Living on: A Qualitative Study of the Experience of Living with Multiple Myeloma

Moira Stephens
RN, BSc(Hons), MSc (Lon)

Submitted to
University of Sydney

in fulfilment
of the requirements for the degree of

Doctor of Philosophy
in the Sydney Medical School

March 2012
Supervisor’s Certification

I, Dr Christopher Jordens, certify that the PhD thesis entitled ‘Living on: A Qualitative Study of the Experience of Living with Myeloma’ by Moira Stephens is in a form suitable for examination.

_________________________________________________
Christopher Jordens
Date _________________________________
Author’s Declaration

I, Moira Stephens, declare that this thesis, submitted for the award of the degree of Doctor of Philosophy, in the Sydney Medical School, University of Sydney, is wholly my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person nor material that to a substantial extent has been accepted for the award of any other degree or diploma at the University of Sydney or any other educational institution, except where due acknowledgment is made in the thesis. Any contribution made to the research by colleagues with whom I have worked at the University of Sydney or elsewhere during my candidature is fully acknowledged. The University of Sydney Human Research Ethics Committee approved all research practices associated with this thesis.

I agree that this thesis be accessible for the purpose of study and research in accordance with the normal conditions established by the Executive Director, Library Services or nominee, for the care, loan and reproduction of theses.

Signed: [Signature] On: 24/3/12
Abstract

This thesis aims to provide a rich, empirically grounded understanding of what it is like to live with myeloma after the first relapse, in ‘the era of novel agents’. This was achieved by exploring the experience of both the person with myeloma and that of their primary support person though an analysis of their narratives.

Consistent with the principles of qualitative enquiry, this study aimed to produce findings that were descriptive, exploratory and explanatory in nature. Qualitative methods were used, involving an inductively-driven analysis of a series of in-depth interviews conducted at six to twelve month intervals. Data sources consisted of 47 in-depth open-ended interviews with ten dyads of a patient and their primary support person, and an additional single participant. Analysis was undertaken using the key attributes of Grounded Theory methods: constant comparison of the data and theoretical coding. As new categories and concepts were developed through inductive analysis, they were further explored in relevant literature from philosophy, sociology and the humanities so that understanding of the experience of living with myeloma was continually and iteratively informed by existing literature.

This research shows that the overall experience of living with myeloma was a complex and arduous struggle. Participants said that ‘having myeloma is hard’, because the effects of myeloma permeated every facet of their lives. Living with myeloma consisted of three key elements: 1) the arduous nature of myeloma; 2) the work of myeloma; and 3) the temporal landscape of myeloma. Living with myeloma required participants to construct a ‘new normal’. This demanded adjustment at first, but participants learned to ‘get on with it’ over time and with experience. The new normal included activities which were focused on managing the symptoms of myeloma. Some required effort and planning and some became taken for granted everyday activities.
I developed an interpretation of these findings through engagement with philosophical and sociological theory. This theory helped me understand that participants described coming to tolerate and live within changed conditions. The process of creating a new normal demanded a great deal of effort including new/different ways of understanding time, normality, and health. The symptoms that participants described were intrusive and initially demanded a great deal of attention and work. Over time, these symptoms became integral components in their lives and they consistently talked about ‘getting on with it’, living with the arduous yet everyday experiences associated with myeloma. I came to conceptualise the way people lived with myeloma as ‘living on.’ This was a dynamic process rather than a state. Participants responded to many changes over time such as multiple relapses, complications of and responses to treatment and hopes for remission, all of which were part and parcel of living and dying with myeloma. Over time, these changes to their environment became part of the everyday fabric of their lives. I use Bourdieu’s concept of *habitus* to explain how living with myeloma became normal or ‘second nature’. The concept of ‘living on’ denotes that the complexity and effort demanded by living with myeloma became second nature and thus a normal state of affairs.

Myeloma is many things; it is a medical problem; it is a social problem; and for those who have it, it is part of everyday life. Interpreted through the lens of Bourdieu’s conceptual tools, the stories of the participants reveal how people managed to live with something that was, at the outset, a catastrophic experience but which over time became a part of everyday life. This study has illustrated the complexity and work that is required to live everyday with myeloma as a normal state of affairs. *Living on* is a process that demands effort and different ways of understanding time, normality and health.
Preface

This study was funded by Cancer Council NSW Project Grant RG 07-11. I was not a named investigator on the grant and had no part in its authorship as it had been successfully gained before I joined the project. The original idea for the study serendipitously arose from two separate lines of enquiry. I had become increasingly curious, as a clinician, about how people with myeloma were living for longer whilst managing numerous adverse effects of treatment. In November 2006, I had started to seek a university and supervisor to investigate the experience of people living with multiple myeloma but had not approached the Sydney Medical School. Coincidently, the team at the Centre for Values, Ethics and the Law in Medicine at the Sydney Medical School had successfully obtained funding from the Cancer Council for this study. The centre has a long-standing programme of research in patient experience and I had previously met Dr Jordens the year before. I also knew Associate Professor Ian Kerridge through membership of various haematology and bone marrow transplant committees and organisations. Therefore, through a happy chance conversation, our two inquiries came together and I became a PhD student on this study. I managed: all of the ethics submissions, study reporting and administration, participant recruitment, data collection and analysis. I wrote the abstracts as principle author in collaboration with Dr Christopher Jordens and I was the sole author of the conference presentations, patient group presentations and paper published in the Australian Journal of Oncology Nursing.

Ethical approval was successfully obtained from: the University of Sydney Human Research Ethics committee, Sydney South West Area Health Service Human Research Ethics committees for the Royal Prince Alfred and Liverpool hospitals, and Sydney West Area Health Service, Westmead Hospital, Human Research Ethics committee.
Acknowledgements

This thesis would not have been possible without the knowledge, inspiration and support of a small army of people, the financial support of the Cancer Council NSW, and the willingness of the participants to share their stories.

It would have been next to impossible to write this thesis without the help and guidance of my Supervisors: Dr Christopher Jordens whose brilliant mind and dogged attention to detail enriched it, ‘cooked it’ and brought it to fruition; Associate Professor Ian Kerridge whose inspiration and encouragement brought me through the door and is ongoing; Associate Professor Heather McKenzie for sharing with me her depth of understanding in illness experience and her sociological approach which showed me different ways of thinking about illness experience, and Dr Stacy Carter, my go-to guru for all things concerned with qualitative research.

I am also grateful to Emeritus Professor Miles Little for the time and shared wisdom that he afforded me in our conversations and those wonderful books that he quietly dropped onto my desk which took me to new places of thinking; Professor Jill White for her belief in me and her support; and Professor Kate White for her support and unfailing ability to say just the right thing at just the right time and keep me moving forward.

It is a pleasure to thank my fellow ‘Velimers’; students and staff in a centre that I shall be eternally grateful for having had the opportunity to work in. In particular I would like to thank Camilla Scanlan, Dr Kimberley Strong and Dr Rowena Forsyth who were unfailingly at the photocopier at precisely the right time.

I am most grateful to Tracy King with whom it is always a pleasure to work and without whom I would not have been able to share and validate my findings with the Myeloma
Foundation of Australia. I owe a deep gratitude to those ‘experts’ who turned up to hear me speak and gave me feedback time and time again.

I would like to thank my parents Frank and Patricia Stephens who encouraged me, from an early age, to ask ‘Why?’.

It is a pleasure to thank my partner Patricia Ryan without whom this thesis most certainly would not have been possible. Her unfailing love and her support in so many ways kept me writing and believing that I could do this. She released me from domestic duties in the style of the Parsonion ‘Rights and Responsibilities of the PhD student’ when I needed it; gave me the space that I needed; but spent too long without my ‘presence’.
Chapter Two: Myeloma—The Medical Model

1. Current understanding of the pathophysiology of myeloma
   a. Myeloma is a plasma cell disorder
   b. Symptoms
   c. Multiple myeloma is not a new disease
   d. The cause of myeloma is unknown
   e. How myeloma is diagnosed and staged
   f. The impact of gene profiling in myeloma
   g. Myeloma is a rare disease
   h. People are living longer with myeloma
   i. The management of myeloma is not focused on cure
   j. Available drug treatments
   k. Stem cell transplantation
   l. The ‘depth’ of remission is important for prognosis
   m. Maintenance therapy to sustain remission as long as possible
   n. Managing relapse as a chronic disease
   o. Conclusion

Chapter Two: Myeloma as a Social and Personal Experience

1. Objective conceptions of disease as a biological phenomenon
2. Changing our understanding of disease and illness
3. Health is a subjective experience
4. Health in the presence of disease
5. Illness as a social construction
6. Taxonomies of illness
7. The experience of illness is subject to the ‘ups and downs’ of everyday life
8. The biographical theories of illness
9. Biographical disruption

Conclusion

References
Chapter Five: Methods

Part II: Theory and Method

Chapter Four: Methodology

Chapter Five: Methods
Part III: Findings ........................................................................................................88
  Introduction to the participants ..............................................................................89
  Participants’ stories ..................................................................................................89
    Anne .......................................................................................................................89
    Brenda and Barry ..................................................................................................89
    Clive and Celia ......................................................................................................89
    David and Delia ....................................................................................................90
    Emilia and Emma .................................................................................................90
    Fred and Fatima ....................................................................................................90
    Garry and Gertie .................................................................................................91
    Harry and Helen ....................................................................................................91
    Ivan and Ismelda ....................................................................................................91
    John and Jane ......................................................................................................92
    Kira and Kerry ......................................................................................................92

Chapter Six: Having Myeloma Is Difficult—The Illness Biography ......................93
  Introduction ............................................................................................................93
  Somatic experience ...............................................................................................93
    Living on steroids ................................................................................................95
    Living with fatigue ..............................................................................................98
    Living with neuropathy ......................................................................................100
    Living with pain ................................................................................................102
    Living by numbers ..............................................................................................106
    ‘The number’ as an indicator of the quantity of myeloma in the body ...............108
    ‘The number’ as an indicator of treatment effectiveness .................................109
    The prognostic meaning of ‘numbers’ ...............................................................109
    ‘Numbers’ having a predictive meaning for treatment ......................................110
    When the numbers and subjective experience disagree ..................................111
  Myeloma as a ‘category-defying’ illness ..............................................................112
  Myeloma as ‘no illness’ ........................................................................................112
  Myeloma as an ‘acute’ or ‘critical’ illness ...........................................................114
  Myeloma as a chronic illness ...............................................................................114
    ‘On and on like Burgess Paint’ ........................................................................115
    Incurable but treatable .......................................................................................115
    Death no longer imminent ................................................................................116
    Getting used to it ...............................................................................................116
  Myeloma as a terminal illness .............................................................................118
    Myeloma as sudden and imminent death .......................................................118
    Myeloma as ‘certain death in uncertain time’ ...............................................120
    Fred summed up this meaning neatly as follows: .........................................120
    Relentlessly ‘hard’ .............................................................................................121

Chapter Seven: Myeloma as Work ........................................................................124
  Introduction ............................................................................................................124
  Knowledge work ...................................................................................................127
    Obtaining and evaluating knowledge ..............................................................128
  Disclosure work ...................................................................................................132
  Health work ..........................................................................................................135
  Reducing risk .........................................................................................................135
    Risk of infection ...............................................................................................136
<table>
<thead>
<tr>
<th>Chapter Nine: Synthesis of the Findings: Discussion</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>173</td>
</tr>
<tr>
<td>The catastrophic and the normal</td>
<td>174</td>
</tr>
<tr>
<td>Living on</td>
<td>176</td>
</tr>
<tr>
<td>The work of living on</td>
<td>178</td>
</tr>
<tr>
<td>Knowledge work and organisation work</td>
<td>179</td>
</tr>
<tr>
<td>Health work</td>
<td>180</td>
</tr>
<tr>
<td>Emotion work</td>
<td>181</td>
</tr>
<tr>
<td>The temporal landscape of living on</td>
<td>184</td>
</tr>
<tr>
<td>Place markers in time</td>
<td>187</td>
</tr>
<tr>
<td>Non-concordant experiences of time</td>
<td>188</td>
</tr>
<tr>
<td>Time – the resource</td>
<td>189</td>
</tr>
<tr>
<td>Waypoints for living on</td>
<td>190</td>
</tr>
<tr>
<td>Living on as habitus</td>
<td>193</td>
</tr>
<tr>
<td>The practices of living on</td>
<td>195</td>
</tr>
<tr>
<td>The field of Myelomia</td>
<td>196</td>
</tr>
<tr>
<td>Insiders and outsiders</td>
<td>197</td>
</tr>
<tr>
<td>Capital in the field of Myelomia</td>
<td>198</td>
</tr>
<tr>
<td>Physical capital</td>
<td>200</td>
</tr>
<tr>
<td>Cultural capital</td>
<td>201</td>
</tr>
<tr>
<td>Social capital</td>
<td>203</td>
</tr>
<tr>
<td>Time capital</td>
<td>203</td>
</tr>
<tr>
<td>Capital, power and position</td>
<td>204</td>
</tr>
<tr>
<td>The hysteresis effect in living with myeloma</td>
<td>206</td>
</tr>
<tr>
<td>Conclusion</td>
<td>207</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Chapter Ten: Conclusion</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>209</td>
</tr>
<tr>
<td>Section</td>
<td>Page</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>------</td>
</tr>
<tr>
<td>Achievement of the aims of the study</td>
<td>209</td>
</tr>
<tr>
<td>Limitations of the study</td>
<td>211</td>
</tr>
<tr>
<td>Bourdieu’s concepts and illness experience</td>
<td>212</td>
</tr>
<tr>
<td>Illness as the norm</td>
<td>216</td>
</tr>
<tr>
<td>Functional health as the norm</td>
<td>216</td>
</tr>
<tr>
<td>The slippery nature of the status quo</td>
<td>216</td>
</tr>
<tr>
<td>Biographical theories of illness</td>
<td>218</td>
</tr>
<tr>
<td>Survivors, survivorship, the ‘new normal’</td>
<td>221</td>
</tr>
<tr>
<td>Living on as a ‘new normal’</td>
<td>223</td>
</tr>
<tr>
<td>Implications of the study for future research</td>
<td>223</td>
</tr>
<tr>
<td>Implications of this study for clinical practice</td>
<td>225</td>
</tr>
<tr>
<td>Concluding comments</td>
<td>227</td>
</tr>
<tr>
<td>Appendices</td>
<td>37</td>
</tr>
<tr>
<td>Appendix 1: Criteria for evaluating disease response and progression in patients with multiple myeloma treated by high dose therapy and haematopoietic stem cell transplantation</td>
<td>38</td>
</tr>
<tr>
<td>Appendix 2: Sample Interview Questions</td>
<td>40</td>
</tr>
<tr>
<td>Appendix 3: Participant Information and Participant Diary Guideline</td>
<td>43</td>
</tr>
<tr>
<td>Appendix 4: Ethics</td>
<td>53</td>
</tr>
<tr>
<td>Appendix 5: Publications and Presentations</td>
<td>66</td>
</tr>
<tr>
<td>Publications directly related to this thesis</td>
<td>67</td>
</tr>
<tr>
<td>Peer Reviewed Publications</td>
<td>67</td>
</tr>
<tr>
<td>Professional Presentations</td>
<td>67</td>
</tr>
<tr>
<td>Conference Presentations</td>
<td>67</td>
</tr>
<tr>
<td>International</td>
<td>67</td>
</tr>
<tr>
<td>National (Australia)</td>
<td>68</td>
</tr>
<tr>
<td>Research Seminars, Presentations, Public Workshops</td>
<td>68</td>
</tr>
<tr>
<td>Myeloma Foundation of Australia Public Presentations</td>
<td>69</td>
</tr>
<tr>
<td>Patient Resources and Literature</td>
<td>70</td>
</tr>
</tbody>
</table>
List of Tables

Table 1: Adapted from ESMO clinical recommendations for diagnosis ....................10
Table 2: Number of interviews completed by individual participants .........................80
Table 3: Comparison of multiple meanings of test results in HIV [423] and Ovarian Cancer [422] ..............................................................................................................................192
List of Figures

Figure 1: Diagram showing the position of plasma cells in the development of immunoglobulins.................................................................6
Figure 2: Key milestones in the management of multiple myeloma, demonstrating corresponding survival improvements ..................................14
Figure 3: Key decision points in the treatment of myeloma ..........................16
Figure 4: Diagram showing the development of all blood cells from haematopoietic progenitor cells (HPCs) produced by the bone marrow ..........18
Figure 5: Myeloma as work—An overview..............................................127
Figure 6: Combining different sources of information to produce knowledge ..........131
Figure 8: The work of attending a hospital appointment ..........................183
**List of Abbreviations**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACP</td>
<td>advanced care planning</td>
</tr>
<tr>
<td>ASCT</td>
<td>autologous stem cell transplant</td>
</tr>
<tr>
<td>BMG</td>
<td>benign monoclonal gammopathy</td>
</tr>
<tr>
<td>CRAB</td>
<td>calcium, renal function, anaemia and bone lesions</td>
</tr>
<tr>
<td>DMD</td>
<td>Duchenne muscular dystrophy</td>
</tr>
<tr>
<td>EBMT</td>
<td>European Group for Blood and Marrow Transplantation</td>
</tr>
<tr>
<td>ESMO</td>
<td>European Society for Medical Oncology</td>
</tr>
<tr>
<td>GCSF</td>
<td>granulocyte colony stimulating factor</td>
</tr>
<tr>
<td>GP</td>
<td>general practitioner</td>
</tr>
<tr>
<td>HPC</td>
<td>haematopoietic precursor cell</td>
</tr>
<tr>
<td>ICU</td>
<td>intensive care unit</td>
</tr>
<tr>
<td>IMWG</td>
<td>International Myeloma Working Group</td>
</tr>
<tr>
<td>ISS</td>
<td>International Staging System</td>
</tr>
<tr>
<td>MFA</td>
<td>Myeloma Foundation of Australia</td>
</tr>
<tr>
<td>MGUS</td>
<td>monoclonal gammopathy of undetermined significance</td>
</tr>
<tr>
<td>MND</td>
<td>Motor Neurone Disease</td>
</tr>
<tr>
<td>NFP</td>
<td>non-for-profit organisation</td>
</tr>
<tr>
<td>NGO</td>
<td>non-government organisation</td>
</tr>
<tr>
<td>NSW</td>
<td>New South Wales</td>
</tr>
<tr>
<td>RA</td>
<td>rheumatoid arthritis</td>
</tr>
<tr>
<td>RCT</td>
<td>randomised controlled trial</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>USA</td>
<td>United States of America</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
</tbody>
</table>
Introduction

I am nurse with 29 years of experience working in the haemato-oncology setting. I have practiced in Australia, the UK and Saudi Arabia. Through my training and experience as a clinician, I have gained a medical understanding of myeloma. Through my training in qualitative social research, I have sought to bring a more social and biographical gaze to bear on my field of practice. In other words, I aim to improve our understanding of myeloma as an experience as well as a disease; as a social and personal problem as well as a medical one.

Multiple myeloma is medical problem because it is an incurable cancer. Because it is incurable, the main aims of treatment are to control the disease, secure remission and maximise the duration and quality of life. Treatment usually involves a course of chemotherapy and (for those patients who are deemed ‘eligible’) a stem cell transplant [1, 2], which is essentially a means of delivering high doses of chemotherapy. People with myeloma are treated as either inpatients or outpatients depending primarily on their physical status and the intensity of the treatment regimen. Treatment is delivered in outpatient settings, cancer care day units, acute cancer, and haematology inpatient settings. There are specialist treatment centres in NSW and some centres administer treatment such as chemotherapy or supportive medications in a shared care arrangement with GPs.

