kids, their partners, their aunties and uncles, parents, whatever… when they come back to us, they're so much more ready to engage, and I feel like it gives them a reason to keep pushing. (RN33, Line 624, p.27)*

The change in the setting of care from rehabilitation unit to home increased the complexity of *The Dance* because people had to adjust to their environment, their greater independence and the different ways of doing things at home. Nurses *danced with the agency* of patients and their families as they navigated the safe relinquishing of agency, while maintaining the continuity of rehabilitation within a collaborative partnership. Nurses facilitated home stays for patients by making essential equipment available (e.g., medical supplies, devices that aid feeding, and personal care supplies) that could safely support periodic or weekends living away from the rehabilitation unit. One nurse participant described the role that nurses played in *handing over the baton* to prepare patients and families for home stays:

> *We have ranges of patients who are walking and talking, they're alert but they're confused. They're able to do everything themselves, and the family are trained, and so we just send them home with whatever they need. It could just be small things, like…mildly thickened fluid… Or sometimes we also have patients who have been for years and it could just be waiting on financial stuff, or a certain company to support them to go home. We give them a gate pass [permission for temporary leave], and we give them all our equipment. They could have a hoist at home already, and we give them [incontinence] pads, blueys [waterproof sheets]… everything that they need for the patient to… enjoy some time at home. To be in their normal environment. (RN33, Line 600, p.27)*

Facilitating transitional living

Another form of *handing over the baton* occurred during the transition in living arrangements. Such transitions occurred, for example, when patients moved from

the inpatient rehabilitation unit to a transitional living unit in preparation for full discharge. Transition to a minimal supervision environment provided an avenue for many dance partners to work with the person to get them to their fullest potential for independent living. A family participant described this strategy:

> *They told me that after Christmas… they plan to send him to the transitional living unit... and then it's home after that… from what I hear they basically try and get them to be more independent at home, like… cooking for themselves, learn to… do things on their own at home. (F8, Line 171, p.8)*

4.5.3.3.3 Structured training programs for patients, family and professional carers

Nurses' *Dance with Agency* included training (teaching or educating) patients, families and carers how to perform various aspects of care during the process of *handing over the baton*. This initiative was both organisational and individually nurse directed. A major nursing role involved imparting practical tips that the person could use to live safely away from rehabilitation. This role was more prominent when the person was getting closer to being discharged from rehabilitation.

Structured training for the patient

As the person's discharge from rehabilitation approached, nurses trained them to be vigilant about their environment and any safety issues that they may encounter upon discharge from the rehabilitation setting:

> *[We train patients] how to survey the environment for risk. These are some of the things you might see in your bathroom. If you see a wet floor, maybe get a loved one to come and dry it for you before you go in… You're constantly*

looking at providing learning opportunities between the clinical setting and what might be encountered in the home setting. (RN10, Line 343, p.15)

Further instances of training as a medium of *handing over the baton* were present when nurses aimed to rebuild the person's ways of living within the community. *Handing over the baton* was shaped through a formal organisational social process, whereby nurses would take the person out of the rehabilitation unit to see, and re-experience, normal living in the community. A family participant explained:

Nurses help Bob [pseudonym] in some stages. For example, the nurse takes him [shopping]. We understand the purpose for [shopping] is to help him get back to normal life, it's not for buying things. So the nurse asks him, 'Whatever you like you buy', and tell him how to shop. That's … teaching him how… [to get] back to normal life. (F1, Line 197, p. 9)

Nurses provided structured patient education on medication safety to gradually *hand over the baton* to patients. The number of dance partners was high because different people were engaged to develop a practical routine to assist the person's transition from being reliant on nurses to being autonomous with making decisions about medications. A nurse participant explained:

We might do a trial for the patient to ask for their medications, instead of us going to the patient, to see if they can independently remember what time and what medications they have. We make a little chart and we do it for a week and they come to the nurses station and say, 'I'm due for my medications now', so we tick that they've attended. That means that they can

independently administer their own medications or remember when they need to take their medications from a Webster pack. (RN27, Line 366, p. 16)

Structured training for the family

A nurse participant explained the medication training given to the family when patients had impaired cognition:

[If] the patient is cognitively impaired and they're on insulin… we liaise with the diabetes educator from the hospital. We train the patient and the family member who [then] takes [on] the responsibility [to facilitate safe medication]. If the family member is not there to look after [the patient's medication needs], … we organise a community nurse to come. (RN26, Line 479, p.21)

Nurses also offered training in other aspects of care for family members in preparation for patient discharge. In one instance, training in how to care for a person with a tracheostomy upon discharge ensured that *handing over the baton* was safe:

If someone has a tracheostomy… we provide training … on how to suction, any complications. For showering, cover the trachy with the trachy guard. How to do the dressings. That's with the supervision of a nurse. We're just observing and then the family members are hands on so they can get practice, and they can feel safe in managing the tracheotomy. (RN27, Line 339, p.16)

Structured training for professional carers

Nurses described the various types, formats, and time periods of professional carer training informed by the expertise of other clinical dance partners with a desired outcome of safety. A nurse participant described how training for carers was structured at her facility:

> *We'll do a full-day training [for carers]… We have a carer training booklet that we provide… [it has] all the information… I don't think anyone should be looking after someone that they have no idea on how to care for. It's for the carer's safety and the patient's safety. (RN11, Line 79, p.4)*

The training was staged and integrated with home visits, as another nurse participant explained:

> *[After] a theoretical session… a practical session [and] two or three weeks of buddy shifts, then… like weekend leave… with carers. Then extended leave for four days, five days. And the family is happy and then we select an official discharge date, and discharge the patient*. *(RN26, Line 255,* p. 11)

Training for carers also included learning strategies for safe medication and the maintenance of physiological integrity. This training was also informed by many allied health dance partners and was integral to *handing over the baton.* As RN11 explained:

> *Some people could be nil by mouth, so we tell them that medication needs to be crushed, it has to go through the PEG. And some people do take it orally, but then can't take a whole tablet, so we have to cut them in half… And depending on the recommendations from the speech [therapists] what [level*

of thickened] fluid to [use]… Pressure area care, especially for those ones who are minimally conscious... So [during carer training] we definitely highlight [the need for] … frequent turning and… skin checks [assessment]. (RN11, Line 79, p.4)

4.5.3.3.4 Discharge planning structures

Nurses were crucial dance partners because they contributed to informing various facets of the patient's care needs. When nurses knew the person well, they were better positioned to provide an expert opinion to inform *handing over the bato*n.

Meetings were held with many decision-making actors to plan for discharge and the number of dance partners engaged depended upon the person's functional status. Allied health were the dominant profession in this dance. RN27 explained:

> *A lot of it [discharge planning] is done by myself [RN role title] and [another role title]… we have an input about nursing care needs, and what consumables they need... Allied health does most of the assessments and the paperwork… [nurses do] the care needs assessment. We have a functional independent measure that we use to determine the burden of care in every aspect, so social, memory, continence, mobility, feeding, planning and things like that. And there are components that are nursing-related which would be all the nursing stuff, toileting, showering, feeding… how much assistance do they need with that. And then we would provide feedback to the MDT and then they will ask us to fill in the part that's relevant to us in the care needs assessment, whether it's for NDIS or for lifetime care for the insurance, for the*

> *provider… that's how they determine how much funding can be provided for the patient. (RN27, Line 335, p.15)*

One family participant explained their experience of the multi-service input to support safe discharge. Liaising with many decision-making actors took a long time and was, at times, daunting for families. However, family participants appeared to appreciate the structure and length of the planning phase and their involvement in it, to support discharge readiness. F7 explained:

> *We had a meeting with the medical team and the doctors… looking at potential discharge planning. Jake [pseudonym] will likely need 24-hour care, so we've already started looking at providers for that through iCare and also providing the OTs with floor plans of the house so they can start preparing for home modifications that may be required. I know some people would be daunted by that, but I know how long things take to get organised and it's not through anyone's fault, it's just because you're relying on external people. I actually feel glad that the ball has already started rolling with that. (F7, Line 412, p.18)*

Sometimes the role reversal could feel overwhelming when family members took over life administration tasks that the patient could not accomplish for themselves due to the impacts of TBI. There was little opportunity to avoid *handing over the baton* in this way to the family, given the person's impending discharge. This family participant explained:

> *It's me [patient's daughter] and my sister at the moment. My mum doesn't really know about all… the paperwork and the bills and the banks… I was holding his phone as well, so I've taken on that role, just navigating all the*

phone calls, and his friends and his work and just all the house stuff, all the CTP stuff, all the iCare stuff, it's all going through me. So I feel like I've taken on the parent role. (F5, Line 390, p.17)

Nurses and medical and allied health professionals collaborated with many external decision-making actors to set up arrangements for funded care packages. RN7 outlined this collaboration:

So we use… NDIS and iCare; iCare also funds therapy… We also use ComPacks… Community Packages - which is a six-week package, [where] people will come and just help them do shopping, or… housework… For therapy, a community brain injury rehabilitation team will pick it. So that's where that fits… We just liaise and fill out the forms. And again, this thing starts months before discharge, for some patients. (RN7, Line 33, p.2)

4.5.3.4 Celebrating handing over the baton

Accomplishing total handover of the baton marked a major achievement for the person with TBI and all the decision-making actors. At one facility, the decision-making actors performed an informal celebratory ritual to mark the discharge of patients from rehabilitation. This ritual, which brought joy to patients, significant others and staff, involved the person's supporters lining up and cheering on people who had reached the point of discharge. One nurse participant described this ritual:

We do a big [ritual cerebration]… we have a big trail and we have all the allied health line up and we clap them [patients] out. We really engage in that… we just have a good laugh with them [patient and family members] and we talk about their experience on the ward… We kind of reflect on things that

happened. It's really good… I look forward to those times. And we reflect and 'do you remember when I first started and this is where you were?... so I think it is really important. So… we cheer them. Yeah. We celebrate! (RN23, Line 563, p.25)

4.5.4 Contextual factors that influence *Dancing with Agency*

4.5.4.1 Introduction: Definition of contextual factors

Blumer (1962) notes that individual agency can persist during social interactions, despite structural factors. However, in Grounded Theory studies, contextual factors are conditions that explain why a social process operates in a particular way (Charmaz, 2025; Strauss & Corbin, 2008) and can incorporate structural elements such as workforce issues, power, hierarchy and resources. In this section, I explore some key contextual factors that influenced the basic social process of *Dancing with Agency*.

4.5.4.2 Rigid and ineffective team practices

4.5.4.2.1 Rigidity of the decision-making actors

The importance of *flexibility of the dance steps* has been highlighted throughout the process of nurses' *Dancing with Agency*. However, nurses frequently experienced rigidity among decision-making actors that impeded the accomplishment of shared rehabilitation goals. Diverse rules and protocols constrained the nurses' choices about their nursing practice. Nurses were faced with multiple formalities that they had to work within or conform to. These formalities comprised guidelines, specifications, directives, policies, rules, regulations, and local practices and traditions that shaped how patient care was delivered.

Organisations and their guiding documents were important acting units in rehabilitation care. When encountering organisational structures, and decision-making actors of higher authority, nurses prioritised their own scope of practice, the authority of policies, and their position in the clinical or organisational hierarchy, and aimed to work within this confined space of limited agency. The nurses' acceptance of organisational rigidity was further supported when the position of these *perceived higher authorities* made clinical and moral sense or framed decisions in the context of risk reduction. Adding to this context, the health system is hierarchical and aspects of rehabilitation administered by nurses were commonly prescribed by other decision-making actors.

Nurse agency was deferred to decision-making actors from other disciplines when aspects of patient care relied on equipment or devices that only allied health and medical staff had expert technical knowledge about, or the authority to prescribe. Sometimes, nurses described their uncomfortable compliance with allied health guidelines when there was a tension between safety and inclusiveness. For example, at one site, family members' involvement in patient care was curtailed by allied health guidelines. Nurses were required to negotiate dynamic guideline changes and communicating these, along with their rationale, to family members who wanted to participate in their loved one's care. This rigidity, rationalised as safety, was described by a nurse participant:

> *… there are very strict guidelines that our allied health have put in place in regard to involving families, and families are only allowed to be involved in transfers or mobilising patients if they've been trained and assessed by both the OT [Occupational Therapists] and the physiotherapists. So even if the*

> *family are willing to, if they haven't been trained, we [nurses] let them know that unfortunately that has to be… cleared by the medical team and the allied health team. (EN29, Line 92, p.4).*

In navigating these rigid guidelines, nurses often struggled to validate, critique, update, and implement, patient-specific rehabilitation guidelines produced by allied health team members in ways that responded to dynamic patient conditions and the promotion of personhood. These guidelines were reported to be very influential at one research site and had to be strictly adhered to. Nurses described feeling that allied health prescriptions hindered their provision of personalised care. The rigidity in these prescribed allied health guidelines impeded the ability of nurses to utilise their agency in ways that supported agile clinical judgement, such as when a person's condition fluctuated or their capacity to do something changed. Nurses described several instances when their clinical judgement was *out-of-step* with allied health prescriptions and what was practically best suited for the person's care needs. A nurse participant described the impact of this rigidity on their clinical judgement when aiming to promote personhood:

> *I think this is the one ward where I've seen that therapists run the show … What is challenging is when we hand over something that doesn't get taken seriously or just because one… senior person hasn't seen it but five other nursing staff have seen it, sometimes things don't get upgraded as fast as we want… Because we are there twenty-four seven, we see patients not follow certain guidelines or we see them actually being able to do more than what the guidelines say. We want to promote that, but then we also have to get everything approved, which is tough.… So we know what [patients] want, we*

know their needs, but then we get in trouble if we do it ourselves… not being able to practice with our clinical judgment... It's a very controlled environment here, very strict guidelines… that also affects personhood… If [patients] communicate something to us and then, we're like, 'We have to wait for them to review it,' the patient's… get a bit upset… It just affects everything … it's very, very strict and guidelines-focused, and a lot of the time our clinical judgment is overruled. (RN33, Line 289, p.13)

A nurse participant from a more flexible unit explained their confidence in questioning an approach that was no longer fit for purpose and in initiating a conversation about the need to change the plan of care. When asked about guidelines in their unit, they explained:

I think [guidelines] create more restrictions, to be honest… just taking the example of splints, your patient's clearly uncomfortable, they're not sleeping – we know sleep and hygiene are important issues. They're in pain, they're causing distress, and they've said that they have to be on for four hours. So, you've given pain relief, your patient's still in distress. What do you do? You take it off and ask them (physiotherapist] to revise the timing. So… it has to be collaborative. (RN10, Line 293, p.13)

The *Dance with Agency* was difficult when nursing advice was ignored despite nursing knowledge and experience exceeding that of an allied health team member. Here, allied health members were leading the interaction, the nurse was resisting the action, and shared goals of rehabilitation were compromised. This was seen as critical when patient safety or patient personhood was at stake. RN27 explained:

At the moment, we have very junior allied team, like let's say the occupational therapists. They're not very experienced in this kind of specialised unit… And because we've been here, some of us, for a very long time… sometimes there is friction because things are not getting done by the junior occupational therapists and we know that it can be done. And it becomes very frustrating for the nursing staff when the patient has to lay in bed for five days because they don't have a wheelchair because it hasn't been set up for them. Or when they do an assessment and they say, 'This patient doesn't need a pin-activated seatbelt or a seatbelt to keep them positioned in their chair, they will be fine'. And I keep saying 'no, they need it for safety' and then the next minute you know the patient's had a fall and we have to do the post-fall management and brain CT … the patient could have had a serious injury. So, there can be friction and conflict because everyone's opinion should be taken, especially from experienced people. (RN27, Line 166, p.8)

EN24 lamented the rigid guidelines that reduced the nurses' abilities to prioritise human connection over clinical tasks and their potentially negative implications for the promotion of patient personhood:

Following these guidelines limits our ability and our interactions with the patient. We have to do certain things for them and… for other patients… that take priority over communication. So there will be days where I wouldn't be able to talk to John or Peter or Tracey or Ryan [patient pseudonyms], because I'll have to follow the guidelines, I'll have to make sure that these things are done, because that's what the guidelines are. (EN24, Line 267, p.13)

There were perceived consequences for nurses not following allied health guidelines. A nurse participant explained this unequal power relationship with allied health staff, and the level of intimidation encountered by nurses who did concede to this power:

> *There are consequences… if allied health see you as doing something that's not in the guidelines. For example, I'm using the wrong shower chair. They don't come to us and tell us. They go to the… manager, and tell them that we are not following the guidelines. (RN35, Line 324, p.15)*

The inflexibility of guideline-directed care led some nurses to activate their own critical thinking to 'skirt' rigid allied health guidelines so they could provide care that promoted personhood. Some nurses privileged patient preferences when allied health prescriptions seemed contradictory to a patient's best interests and constructions of personhood. EN29 explained: "so, it's almost like we have to secretly do what our patients like to do, and we just let them because what else can you give your patients?" (EN29, Line 294, p.13)

Nurses often used informal and creative approaches to *bend the rules* for some interventions, while sticking tightly to rigid allied health prescriptions for aspects that were critical for safe patient care delivery. RN35 explained how they adjusted their responses to the rigid guidelines to preserve personhood:

> *For example, I'm showering a patient and OT have said, 'Wash the patient's face for the patient.' But I have a young girl that I'm showering who's my age and she has a specific face wash and, yeah, she struggles with her*

coordination but for me, instead of doing it for her, I hold under her hand… with my palm, put [the cleanser] on there, and then I help her do it. Which isn't [in the] guide, which I would get told off for… They would say, 'Don't do that.' But she has a specific way she wants to do it so I help her do it … I don't really mess with the transfers because that's quite important but with some things, yes. (RN35, Line 328, p.14)

When communication and teamwork was not well implemented, differences in practice between dance partners became obvious to patients and families. These differences in practice could be perceived as nurse incompetence. A nurse participant described how nurses might use strategies for patient transfers that diverged from prescribed care. These strategies were informed by the nurse's clinical judgement in the context of the patient's and their own physical capacities:

Sometimes the patients do very well with the transfers with the physio, but when they have to do it with the nursing staff they don't do well. They could be tired. Maybe they've had these transfers all day and then when they have to do it with afternoon-shift nurses, well some of the nurses are not strong enough, they're shorter, or little, petite, and it doesn't work for them... They find it very difficult so they use two staff or they might need to use a lifter. That can cause conflict with the carer and the patient… because it makes it look like the nurses are not following the physio guidelines, like the nurses are letting the patients go backwards instead of improving, but actually that's not the case. (RN27*, Line 218, p.10)*

4.5.4.2.2 Ineffective communication and teamwork

In working with multiple and demanding decision-making actors, nurses found that effective care that addressed personhood could be achieved when there were effective processes for communication and teamwork. Several nurse participants spoke to the importance of communication and collaboration with allied health decision-making actors in not only reducing the complexity of the competing agencies, but also in facilitating the direction and effectiveness of their nursing practice.

The need for effective communication between nurses and allied health was amplified by the separation of disciplinary space and time. RN14 described how patient care time was fragmented between time for nursing care, and time for allied health care. The importance of communication arose when people working in particular specialties saw the patient doing different things, or the same things under different circumstances, and perhaps through their different professional lens. While this might seem to increase the complexity within professional relationships the complexity was reduced when multiple two-way communication strategies were used:

> *We [nurses) make sure we have a lot of communication with the Allied Health team, because... we are interacting personally with the patient... quite frequently, but the Allied Health team have also their time away from us. They take the patient to the gym... or they take the patient to outings. They go to different areas. So, we have to both be able to communicate to each other any changes, any needs for the patient … we have a whiteboard for our patients right above their bed, and that is labelled with dates and any*

changes. But if any changes do happen, they [allied health] always come to the nurse, and they let them know personally… there's a form of handover via documentation and verbal handover. So, we're always up to date. (RN14, Line 45, p.2).

Nurses acted as a pivotal source of information about what was going on within the person's rehabilitation world and worked in close proximity to family members. However, there was a perceived distance between other allied decision-making actors and family members. Family members were, in some ways, an extension of the patient as a person and they craved meaningful interactions with the TBI rehabilitation care team. However, family participants described frustration with the lack of regular interactive communication from the medical and allied health decision-making actors in TBI rehabilitation.

Family members considered that the 24-hour availability of nurses meant that they were better placed as sources of information than the medical and allied health decision-making actors who only joined *The Dance* intermittently. A family participant recognised the relative exclusion of nurses from team communication:

> *I just feel they need to talk to each other… doctors, speech pathologists, dietitians, they have to communicate more with the nurses… The doctor comes in and sees them for maybe 10 - 20 minutes a week. The nurses are spending a whole shift, five days maybe, with this patient. The nurses know much more… A dietitian is not even on this floor; she'll come in, 'Oh yes, I've read this on the notes.' She hasn't observed this person like a nurse has done… Like, [Tony(pseudonym)] was vomiting at one stage and it was*

> *because the feed was too heavy for him. The nurses were witnessing that every time. The dietitian would come and he didn't vomit in front of them: 'Oh no, he's fine on this feed.' (*F12*,* Line 360, p.16)

This issue of inadequacy in handover indicated that nurses and allied health decision-making actors were, at times, not aligned. Handover was a key time-point point in the communication strategy. In one instance, transfer of the person from another facility to the rehabilitation unit was identified by a family member as a hazardous time that needed careful attention to team handover: "[the pressure injury] popped up on the second day. Initially… I don't think she [daughter] had an air mattress… there's definitely something missing when handover happens" (F10, Line 222, p. 10).

Another family member explained their frustration with change in a device set-up that was not handed over or understood by the nursing staff:

> *[Nurses should] check when they change shifts, read the details, because [patients conditions and care] change. You might have looked after him last week, you've been off for a couple of days, you come back, it's a little bit different. I've had trouble with the [chair] headrest… We spent four hours with a tech guy stripping the chair, putting it to get a better headrest. He leaves, the nurses come in to put him to bed, they just undone the thing and bent the headrest out of the way. We'd spent four hours [fixing the head rest with the Physio]. I went off my head! (F7, Line 305, p.14).*

Communication also occurred through the structure of the multi-disciplinary team meeting. These meetings seemed to be influenced by power and hierarchy; actors were often *out-of-step* with each other, inviting the input of some and excluding others which hindered shared goals. A nurse participant explained:

> *I think what's difficult is maintaining effective communication in the framework. Each section of the MDT has their own part to play, their own mini agenda within that journey to achieving that [patient's] goal and while best efforts are made to work in unison, that concept doesn't always work… Nursing tends to be on the outside. It would be easier if nurses were a bit more proactive in going to the MDT [so that] … the plan gets adjusted. At times there is an 'us and them' kind of thing… It's allied health versus nursing and never the twain shall meet and it just leads to complaining… and I don't see that as constructive. It doesn't benefit the patients. (EN9, Line 243, p.10)*

Another nurse participant concurred:

> *In previous wards I've worked in… everyone works together. Nurses and allied health talk 24/7 about what we need to do. Here… it's separate… you've got nurses and you've got allied health, which I think is… definitely something that needs to be improved here... It can make it really difficult for nursing staff to … care for the patient. (RN35, Line 214, p.10)*

A nurse from a unit with more flexible guidelines also described an interdisciplinary divide: "that's what sometimes gets nurses upset… I wish there wasn't such a divide. It's more the allied health than the nurses because the nurses try to do everything" (EN13, Line 235, p.11). This poor relationship management between nursing and

allied health staff, and the unnecessary rigidity, led to one nurse participant questioning their own clinical judgement and value to the team: “I feel like my suggestions aren’t appreciated sometimes. Or maybe my suggestions are wrong, I don’t know” (RN36, Line 268, p.12).

When allied health failed to communicate key aspects of patient care to nurses, the complexity of managing multiple decision-making actors increased and high relationship tension arose. In one setting, more senior nursing decision-making actors were integral in intervening when high tension threatened teamwork. One nurse participant illustrated these tense situations between nurses and allied health as partner decision-making actors:

> *So, for us, the challenge is communication… allied health can implement care, but that doesn’t necessarily mean the nursing staff are going to agree with their perspective.… So… that's when we all come together and say, from a nursing point of view, what we think. At the moment we’ve got a really difficult patient to transfer. The equipment is wrong, it’s not good for the nurses, but the [allied health team have] already implemented it from their point of view. We’re asking them to come together then as a team, come and show us what you think we should be doing, and we will show you what we think is not right… So, [it requires] teamwork. (RN28, Line 113, p.5)*

4.5.4.3 Restrictive environment and practice

The three brain injury rehabilitation units involved in this study were designed as locked environments, and nurse and patient participants acknowledged the negative impact of these controls on a person’s sense of autonomy and wellbeing. While the

rationale for the locked environment was to promote patient safety, it presented as a form of power over the patient, and at times, all actors. Without nursing, family, or carer supervision, some people with cognitive impairment were at risk of falling, or of becoming disoriented and not finding their way back to the unit.

Nurse participants from every study site reported patients describing the design of the locked TBI care environment as prison-like. This mode of containment manifested a form of restraint. A nurse participant commented that “they [patients] tend to think that we’re a prison because everything’s locked up. Even the front door is locked so they can’t freely move about” (RN32, Line 551, p.24).

This restrictive environment impacted negatively on the person with TBI’s sense of autonomy, which is an important element of personhood, regardless of their cognitive capacity. Patient participant, P2 explained:

> *Not being able to go anywhere. You're basically stuck inside the walls… I can't… get out of bed and just walk from one place to another. They don't let you. You've got to go with a nurse in case you fall over. There's no going out and getting away from the place or catching up with friends. (P2, Line 138, p.8)*

A young female patient participant explained their fear of being locked in with patients with cognitive impairment, particularly when they felt unable to control who entered their personal space:

> *I feel really negative [about rehabilitation]. I asked the nurse three times if I can change the room, because I’m scared... of the patients mainly, but I just*

don't like to be in the [locked] brain injury unit, seeing those people around. And they're not even conscious, and sometimes, they just can randomly walk by and look into the room. It freaks me out. (P8, Line312, p.15)

The use of physical restraints in TBI rehabilitation limited the *flexibility of the dance steps* for both clinicians and patients due to the power of organisational actors. The primary factors influencing the use of restraints were: clinical risks present for the particular patient that triggered fears for safety; limited organisational resources; and local unit practices. The legal and state policy framework, which is a scripted directive, promoted the principle of least restrictive practice because a person has rights to autonomy even in high-risk situations. This policy framework increased the tension in *The Dance* as nurses sought to balance the safety of all dance partners with this legal requirement. Under certain circumstances, the nurses were able to more easily rationalise the use of restraints and therefore contain their own moral injury. These circumstances included: when the clinical rationale for restrictions was explicit; when the level of restrictions (restraint or seclusion) was matched to the level of risk; when there was medical and psychiatric review of the restraint order; and when the family members were engaged in discussions about the rationale and plan for restraint use and cessation.

Nurses believed that there were risks of unsafe expression of patient agency because the cognitive impairment of some patients with TBI affected their judgement, insight, and impulsivity. While the person may be using their agency in ways that made sense to them, a nurse could perceive their behaviour as creating

unacceptable risks to the person themselves, to other patients, to families, and other staff. This perceived unsafe exertion of patient agency led to frequent use of restrictive practices and devices by nurses, consequently attenuating agency and personhood for patients. Nurses used restrictive practices for 'at-risk' patients when they prioritised physiological safety (*protecting the body of the person*) over personhood. A nurse participant explained this approach to *protecting the body of the person*:

> *So when it comes to restraints, we either use safety vests, or mittens and wrist restraints, and usually we apply them to patients* who … *are more impulsive...and to patients who are very high falls risk... We don't have enough staffing anyway to have one-on-one care for those patients so that's why we apply the restraints … mainly just to prevent falls… especially if we feel like we can't be there constantly to watch them closely. (EN29, Line 183, p.8)*

Opportunities for patients to enact their agency were reduced at times when the level of staffing was inadequate for *protecting the body of the person.* Nurses' inability to accommodate 24/7 patient observation was cited as another reason to limit patient agency through the use of restraints. Use of restraints reduced patient autonomy, compromised nursing care, and threatened personhood. In some situations, nurses could maintain personhood and address safety concerns by engaging a 'special': a worker who would sit continuously with the 'at-risk' person. Use of a 'special' reduced the use of restrictive practices. At other times, family members were invited to supervise elements of patient safety. When they were available, family members

were key decision-making actors. A nurse participant explained that this strategy promoted personhood but did not always prevent unintended events:

> *One-to-one supervision.. only one staff looking after that one patient… he'll be there to protect him from pulling all these things out and causing more trauma… We do [involve family]. If the patient is sitting in the chair… we don't put mittens [on then]. We tell the wife or the family to just keep an eye on them, but it still happens. Either the tube comes out, or he does something… If family is not there then of course we need one-to-one special for that combative patient. (RN39, Line 60, p.3)*

In some situations, nurses could not draw on the use of 'specials' or family members. At one site, due to limited resources, nurses resorted to placing patients at risk of falls in wheelchairs and positioning them in proximity to the nurses' station.
This strategy removed patients from the comfort of their beds or rooms to a public space to be looked at, rather than cared for, thereby diminishing their personhood. RN34 explained:

> *We assess if the patient has any behavioural issues. If they're not walking or they're agitated they might be a falls risk, so… Sometimes we're short of staff, that's why we just sit the patients at the front… At least there's one nurse in the nurses' station and they can keep an eye on them. (RN34, Line 41, p.2)*

Personhood was also threatened when seatbelts were commonly used as a restraint across study sites. Allied health were the decision-making actors who prescribed this commonly used restrictive equipment to assist in maintaining physical patent safety. In this form of *Dancing with Agency* between nurses and allied health, these

professional dance partners were usually *in-step* with each other in prioritising patient safety. However, a field note illustrated a patient's response to this type of restraint:

> *One patient is observed seated in the wheelchair near the nursing station and is trying to unlock the seatbelt. They continue to perform this routine several times over the period of field observation. Due to the impacts of TBI, the patient is unable to verbalise what they need to be done and why. It could be they were feeling uncomfortable as a result of being seated for a long period of time in one position in a semi-inclined wheelchair. (Field note, FN168)*

While patients initially resisted the use of restraints, sometimes nurses would encourage the patient's acceptance by reframing the idea of restraints. This provision of a rationale attempted to treat the person like a rational being by speaking in a way that normalised the intervention as something all people use in particular circumstances. While a joint action was achieved, in that the person 'accepted' the seatbelt use, it was not clear whether the person complied willingly or under coercion. This strategy was reported by nurse participant:

> *A lot of them [patients] don't like it [use of seatbelts] but we just say it's like sitting in a car, you have to have it on for your safety. So that usually gets you around it. They [patients] accept it more that way. (EN13, Line 38, p.2)*

The use of restraints as a strategy for protecting the body of the person could be distressing for patients. Nurses perceived a catch-22 situation in these circumstances: a restraint was seen as necessary for safety reasons, but it also

diminished and denied patient agency, autonomy, and self-determination (and as a consequence, personhood). A nurse participant explained this predicament:

> *…there's a lot of laws against physical restraints… a lot of guidelines and protocols that you have to follow… So, at first I was quite confronted… and then I think I had to come to terms with weighing up whether or not your patient has a fall, or your patient pulls out their tracheostomy or their NG tube… which is obviously also quite dangerous... Because of the amount of staffing that we have… we can't be everywhere… we have to have a safety measure just to prevent things from happening. And especially when you see patients with cranioplasties and they're incredibly impulsive, trying to get out of bed, very high falls risk. The idea of them falling out of bed… that made me think okay, that makes sense as to why we do put restraints on, … we're preventing something worse from happening. (EN29, Line 215, p.10)*

The same participant noted patients' frequent distress in response to the use of this form of restraint and suggested that patients felt a moral injury. Nurses had to weigh up the damage to personhood versus damage to the physical body:

> *But of course they [patients] verbalise! No one wants to be held down and tied down to the bed, and a lot of patients struggle against it. Patients find ways to get out of it, patients have said that they don't want to be tied down. And that's the hard part when you're trying to explain to them… they can't comprehend yet why they've got it on, and trying to explain why they need it, that's hard.* (EN29, Line 247, p.11)

At another site, a patient who had undergone a post-TBI craniectomy felt distressed by, and angry about, the nurses' application of restraints that restricted their agency and freedom of movement in the process of *protecting the body of the person*. The patient's personhood appeared to be attenuated when their numerous assurances that they would exert agency in a safe manner were ignored by nurses and associated *dance partners*, creating a high degree of tension in these social encounters. The patient conveyed these experiences:

> *… they [nurses] belt me in… every second day, they look in, 'Oh, he's unbuckled, let's buckle him again.'… They are just dumb… but I've been here 10 months, not a single time I fell off the chair or I fall on the floor or I slide through. Not a single time, so there is no excuse to close this shit all the time. There is not a single excuse. Okay, [If] I … did, I fall… you saw me on the floor. You are right, it's happened, tie me up. But I never fell, never, never.… These people [nurses], they don't get it. It's unnerving because I'm not even parking on a hill that I'm going to take off and run down. It's flat land. I'm not going to roll down but no, they have to come and fuckin close this belt all the time… At the end of the day, they want to come in, do their job and that's it, have no headache, not get in trouble. They're painful, painful people. It's painful. You can't move. (P10, Line 426, p.21)*

Tensions also arose in encounters between nurses and families when restraints were used for patients without the family members' knowledge. While the medical team were responsible for having a discussion with family members prior to the use of restraints, this prerequisite was not always met. For nurses, the *Dance with Agency*

involved addressing the tense scenario with family members and explaining the rationale for restraints use. A nurse participant explained:

> *…some families will ask, 'Oh, why does he have restraints on?' And then we thought that the doctors had already handed over, but they didn't get a chance to… and then we have to tell them, 'Look, he [the patient] has been very restless and agitated, he's hitting us, he's picking at his poo and putting it in his mouth…'. Sometimes they're understanding, sometimes they're not, so it depends on family. (RN36, Line 122, p.6)*

Nurses were aware that restrictive practices impeded the promotion of personhood, and some opted for more person-centred strategies. Nurse participant (RN27) explained the alternative approach of engaging the multiple decision-making actors whose skills could be called upon to better protect the body of the person. By utilising input from other specialist nurse clinicians and members of allied health, and prioritising patient comfort and agency, this nurse was able to deliver care that appeared to promote and preserve personhood.

> *…you don't promote personhood by restraining someone. We use our ward orderlies to sit with a patient and converse with them, try to distract them by engaging them in different activities rather than having them restrained. For example, we've had one lady that's come to us with an NG [nasogastric tube] that she's pulled out multiple times … and she's had both her hands restrained. But what we did down here is we left her unrestrained and she didn't pull it out…. I think the reason she pulled it out is because that was making her more frustrated and more agitated and irritable... both of her hands were tied and she was just trying to scratch her nose … it was itchy,*

because she's had a nasogastric tube. But we've had someone just sit there and guide her: 'That's okay to scratch but don't pull it out.' I requested for the ICU people to come and put a bridle for the NG, which is like an anchor … And… we asked a speech therapist to do an urgent feeding assessment because it hadn't been done in the acute ward. And we felt that she could eat... None of us want the patient restrained… the Speech was onboard and fed her and she did very well. We made progress with her... In five days, the tube was out and she was on meals. (RN27, Line 108, p.5)

Another nurse participant explained the impact of restraint use on personhood and the tension created by the competing priorities of safety versus personhood. Like the participant quoted above, RN1 found ways to enact 'least restrictive practice':

If someone's at risk of injuring themselves, well then personhood takes a back seat. But in saying that, it's the way you can introduce the restrictive practice that brings in personhood. So for example, a guy that I was helping this morning, he used to pull at his PEG to pull it out, so we … we didn't restrain him. We used an Abdo-binder to cover his PEG… where it's the least restraint possible [this] … supports personhood, because you're not stopping … them from doing what they want to do, you're just mitigating the risk …, because patient safety comes first. (RN1, Line 231, p.10)

Sometimes people were restrained through seclusion. At one site, patients with behaviours that others found challenging were confined in locked rooms. These rooms were accessible using a swipe card. While this locked space was larger than a typical room and had outdoor access, it was designed to isolate the person from

other patients. The monitoring and maintaining of physiological integrity and physical safety were undertaken strategically, with at least two nurses attending to the person's care needs at any time. This strategy promoted staff safety in the event of patients exercising their agency in unsafe ways. The field notes below exemplified how nurses approached patient care in the context of perceived challenging behaviours. They took a cautious approach, bundled care tasks, and remained conscious of safe exits in case of a violent encounter:

- **Approaching the person cautiously:**
  Field note (FN250): A patient with challenging behaviour is approached by two nurses. Caution is exercised when approaching the patient. The patient is assisted with feeding. The room is configured uniquely and includes a bedroom, sitting room, and an outdoor space.
- **Approaching in pairs, offering constant assurance, bunding care tasks:**
  Field note (FN400): Two nurses assist the patient with ADLs, and constant reassurance is given. While one nurse assists the patient with feeding for breakfast, two other nurses perform other tasks e.g. bed making and tidying up of the room. Nurses appear to accomplish multiple tasks in one interactive session with the patient e.g. feeding, bed making, medication and monitoring for vital signs
- **Prioritising situational awareness:**
  Field note (FN310): For patients in a locked room, nursing staff approach with precautions. Nurses are observed to position themselves closer or near the exit door.

4.5.4.4 Nurses' values, beliefs and experience

Nurses' values, beliefs, and levels of experience were closely associated with their ability, or commitment, to provide care that promoted or preserved personhood. This required the nurses to approach their practice with a capacity, a presence, and a passion, to get the person to the best possible endpoint in a way that addressed their personhood. A nurse participant explained:

> *I think you find something that you know is important to you and you try and relate it to the patient… for me, it's important for me to have a shower in the morning and brush my hair and just feel nicer. I believe that all patients should also feel like that… a lot of nurses… engage a lot more with patients and there are some nurses who don't… so – it can be so easy to just go in… and then do what needs to be done without actually conversing with the patient or trying to relate or make them feel like they're a person instead of a patient. Yes, I do think [individual nurse] characteristics [matter]. (RN35, Line 91, p.4)*

When asked, another nurse participant explained the close link between the nurses' values and beliefs and their intention to accommodate the diverse backgrounds and preferences of their patients:

> *There are cultural differences… gender difference… So we as nurses, we should know that so we can help with… promoting the whole person…. So as nurses we are open to advice or… opinion from others…. So I don't know or … understand… I will ask someone to help me… [get] clarification… For the different cultures… Let's say… some they don't eat pork … We have to liaise*

and tell the kitchen… because of their religion… so we have to …be an advocate for them. (RN37, Line 174, p.8)

Having long-term experience working in the TBI rehabilitation unit equipped nurses with a range of strategies and enabled them to mentor less experienced staff. Experience was valuable when caring for patients who were behaving in ways that others considered challenging. An experienced nurse participant exemplified this contextual factor:

> *Being old and long time here I learn more [about how] to deal with difficult patient[s] than probably a young one… I can be a good example on how to deal with difficult patients… and try to show … how to deal with it. I am more than happy to help the new nurses… because they don't have that much of experience and it's hard to deal with this kind of behaviours … with the brain injury. (RN37, Line 192, p. 8)*

A nurse's level of experience influenced how they were able to provide care that promoted patient personhood, with person-centred skills developing over time. RN4 explained:

> *… more inexperienced nurses, tend to focus more on tasks… They don't necessarily remember to think about promoting the independence of the person by allowing the extra time, by giving them short, simple questions that they maybe can answer that can influence the direction that the care is going. They may not have the experience with coaching… [or] getting that person to actively engage in stretching their capacity in care. So, … a more experienced*

*nurse would hopefully have more of those skills in their toolbox. (*RN4*, Line 137, p.6)*

Nurses who had experience working with people living with TBI were better positioned to navigate the care of people with behaviours that others found challenging. A nurse participant explored this aspect:

> E*xperience helps in that journey because sometimes the seniors are kind of [familiar with] the strategies they have to de-escalate the patient. Let's say [better manage challenging] behaviour [in] patients … juniors, because they haven't had that experience, it kind of shocks them… But having that experience, you use that to be able to provide a person- centred care. (RN28, Line 67, p. 3)*

4.5.4.5 Nurse staffing profile and skill mix

The nursing staff profile within the TBI rehabilitation units influenced the nurses' *Dance with Agency*. Family participants frequently noted that there were too few nurses. In some cases, no nursing staff directed their agency to solve issues that supported *body protection* for the patient, and the task remained neglected, causing patient and family distress and threatening dignity and personhood. For example, a family member reported that the "nurses are probably understaffed. There was a couple of times here he [the patient] was probably sitting in his own faeces for about three or four hours until they had a chance to change him" (F4, Line 66, p.3).

When the unit was understaffed, a nurse's *Dance with Agency* sometimes meant transferring some of their duty of care for the patient to the family members. A family member explained:

> *If they're not under pressure from low staff, then they can do their job properly. [At] times I've come in, he's wet, the food [NGT Feeds] is empty, and not even hooked up. So, how long's he been wet for? Who knows? … To be honest, because I come in every day, they know I'm coming. So, they know they can concentrate on someone else, because Dad will be here. (F3, Line 305, p.14).*

Nursing profile and skill mix influenced how nurses were able to protect the body of the person, and how the burden of care was experienced. The nursing profile and skill mix did not always allow the appropriate level of care, nor equitable nursing staff allocation.

4.5.4.6 Nurses feeling mentally and physically drained

Providing care for people with traumatic brain injury was emotionally and physically exhausting for nurses. These effects were exacerbated when nurses were not recognised by patients for their contribution, albeit this lack of recognition could have been caused by patients' altered cognition and behaviours. RN27 described the experience:

> *Burnout… compassion fatigue… sometimes it doesn't matter what you do, it's not enough, and it's not the nurse's fault. It's just the tragedy for the patient and that's how they're feeling. And it's not their intention to make the nurses feel like that, but that's how it plays out. That can really burn the nursing staff*

and make them feel … undervalued or think 'what's the point?' You've worked so hard the whole shift and then it didn't feel rewarding because the patient wasn't happy … or their family member wasn't happy in the end. Because they're grieving and they're going through their own problems, they can't see the nursing side of it, how much nursing is doing. They can't separate it. And the nurses also are always there. They're the ones that get blamed sometimes for small things… we get targeted sometimes and that can be very hard on the nursing staff. Very mentally draining. (RN27, Line 509, p. 23)

Another nurse participant added that:

> *For us, our challenge could be both psychological and physical… we've had some people physically hurt, or the words that they can use can be a physiological trauma to some nurses. Eventually, hearing these nasty words about you, some people don't take it well. But counselling is there… we are all different in the way we cope. (RN28, Line 213, p.9)*

Support was available for nurses who experienced emotional exhaustion or became overwhelmed as a result of caring for people in TBI rehabilitative care. Individual and group employee assistance, and specialist advice to manage behaviours that others find challenging were in place to support nurses. RN27 described these services:

> *We have staff wellbeing and support service that's willing to come and talk to the staff, individually and in group… sessions. But, also, when we have our behaviour-support meetings with a psychologist, which is once a week, to talk about the patients and their behaviours, that's also an opportunity for the staff to debrief about how they feel. (RN27, Line 530, p.14)*

4.6 Chapter summary

This chapter has presented this study's findings. The following chapter will discuss theory of *Dancing with Agency* in relation to global literature, and reflect on the study as a whole.

5 CHAPTER FIVE: Discussion

5.1 Introduction

This chapter presents a discussion of the key findings that support the substantive theory of *Dancing with Agency in TBI rehabilitation care.* This chapter situates this Grounded Theory in relation to pertinent theoretical works and extant literature, and demonstrates how the study findings extend or introduce novel theoretical understandings. The study strengths and limitations are acknowledged and recommendations for practice, policy, education, and further research are presented. A conclusion then synthesises the key elements of significance.

The aim of this study was to develop a Grounded Theory that explored the social processes that promote and preserve personhood in TBI nursing care in inpatient rehabilitation. The theory of *Dancing with Agency* addresses this aim because it explains how rehabilitation nurses navigate interactions with multiple demanding decision-making actors, and conveys how these social processes are influenced by varying levels of flexibility and concordance between dance partners. *Dancing with Agency* seems to operate on a micro-level in individual interactions, framed by institutional and interdisciplinary norms and power structures. The type of social processes required, and whose agency is privileged, depend on whether the nurse is in a mode of *protecting the body of the person*, *engaging the patient as a person*, or *handing over the baton*. A significant theoretical contribution is the focus on agency, which is inherent in all people, but constrained where power structures limit people's freedom to exercise their agency.

5.2 Discussion of key findings

5.2.1 Multiple and demanding decision-making actors as the main concern

Rehabilitation for neurological conditions requires a “package of interventions” (WHO,2024) and it is delivered by “a large set of medical and therapeutic services” (Gao et al., 2021, p.466). This description provides context for the finding that the main concern of rehabilitation nurses was the multiple and demanding decision-making actors with whom they must engage when providing TBI care that promoted and preserved personhood. In constructing care that moved the person with TBI towards functional improvements, some nurses’ practices were influenced by their perceived position within a hierarchical clinical structure. The number of dance partners, the flexibility of the dance steps, and the concordance between dance partners were all shaped by this hierarchy and the nurses’ perceived agency when navigating it. Nurse participants also sought to engage with patients as decision makers while balancing the person’s autonomy and safety. They interacted with family members as decision makers and advocated for the person’s clinical priorities, while acknowledging the family’s investment in the patient’s personhood.

In exerting their agency and clinical judgement during their interactions with clinicians, many nurses seemed to struggle with their role and autonomy in the larger team structure. Another constructivist Grounded Theory study explores nurse role negotiation within a multiprofessional team. The authors describe a process of creating place, as individuals progress from “occupying workspaces” to “defining workplaces” that incorporate their own values, beliefs and expectations (Hewitt et al. 2024, p.1918). This redefinition requires the nurses to navigate pre-existing

organisational practices that presented boundaries to their practice (Hewitt et al., 2024) and can constrain their capacity to prioritise personhood. Similar to Hewitt et al. (2024), my interview data revealed the difficulty nurses had in finding meaningful influence in the multidisciplinary team model within which TBI rehabilitation occurs. The extent of these difficulties varied across sites. It seemed that these constraints on autonomy limited not just the nurses' choices, they also limited the choices of the person with TBI and their family. Powerful organisational structures existed, such as allied health guidelines and multi-disciplinary team meetings, at which nurses passively received information to follow. This finding suggests that other disciplines may have seen the role of nursing role as carrying out other peoples' orders rather than recognising a separately defined role informed by disciplinary expertise, clinical judgement, and a nurse's inherent autonomy to make decisions in the person's best interest. This situation created potential safety and workflow issues and constrained the nurses' ability to offer care that promoted personhood, particularly after hours when other disciplines were not available for consultation.

There was a dichotomy between nurses' perceptions of rehabilitation as a 24-hour, 7-day-per week activity (Pryor & O'Connell, 2009) and the allied health team's business-hours model. A lack of therapy integration between nursing and allied health staff has been found in a review of several studies of inpatient rehabilitation nursing (Baker et al., 2019). The review suggests that nurses are seen as "providing carry-on therapy" (Baker et al., 2019, p.16) on behalf of therapists, rather than as unique contributors to therapy using their own disciplinary expertise. A truly collaborative multi-disciplinary team approach is necessary for rehabilitation care to address each person's needs, continuously support the person's rehabilitation goals,

and enact effective interventions that are tailored to promote personhood (Christophers et al., 2025). The findings of this study indicated that there were times when the team culture fell short of being truly collaborative in these ways.

5.2.2 Ineffective team practices influence protecting the body of the person and handing over the baton

The sheer weight of numbers of multi-disciplinary team members practising in inpatient TBI rehabilitation contributed to the main concern of nurses negotiating with multiple demanding decision-making actors. Perhaps, more than in any other clinical setting, rehabilitation nurses have to negotiate their agency to influence many care tasks that have traditionally been considered core nursing practice, or at least a shared responsibility (Pryor et al., 2009).

Care factors, such as personal hygiene, mobility, feeding, and behaviour support, are accomplished by nurses, though predominantly prescribed by allied health professionals, whose knowledge is privileged in TBI rehabilitation care (Digby et al., 2018). Evidence suggests that allied health professionals do not fully understand the scope of nurses' responsibilities in rehabilitation (Digby et al., 2018). This is not to undervalue the expertise that allied health professionals bring to promoting recovery from catastrophic injury. However, the lack of opportunity for nurses, who deliver the care, to have input into care planning and re-evaluation (Pryor & Buzio, 2010) means that they cannot respond in real-time to threats to personhood.

The effectiveness of collaboration with teams in *protecting the body of the person*, and *handing over the baton* is heavily influenced in this study by the contextual factor of rigid and ineffective team practices. Where health teams rely on rigid hierarchical

structures, it is difficult to shorten lines of communication, meaning response times are longer (Fernandopulle, 2021). The perceived division between nursing and allied health professionals, poor communication practices, and the limited availability of allied health staff outside of business hours, meant that, in some instances, nurses either had to make a clinical judgement call about a person's care (for which they could be disciplined), or repress their clinical judgement and follow orders. These choices seemed to frequently challenge nurse participants' professional identity.

Guideline directed care can reduce care variance, and improve quality of life and functional outcomes for people with TBI (Bragge et al., 2014; Lee et al., 2019). However, it was a well-supported and unexpected finding that patient-specific allied health guidelines had the power to constrain nurses' clinical judgement, and to undermine interactions and person-centred practices. This suggests that teamwork is hindered when power imbalances exist between nursing and allied health professionals in rehabilitation (Digby et al., 2018). Given the assumed power of these allied health guidelines, nurses had to engage in a complex Dance with Agency to provide care that was safe and promoted patient agency and personhood, and that aligned with their own clinical judgement in response to the dynamic status of the patient.

Some nurses engaged with guidelines passively ("we just follow the guidelines" or "we just do what they say"). Other nurses felt uncomfortable complying with guidelines that clashed with the promotion of personhood or with the nurses' own sense of what was best for the patient. Some nurses skirted around guidelines, which left them open to intimidation or disciplinary actions, while others had a

confidence in their own practice or affective systems that allowed them to challenge, critique, or update guidelines with the broader team. To some degree, the rigidity of allied health guidelines was site specific. One site provided nurses with considerably greater opportunities for collaboration and support in exercising their clinical judgement. These contextual variations indicate opportunities to enhance team effectiveness by improving local workplace cultures.

Other researchers recognise problematic multi-professional team relationships in rehabilitation (Digby et al., 2018; Pryor, 2008). These problems are attributed to segregation practices that divide the work of nursing and allied health, and to poor interprofessional collaboration (Pryor, 2008). Scholars contend that these factors lead to, and arise from, poor understanding of the disciplinary expertise that nursing brings to inpatient rehabilitation (Digby et al., 2018; Miller & Kontos, 2013; Pryor, 2008). While the role of nursing in inpatient rehabilitation often overlaps with that of members of other allied health disciplines, the contribution of nursing remains under-recognised (if it is recognised at all) (ARNA, 2023; Tanlaka et al., 2023; Pryor, 2008). Scholars observe that rehabilitation nursing contributions are invisible (Ehrlich et al., 2022; Kearney & Lever, 2010), not respected (Digby et al., 2018), underappreciated and undervalued (Christophers et al. 2025; Kearney & Lever, 2010; Adhikari et al., 2025), and taken for granted (Pellatt, 2003).

A systematic review of nurses' professional autonomy (Pursio et al., 2021) notes the crucial importance of nurse independence. While the constraints of scope, codes of practice, and regulations, are acknowledged, the freedom of a nurse to use their autonomy means they can make care decisions that fully utilise their values,

knowledge, and abilities. This autonomy requires that a nurse's authority be recognised by the institution and that there be a commitment to shared leadership (Pursio et al., 2021). Strict organisational rules and an autocratic style of management reduce nurses' control over their everyday practice (AllahBakhshian et al. 2017) and limit opportunities for professional growth (Pursio et al., 2021). Some nurse participants in this study appeared to have a limited influence over practice in their own unit, and even less influence in their wider organisation.

Part of the problem of rigid and ineffective team practices may be the shared understanding of what teamwork means in these rehabilitation settings. For example, when participants spoke of a multidisciplinary team structure, they were largely describing situations in which multiple professions delivered care and the existence of communication structures that defined the things people could and could not do. As an alternative construct, interdisciplinary teams are characterised by a more horizontal power structure and greater collaboration. Teams are more effective when they foster a culture of decision makers working closely toward addressing collectively-identified problems and attaining shared goals (Christophers et al., 2025). This imperative is supported by the ARNA Competency Element 4.6, which requires that the nurse "contributes to the person's rehabilitation through active participation in allied health and medical interventions, including collaborative assessment, planning, implementation and evaluation of interventions with the person, significant others and/or formal and informal carers and the rehabilitation team" (2023, p.19).

In considering how interprofessional teams might achieve care that promotes personhood, the Person-Centred Nursing Framework (McCance & McCormack, 2025) outlines how governance structures enable person-centred outcomes and healthful work cultures. This framework identifies the essential components of supportive organisational systems, effective staff relationships, power sharing, shared-decision-making, and the potential for innovation and risk-taking. For patients, these elements feed into good care experiences, greater involvement in their own care, and an enhanced sense of well-being (McCance & McCormack, 2025).

5.2.3 Protecting the body of the person and personhood

This study's findings show that nurses in TBI rehabilitation prioritise *protecting the body of the person*. This is a reasonable priority given the extent to which people requiring inpatient rehabilitation have potential disruptions to physical integrity and safety, and given that people who have lived through serious injury to the body, including TBI, are known to experience shifts in their sense of personhood and identity (Mac Conaill et al., 2025). Consequently, nurses constructed much of their rehabilitation care to maintain the person's physiological integrity and physical safety. These priorities are a concern in nursing practice generally, where nurses focus on protecting the person's life and, in avoiding errors, they protect their own professional and personal identity (Najafi Ghezeljeh et al., 2023).

In summary, in *protecting the body of the person,* nurses had varying levels of intent and success in promoting the personhood of the person in their social processes. They *Danced with the Agency* of other actors through strategies of accepting clock-

driven practice routines, and through varying levels of collaboration with the team, the family, and the person with TBI.

5.2.3.1 The impact of schedules and routines on personhood

Protecting the body of the person was largely sought by nurses and organisations through *clock-driven practice routines*. It appears that both nurses and patients accepted these routine processes as a pathway to the shared goals of body protection. Indeed, many patient participants found comfort and security in these routines, and this may have supported their personhood, given that humans find meaning and manage their well-being through the structuring of time (Zizberg et al., 2007). Clock-driven routines can have both positive and negative impacts for nurses. These impacts depend on whether the nurses perceived them as either meaningful (congruent with the nurses' goals), pragmatic (to daily work life), or obstructive (violating a patient's humanity) (Rytterström, 2011).

In a narrative review of rehabilitation nursing practice (Baker et al., 2019, p.9), these routines for protecting the body are recognised as a key element of "nurse-initiated care": nurses take responsibility for monitoring and managing people's acute and chronic health conditions and providing technical care to maintain the person's safety. Routines in nursing are valued as behavioural patterns that are strategically designed to organise the sequence and duration of care activities across space, time and interpersonal interactions (Zizberg et al., 2007). Routines may be conscious or subconscious, and they can incorporate both physical and social contexts. This structuring of routines may conserve both physical and cognitive resources (Zizberg

et al., 2007), which is important when delivering a complex, multidisciplinary service like inpatient rehabilitation.

The notion of clock-driven practices is often referred to conceptually as nursing's task-orientation (Suhonen et al., 2018). Organisational and professional leadership that promotes task orientation values efficiency, productivity, and time management, over relationship-building; the latter being an important basis for promoting personhood. While the routine tasks themselves may require critical thinking, this task focus is most common where patients have complex care needs, or among more junior nurses with developing clinical skills (Bourgault, 2023). A clock-driven approach to care has its basis within a biomedical individualism model, which tends to situate health and disease within an individual body. A clock-driven approach can make it more difficult for nursing care to transcend physical contexts to incorporate communal and spiritual considerations that form part of the person's lived world (Bayuo, 2025). For example, a nursing study exploring time cultures (Deery, 2008) describes a clash between the 'technical administrative rationality' that streamlined service delivery and helped nurses to 'control' and 'get through their work', and the 'nurturing rationality' founded on the creation of relational time.

Both nurse and patient participants in the study underpinning this thesis mentioned the importance of therapy schedules (timetables) in rehabilitation, to organise and communicate the plans for the day. The posting of rehabilitation schedules has been framed positively as a "cognitive technique" and a visual reminder of the strategies to achieve rehabilitation goals for people with TBI who experience difficulty with organisation and executive functioning (Oyesanya & Thomas, 2019). It was a finding

of this study, that the positive contribution of visual timetabling is lost when it is not communicated to patients.

In a critique of scheduled care activities, Simonds (in Deery 2008, p. 354) reflects on scheduling as “hurry-along, bureaucratic time”. When clinicians take this care approach on “bodies to make them stay on time and on course”, it also subjugates nurses’ bodies to be “‘on time’ for clients rather than ‘spending time’ with them” (p. 360). While scheduled therapy sessions are vital to achieving rehabilitation goals, when allied health therapists encourage maximum time for rehabilitation in the clinic, it can result in patients having less time and energy for other activities, including the development of self-care independence (Chang et al., 2013). This created an additional challenge for the rehabilitation nurse participants in this study who adapted their care accordingly.

The nurses’ prioritisation of bodily integrity and safety aligns with other TBI nursing studies. For example, the strategies described by this study’s participants (regular patient rounding, placing the person close to the nurses’ station, and using a constant observer) are echoed and justified in other research on the care of TBI patients who are more likely to have issues with gait, balance, and challenging behaviours (Oyesanya & Thomas, 2019). However, the automatic prioritisation of safety over other considerations has been challenged. For example, a qualitative study exploring the meaning of safety for consumers in mental health units (Cutler, 2021) finds that nurses approached patients as ‘risks to be managed’ because the construct of safety was defined as the avoidance of adverse events. Nurses choose to either work inflexibly under this paradigm of restriction and control, or to work in

recovery-orientated ways that actively pursue strategies to empower the person who is the patient (p. 91).

5.2.3.2 Collaborating with patients and families in body protection

Patient participants appeared to willingly accept nursing's practice routines and body protection strategies, particularly when comfort and well-being was seen as the end-goal. However, sociological research suggests that, in care institutions, there is first a "stripping down" of a person's self, then a "reorganising of self" by the institution to meet the institution's requirements (Brett, 2024, p. 326). It may be that the vulnerability of people following serious injury made it easier to socialise them to body protection routines. There were certainly instances where participants in my study tried to resist body protection if it undermined their comfort and autonomy.

In collaborating with families, nurses' recognition of the importance of relational personhood allowed insights into the person' pre-injury self that enabled a plan for reconstruction of self. A person's agency was promoted when nurses accommodated that person's involvement in personal care or took into perspective family members' opinions about care. Generally, the literature shows that family participation in care decreases distress, improves family functioning, and enhances the quality of personal care (Mackie et al., 2018; Oyesanya & Bowers, 2017a; Ponsford & Schőnberger, 2010 ; Vinarski-Peretz et al., 2023). In rehabilitation settings, the reported benefits of family involvement include protection of patients both physically and emotionally, decrease in carer burden, improvement in decision-making and communication, and an enhancement of the overall experience of rehabilitative care (Mathew et al., 2024; Norup et al., 2017; Oyesanya & Bowers, 2017b; Rasmussen et

al., 2021). The study underpinning this thesis found that tensions arose and family agency was constrained when family members were denied direct involvement in care or were seen as ‘overly-involved’. These contexts for social interaction may have been exacerbated because family members had varying ways of adjusting to the changes in the person experiencing TBI (Ponsford & Schőnberger, 2010), of which participation in care may have been one.

The study’s findings suggest that collaboration between nurses and family members is important because it provides an avenue for the holistic assessment and targeting of person and family-centred care needs. Family members usually have deep knowledge of the person with TBI and so their inclusion in care planning and delivery can better inform personal care (Gebhardt et al., 2011). However, scholars have found that nurse-family relationships can, at times, be problematic or lead to conflicts over healthcare decisions (Vinarski-Peretz et al., 2023). This finding is consistent with the findings of the study underpinning this thesis: moments of tension occurred between nurse and family decision-makers due to a lack of *concordance with the dance steps*, particularly around body protection. Misunderstandings about care strategies that differed between institutions was one area of conflict that required careful negotiation and explanations to decrease family anxiety. In a survey study of caregivers of people with physical or cognitive impairment (Dieker et al., 2024), conflict over care strategies was found to be widespread. Mental and physical exhaustion arising from the family caring role was a significant predictor of conflict.

This study’s findings indicate that, in some units, family participation in personal care was conditional on prior family training. While there may be a safety rationale behind

this condition, it suggests that the privileging of some knowledges over others (i.e., clinical knowledge over the family's deep knowledge of the person) reduces therapeutic interactions to care of *objects* rather than care of *people*. In the study's family data, there were no descriptions of training being offered to support their inpatient contributions. There were merely reports of clinicians rejecting the family members' untrained contributions. Family training was only described in the study data during preparation for discharge. Other qualitative research on traumatic injury found that family members were frustrated when they were barred from assisting the person living with TBI to accomplish activities of daily living (Bond et al., 2003). Johnson et al. (2016) finds strong evidence of the distress of parents who want to help and need to feel close and involved in the care of their adolescent or young adult child.

While some families craved further involvement, others felt exploited by nurses and overwhelmed by the extent of care delegated to them. Nonetheless, the family members felt compelled to continue this level of care because they feared that nobody else would provide it to the required quality. A qualitative study (Monaro et al., 2018) highlights the carer hypervigilance that arises when family members perceive the person as needing more time and space for care than nurses can provide. This experience was described in the context of a perceived chaotic clinical environment and was particularly prominent where the person had a cognitive impairment. There were several intersections between Monaro et al.'s findings and those of the study underpinning this thesis. Carers described never-ending nurse busyness, a high level of patient dependency, and a fear of leaving the person without intensive family supervision and care.

This finding leads to the important contextual factor of the perceived inadequate numbers and skill mix of nursing staff to protect the body in ways that promote personhood. Skill mix relates to the number and classification level of nurses, their educational preparation, their relevant clinical experience, and the technical/non-technical skills they bring to support the care to be delivered (Kushemererwa, et al, 2020). Appropriate skill mix is identified as a core requirement of person-centred practice (McCormack & McCance, 2021). Several family participants and nurse participants reported that nurse numbers and skill mix were barriers to safe care and comfort, and were two of the reasons why nurses delegated care to family members.