During the course of my career, there have been important advances in the medical understanding of myeloma. There have also been important developments in diagnosis, treatment, supportive care and therapy, and management of the disease after relapse. Notably, a new class of useful drugs known as ‘novel therapies’ has become available. All of these developments have contributed to improvements in the life expectancy of people who are diagnosed with myeloma. The median duration of survival in the 1990s was two and a half years [3]. The median duration of survival is now five to seven years [4-6]. Many younger patients now survive 10–15 years, and 48% of people under 50 years of age survive 10 years or more [4]. For older people, the figures are not so promising: of those aged 50–59 years at diagnosis, 29% are still alive after 10 years, and
for those over 69 years of age, the corresponding figure is only 10% [7]. With few exceptions, most patients die at some point as a direct result of their disease, despite the efforts of multi-disciplinary teams of clinicians that are assembled to deliver complex treatment regimens. So despite improvements in the survival statistics, myeloma remains an incurable disease.

Although it is widely acknowledged that living with and dying from multiple myeloma is often a painful and difficult journey, the vast majority of research about myeloma is biomedical in nature, and biomedical research portrays disease as if it were something separate from everyday life. For people who are affected by myeloma, nothing could be further from the truth. For them, myeloma is an intimate and integral part of everyday experience, so it is a social and personal problem as well as a medical problem. This insight is central to my thesis, which aims to augment the small body of existing research that examines the experiences of people with myeloma.

Whilst biomedical research has fuelled the important developments described above, and thereby helped people with the disease to live longer, these people also have to endure repeated cycles of relapse and treatment, so they spend a lot of their time – if not all of their time – undergoing treatment. There has been little research into how this affects their lives [8, 9]. This thesis focuses on patient experience from the point that the disease first recurs or ‘relapses’. Experience prior to this tends to be dominated by the impact of transplantation, and so represents territory that has already been well-mapped: previous studies have clearly shown transplantation to be an arduous experience [10-34]. I aim to provide a rich, empirically grounded understanding of the experience of living with myeloma after the first relapse, in ‘the era of novel agents’, by exploring the experiences of the person with myeloma and their primary support person.

The thesis is organised in the manner of a traditional research report: background and literature review (Part I) followed by methods (Part II), results (Part III), and discussion (Part IV).

Part I consists of three chapters. Chapter 1 provides an overview of myeloma as it is seen by clinicians, that is, as a disease requiring treatment. In Chapter 2 I explore how
myeloma can be understood in terms of sociological and philosophical perspectives on key concepts such as health, illness, personal biography and subjective experience. I also review the existing literature about the experience of cancer and haematological malignancies in particular. Chapter 3 introduces Bourdieu's theory of practice, which I used as an explanatory framework to interpret the interview data I collected during the course of my doctoral research.

Part II consists of two chapters. In Chapter 4 I describe the general approach I have followed in my research (i.e. grounded theory methodology) which combines inductive development of original codes and categories with abductive connections to existing ideas and literature [35-38]. In Chapter 5 I describe the specific methods I have used to collect and analyse my interview data.

Part III consists of three chapters. After introducing the people I interviewed, I describe their experience of living with myeloma. Chapter 6 focuses on the personal difficulties they face. Chapter 7 describes the work they undertook to manage their myeloma, and Chapter 8 describes their altered experience of time.

Part IV consists of two chapters: Chapter 9 synthesises the findings; Chapter 10 presents my main conclusions and presents an explanatory framework for understanding the experience of living with myeloma and assesses the strengths and limitations of the study together with a discussion of its implications for clinical practice and future research.
Part I: Background and Literature Review

Introduction

Chapter One provides background in an overview of myeloma as a disease that requires medical management. It will describe both the biomedical understanding of myeloma and the treatment of myeloma have changed over recent years, and how these changes have affected people who are living with it, from a clinical perspective.

The next two chapters review literature about the social and personal experience of myeloma. There is little literature exploring the personal experience of myeloma, therefore, in Chapter Two, I will consider how the experience of living with myeloma can be understood in terms of sociological and philosophical perspectives on key concepts such as health, disease and illness, personal biography and subjective experience. I will argue that there is a tension in the literature between concepts of ‘biographical continuity’ and ‘biographical disruption’ as outcomes of illness experience.

Chapter Three introduces a particular set of concepts that will be used to explain the findings of the analysis of interviews collected for this study. First, I will describe the concepts individually, and then explain how they relate to each other. I then review how other researchers have used them. This set of concepts explains how ‘continuity’ and ‘disruption’ can both come about and thus offers a framework to resolve these tensions.
Chapter One: Myeloma—the Medical Model

Current understanding of the pathophysiology of myeloma

Myeloma, also known as multiple myeloma, is one of more than 200 different kinds of cancer. Cancer cells have a number of typical characteristics: their metabolism and growth is uncontrolled and disorderly; they have their own growth factors that keep them proliferating; and they tend to develop abnormally, and thus are unable to perform their normal function [39]. Instead of living for a finite period and then dying in a programmed way, they tend to live on and ignore signals to die. They also lose the ability to recognise the kind of cell that they are. They do not stay in contact with like cells, and they have the ability to grow outside of the location where they would normally be expected to grow [39].

Myeloma is a plasma cell disorder

Myeloma is, essentially, cancer of the plasma cells. Plasma cells are a type of white blood cell produced by the bone marrow. They develop from B-Cells that are lymphocytes—a white blood cell concerned with immune response [40]. Plasma cells produce five different kinds of immunoglobulins [41], illustrated in Figure 1. Immunoglobulins are proteins that are found in the blood and are important components of the immune response. There are five different kinds of immunoglobulin, and each has a specific role in the immune response. They are also known as ‘antibodies’ [39, 40, 42].
Multiple myeloma is one of a range of plasma cell disorders that include monoclonal gammopathy of undetermined significance (MGUS), primary amyloidosis, solitary plasmacytomas, Waldenstrom’s macroglobulinaemia, Polyneuropathy, Organomegaly, Endocrinopathy, Monoclonal gammopathy and skin-changes syndrome (POEMS), and multiple myeloma [41-44]. This diverse group of disorders all have varying implications for treatment and survival. Multiple myeloma is a B cell malignancy of the bone marrow, characterised by the uncontrolled self-replication (cloning) of plasma cells [41, 42, 45-47]. This results in the presence of abnormal immunoglobulins in the blood and/or urine in 98–99 per cent of patients [48]. These have unique characteristics and are called ‘paraproteins’ [41, 42]. The characteristics and quantity of the paraprotein are used to diagnose which kind of plasma cell disorder the patient has.
(including myeloma). It is also used to diagnose the type of myeloma that the patient has. The quantity of paraprotein—when considered on an individual level and in relation to their previous levels—is used to measure response to treatment and to prognosticate. In addition, normal immunoglobulin production is impaired. This impairs the body’s ability to mount an effective immune response to infection. The uncontrolled replication of abnormal plasma cells in the bone marrow space impairs the ability of the bone marrow to produce normal quantities of red blood cells, platelets and normal white cells [41, 42, 45-47]. This can result in anaemia, impaired clotting and a further reduction in a person’s capacity to mount an effective immune response. A collection of myeloma cells forming a solid ‘lump’ of myeloma cells are called a ‘plasmacytoma’, and can develop anywhere in the body [41].

Symptoms

Many physiological systems can be affected by myeloma (hence the name ‘multiple’ myeloma). The disease has a variety of symptoms. The most common are bone pain, infection, fatigue, renal failure and neurological problems [41, 43, 45-47].

Bone pain is characteristic of myeloma [41-43]. As well as producing abnormal plasma cells, the bone marrow also produces a protein-receptor activator for nuclear factor κ B ligand, which causes cells in the bone osteoclasts to resorb and create areas of breakdown in the bones, causing skeletal destruction [42, 49-52]. These are called ‘lytic lesions’. The lytic lesions can lead to fractures of the bone. The breakdown of the bone causes pain and the release of calcium into the blood, resulting in ‘hypercalcaemia’. Hypercalcaemia can cause a wide variety of symptoms, ranging from mild confusion and fatigue, through to coma and death [39].

Infection is a common presenting problem because of the incapacity of the immune system to respond effectively to bacteria and other microbials. This is due to a reduced number of normal white cells and of normal immunoglobulins [42, 53].

Fatigue is common, and is thought to be due to the effect of both anaemia and the body’s response to cancer through an inflammatory response [43].
Renal failure in myeloma is caused primarily by large quantities of paraprotein and excess circulating calcium [42, 53-55]. It may be severe enough to require dialysis. Large amounts of paraprotein can increase the viscosity of the circulating blood. This can cause neurological problems such as cognitive changes, altered vision and headaches. Spinal cord compression can also be a problem for people with myeloma. It is usually caused by pressure from a plasmacytoma on the spinal cord or by the vertebrae collapsing due to skeletal destruction. Either way, there is pressure on the spinal cord that impairs neurological function—for example, not being able to walk or to breathe. The impairment depends on where the compression point is, and therefore which nerves are affected. This is an emergency requiring immediate decompression [56] using surgery or radiotherapy.

**Multiple myeloma is not a new disease**

Lytic lesions characteristic of multiple myeloma have been described in Neolithic man circa 4000 BC [57], and in Egyptian mummies. The first recorded description of what was probably a case of myeloma was by Samuel Solly [58]. A record of his examination and treatment of Sarah Newbury was detailed in his paper ‘Pathology of Mollities Ossium’ in June 1844. Sarah was a 39-year-old woman who had presented four years earlier with progressive bone pain and spontaneous fractures. Despite treatment with orange peel infusions, daily stout, opiates and rhubarb pills, she died. In September of 1844, a wealthy London grocer, Mr McBean, developed severe pains in his chest and back together with oedema, and a ‘peculiar reaction’ was observed in his urine when it was heated and cooled. William Macintyre examined Mr McBean, and his urine was sent to Henry Bence-Jones for analysis. McBean died on 2 January 1846. At autopsy, his bones were examined by John Dalrymple and found to be so soft and fragile, that a knife could cut them (‘mollities ossium’). The cause of death was recorded as ‘atrophy from albuminuria’ [59]. All three physicians thought the disorder to be one of malignant bone disease, but it was not until 1873 that von Rustizky described the particular pathological features—multiple tumours of the bone marrow—as multiple myeloma [42]. The role of plasma cells was recognised at the turn of the twentieth century [60].
The cause of myeloma is unknown

Despite advances in describing the biological mechanisms of multiple myeloma, the aetiology of the disease remains unknown. However, there are several known risk factors, and like most malignant disease, the risk of myeloma increases with age. It is also more likely to occur in males than in females, in people of African-American ethnicity, in people who have a positive family history of lymphohematopoietic cancer, and those who have a pre-existing diagnosis of MGUS [61, 62]. A small number of studies have suggested an association between obesity and myeloma [63]. The strongest associations are with exposure to radiation and agricultural herbicides and pesticides [43, 64, 65], but these are inconclusive [43]. Fire fighters were found to be at a higher risk of the disease [66], possibly due to inhalation of carcinogens or radiation from radio transmissions [67]. Early studies [68] suggested a higher incidence of myeloma among people exposed to radiation in Hiroshima and Nagasaki following the atomic bomb blast in 1945; however, subsequent studies have contradicted this [69].

How myeloma is diagnosed and staged

Up to 25 per cent of people with myeloma present without any symptoms of the disease and are diagnosed on a routine blood test [8, 70-72]. The most common presenting symptoms are fatigue and pain [73]. Other symptoms that are frequently reported on presentation are infection, pathological fractures, symptoms of renal failure, and spinal cord compression. Symptoms that occur less commonly on presentation are confusion, carpal tunnel symptoms, and hyperviscosity syndrome [45, 74, 75]. Symptoms of myeloma are sometimes commonplace or ambiguous (e.g. back pain or fatigue). These may appear benign and thus are often ignored by patients, family and health care professionals. This can lead to missed opportunities for early diagnosis.

The criteria used to define myeloma have undergone a number of revisions since the disease was first described by Solly in 1844 [58]. The current definition requires the following three diagnostic criteria to be present [1, 76]:
• ten per cent monoclonal plasma cells in the bone marrow and/or the presence of a biopsy-proven plasmacytoma
• monoclonal protein present in the serum and/or urine
• the presence of one or more of the following clinical signs: calcium, renal function, anaemia and bone lesions—these are known by the acronym ‘CRAB’, and describe myeloma-related organ dysfunction.

Symptomatic myeloma is differentiated from other plasma cell disorders, such as MGUS and ‘smouldering multiple myeloma’ (i.e. asymptomatic myeloma), based on the presence or absence of end organ damage attributable to the underlying disease [77]. The European Society for Medical Oncology (ESMO) published a strategy for diagnosis underpinned by this definition (Table 1) [74].

**Table 1: Adapted from ESMO clinical recommendations for diagnosis**

[74]

<table>
<thead>
<tr>
<th>ESMO clinical recommendations for diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis should be based on the following tests:</td>
</tr>
<tr>
<td>• detection, evaluation and quantification of the paraprotein and myeloma cells (malignant plasma cells)</td>
</tr>
<tr>
<td>• evaluation of bone marrow plasma cell infiltration—bone marrow aspiration and biopsy are the standard option to detect quantitative and/or qualitative abnormalities of bone marrow plasma cells</td>
</tr>
<tr>
<td>• evaluation of lytic bone lesions—full skeleton X-ray survey is recommended, and magnetic resonance imaging (MRI) provides greater detail and is recommended if a spinal cord compression is suspected</td>
</tr>
<tr>
<td>• biological assessments to differentiate symptomatic and asymptomatic MM: i.e, haemoglobin (and full blood cell count), renal function (creatinine) and calcium level (CRAB classification)</td>
</tr>
<tr>
<td>• these tests allow the differential diagnosis between symptomatic MM, smoldering (or indolent) MM, and monoclonal gammopathy of undetermined significance (MGUS).</td>
</tr>
</tbody>
</table>
Historically, two systems of evaluation of newly diagnosed myeloma have guided therapy decisions and prognosis. These are known as ‘staging’ systems. The Durie-Salmon staging system categorises patients primarily according to tumour burden (i.e. the quantity of myeloma) and renal function [78]. The more recent International Staging System (ISS) [79] incorporates reproducible parameters of albumin and β2 microglobulin and assigns patients to high, intermediate or low-risk groups. This provides useful prognostic information.

The impact of gene profiling in myeloma

Myeloma appears to have a heterogeneous biology, and this fact is important in managing the disease [8, 80]. It is important because it means that the prognosis, clinical course, and response to therapeutic interventions can vary from one person to another. This is becoming increasingly apparent as the meaning of variations in gene profiling, differences in response to treatment, and variations in time to progression are evaluated to understand what they mean for the individual. All cases of myeloma are now thought to be characterised by the presence of genetic abnormalities [81], and there are at least six distinct cytogenetic subtypes [75]. Some of these distinctions are useful in prognosis. The idea of personalised medicine, together with an increased understanding of myeloma as a not one disease but several, has changed approaches to therapy [80]. This has added to the complexity of therapy decisions, but has allowed risk stratification. However, risk stratification data takes time to accumulate, as myeloma is a relatively rare disease.

Successfully stratifying treatment according to risk [75, 80] is useful in choosing the optimal therapy for individual patients. For example, patients in lower risk groups should be treated less aggressively to provide a better quality of life, whereas patients in the higher risk groups should be treated more aggressively to maximise their chances of survival. This requires reliable prognostic markers at diagnosis. For example,

---

1 For example, hyperdiploidy (an increased number of chromosomes) is associated with a better prognosis. However, deletion of part of chromosome 17 or translocation of chromosomes 14 and 4 or 14 and 16 are all thought to indicate a poor prognosis (81). Dispenzerie et al. suggested a risk stratification table and a risk-adapted therapy (mSMART), which, they argue, appears to offer greater power and predictive value for risk stratification (82) and therefore treatment decisions.
autologous stem cell transplant (ASCT – see section below) is the gold standard for ‘eligible patients’. However, a risk-adapted approach to treatment from the point of diagnosis includes deciding whether or not a patient is a ‘good risk’ for transplant [75, 80]. In addition, if good risk and poor risk patients are not stratified at the outset, then the apparent overall survival might be a surrogate marker and some patients may have had good outcomes regardless of the transplant and therefore may have over-treated with an expensive, intensive and unnecessary procedure [8].

**Myeloma is a rare disease**

Myeloma accounts for 1.2 per cent of all cancer diagnoses in Australia and 10–15 per cent of all haematological malignancies. In 2010, the age-standardised incidence rate per 100,000 population was 5.6: 7.0 in men and 4.4 in women. That is, it is more common in men than in women by a ratio of 1.6 [82].

United States data show an age-adjusted incidence rate of 5.6 per 100,000 people per year. These rates are based on cases diagnosed in 2002–2006 from 17 SEER² geographic areas [83]. European data are similar, with a rate of 6.0 per cent per 100,000 population per year and a median age at diagnosis of between 63 and 70 years [81]. The rarity of this type of cancer affects the way it is understood, managed and experienced by both patients and health care workers.

The incidence of myeloma appears to be increasing as the median age of the population in Western societies increases [84]. In Australia, the annual rate of change in incidence has remained virtually the same. This is in contrast to some data from the United States of America (USA) and United Kingdom (UK) suggesting that there is an overall increase in incidence, irrespective of age [61, 70, 85]. Some data suggest that myeloma is being diagnosed in younger patients with increasing frequency [70, 71], although it remains rare in younger populations. Only two per cent of newly diagnosed people are less than 40 years old, and five per cent less than 50 years old. However, this increase in incidence in younger people is not supported by Australian data [82].

---

² Surveillance, Epidemiology and End Results (SEER) Program, the primary source for cancer statistics in the United States.
People are living longer with myeloma

The pattern of disease of myeloma has changed over the last two decades [1, 79]. People are presenting with the disease at a younger age, and they appear to be presenting at an earlier stage of the disease. Up to 25 per cent of those diagnosed are asymptomatic when they present [8, 70, 71], and people with myeloma are living longer [6, 86] than previously. Myeloma accounts for 1.8 per cent of cancer deaths in Australia, but the annual rate of mortality has reduced by 6.8 per cent since 2004 [82]. There were 698 deaths from myeloma in Australia in 2007[82].

The median duration of survival in the 1990s was less than three years. In 2008, Wang et al. reported at an American Society for Clinical Oncology meeting [87] a median survival of 10–15 years for a cohort of 759 patients who achieved a complete remission after intensive induction treatment, and who were stage one (ISS). Being diagnosed at an early stage and at a younger age, and being treated with novel agents, have all been shown to independently improve survival. There are a number of reports of improvements in five and ten year survival in younger patients [6, 7, 47, 88-91], although poor risk patients continue to have poor survival[88]. The heterogeneity of the characteristics of myeloma is clearly highlighted in differences in survival [88]. For example, Cavo et al. reported that the expected median survival for standard risk patients is approximately seven years, yet the median expected survival for higher risk patients remains significantly lower, at between three and four years [92]. Survival of people with myeloma now varies from a few months to several decades [86, 91].

The improved survival over the last 20–30 years [1, 2, 6, 8, 47, 88-91] has occurred in tandem with developments in treatment, but also with new technology in molecular biology and, importantly, in supportive care. The relationship between survival and developments in diagnostic technology, treatment, and understanding of the pathology of myeloma and survival is illustrated in Figure 2.
Figure 2: Key milestones in the management of multiple myeloma, demonstrating corresponding survival improvements

Figure 2 key

<table>
<thead>
<tr>
<th>Rad</th>
<th>MP*</th>
<th>SCT*</th>
<th>HDC*</th>
<th>VAD*</th>
<th>RIC*</th>
<th>Thal**</th>
</tr>
</thead>
<tbody>
<tr>
<td>Radiation therapy</td>
<td>Melphalan &amp; Prednisolone</td>
<td>Stem cell transplant</td>
<td>High Dose Chemotherapy</td>
<td>Vincristine, Adriamycin &amp; Dexamethasone</td>
<td>Reduced Intensity Conditioning (transplant)</td>
<td>Thalidomide</td>
</tr>
<tr>
<td>Bisphos</td>
<td>Rev**</td>
<td>HSP90</td>
<td>Perifosine**</td>
<td>CC1779</td>
<td>ISS***</td>
<td>CRAB***</td>
</tr>
<tr>
<td>Bisphosphonate (class of drugs that prevent bone loss)</td>
<td>Revlimid</td>
<td>Therapeutic Compound under investigation</td>
<td>Perifosine</td>
<td>Therapeutic Compound under investigation</td>
<td>ISS</td>
<td>Calcium, Renal, Anaemia &amp; B2M prognostic criteria</td>
</tr>
</tbody>
</table>

* Chemotherapy combination treatments ** Novel agents (new treatments) *** Prognostic criteria and systems. Developments in diagnosis are below the central horizontal line and developments in treatment above.

Adaptation of B.Durie’s presentation at Cedar-Pines 2007, with permission
The management of myeloma is not focused on cure

Because myeloma is regarded as incurable, treatment is focused on three other health-related outcomes:

1. inducing remission
2. maximising the duration of remission
3. maintaining of quality of life and functionality despite relapse.

The specific aims of treatment are:

1. to arrest the malignant process of abnormal plasma cell production
2. to treat and manage the systemic effects of myeloma—for example: renal failure, bone disease, pain and decreased immunity
3. to treat and manage the adverse effects of treatment itself—for example: fatigue, neuropathy, and further reduced immunity.

Immediately following a diagnosis of myeloma, the initial key therapeutic considerations are to treat pain, infection, renal failure and/or other systemic effects of myeloma. In the longer term, there are a number of key decision points [93] in the management of the disease, as shown in Figure 3.
Figure 3: Key decision points in the treatment of myeloma [93]
Available drug treatments

The treatment of myeloma has changed drastically over recent years. Historically, cytotoxic chemotherapy drugs, such as melphalan, doxorubicin and vincristine, as well as glucocorticosteroids, were used alone or in combination to provide the mainstay of myeloma therapy [94-101]. More recently, better understanding of the pathophysiology of myeloma, together with knowledge about signalling pathways, has led to the development of a new class of drugs known as ‘novel agents’. These include thalidomide, bortezomib and lenalidomide. Novel agents aim to destroy myeloma cells in the microenvironment of the bone marrow. They work primarily by targeting and disrupting cell signalling pathways, and thereby cause myeloma cells to apoptose or ‘commit suicide’ [5, 86, 102-105]. Novel agents are used alone or together with conventional chemotherapy, and they have increased the range of drug treatments that are available, especially at the point of initial (or induction) therapy [3, 75, 106-108]. The common adverse effects of conventional chemotherapy arise from the fact that it systemically damages or destroys all fast dividing cells in the body regardless of whether they are cancerous or not. Novel therapies work in a more specific way in that they target the malignant cells [5, 86, 102-105]. Nevertheless, they also have adverse effects that can have an enormous impact on patients’ lives [47, 86, 109-117].

Following the initial induction treatment described, the next phase of treatment may be a stem cell transplant.

Stem cell transplantation

Stem cell transplant is an expensive, arduous and resource-intensive treatment that has been shown to improve survival in the treatment of myeloma. It may require three to five weeks in hospital with considerable morbidity from the numerous adverse effects of the high dose chemotherapy. This is followed by weeks, months or years of follow up and recovery. If a decision has been made to include a haematopoietic stem cell transplant in the treatment programme, it is usually undertaken within three to six
months of completion. Transplant is a treatment modality that is most effective with a ‘low tumour burden’, that is, with as little myeloma as possible [6, 45, 75, 80, 118-123].

McElwain and Powles [124] first reported the results of a stem cell transplant in a patient with plasma cell leukaemia (a variation of myeloma involving the presence of plasma cells in the blood) in 1983. In a stem cell transplant, it is not a solid organ that is transplanted but a population of haematopoietic stem cells. These are cells produced by the bone marrow, and they are the precursors of red cells, white cells and platelets (Figure 4). For this reason, they are sometimes called ‘haematopoietic progenitor cells’ (HPCs) but I will refer to them here simply as ‘stem cells’.

![Diagram showing the development of all blood cells from haematopoietic progenitor cells (HPCs) produced by the bone marrow](image)

**Figure 4:** Diagram showing the development of all blood cells from haematopoietic progenitor cells (HPCs) produced by the bone marrow

A stem cell transplant can be either ‘autologous’ or ‘allogeneic’. In an autologous stem cell transplant, haematopoietic stem cells are collected from the patient and then
returned to the patient after a high dose of chemotherapy. In an allogeneic transplant, the cells are collected from a donor and then transfused into the patient after they have received ‘high dose’ chemotherapy. Donors are usually related to the patient (most are siblings), but if a suitable donor cannot be found among the patient’s close relatives, HPCs are obtained from an unrelated volunteer donor who is a good ‘match’ for the patient. Allogeneic transplantation has much higher morbidity and mortality rates than autologous transplantation, and is rarely indicated in patients with myeloma except in younger patients with aggressive disease (and even then, it is usually used in the context of a clinical trial rather than routine treatment). Autologous stem cell transplantation is therefore more relevant for this thesis, and I shall refer to it henceforth simply as ‘ASCT’.

In order to collect haematopoietic stem cells from the patient, they must undergo a process known as ‘stem cell mobilisation’. She or he is given a course of granulocyte colony stimulating factor (GCSF), usually after a course of infusional chemotherapy. The bone marrow responds to the effects of the chemotherapy (i.e. the destruction of blood cells) by producing new haematopoietic stem cells and releasing them into the blood stream. The GCSF enhances the bone marrow’s ability to produce large numbers of these cells.

One they are mobilised, the stem cells can then be collected using a technique called ‘leucopheresis’. A quantity of blood is drawn from the patient and put in a centrifuge which separates the stem cells from the rest of the blood. Haematopoietic stem cells can also be collected directly from the bone marrow in a surgical operation known as a ‘bone marrow harvest’. This is much more invasive, however, and it is rarely used nowadays for ASCT. If a sufficient number of haematopoietic stem cells are collected by means of leucopheresis, they are cryopreserved (i.e. stored in deep freeze).

The patient then receives a high dose of chemotherapy. The stem cells are subsequently thawed out and returned to the patient’s body by intravenous infusion, much like a routine blood transfusion. Because haematopoietic stem cells are simply immature blood cells, when they are reintroduced into the patient’s body they find their way back into the bone marrow where they mature and develop into the three major blood cell
types and reconstitute the patient’s immune system. Stem cell transplants are sometimes more accurately called ‘stem cell rescues’ because the high-dose chemotherapy effectively destroys the patient’s immune system, and if the immune system were not rebuilt (either with the patient’s own HPCs, or with those of a donor), the patient would soon die from an infection.

High dose chemotherapy with ASCT aims both to reduce the number of myeloma cells (tumour burden), and to achieve a state of remission for a longer period than can be expected with conventional doses of chemotherapy [2, 45, 75, 125-128]. It is now considered to be standard treatment for myeloma [6, 45, 75, 80, 118-123] and has been termed ‘the gold standard’ as a consolidation treatment for eligible patients [2, 45, 125-128]. This means that when a patient is diagnosed with myeloma, a decision needs to be made about whether to include an ASCT in the treatment plan [75, 128]. For patients who have an adequate or good ‘performance status’ (this is a scoring system for quantifying an individual’s level of wellbeing3) and who are less than 70 years of age [2, 127], a transplant is likely to maximise the response to the chemotherapy treatment, and improve overall survival [129, 130]. It has been argued that some patients might be able to enjoy a durable ‘good partial remission’ without transplant [8, 80]. If transplant is not an option because the patient or the treating haematologist have decided against it for reasons of age, co-morbidities or personal choice, then oral chemotherapy or a novel agent is offered together with symptom management (i.e. palliative care).

The ‘depth’ of remission is important for prognosis

 Following the initial induction treatment, the ‘depth’ of remission is usually assessed, that is, how effective the initial treatment has been in treating the myeloma. Quantifying the number of myeloma cells in the bone marrow, the level of paraprotein in the blood, and the extent of end organ damage assesses this. The European Group for Blood and Marrow Transplantation (EBMT) criteria for measuring response were widely used

3 There are two systems for measuring performance status in clinical practice. The Karnofsky score ranges from 0 (dead) through to 100 (perfect health) and the ECOG (also called the WHO or Zubrod) score, which ranges from 0 (fully active, well, able to perform all activities) through to 5 (dead). They are frequently used to guide treatment decisions with regard to reducing the dose of therapy or ceasing it all together. They are also incorporated into quality of life assessment in clinical trials.
[131] for eight years but have been superseded by the International Myeloma Working Group (IMWG) [132] criteria, which are shown in Appendix 1. The IMWG included additional criteria specifying differences in the quality of a complete response. This has been shown to have implications for prognosis and, therefore, further treatment. For example, a complete response ranges from no molecular evidence of myeloma cells and normal immunoglobulin levels (known as ‘CR+’) to an absence of overt measurable myeloma disease (known as ‘CR’) alone (i.e. without molecular evidence). The development of more sensitive and reproducible ways of measuring serum free light chains (immunofixation) has led clinicians to consider complete response as a surrogate marker of quality of life and an independent prognostic factor for survival [133-135].

The addition to the EBMT criteria of ‘very good partial remission’ demonstrated that developments in technology have allowed increasingly small amounts of quantifiable myeloma to be detected. Advances in technology such as this was demonstrated at a conference in London (Royal Marsden Hospital) [136] where 13 patients who had been considered to be in complete remission (i.e. with no evidence of myeloma disease) for more than 10 years following ASCT were discussed as case studies. All diagnostic materials (such as sera and bone marrow) were re-evaluated. Following re-evaluation with newer technology not available at the time these patients were treated, none of the 10 was found to have achieved a complete response. Thus, even though they were all found to have evidence of myeloma in their bodies, they were not ill.

The addition of the criterion ‘stable disease’ may point to living with a more indolent form of myeloma that grows slowly and is characteristic of patients with long survival. Identifying this subgroup can arguably spare patients from unnecessary maintenance therapy or intensive treatment. Durie [8] argued that as the management of myeloma changes, the goals of treatment should also change accordingly.

Complete remission is an important prognostic factor [135] and it is an important goal of treatment, but it is not the only goal of treatment [8, 75, 137]. Responsiveness to therapy and time to subsequent disease progression after therapy are two very different endpoints and it has been suggested that the latter may ultimately be more important [8].
**Maintenance therapy to sustain remission as long as possible**

If induction therapy brings about a remission, the role of maintenance therapy is to maintain the remission for as long as possible by controlling the myeloma. Therefore, it is not a curative option [75, 138]. Some drugs used in maintenance programmes have significant adverse effects, and any measure of benefit has to be weighed against them. Thus, maintenance treatment is a trade-off between maximising quality of life and extending the duration of survival [8, 139]. For standard risk patients, no therapy has yet been shown to prolong survival sufficiently to justify the associated adverse effects [80].

**Managing relapse as a chronic disease**

People are living for longer with myeloma [75, 86, 137] and despite the fact that it remains incurable, it has become increasingly treatable. Durie and others [8, 137] have suggested that the ‘control’ of myeloma is therefore as valid a goal of treatment as cure. To this end, Durie [8] suggested that the best surrogate markers for overall survival are time to progression and event-free survival rather than measures of a micromolecular nature. The idea of an ‘operational’ cure [136] where event-free survival is the aim has fuelled the so-called ‘cure versus control’ debate [8, 137]. Rather than cure being considered the only ‘successful’ outcome, the availability of new treatment options together with the idea of an approach aimed at living with myeloma have led to event-free survival becoming the aim of treatment following relapse. Durie et al and others have emphasised the ongoing nature of managing myeloma by arguing that relapse management is as important as initial treatment decisions [8]. This highlights the chronic nature of myeloma: it is an incurable but treatable disease, and multiple relapses are to be expected. Effective management of the relapse of myeloma is equally as important as effective treatment at diagnosis. Indeed, management of relapse, management of myeloma that no longer responds to treatment, effective symptom control, and quality of life are key considerations for successful myeloma management [1, 8, 30, 140-143].
Conclusion

The clinical perspective on myeloma is that it is a complex disease with varying biological behaviours, illness courses and prognoses. Its management is changing as it is situated within a rapidly expanding field of research. The changes in understanding about the pathophysiology, cell signalling pathways (epigenetics) and genetic profiling of the disease brought about by ever-advancing technical advances in the fields of molecular biology are changing the way in which myeloma is managed. The idea of a personalised approach to treatment is already being used. The advances have also brought about new and different treatments, including ‘novel agents’, to treat this incurable but increasingly treatable disease.

The next chapter reports on personal and social understandings of myeloma by reviewing relevant literature about the experience of illness. This includes the relationship between health and illness, a taxonomy of illness, and biographical theories of illness experience.
Chapter Two: Myeloma as a Social and Personal Experience

As well as being a malignant disease, myeloma is a personal experience that affects human individuals in fear-reaching ways. To date, only a handful of published studies have examined myeloma from this perspective [34, 117, 144]. These studies did not emerge in isolation, however: they belong to a body of qualitative health research that stretches back to the 1960s. Furthermore, the emergence of this literature has been attended by major philosophical shifts that underpin how we understand the relationship between health and disease more generally, and that explain why concepts of disease are increasingly differentiated from concepts of illness and related concepts that seek to account for phenomena that are systematically overlooked by the ‘medical gaze’.

In this chapter, therefore, I shall begin with a brief survey of key concepts such as health, disease and illness in order to highlight philosophical insights and debates that are relevant for understanding myeloma as a human experience rather than as a unique pathology of plasma cells. I will then review some key insights, concepts and conceptual tensions that have emerged over recent decades in the body of qualitative health research that has grown alongside the medical advances in myeloma reviewed in the previous chapter. This literature has revealed many important insights into the relationship between illness and other aspects of human experience, such as everyday life, biography, time, work, death, and dying. Many of these insights are relevant to my investigation of the experience of myeloma. In fact, because myeloma cuts across so many of the categories that are used frame the experience of illness (e.g. ‘chronic’, ‘acute’, and ‘terminal’), it is necessary to range widely across the qualitative literature. At the end of this chapter, I will position my own research in relation to the existing qualitative studies of haematological malignancies, and myeloma in particular, and set out the specific aims of my research.
Objective conceptions of disease as a biological phenomenon

Attempts to account for health and disease in objective terms are characteristic of a scientific, medical perspective. They can also be found in medical philosophy, however. For example, in a highly influential article, Boorse [145] argued that physical health is a property that can be defined objectively – that is, in a ‘purely descriptive’ and value-free way. On his account, to be healthy is to be normal, where ‘normality’ is understood in terms of ‘species typical functioning’. Diseases are classifications that describe deviations from normal function. Boorse distinguished these ‘theoretical’ concepts of health and disease, which apply to all living organisms, from the ‘practical’ and value-laden concepts of health and illness. He characterised illness as a subclass of disease – roughly, one that encompasses those diseases that cause individuals to suffer, and that provide a warrant for special treatment and diminished moral accountability [145 pp61]. Boorse’s central aim was to counter what he saw as the prevailing ‘normativism’ of the day – that is, the view that medical concepts of health and disease rest on value judgements. The distinction between disease and illness is a crucial one, because one of the central tasks of health sociology has been to give content to the latter.

Changing our understanding of disease and illness

Whitbeck [146] conceptualised health as being experienced when an individual has the capacity to support their goals, projects and aspirations and Canguilhem also characterised health as functional [147]. McWilliam et al. illustrated this empirically in his study of older people and their ideas about health. Health, they said, is ‘being able to do what you want to do’ [148 pp7] as well as feeling in harmony with the environment, thus being able to carry out everyday activities within one’s own environment. This they characterised as balancing. Both ‘balance’ and ‘balancing’ in health were found by Lipworth et al. in their investigation of lay conceptualisations of cancer risk, to be focused on health maintenance. Participants were ‘focused on living a balanced life’ [149 pp715] rather than focusing on risk assessment and vigilance, for example. Balance has also been used as a metaphor for managing daily life in the context of living with an intrusive chronic illness such as Parkinson’s Disease [150], Systemic Lupus Erythematosus, Arthritis and other such conditions [151].
Early systems of belief upheld positive ideals of health that were based on the notion of balance with disease or illness conceptualised as disruptions of that balance. The idea of disease as a quantitative departure from normality was a much later historical development. The idea of ‘normal’ health, or of the body having a ‘normal state’, stemmed from the idea of homeostasis (a term derived from the Greek word for ‘balance’), which underpinned early Western medicine. Both the Hippocratic and Galenic schools of medicine [152] proposed that for the body to be healthy, it must hold its ‘primary properties’ in balance (i.e. wet, dry, cold and hot). Medieval Schools of thought later formulated the balance as being one between the four humours: blood, phlegm, yellow bile and black bile [152, 153] The idea that health is a state of balance or equilibrium and that disease is the result of imbalance is also prominent in Eastern Medicine. For example, in Indian traditional Ayurvedic medicine, maintaining a balance between the three elements (or humours) of wind (air and space), bile (fire and water) and phlegm (water and earth) is essential for a healthy body. This is one of the most widely practiced kinds of medicine on the Indian subcontinent today [154].

In contrast to the medical model, the concept of Ayurvedic medicine is to promote health rather than to fight disease. Ayurveda aims to maintain harmony between nature and the ‘individual’ in daily life as a way to achieve optimal health [154]. This is similar to Antonovsky’s [155] concept of ‘salutogenesis’ [155-157]. Salutogenesis focuses on health and holds the view that all individuals are inevitably subject to stressors and disease and the focus must be on how to manage these well. The emphasis is on that which facilitates health, rather than what causes disease. Antonovsky argued that this is a challenge within the biomedical model of health and disease, where more attention is paid to disease than it is to health: ‘We do not ask about the smokers who do not get lung cancer, the drinkers who stay out of accidents, the Type A’s who do not have coronaries’[155 pp203]. Blaxter called this concept health ‘coherence’ [158]. The components of this coherence were ‘measures of the extent to which individuals perceived the world as comprehensible, manageable and meaningful’ [158 pp17]. In other words, the idea of coherence explained an individual’s relationship with their environment.
Canguilhem’s [159 pp199] notion of health for an individual also involved their relationship with the environment. Good health means being able to respond to changes and obstacles in the environment by adapting and overcoming them: good health ‘means being able to fall sick and recover’ [159 pp199]. Health, he argued, was the prime regulator of wellbeing or not: ‘health is a regulatory flywheel of the possibilities of reaction’ [159 pp198]. Thus, adaptation to changes in the environment (i.e. health) is an active process, not a passive one. Therefore, disease can be seen as something that reduces the margin of tolerance to change in the environment, but ‘this reduction results in the ability to live only in another environment and not in parts of the previous one’ [159 pp198]. The individual, by tolerating changes to the norm, creates new norms in response to changes in the environment. This is what Canguilhem called normativity [159]; it is the relationship between the individual and the environment that determines what normal health is:

A living being is normal in any given environment in so far as it is the … functional solution found (by life) as a response to the demands of the environment [159 pp14]

The term ‘environment’ is used here in its broadest sense to mean the sum total of all conditions that affect the development of an individual. This includes the surrounds and the intracellular and intercellular conditions of an individual. Horton’s [160] example of HIV illustrates this point:

Progressive immunosuppression that follows infection by HIV is a normal response to that virus. ‘Health’ (normal) may be conceived as the ability to tolerate the virus despite clear evidence of infection [160 pp318].

Thus, when the body is ‘healthy’, it can tolerate the challenges posed by its environment [161 pp31] therefore, health is not an absence of disease but rather an absence of illness. Blaxter argued that health equates to not being ill, where illness equates to having symptoms of disease [162]. Further, she found, people in ‘poor health’ were less likely to define health in terms of illness, but rather in terms of their ability to cope. In other words, they conceptualised ‘health’ in terms of their relationship with their
environment—which included their ability to function and to do what they wanted to do.