Maintaining an optimal skill mix was not always possible in the three inpatient rehabilitation units involved in this study and casual nurses were frequently utilised. However, casual nurses were not always familiar with the specific requirements of inpatient rehabilitation. This study found that poor skill mix was linked to negative experiences and outcomes, including what family members perceived to be missed nursing care, or low-quality care, resulting from a chronic and systemic organisational inadequacy. Missed nursing care refers to “the partial or complete neglect or significant delay of any nursing care required by a patient” (Taskiran Eskici et al., 2025, p.1). The literature attributes missed care to a lack of, or the inadequacy of, nursing personnel (Danielis et al., 2021) and it is associated with unfavourable patient care outcomes. Missed care is also attributed to a lack of insight into one’s personal and professional accountability (Mills & Duddle, 2022). Missed care has implications for personhood: it alters a person’s sense of self, thereby violating their dignity and autonomy (Kivunja et al., 2018; Slettebø et al., 2009). The long-term

impacts on nurses who experience missed care include moral distress and burnout (Taskiran Eskici et al., 2025).

While rounding was described by nurse participants as an acceptable way to ensure basic tasks were done and safety maintained, family members spoke at length about missed care and the perceived need for them to fill in the gaps. Filling in the gaps addressed physical integrity as well as the provision of personal care that afforded dignity. However, assuming the caring role in hospital disrupts family members' usual roles (Gwaza et al., 2022). Family members that participate in personal care are susceptible to cumulative caregiver fatigue and burnout, particularly when they are unable to accommodate the complexities associated with personal care (Gwaza et al., 2022). It is likely that carer experiences can be enhanced by the preparation of families for their caring role, and by encouraging their sense that they are partners in care, rather than safety nets for missed care.

5.2.3.3 Restrictive practices, protecting the body of the person and personhood

In inpatient rehabilitation, the altered patient cognition that leads to impulsivity and behaviours that others find challenging, created a contextual factor in the use of restraint and seclusion practices. These practices were intended to protect the bodies of the person, other patients, visitors, and staff. Institutional and government policies acted as decision-making units in relation to restrictive practices. Nurses had to *Dance with the Agency* and power of these actors while simultaneously *Dancing with the Agency* of the patient who is a person, the family, and other health care workers. In this study, the nurses' Dance with Agency required them to collaborate with multiple decision-making actors from a range of disciplines to find the most

person-centred approach to managing behaviours considered challenging. Similar to other studies that explored inpatient restraint use (Salehi et al., 2019; Wong et al., 2020), the study findings revealed that the use of restraints for people with TBI can be distressing for the person, family members, and clinicians. Tensions arose between nurses, the person with TBI, and family members, when they did not agree on restraint use. Nurses were also confronted when they thought the restraint use attenuated, denied, or devalued personhood.

A literature review of patient experiences of restraint (Douglas et al., 2022) identifies a small number of studies that report neutral attitudes among patients towards restraints (beliefs that restraints were necessary to avoid harm to self and others) (Haw et al., 2011; Knowles et al., 2015; Spinzy et al., 2018). Other studies contend that restraint use is incongruent with the concept of recovery, causes denial of autonomy and psychological trauma for patients, may trigger past memories of trauma for patients, and may lead to decreased patient-nurse interactions and decreased patient adherence to treatment (Cui et al., 2023; Li et al., 2023). Studies in mental health and critical care settings identify moral distress among nurses implementing restraints, with negative outcomes for patients, nurses, and their organisations, and an absence of interventions to address these outcomes (Lamoureux et al., 2024; Salehi et al., 2019).

The New South Wales Health Policy Directive (NSW Heath, 2020) on the use of Seclusion and Restraints in Public Health Settings recognises the competing priorities in the enactment of least restrictive practices, using terms that signify personhood: “NSW Health staff will maximise a person’s choices, rights and freedom

as much as possible while balancing healthcare needs and safety for all." (NSW Health, 2020, p.9). The Policy Directive requires clinicians to "comply with relevant legislation, understand the human rights implications of restrictive practices and continually consider the principles of fairness, respect, equality, dignity and autonomy, as well the safety of people accessing services, staff and others" (NSW Health, 2020, p.9). The Policy Directive recommends a multidisciplinary team approach to minimising the use of seclusion and restraints where "prevention occurs at both a system level (therapeutic programs, models of care, built environment) and an individual level (risk assessment, safety planning, positive behaviour support)" (NSW Health, 2020, p.9).

Many nurse participants displayed sophisticated skills when minimising restrictive practices and maximising the person's sense of autonomy and dignity. The nurse participants used these skills to avoid triggering behaviours of aggression, to de-escalate episodes of conflict, and to take a flexible approach to routines in consultation with the person with TBI. Nurse participants understood the human rights implications of restrictive practices, and in their reflections, they mostly promoted "principles of fairness, respect, equality, dignity and autonomy" (NSW Health, 2020, p.9).

Nurse participants gave numerous examples of seeking least restrictive practices while also being challenged by genuine concerns about falls, potential aggression, and absconding. Not many patient participants referred to restraint use, perhaps because those most affected may not have had capacity to participate in rehabilitation. However, one patient spoke at length about the inappropriateness of

their restraint and the impact on their autonomy. It is not clear whether the restraint use in that case was based on sound nursing assessment. However, this example highlighted the tension between *protecting the body of the person* and affording a person the ‘dignity of risk’. Risk-taking is a vital component of human agency; it contributes to the enhancement of life quality, and it is an acknowledgement of personhood (Ibrahim & Davis, 2013). However, part of nursing’s role is to consider the person’s capacity to cognitively engage in an assessment of risk, and the severity of the associated potential outcomes.

An evidence check on restraints use in health settings (ACI, 2025) notes the now interchangeable use of the terms ‘restrictive practice’ and ‘coercive practice’. Staff are more likely to use restraints where they are unfamiliar with workplace procedures, where they have less knowledge about restrictive practices, and where they score lower on scales of empathy and leadership (ACI, 2025). Where a staff member has previous experience of assault, or where they feel unsafe, they are more likely to use restrictive or coercive practice (ACI, 2025). While use of restraints and seclusion may be considered formal restrictive practices, a systematic review (Hotzy & Jaeger, 2016) discusses research on informal coercion. Informal coercion may include subtle interactions between two or more people, such as inducements, persuasion, or the leveraging of an interpersonal relationship. Informal coercion may also extend to threats, or forceable treatment, to achieve a specific clinical outcome (Hotzy & Jaeger, 2016). While high quality evidence was scarce in this review, informal coercion was widely used during therapeutic interactions. The use of informal coercion was often unintentional and embedded in the therapeutic relationship. While most clinicians and one-to two thirds of patients saw these

practices as useful under certain circumstances, defendable informal coercion required reflective practice and consideration of other alternatives (Hotzy & Jaeger, 2016).

While the TBI units participating in this study were locked, all research sites had a built environment designed to promote a sense of freedom (an element of personhood) in that they provided single rooms and access to an outside area, including access from rooms used to separate some patients from others for safety purposes. As a contextual factor, the built environment is crucial to the experience of recovery after TBI, with key features being access to privacy and a sense of control, an environment conducive to social support, and access to nature and other activities (Colley et al, 2020). It should be noted that rates of seclusion are higher in contexts where a seclusion room is available (ACI, 2025).

5.2.4 Engaging the patient as a person and personhood

The important social processes nurses used to engage the patient as a person included understanding the personhood of the patient; understanding the capacity of the patient; prioritising intentional communication; knowing the person, and personalising care.

When introducing a discussion of *engaging the patient as a person*, it is useful to consider the Grounded Theory study of “protecting personhood” by Didier et al. (2023). This work explained the process people go through to find a balance between being a person and a patient in an unfamiliar hospital environment. Didier et al. (2023) theorise that people move through the following stages: a) *introspection*

(where they become aware of, and oscillate between, their dual identities of person and patient; b) *preservation* (where the person attempts to transmit signs about their need for personhood in order to seek a balance between personhood and patienthood); c) *rupture* (where personhood is ‘wrecked’ as health professionals fail to meet the expectations of the person, causing an imbalance between personhood and patienthood, and an objectification that leads to the person’s avoidance of, evasion of, and withdrawal from, care engagement); and d) *reconciliation* (where the person looks for in-the-moment opportunities to find balance to restore their personhood, usually before a sense of complete rupture is perceived). The importance of the findings of Didier et al. is that personhood is lost and regained during in-the-moment social interactions with health professionals. This finding means that there exists an opportunity for nurses to focus on those social interactions that can have such a profound effect on the persons experience of personhood in care.

During the delivery of rehabilitation care, multiple strategies were used by nurses to facilitate *engaging the person who is the patient*. These strategies align with the Australasian Rehabilitation Nurses’ Association Competency Element 1.2 requiring that a nurse “actively seeks to understand each individual in their context and possess a sense of their personhood” (ARNA, 2023, p.11).

5.2.4.1 Understanding the capacity of the person

In *understanding the capacity of the person*, nurse participants directed questions to the person about what they needed and what worked for them (for example, regarding movement, mobility, and ADLs). The nurses combined this learning,

gained through engagement with patients, with information from allied health clinicians so that they were able to ‘fill in the gaps’ in rehabilitation care. In developing a ‘capability framework’ for rehabilitation, understanding a person’s capacities allows clinicians to talk about choices, which helps a person “choose and realise aspects that are of value to them” (Pijpers et al, 2025, p.772). In assessing functional capacity in rehabilitation, important elements to understand are the “beings and doings” of function that people value, such as exercising, resting, and belonging to a family and community. This assessment also considers the current freedoms and opportunities a person has, their ability to make choices, and the social, environmental and personal factors that convert the person’s resources into capacities (Pijpers et al, 2025). Nurses were mindful that understanding the capacity of the person begins with in-the-moment assessments of the individual’s current capacities. This is supported by the ARNA Competency Element 1.4, which “focuses on each person’s abilities and strengths” (ARNA, 2023, p.11).

In understanding the capacity of the person with cognitive impairment, this study has demonstrated that nurses were less likely to consider a person as credible when they had reduced cognitive capacity. Specifically, they were deemed less reliable informants about their care, and less reliable decision makers. This is an important finding because literature has shown that care is frequently perceived as undignified, infantilising or dehumanising for people with cognitive impairment (Cain, 2025).

5.2.4.2 Understanding the personhood of the patient

This study’s findings reveal how rehabilitation nurses *understand the personhood of the patient* through items of personal significance, such as photographs and familiar

objects from home, and via conversations with family members. While these practices were accepted in these rehabilitation units, individual nurses used them as purposeful social processes with therapeutic intent. Research demonstrates that the display of photographs at the bedside has a positive impact on a person's dignity, stimulates nurse and patient conversations, and complements patient-derived delivery of meaningful care by clinicians (Mendelson et al., 2023). A photograph including human figures engaged in meaningful tasks in real world settings may be particularly useful for people with TBI (Thiessen et al., 2017). This type of photograph also humanises patients and generates a positive work experience for clinicians. Photographs remind nurses and other clinicians that the person has important relations with others, and improves the person's sense of belonging (Mendelson et al., 2023).

5.2.4.3 Prioritising intentional communication

Key requirements during patient-nurse care interactions should include consideration of the person's feelings of personal autonomy and dignity, and whether they perceive they are being heard and understood (Didier et al. 2023). Three factors are key to protecting personhood: the provision of consistent information that is meaningful to the person; making the person feeling safe during care; and receiving assurances that they are heard by others when personal choices are raised (Didier et al., 2023; Monaro, et al. 2018).

The nurses participating in this study employed a range of intentional communication strategies that used knowledge gleaned from photos, personal items, and discussions with the family members to trigger meaningful conversations that

connected to constructions of personhood. Scholars have demonstrated that nurse-patient conversations that may first appear as ‘idle talk’ can have therapeutic intent and enhance a patient’s sense of inclusiveness (Gullick et al., 2020). More focused conversations – for example, exploring the patient’s care preferences – require time, space, the nurse’s commitment, and an in-the-moment intermingling with care (Monaro, et al. 2018; Gullick et al., 2020). Intentional communication practices are associated with improved person-centred care outcomes, better self-esteem and satisfaction with life, and improved psychological, physical, and mental health for people receiving care (Sharkiya, 2023).

5.2.4.4 Knowing the person and personalising care

A number of well-recognised models of nursing clinical judgement (Tanner, 2006; Dowding et al. 2016) recognise the critical importance of knowing the person for patient assessment and personalised care. Knowing the person includes understanding the person’s background, the context of their health challenges, and the important relationships that underpin their recovery (both personal and with clinicians) (Tanner, 2006). Knowing the person allows the nurse to pre-empt situations that may challenge personhood and to notice when things change (for example, physical integrity, or progress towards or away from rehabilitation goals). Knowing the person encompasses the identification of risks for the person and caregivers, the use of the ‘right’ resources to deliver care, and the utilisation of person-centred approaches (Block et al., 2023). This type of nursing assessment facilitates emotional care to support the person’s adjustment to the biographical disruption arising from their injury (Baker et al., 2019).

In a meta synthesis of studies that explored ‘being-with in the nurse-patient relationship’ (Gullick et al., 2020), the construct of knowing the person required the nurse to actively seek a connection with the person in ways that encompassed all their humanness, and this reflected a degree of intimacy not found in most professional relationships. Some nurses framed their nursing identities around what the person “gave them” when care was authentic, and this required nurses to see their own being, and that of others in a certain way. This approach required nurses to view their role as “more than just a job” (Gullick et al., 2020, p. 654).

An important sequelae to knowing the person is the nurse’s intention to humanise and personalise care (Benner et al., 2009). Personalising of care entails tailoring it towards what is unique and of significance to the individual and it contributes to the promotion and preservation of personhood (Bell, 2022; Mendelson et al., 2023). A nurse’s intention to humanise and personalise care was explained as a contextual factor in this study: in *nurses values, beliefs and experiences.*

This study’s findings indicated that individual nurses differed in their approach to practice. While some nurse data indicated that their values, beliefs, and experiences positively influenced how they interacted with or provided patient care, other data indicated that some nurses seemed to slavishly follow guidelines and orders and seemed more inclined to attribute lack of personalised care to things like staff shortages. The data also indicated that less experienced nurses were more likely to be focused on the task at hand and not on the patient as a whole. Many (but not all) nurse participants believed that those with more experience were more likely to address the person as a whole and thereby accommodate more elements of

personhood in their practice. A study (using a validated survey tool) that links the beliefs of dementia care professionals with care that promotes personhood finds a positive correlation between years of clinician experience and personhood scores (Koswatta, et al., 2025).

5.2.5 Handing over the baton

5.2.5.1 Taking-in-the moment opportunities to promote self-care

During *handing over the baton*, the participating nurses privileged and prioritised the agency of the person who is the patient. The nurses' main aim was to encourage the person to participate in self-care activities, while working with the limitations imposed by TBI. Promoting personhood while *handing over the baton* was framed by the idea that the person was moving toward a new normal. Orem (2001) provides, perhaps, the most influential theoretical foundation for rehabilitation nursing assessment and practice. Orem's Self-Care Deficit Theory refers to three systems. The first system is a wholly compensatory system, whereby the nurse determines through assessment that they must perform all care for the patient. The second system is partially compensatory, whereby there is a mingling of nurse and patient involvement in self-care according to specific deficits. The third system is supportive-educative, whereby the nurse encourages and teaches the person in ways that support the potential for growth in self-care (Orem, 2001). Orem's work on self-care speaks to personhood as it identifies human agency, enacted through structured relationships and the sharing of responsibility, as central to determining needs and creating practical inputs that support self and others (Orem, 2001). This theory explains how nurses in this study carefully sought strategies to connect with people, sought their input into care in

flexible ways, and determined what they could do between them to achieve rehabilitation goals.

There were many examples of nurses carefully and tactfully assessing a person's ability to complete a self-care task and using this assessment to encourage the person to move beyond their comfort zone in task completion. In doing so, nurses were led by the person in deciding whether this stretching of capacity felt appropriate for them at that time. These subtle and highly skilled interactions meant that patients could grow their self-care capacity, while feeling safe. These activities occurred through “coaching patients to self-care”, which is seen as a primary responsibility of rehabilitation nursing (Pryor, 2009, p.79). This type of coaching is structured firstly through “easing the person into rehabilitation” by socialising them to the philosophy and practices of rehabilitation. Secondly, rehabilitation nurses “maximise patient effort” through teaching, cueing, prompting, and encouraging the person’s efforts to keep trying, while downplaying failures and arranging the physical environment to be more accommodating. Finally, rehabilitation nurses provide “graduated assistance” through a staged removal of compensatory nursing care (Pryor, 2009, p.82).

Nurses’ capacities to work within a partially compensatory or supportive educative mode were constrained by the pressure to get the person to allied health therapy sessions on time. While getting the person ready for therapy was important for nurses, accomplishing such tasks in a timely manner required doing things *for* the person (wholly compensatory) rather than doing things *with* them. This emphasis ran counter to the goals of rehabilitation. While partially compensatory and supportive educative strategies promoted independence and maximised the person’s input,

these strategies were time-intensive. Pryor (2008) has found that nurses are pressured and frustrated because they need to take short-cuts to have patients ready for allied health sessions. This pressure, which likely arises from the practical need to organise structured rehabilitation delivery, nonetheless presents as a missed opportunity to promote autonomy and personhood.

5.2.5.2 Acknowledging and addressing discharge anxiety

The nurses participating in this study identified patient discharge anxiety as an impediment to their preparing for life outside of inpatient rehabilitation. Participants in a study by Turner et al. (2009) described their approaching discharge as “stressful” and “overwhelming”. Nalder et al. (2012) reported depression, emotional distress and high anxiety levels among family members during the discharge phase . Specific sources of discharge anxiety included concerns about capacity for self-care, being dependent on other or unfamiliar people, family and caregiver strain, and potential difficulty with social and work integration (Keenan & Joseph, 2010; Nalder et al., 2012; Turner et al., 2009a; Turner et al., 2011b). Discharge anxiety may lead to psychological changes arising from simply moving from one location to another, which has been described as relocation stress (Genis et al. 2016). Relocation stress may be intensified by the length of time many people with TBI spend in inpatient rehabilitation. The provision of psychological support during the early discharge phase can facilitate emotional adjustment and help alleviate relocation stress (Stenberg et al., 2022; Turner et al. 2011c). Loflin et al. (2025) designed a novel intervention for transitional care which lessened discharge anxiety in TBI by providing tailored periodic social support and education for patients, families and carers.

In a multivariate analysis of factors contributing to discharge anxiety (Genis et al., 2016) perceived self-efficacy explained 69% of the variance. Self-efficacy mediated the effects age and internal health control beliefs which were also important contributors to discharge anxiety (Genis et al., 2016). While self-efficacy is to some degree inherent (Genis et al., 2016), graded pre-discharge activities, such as the care transitional activities described by participants in this study, may support patients' sense of control over their situations, improve patient's quality of life and lessen caregiver strain post discharge (Oyesanya et al., 2022).

5.2.5.3 Considerations for personhood when preparing for discharge

In preparing for discharge for people with altered cognitive capacity, nurse participants engaged with substitute decision-makers. Literature suggests that, in regard to these engagements, nurses utilise trust-building strategies (being present in care, attentive, actively listening, and engaged). The utilisation of these strategies enables the nurses to ascertain what values matter the most for substitute decision-makers (Cresp et al., 2022). Because of their understanding of relational personhood, when nurses address the values of the substitute decision-makers they might also access the values of the person by proxy. The substitute decision-makers' trust in nurses includes the hope that their loved one's wishes will be supported even in the substitute decision-maker's absence (Cresp et al., 2022; Momiyama et al., 2023).

Rehabilitation nurses have a major role to play in preparing the person for discharge. These nurses support the person's return to community living and they educate the person so that they can transfer new skills into their daily activities of living (Christiansen & Feiring, 2017; Eghbali et al., 2020). This study's findings indicated

that nurses rely heavily on organisational structures such as training programmes and transitional living units when preparing for discharge. The use of transitional living units is an effective intervention that supports the person with a TBI to gradually move from inpatient rehabilitation to community living (Genis et al., 2016). Nurses also rely on third-party funders and service providers, such as the NDIS and iCare. These funders and providers are key community decision-making agencies in relation to several aspects of the person's care that need facilitation during *handing over the baton*.

The practice of celebrating *handing over the baton* recognised when the person reached the milestone of discharge readiness; a major achievement for people with TBI. While the celebration of discharge from rehabilitation was only a ritual at one site, the practice represented a rite of passage that the person went through to disconnect from the inpatient clinical world and connect to the community. In relation to recovery from TBI, an older study by Gutman (1999) discusses rites of passage as social events through which one's achievement is acknowledged by members of the community. Rituals, such as celebrating the completion of TBI rehabilitation, may decrease the person's anxiety (Gutman,1999) at the point of *handing over the baton*.

5.3 Strengths of the study

5.3.1 A strong application of symbolic interactionism

This thesis demonstrates the rigorous application of Constructivist Grounded Theory (CGT) methodology (Charmaz, 2006, 2014, 2025), underpinned by the guiding theory of Symbolic Interactionism. Symbolic Interactionism, which has been applied widely across other robust nursing studies (Chamberlain-Salaun et al., 2020; Ligita et al., 2019; Nowell et al., 2025), provided a strong analytic structure for this study.

Symbolic Interactionism led me to view the interchange of symbolic actions by nurses as *acting units* with other agents, such as people with a lived experience of TBI, family members, other clinicians, and their institutions. These symbolic actions influenced if, and how, common meanings were generated between acting units as they worked towards promoting and preserving personhood in care. In line with symbolic interactionism, my analysis demonstrated that one's sense of self, situation and society are socially constructed, and that meanings and actions are moulded and shared through language and symbols (Blumer, 1969; Charmaz et al., 2019; Stern & Porr, 2011). Participant exemplars illuminated the reciprocal relationship between how people acted and how these interactions then fed into an interpretation of social situations.

During my time in the field, it was frequently evident that symbols shape meanings during social interactions. As some of my research participants with TBI were experiencing the injury sequelae that affected their ability to speak, to verbally express their feelings about complex situations, or to verbally convey their personal care needs, I frequently relied on the symbols that I observed in the field. These symbols included body language, sign language, items in the patients' rooms, and patient gestures to generate meanings based on my interpretation of what they represented or conveyed. The use of symbolic interactionism enabled me to raise theoretical questions about social behaviours and consider the contexts in which research participants existed and related (Charmaz, 2014; Benzies & Allen, 2001; Handberg et al., 2015; Simmons et al., 2022).

Symbolic interactionism allowed me to understand how interactive social processes were created between participant groups and how these processes were sustained (Carter & Fuller, 2016), partly through a striving towards shared goals, and partly through contextual factors that shaped the possibilities for outcomes. This theoretical perspective allowed me to focus on the interpretation of these subjective perspectives at the micro-level (Charmaz et al., 2019). Practical tools for analysis encompassed my initial use of Denzin's (2001) techniques to break down analysis into interactions, symbols/language and meanings. I then refined my analysis through the application of the "triadic nature of meaning" (Blumer, 2003, p. 142). In this analytic structure the meaning of a gesture signified: 1) what the person reading the gesture is directed to do; 2) what the person who sends the gesture is planning; and 3) what combined action results from these exchanges of meaning. These analytic strategies, drawn from symbolic interactionism, helped me move from a description of themes to an interpretation of interactions between acting units.

In explaining how rehabilitation nurses responded to multiple and demanding decision-making actors, Blumer's analytic structure helped to reveal the ways in which nurses assess situations, what they prioritise, how they initiate an interaction which has an underlying intent, and how the receiver then understands and responds to that message. The number of actors with whom the nurse has to negotiate (*the number of dance partners*), the 'wriggle room' in a directive (*the flexibility of the dance steps*), and the *concordance* between dance partners (whether the actors are *in-step* with each other) influence the extent to which the joint goals of progressing rehabilitation and promoting personhood are achieved.

How these in-the-moment interactions become normalised by acting units over time can define and structure group life. Applying Blumer's (1962) ideas, the social organisation of the rehabilitation unit is a space where a collection of acting units independently construct their own actions under conditions that are influenced by social roles (such as role descriptions, or one's status as a patient or family member), social systems (ways of working), culture (what is prioritised, valued and made possible), and social stratification (what elements of power and hierarchy shape possibilities and agency).

5.3.2 Multicentre study with multiple data sources

Multiple sources of data – interviews and field observations across three participant groups – strengthened this study's findings (Turner, 2016). I was able to ask questions of the participants in the field when I observed something that needed clarification. Spending extensive time in these rehabilitation units, and recording field notes, provided further insights that aligned with, expanded, or led me to revise, my understanding of the interview data.

The study's multi-centre design enabled me to have access to a robust sample size of 67, which supported theoretical saturation and helped me to identify the influence of local management, policies and resources, and increased the sample diversity, clinical relevance, and transferability of the findings (Cheng et al., 2017; Das, 2022; Jo, 2020). This design is especially relevant given the variance in the rigidity of guidelines used across centres. The integrative review on personhood (Chapter 2) revealed a lack of primary research studies that incorporate data across patient, family, and nurse cohorts (Kivunja et al., 2024). This study included diverse

participant cohorts, who demonstrated when and how care that promotes personhood is received, and how that care either supports or undermines rehabilitation goals. My understandings of the data were tested and challenged during supervisory team meetings when the team compared insights and helped to reconcile analytical thoughts (Turner, 2016).

5.4 Limitations of the study

The population of NSW in Australia is among the most culturally and linguistically diverse in the world, with almost one-third of citizens born overseas and one-quarter speaking a language other than English at home. People from NSW represent 310 cultures, 283 language groups, and practice 139 religions (Multicultural NSW, 2025). Because of the reliance on semiotic interpretation of interview text, people who were not fluent in English were excluded from participation. Consequently, this study does not contribute to an understanding of the promotion of personhood for people with low English proficiency.

In this study, there were people receiving inpatient rehabilitation care who did not meet the ethical threshold for capacity to provide consent or to fully participate. They were, therefore, not recruited. These people are perhaps most vulnerable to care that attenuates personhood. While I sought proxy access to such stories via family members, their direct experiences remain unknown. This limitation is particularly relevant as these people may have been more exposed to the routine use of restraint and seclusion, with potentially greater impacts on personhood.

5.5 Recommendations to promote personhood through nursing practice, education, policy, and research

5.5.1 Recommendation 1: Promote interdisciplinary team practices

Nurses should be fully integrated into the rehabilitation team structure and considered equal members of the team (Gutenbrunner et al., 2021). Rehabilitation services providers should consider a formal process to promote interdisciplinary practices in order to design, enact, and maintain collaborative initiatives that are effective in promoting and preserving personhood for people with TBI. Nurses may benefit from the embedding of negotiation skills in undergraduate education programs.

Justification: An interdisciplinary approach can address the key challenges this study identifies for delivering care that promotes personhood. These challenges include communication barriers, differing disciplinary and workplace cultures, and unequal power and conflicting priorities between disciplines. Christophers et al. (2025) establish the differences between multidisciplinary and interdisciplinary teams in rehabilitation practice that have potential to influence patient outcomes. ARNA performance criteria 6.4 stipulates that the rehabilitation nurse “actively participates in clinical meetings to negotiate each person’s goals, and develop and review the rehabilitation plan” (2023, p.25). This active participation is difficult to achieve when nurses are excluded from MDT forums. Multidisciplinary rehabilitation teams reflect traditional healthcare system hierarchies, with disciplines working in parallel on different elements of patient care. Alternatively, interdisciplinary rehabilitation teams and practices have a blurring of the lines between disciplines. There is greater collaboration, with disciplines working together to prioritise and solve problems.

These interdisciplinary team approaches are demonstrated to outperform multidisciplinary teams because of their ‘bottom-up’ approach to practice change, and their commitment to long-term coalition-building (Korner, 2010). Interdisciplinary team approaches have led to improved patient outcomes, more successful teamwork, and improved staff satisfaction (Korner, 2010).

Instigating such change to team practices requires an across team approach that incorporates early discussions about power and hierarchy and their influence on effective team functioning (Christophers, 2025). This approach is also facilitated by the embedding of interdisciplinary education at undergraduate level as an expected way of working (O’Leary et al., 2023; Dyess et al.. 2019). Negotiation is a common and important element of interdisciplinary care and a vital tool for organising work in healthcare settings (Clay-Williams et al., 2018; Moustafa et al., 2025). However, this skill may be missing in undergraduate health education programs (Conway et al. 2025). Developing nurses’ negotiation skills may better equip them to contribute their disciplinary expertise and their deep knowledge of their patients and their patients’ families to enhance team decision-making and to promote personhood in rehabilitative care. The ARNA (2023) competence standards, performance criteria 6.4 stipulates that the nurses “actively participate in clinical meetings to negotiate each person’s goals, and develop and review the rehabilitation plan” (p.25). This is difficult to achieve when nurses are excluded from MDT forums.

5.5.2 Recommendation 2: Facilitate early family engagement in rehabilitation

Rehabilitation service providers should facilitate early family engagement in rehabilitation.

Justification: Better outcomes have been reported when early family engagement is prioritised for people with moderate to severe TBI (Foster et al., 2012). This study revealed that, in some cases, the requirement for prior training and clearance from allied health was a key barrier to early family engagement. If this controversial practice of mandating prior training is retained, it should be facilitated early and systematically for significant others who wish to be involved in personal care. The seemingly ad hoc nature of its current application hinders the harnessing of family member input, which is a problem because family member input can contribute positively toward reconstructing personhood post TBI. Early family engagement in rehabilitation allows for timely emotional connectedness between people with TBI and their families (Leith et al., 2004) and supports the transfer of knowledge about how key aspects of the person's care are managed. Family members can then apply these learned skills during home stays following discharge.

Education for family members and caregivers about ongoing impacts for the person, family and long-term progression should be commenced in the early stages of rehabilitation rather than left for later stages. Early acquisition of knowledge by family members can decrease anxieties at discharge (Horn et al., 2017; Loflin et al., 2025) and facilitate transitioning from rehabilitation to home or other external care settings.

5.5.3 Recommendation 3: Support least restrictive practice

The least restrictive practice should be considered in all situations that warrant supporting the person when behaviours that others consider to be challenging are observed. Education and policies that align with this strategy should be considered including restraint prevention and early intervention strategies, therapeutic and safe

last resort strategies, and continuous reflection aimed at progressive skills development (Australian Health Minister's Advisory Council, 2016).

Justification: Restraint use can have consequences for patients, families, caregivers and staff (Belayneh et al., 2024; Carrier et al., 2023). NSW Health (2020) has a robust policy to support least restrictive practice. Even with this policy in place, some nurses and patients were distressed by restraint use and its impact on personhood. Least restrictive practice may be implemented to different levels internationally, influenced by resources, the built environment, staff educational preparation, and wider workplace culture and society. Evidence-based clinical practice guidelines for restraint use should be used to inform education, training, partnering with interprofessional teams, families and carers, while placing patients at the centre of care (Cui et al., 2023). A 2019 Australian Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability sought an expert review on reducing the use of restrictive practices, and of evidence-based alternatives (Cortis et al., 2023). One useful bundle was the "Six Core Strategies": an evidence-based systems approach that, when treated as a bundle, may support least restrictive practice. These recommended strategies are: "1) Leadership toward organisational change; 2) Use of data to inform practice; 3) Workforce development; 4) Use of seclusion and restraint prevention tools; 5) Consumer roles in inpatient settings; and 6) Debriefing techniques" (Cortis, et al., 2023). While formal restrictive practices are widespread and often supported by organisations for safety reasons, the notion of informal coercion should receive attention in practice development strategies. The provision of education for all clinicians on informal coercion using case studies, workshops and group work via multidisciplinary sessions should be priotised to improve awareness of this issue (Eskandari et al., 2018).