**Health is a subjective experience**

Health is ‘grounded in the experiences and concerns of everyday life … [and it] provides a means for personal and social evaluation’ [163 pp62]. Health has been conceptualised in the literature in two key ways: as an experience and as something that can be attained or achieved.

The experience of health is what Gadamer has described as ‘phenomenological health’. This is the experience of health where health is forgotten and in the background [164 pp96].

Health is not a condition that one introspectively feels in one self. Rather it is a condition of being involved, of being in the world, or of being together with one’s fellow human beings, of active and rewarding engagement with one’s everyday tasks [164 pp113].

The world is experienced through the body yet we are often not aware of the organs and physiological processes that keep the body alive from day to day. However, health and illness can cause the body to be consciously experienced. Canguilhem and Leder suggested similarly that health was experienced when ‘the organs are silent’ [147 pp468]. Health can thus be considered an ‘absent presence’ [165]. For Leder, health does not always cause the body to be an experience of absence. For example, an athlete who is extremely fit and has a finely tuned nutritional intake and exercise programme may be aware of every detail of his or her body pertaining to his or her ability run fast or perform feats of endurance. Similarly, illness causes an awareness of the body.

The subjective lived experience of ‘health’ or the ideal of ‘being healthy’ [166] may be different from the perspective of the individual who is ‘functioning well’ to that of the
community [167]. Radley and Billig [168] argued that health was not socially constructed by the community, but was best understood in their accounts to others. This is similar to Blaxter’s argument that an individual’s view of their own health is different to and distinct from the definition of health in others [162]. Similarly, Gelech and Desjardins’ conceptualised this difference as being between private and public constructions of health [169].

Health, then, can be understood subjectively as well as objectively and can be understood as being relational. In other words, it has several dimensions that may be applied to different areas of life and lifestyles [158, 162, 170] at different times and thus is enigmatic [164], which has been empirically illustrated [162, 166, 170]. Hughner and Kliene [170], in their meta-analysis of lay conceptions of health, found 18 different ways in which people thought about health. These fell into four broad categories: definitions of health; explanations for health; external and/or uncontrollable factors impinging on health; and the place health occupied in people’s lives. When 9,000 people in the UK [162] were asked ‘what is health?’, ten per cent of respondents said that they did not know. When pushed to define health, people have said that health can be defined negatively, functionally or positively. Defined negatively, health is the absence of illness. Defined functionally, health is the ability to carry out everyday activities. Defined positively, health is the feeling of fitness and well-being [162 pp14, 166 p1085, 170].

The idea of health as ‘wellbeing’ [163] has been characterised as something of value that should be achieved. In other words, health is an ideal. Crawford argued that this notion of health is one that must be actively sought out. In other words, being healthy means to ‘demonstrate self-control, self-discipline, denial and willpower’ [163 pp78]. This implies that striving to be healthy is a ‘moral code’ [166, 171, 172] and it builds on the idea of medicalisation of the healthy lifestyle [173, 174 pp412] or, alternatively, ‘healthism of everyday life’ by Crawford [175, 176]. Crawford saw healthism as an ideologically insidious force: ‘By elevating health to a super value, a metaphor for all that is good in life, healthism reinforces the privatization of the struggle for generalised well-being’ [175 pp365]. Healthism has been described as a Western middle class aspiration that expects modern medicine to go beyond treating disease to providing
health a feeling of well-being and quality of life without symptoms of any kind [177]. Being healthy and having health in this way has been idealised as a goal for all by the World Health Organization (WHO).

The WHO’s holistic definition of health was first published in 1946 and it has not been changed since. It states that health is ‘a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity’[178 pp96]. This is consistent with Gadamer’s holistic characterisation of health.

Therefore, both philosophically and socially, health is clearly a subjective concept. If health is viewed subjectively, there can be non-concordance between private and public constructions of health. In contrast, the biomedical construction of health is as something that is a biological state and more concerned with an absence of disease.

**Health in the presence of disease**

Health can be experienced in the presence of disease [159, 160, 179]. Herzlich [180] argued it is important not to confuse the subjective state of health ‘in itself’ and the state of health as defined by medicine and the physician. She further clarified this by citing epidemiological studies that have demonstrated that symptoms are found in the so-called normal population without causing illness, and that medical knowledge is therefore more than a reading of symptoms. In other words, it is a process of constructing disease, according to the interpretation of the symptoms, or signs. The medicalisation of menopause and obesity are two examples of this. Throughout history, symptom complexes have been described and later acquired the status of specific diseases. The idea of ‘pre-disease’ -nearly having a disease - is a contemporary example of historical and cultural influences on disease categorisations. Green has called this an ‘actuarial’ model of disease where the presence of factors that increase the risk of a disease without the presence of symptoms or an overt pathological process detrimental to normal function, is sufficient for there to be disease [181]. Hypertension and obesity are examples. Pre-diabetes is another. An individual may have a blood glucose reading of 124mg/dL. The individual’s blood glucose reading is a ‘brute’ fact, but the interpretation of the reading is societal, or an ‘institutional fact’ [167]. According to the
biomedical paradigm of disease, blood sugar is measured along a continuum and at some point along the continuum, above the ‘normal’ range, blood glucose levels are said to be ‘high’, which indicates that the individual is likely to develop a disease (diabetes). Thus, they are categorised as pre-diabetic, yet a little further along the continuum, with a reading just slightly higher—126mg/dL, for example—they would be diagnosed as having diabetes. There are similar categories relating to other diseases, such as pre-renal or pre-cancerous categories of ‘carcinoma in situ’ and ‘smouldering’ or ‘asymptomatic’ myeloma. MGUS or benign monoclonal gammopathy (BMG), as it is more benignly known, is not an illness or a disease but is situated somewhere along the spectrum of the range of levels of raised (single) immunoglobulins.

Individuals who are diagnosed with ‘pre-diseases’ may be able to function well in their environment and feel well, yet they have an actual or potential disease. The intrusive nature of the clinical gaze afforded by ‘modern medicine’ and diagnostic technology has added further complexity to the understanding of health and disease. Blaxter calls this the ‘surveillance society’ that is ‘resting on technological developments’ [158]. Instead of a clear division between health and disease, there is a continuum [159] along which individuals are ‘potentially ill’ [158 pp132]. Along this spectrum also are those who are ‘ill-in-remission’ or have ‘techno-health’, that is, individuals who function well with the aid of technology such as a pacemaker, wheelchair or prosthesis. These people are members of what Frank calls the ‘Remission Society’ [182]. Cancer survivors, who are not ill but remain in ‘liminality’ [183] and live in fear of the possibility of recurrence [184, 185] are also situated on this spectrum. Sadegh-Zadeh called this ‘fuzzy health’, emphasising that disease and health are ‘not dual and mutually exclusive … [because] a person is healthy with a disease, or is unhealthy without a disease’ [186 pp607].

**Illness as a social construction**

Illness is the subjective experience of disease; however, illness is not always accompanied by disease, just as disease is not always accompanied by illness. Illness is a subjective experience but the idea of illness is culturally and historically informed by an individual’s relationship with their body [145] and thus is also a social construction.
Klienman [187] suggested that there were three ‘arenas’ in which healing and illness experience took place:

1. the popular arena—the home and community where illness was first defined and health care activities initiated
2. the folk arena—non-medicalised, non-professional, such as faith healers and folk psychotherapists
3. the professional arena—biomedicine and professionalised healing traditions, such as Ayurvedic and Chinese medicines.

In all of these arenas, illness is considered to be in relation to health, not independent of it. Illness is a subjective and thus very personal experience of ‘unhealth’ [188 pp10] or of suffering. Cornwell differentiated between public and private conceptualisations of health and illness [189] where people’s concepts of health and illness depended on the kind of account that they were giving [168]. Thus, ways of approaching and understanding illness are intrinsically linked to societal norms [190, 191] or a ‘social model of health’ [158 pp16].

**Taxonomies of illness**

One understanding of illness is as a taxonomy that categorises illness as acute, chronic or terminal. Blaxter called this ‘states’ of illness, using the term in a biomedical sense. She distinguished between a health state (the present health state of the individual) and the ‘health status’ (a longer-term attribute) [158 pp10]. Thus, she argued, an individual can have a long-term chronic condition such as diabetes (health status), but be in good health (health state). Alternatively, they can be in a poor health state with an acute illness such as influenza, but generally be in good health (health status). People with myeloma, then, have a chronic or terminal health status because myeloma is an incurable disease, and may suffer rapidly changing acute health states, such as an episode of infection and can also feel well. Thus, their illness experience does not fit neatly into the taxonomy but constantly cuts across it.
Cancer is a broad category of diseases based on a similarity at the cellular level: these diseases are all characterised by uncontrolled cell replication [192 p163]. Cancer can be sub-clinical, acute, chronic or terminal depending on the quantity of malignant cells and their effects on the functional health of the individual. Cancer is increasingly being viewed as chronic illness [192] because, like other chronic illnesses, it can be disabling and socially isolating, it can cause pain and embarrassment, the diagnosis can be stigmatising, and people with cancer are increasingly expected to take at least some responsibility for managing their own care [193-195]. Myeloma is a type of cancer. It can also be disabling, socially isolating and managed by those who are diagnosed with it. However, it can also warrant admission to the closest emergency department because of a sudden and unanticipated bout of septic shock. It is a terminal illness in that people will certainly die of it unless something else ‘gets’ them first. Therefore, myeloma can be experienced as a chronic illness, a terminal illness or an acute illness, or all three.

**The experience of illness is subject to the ‘ups and downs’ of everyday life**

One day my body broke down, forcing me to ask, in fear and frustration, what’s happening to me? Becoming ill is asking that question. The problem is that as soon as the body forces the question upon the mind, the medical profession answers by naming a disease … Medicine can diagnose and treat the breakdown, but sometimes so much fear and frustration have been aroused in the ill person that fixing the breakdown does not quiet them. At those times, the experience of illness goes beyond the limits of medicine [161 pp8].

Frank was 39 years of age when he suffered a myocardial infarct. The answer he received to the question ‘what’s happening to me’ was a medical one. He said that it told him what had happened to the organ in his body, but not what had happened to him, as a subjective, emotional, life-changing experience. Frank distinguished between ‘disease talk’ (pathological, categorical and able to be charted) and ‘illness talk’ (about the subjective to ‘my’ body).

Studies of the experience of illness have described the toll that it has on an individual’s life [182, 196-206]. They have also revealed profound resilience and adaptability [182, 189, 206-210]. The experience of illness has been found to be malleable, characterised
by times of wellness and of deterioration but also by emotions and by interactions with
the surrounding social world [168, 211-214]. Thus, experiences of illness are individual
experiences and subject to the difficulties of everyday life.

The biographical theories of illness

Lawton [215] mapped a conceptual shift within medical sociology from the ‘outsider
perspective’, which is exemplified by Parsons’ functionalist sociology [216] and the
biomedical understanding of disease, to an ‘insider perspective’ that attends to the
experiences of the patients and carers, and thereby to subjective phenomena. She
suggested that a key conceptual change was introduced to this genre by Bury’s [200]
theorisation of the impact of the diagnosis of a chronic illness as ‘biographical
disruption’. This initial biographical concept as one of disruption is a seminal one that
encapsulates the total and catastrophic effect of the diagnosis of a chronic illness.

Biographical disruption

In his paper, [200] Bury characterised the impact on an individual’s assumptions about
themselves, their future, and their world as ‘biographical disruption’. The paper was
based on interviews with people who had recently been diagnosed with rheumatoid
arthritis (RA). Bury aimed to study people with what he called ‘an emerging illness at
the earliest possible point’ [200 pp167] and found that the illness profoundly disrupted
the activities they took for granted in their everyday lives. He drew on Giddens’s [217]
term ‘critical situation’, which, he said, were a set of circumstances that ‘radically
disrupts accustomed routines of daily life’ [217 pp124]. This is similar to Bourdieu’s
[218] concept of hysteresis (which I will describe in more detail on p71) where a change
is imposed on an individual’s life that is so catastrophic that the skills and
understandings of the world the individual knew no longer gave meaning nor allowed
them to make sense of their new situation.

Shortly after the publication of this paper, Williams [219] and Cornwell [189] published
their findings of causality within a biographical framework. Williams conceptualised
this as ‘narrative reconstruction’ [219] suggesting that ill people are agentic: People do
things to effect repair. Cornwell proposed that illness could be part-and-parcel of a ‘hard earned life’ and that, for some individuals, illness is ‘par for the course’ [189].

Others have challenged and extended Bury’s [220-222] work to propose alternative theorisations of illness experience, such as abrupton and repair [223], fracture [224], reinforcement [225], flow, and continuity [208, 209, 226].

**Narrative reconstruction**

Williams [219] conceptualised narrative reconstruction as a way in which individuals ‘reconstitute and repair’ ruptures between ‘body, self and the world’ [219 p197]. They do this, Williams’ suggested, by making causal links between their illness experience and significant events in their past, thus situating the ‘cause’ of their illness experience within their biography and social world, and not simply as a pathological disease. Williams’s participants also had RA (as did Bury’s) but he chose to interview those whom he called ‘seasoned professionals’ [219 pp176] rather than newly diagnosed individuals to gain what he called a ‘more structured self-image of the chronically sick person’ [219 pp176]. In other words, he wanted to know about living with the illness after individuals had lived with it for some time.

Of course not all experiences of illness are disruptive and biographical disruption has been challenged as not being able to account for all experiences [220] and alternative concepts have extended this concept in different chronic and terminal illness contexts. Other researchers have suggested that illness did not always cause biographical disruption by emphasising continuity rather than disruption [189, 208, 226, 227] and, later, biographical ‘flow’ [209]. Bury’s original emphasis on disruption was developed further in studies of people with terminal illnesses such as Motor Neurone Disease (MND) and cancer. Sinding [210], for example, wrote about the ‘foreclosure’ of disruption, Locock [223] wrote of biographical ‘abruption’ and repair, and Reeve [224] wrote of biographical fracture. These concepts suggested that when there is disruption, it could change and become a part-and-parcel of normal life.
Biographical continuity

Cornwell’s [189] study interviewing family members living in London’s East End was descriptively entitled ‘Hard Earned Lives’. For many of her participants living lives that were dominated by hard work, hardship, disaster and loss - illness and death were not out of the ordinary. Illness, including cancer, was biographically anticipated and thus was socially and temporally contextual [219]. This is to say that participants had already experienced multiple crises and the diagnosis of an illness (even a life-threatening one) was an ‘anticipated’ part of their biography [220 pp51]. In a number of studies; women with HIV [227]; men with both haemophilia and HIV [225]; people suffering stroke [208, 209]; and osteoarthritis [226] incorporated their diagnosis into their ongoing lives. Men who were both HIV positive and who had a pre-existing diagnosis of haemophilia [225] did not consider their haemophilia as ‘something out of the ordinary’ [225 pp81] because they had accommodated changes demanded by the illness into their everyday lives. When they were later also diagnosed with HIV - following infection through contaminated blood products that were part-and-parcel of having haemophilia - they considered this a continuity of their haemophilia trajectory and there was no disruption as it proved ‘the fatality of being a haemophiliac’ [225 pp81]. However, there was biographical disruption among men who had previously denied their haemophilia or had tried to ignore any consequences. Similarly, for women with HIV/AIDS, their diagnosis was initially disruptive but, in relation to other life events it was not (or was less) disruptive when it was compared to other everyday devastating events of their everyday lives [227]. The interviews took place an average of six years post-diagnosis, further allowing time for the diagnosis to be contextualised in the women’s ongoing lives [227].

Pound et al. [208] undertook in-depth interviews with 21 men and 19 women living in the East End of London, UK. Part of a larger study examining the outcomes of stroke among people in North-East London, the single interviews were undertaken in the 10 months following a diagnosis of stroke. Similar findings to those above revealed that the stroke did not ‘disrupt a previously unproblematic life’ [208 pp497]. While the stroke was a ‘crisis’ in its immediate impact, the presence of crises in the course of their lives was not unusual. Pound argued that for people who had survived more than 70
years, their experience may have equipped them to cope with ‘crisis’ and accommodate chronic illness into their lives. Given the age and experience of the participants, ‘there was something normal about stroke’ [208 pp497].

In the context of age, other health concerns, other life events and previous knowledge of illness, biographical disruption was not inevitable, and Faircloth et al [209] suggested that ‘biographical flow’ was a more applicable concept for some chronic illnesses when contextual factors were taken into account [209 pp242]. Sudden illness, such as stroke, did not always serve as a disruptive event, but instead could meld into an enduring chronic illness narrative, part-and-parcel of biography [209 pp245]. In other words, the effects of stroke, and other illness, may become part of the norm [208]. Whereas individuals with osteoarthritis described their symptoms as a normal and integral part of their biography. They described the impact of their symptoms as highly disruptive [226]. The authors accounted for this by conceptually distinguishing between the meaning of participants’ symptoms as consequence and as significance [228]. In their study, women diagnosed with painful osteoarthritis rarely went out, were restricted in what they could do and felt socially isolated. Thus, their experience of illness was disruptive in that it caused hardship and suffering even though they considered the pain and disability to be a part-and-parcel of normal life for them.

Private biographical continuity and public disruption

Faircloth et al. [209] argued that the concept of biographical flow suggested a different biographical construction of lived self that had been largely ignored. Gelech and Desjardins [169] suggested that not only was the biographical construction of self as continuous largely ignored in the literature, but it was also ignored by those close to the individual. Examining constructions of ‘self’ in response to what they characterised as dominant themes in the literature of the ‘lost or shattered self’ [169 pp62] Gelech and Desjardins found that their participants maintained continuity of their inner or ‘core self’ [169 pp67]. Their sense of continuity, however, was in contrast to the view of those around them - specifically health care professionals and family and friends. This latter self was they called a public aspect of self. Friends, family and health care professionals ‘delegitimised’ [169 pp68] the participant’s experience of continuity by
overtly disputing their stories of a continuous self, pointing to changes in mood, personality, cognition, abilities or emotions as evidence. Health care professionals suggested and encouraged this by telling family and friends that the person would never be the same. In contrast, the participants identified themselves as the same person.

Biographical conceptualisations of illness literature are largely situated in the experience of chronic illness and there are fewer studies that suggest biographical explanations in the experience of terminal illness [223] or cancer [210, 224].

Biographical theories in terminal illness

Locock et al. [223] examined the biographical impact of terminal disease and suggested that it was more akin to ‘abruption’ than to disruption. They interviewed 35 people with MND and 11 carers and adapted their data collection methods to allow contributions from people who were unable to speak: Respondents Lawton described as ‘missing voices’ [215 pp73]. The authors had anticipated findings of disruption but found that in addition, there was a ‘sudden ending’ or ‘breaking off’ [223 pp1047] of their familiar life that came with the diagnosis of a terminal disease. They conceptualised this as an abruption. Participants said that being told that they had MND was a death sentence. The authors built on Brown’s [229] work describing ‘existential shock’ at the diagnosis of MND, which was followed by the creation of a ‘dynamic normality’ [229 pp210]. (The idea of normality as a concept in illness is discussed further in the following section). Thus, in contrast to life going on but being disrupted and requiring adaptation, ‘biographical abruption imagined life simply not happening at all’ [223 pp1048]. Participants reported that, alongside their abruption, there was disruption for them as they tried to undertake their daily activities. There was disruption to their social, relational, leisure and work activities. The consequences of the illness were disruptive [226]. However, despite the devastating diagnosis, the authors found that participants emphasised a sense of reasserting control and trying to re-establish normality, which the authors conceptualised as ‘repair and reconstruction’. They found that despite the initial severing of their biography, this was a common theme.