5.5.4 Recommendation 4: Research recommendations

Future research could expand the scope of this investigation of social processes that nurses use to promote and preserve personhood following TBI to include intensive care units, acute care wards, and emergency departments.

Justification: As these more acute settings see people at different stages of recovery, where they may be more vulnerable to threats to personhood, the findings of this study set in inpatient rehabilitation may not necessarily be extrapolated to those care environments.

Further research could also be undertaken on informal coercion.

Justification: Although informal coercion is widely used in healthcare settings, there is limited high quality research evidence relating to how staff understand the practice and how they may avoid it (Hotzy & Jaeger, 2016). More robust studies should be considered to explore this gap in healthcare services delivery with the aim of improving patient outcomes. These studies could inform structured education that could sensitise clinicians to the adverse impacts of informal coercion practices, as has been recommended in a systematic review of informal coercive practice research (Hotzy & Jaeger, 2016).

Further research should be conducted on the views of allied health staff working in TBI rehabilitation. This research should focus on allied health staff attitudes towards the role and autonomy of nurses in inpatient rehabilitation, their views on how the contributions of these disciplines currently intersect, and what they see as the barriers to, and opportunities for, stronger interdisciplinary team practices.

Justification: This study's findings revealed that the nurse participants perceived a divide between the disciplines of allied health and nursing in inpatient TBI rehabilitation. This divide impacted the nurses' capacities to provide care that preserved and promoted personhood. Undertaking research to explore how allied health staff understand the role, scope of practice, and unique disciplinary expertise of nurses could provide a firmer basis for collaborative interdisciplinary care and for the championing of quality healthcare services for people with TBI.

5.6 Conclusion

This study developed the *Theory of Dancing with Agency*, which explained the social processes that nurses use to promote and preserve personhood for people receiving inpatient rehabilitation care following TBI. This study identified three important non-linear components of this nursing care: *protecting the body of the person*, *engaging the person who is the patient*, and *handing over the baton*. The main concern of nurses related to their engagement with multiple and demanding decision-making actors, who they encountered in their everyday practice. Nurses responded to this main concern using the basic social process of Dancing with the Agency of other dance partners. Symbolic interactionism supported the development of insights into these other dance partners as acting units who either initiated or responded to language or symbols that carried meaning. Dance partners included people with TBI, their family members, other nurses and clinicians, policies, guidelines, and other institutional structures. Depending on the number of dance partners involved, the flexibility of the dance steps, and the concordance between dance partners, the resulting action either empowered or constrained nurse agency, supported or

challenged patient autonomy and personhood, and influenced the pursuit of rehabilitation goals.

In *protecting the body of the person*, nurses used thoughtful and skilled approaches, based on routines that patients found reassuring. However, nurses had to balance the sometimes-competing priorities associated with care that preserved and promoted personhood and those associated with care that was more risk-averse. While nurses sought collaboration with patients, families, and allied health team members, safety considerations, risk avoidance, and the assumed power of allied health guidelines could dominate their decision-making. Falls risk, and behaviours that others found challenging, resulted in a restrictive environment and restraint use that could be both a safety strategy and, at the same time, a confronting practice for nurses, patients, and family members. Due to an inadequate staffing and or skill mix, nurses were at times unable to provide adequate care and supervision. This inability contributed to the use of informal coercion and restraints, as well as to missed care events, to the placing of an increased burden of care on family members, and to the reduction of the time available to nurses to provide care that prioritised personhood. Because of the demands of providing patient and family care, nurses felt mentally and physically drained.

In *engaging the person who is the patient*, nurses used sophisticated strategies to get to know the person, their previous life, and the elements that connected the person with TBI to their personhood. While these strategies were incorporated into institutional ways of working, they were also dependent on the values, beliefs, and experience of the individual nurse, and the intentional communication strategies they

employed for knowing the person and individualising care. In *handing over the baton*, nurses undertook a nuanced approach to finding a balance between doing things the person with TBI could not do for themselves and encouraging them to stretch beyond their comfort zone in safe and supported ways to reach their rehabilitation goals. Finding this balance required in-the-moment assessments of the dynamic capacity of the patient. Important structures supporting a patient's readiness for discharge included patient, family, and carer education, linking with community support providers, assisting the person and family to overcome discharge related anxiety, and celebrating discharge. Rigid and ineffective team practices negatively impacted care that preserved and promoted personhood particularly while *protecting the body of the person* and *handing over the baton*.

Recommendations for practice, policy, education and research include: a strengthening of interprofessional team practices; early and appropriate engagement of families in care where they desire it; a revisiting of least restrictive practice, including reflection on informal coercion; and further research that explores personhood in acute and critical care settings. While this study has revealed rehabilitation nurses' perceptions of their exclusion from multidisciplinary team decision-making, it is unclear how the role of nursing is viewed by other disciplines providing TBI rehabilitation. Further research on this question could provide the basis for more collaborative team practices that maximise the contribution of nursing expertise and produce the best outcomes for patients.

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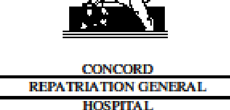
7 APPENDICES

7.1 Appendix 1: ETHICS DOCUMENTS

7.1.1 Appendix 1.1A: Initial HREC Approval

Contact: Sydney Local Health District Human Research Ethics Committee – CRGH
Concord Repatriation General Hospital (CRGH)
Concord NSW 2139
Telephone: *(02) 9767 5622*
Email: SLHD-ConcordEthics@health.nsw.gov.au
Local Ref: *CH62/6/2019-186*



10 February 2020

A/Prof Janice Gullick
C/- Mr Stephen Kivunja
Faculty of Medicine & Health, University of Sydney
Camperdown NSW 2006

Dear A/Prof Gullick,

Re: **Local reference number:** CH62/6/2019-18
REGIS ethics application number: 2019/ETH13511
REGIS project ID number: 2019/PID15131
Project title: Social processes that promote and preserve personhood in Traumatic Brain Injury nursing care in hospital and rehabilitation settings

Thank you for submitting the above research proposal for single ethical and scientific review. This project was first considered by the Sydney Local Health District Human Research Ethics Committee – CRGH at its meeting held on 28 November 2019. This Human Research Ethics Committee (HREC) has been accredited by the NSW Ministry of Health as a lead HREC under the model for single ethical and scientific review.

This lead HREC is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research* and the *CPMP/ICH Note for Guidance on Good Clinical Practice.*

I am pleased to advise that final ethical approval has been granted on the basis of the following:

- The research project meets the requirements of the *National Statement on Ethical Conduct in Human Research*.

The documents reviewed and approved include:

	IDENTIFICATION NUMBER	DATE
Human Research Ethics Application (HREA)	Version 2	03/12/2019
Protocol	Version 2	08/01/2020
Master Patient Opt-out Consent Form	Version 1	08/01/2020
Master Family Consent Form	Version 2	08/01/2020
Master Nurse Consent Form	Version 2	08/01/2020
Master Patient Consent Form	Version 2	08/01/2020
Master Proxy Consent Form	Version 2	08/01/2020
Data Collection Form Nurses	Version 1	08/01/2020
Data Collection Form Nurses	Version 1	08/01/2020
Data Collection Form Patients	Version 1	08/01/2020
Master Family Participant Flyer	Version 2	08/01/2020
Master Nurses Flyer	Version 2	08/01/2020

Page 1

Master Framework for observation	Version 1	14/11/2019
Guide to determining capacity for consent and suitability for participation	Version 1	08/01/2020
Master Interview Guide Family	Version 1	14/11/2019
Master Interview Guide Nurses	Version 1	14/11/2019
Master Interview Guide Patients	Version 1	14/11/2019
Master Introductory Letter Family	Version 2	08/01/2020
Master Introductory Letter Nurses	Version 2	08/01/2020
Master Introductory Letter Patients	Version 2	08/01/2020
Participant Distress Protocol	Version 1	14/11/2019
Master Participant Information Statement Proxy	Version 2	08/01/2020
Master Participant Information Statement Family	Version 2	08/01/2020
Master Participant Information Statement Nurses	Version 2	08/01/2020
Master Participant Information Statement Opt-out Patients	Version 2	08/01/2020
Master Participant Information Statement Patients	Version 2	08/01/2020
Research Data Management Plan	Version 1	08/01/2020
Stop sign for Interviews	Version 1	08/01/2020

The HREC has provided ethical and scientific approval for the following sites:

1. Concord Repatriation General Hospital
2. Royal north Shore Hospital
3. Royal Rehab, Ryde – It is noted that Royal Rehab is a Schedule 3 Affiliated Health Organisation under the Health Services Act and is able to be reviewed by a Public Health Organisation as a Public Health Site. Under this Schedule, an External Entity Agreement is not required.

You are reminded that this letter constitutes ethical approval only. You must not commence this research project at any site until you have submitted a Site Specific Assessment (SSA) Form to the Research Governance Officer (RGO) and received separate authorisation from the Chief Executive or delegate at that site.

Please note the following conditions of approval:

1. HREC approval is valid for five (5) years subject to the supply of an annual progress report. The first report should be sent to the HREC by **10/02/2021.** You must also provide an annual report to the HREC upon completion of the study.

2. You will adhere to the study protocol at all times.

3. Proposed changes to the research protocol, conduct of the research, or length of HREC approval will be provided to the HREC for review.

4. You will notify the HREC, giving reasons, if the project is discontinued at a site before the expected date of completion.

5. You will immediately report anything which might warrant review of ethical approval of the project, including unforeseen events that might affect continued ethical acceptability of the project, (including Significant Safety Issues).

6. HREC approval is granted on the assumption that all students and early career researchers are adequately supervised by the principal and senior investigators on a project. This supervision would ensure that all privacy concerns are met (including the completion of confidentiality agreements by participating students) and that both students and participants are supported in the conduct of the study in line with the approved research protocol.

7. In the current format, the Data Collection Forms contains identifiable data. The identifiable data must be separated into a Master Code Sheet as a condition of this approval.

Should you have any queries about the HREC's consideration of your project please contact the Executive Officer - (02) 9767-5622. The HREC Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the website: https://www.slhd.nsw.gov.au/concord/Ethics/Ethics.html

We wish you every success in your research.

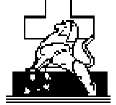
Please quote the local reference number at the top of this letter in all correspondence.

Yours sincerely,

Professor David Le Couteur
Chair
Sydney Local Health District Human Research Ethics Committee – CRGH

7.1.2 Appendix 1.1B : Revised HREC Approval

Contact: Sydney Local Health District Human Research Ethics Committee – CRGH
Concord Repatriation General Hospital (CRGH)
Concord NSW 2139
Telephone: (02) 9767 5622
Email: SLHD-ConcordEthics@health.nsw.gov.au
Local Ref: *CH62/6/2019-186*



CONCORD
REPATRIATION GENERAL
HOSPITAL

10 February 2020 - Revised 10 September 2020

A/Prof Janice Gullick
C/- Mr Stephen Kivunja
Faculty of Medicine & Health, University of Sydney
Camperdown NSW 2006

Dear A/Prof Gullick,

Re: **Local reference number:** CH62/6/2019-18
REGIS ethics application number: 2019/ETH13511
REGIS project ID number: 2019/PID15131
Project title: Social processes that promote and preserve personhood in Traumatic Brain Injury nursing care in hospital and rehabilitation settings

Thank you for submitting the above research proposal for single ethical and scientific review. This project was first considered by the Sydney Local Health District Human Research Ethics Committee – CRGH at its meeting held on 28 November 2019. This Human Research Ethics Committee (HREC) has been accredited by the NSW Ministry of Health as a lead HREC under the model for single ethical and scientific review.

This lead HREC is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.

I am pleased to advise that final ethical approval has been granted on the basis of the following:

- The research project meets the requirements of the *National Statement on Ethical Conduct in Human Research*.

The documents reviewed and approved include:

	IDENTIFICATION NUMBER	DATE
Human Research Ethics Application (HREA)	Version 2	03/12/2019
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Page 1

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Master Participant Information Statement Patients	Version 2	08/01/2020
Research Data Management Plan	Version 1	08/01/2020
Stop sign for Interviews	Version 1	08/01/2020

The HREC has provided ethical and scientific approval for the following sites:

1. Royal Prince Alfred Hospital
2. Royal North Shore Hospital
3. Royal Rehab, Ryde – It is noted that Royal Rehab is a Schedule 3 Affiliated Health Organisation under the Health Services Act and is able to be reviewed by a Public Health Organisation as a Public Health Site. Under this Schedule, an External Entity Agreement is not required.

You are reminded that this letter constitutes ethical approval only. You must not commence this research project at any site until you have submitted a Site Specific Assessment (SSA) Form to the Research Governance Officer (RGO) and received separate authorisation from the Chief Executive or delegate at that site.

Please note the following conditions of approval:

1. HREC approval is valid for five (5) years subject to the supply of an annual progress report. The first report should be sent to the HREC by **10/02/2021.** You must also provide an annual report to the HREC upon completion of the study.

2. You will adhere to the study protocol at all times.

3. Proposed changes to the research protocol, conduct of the research, or length of HREC approval will be provided to the HREC for review.

4. You will notify the HREC, giving reasons, if the project is discontinued at a site before the expected date of completion.

5. You will immediately report anything which might warrant review of ethical approval of the project, including unforeseen events that might affect continued ethical acceptability of the project, (including Significant Safety Issues).

6. HREC approval is granted on the assumption that all students and early career researchers are adequately supervised by the principal and senior investigators on a project. This supervision would ensure that all privacy concerns are met (including the completion of confidentiality agreements by participating students) and that both students and participants are supported in the conduct of the study in line with the approved research protocol.

7. In the current format, the Data Collection Forms contains identifiable data. The identifiable data must be separated into a Master Code Sheet as a condition of this approval.

Should you have any queries about the HREC's consideration of your project please contact the Executive Officer - (02) 9767-5622. The HREC Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the website: https://www.slhd.nsw.gov.au/concord/Ethics/Ethics.html

We wish you every success in your research.

Please quote the local reference number at the top of this letter in all correspondence.

Yours sincerely,

Professor David Le Couteur
Chair
Sydney Local Health District Human Research Ethics Committee – CRGH

7.1.3 Appendix 1.1C: Addition of new sites & removal of two sites

FW: 2019/ETH13511: Notification of an amendment to a research study - Addition of a New Site - (77084) - Approved

Kalissa Brooke-Cowden (Sydney LHD) <Kalissa.BrookeCowden@health.nsw.gov.au>
Tue 15/03/2022 10:18 AM
To: Janice Gullick <janice.gullick@sydney.edu.au>
Cc: Stephen Joshua Kivunja <skiv6775@uni.sydney.edu.au>

Dear A/Professor Gullick,

Please see the Revised Approval below with document versions and dates:

Date of Decision Notification: **19 Jan 2022**
Greater than low risk review pathway
Revised 15 March 2022

Dear Associate Professor Gullick,

Thank you for submitting a Notification of an amendment to a research study - Addition of a New Site with ID (77084 for the following study;
2019/ETH13511: Social processes that promote and preserve personhood in Traumatic Brain Injury nursing care in hospital and rehabilitation settings

The Amendment has been reviewed on 19 Jan 2022, by the Executive Officer as delegated by the HREC Chair and has been approved.

Notification of an amendment to a research study - Addition of a New Site with form ID 77084

- Westmead Hospital
- Liverpool Hospital

PI name:

- Mr Stephen Kivunja
- Mr Stephen Kivunja

PI email: skiv6775@uni.sydney.edu.au

Removal of the following sites:

- Royal Prince Alfred Hospital
- Royal North Shore Hospital

The following documentation is included in this approval:

- Master Introductory letter – Family, version, 4 dated 16/01/22
- Master Introductory letter – Nurses, version 4, dated 16/01/22
- Master Introductory letter – Patients, version 4, dated 16/01/22
- Master Participant Information Statement – Family, version 4, dated 16/01/22
- Master Participant Information Statement – Nurses, version 4, dated 16/01/22
- Master Participant Information Statement – Patients, version 4, dated 16/01/22
- Protocol, version 5, dated 16 January 2022
- Research Data Management Plan, version 3, dated 16 January 2022
- Stephen Kivunja - CV

It is noted that the Sydney Local Health District Human Research Ethics Committee - Concord Repatriation General Hospital is constituted in accordance with the National Statement on Human Conduct in Research, 2007 (NHMRC).

This email constitutes ethical and scientific approval only.

This project cannot proceed at any site until separate research governance authorisation has been obtained from the Institution at which the research will take place.

A copy of this email must be submitted to the Research Governance Officer at the site.

Please contact us if you would like to discuss any aspects of this process further, as per the contact details below.

Regards,

Kalissa Brooke-Cowden
Research Administrative Officer | Concord Hospital Research Office
Building 20, Ground Floor, Hospital Road, Concord, NSW, 2139
T: 02 9767 7990 F: 02 9767 6569
Available: Monday – Wednesday, 7:00am – 3:30pm
SLHD-ConcordEthics@health.nsw.gov.au
https://www.slhd.nsw.gov.au/concord/ethics/

This message is intended for the addressee named and may contain confidential information. If you are not the intended recipient, please delete it and notify the sender.

Views expressed in this message are those of the individual sender, and are not necessarily the views of NSW Health or any of its entities.

7.1.4 Appendix 1.1D: Change of site Principal Investigator

4/20/22, 1:47 PM Mail - Stephen Joshua Kivunja - Outlook

From: no_reply@regis.health.nsw.gov.au <no_reply@regis.health.nsw.gov.au>
Sent: Wednesday, 20 April 2022 11:29 AM
To: Janice Gullick <janice.gullick@sydney.edu.au>
Cc: Janice Gullick <janice.gullick@sydney.edu.au>
Subject: 2019/ETH13511: Notification of an amendment to a research study - PI Change (86782) - Approved

Date of Decision Notification: **20 Apr 2022**
Greater than low risk review pathway

Amendment - Change CPI/PI - Approved
Dear Associate Professor Janice Gullick,

Thank you for submitting an Amendment for the following study;
2019/ETH13511: Social processes that promote and preserve personhood in Traumatic Brain Injury nursing care in hospital and rehabilitation settings

The Amendment has been reviewed on **20 Apr 2022**, by the Executive Officer as delegated by the HREC Chair and has been approved. This will be ratified at the HREC meeting scheduled (Insert Date).

Notification of an amendment to a research study - PI Change with form ID (86782)

Outgoing PI name: Stephen Kivunja
Incoming PI name: Jhoven De Jesus
Incoming PI email: Jhoven.DeJesus@health.nsw.gov.au

The following document is also included in this approval:

- Research protocol version 5 dated 19 April 2022

This amendment notification has been provided to any NSW Health Site Research Governance Officers that require notification, you are not required to submit any further documentation to any NSW Health Sites (listed in REGIS). You will receive further communications from NSW Health sites to acknowledge this change or request further information e.g submit CV.

You may be required to submit this to approved sites outside of NSW.

The following documentation is included in this approval:

It is noted that the Sydney Local Health District Human Research Ethics Committee - Concord Repatriation General Hospital is constituted in accordance with the National Statement on Human Conduct in Research, 2007 (NHMRC).

Please contact us if you would like to discuss any aspects of this process further, as per the contact details below.

Regards,

Sarah Truong

Acting Executive Officer | Research & Ethics Office
Concord Repatriation General Hospital
Building 20, Hospital Road, Concord NSW 2139
SLHD-ConcordEthics@health.nsw.gov.au
http://www.slhd.nsw.gov.au/concord/ethics/

https://outlook.office.com/mail/inbox/id/AAQkAGE2MmE2MTNhLWY0MWQtNDlhYi05MWI5LTU3NTY3OGQ3Y2U4ZgAQAHVwcR2Av2RKoWO7t... 1/1

7.1.5 Appendix 1.1E: Extension of HREC Approval

5/6/25, 9:28 AM Mail - Stephen Kivunja - Outlook

Outlook

2019/ETH13511: Notification of an amendment to a research study - Request for extension of HREC Approval - (201939) - Approved (ethics and NSW site acknowledgement)

From no_reply@regis.health.nsw.gov.au <no_reply@regis.health.nsw.gov.au>
Date Mon 5/05/2025 9:38 AM
To janice.gullick@sydney.edu.au <janice.gullick@sydney.edu.au>
Cc janice.gullick@sydney.edu.au <janice.gullick@sydney.edu.au>; Stephen Kivunja <skiv6775@uni.sydney.edu.au>; jhoven.dejesus@health.nsw.gov.au <jhoven.dejesus@health.nsw.gov.au>

2019/ETH13511: Notification of an amendment to a research study - Request for extension of HREC Approval - (201939) - Approved (ethics and NSW site acknowledgement)

Date of Decision Notification: **05 May 2025**
Greater than low risk review pathway

Dear Associate Professor Janice Gullick,

Thank you for submitting an Amendment for the following study;
2019/ETH13511: Social processes that promote and preserve personhood in Traumatic Brain Injury nursing care in hospital and rehabilitation settings

The Amendment has been reviewed on **05 May 2025**, by the Executive Officer as delegated by the HREC Chair and has been **approved**.

Notification of an amendment to a research study - Request for extension of HREC Approval - (201939)
Previous HREC expiry date: 10/02/2025
New HREC expiry date: **30/09/2025**

It is noted that the Sydney Local Health District Human Research Ethics Committee - Concord Repatriation General Hospital is constituted in accordance with the National Statement on Ethics Conduct in Human Research, 2023 (NHMRC).

https://outlook.office.com/mail/inbox/id/AAQkAGE2MmE2MTNhLWY0MWQtNDlhYi05MWI5LTU3NTY3OGQ3Y2U4ZgAQABzAUCPGGDIIoKjJPIIE... 1/2

This notification is on behalf of the Sydney Local Health District Human Research Ethics Committee - Concord Repatriation General Hospital and each NSW site listed in REGIS.
The new end date has been updated across the system, you are not required to submit to any NSW sites (listed in REGIS) and will not receive individual acknowledgements.
Each NSW Principal Investigator and Administration Contact will receive this notification.

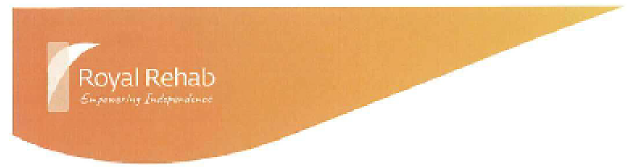
If contract changes or site specific documents require RGO authorisation please submit a Site Amendment Form to each individually affected site.
See QRG: Site Amendment - Completing and Submitting

Please contact us if you would like to discuss any aspects of this process further, as per the contact details below.

Yours Sincerely,
Sarah Truong
Acting Manager | **Research Office**
Concord Repatriation General Hospital
Building 20, Hospital Road, Concord NSW 2139
Ph: 02 9767 6233 I Sarah.Truong@health.nsw.gov.au
http://www.slhd.nsw.gov.au/concord/ethics/

7.2 Appendix 2: SITE APPROVAL LETTERS

7.2.1 Appendix 2.1: Research Site 1 -SSA authorisation letter



Application SSA – Authorised

Date of Decision Notification: 4 January 2021

Dear A/Prof Gullick,

Thank you for submitting the following Site-Specific Assessment (SSA) for governance review;

2019/PID15131: Social processes that promote and preserve personhood in Traumatic Brain Injury nursing care in hospital and rehabilitation settings

The Application has been reviewed by the Chief Executive Delegate who has determined the application can now be authorised. It is noted that the application has been authorised for the following site:

Royal Rehab

The following documentation is included in this authorisation:

HOSPITAL Human Research Ethics Application (HREA)	Version 2	03/12/2019
Protocol	Version 2	08/01/2020
Master Patient Opt-out Consent Form	Version 1	08/01/2020
Master Family Consent Form	Version 2	08/01/2020
Master Nurse Consent Form	Version 2	08/01/2020
Master Patient Consent Form	Version 2	08/01/2020
Master Proxy Consent Form	Version 2	08/01/2020
Data Collection Form Nurses	Version 1	08/01/2020
Data Collection Form Nurses	Version 1	08/01/2020
Data Collection Form Patients	Version 1	08/01/2020
Master Family Participant Flyer	Version 2	08/01/2020
Master Nurses Flyer	Version 2	08/01/2020

royalrehab.com.au

Master Framework for observation	Version 1	14/11/2019
Guide to determining capacity for consent and suitability for participation	Version 1	08/01/2020
Master Interview Guide Family	Version 1	14/11/2019
Master Interview Guide Nurses	Version 1	14/11/2019
Master Interview Guide Patients	Version 1	14/11/2019
Master Introductory Letter Family	Version 2	08/01/2020
Master Introductory Letter Nurses	Version 2	08/01/2020
Master Introductory Letter Patients	Version 2	08/01/2020
Participant Distress Protocol	Version 1	14/11/2019
Master Participant Information Statement Proxy	Version 2	08/01/2020
Master Participant Information Statement Family	Version 2	08/01/2020
Master Participant Information Statement Nurses	Version 2	08/01/2020
Master Participant Information Statement Opt-out Patients	Version 2	08/01/2020
Master Participant Information Statement Patients	Version 2	08/01/2020
Research Data Management Plan	Version 1	08/01/2020
Stop sign for Interviews	Version 1	08/01/2020

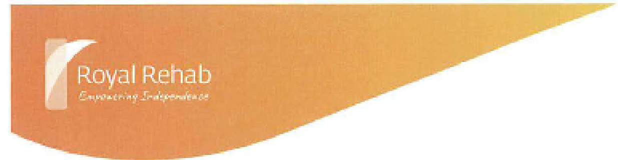
The Site-Specific Assessment authorised is:
Version: Version 1
Date: 24/11/2020

It is noted that the Sydney Local Health District Human Research Ethics Committee approved the Human Research Ethics Application (HREA) associated with the SSA on **3 December 2019**. Site authorisation will cease on the date of HREA expiry **3 December 2024.**

235 Morrison Road, Ryde NSW 2112
PO Box 6, Ryde NSW 1680 Australia

ABN 34 000 025 704

T. 02 9808 9222
E. info@royalrehab.com.au
royalrehab.com.au



The Principal Investigator will:

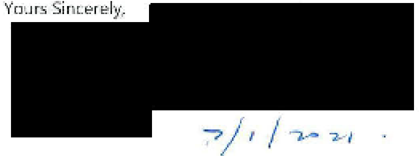
1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the lead HREC for review, are copied to this office.
2. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project, are to be submitted to this office.
3. The appropriate documentation must be submitted to me for authorisation before any external researcher is authorised to conduct research procedures at Royal Rehab.

Royal Rehab requests a copy of an annual progress report. The first report should be sent to the HREC by **10/02/2021.** You must also provide an annual report upon completion of the study.

We wish you all the best with the study and remind you that any changes to the application and safety reports will need to be submitted via REGIS and authorised by the approving HREC prior to implementation.

Please contact us if you would like to discuss any aspects of this process further, as per the contact details below.

Yours Sincerely,



7/1/2021.

235 Morrison Road, Ryde NSW 2112
PO Box 6 Ryde NSW 1680 Australia

ABN 34 080 025 794

T. 02 9808 9222
F. 02 9809 607
E. info@royalrehab.com.au
royalrehab.com.au

7.2.2 Appendix 2.2: Research Site 2 -SSA authorisation letter

3/28/22, 7:04 PM Mail - Stephen Joshua Kivunja - Outlook

2022/STE00094: SSA - Authorised

no_reply@regis.health.nsw.gov.au <no_reply@regis.health.nsw.gov.au>
Thu 24/03/2022 1:25 PM
To: Stephen Joshua Kivunja <skiv6775@uni.sydney.edu.au>
Cc: SWSLHD-Ethics@health.nsw.gov.au <SWSLHD-Ethics@health.nsw.gov.au>

Date of Decision Notification: **24 Mar 2022**
Greater than low risk review pathway

Dear Mr Stephen Kivunja,

Thank you for submitting the following Site Specific Assessment (SSA) for governance review;
2022/STE00094: Social processes that promote and preserve personhood in Traumatic Brain Injury nursing care in hospital and rehabilitation settings

The Application has been reviewed by the Chief Executive/Delegate who has determined the application has been **AUTHORISED** to begin at this site:
Liverpool Hospital

The following documentation is included in this authorisation:

	MASTERs		Site Specific	
Document	**Version**	**Date**	**Version**	**Date**
Participant Information Statement – Patients	**4.0**	**16.01.2022**	**4.0**	**16.02.2022**
Participant Information Statement – Family	**4.0**	**16.01.2022**	**4.0**	**16.02.2022**
Participant Information Statement – Nurses	**4.0**	**16.01.2022**	**4.0**	**16.02.2022**
Family Consent Form	**3.0**	**07.10.2020**	**3.0**	**16.02.2022**
Nurse Consent Form	**3.0**	**07.10.2020**	**3.0**	**16.02.2022**
Patient Consent Form	**3.0**	**07.10.2020**	**3.0**	**16.02.2022**
Nurses Flyer	**3.0**	**07.10.2020**	**3.0**	**16.02.2022**
Introductory Letter Family	**4.0**	**16.01.2022**	**4.0**	**16.02.2022**
Introductory Letter Nurses	**4.0**	**16.01.2022**	**4.0**	**16.02.2022**
Introductory Letter Patients	**4.0**	**16.01.2022**	**4.0**	**16.02.2022**

The Site Specific Assessment reviewed/authorised is:
Version: 1.01
Date: 21 Mar 2022

Site authorisation with cease on the date of HREA expiry **9/02/2025**.

The following conditions apply to this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:

https://outlook.office.com/mail/inbox/id/AAQkAGE2MmE2MTNhLWY0MWQtNDlhYi05MWI5LTU3NTY3OGQ3Y2U4ZgAQACmKcHEpyOxCsifvHp... 1/2

*****Condition of approval: Please ensure that the restrictions and social distancing for COVID-19 are followed until the restrictions have been lifted*****

1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the lead HREC for review, must be submitted to SWSLHD Research Governance via submission of a Multicentre Cover Letter.

1. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project, must be submitted to SWSLHD Research Governance via submission of a Multicentre Cover Letter.

1. Please note that you are responsible for making the necessary arrangements (e.g. identity pass and vaccine compliance as per NSW Health Policy Directive PD2011_005) for any researcher who is not employed by the South Western Sydney Local Health District and is conducting the research on-site.

1. The Principal Investigator is responsible for ensuring the research project is conducted in line with relevant NSW Health, South Western Sydney Local Health District and Hospital policies available from: https://www.swslhd.health.nsw.gov.au/ethics/policies.html

1. Proposed changes to the personnel involved in the study at South Western Sydney Local Health District sites are submitted to the South Western Sydney Local Health District Research Directorate accompanied by the required supporting documents. A list of the documentation required to add an Investigator to a study is located on the South Western Sydney Local Health District Research Directorate website: https://www.swslhd.health.nsw.gov.au/ethics/forms.html

Kind regards,
Cameron Lutman
Mrs Jessica Grundy
Research Ethics and Governance Manager
Research Directorate
South Western Sydney Local Health District (SWSLHD)

7.2.3 Appendix 2.3: Research Site 3 -SSA authorisation letter

2019/PID15131 - 2022/STE00093: SSA - Authorised

no_reply@regis.health.nsw.gov.au
Tue 21/06/2022 1:55 PM
To: jhoven.dejesus@health.nsw.gov.au <jhoven.dejesus@health.nsw.gov.au>
Cc: Stephen Joshua Kivunja <skiv6775@uni.sydney.edu.au>

Date of Decision Notification: **21 Jun 2022**
Greater than low risk review pathway

Dear Jhoven de Jesus,

Thank you for submitting the following Site Specific Assessment (SSA) for governance review;
2019/PID15131 - 2022/STE00093: Social processes that promote and preserve personhood in Traumatic Brain Injury nursing care in hospital and rehabilitation settings

The Application has been reviewed by the Chief Executive/Delegate who has determined the application has been **AUTHORISED** to begin at this site:
Westmead Hospital

The following documentation is included in this authorisation:

- **Protocol version 5 dated 19/04/2022**
- **Westmead -Participant Information_Patients_Version-4_26-04-2022 Based on Master Participant Information_Patients_Version-V4_16_01_2022**
- **Westmead -Participant Information_Family Version-4_26/04/2022 Based on Master Participant Information_Family Version-4_16_01_2022**
- **Westmead -Participant Information_Nurses_ Version-V4_26/04/2022 Based on Master Participant Information_Nurses_ Version-V4_16/01/2022**
- **Westmead Patient Consent Form Version_3_16/02/2022 Based on Master Patient Consent Form Version_3_07/10/2020**
- **Westmead Family Consent Form Version_3_ 16/02/2022 Based on Master Family Consent Form Version_3_ 07/10/2020**
- **Westmead Nurse Consent Form Version_3_16/02/2022 Based on Master Nurse Consent Form Version_3_07/10/2020**

Application Documents (Please note : Due to security reasons, this link will only be active for 14 days. The approved documents are also available to download from forms section of this project in REGIS)

The Site Specific Assessment reviewed/authorised is:
Version: 1.03
Date: 14 Jun 2022

Site authorisation with cease on the date of HREA expiry **9/02/2025**.

The Principal Investigator will:

- Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the lead HREC for review, are provided to the office through REGIS.

- Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project, are to be submitted to this office, via REGIS.
- The appropriate documentation must be submitted for authorisation before any external researcher is authorised to conduct research procedures at this site.

We wish you all the best with the study and remind you that any changes to the application and safety reports will need to be submitted via REGIS and acknowledged prior to implementation.
Please contact us if you would like to discuss any aspects of this process further, as per the contact details below.

Yours Sincerely,
Tiffany Jessop
Research and Education Network
Westmead Hospital cnr Hawkesbury & Darcy Rds Westmead NSW 2145
Tel 02 8890 9007
wslhd-researchoffice@health.nsw.gov.au

7.3 Appendix 3: DOCUMENTS COMMON ACROSS ALL THREE SITES

7.3.1 Appendix 3.1: Guide to determine capacity for consent & participation

Guide to determining capacity for consent and suitability for participation

Title of the research:

Social processes that promote and preserve personhood in traumatic brain injury nursing care

Participation in field observations of care with proxy consent

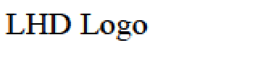
- Is this person likely to be easily distressed if a researcher is sitting in proximity to the bed space observing their care?

Participation in field observations and / or interviews (patient consent)

- Is this person likely to be easily distressed if a researcher is sitting in proximity to the bed space observing their care?
- Is this person likely to be easily distressed if a researcher asks them questions about their injury and nursing care?
- Can this person express their wishes about things that affect them in their day-to-day life? E.g. things they don't want to do
- Can this person conduct a simple conversation about recent events in their life?

Guide to determining capacity for consent and suitability for participation_V1_08_01_2020

7.3.2 Appendix 3.2: Master Patient Consent Form



Social processes that promote and preserve personhood in TBI Nursing Care

PARTICIPANT CONSENT FORM (Patients)

I, ...[name]

of..[address]

have read and understood the Information for Participants for the above named research study and have discussed the study with: ....
I have been told about interviews and observations that I may take part in, including any possible inconvenience, risk or discomfort that I may experience

- I understand that if I take part in this study the researchers will have access to my medical record as described in the Information for Participants, and I agree to this
- I understand that the interview will be audio-recorded, and I agree to this
- I freely choose to participate in this study and understand that I can withdraw at any time. I consent to participate in the following research procedures:

  ☐ Interview only ☐ Observation only

  ☐ Both interview and observation

- I also understand that the research study is strictly confidential. I agree to participate in this research study.

Participant Name (Please Print):...

Participant Signature: .... **Date:** ....

Witness Name (Please Print) ....

Witness Signature: ....**Date:** ....

The participant's signature should be witnessed by a person who has the capacity to understand the merits, risks and procedures of the research, is independent of the research team and, where possible, knows the participant and is familiar with his or her condition.

Name of person who conducted informed consent discussion (Please Print):

....

Signature of person who conducted informed consent discussion:

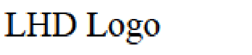
....

Date:.. ....

Participant Code:

Master Patient Consent Form Version_3_07/10/2020 Page 1 of 1

7.3.3 Appendix 3.3: Master Family Consent Form



Social processes that promote and preserve personhood in TBI Nursing Care

PARTICIPANT CONSENT FORM (Family)

I, ...[name]

of..[address]

have read and understood the Information for Participants for the above named research study and have discussed the study with:

....

- I have been made aware of interviews and observations that I may take part in for this study, including any possible inconvenience, risk or discomfort that I may experience
- I understand that the interview will be audio-recorded, and I agree to this
- I freely choose to participate in this study and understand that I can withdraw at any time. I consent to participate in the following research procedures: (please tick)
  - ☐ Interview only
  - ☐ Observation only
  - ☐ Both interview and observation
- I also understand that the research study is strictly confidential. I agree to participate in this research study

Participant Name...DoB:..................

(Please Print)

Participant Signature: .... **Date:** ....

Name of Person who conducted informed consent discussion (Please Print):

....

Signature of Person who conducted informed consent discussion:

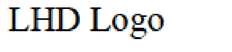
....

Date:..

Participant Code:

Master Family Consent Form Version_3_ 07/10/2020 Page 1 of 1

7.3.4 Appendix 3.4: Master Nurse Consent Form



Social processes that promote and preserve personhood in TBI Nursing Care

PARTICIPANT CONSENT FORM (Nursing staff)

I, ...[name]

of..[address]

have read and understood the Information for Participants for the above named research study and have discussed the study with:

....

- I have been made aware of interviews and observations that I may take part in for this study, including any possible inconvenience, risk or discomfort that I may experience.
- I understand that the interview will be audio-recorded, and I agree to this
- I freely choose to participate in this study and understand that I can withdraw at any time. I consent to participate in the following research procedures: (please tick)

  - ☐ Interview only
  - ☐ Observation only
  - ☐ Both interview and observation

- I also understand that the research study is strictly confidential. I agree to participate in this research study.

Participant Name (Please Print):...

Participant Signature: .... **Date:** ....

Name of Person who conducted informed consent discussion (Please Print):

....

Signature of Person who conducted informed consent discussion:

....

Date:..

Participant code:

Master Nurse Consent Form Version_3_07/10/2020 Page 1 of 1

7.3.5 Appendix 3.5: Master Data collection form -patients

Patients data collection form

Title of the research:

Social processes that promote and preserve personhood in traumatic brain injury nursing care

Item No.	Variable	Remarks/description
1	Participant Code	P=Patient e.g. P1, P2, P3 etc
2	Age	In years
3	Gender	Male, female or not specified
4	Cultural background	Cultural background Culture person identifies with Language spoken at home
5	Next of Kin	Name Contact details
6	Preferred family/significant other for interview	Name Contact details
7	Mechanism of injury	E.g. fall, MVA etc
8	Severity of injury	Acute Physiology and Chronic Health Evaluation (APACHE) score: Glasgow Coma Scale (GCS) on admission: GCS - Most recent documented: Glasgow Outcome Scale (GOS) score: Richmond Agitation & Sedation Scale score (RASS): Current sedation (ie.induced coma?):
9	Functional status	Bedridden Sits Out of Bed (SOOB) Ambulant with assistance Ambulant without assistance Capacity for Activities of Daily Living (ADLs)
10	Length of ICU stay	In days
11	Length of ward stay	In days
12	Length of inpatient rehabilitation stay	In days
13	Total hospital length of stay	In days
14	Procedures and interventions	Nature of surgery and treatment received

Data collection form_Patients_V2_07_10_2020

7.3.6 Appendix 3.6: Master Data collection form Nurses

Nursing staff data collection form

Title of the research:

Social processes that promote and preserve personhood in traumatic brain injury nursing care

Item No.	Variable	Remarks/description
1	Participant Code	N=Nursing staff e.g. N1,N2,N3 etc
2	Age range	18-20 (relevant to some AINs); 21-25; 26-30; 31-35; 36-40; 41-45; 46-50; 51-55; 56-60; 61-65; 66-70; >70 years
3	Gender	Male, female or not specified
4	Years of nursing experience	Total nursing experience
5	Years of neuroscience nursing experience	Neuroscience nursing experience
6	Role type in TBI setting	Assistant in Nursing (AIN), Registered Nurse (RN), Advanced Practice Nurse (APN) (i.e. CNE,CNS,CNC,NP)
7	Education	Certificate, Diploma, Bachelor's degree, Postgraduate degree

Data collection form_Nurses_V2_07_10_2020

7.3.7 Appendix 3.7: Master Family flyer

7.3.8 Appendix 3.8: Master Nurses flyer

7.3.9 Appendix 3.9: Participant Distress Protocol

PARTICIPANT DISTRESS PROTOCOL

RESEARCH PROJECT

Social processes that promote and preserve personhood in TBI Nursing Care

A guide for management in the case of a participant's emotional distress during or after the interview.

1. It is recognised that research participants discussing emotive topics in in-depth interviews may become emotionally distressed. In such instances the following management will occur.

Scenario	Action
The participant has a short, self-limiting period of emotion in response to a difficult topic	1. Pause the interview 2. Ask the participant if they would like to take a break or stop the interview completely 3. If the participant expresses a wish to continue the interview and is able to do so without undue distress, allow them to do so 4. If the participant wishes to stop the interview ask if they would like to continue the interview at a later time or date, or withdraw from the study. 5. At the end of the interview, explore the five elements of psychological first-aid (safety, calm, connectedness, self/group -efficacy and hope) 6. Offer to refer them to the counselling support programme at the site Hospital.
The participant has an extended period of emotional distress.	1. Stop the interview 2. Ask if they would like you to call a support person 3. Stay with the participant until they are calm. 4. Explore the five elements of psychological first-aid (safety, calm, connectedness, self/group -efficacy and hope) 5. Refer them, with their permission, to the 'Employee Assistance Program (staff participants) or to the social worker or psychologist for the TBI Unit (patient and family participants). 6. In the case of a patient participant, significant distress will trigger immediate cessation of the interview or observation. We will thank the participant for their time and will destroy any data collected and withdraw the participant from the study. 7. Call the next day to check on their well being 8. Offer them the option to withdraw from the study. 9. Report to the ethics committee as an adverse event.

A/Prof Janice Gullick, Principal Investigator
Date 14th November 2019

Participant Distress Protocol_Master V2_07.10.2020

7.3.10 Appendix 3.10: Framework for Field Observations

Framework for field observation

The following questions will guide field observations and data collection

Patients

A: In the ICU setting

- What are the apparent physical care needs of the patient?
- How responsive / interactive / cognitively intact does the patient seem to be and how does this seem to flow on to how nursing staff / family interact with them?
- How does the patient communicate their care needs to nursing staff? (including verbal, gestural, behavioural
- What else does the patient seem to communicate to nursing staff or others (eg feelings, emotions, preferences, including verbal, gestural, behavioural)
- What types of things do nursing staff / family say to this patient that seem to promote their personhood?
- What types of things do nursing staff / family do to this patient that seems to support their personhood?
- What situations/environmental factors seem to create a barrier to preserving personhood in this observation?
- What situations/environmental factors seem to provide opportunities to promoting personhood in this observation?
- How do the nursing staff and family interact with each other?

B: In the acute care ward and rehabilitation setting
Nursing staff & Patients

- What are the observable physical/comfort care needs of the patient?
- What are the observable emotional needs of the patient?
- What things does the patient seem to be able to do for themselves?
- What things does the patient seem to need help with?
- How responsive / interactive / cognitively intact does the patient seem to be and how does this seem to flow on to how nursing staff / family interact with them?
- How does the patient communicate their care needs to nursing staff? (including verbal, gestural, behavioural)
- How does the nursing staff / family communicate what they need of the patient?

Master Framework for Observation Version 2_07-10-2020 Page 1 of 2

- What else does the nursing staff / family seem to communicate to the patient (eg feelings, emotions preferences, including verbal, gestural, behavioural)
- What types of things do nursing staff / family say to the patient that seems to promote their personhood?
- What types of things do nursing staff / family do to the patient that seem to support their personhood?
- What situations seem to create a barrier to promoting personhood in this observation?
- What situations seem to provide opportunities to promoting personhood in this observation
- How do nursing staff involve patients / family in designing their care?
- How are patients / family care preferences accommodated by nursing staff?
- Is there any observable setting or discussion of hopes or goals for the future? (these may be immediate eg sitting out of bed after lunch, or longer term)

Families (all settings)

- How do family members communicate their needs to nursing staff?
- Who leads the discussions during family - nurse interactions?
- Where do discussions regarding patient care between family and nursing staff take place?
- How do family members convey their concerns to nursing staff?
- Are family members invited to make decisions for patients? If so How?
- How do families advocate for patients in relation to quality of care being provided?
- Are families invited to participate in care?

Organisation of care (all settings)

- How is nursing care delivery structured within the TBI care environment? (eg what happens when? Patient allocation versus team nursing? Multidisciplinary interaction? Apparent skill mix? Structure for handover / rounds? Patient / family inclusion in handover / rounds? Assessment / management of risks such as falls or aggression?

7.3.11 Appendix 3.11a: Introduction letter -Patients

LHD LOGO

Social processes that promote and preserve personhood in TBI nursing care in hospital and rehabilitation settings

You are invited to participate in a study that will explore how 'personhood' is preserved and promoted during nursing care for people with head injury. Care that preserves personhood includes respect for a person's needs, culture, beliefs, family relationships and life experiences. The research also aims to explore how nurses listen to and work together with patients and families to plan care and support for people with head injury.

The study is being conducted by principal researchers A/Prof Janice Gullick, Stephen Kivunja and Dr Jo River from the University of Sydney, and a group of specialist nurses from the Royal Prince Alfred Hospital, Royal North Shore Hospital, and Royal Rehab Hospital.

If you are interested in this study, please let the nurse caring for you know. Stephen Kivunja will then visit you and answer any questions you may have about taking part in the study. If you participate, you will take part in a face-to-face interview, and / or have your nursing care observed by a researcher. Participation in this study is voluntary. You are under no obligation to participate – it is your choice. If you choose not to participate in the research, it will not affect your current or future relationships with staff at the XXXXXXX hospital.

Please feel free to discuss your participation in the study with family or friends.

Yours faithfully

Signature...

Nurse Unit Manager
XXXXX Unit
XXXXX Hospital
XXXX Local Health District

Social processes that promote and preserve personhood in TBI nursing care
Introductory letter_Patients_Master V2_08.01.20

7.3.12 Appendix 3.11b: Introduction letter -Family

LHD LOGO

Social processes that promote and preserve personhood in TBI nursing care in hospital and rehabilitation settings

You are invited to participate in a study that will explore how 'personhood' is preserved and promoted during nursing care for people with head injury. Care that preserves personhood includes respect for a person's needs, culture, beliefs, family relationships and life experiences. The research also aims to explore how nurses listen to and work together with patients and families to plan care and support for people with head injury.

The study is being conducted by principal researchers A/Prof Janice Gullick, Stephen Kivunja and Dr Jo River from the University of Sydney, and a group of specialist neuroscience and rehabilitation nurses from the Royal Prince Alfred Hospital, Royal North Shore Hospital, and Royal Rehab Hospital.

Participation requires you to take part in a conversational-style face-to-face or telephone interview at a time and place of your choosing, and/or observations of nurses caring and interacting with patients with a head injury and their family or support people.

Participation in this study is voluntary. You are under no obligation to participate – it is your choice. If you choose not to participate in the research, it will not affect your current or future relationships with staff at the XXXXXXX hospital.

Please find included a copy of the Participant Information Sheet and Consent Form. If you are interested in this study and would like further information about participation, please contact Stephen Kivunja (by email skiv6775@uni.sydney.edu.au or by phone 0450 702 285), who will answer any questions you may have. If you agree to participate in this study you can then sign the Participant Consent Form and return it in the stamped, addressed envelope that is provided.

Please feel free to discuss your participation in the study with family or friends.

Yours faithfully

Signature...

Nurse Unit Manager
XXXXX Unit
XXXXX Hospital
XXXX Local Health District

Social processes that promote and preserve personhood in TBI nursing care
Introductory letter_Master Family_V2_08.01.20

7.3.13 Appendix 3.11c: Introduction letter – Nurses

LHD LOGO

Social processes that promote and preserve personhood in TBI nursing care in hospital and rehabilitation settings

You are invited to participate in a study that will explore how 'personhood' is preserved and promoted during nursing care for people with head injury. Care that preserves personhood includes respect for a person's needs, culture, beliefs, family relationships and life experiences. The research also aims to explore how nurses listen to and work together with patients and families to plan care and support for people with head injury.

The study is being conducted by principal researchers A/Prof Janice Gullick, Stephen Kivunja and Dr Jo River from the University of Sydney, and a group of specialist neuroscience and rehabilitation nurses from the Royal Prince Alfred Hospital, Royal North Shore Hospital, and Royal Rehab Hospital.

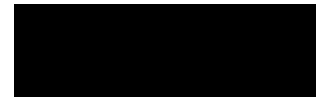
Participation requires you to take part in a conversational-style face-to-face or telephone interview at a time and place of your choosing, and/or observations of nurses caring and interacting with patients with a head injury and their family or support people.

Participation in this study is voluntary. You are under no obligation to participate – it is your choice. If you choose not to participate in the research, it will not affect your current or future relationships with staff at the XXXXXXX hospital.

Please find included a copy of the Participant Information Sheet and Consent Form. If you are interested in this study and would like further information about participation, please contact Stephen Kivunja (by email skiv6775@uni.sydney.edu.au or by phone 0450 702 285), who will answer any questions you may have. If you agree to participate in this study you can then sign the Participant Consent Form and return it in the stamped, addressed envelope that is provided.

Please feel free to discuss your participation in the study with family or friends.

Yours faithfully



A/Prof Janice Gullick
Coordinator, Intensive Care Nursing
Susan Wakil School of Nursing (Sydney Nursing School)
University of Sydney

Social processes that promote and preserve personhood in TBI nursing care
Introductory letter_Master Nurses V2_08.01.20

7.3.14 Appendix 3.12a: Participant Information Statement - Patients

Social processes that promote and preserve personhood in traumatic brain injury nursing care

PARTICIPANT INFORMATION STATEMENT (Patients)

Introduction

You are invited to participate in a research study that aims to develop a deeper understanding of the experiences and care needs of people who have experienced a head injury, and who are currently receiving care in a hospital or rehabilitation setting. The study aims to understand the type of nursing care that promotes your "personhood", by respecting your needs, culture, beliefs, family relationships and life experiences. It also aims to explore how nurses listen to and work together with you and your family to plan your care and support you.

We hope the findings of this research will inform nursing practice and support hospital and rehabilitation clinicians to provide the best possible head injury care.

The study is being conducted by the following researchers:

Principle Researcher: Stephen Kivunja is a registered nurse and a Clinical Nurse Specialist who cares for people with head injury at Westmead Hospital. He is also a research student at the University of Sydney.

Associate Professor Janice Gullick is a nurse educator and researcher at the University of Sydney (Stephen's Principal Research Supervisor).

Dr Jo River is a nurse educator and researcher at the University of Sydney (Stephen's Research Supervisor).

Ms Elaine McGloin is a Clinical Nurse Consultant (Intensive Care Unit) at Royal Prince Alfred Hospital, Sydney (RPAH site representative)

Ms Vicki Evans is a Clinical Nurse Consultant (Neurosciences) at Royal North Shore Hospital, Sydney (RNSH site representative)

Stephen Kivunja is conducting this study as the basis for a research training degree (Doctor of Philosophy) at the Susan Wakil School of Nursing and Midwifery, University of Sydney.

Study Procedures

- If you agree to participate in this study, you will be asked to sign a Participant Consent Form. You can then take part in an interview, or in observations of your hospital care, or both. We will access your medical record so that we understand the nature of your head injury, how long you have spent at each stage of your hospital recovery, and any surgery or complications that are documented.

Interviews

- If you agree to be interviewed, you will be asked questions in a face-to-face conversation with Stephen Kivunja. You can choose to either be by yourself during this interview, or to have someone you trust stay with you, such as a friend or family member. We will ask you these questions in a private place at your hospital.
- We will ask questions about your life before your injury (e.g. "Tell us something about yourself before your injury"; "What is your life like since you had your accident?" and "What things do your nurses and family members do that help you feel respected and valued?
- The interviews will take around 30 - 60 minutes, but you can either stop earlier, or talk for longer if you wish.
- You can ask to take a break if you are getting tired.
- If you want to stop the interview for any reason, or don't want to answer a question, we will give you a stop sign to hold up
- We want you to feel free to talk about anything related to your care and there are no right or wrong answers.
- We will audio-record your interviews so we can accurately write down what you tell us about your experience.
- Your answers will remain confidential and we will keep your interview data in a safe place.
- If you move to a different care setting (for example from a hospital ward to a rehabilitation setting), we might ask to interview you again. If you would like to take part in another interview, we will ask you to sign a new consent form. You don't have to take part in a second interview if you don't want to.

Observations

- Some patients will be observed while receiving care. This means, if you, your nurse and your family member agree, Stephen will sit quietly near your bed space for one or more periods of around 30-60 minutes and watch the type of care you receive and the interactions between you, your nurse and your family member. He will take notes about the things he sees and hears that may help you feel respected and valued. Stephen is a nurse, and so is familiar with hospitals and patient care. He will not watch anything that is very personal such as having a shower or going to the toilet. If you don't want Stephen to watch something, you can ask him to leave. If you do not want to take part in further observations you can say so.
- You can take part in both the interview and the observation, or you can choose to take part in the interview only, or the observation only. It is your choice.

What are the possible risks of taking part?

Sometimes people become sad or distressed when remembering and talking about their experience after an injury. If this occurs, we can either pause the interview until you feel ready to continue, or we can stop the interview completely. Stephen can provide some immediate emotional support, but you will also have access to counselling if required. Sometimes people's stories are unique and memorable. If we think something about your story would make it easy to identify you, we would either slightly change, or not report that part of your story.

What are the possible benefits of taking part?

While we hope this research study improves our knowledge and our care planning for people with head injury in the future, it may not be of direct benefit to you. The findings may be of use to a person who has a head injury in the future, and to nurses who help them recover.

Costs: Participation in this study will not cost you anything, nor will you be paid.

Participation is voluntary

Being in this study is completely voluntary. You do not have to consent. If you do not consent you will not be in the study and your care would go on as normal. If you do consent, you can change your mind and withdraw from the study at any time – this would not affect your hospital treatment, or the relationships you have with the researchers or other people who work at the hospital. If you withdraw from the study, your interview data (the audio-recording and any written record of your interview) would then be destroyed.

Confidentiality

All the information collected from you for the study will be treated confidentially, and only the researchers named above will have access to it. The study results may be presented at a conference or published in a scientific publication, but you would not be identifiable in such a report.

Data Security

We will keep your data in a safe place for 5 years. We will then destroy the data when the study is finished and our reports are complete.

Further information

Please feel free to discuss your participation in this study with family and friends. When you have read this information, Stephen Kivunja will discuss it with you further and answer any questions you may have. Please feel free to contact Stephen via:

Email: skiv6775@uni.sydney.edu.au
Mobile: 0450 702 285

Ethics Approval and Complaints

This study has been approved by the Ethics Review Committee - CRGH of the Sydney Local Health District. If you have any concerns or complaints about the conduct of this research study, you may contact the Executive Officer of the Ethics Committee, on 02 9767 5622 and quote protocol number: 2019/ETH13511.

The conduct of this study at the [**name of hospital**] has been authorised by the [**name of Local Health District**]. Any person with concerns or complaints about the conduct of this study may also contact the Research Governance Officer [or other officer] on [**telephone number**] and quote protocol number [**insert local protocol number**].

This information sheet is for you to keep

7.3.15 Appendix 3.12b: Participant Information Statement - Family

Social processes that promote and preserve personhood in traumatic brain injury nursing care

PARTICIPANT INFORMATION STATEMENT (Family)

Introduction

You are invited to participate in a research study that aims to develop a deeper understanding of the care needs of people who have experienced a traumatic brain injury. We are interested in the experiences of people who are currently receiving care in a hospital or rehabilitation setting. The study aims to understand the type of nursing care that promotes "personhood": respect for a person's needs, culture, beliefs, family relationships and life experiences. It also aims to explore how nurses listen to and work together with patients and families to plan care and support for people with traumatic brain injury.

We hope the findings of this research will inform nursing practice and support hospital and rehabilitation clinicians to provide the best possible traumatic brain injury care.

The study is being conducted by the following researchers:

Principle Researcher: Stephen Kivunja is a registered nurse who cares for people with traumatic brain injury at Westmead Hospital. He is also a research student at the Susan Wakil School of Nursing and Midwifery, The University of Sydney.

Associate Professor Janice Gullick is a nurse educator and researcher at the Susan Wakil School of Nursing and Midwifery, The University of Sydney (Stephen's Principal Research Supervisor).

Dr Jo River is a nurse educator and researcher at the Susan Wakil School of Nursing and Midwifery, The University of Sydney (Stephen's Research Supervisor).

Ms Elaine McGloin is a Clinical Nurse Consultant (Intensive Care Unit) at Royal Prince Alfred Hospital, Sydney (RPAH site representative)

Ms Vicki Evans is a Clinical Nurse Consultant (Neurosciences) at Royal North Shore Hospital, Sydney (RNSH site representative)

Stephen Kivunja is conducting this study as the basis for a research training degree (Doctor of Philosophy) at the Susan Wakil School of Nursing and Midwifery, University of Sydney.

Study Procedures

If you agree to participate in this study, you will be asked to sign a Participant Consent Form. You can then take part in an interview, or in observations of care, or both.

Interviews

- If you agree, you will take part in conversational style interview with Stephen Kivunja at a time and place that is convenient to you, either face-to-face or by telephone.
- Stephen will ask questions about your relationship to the person with traumatic brain injury, and about your role as a family member or support person. He will ask about the things nurses do or say to patients and family/support people to address their needs, culture, beliefs, family relationships and life experiences. He will ask how you communicate with nurses, and how you are able to promote the needs of the patient during their hospital or rehabilitation stay.
- The interview will take between 30 - 60 minutes.
- We want you to feel free to talk about anything related to the person's care and there are no right or wrong answers.
- We will audio-record your interview so we can accurately write down what you tell us about your experience. Your answers will remain confidential and you will not be identifiable in any published reports. We will not use your real name, nor anyone else's on the interview transcript. We will instead refer to people by a pseudonym.
- If your friend/family member moves to a different care setting (for example from a hospital ward to a rehabilitation setting), we might ask to interview you again. If you would like to take part in another interview, we will ask you to sign a new consent form. You don't have to take part in a second interview if you don't want to.

Observations

- Some patients will be observed while receiving care. This means, if you, the nurse and the person with a traumatic brain injury agrees, Stephen will sit quietly near the patient's bed space for one or more periods of around 30-60 minutes and observe the type of care/support provided and the interactions between you, the nurse and the patient. Stephen is a clinician, and so is familiar with hospitals and patient care. We are interested in how nurses and family members promote *personhood* and the things they do help a person feel respected and valued. We are also interested in how nurses include family and support people in their care planning and provision. Stephen will not watch anything that is very personal such as the person having a shower or going to the toilet. If you don't want Stephen to watch something, you can ask him to leave. The number of observation periods will be determined by the data collected. If you no longer wish to be observed, you can ask for your participation in observations to cease.
- You can take part in both the interview and the observation, or you can choose to take part in the interview only, or the observation only. It is your choice.

What are the possible risks of taking part?

Sometimes people become sad or distressed when remembering and talking about their experience of caring for a person after a serious injury. If this occurs, we can either pause the interview until you feel ready to continue, or we can stop the interview completely. Stephen can provide some immediate emotional support, but you will also have access to counselling if required. Sometimes people's stories are unique and memorable. If we think something about your story would make it easy to identify you, we would either not describe that element in any published report, or we would change the details slightly in a way that protects your privacy, but doesn't alter the meaning of your interview data.

What are the possible benefits of taking part?

While we intend that this research study improves our knowledge and our care planning for people with traumatic brain injury, and for families and support people in the future, it may not be of direct benefit to you. The findings may be of use a person who has a Traumatic Brain Injury (TBI) in the future, and to the professional development of nurses who help them recover.

Costs: Participation in this study will not cost you anything, nor will you be paid.

Participation is voluntary

Being in this study is completely voluntary. We understand that in times of stress, it is difficult to make a decision about research participation, particularly when your family member is highly dependent on medical care and you wish to do the best for them. You should be assured that you do not have to consent, and if you do consent, you can change your mind and withdraw from the study at any time. This would not affect your family member's hospital treatment, or the relationships you have with the researchers or other people who work at the hospital. If you withdraw, your interview data (the audio-recording and any written record of your interview) would then be destroyed.

Confidentiality

All the information collected from you for the study will be treated confidentially, and only the researchers named above will have access to it. The study results may be presented at a conference or published in a scientific publication, but you would not be identifiable in such a report.

Data Security

The audio-recording will be transcribed by the researcher and the electronic voice file, interview transcript, and any electronic transcript of field notes will be stored securely in electronic form in the University of Sydney Research Data Repository for five years. Audio recordings will then be deleted as per The University of Sydney Research Code of Conduct 2019. The transcripts will be retained for a minimum of five years and will be deleted/shredded when all reports arising from this research have been completed.

The research data remains the property of the researcher and apart from dissemination of the research findings, will not be shared for any other purpose. The Intellectual Property generated from the study is owned by the research team and the intellectual property rests with the primary researcher. Data analysis will be undertaken at the University of Sydney by the research team.

Further information

Please feel free to discuss your participation in this study with family and friends. When you have read this information, Stephen Kivunja will discuss it with you further and answer any questions you may have. Please feel free to contact Stephen via:

Email: skiv6775@uni.sydney.edu.au
Mobile: 0450 702 285

Ethics Approval and Complaints

This study has been approved by the Ethics Review Committee- CRGH of the Sydney Local Health District. If you have any concerns or complaints about the conduct of this research study, you may contact the Executive Officer of the Ethics Committee on 02 9767 5622 and quote protocol number:2019/ETH13511**.**

The conduct of this study at the [**name of hospital**] has been authorised by the [**name of Local Health District**]. Any person with concerns or complaints about the conduct of this study may also contact the Research Governance Officer [or other officer] on [**telephone number**] and quote protocol number [**insert local protocol number**].