When circumstances were so overwhelming that continuity could not be maintained, Reeve et al. [224] suggested that this was biographical fracture. In their study exploring
the emotional and embodied experiences of eight men and 11 women—whom their general practitioners (GPs) had estimated were in their final six months of life—most maintained an overall ‘sense of well-being’ and managed ‘disruption’ [224 pp178] in their everyday lives. Maintaining continuity demanded creativity, and was draining physically and emotionally. Exhaustion could precipitate a ‘fracture’ in the continuity. Most participants experienced periods of continuity and biographical flow interspersed by periods of ‘turbulent flow’ [224 pp183]. Most of the participants had strategies and managed these episodes to maintain overall continuity. However, for two participants, the disruption was overwhelming and they were unable to maintain continuity without assistance. Both had been able to maintain continuity with their initial diagnosis and that of relapse. One of them, Mark, a man in his forties with lung cancer, had managed initially. When he was informed that his cancer was terminal, he became distressed and thereafter required external help to keep going. Joan, a woman in her fifties, had also coped well initially at the times of both her diagnosis and her relapse. An emergency admission to hospital with spinal cord compression, adverse effects from her radiation therapy, the unexpected death of her sister, together with being told that her cancer was terminal proved overwhelming for Joan. She also suffered from profound physical and emotional exhaustion. Both of these stories were examples of what Reeve et al. [224] conceptualised as biographical fracture. With additional help and assistance, both Mark and Joan were able to continue.

Maintaining biographical continuity by foreclosing on disruption

Sinding and Wiernikowski described the ‘normal hardship’ theory [210]. According to this theory, for people who are older and already living with illness or socially marginalised, ‘illness - like hard work itself - is only to be expected’ [220 pp50](see also Cornwell [189], Pound [208], Faircloth [209] and Sanders [226]). They argue that biographical continuity was possible because people ‘foreclosed’ on their disruption by not ‘dwelling on it’ [210 pp402], nor ‘focusing on it’[210 pp403]. In other words, by ignoring their illness, they accommodated what had been disruptive into their everyday lives. The 15 women in their study, all of whom were over 70 years of age, were participants in a larger study exploring the cancer experiences of women in Canada, specifically of women who were older, on low incomes, and Indigenous. The
experience of living with cancer was either not found to be disruptive when its significance was offset by other health and social problems, or it was found to be disruptive but the disruptions were mostly transient and associated with adverse effects of treatment. Consequently, the authors argued that neither biographical continuity on the basis of age, social conditions or pre-existing illness [189, 208, 209, 220], nor ongoing disruption [200] should be assumed for people diagnosed with chronic illness. They suggested that illness might be anticipated and continuous while also being disruptive [210]. Similarly, Taghizdah Larsson and Jeppsson Grassman [230] argue that despite a lifetime of disability and chronic illness, new ‘critical events’ and ‘disruption’ continue to reoccur. The critical events that caused disruption were those that were feared, such as total blindness or a leg amputation for a person with diabetes [230]. The impact, however, caused the disruption rather than the event itself as a participant who had spent much of their life unable to walk described his leg amputation as ‘non-problematic’ [230 pp10]. These events were not unexpected, however, the authors argue that they were unexpected at this time, now – thus they were disruptive in a Buryan sense [230 pp9].

**Shifting models of illness experience**

Charmaz [199] explored the ‘progressive gains, plummeting losses and plateaus’ [199 pp1] of chronic illness as an interruption, intrusion and immersion ‘where illness keeps shooting to the foreground’ [199 pp79]. More recently, a few authors have considered illness in its relationship with wellness. A number of ‘shifting’ models of living with chronic illness suggest transience and fluctuation between phases or different kinds of illness experience rather than individuals being distinctly ill or well [211-213, 231]. This fluctuation has been described as having a ‘sense of wellness’ and a ‘sense of illness’ [231 pp1365], ‘illness-in-the-foreground or wellness-in-the-foreground’ [213 p2p1], ‘extraordinariness’ or ‘ordinariness’ [212 pp146], and ‘living an illness’ or ‘living a life’ [211 pp177]. Sontag likened this composite experience of illness and wellness as holding ‘dual citizenship in the kingdom of the well and the kingdom of the sick...where illness is the more onerous citizenship’ [190 pp3].
Beech et al. [231] suggested that people oscillate between having a sense of wellness and of illness. Their wellness may not necessarily be a ‘complete restoration of physical health’ [231 pp6] but health in the sense that their participants had functional health and could engage in activities that they wanted to. They were living with illness when new symptoms arose or appointments were due. The illness could be transient or could prevail, depending on whether the distressing symptoms persisted. Paterson’s [213] ‘Shifting Perspectives Model’ of chronic illness was derived from a meta-analysis of 292 qualitative studies exploring chronic illness. Rather than characterising chronic illness as a process, in which a person follows a trajectory with phases and an end goal, they argued that living with chronic illness it is an ‘ongoing continually shifting process’ [213 pp23]. (This is discussed further in the following section). In contrast, the idea of a trajectory pertaining to illness has also been characterised as progressive illness travel [232] and as being similar to the idea of ‘transition’ as a characterisation of illness experience [233]. Although Paterson took a different epistemological approach to me in her analysis, suggesting that it is ‘the perception of reality, not the reality itself, [that] is the essence’ [213 pp23] of how people experience illness, her point is that the experience of illness is subjective. Similarly, the perspective of illness in the model shifted from illness in the foreground to one where wellness was in the foreground. When illness was salient, there was a focus on ‘suffering, loss, burden’ [213 pp23] and adaptation. For example, in the event of diagnosis, relapse of disease or new treatments an individual was forced to ‘attend to the illness’ [213 pp23]. When wellness was in the foreground, people got on with their lives and there was continuity together with a ‘re-visioning of what was possible and normal’ [213 pp23]. Knowledge, acceptance and supportive networks facilitated this.

Kralik [212] gathered data through email and letter correspondence with 81 women, aged 30–50 years, who identified themselves as living with chronic illness. Participants also contributed to the data analysis and were invited to review the findings. The two major themes emerging from this participatory study were ‘extraordinariness’ and ‘ordinariness’. On diagnosis, the women experienced profound disruption, turmoil and distress, which was characterised as extraordinary. Over the course of time as the women gained experience in living with their illness, the experience of illness became ordinary, or a part of the fabric of everyday life. Sudden changes brought about by their
diagnosis or deterioration made their illness experience extraordinary. The women integrated the illness into their lives and worked with their emotional response to their illness to make it ordinary. They described this as ‘transformative’ if they were successful in maintaining their ‘vigilance’ over their thoughts and responses [212 pp150]. Kralik emphasised that this was transition rather than change, as it incurred an internal, reflective component of change in addition to an external process [212, 233-235].

Whittemore and Dixon [211] built on this work, and that of others, to explore how people transitioned and integrated their illness into their ongoing lives. They suggested that there was a complex co-existence between ‘living a life’ and ‘living an illness’ [211 pp177]. The authors undertook a mixed method descriptive study using semi-structured interviews with 27 men and women in Connecticut, USA. The age range was 25–80 years and the range of illness experience was 1–39 years. They described the complex process that participants undertook to integrate their illness or illnesses (some participants had up to four co-morbidities) into their everyday lives. The authors identified five phases of integration, which they characterised as: ‘shifting sands’, ‘staying afloat’, ‘weathering the storms’, ‘rescuing oneself’, and ‘navigating life’ [211 pp181]. (Connecticut is situated on the north-east coast of the USA, which may account for the nautical terms.) The unpredictability and difficulties inherent in the experience of illness suggested that participants ‘fluctuated between living a life and living an illness’ [211 pp183], and this became the norm. So living with a fluctuating experience of illness became a normal part of life.

*Living with illness can be normal*

I have outlined Canguilhem’s [159] construct of health as normality, and in light of this, it is important to consider that living with illness may also be the norm. The normalisation of illness has been described in different ways; as a complex process, as a coping mechanism and as an embodied process. The notion of normalisation in illness experience literature, however, mostly refers to normal as something to be returned to, something to be achieved or maintained, rather than the illness experience being the norm. For example, women with breast cancer focused on ‘keeping normal’ and
‘getting back to normal’ [236 pp605], people being treated with dialysis sought a normal life [237], and people with myeloma endeavoured to ‘maintain normality’ [144]. Strauss et al. describe normalising as a tactic that people used to appear ‘normal’ by preventing what they called ‘identity spread’ [196 pp81]. ‘Identity spread’ occurs when a person’s visible symptoms dominate their interactions with other people. This was a particular issue with strangers who offered to ‘help’ on the assumption that that the illness rendered the individual incapable [196 pp81]. They described how an individual with emphysema ‘rested artfully’ to disguise their dyspnoea and the need for people with chronic illness to ‘appear normal’ and avoid the stigma of illness, which Goffman termed ‘passing’ [238].

Women with fibromyalgia ‘recalled perceived normality’ [239 pp97] as a basis for how life was for them in the present. So rather than normalising living with fibromyalgia, they endeavoured to ‘maintain a balance’ [239 p101] with a past norm and their present experience. When successful in maintaining the balance, they were able to move on into a new kind of normal life. Illness becomes the normal experience of embodiment when it becomes part-and-parcel of everyday life. Illness during a hard life [189, 208] and biographical flow following stroke [209], discussed previously, illustrate how illness can be a normal state of affairs.

Sanderson et al. [240] studied how people with Rheumatoid Arthritis responded to changes in symptoms and treatment and characterised different kinds of normality according to the participants’ ‘embodied experience’. Similarly, Locock [223] found that people with MND had to make continual adjustments in a ‘repeating cycle of confronting each new phase of deterioration (and improvement) and incorporating it into normal daily life’ [240 pp9619] ; thus, normality was characterised as ‘dynamic’. Locock’s conceptualisation of a shift from biographical disruption at diagnosis to ‘biographical repair’ [223 pp1043] in effect describes how people re-establish a sense of normalcy over time.
Illness changes experiences of time

Time, like normality, is experienced subjectively. The disruption that illness can cause profoundly impacts on experiences of lived time (that is, temporal orientation) [200, 241-245]. Charmaz showed that time was an integral component of (chronic) illness experience [199]. Building on Idlers’ suggestion that ‘sickness creates and measures its own time’ [246 pp727], she argued that chronic illness forced people to restructure their use of time and changes to the structure of their use time promoted changes in perspectives about time [199].

Clock time or ‘outer time’ is bound to measurement and understanding of units of time. Clocks and calendars provide a framework of understanding. Newton’s conception of time characterised it as linear, quantifiable uniform units that were measurable. This was the keystone upon which Western society came to conceptualise time. As such, it is referred to as ‘conventional time’. The notion of clock time is governed by temporal units, through which time takes on meaning [247]. Standardised units, such as minutes and hours or days and years, are almost universally recognised and accepted and enable communication, organisation and control. Mumford argued that the clock was the most important player in industrialisation. He suggested that ‘the clock is not merely a means of keeping track of the hours, but of synchronising the actions of men’ [248 pp14].

There are cultural differences in the measurement of time. In Saudi Arabia, for example, the Islamic (Hijra) Calendar operates alongside the Christian (Gregorian calendar). The Hijra calendar is a purely lunar calendar and as such contains 12 months that are based on the lunar cycle. It is shorter than the tropical or solar year and therefore shifts in relation to the Gregorian calendar. Bourdieu conceptualised this as the ‘synoptic illusion’ [218 pp97] when commenting on two informants, one from the Islamic tradition and one Berber, who talked about the same time point in the year using different names, thus describing some of the difficulties inherent in so-called conventional time and suggesting that there may not always be universal understanding:

\[ 4 \text{ synodic months} = 12 \times 29.53 = 354.36 \text{ days.} \]
As soon as one undertakes to draw up a synoptic calendar which combines the features most frequently attested and indicates the most important variants (instead of presenting a single calendar chosen for the sake of its particular quality or a set of particular calendars), one comes up against a primary difficulty: identical periods are given different names, and still more often, identical names cover periods varying considerably in length and situated at different times in the year depending on the region, the tribe, the village and even the informant [218 pp98].

Relationships with time within individual social contexts have also been shown to change. Tsuji’s [249] study in Japan found a paradox among Japanese workers in their attitude to time. Punctuality, speed and productivity are held in the highest esteem, and in situations of work, clock time is the sole regulator. However, Tsuji described a temporal shift in the attitude of Japanese workers to this outside of work. Participants rarely made appointments to meet friends or to visit the hairdresser, for example, preferring to ‘turn up and wait’, and the clock was ignored. He neatly conceptualised this paradox by distinguishing between ‘railway time’ and ‘rubber time’ [249].

**Phenomenological time**

Bergson [250] characterised time as both lived time and mathematical time. Time, he argued, is the basic form of all experience [251] and it is self-conscious thought that links memory, perception and anticipation into a coherent sense of duration or *durée*. In other words, as Husserl argued, the ego is the source of time [251, 252].

For Heidegger [253], the experience of time was central to ‘being in the world’ (*dasein*). To emphasise the central importance of time in experience, he argued that ‘being cannot be grasped except by taking time into consideration’ [253 pp40]. He emphasised that *dasein* could not be isolated in an experience and that time was a constituent of being in the world.

Bergson suggested that because mathematical time was divisible into units or intervals, it did not reflect the flow of real time [250]. Concepts of phenomenological time such as *durée* or lived time [250], ‘stream of lived-experiences’ [254] (*erlebnisstrom*), ‘being in
the world’ (*dasein*)[253] and ‘inner time’ [255] are all ways of understanding the subjective experience of time. The experience of time can be non-concordant between individuals and between the individual and the social world. *Dasein*’s temporality was always forward moving, towards death, or as Gadamer puts it, towards ‘radical finitude’ [256].

Bergson’s notion of duration, or *durée*, suggested that the experience of time was not a series of discrete moments or points in time but a ‘unified process’ [257 pp26]. In doing so, he distinguished between two forms of time: pure time and mathematical time. Pure time was ‘real duration’ (*durée*). Mathematical time was measurable duration, as with Newtonian or clock time. *Durée* was continuous and indivisible, and thus lived time. William James suggested that the ‘specious present’ is the: ‘prototype of all conceived times … the short duration of which we are immediately and incessantly sensible’ [258 np]. Gadamer called this ‘existential temporality’ when the present was not a passing moment, but was experienced as the ‘fullness of time’ [256 pp119]. In other words, it was ‘part of the process of the passage of events that is directly there in our experience, including some of the past and some of the future’ [259 pp176] Mead [259] used the analogy of a ball being tossed in the air with the specious present being the moment when the ball was partially uncovered as it passed the line of vision. This notion has been conceptualised in the illness literature as the ‘intense present’ where ‘the past separates from the present and the future grows distant’ [199 pp245]. Charmaz described three forms of living in the present of which the intense present was one. The intense present was qualitatively different to the other two categorisations and was associated specifically with an involvement and passion for living, which accepted and accommodated illness as well as the notion of time as a limited resource. The filled present was always very busy, crammed with activities, sometimes to the further detriment of one’s health. The slowed present was also marked by activity and speed, but at the opposite end of the spectrum. Focus was placed on the illness, which in turn fostered the slowing down of the present [199].
Autobiographical time

Time is most often represented as linear, and linear time suggests that it is continuous and always moving forward in an ordered and regular fashion. As such, it has been characterised as the ‘Arrow of Time’ [260]. Linear time provides a framework for cycles, rhythms and mutual understanding [261]. However, it is only one of several paradigms of time giving temporality [260] its complexity. Experiences of time can be simultaneously linear and circular [262]. This synthesis of cultural and individual orders of time has been conceptualised as ‘autobiographical time’ [263] where time experienced can be linear, circular, cyclical, spiral, static or fragmentary.

Lived time does not always synchronise with clock time and while it may be experienced as synchronised: It may be that the experienced of time is protracted or compressed when compared to clock time [264-266]. This suggests that one’s experiences of time can be non-concordant with other individuals. Charmaz described this as temporal incongruence; a mismatch between what could be achieved in a day before illness and what could be achieved after diagnosis when pre-existing time structures no longer fitted. Management of once taken-for-granted activities became redefined by the clock [267]. This has been conceptualised as having a lack of control of time, in terms of both the length of time taken to prepare to undertake the task and its duration [244]. Time has been described as being stilled, stretched, compressed or lost. Hellström and Carlsson [268] sought to deepen understanding about the experience of time by undertaking a case study that focused on the meaning and experience of ‘lived temporality’ in people with long standing pain. Their findings illuminated tensions between their participants’ experience of time and the outer or Newtonian time of society. They also found that patients used their experience of time as a strategy to cope with their pain. In Orona’s study of temporality in caregivers of people with Alzheimer’s disease, temporality was focused in a backward direction because people who were caring for a partner or close relative who suffered from Alzheimer’s disease retained memories of how they were, in an attempt to preserve their patients’ identity [267].

Corbin differentiated between five experiences of time: clock time, historical time, biographical time, perceived time, and the rhythm of life [202 pp259]. Adam argued
that temporal landscapes change with the experience of health and illness: ‘encounters with birth and death take those involved beyond the realm of everyday time and bring to the fore times that are normally … submerged’ [262 pp58]. Davies [245] and Ezzy [269] found that everyday assumptions about time were ‘shattered’ for people with HIV. Specifically with regard to cancer illness, Adams suggested that ‘time becomes specific’ and limited [262 pp55]. Rasmussen and Elverdam [243] illustrated how people with cancer re-prioritise and manage time differently after diagnosis. They conceptualised this as ‘time appropriation’. Time, like ‘health’, no longer sat in the background following a cancer (illness) diagnosis, but was brought to the foreground and purposefully reconstructed.

Markers in time and emplotment

The concepts of ‘markers in time’ [199, 267, 270] and ‘emplotment’ [271, 272] have been used to explain experiences of time in illness. Both Corbin and Charmaz included lived time as an important component in illness experience arguing (like Bergson) that the experience of time is part of the very fabric of illness experience [199]. Markers in time were shown to give meaning and structure to experiences of illness [199], for example, they shaped experience for people affected by Alzheimer’s disease [267]. Charmaz differentiated between time markers and turning points, and described turning points as identifying moments, which are ‘telling’ and ‘existential’. They are moments of change that are ‘filled with new self-images’ [199 pp207]. A turning point, or an identifying moment for an ill person, was a point after which nothing was the same.

Emplotment has been proffered as one response to the diagnosis of a life-threatening illness, such as cancer [273]. Ricoeur used the notion of emplotment [274] to explain how time is embedded in the structure of existence and this is represented by narrative: ‘I take temporality to be that structure of existence that reaches language in narrativity, and narrativity is the language structure that has temporality as its ultimate referent’ [274 pp167]. Ricoeur argued that the plot provides the underlying structure of the narrative, constituting stories and experience as unfolding through time, constructing ‘meaningful totalities out of scattered events’ [275 pp278]. Plots in a narrative can help to make sense of illness experience [276].
Mattingly [272] conceptualised six features of narrative time and extended Ricoeur’s work to demonstrate that they were key in understanding lived time. The way in which health care professionals frame timelines or ‘temporal horizons’ both for and with patients has been conceptualised as ‘therapeutic emplotment’ [271, 272]. Building on the notion of the plot in storytelling, ‘emplotting’ (constructing a ‘virtual plot of remembered pasts and imagined futures’), is an activity that is ‘central to Western historical consciousness’ [271 pp855]. Crossley [276] documented the process of therapeutic emplotment from the person with cancer’s perspective in her analysis of John Diamond’s diarised experience [273]. Therefore, time can be used to create order and to create relationships between events and is most commonly viewed as being linear.

*Making sense of illness using a trajectory model*

The trajectory model of chronic illness was first used as an attempt to explain how people made sense of illness experience over time [270, 277] and was developed to conceptualise illness as a sociological experience rather than a medical categorisation [278]. The metaphor of an illness trajectory was used to describe the temporal course of an illness and the work and relationships involved in shaping its course [279]. Strauss and Corbin [196] used this metaphor to characterise the course of an illness to understand the work associated with it, the impact the illness on those affected by it, and how its management and outcomes were shaped.

However, the trajectory model of illness has an inherent challenge. A trajectory is a flight path taken by an object moving in a direction under the action of certain forces, for example, a rocket or a piece of coal flying from a conveyer belt [280]. A trajectory is something that is acted upon. This was illustrated by Corbin and Strauss [279] when they likened it to voyage. They used the voyage metaphor to argue that an illness trajectory, like a boat on a voyage, is subject to forces around it pulling, pushing and altering its direction. However, illness demands agential work whereas a trajectory is acted upon.
Charmaz described illness experience as a series of ‘good days’ and ‘bad days’, and suggested that the idea of an illness trajectory was ‘removed’ and ‘abstract’ as people were immersed in their experience of illness [199 pp9]. In her analysis of 160 in-depth interviews with 90 participants, she focused on trade-offs and compromises necessary for day-to-day living with chronic illness, disclosure and the calculations about who to tell and how much, and the dimension of time in relation to illness experience.

**The work of illness**

Corbin and Strauss [278, 279] argued that chronic illness requires significant amounts of work for the person with illness and those around them, particularly their spouse [278]. They defined the work of managing illness as:

> A set of tasks performed by an individual or a couple, alone or in conjunction with others, to carry out a plan of action designed to manage one or more aspects of the illness and the lives of people and their partners [279 pp9].

The set of tasks comprised different kinds of work and they suggested that there were three key categories: illness work, everyday life work, and biographical work. Illness work and everyday life work were concerned with the day-to-day or month-to-month work required to manage the home, the family and the illness (1985). May argued that ‘being ill is hard and heavy work’ [281 pp161] and ‘work in its truest sense’ [282]. Many studies have also emphasised the processual nature of living with chronic illness. Kralik et al., for example, found that this process was relentless and required actions requiring vigilance, planning and learning new strategies [234, 235].

**Biographical work**

Biographical work, according to Corbin and Strauss [278, 279], is the kind of work demanded to manage the life course in relation to concepts of the self. It comprised four types of activities: contextualising and incorporating the illness into the biography; coming to terms with and thus accepting the consequences of the illness; reconstituting identity and self (creating a ‘new normal’); and recasting biography (that is, having a
new imagined future). Boeji et al. [283] used this framework in their qualitative study of 21 people with multiple sclerosis to illustrate that there is a range of ways in which people accommodated their illness into their biography. Corbin and Strauss [279] suggest accommodation is the way in which people regain continuity and a sense of control despite the consequences and significance of illness. Whittemore and Dixon [211] characterised this kind of work as ‘integration work’ and Kralik et al. [234] as ‘self-management work’ required to transition [212, 233, 235]. Self-management work has also been used as a strategy for end-of-life planning. Sanders et al. [284] conducted 43 in-depth interviews with participants in a UK-based ‘Expert Patients Programme’ that included topics on death, dying and preparing for death—specifically Advanced Care Planning (ACP). They found that participants were distressed, upset, and angry, and questioned the appropriateness of the material as they had a ‘chronic condition, not a terminal one’ [284 p989]. The authors concluded that the ACP material was in stark and confronting contrast to the positive orientations that they had (biographically) worked to build.

Managing illness requires information and individuals need different kinds of information at different times [279]. Corbin and Strauss described ‘information work’ as the use of information to shape the course and experience of illness [278]. They went on to suggest that without (successful) information work, other work cannot be completed [279]. Conrad identified information work as central to ‘reducing uncertainty, biographical work, creating medication practices and developing practical strategies to manage illness’ [285 pp14]. Other kinds of ‘information work’ included choosing doctors, considering treatment options, managing symptoms, and dealing with emotional and social aspects of illness [286, 287].

The importance of information work as a foundation for managing illness has been supported by medical sociologists as is can help people to understand what is happening physiologically, situate their experience in their life, reduce fears, misunderstandings and misconceptions, and to promote a sense of personal control [288]. However, information can also increase uncertainty. Individuals with HIV were described as trapped ‘between their desire to know as much as possible about HIV and their fear of becoming immobilised by bad news’ [289 pp18] p18. Information seeking could thus
reduce uncertainty or increase it. Hogan and Palmer [287] found that people with HIV and Multiple Sclerosis had different needs for different information sources—verbal and written and of a lay or professional nature. They used Strauss and Corbin’s trajectory model to suggest that this could be attributed to a need for different sources of information at different phases of illness.

Another kind of work described in the literature is that of emotion work. Thomas et al. [290] explored the experiences of people providing informal care to cancer patients, drawing from a larger mixed methods study looking at the psychosocial needs of cancer patients and their carers. The group found that those in close personal relationships had little choice but to engage in emotion work [290]. The energy, time and skill [291] of ‘sentimental work’ has been reported as a strategy that nurses employ for maintaining composure when patients die, particularly in difficult deaths [292].

There has been little research exploring the emotion work of patients and caregivers, but there is research into the emotional labour of paid workers. Hochschild [293] described emotion work in terms of emotion management in a study of relationships between service providers and clients. Hochschild defined emotion work as ‘the act of trying to change in degree or quality, an emotion or feeling’ and argued that emotion work referred to ‘the act of trying’ rather than the outcome [293 pp561]. Hochschild proposed three techniques of emotion work. In ‘cognitive emotion work’, attempts are made to change thoughts and images about a situation in order to change feelings. In ‘visceral emotion work’, effort is invested in controlling physical symptoms of emotion such as trying not to sob or trying to control one’s breathing. In ‘expressive emotion work’, effort is focused on changing expressive gestures such as trying to smile or cry. This latter work was, Hochschild proposed, not simply an attempt to alter the expression of emotion for the actor, but an attempt to change the underlying feeling [293]. The concept of emotion work has been criticised [184, 294, 295]; in particular the idea that it can change an underlying feeling rather than simply suppress the expression of it. Goffman also described workers’ efforts to adopt an outward appearance of expected emotions while concealing their true feelings, calling it ‘impression management’ and ‘presentation of self’ [296].
Living with myeloma includes dying with myeloma

While there is no literature that specifically explores the experience of dying with myeloma, it is relevant to look to literature that explores and conceptualises dying. As discussed previously, a diagnosis of a terminal illness has been described as creating ‘biographical abruption’ [223], ‘disruption foreclosed’ [210], and ‘fracture’ [224]. Lawton [297] in a study of hospice patients with advanced cancer found that the effects of terminal illness on functionality were particularly distressing, particularly deterioration or changes in mobility. Research exploring the experience of dying is limited but most prevalent over two decades of the 1960s and 1970s. Key researchers, usually sociologists, examining the experience of death sought to gain a deeper understanding of the experience of dying [298-305]. Glaser and Strauss’s [298] initial work was significant in both its findings and methodology.

Having an awareness of dying

Glaser and Strauss [299] studied interactions among hospital staff and between the staff and patients who were dying in a hospital setting. They described four kinds of awareness between health care staff and patients. ‘Closed awareness’ occurs when staff are aware of the prognosis and do not share this with the patient. ‘Suspicion awareness’ is when the patient begins to suspect their poor prognosis, but staff use strategies to avoid confirming the patient’s suspicion. ‘Mutual pretence awareness’ occurs when both staff and patient know that they are dying, but both pretended that this is not so. Open awareness occurs when both patient and staff acknowledged the terminal prognosis.

According to Glaser and Strauss [299], the dying trajectory for any individual ‘takes place over time; has duration and shape; and, can be graphed’ [299 pp5-6]. They described four basic trajectories leading to death: sudden, prolonged, unexpected or expected. The type of trajectory determined how staff defined and planned the patient’s experience on the unit. It also accounted how the staff constructed and reinterpreted the patient’s story.
Kubler-Ross [302] built on the idea of dying as a trajectory and a process and, based on her clinical experience, described five psychological stages of dying: denial, anger, bargaining, depression and acceptance. These stages have been used extensively in clinical practice. However, her work has been criticised for lacking evidence and methodological rigour [306-308] and other frameworks or models of dying have subsequently been developed. Copp argued that patients and nurses continually engage in what she described as ‘encountering’ [308 pp388] as they found meaning, planned and manoeuvred situations in their delivery of care. Copp’s thesis may also be relevant to patients’ encounters with their family and friends. Building on Glaser and Strauss’s work, it may also be a useful framework for understanding how families manage disclosure.

Lawton [297] describes cancer patients’ experiences of dying in a hospice in the UK. Her observations contrast sharply with the romanticised idea of the peaceful and controlled ‘good death’ idealised by Kubler-Ross and aided by palliative care. In her account, patients fought against death and were sedated, isolated both physically in side rooms and socially as their families ceased to visit, as their bodies deteriorated in sometimes distressing ways. Lawton suggested that patients who had lost their mobility or were no longer self-reliant considered themselves ‘objects’ rather than ‘subjects’, and this contributed to their existential distress.

Learning from personal accounts of dying and death

Contemporary expectations of dying, particularly with regard to when and how, are complicit with what Elias described as the ‘relative security and predictability of individual life and the corresponding increased life expectancy’ [309 pp8]. Autobiographical accounts of terminal illness and dying [310-312] provide insight into the experience of living while dying. However, one criticism has been that the authors are usually educated, articulate and in a position to publish their stories. Therefore, even though these accounts are moving, insightful and powerful, they are representative of how middle class people die. Biographical stories [313, 314] highlight the experience of the immediate family as an onlooker. They are powerful accounts of personal stories of individual traversing an extraordinary experience of suffering, unable to intercede,
unable to do anything but watch. These works highlight ‘that death is a problem for the living’ [309 pp3]. Knowledge of impending death is a problem both for the dying and for those close to them. The knowledge of death Elias referred to was not the abstract knowledge that we all know of, as in the intention of the phrase ‘I may be knocked down by a bus tomorrow (someday)’ but the knowledge of death that accompanies a life-threatening event or terminal illness. This kind of knowledge transformed the bus analogy to ‘I have seen the bus that will knock me down’.

Works of classical literature, for example, *Cancer Ward* [315], *The Death of Ivan Ilyich* [316], *The Magic Mountain* [317], and *The Spare Room* [318], have provided rich descriptions and insights into illness and dying. Tolstoy, Mann and Solzhenitsyn all experienced death and suffering in their lifetimes. Garner wrote *The Spare Room* shortly after caring for a close friend who was dying of cancer. Garner’s in depth description of the physical and emotional work that the two friends experienced, was a rollercoaster experience of pain, anger, compassion and humour. It portrayed the relationship between the two friends as they both faced the death of the friend, each grieving and preparing themselves in their own way. Although these works are not strictly biographical, they are the product of reflections on experiences of dying.

Solzhenitsyn, like his protagonist Kostoglotov, had a tumour removed while serving time as a political prisoner. He too nearly died from his undiagnosed malignant seminoma, and recovered having been permitted treatment in a hospital in the town of Tashkent (now in Uzbekistan) in 1954. *Cancer Ward* is a novel that exposes and questions the political rule of the Soviet Union, but it is also an autobiographical account of Solzhenitsyn’s experience of cancer. Through the various characters, he conceptualises the experience of illness—and of pain in particular—as one of exile and the experience of illness as a liminal state. The idea that illness is a liminal experience is echoed by Mann in *The Magic Mountain* [317].

The following section reports on the literature that specifically explores living with a malignant haematological illness, including the experience of myeloma.
The experience of living with a haematological illness

There are few studies exploring the experience of living with a haematological malignancy and even fewer that focus on myeloma. One study has explored the experience of living with leukaemia or lymphoma [319], and others, the experience of people with different haematological malignancies following stem cell transplant. Three of these studies included people with myeloma [25, 32, 34]. None of these studies included the experience of the carers.

Persson and Hallberg [319] used a phenomenological-hermeneutic approach to understand the experience of 18 people in remission following treatment for acute leukaemia and high-grade lymphoma. There were three basic stories (which the author described as ‘themes’) that were each told by one of three groups of participants. The three basic stories were:

- believing in life—fighting for it and coming through stronger
- life goes on—adaptation and finding balance
- life is over—out of control and a loss of belief in life

These stories resonate with Frank’s three main types of illness narratives [182]. The first basic story resonates with Frank’s quest narrative in which the protagonist meets suffering head-on: ‘they accept illness and seek to use it. Illness is the occasion of a journey that becomes a quest … The quest is defined by the ill person’s belief that something is to be gained through the experience’ [182 pp115]. The second basic story could be a restitution narrative, for example, ‘I was sick and now I am better’, or ‘I have found a ‘new balance’ [319 pp308]. The third basic story type resembles a ‘chaos narrative’—a disordered story that describes anxiety, uncertainty, vulnerability, futility, and impotence and provides no answers.

Stephens [32] and Jones and Chapman [25] explored the experience of people with different haematological malignancies including myeloma, focusing on the experience during [25] and after [32] ASCT. Both argued that participants reoriented their sense of self and could not return to the self that they were before (transplant) [25, 32].
Stephens’s phenomenological study of five patients who had undergone ASCT for haematological cancers and Jones’ qualitative study of seven haematological cancer patients undergoing ASCT both demonstrated that participants had undergone a transformative experience. The idea that their lives were irrevocably changed was a key theme in both.

Fine Dahan and Auerbach [34] conducted a qualitative study of six people undergoing ASCT for myeloma in order to explore the emotional impact of transplant. They reported five broad constructs derived from their data: diagnosis; treatment; network of safety; recuperation; and post-transplant reflection and new existence.

The lack of awareness about the disease made the significance of the diagnosis difficult to register for some participants and the concept of ‘living while dying’ was illuminated together with the adjustment in attitude (biographical work) required to manage this challenge. In addition, participants accepted that the diagnosis of myeloma has an enduring reality and that they needed to ‘grow’ and learn a new and challenging existence. Fine Dahan [34] argued that the core difference between myeloma and other cancers was that it was incurable and the initial reaction was that death was imminent. This initial belief dissipated and, at some point, a decision was made to live life. She described the ongoing nature of the struggle with myeloma, which characterised the chronicity and terminally in the face of an acute experience.

Maher and De Vries interviewed eight people with myeloma who were attending a large hospital in London. The participants were ‘living with uncertainty’ [144 pp268] but this uncertainty became a ‘way of life’ and they managed it by adjusting their lives to the limitations created by their myeloma. Important to them was knowledge, support from health care professionals and family, together with a forward-looking orientation of ‘hope’ [144 pp275].

Portrata et al. [117] conducted a qualitative study of 15 people with myeloma as part of a larger programme of research looking at the symptom experiences and associated distress of eight different types of cancer. They reported that symptoms associated with the rigours of ASCT and symptoms obvious to others were particularly distressing, but
many symptoms beyond the initial acute phase of treatment were not particularly distressing. Symptoms such as ‘brittle bones’ or immobility were not thought of as distressing. Fatigue, pain and nausea were associated with treatment, and did not feature as distressing symptoms beyond the acute phase of treatment.

The experience of living with myeloma is a social one and an everyday personal experience that impacts carers and those around the person with myeloma. Myeloma is an incurable disease, the usual course of which involves living in an ongoing cycle of relapse and treatment. These experiences have not been reported in the literature. Myeloma is a terminal disease that is lived each day—sometimes for weeks or years. Myeloma significantly affects a person’s life course, turning it upside down. New developments in the management of myeloma mean that people are living with it for much longer as a component of their life course (or biography).

In addition, there is tension in the literature between biographical disruption and continuity in illness experience. If disruption and continuity can both be outcomes of an illness experience—how does this come about? Both disruption and continuity require work by the person with the illness to shape their experience. This agential work is aimed at managing outcomes that reduce or mitigate the disruption caused by illness. One way to understand the tension between disruption and continuity is to use a set of concepts developed by Bourdieu. The next chapter provides background about Bourdieu’s concepts and how they may be useful in framing the illness experience.
Chapter Three: Illness Experience as *habitus*

Illness is a personal experience, but it unfolds in a social world that is governed by powerful institutions. Hence the personal, social and institutional dimensions of illness do not exist in isolation; they overlap with each other. In order to study the experience of living with myeloma, it is therefore useful to apply a theoretical framework that explains how these worlds interact. The framework adopted in this thesis is based on the work of Pierre Bourdieu.

Bourdieu (1930–2002) was a social philosopher who published widely and influentially in the fields of anthropology, education and culture. His early work was undertaken in Algeria, where he started to conceptualise his theory of practice that incorporated his concepts of *habitus*, field, capital and hysteresis. His theoretical ideas have been applied widely in many fields of study since but less so in the literature on health experience. In this section, I will review some of his main ideas, and examine how others have applied them in empirical studies of illness experience.

**The theory of practice seeks to explain how people do things**

Bourdieu sought to explain how people do things in a way that reveals how people relate to their social world. Individuals who are living with illness are always in a relationship with their social world. Bourdieu’s ‘A Theory of Practice’ [218] was intended to ‘provide a means of analysing the workings of the social world through empirical investigations’ [320 pp49]. The cultural, temporal, traditional and structural influences on an individual’s social world—and thus their actions—are incorporated into his theory of practice through the concepts of field, capital and *habitus*.

*Habitus* is central to what makes human beings ‘selves’ [321, 322], and can be used to describe habitual actions that are intuitively anticipated and followed, that is, the things we do and the ways we do them unconsciously, out of habit and as a result of
socialisation [321]. For Bourdieu, it was the core explanatory concept of the relationship between ‘agency and structure’ [323], between people’s actions and their social environment, influences and history. Bourdieu defined habitus as:

Systems of durable, transposable dispositions, structured structures predisposed to operate as structuring structures, that is, as principles which generate and organise practices and representations that can be objectively adapted to their outcomes without presupposing a conscious aiming at ends or an express mastery of the operations necessary in order to attain them [324 pp53].

Therefore, habitus may be perceived as a way of being. It is both individual and social. It is a dynamic and evolving experience; a jigsaw of total experience that changes over time and guides action, belief and perceptions, itself constructed of actions, perceptions and beliefs. An individual’s habitus embodies personal values, traditions, cultures and beliefs and is developed through socialisation, experience, personal understanding and learning. Habitus encompasses the environment of a person that includes (social) structures and beliefs, perceptions and dispositions, or ways of doing [324, 325]. However, the habitus is not only structured by this environment, it also generates actions, beliefs and perceptions [320, 326], hence its dynamic nature.

Habitus sits as a cognitive framework or map; it is a set of perceptions that guide and evaluate choices and options as a matter of course or routine [327]. It explains how the decisions people make are influenced by the ‘profoundly buried structures’ [328 pp556], that organise social worlds. These Bourdieu calls dispositions [324] and Dewey called habits [321]. Habitus can be conceptualised as an internalised manual of ways of doing things and ways of being, that is, an ‘emergent process of a social system’ [329 pp443]. Whereas some elements of habitus remain stable, others are constantly changing, as the habitus is constantly reshaped [320, 326, 329].

Bourdieu distinguished between two kinds of habitus—class habitus and subjective habitus. The former is the habitus as a collective phenomenon—something that would differentiate, for example, a group of academics from a group of stockmen. Subjective
Habitus is habitus as embodied in individuals. Both kinds of habitus are useful for understanding the experience of living with illness.

Bourdieu’s notion of habitus is often interpreted to imply ‘conditioned’ and ‘pre-reflective’ praxis [326] and thus is not merely a state of mind but is also a state of bodily being [330, 331]. Habitus is thus located within the body and affects every aspect of human embodiment [332 pp113]. When habitus and internalisation are interpreted in a literal sense, that is, when we internalise something, it literally becomes part of us, bringing about continuity, as things become part of the ‘norm’.