This information sheet is for you to keep

7.3.16 Appendix 3.12c: Participant Information Statement - Nurses

Social processes that promote and preserve personhood in traumatic brain injury nursing care

PARTICIPANT INFORMATION STATEMENT (Nurses)

Introduction

You are invited to participate in a research study that aims to develop a deeper understanding of the care needs people who have experienced a traumatic brain injury (TBI). We are interested in the experiences of people who are currently receiving care in a hospital or rehabilitation setting. The study aims to understand the type of nursing care that promotes respect for "personhood", encompassing a person's needs, culture, beliefs, family relationships and life experiences. It also aims to explore the social processes that support and promote partnership in care planning between families/carers and nurses.

We hope the findings of this research will inform nursing practice and support neuroscience and rehabilitation nurses to provide the best possible TBI care.

The study is being conducted by the following researchers:

Principle Researcher: Stephen Kivunja, PhD Candidate, Susan Wakil School of Nursing and Midwifery, The University of Sydney and Clinical Nurse Specialist (Neurosciences), Westmead Hospital.

Associate Professor Janice Gullick, Susan Wakil School of Nursing and Midwifery, the University of Sydney (Principal Supervisor)

Dr Jo River, Senior Lecturer, Susan Wakil School of Nursing and Midwifery, The University of Sydney (Supervisor)

Ms Elaine McGloin is a Clinical Nurse Consultant (Intensive Care Unit) at Royal Prince Alfred Hospital, Sydney (RPAH site representative)

Ms Vicki Evans is a Clinical Nurse Consultant (Neurosciences) at Royal North Shore Hospital, Sydney (RNSH site representative)

Stephen Kivunja is conducting this study as the basis for the degree of Doctor of Philosophy at the University of Sydney. This will take place under the supervision of Associate Professor Janice Gullick and Dr Jo River.

Study Procedures

- If you agree to participate in this study, you will be asked to sign a Participant Consent Form. You can then take part in an interview, or in observations of care, or both. We will collect demographic data: age range, years of nursing and

neuroscience experience, nursing educational background. This will be reported as pooled data and will not make you identifiable.

Interviews

- If you agree, you will take part in conversational style interview with Stephen Kivunja at a time and place that is convenient to you, either face-to-face or by telephone. We will ask questions about your role as a TBI nurse, and the things you say and do in your daily care that promote and preserve *personhood* (respect for a person's needs, culture, beliefs, family relationships and life experiences). We are also interested in the social processes that underpin this care (how you liaise with and advocate for other clinicians, patients and families) in your work setting.
- The interview will probably take between 30 - 60 minutes.
- We want you to feel free to talk about anything related to providing TBI care, including the challenges, and there are no right or wrong answers.
- We will audio-record your interviews so we can accurately write down what you tell us about your experience.
- Your answers will remain confidential and we will keep your interview data in a safe place.

Observations

- Some patients and family members/carers will be observed while receiving or giving care. This means, if you, the patient's family member and the patient agree, Stephen will sit quietly near the patient's bed space for one or more periods of around 30-60 minutes and watch the type of care/support you provide and the interactions between you, the patient and the family/support person. Stephen is a clinician, and so is familiar with hospitals and patient care. We are interested in how nurses and family members promote *personhood* and the things nurses do help a person feel respected and valued. We are also interested in how nurses include family and support people in their care planning and provision. Stephen will not watch anything that is very personal such as showering or toileting. If you don't want Stephen to watch something, you can ask him to leave. The number of observation periods will be determined by the data collected. If you no longer wish to be observed, you can ask for your participation in observations to cease.
- You can take part in both the interview and the observation, or you can choose to take part in the interview only, or the observation only. It is your choice.

What are the possible risks of taking part?

Sometimes people become sad or distressed when remembering and talking about their experience of caring for critically injured people. If this occurs, we can either pause the interview until you feel ready to continue, or we can stop the interview completely. You will have access to counselling if required.

Sometimes people's stories are unique and memorable. If we think something about your story would make it easy to identify you, we would either not describe that element in any published report, or we would change the details slightly in a way that protects your privacy but doesn't alter the meaning of your interview data.

What are the possible benefits of taking part?

While we intend that this research study improves our knowledge and our care planning for people with TBI, families and carers in the future, it may not be of direct benefit to you. The findings may be of use to a person who has a TBI in the future, and to health professionals to promote better support and training for nurses and a more positive patient and family experience.

Costs: Participation in this study will not cost you anything, nor will you be paid.

Participation is voluntary

Being in this study is completely voluntary. You do not have to consent, and if you do consent, you can change your mind and withdraw from the study at any time. This would not affect the relationship you have with the researchers or other hospital employees. If you withdraw, your interview data (the audio-recording and any written record of your interview) would then be destroyed.

Confidentiality

All the information collected from you for the study will be treated confidentially, and only the researchers named above will have access to it. The study results may be presented at a conference or published in a scientific publication, but you would not be identifiable in such a report. If during an observation, the researcher notes an imminent safety issue such as a likely fall or medication error (e.g. wrongly identified patient) he would raise this immediately with you so you could respond to the safety issue yourself. If the researcher observes something that constitutes "Notifiable behaviour" under the Nursing and Midwifery Board of Australia's "Guidelines for Mandatory Notifications" (NMBA 2014) (e.g. intoxication, sexual misconduct, or significant departure from accepted professional standards that has placed the public at risk) he would seek advice before making any notification. Behaviour that is unprofessional in some way but not unsafe would be considered part of the confidential research data. In all cases, the researcher would aim to manage the situation in a respectful and just way.

Data Security

The audio-recording will be transcribed by the researcher and the electronic voice file, interview transcript, and any electronic transcript of field notes will be stored securely in electronic form in the University of Sydney Research Data Repository for five years. Audio recordings will then be deleted as per The University of Sydney Research Code of Conduct 2019. The transcripts will be retained for a minimum of five years and will be deleted/shredded when all reports arising from this research have been completed.

The research data remains the property of the researcher and apart from dissemination of the research findings, will not be shared for any other purpose. The Intellectual Property generated from the study is owned by the research team and the

intellectual property rests with the primary researcher. Data analysis will be undertaken at the University of Sydney by the research team.

Further information

Please feel free to discuss your participation in this study with family and friends. When you have read this information, Stephen Kivunja will discuss it with you further and answer any questions you may have. Please feel free to contact Stephen via:

Email: skiv6775@uni.sydney.edu.au
Mobile: 0450 702 285

Ethics Approval and Complaints

This study has been approved by the Ethics Review Committee - CRGH of the Sydney Local Health District. If you have any concerns or complaints about the conduct of this research study, you may contact the Executive Officer of the Ethics Committee on 02 9767 5622 and quote protocol number: 2019/ETH13511.

The conduct of this study at the [**name of hospital**] has been authorised by the [**name of Local Health District**]. Any person with concerns or complaints about the conduct of this study may also contact the Research Governance Officer [or other officer] on [**telephone number**] and quote protocol number [**insert local protocol number**].

This information sheet is for you to keep

7.4 Appendix 4: INTERVIEW GUIDES USED IN PHASE ONE

7.4.1 Appendix 4.1: Phase 1- Interview guide -patients

Interview guide for patient participants

I am going to ask you some questions about your life before your injury, then what happened after your injury, including your stay in hospital. If there is anything you don't want to answer just tell me. If you want to stop the interview at any time it is OK to tell me that too.

FAMILY HISORY

1. **Can you tell me about who provides support for you while you are in hospital (e.g. family/friends)**
   Possible prompts
   - Who are the people important to you in your 'family'?
   - What makes them important to you?
   - Who do you live with?
   - Who else is important to you who isn't in your family?
   - Can you tell me a little about your cultural background, religion or ethnicity or community?
   - What language do you speak at home?
   - If you don't speak English at home, does that make it hard communicating in English with hospital staff?

   LIFE BEFORE HEAD INJURY
2. **What was your life like before your accident?**
   Possible prompts
   - Did you have paid or unpaid work?
   - What does your work involve?
   - How important was that work to you? (i.e. how much was your work tied up in your identity?)
   - Do other people depend on you?
   - Do you care for children?
   - What type of things do you do for your children?
   - What did you like to do in your spare time?

   EVENTS LEADING TO HEAD INJURY
3. **Can you tell me how you came to experience a head injury?**
   Possible prompts
   - What happened on the day of your injury?
   - What events led to your injury?
   - How did that injury change you?
   - Do you have any physical changes that make it harder to think/talk/ do things?

Master Interview Guide_Patients_ Version-2_07/10/2020 **Page 1 of 2**

- What are the hardest things about your life since the injury?
- What can you remember about your hospital stay?
- What are the hardest things about being in hospital?
- What skills or strategies have you used to cope with that?

CARE IN HOSPITAL AND REHABILITATION

4. **Tell me about the nursing care you receive while in hospital/rehabilitation?**

   Possible prompts
   - What sort of things do the nursing staff have to do for you?
   - What are the things they do that are most helpful to you?
   - What are the things they do that you don't like?
   - Is there anything that you wish they would do to help you feel more like a person?
   - Do you understand everything that has been done to you in hospital?
   - How do you talk to nursing staff or others about what you would like?
   - Is there anything you have trouble asking for?
   - Is there anything about your culture that makes being in hospital harder or changes what you need?

FAMILY AND SOCIAL SUPPORT

5. **Tell me about how your family have been while you are in hospital?**
   - Do you see your family or friends often?
   - Who is the person who is most important to you while you are in hospital?
   - What do they do that helps you?
   - How do your family help stand up for what you need with nursing staff or other health professionals?
   - Is there anything your friends or family do that makes things harder for you?
   - What is it like having to have your family or friends do things for you?
   - Can you talk to your family/friends about what you want in hospital?
   - What do you think life has been like for them since your injury?
   - What could nursing staff do to help your family?
   - How important will your family be when you go home?

FUTURE PLANS

6. **What plans do you have for the future?**
   - How could nursing staff help you to achieve what you would like to in the future?
   - What would you like to get back to when you go home?
   - Has anyone in hospital talked about setting goals for the future?
   - What help would you need to get back to the things you would like to do?
   - Who are the important people in your life that can help you when you go home?
   - What things do you think they can help you with?

7. **Is there anything else you would like to add?**

7.4.2 Appendix 4.2: Phase 1- Interview guide - family members

Interview guide: Family/support people

(all references to 'the patient' or the person' will be substituted with their name)

I am going to ask you some questions about the person's life before their injury, then what happened after the injury, including the nursing care they received in hospital. I'm also going to talk about the idea of personhood, and what that means to you (there are no right or wrong answers). If there is anything you don't want to answer just tell me. If you want to stop the interview at any time it's OK to tell me that too.

FAMILY/SOCIAL ENVIRONMENT

1. **Can you tell me about your family/social environment?**
   Possible prompts
   - What is your relationship with the patient?
   - Who else is involved in the care and support of the patient?
   - Can you tell me a bit about the person's life before the injury?
   - What happened on the day of the injury?
     - How do you feel about that?

ROLE OF FAMILY/CARER

2. **What kind of care/support do you provide for the patient?**
   Possible prompts
   - What social, physical or practical things do you do to support the patient's health and wellbeing?
   - What social arrangements do you have in place to assist your supporting role?
   - Can you talk to me about any formal support you have access to? (e.g. carer's leave, access to counselling services)
     - Are there any other services that you need?

UNDERSTANDING PERSONHOOD

- What do you think the term *personhood* means?
  - How do you think a brain injury affects personhood?
  - What important nursing care activities target personhood?
  - What important family activities target personhood?
- Is there anything you see nursing staff do with patients and families that promotes their culture?
- Is there anything you see nursing staff do with patients and families to try and understand their beliefs? (e.g. about life, health, place in society, how the injury happened)
- Is there anything you see nursing staff do with patients and families to try and understand important family / other supportive relationships?

Master Interview Guide_Family_ Version-2_07-10-2020 **Page 1 of 2**

- Is there anything you see nursing staff do with patients and families to try and understand their past life experiences?
- How important are these things (culture, beliefs, life experiences, important relationships) to the way you support your loved one?
- Is part of personhood lost with brain injury, or do you think personhood remains regardless?

FAMILY CHALLENGES

3. **Can you tell me about the hardest things that you face as a support person?**

   Possible prompts
   - What changes in behaviour do you need to deal with?
   - What changes in memory or physical function do you need to deal with?
   - What resources /strategies do you use to cope with these problems?
   - What are your greatest concerns for the patient?

ADVOCATING FOR THE INJURED PERSON

4. **What type of care does the patient need?**
   - In what ways do nursing staff include you or other support people in decisions about patient care?
   - Are there any issues you have raised about the care provided?
   - How do you communicate with nursing staff?
   - How do you communicate with the medical and allied health team?

SOCIAL INTERACTION BETWEEN FAMILY/NURSING STAFF AND PATIENT

5. **What kind of nursing care do you think is important for patients and their support people?**

   Possible prompts
   - What sorts of qualities are vital for nursing staff caring for patients with a head injury?
     - What sort of support do you personally want from nursing staff?
   - What type of nursing care and support do you receive as a family?
     - What works well for you as family/support person?
     - What else could nursing staff do to support you and the patient?
     - What is most important to you in supporting a patient with a head injury

LIFE CHANGES FOR FAMILY / SUPPORT PERSON

6. **How has the support role affected your life?**

   Possible prompts
   - What has changed in your life?
     - How will this alter your living arrangements?
     - How has this altered your plans for the future?

7. **Is there anything else you would like to add?**

7.4.3 Appendix 4.3: Phase 1- Interview guide -nurses

Interview guide for nursing staff participants

I'm going to ask you some questions about your experience working in a TBI setting, and how your care might preserve or promote personhood. If there is anything you don't want to answer just tell me. If you want to stop the interview at any time its ok to tell me that too.

DEMOGRAPHIC DATA

1. **Can you talk to me about your nursing background?**
    - What is your nursing role? AIN/New Grad/RN/CNS/CNE/CNC
    - How long have you worked as a nurse? 0-3/3-10/10-20/>20 years
    - How many years have you worked with people with TBI? 0-3/3-10/10-20/>20 years
    - What decade were you born in?

THE TBI NURSING STAFF ROLE

2. **Can you tell me about your experience with providing TBI nursing care?**
   Possible prompts
    - Why did you choose Neuro nursing?
    - What does your role in TBI care involve?
    - How are you supported in your role?
    - Can you talk to me about some of your experiences relating with patients with TBI and their families? (Good experiences / challenging experiences)
3. **What type of care do you provide for patients on a day/afternoon/night shift?**
   Possible prompts
    - What is the composition of tasks/duties during these periods?
    - How do nursing staff work as a team to provide patient care?
    - Who else do you liaise with during the provision of TBI nursing care?

UNDERSTANDING PERSONHOOD

- What do you think the term *personhood* means?
    - How do you think a brain injury affects personhood?
    - What important care activities target personhood?
- How important is culture to personhood?
    - Is there anything you do with patients and families that promotes their cultural safety or cultural expression?
    - Can you think of a specific example?
- How important are the patient/family's personal beliefs to personhood (e.g. about life, health, place in society, how the injury happened)
    - How do you identify those beliefs?
    - How are you able to support these beliefs?

  - Can you think of a specific example?
- How does the context of the injury influence the way you think about patients or interact with them? (e.g. what if the injury substance use related, self-inflicted or due to reckless behaviour?)
  - Can you think of an example?
- How do you understand a person's family relationships?
  - How important are these relationships in your own care provision?
  - What do you think your role is in relation to families or support people?
- How do you think a person's past life experiences influence their personhood?
  - How can life experiences affect the way they deal with their injury?
  - How do you understand these past life experiences?
  - How important are the person's life experiences in your own care provision?
  - Can you think of an example?

UNDERSTANDING THE CHALLENGES OF TBI NURSING

- Sometimes people with TBI aren't responsive, or have trouble communicating. How do you deal with this?
- Sometimes people with TBI have challenging behaviours. How do you deal with this?
- Sometimes we have to use chemical or physical restraints for people with TBI. Can you talk about your experiences with this?
  - Can you think of examples of how you preserve personhood when people are restrained?
- What are the social, physical or practical things you have to do for the patient/family?

THE IMPACT OF RESOURCES ON PERSONHOOD

- How does your 'team' make up, environment and resources either support or challenge personhood?
- How does your own education or level of experience either support or challenge your patients' personhood?
- What are the hardest things about nursing people with TBI?
  - Can you suggest some practical solutions to these challenges?

SUPPORTING FAMILIES

- How do you involve families/carers in the provision of patient care?
  - What sort of things do you talk to families about?
  - How do you handle patients or family members' concerns or complaints?
  - Are there any supportive resources for addressing patient and family concerns?

ENHANCEMENT OF NURSING PATIENT CARE

4. **How does your workplace enable care that preserves personhood?**
5. **How would you like to be supported in your role?**
   Possible prompts

- What other assistive services would you like to be provided with?
- Can you think of any organisational practices/policies that may influence the nursing care and support you provide for patients or family/carers?

6. **Is there anything else you would like to add?**

7.5 Appendix 5: INTERVIEW GUIDES USED IN PHASE TWO

7.5.1 Appendix 5.1: Phase 2-Interview guide -patients, family members and nurses

Interview guide: Patients

1. General question about personhood (from original interview guide)

   I am interested in knowing what things are important for you during your rehabilitation journey

   - How do you talk to nurses or others about what you would like?

   Possible prompts

   - What sort of things do nurses do that are most helpful to you?
   - What are the things that they do that you don't like?
   - Is there anything that you wish nurses would do to help you feel more like a person?

2. Some people find that being a patient in a rehab Unit has made it harder for them to make decisions for themselves. Can you tell me about any difficulties that you find about making decisions for yourself.

   Possible prompt

   - Can you give some examples?
   - Who do you talk to when you want to make your own decisions?

3. What do nurses do to include you in decisions about your care?

4. Can you give me an example or 2 of when nurses do this really well? Can you tell me about when they don't do this well and what this is like for you?

5. What kinds of situations cause tension between nurses and patients? Can you give me some examples.

6. There are lots of different types of clinicans (e.g. doctors, physio therapists etc) involved in patient care. When there are so many people involved, how do you communicate your needs?

7. Some patients talk about how nurses help them to gradually do more for themselves. Have you experienced that? Can you tell me how the nurses here gradually help you do more for yourself?

8. Are there ever times that nurses want you to do something that you don't feel ready to do? How do you manage the situation?

1

9. Have you ever had to wear restraints or not being able to move around freely in the rehab Unit?

   Possible prompts

   - Can you tell me about that?
   - How did it make you feel?
   - From your perspective could this have been done better?
   - Do you ever feel you are not allowed to take small risks?

10. What are your thoughts about rehab being a locked Unit?

    Possible prompts
    - Tell me how you feel being in a rehab Unit?
    - What changes would like to see in rehabilitation care?

Thanks, that is all the questions I have to ask. Is there anything else you would like to add?

Interview guide: Family

1. Can you tell me a little bit about [NAME]

2. Personhood question (from original interview guide)
   -What do you think the term personhood means?

   Possible prompts

   - How do you think a brain injury affects personhood?
   - What important nursing care activities target personhood?
   - What important family activities target personhood?

3. How do nurses go about getting [NAME] to gradually do things for themselves?

4. Are there ever times that nurses want [NAME] to do something that he/she doesn't feel ready to do? How do you manage the situation?

5. Has [NAME] ever had to wear restraints or has not been able to move around freely in the rehab Unit?
   Possible prompts

   - Can you tell me about that?
   - How did it make you feel?
   - How do you think it made him/her feel?
   - From your perspective could this have been done better?
   - Do you ever feel [NAME] was not allowed to take small (calculated) risks?

6. Some families have said they participate in providing personal care for their loved one during rehabilitation (such as bathing them or cleaning their teeth), Is this something you have done?
   Possible prompts

   - How do you feel about that?
   - Have the nurses helped guide you in how to do this?
   - Does doing these things help you in any way in dealing with the injury and recovery for (NAME)?

7. Have you ever been asked to supervise (NAME) when nurses aren't present? - -- How do you feel about this?

8. Thinking over the time that your loved one has been in hospital, I suspect some nurses are better at making you feel involved in care and decisions than others. If this is the case, can you give some examples of when nurses do this well?

9. Can you think of examples when nurses may have made you feel excluded from care and decision making ?

10. What kinds of situations cause tension between nurses and patients?

11. What kinds of situations cause tension between nurses and family?

12. Families probably know all sorts of things about their loved one that clinicians don't know. Is there any particular knowledge that you bring that should be considered in decision making?
    Possible prompts
    - Have you had the opportunity to bring that knowledge to clinicians? And if so, how was that received?
    - Do you have different priorities as a family member?
    - Did you ever feel any difficulty in having your opinions heard or used in care?

13. Sometimes there are lots of different types of clinicans (e.g. doctors, physio therapists etc) involved in patient care. How do you navigate this as a family member?
    Possible prompt
    - Does it make it hard to communicate your needs?

14. From the interviews I have had so far, it feels like the closer someone gets to discharge, the more that the role of the family moves to the foreground, I am interested in your thoughts about this. How has your role and your decision making changed over the course of [NAME's] admission?

    -How have nurses influenced your sense of being able to cope as discharge gets closer?
    -How ready do you feel to support your loved one at home?

Thanks, that is all the questions I have to ask. Is there anything else you would like to add?

Interview guide: Nurses

1. Question about understanding of personhood (from original interview guide) (only ask if never interviewed before)
   The aim of this study is to try and understand how nurses promote personhood for people with a TBI. What does the term *personhood* mean to you?

   Possible prompts

   - How do you think a brain injury affects personhood?
   - What important nursing care activities target personhood?

2. A lot of rehab nursing is about monitoring and maintaining physiological stability and safety. Do you think these nursing activities support the patient's personhood in any way? If so, how?

3. Some nurses describe using family members to help supervise or give personal care to the patient. Do you think engaging the family in these tasks supports the patient's personhood in anyway? If so, can you tell me about that?

   Possible prompts:

   - How do you go about engaging family in these types of activities?
   - Do you ever have difficulty in engaging family members to take part in care activities or monitoring the patient? Can you tell me about that.
   - Why do you think some people do and some people don't want to engage?

4. How do you go about involving family in decision making? Why do you do this?

5. Do nurses' values and beliefs influence how they promote a patient's personhood? Can you please provide some examples?

   Possible prompt

   - Are there any specific nurse characteristics associated with promoting personhood for the patient? (or person-centred care if they don't seem to understand the personhood thing)

6. Does a nurse's' level of experience or expertise influence how they promote a patient's personhood? Can you please provide some examples?

7. There are probably times when having to bring lots of other people into a decision making process makes your role more complex. Can you think of examples of where having lots of people involved makes decision making harder?

8. Can you think of examples where having lots of others involved in decision making makes things easier?

9. What happens when you can't meet the preferences of patients and family member? This might be in relation to things like food, or rehab routines

Possible prompts

- Does this create tension?
- If so, how do you navigate this?

Guidelines

10. Some rehab facilities have quite strict guidelines set by e.g allied health. Is this the case for your facility? Can you tell me about how nursing and allied health work together here?

Possible prompts

- If so, in what circumstances does working with allied health make your work easier?
- Are there any circumstances where working with allied health makes your work harder? If so, give me some examples
- Does the need to work with allied health ever override your own clinical judgement?
- If so, what is that like to have your clinical judgement overridden?

11. What are the consequences if nurses don't follow the set guidelines?

12. How do you know you have to stick to the guidelines? Is it written down somewhere or is it something that everyone just does?

13. How do guidelines influence your capacity to give person centred care?

14. Are you ever able to negotiate the content of the guideline? What kind of things make it easier or harder to negotiate these guidelines? (Was it only about power and authority, or were there other factors e.g., exhaustion due to lack of staff)

Possible prompts

- If you can't negotiate the content of the guideline e.g. because it is afterhours, do you find ways to work around them?
- Do these work arounds complicate your job?
- Does having to work around rules in the middle of a shift affect you emotionally?
- Does it have any impact on patient care?

15. Are there any other organisational policies that influence how nurses provide patient care?

    Possible prompts

    - If so who makes these policies?
    - How do nurses navigate these policies?
    - How do these policies hinder/support promoting personhood for patients?

Handing over the baton

16. Nurses may have a particular role the closer someone gets to discharge; I am interested in your thoughts about this.

Possible prompts

- Tell me more about the role of nursing in relation to patient discharge
- Who do nurses relate with to prepare patients for discharge?
- Are there any difficulties for nurses during getting patients ready for discharge?

17. There may be patients who are still unable to make decisions for themselves about day to day things as their discharge gets closer. What is your experience with this?

    Possible prompts

    - How do nurses work with this situation?
    - What do you think this means for families?

18. Do you find many patients who do not have family around to support them?

    Possible prompts

    - What does this mean for the personhood of the patient when family is absent or present?
    - If so, What does this mean for the role of nursing?

19. How does the balance of decision making change between nurses and families as the person gets close to discharge? What kinds of things create tension or complexity between nurses and others as the person gets closer to discharge?

20. Going home is kind of a risk; how do you start to prepare patients and families for calculated risks as their independence grows?

Thanks, that is all the questions I have to ask. Is there anything else you would like to add?

7.6 Appendix 6: Research Data Management Plan

Research Data Management Plan (RDMP template)

The Data Management Plan can be used in a number of ways to assist with data management planning.

These include:

- To identify a series of issues and underlying questions that should be considered when planning a research project and initiate discussions within a project (team)
- For the development of a data management plan
- To raise awareness of good practice when planning for data management during the life cycle of a research project.

The RDMP is informed by the requirements set out in the Australian Code for the Responsible Conduct of Research, the UK Digital Curation Centre Checklist and current SLHD governance practices.

Use the template effectively to develop a data management plan by providing detailed and descriptive responses to the following questions. Please provide as much descriptive information as possible and indicate 'Not Applicable' (N/A) for those elements you determine are not relevant to your project.

Document History	
Author of this document	Associate Professor Janice Gullick
Author's relationship to the project/data	Coordinating Principal Investigator
Date document created	10/12/2019
Document Version	Two
Date document modified/updated	21 September 2020
Date to review this document	1st March, 2021
Position or person responsible for reviewing the plan, if applicable	Coordinating Principal Investigator (A/Prof Janice Gullick) ,Principle Investigator (Stephen Kivunja),Research Supervisor (Dr Jo River) and Research Supervisor & PI at Royal Rehab (A/Prof Julie Pryor)

Research Data Management Plan_V2_07_10_2020

1.0	ABOUT THE RESEARCH PROJECT	
1.0	Project title	Social processes that promote and preserve personhood in TBI nursing care in hospital and rehabilitation settings
1.1	Project description	This study aims to develop a theoretical understanding of the social processes that promote and preserve 'personhood' for people who have experienced a traumatic brain injury (TBI), and are receiving care in an intensive care unit, an acute neuroscience ward or an inpatient rehabilitation centre. The study will be conducted at Royal Prince Alfred Hospital, Royal North Shore Hospital and the Royal Rehab, Ryde. Participants are people with TBI, their family members or support persons, and neuroscience or rehabilitation nursing staff. Participants will take part in semi-structured interviews and/or field observations of care. Data will be analysed using a qualitative research method known as Grounded Theory which is designed to develop a theory about a subject that is dependent on social processes.
1.2	Date project commenced/ing	2020
1.3	Estimated date of project completion	2024
1.4	Name of Chief Investigator	Coordinating Principle investigator: A/Prof Janice Gullick Principle Investigator: Stephen Kivunja
1.5	Name/s of Partner Investigators	Dr Jo River, A/Prof Julie Pryor, Elaine McGloin, Vicki Evans
1.6	Name of Supervisor (if applicable)	A/Prof Janice Gullick
1.7	Primary contact for the data	A/Prof Janice Gullick
1.8	Name of Department/Centre	Susan Wakil School of Nursing and Midwifery, The University of Sydney
1.9	Lead partner organisation	The University of Sydney
1.10	Other partner organisations	The research team includes senior clinicians at the Sydney Local Health District, Northern Sydney Local Health District and Royal Rehab.

2.0	FUNDING BODY
Provide details of relevant funding bodies and their Grant application numbers.	
The University of Sydney Postgraduate Research Support Scheme. (No grant numbers)	

3.0	DATA TO BE PRODUCED
Describe the type of data; its characteristics and features; the methods or processes for producing the data; expected file formats; use of existing or third party data and any requirements associated with its use.	
Type of data will be produced, collected, generated or captured during the project?	Demographic and clinical data: age, gender, cultural background, length of stay, mechanism and severity of injuries, procedures, functional status In-depth interview data Field observation data.
How will the data be captured, collected or created? (describe process)	Semi-structured interviews with people with traumatic brain injury (TBI), family members and nursing staff will be audio-recorded and later transcribed for analysis and interpretation. The primary researcher will also observe how participants interact during nursing care delivery, creating field notes in hard copy that will be transcribed into deidentified electronic form.
What tools, instruments, equipment, hardware or software will you use to capture, produce, collect or create the data?	Researcher- primary instrument for interviews and observations. An interview guide and observation guide will help to structure this data collection -A digital audio-recorder will be used to capture semi-structured interview data -Other equipment will include: Laptop computer, Note pads, pens, and paper -Video conferencing equipment
What are the expected file formats of the data that will be captured, produced or created?	Interviews will be captured by way of audio-recording. These files will be created in a digital/MP3 format. The field observation notes will be recorded in a note-pad/paper form using only a participant code.
Are these file formats based on open standards, non-proprietary or widely used, documented and supported?	The audio data will be MP3 files. The audio transcripts and transcribed field notes will be in word document format. Labelled with a participant code.
Will the project use existing or third party data as part of the	Only existing eMR demographic and clinical data, and first party interview and observation data will be used.
Are there any requirements for use of third party data such as licensing	No

4.0	DATA DOCUMENTATION AND METADATA
Provide details of: any supporting information to be developed or documented; any metadata standard, controlled vocabularies or ontologies that will be used to describe the data; quality assurance processes(calibration, validation, etc) to be applied to the data; and any processes that will be followed for documenting or organizing the data such as file name conventions, directory structures, etc.	

What supporting information/documentation will you create to enhance understanding of the data? e.g. codebooks, data dictionaries, data definitions, publications, websites. (please attach data dictionary as appendix to this document)	Data definitions for clinical and demographic data have been provided as an appendix
Are you using any metadata standards, controlled vocabularies or ontologies to describe the data?	Qualitative data will be interpreted using a social constructionist approach.
Are there any Quality Assurance processes that could be applied to your data? e.g. calibration, validation, transcription, peer-review etc.	Transcription will be verbatim by the researcher or by a secure professional transcription service. Data transcribed professionally will be reviewed for accuracy. Initial coding will be conducted by 4 researchers. Supervision team for peer-review.
What processes will be established and followed to document and organise data? i.e. version control, filename conventions, directory structures etc.	Version control will be facilitated by filename conventions, updated with each version and date.

5.0	DATA STORAGE AND SECURITY
Describe data storage and security arrangements: estimated size/amount of data; the location of where the data will be stored; the location of where the data will be backed-up to; frequency of back-up procedures and person responsible; how access to the data will be managed; any security or restriction issues relating to access or storage; and details of any physical or non-digital outputs that need to be stored including their location.	
How much data are you likely to collect/generate throughout the project? (numbers of records/patients/surgeries or sizes of files /sizes of databases) Where will the data be stored during the project?	We anticipate an approximate number of 8– 20 in each group of participants (patients/ family members / nursing staff) per site. Deidentified data will be stored on a password protected University of Sydney computer.
Will your data be backed up, by whom, how often, where?	Data will be backed up by the primary researcher in the University of Sydney Research Data Repository as acquired.
How will access to the data be managed during the project?	Access to data beyond the primary researcher (PhD student) will be limited to the student's supervisory team in deidentified form.
Are there any commercialisation, ethical or confidentiality restrictions relating to accessing or storing the data during the project?	No, apart from the standard confidentiality concerns. Data will remain confidential.
Is there any non-digital data or outputs that the project will generate? Where will these outputs be stored?	1) Deidentified observation notes (marked by participant codes) will be stored in a secure locker at the University of Sydney until transcribed. They will then be destroyed (shredded) once transcribed. 2) Any video-conferenced interview will be retained as an audio file only. The video file will be permanently erased to protect participant confidentiality. The audio file will be stored in the University of Sydney Research Data Repository.