Dispositions

In examining how prize fighters became what they were, Wacquant [333] argued that habitus is a set of acquired dispositions. For example, no one is born a boxer but the training and drilling of would be boxers internalises in them desires and abilities as acquired dispositions of the boxer. Similarly, Bourdieu used the example of the tennis player whose training allows them the disposition to return a shot without conscious deliberation. Both of these examples illustrate that dispositions can be acquired:

Habitus is not the fate that some people read into it. Being the product of history, it is an open system of dispositions that is constantly subjected to experiences, and therefore constantly affected by them in a way that either reinforces or modifies its structures [334 pp133].

Therefore, habitus can be developed, questioned and adapted, with the agents as creators [326]. The nature of the personal habitus experience changes as new experiences produce an environment for new dispositions to be acquired, such as with the diagnosis of an illness.

Because dispositions are taken for granted, they have been described as being like water to a fish [334 pp127]. People acquire their habitus through their social experience and their history. It is a theory of human action, because it explains why and how people act the way they do in particular places and situations. Bourdieu argued, based on his study
of the Kabylia people in Algeria [218], that people act on ‘cultivated dispositions’ which provide a schema of perceptions and thought about how actions, or practices should be carried out. The perceptions and thought do not consciously permeate the decision about how to act but exert an influence unconsciously, as a disposition.

The field provides the frame

The field provides the frame of analysis and can be described as a series of structures, institutions, authorities and activities than influence how people act [335]. The field is the social arena in which people manoeuvre and struggle. Different fields can be autonomous or interrelated (e.g. the separation of practice and power differentials between nurses and doctors) and societies that are more complex have more fields. Fields are influenced by social structures and it is within the field that an individual develops dispositions and acquires schemes of perception, thought and action, and opinion [323]. The field is negotiated through the skills or system of dispositions cultivated in habitus. A field, according to Bourdieu, consists of a set of objective, historical relations between positions. The existence of the field depends on the players it contains. The field exists [334] only as far as the people that inhabit it believe in it and actively pursue the prizes that it offers [334, 336].

The field frequently refers to a social space where a community of individuals interact, for example, academics in the academy [218, 337] or ballet dancers in the field of dance [331]. Every individual acts within the field and thus is capable of producing effects on it [334]. Therefore, the field is a field of forces or a force field [338 pp40-41]. The field is a ‘self-contained world’ [339 pp70] and as such, the (force) field provides a boundary between inside (and insiders) and outside. Positions and power within this self-contained world are determined by capital.

Capital determines position and power in the field

‘Capital’ refers to a resource that is valued within the field, and one’s position or status within the field is determined by how much capital one possesses [335, 340, 341]. The value of a specific type of capital hinges on the existence of a field in which the capital
is valued and can be used [323, 334]. Bourdieu expanded the meaning of capital beyond simply its economic exchange value to be any kind of asset in a taxonomy from economic through to symbolic capitals that could be transformed and exchanged across and within different networks or fields [342, 343] and that may bring economic, social or cultural advantages or disadvantages. Thus, the value of a specific type of capital hinges on the existence of a field in which the capital is valued and can be used [334].

Anything may count as capital that has an exchange value in a given field [326]. Bourdieu lists as the main forms of capital: symbolic capital (for example, status); social capital (for example, useful contacts and networks), and cultural capital (for example, qualifications, legitimate knowledge, tasteful dispositions and manners or the possession of highly regarded artefacts) [326]. Capital, along with dispositions and position in the field, shapes the possibility for action. Bourdieu argued that capital assets largely define one’s social position, which in turn determines the conditions and shapes one’s life experiences, and thus habitus [323].

_Habitus_ is the subjective component of practice and the field is the objective component of Bourdieu’s two principle thinking tools [340]. The field and habitus are interrelated and mutually complicit:

> On one side, it is a relation of conditioning: the field structures the habitus … on the other side, it is a relation of knowledge or cognitive construction. Habitus contributes to constituting the field as a meaningful world [334 pp127].

The field structures the way we live—it structures the habitus. At the same time, the habitus provides us with understanding for the fields in which we live [320]. Bourdieu explained the interdependent nature of the relationship between his thinking tools as an equation:

$$[(\text{Habitus})(\text{Capital})] + \text{Field} = \text{Practice} [323 \text{ pp101}]$$

An example of this is an experienced nurse’s intuitive actions in assessing a patient. To understand the way in which an experienced haematology nurse behaves or acts in
expertly and intuitively assessing a rapidly deteriorating patient, it is necessary to take into account her ‘feel for the game’ (*le sens pratique* or practical knowledge) [325 pp108]. Her years of experience in this field means that she assesses the patient and is disposed to making clinical decisions rapidly and accurately. Her intuitive actions have been developed by her past experiences of nursing acutely ill haematology patients and her understanding of the field (*habitus*). This, together with her knowledge, trained eye and assessment skills (capital) and the rules within the haematology unit, hospital and nurses’ code of practice (field) comprise her *sens pratique*, which explains why she decides and acts in the way that she does.

*Habitus*, capital and field are interrelated, both conceptually and empirically [334]. Understanding their relationship is fundamental to Bourdieu’s theory of practice. The relationship between the field and *habitus* is a complex dynamic matrix in which one exerts influence on the other. The field provides context for the way we live and thus structures the *habitus*, and the *habitus* describes how that way of life is understood [320].

_Hysteresis is what happens when the change is catastrophic_

*Habitus* has plasticity or is malleable, and can be modified through the acquisition of new dispositions. It can trigger innovation when it encounters a social setting that is not familiar [218 pp79]. It can also be ruptured or fractured. When a change occurs that is so catastrophic that an individual’s skills and understanding of the world no longer allows them to make sense of the new situation, there is a disjunction or fracture between the field and the *habitus*. Such a fracture can occur with the diagnosis of serious illness. Bourdieu conceptualised this kind of catastrophic disjunct as the ‘hysteresis effect’ [218, 344].

The hysteresis effect accounts for the tension between existing dispositions and new (cultural) dispositions that are formed in an unfamiliar situation [218, 344, 345], which, until new dispositions are formed, are all that are known. In other words, there is a disjunct between the field, which has changed catastrophically and suddenly, and the *habitus*, which takes time to acquire new dispositions and to catch up with the changes
in the field. When there is a change in the structure and conditions of the field that is catastrophic, the dispositions, skills, rules of embodied in the habitus are no longer sufficient to understand and move in the field. Being diagnosed with a serious illness might be sufficiently disruptive to a person’s biography to create a ‘hysteresis effect’.

*Habitus orientates the researcher*

Habitus orientates the researcher to a relational way of thinking about empirical research and ‘draws attention to something significant, offering a different way of thinking about it’ [320 pp61]. Bourdieu’s concepts have been used in the health and illness literature in two ways: to explain health-related behaviours and theorise relationships between class, ‘health’, lifestyle, [346, 347] process and agency [348] [349]. They have also been used to explain illness experience [328, 336, 341, 350], and to account for the relationship between people’s illness experience and their social world.

Gibson et al. [328, 341] used Bourdieu’s conceptual tools [328, 341] in a qualitative study of the experiences of men with Duchenne muscular dystrophy (DMD) who were living in the community in Canada. In the past, young men with this disease were often institutionalised and died at an early age. The habitus of the young men in the study was thus conditioned to a short life expectancy: they did not expect to live much beyond late childhood[328, 341]. Recent technological advances such as home and mobile ventilators meant that they were able to live into adulthood, however, and this ‘shift’ in their anticipated future created a ‘mismatch’ [328 pp566] between their habitus and their survival experience. Their experience also violated norms about how adults should use their time. The young men in the study spent large amounts of their time on daily activities of self-care. Furthermore, venturing out of their homes took an enormous amount of time and effort, and their time out in the community was limited by the availability of their assistant and the life of the battery that powered their respirator. Thus, they felt that, as young men, they were not using their time as productively as their peers who did not have DMD. Using a Bourdieusian frame, the authors were able to explain how and why these young men were marginalised in terms
of their ‘temporal landscape’ [328], their social engagements, and their membership of the wider community [341].

Crossley and Crossley [336] also used the concept of habitus in a study of people who used mental health services. They studied the ‘voice’ of this marginalised social group at two points in time separated by a period of some 40 years. During those years, new social movements had demanded ‘equal rights’ for service users, and the social organisation of mental health had changed dramatically. The researchers found that these developments had changed the way in which the ‘voice’ of the mental health user is heard, and that it had also changed the discourse of this group – and, thereby, their habitus.

Angus et al. [350] drew on data gathered in an ethnographic study of people who were receiving health care at home in Canada. Drawing on data from an ethnographic study conducted in 16 homes, they described how the relationship between participants and their home was disrupted by the ‘logics’ of the health care service — that is, the practices, equipment, schedules and order it imposed. In other words, the home environment came to be governed by the structures and capitals of the health care field, and it thereby effectively became an institutional environment.

Bourdieu’s concepts have thus provided valuable insights into the day-to-day experience of individuals who are diagnosed with different kinds of illness. His ‘conceptual tools’ (i.e. habitus, field and capital) have helped researchers to relate illness experience to the social contexts in which it unfolds.

**The aims of this study**

People who are diagnosed with myeloma have to deal with the catastrophe of a cancer diagnosis, and they have to endure onerous treatments such as chemotherapy and stem cell transplant. But given the consistent and incremental improvements in survival for some people that I described in Chapter 1, myeloma has also become a part of an everyday experience for a number of people. This fact has not been adequately described in the current literature on myeloma. Consistent with the principles of
qualitative enquiry, this study aimed to produce findings that were descriptive, exploratory and explanatory in nature. The main aim of this study was therefore to provide an account of myeloma as an ongoing experience that is a part of everyday life and one which impacts on others, in particular carers. This study sought to uncover how individuals constructed their world of living with myeloma and explored experiences and beliefs about them [351] and to describe an illness experience from several different perspectives rather than attempt to produce a definitive account of what is like to live with myeloma. In addition, this study sought to explore how meaning is created and modified over time by individuals who were living with myeloma. Bourdieu’s ‘conceptual tools’ provided a theoretical framework for analysing empirical observations that were collected by methods that are set out in the following chapter.

The overall aim of this study, therefore, was to explore the experience of people living with myeloma through analysis of their stories and those of their immediate carer or significant other. Specifically, the aims of this study were:

- to develop new knowledge about the experiences of people who are living with multiple myeloma, and their primary carers
- to develop a new vocabulary for describing and discussing the experience of multiple myeloma based on participants’ own discourse
- to improve care for patients and their carers with multiple myeloma by using the findings to produce and publish educational literature for both patients and health care professionals.
Part II: Theory and Method
Chapter Four: Methodology

A Qualitative Approach

Qualitative research is well placed to seek answers to questions about experiences about which little is known [352, 353]. While there is literature to quantify the number of people affected by myeloma [70, 82] or to ‘measure’ their quality of life [354-358], there is little to describe their experiences [117, 144] and virtually none to explain it. Qualitative methodology provides a framework that is descriptive, exploratory and explanatory in nature when seeking to find perspectives and understand experiences, as in this study.

Exploring illness experience: data collection methodology

This study, in exploring human illness experience, is underpinned by a constructionist approach. The unexplored and sensitive nature of this area of research, coupled with a desire for a full, rich examination of this experience, meant that qualitative enquiry and, specifically, a longitudinal study using a grounded theory approach was fitting.

Attempts to fashion true representations of reality are influenced by cultural, economic, psychological and historical factors and thus systems of representations, such as vocabularies, definitions of diseases and conceptual schemes generally, are human creations [167]. Our epistemology is relative to the times in which we live; the accepted wisdom, experiences and values that surround us; and the means that we have at our disposal with which to investigate what exists in our environment. Experience in the world is socially shared, and meanings may be revised as perceptions of what happened change, for example, in the experience of illness over time. People create meaning together through their social actions, interactions and reactions by the use of symbols and in particular, language in their daily activities and encounters [259]. Much of contemporary qualitative research is based on a set of basic tenets that were articulated some time ago by symbolic interactionists.
Symbolic Interactionism

Symbolic interactionism [259, 359, 360] is an inherently dynamic and interpretive perspective that looks at how people create, act and construct meaning [37]. For symbolic interactionism, there are three basic tenets for understanding the world[360]:

- human beings act towards objects based on meanings that these objects have for them
- meaning arises out of interaction with others
- meaning can change over time in the light of new experiences

At the time that Blumer wrote this essay, much qualitative research was undertaken by observation however, in the light of these tenets, interviews have since become the mainstay of qualitative research. Interactionist theory informed this study as it aimed to uncover how individuals constructed their world of living with myeloma from the perspectives of patients and carers affected by myeloma, over time. Interviews were the primary method of data collection in this study. The researcher is clearly present during the interview and in the analysis, therefore the experience of living with myeloma in this study was arguably, a co-construction [361].

Interviews

The interview itself - the telling of the participant’s story - is a symbolic interaction. Through interview, the actions, the meaning of objects, the way that this meaning comes out of the interaction and the way that the meaning changes over time can be explored. In other words, the participant’s feelings, perceptions of experiences, and knowledge of the social world beyond the interaction can be explored [362 ]. Symbolic interactionism is compatible with a constructionist epistemology as it always assumed that different participants would interpret the same actions and situations differently [198]. To understand the experience of living with myeloma, it is necessary to include the context or the situatedness of the participants, their stories and that of myself, the researcher [36]. The situatedness includes temporality.
Interviews are a widely used method of data collection in qualitative research [363] and are considered useful to gain an in-depth understanding of potentially sensitive topics—such as living with cancer[364-367]. This made in depth interviewing an appropriate and useful data collection tool for this study. However, Bourdieu warned about the problems inherent in inviting people to give an account of their experiences [218]. He argued that two (opposing) problems can occur. Firstly, participants enter into a ‘discourse of familiarity’ [218 pp18] and leave unsaid what is assumed to be known by the researcher and therefore considered taken for granted. Secondly, participants engage in an ‘outsider-orientated discourse’ [218 pp18] and generalise, leaving out reference to specific detail about particular experiences or events. In addition, as the researcher, I was a haematology nurse who was already immersed in the clinical setting of myeloma and thus, there was a potential to contribute to this effects and the potential loss of important issues or considerations by being ‘familiar’. I tried to minimise these effects in the interviews by not taking the participants’ world of myeloma for granted, by constantly questioning my own assumptions and by trying to be as a stranger or a ‘naive observer’. I attempted to ‘make the familiar strange’ [368] by using open questions and in depth probing, particularly if the answer appeared to assume a level of shared knowledge. In addition, diaries were offered in recognition of this effect during the interviews as the diary provided opportunities for participants to record at times apart from the interviews.

Diaries

Diaries have also been used in qualitative research, either alone or together with interviews. They have been used to record both outcomes and process. In recording outcomes, they encourage the participant to focus on daily activities and record them. In diarising process, they are used to record reflection on thoughts and experiences [369]. They have been shown to be useful as an aid to memory to improve recall of events for interviews as well as being useful as a primary data source [370]. Diaries used in qualitative research are of two main kinds: solicited or unsolicited. Unsolicited diaries are private in origin; they may either be intended or unintended to be read by another person [369, 371]. Solicited diaries may be written with the researcher in mind, that is,
written for the researcher. Diaries may allow the participant to prioritise their thoughts [372] for the interview and to record their thoughts and experiences over time.

**A longitudinal approach: Change over time**

This was a longitudinal study. Longitudinal studies enable factors of interest to be examined for their stability and continuity over time. In longitudinal studies, participants are interviewed at a minimum of two points in time [373, 374]. The duration of the interval between interviews is determined by the subject matter and context [373, 375]. While cross-sectional studies only allow investigation of differences between individuals (macro-level change), a longitudinal study design allows the research to observe stability and change within individuals over time [376], as well as variation between them [377] (i.e. microlevel change) {Ritchie, 2003 #1510}. Despite their advantages, longitudinal studies also pose several challenges, such as keeping track of participants; dealing with missing data when participants are lost to follow up or decline to participate at any point [378, 379], increased attrition rate through death (which is a particular issue in studies of serious illness); and the additional expenses that these problems entail [377]. A longitudinal study situates the participants and the researcher in a temporal dimension. The temporal dimension is one constituent of an individual’s situatedness which is an important consideration in qualitative research.

**Situatedness**

Social sciences – particularly sociology and anthropology – traditionally emphasise that an individual does not act alone in a void but is situated in a complex and social world. The term ‘situatedness’ has been coined to capture this idea [380]. Theories of situatedness suggest that individuals are produced through and by the environments we inhabit—technological, literary, cultural, political, economic, and social situations. Researchers and research participants are also situated socially, temporarily and among objects [36]. Therefore, knowledge may also be considered as situated [381]. Clarke [36] enumerated a variety of situational elements: Non-human elements such as technologies and infrastructure; implicated and silent actors; sociocultural, spacial and symbolic elements; and related discourses such as political, historical and specialist
knowledge discourse [36]. It was therefore appropriate and important to include relevant discourses, such as specialist biomedical knowledge, media discourse and that of ‘expert patients’ in the analysis [36]. These are integral elements of the construction of experience and therefore are important in the analysis. Interpreting relationships within and between elements of Clarke’s ‘situation’ can thus assist an understanding of the illness experience being explored. This position provides a foundation for situating the phenomena being studied within a wider background of circumstances as described above. The wider social world and particularly the relational ties both within and between participants’ worlds [36], and, also to extant theory [382], are important elements in this study.

**Reflexivity**

The principle of reflexivity is important in qualitative research. Reflexivity is an integral part of the research process in the sense that ‘we are, through the very act of research itself, directly in the situation we are studying’ [36 pp12]. A constructionist epistemology acknowledges the position of the researcher as well as the participants in the construction of knowledge and is encourages the researcher to be reflexive. Both data and analysis are understood to have been created from shared experiences and relationships, the interaction between the researcher and participants [37] and between the researcher and the data; thus, it is inevitable that the researcher is part of the data collection [383].

A reflexive approach positions the researcher transparently with regard to her prior reading and experiences. The way the researcher examines the literature, decides on the questions asked during the interview, interacts during the interview, and analyses the data is influenced by prior work, experience and reading. The researcher can only start from a position of prior constructed knowledge. However, a number of authors suggest that the researcher must ‘hold in abeyance’ his or her own preconceptions, values and beliefs [383, 384]. This approach tends to be more associated with a positivist approach to grounded theory in which the theory must ‘emerge’ from the data and be ‘discovered’ [385, 386] rather than the constructed as in the approach taken in this study.
A reflexive approach is consistent with some feminist epistemologies, in that the ‘knower’, in this case the researcher, is positioned in her own professional, social and experiential contexts. The researcher’s interpretations are reflexively a part of the constructed theory [387, 388] and have informed the methodology of grounded theory and the methods of data collection and analysis.

Reflexivity means being explicit about my own situatedness and that of this project. Thus, I have provided an account of my experience and myself in the introduction and an account of the funding and origin of ideas for this study in the preface. Throughout this thesis I have tried to be explicit about how and why explanations and interpretations arose and what informed their conceptualisation. I was cognisant of bringing my prior knowledge and experience of working with people with myeloma to the interviews and to the analysis. I was also cognisant that the relationship between myself and the participants was one that engendered a kind of rapport – by probing questions and expectations inherent in the nature of the research – that may have pushed normal social boundaries [389]. I had never met the participants before, and did not expect to meet them after a maximum of three interviews and yet I expected them to allow me to sit in their home, probe potentially distressing experiences and reveal to me their most private thoughts [389 pp293].

The choice of method was important in allowing an explicitly reflexive approach. For example, the practice of memo-writing in grounded theory facilitates reflexivity by encouraging the researcher to record their thoughts, feelings and provide explicit links between the data and the emergent theory [390].