6.0	ETHICS, COPYRIGHT, IP AND AUTHORSHIP
Provide information on Ethics, copyright and IP arrangements : methods used to manage sensitive, confidential or private information; details of any restrictions due to ethical or privacy considerations on the data; information for consent forms relating to retention of the data and protection of privacy and confidentiality and steps taken to manage these (de-identification, etc); details of any agreements reached with partner organizations concerning ownership of the data; any copyright or licensing restrictions; or legislative regulations or requirements associated with collecting data from/sending to countries/locations outside of Australia.	
Does/will the data contain sensitive, confidential or personal information? If yes, what methods will be used to protect the data e.g. encryption, password restrictions etc.	Data will contain sensitive and confidential information. Data from interviews will be stored in de-identified form where pseudonyms will be applied

Are there ethical/privacy considerations surrounding the ability to share/publish the research data outside the immediate research team?	Data will not be shared. Findings will be disseminated through conferences and peer-reviewed journals in a way that does not breach participant confidentiality. (Noted in participant info sheets).
If intending to share any part of the data, do your participant consent forms include information about intentions for sharing, retention of data and steps taken to protect participants privacy and confidentiality?	We do not intend to share data.
What steps will be taken to protect privacy and confidentiality? e.g. de-identification, re-identification or anonymising data.	Transcripts will be labeled with participant codes, and participants will be referred to by pseudonym. No data stored with identifying details. Minimal or pooled participant characteristics will be reported if detail threatens confidentiality.
Has an agreement about the ownership of research data and primary materials been reached between partner institutions? Provide details. If the agreement is in writing, add as appendix to this RDMP	3 investigators from the Sydney and Northern Sydney LHDs and Royal Rehab have been provided with the Research Protocol stating that "The Intellectual Property generated from the study is owned by the research team and the intellectual property rests with the primary researcher."
Are there likely to be any copyright restrictions that will apply to the data?	No
Will the data be collected in or transported to another country or area outside of Australia? Are there any legislative requirements to meet?	No
Have you considered and discussed authorship? Who are the intended authors of any products of the research project?	Stephen Kivunja (PhD student) will be the first author. Other authors will be the supervisors (A/Prof Janice Gullick, Dr Jo River). Co-investigators from LHDs have been offered contribution and authorship on resulting publications.

7.0	ACCESS, SHARING, REUSE OF DATA
Provide information on access, sharing and reuse arrangements including : what data or non digital outputs will be retained on completion of the project; where will these be stored; will some/all of the data be shared or published; any restrictions that negate sharing or re-use of the data; any requirements for mediating access to the data; what supporting information will be available to assist with interpretation of the data; what processes or steps will be taken to protect privacy and confidentiality; intent to deposit in data repository or archive; how soon after completion of the project can the data be shared; and any costs associated with making the data available for sharing or re-use.	
Will part/all of the data be retained on completion of the project? Where will this data be stored?	Deidentified data retained for a minimum of 5-yrs and stored in the University's secure Research Data Repository. It will then be destroyed, pending completion of research reports
Where will non-digital data be stored post project?	Non-digital data (observation field notes) will be transcribed to electronic form, and hard copy destroyed (shredded)
How will access to the data be managed post project?	CI (A/Prof Gullick) and PI (Stephen Kivunja) will take joint responsibility for ongoing safe/secure storage and disposal of research data according to this data management plan and the University of Sydney's Research Data Management Policy (2014)
Do you plan to share some/part of the data post project? Will the data be deposited with an archive or repository or published on the web?	No
Are there any restrictions placed on sharing/reuse of some/all of the data?	Yes. No data will be shared
Can these be managed by setting mediated access to the data? e.g. access to the data must be negotiated via Chief Investigator.	Qualitative data is of minimal use when removed from its context, and there may be unique events and experiences in raw interview data that could render people identifiable in small connected communities. There will be no data sharing.
What supporting information to assist with interpretation of the data will be made available? How will the information be made available?	A data definition list will be maintained to assist accurate use of demographic/clinical data. This data will be used to understand and describe the context of qualitative interview and field observation findings in published reports. It will not be used in published reports in a way that makes participants identifiable.
How will you ensure that identified processes or steps taken to protect privacy and confidentiality will be achieved prior to completion of the project and sharing of the relevant data.	No data will be shared.
When will the data be shared post project? e.g. immediately, 3 months, 6 months,1 year.	No data will be shared.
Is there likely to be any costs associated with making the data available for sharing or re-use?	No data will be shared.

8.0	DATA RETENTION AND DISPOSAL
Provide information on data retention and disposal, including : how long the data should be retained (in line with University Policy , State Records Act 1998, and/or Funding Body requirements; the disposal date and data disposal approval process that will be followed, in line with University Policy.	
How long the data should be retained for? i.e. permanently, 5 years, 7 years, 20 years, etc	Data will be retained for a minimum of 5 years. It will be retained until all associated publications and conference presentations have been completed.
If disposing of data, outline how will you handle the disposal of sensitive, confidential data	Electronic data will be permanently erased and remaining hard copy data will be shredded.

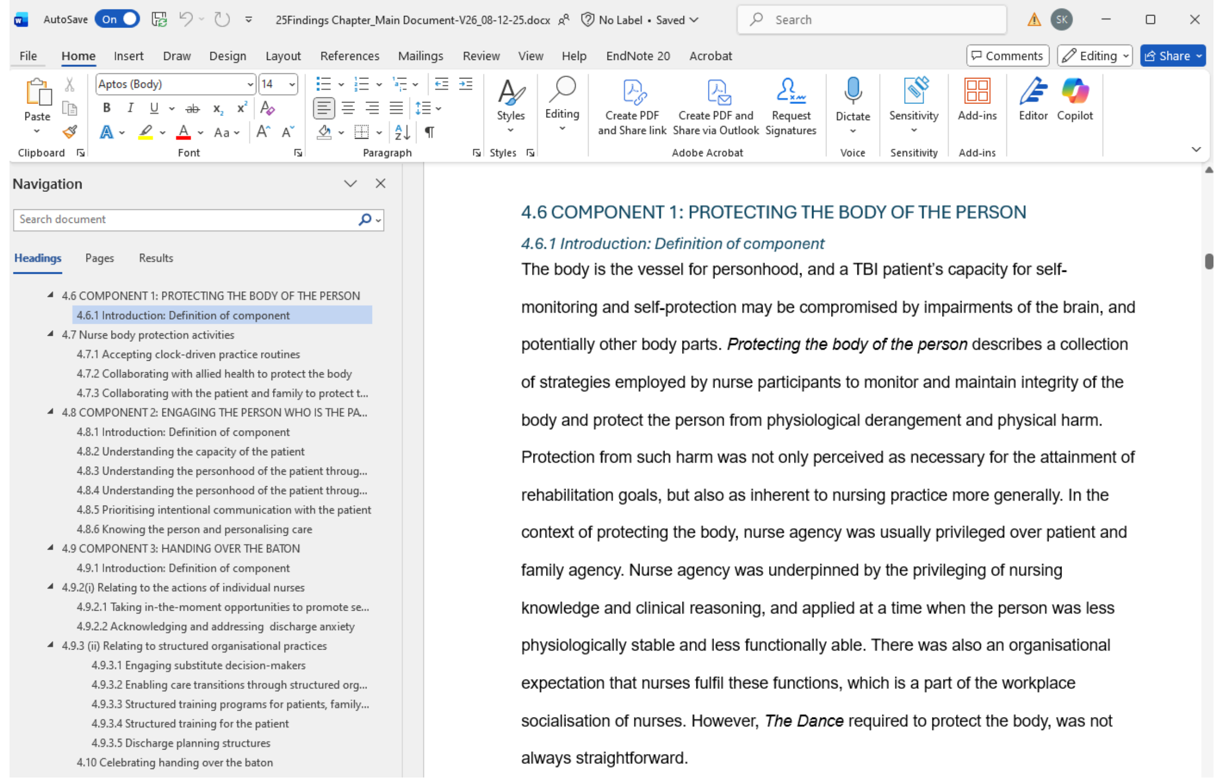
9.0	PRESERVATION & ARCHIVING
Provide information describing preservation and archiving arrangements, including: the sustainable file formats that will be used for long term access; descriptive information details the organization and structure of the data and supporting information that will be made available with the data for re-use and interpretation; the person or position responsible for managing long-term access to the data; and any expected costs associated with long term storage of the data.	
Will the final format of the data files be in a sustainable format supporting long term access? i.e. based on open source standards, non-proprietary.	The format of data files will be in original sustainable format, available for access for a minimum of five years. It will be retained in this format until all associated publications and conference presentations have been completed. It will only be available for access by the Chief and Primary Investigators, and thereafter destroyed.
Will the supporting documentation be stored with the data to enable future interpretation?	Supporting documentation be stored with the data for a minimum of five years. It will be retained in this format until all associated publications and conference presentations have been completed. It will only be available for access by the Chief and Primary Investigators, and thereafter destroyed.
Who is responsible for maintaining the data after the research project is complete? e.g. Chief Investigator, data manager, research assistant.	CI (A/Prof Gullick) and PI (Stephen Kivunja) will take joint responsibility for ongoing safe/secure storage and disposal of research data according to this data management plan and the University of Sydney's Research Data Management Policy (2014)
Are there likely to be any costs associated with the long term storage of the data?	No

APPENDIX

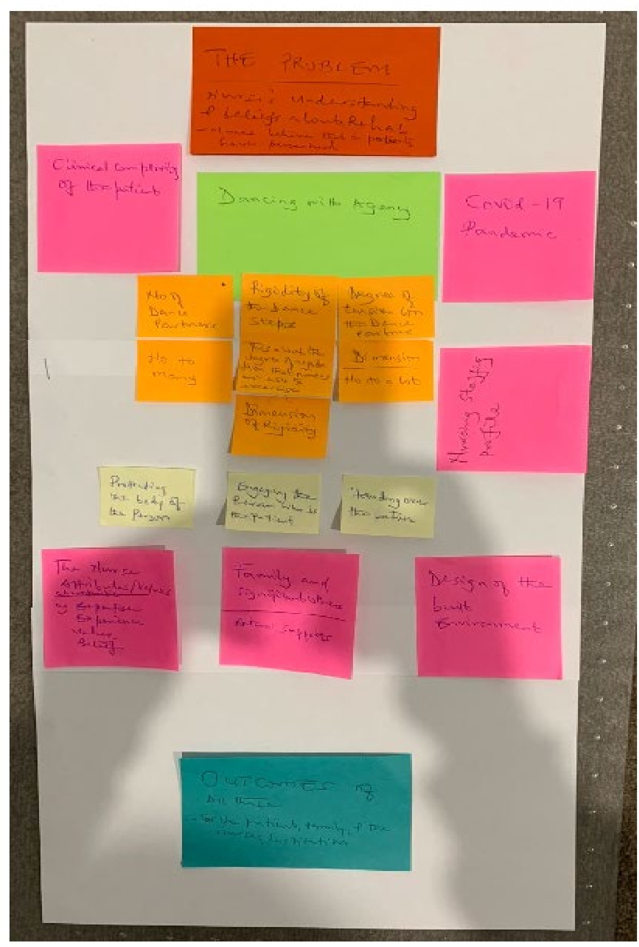
Data Definitions

1. Length of ICU stay: measured in days, by counting the days between ICU admission and ICU discharge from the eMR
2. Length of Hospital Stay: measured in days, by counting the days between ED admission and hospital discharge from the eMR
3. Length of Ward stay: measured in days, by counting the days between ward admission and discharge to rehabilitation setting
4. Length of rehabilitation stay: measured in days, by counting the days from admission into rehabilitation setting from hospital
5. Severity of injury: extent/intensity of head injury
6. Acute Physiology and Chronic Health Evaluation (APACHE) score, this scale categorises the outcomes of patients after traumatic brain injury i.e. severe, moderate and low disability
7. Glasgow Coma Scale (GCS): Scale recording the state of a person's consciousness after head injury for initial and subsequent assessment, measured out of 15 points
8. Activities of daily living (ADLS) e.g. showering, feeding self, and maintaining personal hygiene

7.7 Appendix 7: Example of Navigation pane snippet



7.8 Appendix 8: Post-it-notes



7.9 Appendix 9: Examples of memos

Examples of memos

1) Memo : Coding-data analysis – 03-10-2023 10:00hrs

While coding, there is the Basic Social Process (BSP) that consists of 3 elements i.e. holding control (Nurse led care), negotiation control (personalised care) and giving control (patient led care). There is also other elements of – contextual factors, family involvements and nursing care. How do all these elements fit together within the developing BSP?

2) Memo: Relinquishing control – 31/1/2023 -1900hrs

-The Basic Social Process appears to be shifting to 'Relinquishing control'

-Relinquishing control refers to a process undertaken by nurses that starts with nurses holding control and then ….this notion and handing control over, it is a continuum, nurses come in and out of it as they make decisions .

1a)-Holding control -YES

-System holding control (organisation-BIU,NSW Health, National Standards-the 'Whole' at any level)

-Clinical team holding control – other disciplines -MDT, AH, MT, (Accepted ways of working together)

-the nursing profession holding control -RN standards for practice-NMBA standards/code/guidelines e.g falls risk management,

-the individual nurse is holding control – clinical judgement while in practice

-the family holding control -any factor that the family holds in relation to patient care e.g toiletries, clothes from home

1b)-Relinquishing control to the family (involving family in the care) – bringing in photos

1c)-Relinquishing control to the patient (involving the patient)

1

3) Memo: The Basic Social Process evolution -21/02/2023 -1800hrs

-The Basic Social Process has shifted from 'Relinquishing control' to being one where nurses are 'Valuing the person who is the patient'.

-The definition of personhood falls under three domains i.e Biological Personhood, Relational Personhood and Individual Personhood. An operational definition for each of these three concepts will be developed in relation to literature and participants' interview data.

Structure for data analysis

Valuing the person who is the patient – (Overarching theme)

1(a) Holding control to preserve biologic personhood

1(b) Facilitating relational personhood

1(c) Facilitating individual personhood

For each of the above phases/ stages there will be data that make it visible what the nurses are doing to promote and/or preserve personhood for the patients.

4) MEMO: 4/4/2023 Meeting note

Requirement of the nurses to do rounding is a Contextual Factor

I will need to find out in the next interviews if this is the case

Supervisor X suggested that the system requirements for rounding appear to push practice in a different direction. Do these always preserve personhood? How does rounding impact nurses capacity to provide person centred care?

The system brings the nurse to the patient, but the nurse does something else once they get there. Is this limited to biologic personhood or something else?

5) Memo: Dancing with agency: 17/8/24

This is appearing to be the main category as nurses dance with agency of other nurses and other parties e.g AH, medicine, managers to apply strategies that privilege patients' agency. The dance has four properties : Tension (low and high), Number of dance partners; music in the background; and philosophy of the dance

Memo: Strategies for managing challenging behaviours -10/05/23 -0330hrs

There are several strategies that nurses use to manage challenging behaviours. Some of these appear to be promoting personhood and others appear to be directed at nursing staff aiming at controlling the challenging behaviour by whatever resources are available to them. Should the grouping under the above category of be separated into two sub-categories or presented as one major category?

MEMO: 05/06/2023 -1730hrs Thought from face-to-face-team meeting discussion

This content describes what the 3 non-linear processes or parts (i.e. 1a,1b & 1c) represent/mean in relation to data analysis in this intermediary phase

1(A) Monitoring and maintaining physiologic integrity

This section consists of categories that symbolise that nurses are monitoring and maintaining physiologic integrity for patients. Nurses do not have (agency)/power as to determine what needs to be done. Policies, directives, organisational guidelines appear to direct how care is delivered

- The nurse's agency is constrained by policies, directives, or organisational guidelines and physiological integrity takes priority over the promotion of personal agency.

1(B) Engaging the person who is the patient

- Nurses are engaging the person who is the patient and activate their own agency and clinical expertise to promote the agency or the person, finding in-the-moment opportunities to encourage participation in self-care activities.

-Here the nurses have agency and determine what needs to be done for patients

1 (C) No name yet for this code/category (Advancing independence of the person who is the patient)

Still considering what this is :

- ? Nurses giving agency to the patient, families, cares, community relationships

-The nurses are enabling the patient to take the lead regarding their care

- Nurses are advancing independence of the person who is the patient and use their own agency and expertise to support the person, family, and carers to take-back control and decision-making about daily activities.

Memo: Patient Services Assistants (PSAs) : 17-8-2023 ; 19:28hrs

The role of PSAs is to provide support to the nursing team in the delivery of nursing care to patients as directed by Registered Nurses (RNs). PSAs assist patients with all activities of daily living in accordance with the nursing care plan and under the supervision of a Registered Nurse. They assist in collecting accurate health care information, communicate effectively with patients and health care team members, and are expected to report all relevant information timely and accurately.

Memo: 02-05-2024- Impact of TBI on mental health

There are references to the impact of TBI on mental health for , though these are not extensive in the data reviewed so far. These will be explored across all the interviews to ascertain whether this si a major contextual factor that could be examined at length

7.10 Appendix 10: Storyline - early draft

Storyline: Dancing with Agency

The storyline in grounded theory is an analytical strategy that is intended to facilitate the construction, integration, visualisation and dissemination of a theory that is grounded in data (Birks et al., 2009). The guiding principles utilised to construct a storyline are aligned with the acronym 'TALES', meaning: "*Theory takes precedence* (as the final product of data analysis), *Allows for variation* (an abstraction of theory that makes room for multiple dimensions and negative cases), *Limits gaps* (weaknesses in the developing theory are identified for the purpose of informing further data collection/analysis), *Evidence is grounded* (while an abstraction, the storyline is accurate and valid in drawing together analytical relationships), and *Style is appropriate* (in this case, the style is framed by this document being a tool for the research team to structure and critique the theory (Birks et al., 2009).

This storyline arose from the Constructivist Grounded Theory study that explored how nurses promote and preserve personhood in traumatic brain injury (TBI) care in rehabilitation settings. Key challenges to the capacities of people with TBI that threaten personhood, and lead to the need for nursing care interventions, include: physiological, functional, and cognitive impairments and behaviours that other people find challenging.

The guiding theoretical construct in this study is symbolic interactionism which assumes that "people construct selves, social worlds, and societies through interactions" (Charmaz et al., 2019, p.18). Agency is an important concept in the guiding theory of Symbolic Interactionism, where it refers to "the feeling of control over actions and their consequences"(Moore, 2016, p.1). *Dancing with Agency,* as the basic social process in this theory, is expressed through 1) language (e.g. the words one chooses, whether written or verbal), and 2) symbols that create meaning in interactions (examples could include symbols of authority such as job titles, published policies, and uniforms; symbols that convey meaning about an environment; and body language and actions that carry meaning for the observer).

This storyline describes the theory of *Dancing with Agency* as rehabilitation nurses select (or neglect) strategies to promote and preserve personhood in their care of people with TBI. This *Dancing with Agency* may occur when nurses interact with the others (e.g. personal care assistants, doctors, allied health, families, patients, local managers, and professional organisations or government bodies). There is an interdependence/relationship between these parties who ideally have the patient as the focus of their concerns. Each person or entity will bring their own agency to interactions and sometimes these agencies will compete for priority.

Properties of the dance

The dance consists of five properties: tension(low and high); number of dance partners; music in the background, philosophy of the setting; and impacts of the dance

Tension that rehabilitation nurses encounter

An important property of *Dancing with Agency* is the tension that rehabilitation nurses encounter and negotiate as they deliver care that impacts personhood. The tension (around whose agency is privileged) can vary in its degree. Nurses encounter situations with low levels of tension and high levels of tension. The degree of tension is informed by a nurse's perception of their agency in relation to the agency of others, and whether any one party perceives a need to privilege their own agency above another's. Low tension situations might be characterised by everyone (nurses and others) being aligned with a particular strategy or position. High tension situations might be characterised by situations of conflict or complexity where nurses need to consider whose agency to privilege to achieve the best outcome. Sometimes the best outcome may be the promotion of personhood and at other times, other priorities may prevail.

Number of dance partners

Another property of Dancing with Agency is the number of dance partners whose agency the nurse takes into account (e.g. own agency vs agency of others). The exertion of nurse agency necessitates taking into account agency of others that have capacity (dance partners) to influence/shape patient care. Operating within this context requires nurses to dance with the agency of: patients, family members, managers, members of allied health and medicine. Professional actors have different scopes of practice and responsibilities and may bring a specific disciplinary lens. Patients and families hold different knowledges and interests in relation to a clinical issue. The greater the number of dance partners the more complexity is present in the dance. When the number of dance partners is small (e.g. a two way interaction), there are fewer perspectives that the nurse needs to consider. This may make it easier to determine whose agency should be privileged and to negotiate that agency. When there are many dance partners, nurses' ability to dance with agency effectively depends on the level of collaboration in working relationships, shared knowledge of the situation and shared rehabilitation goals. The contextual factors are that rehabilitation is a highly specialised field; there exists multiple partners that shape what comprises nursing care for patients in rehabilitation.

Music in the background

Another property of Dancing with Agency is the music in the background that the dance relates to (the rules of the dance and prescription of the dance). The music in the background is set by multiple parties. However, a major source of the background music that nurses dance to in TBI rehabilitation are members of allied health who have agency to 'script' or make rules/specifications/ directives/ guidelines that affect/influence nursing agency. The dance occurs when nurses liaise with members of allied health to deliver 'scripted' personal care. At one particular research site, delivering 'allied health scripted care' was mandated and nursing agency was fundamentally supressed. Nurses' have the agency to contribute to allied health dynamic guidelines (these change frequently), although at times there seems to be an uneven two way collaboration between nursing and allied health. Nurses appreciate allied health prescriptions for the dance when such input enhances or arguments nursing care effectiveness. For example the use of communication tools designed by speech pathologists enhances nurses ability to communicate with non-verbal patients thereby supporting the delivery of care that promotes personhood. In other instances, allied health *prescriptions can* hinder the provision of personalised care as patient specification (e.g. cultural preferences, dynamic conditions of the patient that a nurse may access and respond to) are overlooked by prescriptive guidelines. Keeping up with the ever changing allied health scripted guidelines makes it hard for nurses as they have to dance with AH agency in both written (documented) and verbal forms to be able to provide personalised care. Contextual factors include: the dominance/assumed power of allied health over nursing, status of allied health prescriptions, site specific practice, nurses' level of critical thinking, and existence of a range of possible equipment with varying application between patients in rehabilitation.

Nurses agency influenced by uncomfortable compliance with AH guidelines

At one site, delivery of nursing care is mostly guided by allied health agency. Nursing agency toward allowing family members involvement is curtailed by AH guidelines or specifications (e.g. AH mandate prior training for family before participating in patient care). The dance with agency requires being up-to-date with AH specifications and negotiating these along with their rationales with family members who opt or request to patriciate in patient care. Complying with AH specifications present discomfort for nurses as they dance with agency to fulfill AH prescriptions and at the same time addressing views from family members that at times may be in contrast with scripted approach to rehabilitation care.

Nurse agency crafted to navigate around rigid AH guidelines

Some nurses activate own critical thinking to ‘skirt’ around rigid AH guidelines to provide personalised care. The dance is between nurses, patient preferences and AH prescriptions evidence in form of guidelines. Nurse agency works to privilege patients’ preferences over AH prescriptions when these are contradictory to the patients preferred choices of care. Less experienced nurses may be constrained with how to navigate or ‘bend the rules’ around the rigid AH guidelines. Rationale for navigation is aimed at providing patient informed care rather than clinician/AH informed care with a goal of promoting personhood where patient safety is not compromised. Contextual factors include: site specific practice, status (sanction) of AH guidelines, level of critical thinking of a particular nurse.

The music in the background is also symbolised by ‘invisible factors’ that impact nurses’ agency to fulfill their role to the level perceived by patients or family members to be of a high quality. Families have expressed this background music as ‘nurses being understaffed’. Consequences of nurse understaffing are that patients’ incontinence needs are not addressed promptly, there is increased use of restrictive practices that limit personal agency, and family members decrying substandard quality of care/missed care. The dance occurs when nurses explain their actions or inactions to patients or their families for the missed care/perceived inefficiency. A contextual factor is that there is a shortage of nursing staff which is a limiting factor to staffing levels withing the rehabilitation setting.

Another example of the music in the background are the rules of the dance which mandate that the rehabilitation settings are locked environments. Patients are confined within these settings with restrictions on freedom of movement. Nurses have reported that some patients described their rehabilitation world as feeling as though they are in a prison and do not want to be there. The dance with agency is witnessed as nurses device/contemplate ways to negotiate providing meaningful patient care in the context of patient dissatisfaction with their rehabilitation environment. A contextual factor is that rehabilitation settings are kept locked to promote patient safety as some patients may have impairments (cognitive/physical) that put them at risks for getting disoriented regarding their whereabouts, harm to others, falls or absconding. Nurses also dance with background music in the form of the ever changing ‘tunes’/allied health directives regarding how patient care is to be delivered (e.g. during transfers or feeding). Failure to be abreast with current changes leads to delivery of incongruent nursing care that is decried by families when witnessed. A contextual factor is that rules ‘governing’ rehabilitative care are dynamic and some nurses may not be knowledgeable about current updates.

Philosophy of the setting

Another property of *Dancing with Agency* is the philosophy of the setting (inpatient rehab in general) in which the dance is taking place (that may provide the theme of the dance). Nurses have reported the goal of rehab as: getting the person ready to go home; getting the

person as close to normal as possible; facilitating the regaining of functional capacity; maximising independence in the context of the person's ability; 'giving the patient's life back'. Nurses dance with agency involves acting as facilitators to advance rehabilitation goals that are often set by patients and their families. Nurses prioritise patient's agency and promote/encourage independence with basic ADLs. The role of nurses is to facilitate the engagement of the patient in self-care and not '*to do it all*' for them. The dance also involves nurses continuously exploring that patients' are aware of their rehabilitation goals. Nurse agency is focussed on maximising personal capacities and encouraging patients' participation toward attainment of specific pre-set personal goals.

Consequences of nurses engaging in the dance

These are outcomes for nurses, dance partners and the organisation. (Will appear at the end of the theory)

There are notable outcomes for *Dancing with Agency* for nurses, dance partners and the organisation. The outcomes for nurses are physical, emotional, mental, and psychological in nature. These are generated by patients with TBI who present with behaviours that nurses and others find challenging. Nurses have reported being victims of assault, having objects thrown at them, spat at, threatened, felt scared of turning up for duty, being tired, emotionally drained and calling in sick on rostered days. Physical harm from patients can generate traumatic experiences, distress, emotional and psychological discomfort for nurses. Nurses are prone to being in the 'arms way' for patient-harm due to the nature of nursing work necessitating being in close proximity with patients. The dance is shaped by how each nurse navigates the consequences of being a victim of '*clinical harm*' and yet continue to provide care that promotes personhood for patients. Some nurses have expressed being in a dilemma and contemplated leaving their jobs, another form of dancing with their agency. The contextual factors are that patients with TBI may present with a variety of behaviours that others find challenging, and caring for this category of patients can generate physical and emotional outcomes.

PROTECTING THE BODY OF THE PERSON

Definition of phase and its relation to personhood in rehabilitation nursing

In this phase, rehabilitation nurses use various strategies to protect the body of the person who is the patient from physiological and physical harm. Body is the vessel for

personhood and patients' capacity for self-monitoring and self-protection may be compromised by the impairments of the brain and potentially other body parts. Protection from such harm facilitates working toward attainment of rehabilitation goals. In this phase nurse agency is usually privileged over patient and family agency by nurses monitoring and maintaining physiological integrity, and monitoring and maintaining physical safety. Nurse agency is underpinned by the privileging of nursing knowledge and clinical reasoning at the time when patients may be less physiologically stable and less functionally able. There is an organisational expectation that nurses fulfil these functions and is part of the socialisation of nurses.

(i) Monitoring and maintaining physiological integrity

Rehabilitation nurses enact various strategies to monitor and maintain patients' physiological integrity. Physiological integrity (e.g. homeostasis) is vital to the promotion of personhood in rehabilitation nursing as the patients' ability to participate in any form of therapy is influenced by their level of physiological stability and function.

Nursing strategies used to monitor and maintain physiological integrity

Nursing strategies that are used to monitor for physiological integrity include: observation of vital signs, blood glucose monitoring, observing for swallowing, nutrition, elimination; observing for skin integrity. The patients' physiological deficits may introduce specific physiological risks such as the risk for: aspiration, infection, and multi-organ failure (e.g. in the case of sepsis). Nurses monitor to enable early intervention.

Nursing strategies that are used to maintain physiological integrity include: feeding, hydration, periodic patient repositioning, medication administration, request for medical review.

Nurses often delegate or enable family members to contribute to the monitoring and maintaining of physiological integrity. Common tasks conducted or assisted by family are showering, teeth cleaning, feeding, transfers and exercises. There is suggestion in the data that families may at times clean patients after episodes of incontinence.

(ii) Monitoring and maintaining physical safety:

Rehabilitation nurses participate in monitoring and maintaining physical safety with the intent of minimising or preventing harm for patients. Physical safety is paramount for the person receiving rehabilitative care and forms the foundation upon which the will/ability to participate in therapies is built.

Nursing strategies used to monitor and maintain physical safety

Nursing strategies that are used to monitor for physical safety include: assessment for falls risk, assessing for patency and security of clinical/assistive devices; monitoring patient emotional cues (e.g. for aggression), monitoring for emotional safety, risk of absconding , monitoring the patient's immediate environment and its appropriateness, and one-to-one nursing allocation.

Low tension encounters while Dancing with agency

Agency is shared through accepted practice routines:

A key contextual factor is that rehabilitation nurses are socialised to attend to routine tasks in a way that is often clock driven. Nurses adhere to routines when performing tasks that pertain to protecting the body of the person for aspects pertaining to both physiological integrity and physical safety. Completing practice routines may require nurse to dance with the agency of others in order, for example the permission of patients, the engagement of families and the priorities of other staff. The focus on the timing of tasks might have a clinical imperative (e.g. blood glucose monitoring before meals), a work flow imperative (having patients showered before their physical therapy sessions) or an organisational safety imperative (e.g. hourly rounding). Because nurses are socialised to value these routines and their imperatives, even when the routines are demanding, there is often little tension between a nurse's agency and the workplace that holds these expectations.

Patients are also commonly socialised to fit with these routines. The *Dance with Agency* remains low tension where the patient sees the routine as a reflection of a nurse's thoroughness, competence and consistency, which makes the patient feel valued and safe. Low tension also prevails when patient comfort is a focus of the nurse's routine (e.g. changing the patient into their personal clothes at the end of the day and scheduling times for relaxation), given the concordance between nurse and patient agency. This focus on patient comfort may be a contextual factor (or a manifestation of a broader nurse characteristic) that resides within the individual

nurse with this priority engrained in varying degrees in the clinical duty of care that they have toward the promotion of personhood.

When the nurse perceives a patient as not ready to engage with a routine, the *Dance with Agency* remains low tension when the nurse takes a flexible approach to delaying or reordering tasks. A contextual factor might be the nurse's confidence, their sensitivity to the patient's dynamic energy levels and emotional state, and the importance to the nurse of the timeliness of the task to patient safety.

Agency ceded by the nurse to a perceived higher authority

When nurses willingly concede their agency to a perceived higher authority in the system, there is low tension. In such scenarios, nurses prioritise their scope of practice, the authority of policies and their position in the clinical or organisational hierarchy and aim to work within this 'confined space' when exercising their agency. The low tension in this dance is further supported when the position of these higher authorities makes clinical and moral sense or is framed in the context of risk reduction. A contextual factor is that the health system is hierarchical and many rehabilitation therapies administered by nurses are predominantly prescribed by others.

Agency negotiated by nurses through collaboration

Potentially complex situations can remain low tension for nurses when a collaborative culture means that problems are anticipated, plans put in place with input from other team members, and ongoing multidisciplinary evaluation and adjustment of care occurs. Low tension is further enabled when nurses include families in the collaboration, particularly where a clinical approach might be distressing, such as in the use of restraints. Even though nurses and other parties involved in decision making might have differing views, the low tension negotiation of agency is made easier when multiple patient factors are considered in relation to promoting personhood.

When working collaboratively, nurses frequently bring family members into the work of protecting the body of the person that requires monitoring and maintaining physiological integrity. Requesting family to 'keep an eye out' for their loved one may lead to a low tension collaboration when the family has a sense that this facilitates their own agency to express any issues they observe. Including those families to either observe or take over some elements of body care occurs as a low tension situation when it increases the family members sense of connection, contributes to patient comfort, or is framed as preparing them to support care after discharge.

Contextual factors are the frequency and duration of the family's presence on the unit and their willingness and confidence to engage in these activities.

Nurse agency supported by clinical reasoning

When protecting the body of the person (during the monitoring and maintaining of physiological integrity), nurses may need to negotiate when there are multiple opinions about a particular direction of care between themselves, patients, family and other staff. When a clear clinical rationale is at the centre of this negotiation and is accepted by all, this dance is one of low tension. Contextual factors are the patient's and family's capacity to understand that rationale and the nurse's confidence and ability to explain that rationale in an accessible manner.

High tension encounters while Dancing with agency

Limited resources negatively impacting nurse agency

As a result of limited resources in rehabilitation settings, the level of staffing may be perceived as inadequate in relation to the patient load, and some patients require 24/7 observation that is not serviced. Patients with TBI may be unable to attend to their self-care needs, and the nurse's agency or capacity to co-opt others to take responsibility for this care may be constrained. In such cases, nurse agency can be diverted due to competing priorities. Consequently, the nurse's ability to perform a dance that protects the body may also be suppressed in due course. Families describe epidemic understaffing as leading to missed care, and the resulting concern creates tension in the nurse-patient-family relationships.

When understaffed, a nurse's dance with agency may mean extending their duty of care for the patient to the family, or the family may use their own agency to take on these tasks in the absence of the nurse. In some cases, no one directs their agency to solve this issue, and the task remains neglected, causing distress and threatening dignity and personhood. An alternative family perspective is that missed care arises from an individual nurse's lack of competence rather than from understaffing. The inability for usual staffing levels to accommodate 24/7 patient observation is cited as a reason for high levels of restraint use in rehabilitation settings.

Nurse agency in the context of multiplicity of patient incapacities

Nurse agency can be challenged when patients have a multiplicity of physical needs that require shaping through diverse multidisciplinary input e.g. prescribing supportive devices and their application, safety requirements (e.g. bed alarms), and processes for transfer and mobility. Some of these interventions could be sources of patient discomfort and/or may require patient input and cooperation to fulfil. This situation increases the tension as nurses dance with the agency of all parties and manage their own expectations while addressing the rehabilitation goals. Contextual factors are the nurses' familiarity with the patient, the skill of the nurse, the patient's physical limitations, their prescribed care requirements and the nurse's general knowledge of rehabilitation aids.

Nurse agency when patient agency is exerted in ways that are deemed unsafe

A fundamental contextual factor is that some patients with TBI have cognitive impairment that may affect judgement, insight and impulsivity. While a person may use their agency in ways that makes sense to them, a nurse may perceive their behaviour as creating unacceptable risks to the person themselves, to other patients, to families, and other staff. This perceived unsafe exertion of patient agency leads to frequent use of seclusion and restraint that can cause moral distress among a range of parties. The source of this moral distress is the denigration of personhood. The frequency and subsequent distress increases the tension in the dance with agency. The legal and policy framework that promotes the principle of least restrictive practice may also increase the tension as nurses balance the safety of all parties. The nurse can better manage the *Dance* when the clinical rationale for restraint is explicit, the level of restraint or seclusion is matched to the level of risk, there is medical and psychiatric review of the restraint order and the family are engaged in discussions about the rationale and plan. Understaffing makes it harder for patients to exert their agency safely.

Nurse agency disrupted during COVID-19 pandemic

The COVID-19 pandemic changed the way nurse agency operated in the clinical environment creating many high tension encounters. Government mandated practices included: no visitors or visitor restrictions impacting the agency of nurses, patients and families: and mask wearing that could hamper verbal and non-verbal communication between nurses, patients, families and others , changing the way that patients receive messages including their interpretation of facial expressions as symbols of meaning. The increased tension while *Dancing with Agency* often resulted from a change in the nurse's priorities. To maximise efficiency, nurses would attend to as many duties as possible in one encounter to reduce the number of times they

would have to change personal protective equipment (PPE). Due to fear of taking COVID-19 back to their families, nurses would limit their time with infected patients. Nurses who developed COVID-19, had mandatory stay at home periods that adversely impacted staffing levels. Patients who contracted COVID-19 were nursed in single rooms with restrictions on movement within the rehabilitation setting. This practice negatively impacted personal agency and amounted to denial of personhood.

Any inconsistencies or gaps that jump to mind

-There are some commonalities between monitoring & maintaining physiological integrity Vs monitoring and maintaining physical safety. For example the routine practices such as periodic patient rounding that aims to address both categories

-There are some instances/situation where there is no tension e.g. when nurses are using routine interventions/strategies

ENGAGING THE PERSON WHO IS THE PATIENT

Definition of phase and its relation to personhood in rehabilitation nursing

Engaging the person who is the patient is the phase where rehabilitation nurses have agency and determine what needs to be done for patients. Nurses use various strategies to facilitate the person who is the patient to enact their agency. Nurses prioritise the agency of the patient by finding in-the-moment opportunities to encourage participation in self-care activities. Facilitating patients' ability to enact own agency contributes to the promotion of personhood in that the person is empowered to have a sense of autonomy and self-determination.

Nursing strategies used to engage the person who is the patient

Nursing strategies that are used while engaging the person who is the patient include: privileging patient preferred choices in relation to care, promoting the ability to develop patient informed rehabilitation goals, encouraging participation in personal care, and facilitating the person's decision making about own care.

Low tension encounters while Dancing with agency -category specific

- Category-specific, but general examples of low-tension situations (including contextual factors)

Nurse agency activated to understand the personhood of the patient

Nurses seek to understand the personhood of the person who is the patient by enabling patient focused goal setting. In the dance, nurses activate their agency to explore ways to construct the patients' personhood. The patient is prioritised as the source of elements that comprise personhood and family are secondary where severity of TBI impedes patient input. The family are an extension of the person's relational personhood and offer a wealth of information that informs personal care. Low tension exists when family are willing participants in rehabilitation, and where the person's preferences can be accommodated to the greater extent. Contextual factors are: TBI can impair one's capacity to communicate personal needs; family members may be willing/unwilling participants in rehab.

Nurses engage the person who is the patient to establish unique characteristics that can contribute to delivering care that is the 'best fit'. Low tension can occur between a junior nurse and senior colleagues when the former perceives 'basic things that senior nurses tend to overlook' (e.g. purposeful engagement with the patient).There is low tension when nurses concur as to what aspects of patient care promote their personhood. A contextual factor is junior nurses' being able to advocate for patients' personhood.

During the engagement of the person who is the patient, nurses act as facilitators of rehabilitation goal setting where patients and families take the lead. The nurse' agency is shaped by the patient's choices in relation to what is feasible in the context of TBI impairment/severity.

Nurse agency activated to understand the capacity of the patient

To establish patient capacity, nurses dance with their agency (in the form of clinical assessment and judgement) and agency of the patients (needs, strengths and weaknesses in the context of TBI). Purposeful interactions between the nurses and the patients enable the collation of information that can guide nurses' decision relating to the most optimal personal care choices. The nurse agency is further supplemented by specialised input from allied health. There is low tension when the nurse is able to navigate smoothly the intricacies present within patients and AH interactions. Contextual factors are: the capacity of patients to voice their needs, strengths and weaknesses and dominance of AH in rehabilitation.

Nurse agency reconnecting patients with their personhood

The use of personal photos in patients' rooms is closely associated with rehabilitation care. Nurses help patients to stay connected with their personhood by personalising their rehabilitation space with personal photos. Photos placed in patients symbolise a medium

through which patients develop familiarity with their previous world rather than being in a '*blank hospital room'*. Photos may represent the patients family, hobbies, pets, and lived world that bring back meanings which contribute to the promotion of personhood. Nurse agency is supplemented when nurse-patient interactions are guided or informed by what is depicted in the personal photos.

The dance is between nurse, patients and families. Nurses support families to make rehab a feel-like-home for patients by encouraging the use of personal items from home e.g. clothing, dolls, blankets, shoes is encouraged. A nurse perceived personal items as medium through which patients can '*get their old self back'*. Family consider personal photos to be drivers of patients' motivation to work toward getting back to their previous lived worlds.

Nurses are able to 'visualise' patients' lived world through the voice of family. The voice of family contributes to shaping/informing what patients' topics of interest are and food choices. Low tension may occur where patient preferred choices cannot be met by nurses or the local rehabilitation facility.

A contextual factor is the presence of family/other partners that can provide photos to support the enactment of past memories and the ability of nurses to utilise such images to personalise care.

Nurse agency challenged when prioritising communicating with the patient

The nurse's initial communication with the patient sets the foundation for establishment of a meaningful therapeutic relationship. Prioritising meaningful interactions sets precedence for exploring the person's rehabilitation world. The nurse's dance takes various shapes as the person who is the patient changes by the day. The dynamic status/condition of the person presents a form of tension and provokes a change in the nurse's approach to nurse-patient interactions. Applying nurse agency allows for the initiation of nurse-patient conversations around topics of interest to the patient, and compliments the delivery of personalised care. The contextual factors that determine the level of tension relate to severity of TBI or incapacities of the patient. When behaviours that others finds to be of concern are present, high tension arises as the nurse's agency is challenged. The tension is in the form of to how effective nurse-patient communication can be established in the context of the situation at hand.

The nurse also dances with the agency of the dynamic/ever changing nature of person who is the patient. The 'dynamic' nature of the patient is contingent to the severity/effect of TBI and this may influence cognition, behaviour or personal agency.

At a particular site, nurse agency when communication with patients was informed by clinical tools (colour-coded time tables). Yellow coloured timetables dictated how patient care was structured and were bound to lead to low/high tension, while white timetables

advanced patient agency and self-determination. The dance with agency involved the nurse constantly navigating the 'rigid' and 'flexible' tools that shaped the patients rehabilitative world. The flexible 'white timetables' allowed nurses to use their agency to explore avenues that promoted decision making relating to personal care choices. The key contextual factors are: site specific practice and the assumed/sanctioned power of allied health for this particular facility.

Nurse agency fluctuating when knowing the person and personalising care

Nurse agency may fluctuate depending on whether there is need to 'push the patient' or have empathy for the patient in order to attain rehabilitation goals. At times nurse agency is shaped as '*tough love'* and '*boundary setting'* which impeded/denies/takes away the patient agency and leading to high tension. The dance involves nurses utilising different strategies to generate patient responses that align with rehab goals. Nurses strategically apply a tactical rather than a 'robotic' approach to shaping and delivery patient care as 'no person is alike'. There may be a need to apply a stricter approach to delivering personal care for some patients where clinically/therapy indicated. The need for an empathetic approach might be more beneficial in other instances (e.g. when the patient responds to nursing care at their preferred times) and the nurse has to fit into their pattern. Above all, nurses are aware and mindful of patients' right to exercise personal agency. Although, such right may be attenuated or denied where achievement of rehabilitation goals is privileged by others. Personalising the person's care contributes positively toward, building rapport, encouraging and supporting the attainment of rehabilitation goals. Tension may vary from low to high depending on the founding factors such as the level of experience of the nurse, the patient load, severity of TBI, patient capacities, competing resources and local protocols. Contextual factors: TBI can affect person's cognition and thought process, the nurse's individual critical thinking, and the experience of the nurse.

Nurse agency gradually delegated in the context of rehab progression

At times patients activate their agency either personally or through family to shape their care in rehabilitation e.g. deciding when to do certain things or participate in therapies. Nurse have the agency to oblige such requests knowing that some essential aspects such as medications cannot be overly prolonged or delayed. Promotion of personal independence occurs gradually in the context of the patients strengths and weaknesses in relation to progression toward rehabilitation goals. The dance occurs when nurses negotiate with patients to come to the 'same page' as what can be done by patients with no or limited nurse input at any particular time/occasion. Nurse agency is informed by experience, and clinical assessment and judgement. There is potential for both low and high tension, particularly when the two parties have differing views. Nurse agency can also be influenced with organisational agency with which they have to dance with in terms of clinical protocols

and policies. Contextual factors include: the level of experience of the nurse, clinical expertise of the nurse, and patient capacities for self-care are consequential to severity of TBI

Nurse agency enacted in the context of the patient's cognitive capacity

The patient's cognitive capacity forms the foundation upon which the nurse-patient interaction is based. Formal assessment using clinical tools enables ascertainment of cognitive capacity. The patient's agency is prioritised depending on the extent of cognitive capacity where the nurse takes the lead when cognitive impairment impacts enactment of personal decisions. The nurse dances with agency in the process of listening to patient preferences in the context of personal care and deciding when to allow patient input or disregard such request. Tension (low or high) is bound to arise when there is a mismatch between patient preferences and the nurse's prioritised clinical options. Contextual factors are: level of experience of the nurse, clinical expertise of the nurse and TBI can cause impairment.

Nurse agency guided by progression toward rehabilitation goals

The patient agency is gradually allowed by the nurse and is dependent on the progression towards attaining desired TBI rehabilitation goals. Nurse-patient engagement can be shaped as tight or relaxed and the dance similarly shaped. The dance is shaped by how nurses decide when patients are to take the lead about personal capabilities while in rehabilitation. Movement toward independence is initially closely guarded by nurses (i.e. tight dance), then there is less prompting when patient progression is deemed safe (i.e. relaxed dance). Nurses relinquish the leading role for patients in situations where it is safe to do so, thereby contributing to promotion of patient agency and personhood. There is low tension when the patient's requests are honoured by nurses. Though, there is potential for such tension to heighten if the patients' desired option is disallowed. The contextual factors are that TBI can cause impairments that affect the person's ability to self-care, rehabilitation care is/may be shaped by others.

High tension encounters while Dancing with agency -category specific

- Category-specific, but general examples of high-tension situations (including contextual factors)

Nurse agency that prioritises explanation reinforces patient sense of self

Patients value nursing care that is proceeded by clear explanations in the context of what is happening in their world. Nurse agency that prioritises patient's understanding of personal care intentions promotes a sense of selfhood and authenticity. High tension is bound to occur where nurse explanations are missing or inadequate. The patient in such a scenario

would resist what nurses are requesting to be done. The dance with agency is shaped/challenged by how to construct and convey explanations that are easily understood by the patient keeping in the mind the impact of TBI/cognitive impairment. Contextual factors are the patient's cognitive capacity, severity of TBI, clinical expertise and experience of the nurse.

Any inconsistencies or gaps that jump to mind

-Data that are not included in the storyline/not falling in any of the properties of the dance

-The dance occurring without tension e.g. routine nursing work

-There are data that is not possessing other 'properties of the dance'

HANDING OVER THE BATON

Definition of phase and its relation to personhood in rehabilitation nursing

Handing over the baton is a phase where nurses' use their agency to facilitate the relinquishment of the things that patients can do for themselves. The hand over is to the patients, families, paid carers or significant others. The relinquishment of agency for patients promotes enables the person to take back control and decision making about their daily activities . This process promotes self-determination, autonomy, and above all personhood.

Nurse strategies used to hand over the baton

Nursing strategies that are used to handover the baton to the patient include: facilitating return to home or independent living, facilitating links/connection with auxiliary TBI rehabilitation services in the community of patient and family access, training family, cares and significant others in rehabilitation tasks/procedures, patient and family education regarding how to effectively work toward attaining goals of rehabilitation.

The end goal of TBI rehabilitation is centred around maximizing the person's abilities in the context of what they can do within the confines of their safety. The return to the person's social world may necessitate modifications to their home environments to facilitate ease of mobility and performance of ADLs. Training for family or carers supports the person's 'temporarily/short stays' away from rehabilitation. Periods away from the rehabilitation environment promote a sense of return to the 'normal lived world' for the person. Families report varying outcomes when patients have time away from rehabilitation for home

stay/visits. Positive outcomes are associated with smooth transition while negative outcomes are associated with eventful/problematic outings. Nurses dance with agency as to how to safely relinquish agency to the patients and their families while maintaining continuity of rehabilitation within a safe and collaborative partnership. Contextual factors include: the presence of family/carers that are willing to engage in rehabilitation, availability of auxiliary services' providers that can support return to home living (e.g. NDIS), and availability of equipment needed to supplement home stays.

Low tension encounters while Dancing with agency -category specific

- Category-specific, but general examples of low-tension situations (including contextual factors)

Nurse agency facilitating home stays

Nurses facilitate home stays for patients by making available the rehabilitative items (e.g. medical supplies, mobility assistive equipment, devices that aid feeding, and personal care supplies) that can safely support periodic/weekends living away from the rehabilitation environment. Brief home stays are highly valued by patients and families. Facilitation also encompasses the provision of education and training to patients and family members so that they are able to leave safely away from the rehabilitation setting in the absence of nurses. Another mode of facilitation occurs in the form of home modifications to allow ease of mobility for patients. Temporary paid for accommodation is also arranged for families that come from far away from the rehabilitation facility. The dance for nurses involves negotiating how to provide education and training in a non-clinical language for the patient and family, particularly if the task at hand is one that involves application of clinical skills such as administering injections, transferring patients e.g. from wheel chair to bed, and remembering not to do it all for the patient but support when needed. Low tension can occur when family members do perform the 'carer' role centrally to what nursing instructions suggest. The contextual factor is the availability of family members who are willing to participate in rehabilitation.

High tension encounters while Dancing with agency -category specific

- Category-specific, but general examples of high-tension situations (including contextual factors)

Nurse agency exhausted due to delayed discharge formalities

Discharge from the facility forms part of handing over the baton to the patient and family. However, nurses report that delays to patient discharge sometimes occur for a year or beyond. Nurses experience tension where they have to continue caring for patients with

behaviours that others find challenging who are ready for discharge but due to one reason or another, there is no known discharge destination. Tension occurs in the form of being emotionally, mentally and physically drained due to prolonged exposure to challenging patient practices. The delays to patient discharge are largely due to lack of funding from NDIS along with the associated formalities. Nurses dance with the changing/unpredictable condition of the patients whose behaviours others find challenging. The dance also includes how nurses find self-care strategies to continuing delivering meaningful patient care despite the hardships they encounter when promoting patient agency. Contextual factors include limited availability of discharge destinations/options and lack of funding to facilitate living away from rehabilitation.

Any inconsistencies or gaps that jump to mind

-Situations that address the properties of the dance may be limited or missing

-Could these limitation be explored in second phase of interviews?

CONCLUSION

Summary of the similarities & differences in how the dance operates between the three non-linear phases

Phases	How the dance operates	Similarities	Differences
Protecting the body of the person -Monitoring and maintain physiological integrity -Monitoring and maintaining physical safety	-Nurses having to dance with the agency of others e.g. when completing routine tasks -NA ceded to a perceived higher authority -NA negotiated collaboratively -NA supported by clinical reasoning -Dancing to resources limitations (understaffing)	Routine nursing practices e.g. periodic rounding (socialised nature of nursing work) -Nurse agency ceded to the perceived higher authority -Nurse agency negotiated collaboratively	-The nurses take the lead most of the time -severity of injury is higher -Greater degree of patient incapacities

	-Dancing with other partners multiplicity of patient incapacities -Impacts of COVID-19	-Nurse agency impacted by limited resources	
Engaging the person who is the patient	-Nurses exploring ways to construct the patients' personhood -Activation of clinical assessment & judgement -dancing with specialist input from e.g. AH, medicine etc -Using images to reconnect the patient to their 'previous world' -Prioritising communication with patients (AH Tools can help) -Fluctuating nurse agency requiring (laid-back , push, tough love, boundary setting strategies) -Gradually delegating agency in the context of achieving rehab goals & patient's cognition -Effective nurse explanations reinforce sense of self for patients		-Nurses/patients may take the lead -Patient agency is facilitated -Cognitive capacity determines whether nurses grant agency to patients
Handing over the baton	-Nurses working o facility patient return to the 'outside world' -Relinquishing agency safely for patients/families -Working collaboratively with other partners e.g. NDIS in multiple ways to facilitate discharge from rehabilitation		-Nurses are facilitators -Patients family 'carry the heavy load' -Other partners have greater control of how the patient agency (i.e. transition from rehab to the outside world) transpires

Summary of the types of tensions that arise

-Low tension
-High tension
-Situation of no tension (e.g. when performing routine nursing work)

Summary of the common contextual factors

Nurse confidence, nurse sensitivity, emotional state of the nurse, hierarchical nature of the healthcare system, many therapies administered by nurses are predominantly prescribed by others, presence of family and willingness to engage in rehabilitation, the patient's and family's capacity to understand rationale of nursing practice, limited nursing resources/understaffing, experience and skill of the nurse, the nurse's critical thinking, severity of TBI, TBI can cause cognitive impairment that may affect one's judgement, COVID-19 pandemic impacts agency, the dominance or assumed power of AH in rehabilitation, the patient capacity to self-care, rehabilitation care is shaped by others, availability of auxiliary services to facilitate discharge e.g. NDIS funding

Summary of perceived inconsistencies/gaps and what this might mean for further theoretical sampling

1- There are some commonalities between monitoring & maintaining physiological integrity Vs monitoring and maintaining physical safety. For example the routine practices such as periodic patient rounding that aims to address both categories.
Querry: Could there be another property of the dance named 'No Tension'? This is where nurses are simply performing routine work but negotiating agency of others

2-There are some instances/situations where there is no tension e.g. when nurses are using routine interventions/strategies
Querry: How would this data be captured within the storyline?

3-Some data are not included/captured in the storyline/not falling in any of the properties of the dance i.e. data that is not possessing other 'properties of the dance'
Querry: Is there further need to re-structure the storyline as the 'data' is driving theoretical development?
4-Situations that address the properties of the dance may be limited or missing (Mostly in Handing over the baton -phase)
Querry: Is this a call for further theoretical sampling with participants to explore deeper insights about the properties of the dance?

5 -Could these gaps be explored in the second phase of interviews?

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7.11 Appendix 11: Presentations at conferences, symposiums and workshops

Published papers:

Kivunja, S., Pryor, J., River, J., & Gullick, J. (2024). Conceptualising personhood in nursing care for people with altered consciousness, cognition and behaviours: A discussion paper. *Nursing Philosophy, 25*(3), e12490. https://doi.org/10.1111/nup.12490

Kivunja, S., Pryor, J., River, J., & Gullick, J. (2022). Navigating the role of clinician-researcher: Insights from a Constructivist Grounded Theory study in traumatic brain injury. *Australasian Journal of Neuroscience, 32*(2), 6-17. https://doi.org/10.21307/ajon-2021-008

Kivunja, S., River, J., & Gullick, J. (2018). Experiences of giving and receiving care in Traumatic brain injury: An integrative review. *Journal of Clinical Nursing, 27*, 1304-1328. https://doi.org/10.1111/jocn.14283

Conference, Symposium & Workshop Presentations:

Kivunja, S., Pryor, J., River, J., & Gullick, J. (2024). Insights from a nurse-led project in traumatic brain injury care: A doctoral nurse-clinician researcher's journey. WSLHD Nursing & Midwifery Research Information Symposium, April 16, 2024, Westmead Hospital, NSW, Australia

Kivunja, S., Pryor, J., River, J., & Gullick, J. (09 November, 2023). Examining agency: Reporting on analytical insights from a Constructivist Grounded Theory study of social processes that promote personhood in traumatic brain injury care. Australasian Neuroscience Nurses' Association Annual Conference 2022, Perth, Western Australia

Kivunja, S., Gullick, J., Pryor, J., River, J. (27 September, 2023). Exploring 'Personhood' as the basis for understanding social processes in traumatic brain injury care. The 26th International Nursing Philosophy Conference in association with IPONS: Re-imagining a nursing ecosystem in an uncertain world, The University of Sydney, Sydney Nursing School, Sydney, NSW, Australia. https://doi.org/10.1111/nup.12495

Kivunja, S., Pryor, J., River, J., & Gullick, J. (06 September, 2023). A doctoral researcher's journey: Insights from a nurse-led project in traumatic brain injury care. WSLHD Nursing and Midwifery HDR Symposium 2023, Westmead Hospital, NSW, Australia

Kivunja, S., Pryor, J., River, J., & Gullick, J. (11 November, 2022). Social processes that promote and preserve personhood in traumatic brain injury nursing care: Exploring lines of inquiry. Australasian Neuroscience Nurses' Association Annual Conference 2022, Melbourne - Poster

1

Kivunja, S., Pryor, J., River, J., & Gullick, J. (20 July, 2022). Social processes that promote and preserve personhood in traumatic brain injury nursing care. Faculty of Medicine and Health, HDR Conference 2022, The University of Sydney - Poster

Kivunja, S., Pryor, J., River, J., & Gullick, J. (11-12 November, 2021). Navigating the role of a clinician and a researcher: Insights from a Constructivist Grounded Theory study in Traumatic Brain Injury. Australasian Neuroscience Nurses' Association Annual Virtual Conference 2021

Kivunja, S., Pryor, J., River, J., & Gullick, J. (9-11 June 2021). Ethical research design for vulnerable populations-Social processes that promote and preserve personhood in traumatic brain injury nursing care. International Collaboration of Nurse Scholars (ICoNS), International PhD Summer School, Virtual Workshop, hosted by The University of Sydney

Kivunja, S., Pryor, J., River, J., & Gullick, J. (17-18 October, 2019). Constructing the meaning of personhood for people with traumatic brain injury. Australasian Neuroscience Nurses' Association Annual Conference, Wellington, New Zealand

Kivunja, S., River, J., & Gullick, J. (24 July, 2019). Three Minute Thesis Presentation: Social processes that promote and preserve personhood in TBI nursing care in hospital and rehabilitation settings. Susan Wakil School Nursing and Midwifery, Faculty of Medicine and Health, HDR Workshop, The University of Sydney

Kivunja, S., River, J., & Gullick, J. (04 May, 2019). Navigating participant access and field observations in a Grounded Theory Study: International Institute for Qualitative Methods (IIQM) Conference, Brisbane, Australia

Kivunja, S., River, J., & Gullick, J. (04 May, 2018). Constructivist Grounded Theory: It's appropriateness to understanding care in traumatic brain injury: IIQM Conference, Banff, Alberta, Canada

Kivunja, S., River, J., & Gullick, J. (29-31 August, 2018). Experiences of giving and receiving care in Traumatic brain injury: Westmead Hospital Research Week, Westmead, Australia

Kivunja, S., & Gullick, J. (2-7 June, 2017). Understanding of ethical issues, theoretical and methodological framework, and international research positioning as a PhD researcher: International Collaboration of Nurse Scholars PhD Summer School, University of Lleida, Catalonia, Spain

7.12 Appendix 12: PERMISSIONS TO USE PUBLISHED MANUSCRIPTS

7.12.1 Appendix 12.1: Publication 1 -Journal of Clinical Nursing

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7.12.2 Appendix 12.2: Publication 2- Nursing Philosophy

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7.12.3 Appendix 12.3: Publication 3 – Australasian Journal of Neuroscience Nursing

Stephen Kivunja

The University of Sydney
Faculty of Medicine and Health
Susan Wakil School of Nursing and Midwifery (Sydney Nursing School)
Camperdown NSW 2006
Australia

The Editor
Australasian Journal of Neuroscience Nursing

Dear Dr Linda Nichols

Re: Request for permission to use published manuscript in PhD Thesis

I am PhD candidate at the University of Sydney, and I am in the process of compiling my PhD Thesis. I would like to request for permission to use/include the following published manuscript (for which I am one of the authors) in my PhD Thesis.

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Kivunja, S., Pryor, J., River, J., & Gullick, J. (2022). Navigating the role of clinician-researcher: Insights from a constructivist grounded theory study in traumatic brain injury. *The Australasian Journal of Neuroscience*, *32*(2), 6–17. https://doi.org/10.21307/ajon-2021-008

Best regards

Stephen

STEPHEN KIVUNJA | RN PhD Candidate | Casual Academic |
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AWARD: The Neurosurgical Society of Australasia Prize

Susan Wakil School of Nursing and Midwifery acknowledges the traditional custodians upon whose ancestral lands the University of Sydney campuses stand and pay our respect to Elders both past, present and future.

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Congratulations Stephen you are nearly at the end.

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Linda

Dr. Linda Nichols

Adjunct Researcher

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7.13 Appendix 13: The Consolidated criteria for reporting qualitative research (COREQ) checklist

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:
Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

PROVIDE A RESPONSE FOR ALL ITEMS. ENTER N/A IF NOT APPLICABLE

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	Methods -P.107
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	Methods -P.78
3. Occupation	What was their occupation at the time of the study?	Methods -P.78
4. Gender	Was the researcher male or female?	Methods -P. 81
5. Experience and training	What experience or training did the researcher have?	Methods -P.82
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	Methods -P.99
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Methods -P.100
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Methods -P.101
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g.	Methods -PP.70

	grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Methods -P.96
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Methods -P.99
12. Sample size	How many participants were in the study?	Methods -P.102
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Methods -N/A
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Methods -P.107
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Methods -P.109
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Methods -P.105
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Methods -P.108
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	Methods -PP.103, 108
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Methods -P.110
20. Field notes	Were field notes made during and/or after the interview or focus group?	Methods -PP.107,112,116
21. Duration	What was the duration of the inter views or focus group?	Methods-P.109
22. Data saturation	Was data saturation discussed?	Methods -PP.102,109,123
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Methods -N/A
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	Methods -PP.116,117
25. Description of the coding tree	Did authors provide a description of the coding tree?	Findings diagram -P.136
26. Derivation of themes	Were themes identified in advance or derived from the data?	Methods -P.121

27. Software	What software, if applicable, was used to manage the data?	Methods - P.114
28. Participant checking	Did participants provide feedback on the findings?	Methods-N/A
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Findings -P.134
30. Data and findings consistent	Was there consistency between the data presented and the findings?	-Findings -P.134 -Discussion - P.243
31. Clarity of major themes	Were major themes clearly presented in the findings?	Findings diagram -P.136
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Findings chapter -P.134