**Grounded Theory**

Grounded theory is an established, qualitative methodology that can be characterised as inductive, interpretive, naturalistic and pluralistic. It is inductive because it seeks to generate theory from empirical data [391 pp41]. It is interpretive because it orients to the meanings that research participants attach to the phenomenon under investigation [37, 38, 392] acknowledging that knowledge is both constructed and situated [36, 387, 393]. It is ‘naturalistic’ because it reaffirms a general principle of qualitative research:
that people should be studied in their natural settings. And it is pluralistic because it recognises that multiple social realities exist in our social worlds at any one time [394].

Grounded theory does not articulate a set of rigid methodological rules so much as provide principles and practices to guide systematic analysis of empirical data [35, 37, 394] such as in-depth interviews. These include constant comparison of the data and theoretical coding [35, 385]. Because the analysis is detailed, grounded theory studies usually involve only a small number of purposively selected participants. Data sources are selected to progressively build up a rich description of the process or phenomenon of interest (theoretical sampling), and data collection continues until no new information emerges (i.e. the point of saturation) [37, 38, 392, 394]. One of the original aims of grounded theory was to explore social processes over time and through this provide theoretical insights that had practical application [385, 394].

Grounded theory has evolved since its initial ‘discovery’ [385] and one relatively recent development was what has been called a constructivist approach. Charmaz [37, 38, 394], for example, has argued that grounded theory should be based on the principle that meanings are ‘co-constructed’ between the participant and the researcher in the process of interaction (e.g. interview) and analysis [395]. This contrasts with a positivist approach to grounded theory where data are seen as ‘there to be discovered’ [385, 394]. Constructionism seeks to acknowledge the impact of the researcher’s dialogue, perspective and prior knowledge in their interaction with the participant, analysis of the data and construction of theory. In terms of the practice of analysis, it entails a constant tacking back and forth between empirical data and theory (i.e. constant comparison, or theory construction) [37, 38, 394].

According to the principle of pluralism, those with different perspectives on an experience can be expected to give different accounts of it. Thus a patient, their partner and their treating doctor [36-38, 259, 394] are likely to construct the experience of myeloma in different ways. In a constructivist approach to grounded theory, all three accounts are treated as having value: it is not assumed that there is one ‘true’ story [396]. Furthermore, because meanings are understood to be constructed in interactions,
it in not assumed that they are stable over time. The meaning attached to an experience might change and each time a new account of it is given [396].

In a constructivist approach, therefore, knowledge is not ‘discovered’ so much as ‘constructed’, and concepts and models are invented to make sense of experiences. The fundamental rubric of this approach is the emphasis on the world of experience as it is lived by individuals [397]. Given that this study aims to generate new insights into what it is like to live with multiple myeloma, a constructivist approach to grounded theory is an appropriate choice of methodology on the grounds that:

- it provides a systematic approach to interpreting complex phenomena [394]
- it can account for the socially constructed nature of experience [36, 385]
- it does not rely on a priori knowledge [35, 385, 386]
- it is a rigorous yet flexible method of enquiry that can be used by researchers with a variety of different disciplinary backgrounds [391].
Chapter Five: Methods

Setting and participants

This study was initially conducted in two haematology departments in Sydney, New South Wales (NSW). Because recruitment was initially slow, a third centre was added later.

Patients at these treatment centres were eligible for the study if they were aged 18 years or older, if they were diagnosed with relapsed or progressive myeloma following initial induction therapy, and if they could speak English of a standard sufficient to understand a basic explanation of the study and its aims, and participate in an in-depth interview conducted in English.

In keeping with the nature of qualitative research, initial sampling was purposive. That is, it was selective and based on a preconceived set of dimensions [35, 398]. Purposive or selective sampling is used by many qualitative researchers [352], and involves a conscious selection by the researcher of participants with certain attributes [399].

The study participants were selected on the basis of their willingness to participate, their resilience, and their potential ability to communicate their insights through a series of interviews, as judged by treating clinical staff. Therefore participants were initially chosen according to the likelihood that they would be able to talk about living with multiple myeloma [400] following relapse or progression of their disease. How theoretical sampling was undertaken in this study will be discussed below.

Recruitment

A two-stage recruitment process was used. First, treating physicians asked eligible patients if they were willing to be invited to participate in the study. If they consented to this, the treating physician provided patients’ contact details in confidence to the
researcher, who was not involved in the treatment or care of the patients. The researcher then sent a letter of invitation within two weeks to those patients who had consented to be contacted (see Appendix 3). The letter explained the study in lay terms and notified recipients that an interviewer would contact them by telephone within approximately two weeks. The letter contained a stamped envelope addressed to the research team, and a form that the patient could complete and return in the envelope, should they prefer not to be contacted. Two patients returned this form and they were not contacted again. The remainder were contacted by phone two weeks later. If they agreed to participate in the study, they were invited to nominate a lay carer to participate (i.e. a partner or close relative) and they were sent a more detailed information pack about the study, which included appropriate consent forms (see Appendix 4).

The researcher arranged the initial interview only in cases where both the patient and their primary support person returned their consent forms. It was made clear to all research participants that they were not under any obligation to remain in the study and that withdrawal would not affect their treatment and care in any way.

The only involvement of treating clinicians in the study was the provision of patients’ contact details to the researcher. Recruitment and interviewing was managed entirely by the researcher (i.e. myself).

**Data collection**

The study used a prospective, longitudinal design in which each participant would be interviewed up to three times at six to 12 month intervals. Initially, the plan was to interview 10 patients and 10 carers, which meant a possible total of 60 interviews. Twenty-one participants were interviewed. There were 10 dyads of a patient and their primary support person, and an additional one participant died shortly after her first interview, before her daughter had been interviewed. A decision was made not to approach the daughter for an interview, and another patient was recruited to make up the numbers. During the course of the study, 21 individual participants were recruited (11 patients and 10 carers). Twelve of the 21 participants declined to be interviewed at different times, as they found the interviews taxing and difficult; one participant died.
and his wife felt unable to continue to participate afterwards, and one participant was unable to be contacted after the first interview. In the end, 48 interviews were completed over a 19-month period, however one was lost due to a malfunction of the recording device (Table 2).

Interviews were conducted with participants in their own homes or at another location of their choice. Eleven interviews took place in a hospital setting. One dyad chose to be interviewed at the hospital and met me there on each occasion. One dyad was interviewed at the hospital while the participant with myeloma was receiving her treatment (an intravenous infusion administered over a number of hours). Two participants were interviewed while inpatients. In addition, another interview took place during an outpatient consultation visit. All other (37) interviews took place in participants’ homes. Table 2 shows the interviews completed by each participant. The names of the participants listed in the table and throughout the thesis are pseudonyms.
<table>
<thead>
<tr>
<th>Pseudonym of participants, in their dyads</th>
<th>Relationship</th>
<th>Role and gender</th>
<th>Number of interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anne</td>
<td>Patient</td>
<td>Female</td>
<td>1 (died during study)</td>
</tr>
<tr>
<td>Barry</td>
<td>Spouse</td>
<td>Patient</td>
<td>Male</td>
</tr>
<tr>
<td>Brenda</td>
<td>Spouse</td>
<td>Carer</td>
<td>Female</td>
</tr>
<tr>
<td>Clive</td>
<td>Spouse</td>
<td>Patient</td>
<td>Male</td>
</tr>
<tr>
<td>Celia</td>
<td>Spouse</td>
<td>Carer</td>
<td>Female</td>
</tr>
<tr>
<td>David</td>
<td>Spouse</td>
<td>Patient</td>
<td>Male</td>
</tr>
<tr>
<td>Delia</td>
<td>Spouse</td>
<td>Carer</td>
<td>Female</td>
</tr>
<tr>
<td>Etna</td>
<td>Mother</td>
<td>Patient</td>
<td>Female</td>
</tr>
<tr>
<td>Emma</td>
<td>Daughter</td>
<td>Carer</td>
<td>Female</td>
</tr>
<tr>
<td>Fred</td>
<td>Spouse</td>
<td>Patient</td>
<td>Male</td>
</tr>
<tr>
<td>Fatima</td>
<td>Spouse</td>
<td>Carer</td>
<td>Female</td>
</tr>
<tr>
<td>Gary</td>
<td>Son</td>
<td>Patient</td>
<td>Male</td>
</tr>
<tr>
<td>Gertie</td>
<td>Mother</td>
<td>Carer</td>
<td>Female</td>
</tr>
<tr>
<td>Harry</td>
<td>Spouse</td>
<td>Patient</td>
<td>Male</td>
</tr>
<tr>
<td>Helen</td>
<td>Spouse</td>
<td>Carer</td>
<td>Female</td>
</tr>
<tr>
<td>Ivan</td>
<td>Partner</td>
<td>Patient</td>
<td>Male</td>
</tr>
<tr>
<td>Ismelda</td>
<td>Partner</td>
<td>Carer</td>
<td>Female</td>
</tr>
<tr>
<td>John</td>
<td>Spouse</td>
<td>Patient</td>
<td>Male</td>
</tr>
<tr>
<td>Jane</td>
<td>Spouse</td>
<td>Carer</td>
<td>Female</td>
</tr>
<tr>
<td>Kira</td>
<td>Mother</td>
<td>Patient</td>
<td>Female</td>
</tr>
<tr>
<td>Kerry</td>
<td>Daughter</td>
<td>Carer</td>
<td>Female</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>48</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The interviews were conducted with each participant individually and were 46 minutes long on average (range 12 minutes to 78 minutes). They were semi-structured: the initial interview was informed by a set of questions that was compiled on the basis of previous qualitative studies into illness experience and my own clinical experience (see
Appendix 2) [37]. Spontaneous questions tended to follow the participants’ lead by probing topics that were evidently of importance to them. Each interview concluded with the question ‘is there anything that I haven’t asked that you feel is important for me to know in order to understand about living with myeloma?’

The interviews were audio-recorded using an Olympus DS-2200 digital recording device. Sound files were uploaded into a PC and transcribed verbatim by a commercial transcription company. Pseudonyms were used for the participants and transcripts were reviewed to remove any identifying information. In addition, I recorded field notes and offered participants a diary to record their thoughts in between interviews, along with some general guidelines as to how these might be used (see Appendix 3). One participant shared her (solicited) diary at the second interview, and this served as a point of departure for the second interview. One participant gave me her (unsolicited) diary in which she recorded her husband’s consultations and illness experiences. No other participants returned diaries.

*Theoretical Sampling*

Because the process of analysis began as the interview transcripts became available, questions were asked in follow-up interviews so as to explore in depth topics or themes that were deemed to be of particular interest and importance given the aims of the study. This was consistent with the grounded theory tenet of theoretical sampling and allowed me to formulate questions in follow-up interviews so as to explore a particular topic or theme in *more* depth. Theoretical sampling in this way meant that pertinent data was sought to develop an emerging theory or theories [37, 401]. Therefore, theoretical sampling in this study focused on finding new data that could further illuminate and explain the emergent theory [36]. This was an application of the principle of theoretical sampling. Modifying data collection by redirecting subsequent interviews and focusing questions or probes has been described by a number of authors as one way of theoretical sampling [402-405].
Throughout the data collection, I made field notes in which I recorded observations and placed participants in scenes and contexts [37, 38, 367].

**Data analysis**

My analysis aimed to develop a theory, based in the data, that would produce and link concepts to explain the complexity of the experience for people living with myeloma [406]. While these are narratives that are being interpreted, I have not used narrative research techniques of analysis. I chose to ‘fracture’ [392 pp301] the narratives and put them together as a collective analytical story to provide an explanation. Narrative research aims to interpret, explore and conceptualise people’s experience as represented in written or oral form [407 pp225] but tends to keep the integrity of the story as a whole. In keeping with grounded theory methods, data analysis was undertaken systematically and concurrently with data collection [37, 367, 386, 394, 408-413]. In keeping with a constructivist grounded theory approach, the key analytical tools and strategies used were open coding, constant comparison, memoing and the use of integrative diagrams [37, 367, 394, 409].

The participant told a story describing and interpreting their experiences and feelings, of what went before and of what may come—but not necessarily in a chronological order. During the interview, and later in the analysis, I listened, interpreted and initially tried to impose an order on events in trying to understand the participant’s experience. In keeping with grounded theory coding and analysis, I rearranged the ‘order’ in trying to understand the experience of the participant.

Open coding is a necessary initial step in a grounded theory analysis [36-38, 414]. It involves repeatedly listening to all of the interviews, and reading the transcripts, together with field notes, and assigning short sections of text to interpretative categories [36-38, 414]. All data is open to being ‘coded’ in this way, and can be assigned to multiple codes simultaneously. Initial codes are considered provisional as the analysis develops [36].
In order to facilitate coding of the interviews, I loaded the interview transcripts into NVivo, which is a commercially available software program for managing and analysing qualitative data. My coding categories drew on my previous clinical experience, my interaction with the participant during the interviews, and the content of the participant’s story.

This initial open coding exercise was followed by more focused coding in which open codes were organised into a coherent set of concepts and categories [37, 38, 367, 394]. This process synthesised different ‘threads’ of the analysis. In keeping with the strategy of ‘constant comparison’ [37, 38, 367, 386, 394], as the focused coding developed and themes and categories become apparent, I re-read the transcripts for these concepts in case I had been missed or glossed over them [37]. In other words, I repeatedly revisited and reread the data within a ‘spiral of conceptual development’ [184].

I drew and re-fashioned diagrams throughout the analysis both to clarify the relationships between codes and concepts, and to try to situate the constructed experience in context. Clarke has described this as analysing the data through examination of the most salient elements of the situation [36]. I also drafted theoretical memos in order to develop my ideas and create a record of their development. I wrote memos based on analytical codes and on individual participants, and I also kept a journal which related my analysis to extant theory, discussions with supervisors and others, and generally sought to synthesis various elements of the my analysis.

**Trustworthiness**

Glaser and others have suggested that validity in grounded theory should be judged by fit, relevance, workability, trustworthiness and modifiability [35, 352, 353, 385, 397, 415]. Validity, or trustworthiness, pertains to the credibility, believability and faithful interpretation of participants’ experiences [353, 411, 416]. Pawson et al. [417] have suggested a framework of six standards known by their acronym, TAUPA. In addition to validity, these standards may be useful in addressing issues related to ethics and accessibility examining: transparency, accuracy, purposivity, utility, propriety and accessibility. This raised questions such as:
1. Are the claims of knowledge supported by and faithful to the participants?
2. Are the research methods suitable (fit) for the study (purpose)?
3. Is the knowledge appropriate to the setting in which it is to be used?
4. Has the study been conducted ethically, legally and with due care?
5. Is the research presented in such a way that it is of value to the user?

In keeping with the suggestion that trustworthiness is a process that refers to the way in which a researcher meets the criteria of validity, credibility and believability of research [418], I used the TAUPA [417] framework as guidance.

Throughout the study and analysis, I shared my findings and analysis with people affected by myeloma attending Myeloma Foundation of Australia (MFA) support groups and educational days (Appendix 5). I reported my findings, by discussion and using PowerPoint presentations to illustrate my diagrams, analysis and findings and consistently asked attendees if my findings resonated with them. I specifically asked them to comment on whether my findings were a representation their experiences and asked if they recognised them. I engaged in a dialogue with group members who contributed to my analysis and thinking, and therefore, my conceptual development. Feedback from participants both affirmed my findings and enabled me to modify my analysis. I was invited to speak to the myeloma support group at Camperdown, Sydney, NSW and on educational days on 7 occasions at Camperdown and St. Leonards in Sydney, Gosford, Wollongong and Dubbo in NSW and Canberra, ACT (Appendix 5)5.

**Ethical considerations**

Ethical approval for the study was obtained from The University of Sydney (see Appendix 4) and the three hospitals where participants were receiving treatment. A principle-based approach to conducting ethical research was taken with regard to the ethical considerations obtaining valid consent and the requirement for confidentiality and de-identification of participants and places. This approach is commonly cited as the

---

5 I was also invited to both Camperdown and Liverpool support groups to talk about fatigue management and living with compromised immunity. In addition I spoke on other, additional, MFA education days about these two topics.
most appropriate standard for judging moral attributes of studies [419, 420]. A principle-based approach, such as that developed by Beauchamp and Childress [421], provides guidelines for navigation through some of the ethical issues and expectations of conduct to be found in research.

Coercion

This study involved patients who had been diagnosed with multiple myeloma and treated in the Haematology Departments of three metropolitan hospitals. It was possible that two of the associate investigators and one of the investigators on the project may have been in clinician-patient relationships with some patients. Recruitment procedures, therefore, were designed to minimise any potential for coercion. All participants were recruited and interviewed by a researcher who was not involved in the patients’ care. Participants were advised that there was no obligation to participate and that they may withdraw from the study at any time, and that this would not affect the care they were receiving at that time or in the future. All transcripts were de-identified, and practicing clinical staff did not have access to transcripts of interviews with patients in their care. A two-stage recruitment process, which had previously been used in a similar study of patients with advanced ovarian cancer, was used to create a clear separation between the roles of clinicians and researchers.

Privacy and confidentiality

Participants were interviewed in a setting of their choosing and where this was a public place such as a hospital, privacy was maintained by ensuring that the interview took place in a private room with the door closed. Digital audio recordings were made of the interviews for the purpose of transcribing them. Recordings were stored on a password-protected computer and on a CD in a locked cabinet at the University of Sydney for the duration of the project. Transcripts have been stored as computer files and identified by the interviewee’s pseudonym only. When the study is completed, CDs and hard copies of transcripts will be shredded and audio recordings erased. Computer files containing transcripts will be stored securely for 7 years and then erased. All publications and dissemination of the study will refer to participants by their pseudonym only.
Risks and benefits

This study involved vulnerable participants, sensitive topics and an intrusive method of data collection, therefore a care ethics approach was adopted as an over-arching ethical orientation [363]. Care ethics centres the relationship, in this case between the participant and myself. In doing so, as an orientation of care, it can maintain the relationship between the researcher and the participant and at the same time be sensitive to the participant’s needs. I had an interest in, and concern for, the participants. I was attentive and interested in their stories, and attempted to understand events in their experiences.

In particular, this study was based on interviews with patients who have a diagnosis of a life-threatening malignant disease, as well as interviews with people who are close to them (e.g. partners, friends and/or close relatives). Interviews explored the participants’ experiences of illness and treatment (or of supporting someone going through this experience), and the impact this has had on their life, relationships, identity and perception of the future. The research interviewer was a nurse who has extensive clinical experience in haematology and who previous experience conducting in-depth interviews with cancer patients. Given the focus of the interviews, it was possible that participants could become upset during the interview. This is not uncommon in qualitative research, and when it does occur, although the distress can often be handled by an experienced interviewer, it creates an ethical dilemma [422]. Should the distress be more serious or arise between interviews, however, I had an arrangement in place whereby I would put the participant in contact with the appropriate support service at the hospital where the patient received treatment. At all three hospitals, the normal pattern of referral was to haematology nursing staff in the first instance and then (if necessary) to the social worker and/or clinical psychologist on rotation in Cancer Services. Participants in similar studies have reported that interviews can be of benefit in that they provide opportunities for reflection that may not otherwise be available. Therefore some participants may have obtained some short-term therapeutic benefit. It is also possible that participants who survive long-term may benefit from any improvements in health care organisation or delivery that are made as a result of this study.
Role of researcher vs nurse

As a nurse, I also reflected on my position within a potentially therapeutic relationship with the participant. Later, during the study, a number of the participants knew that I was an experienced haematology nurse, as either they had been informed by their clinician when told about the study or, more commonly, I had told them when I met them. Self-disclosure has been reported by a number of qualitative researchers as ‘good practice’ and as a method to ‘enhance rapport, show respect for their participants and validate their stories’ [423]. During some interviews, participants asked me specifically clinical questions and at least two participants appeared to be struggling with suboptimal symptom management. I resolved these issues by offering advice within my area of expertise, after the interview with the recorder off (having told the participant that I would do this at the time of the question within the interview). This may have blurred boundaries between the roles of researcher and nurse [424]. I was a nurse, and as such could be described as ‘an autonomous moral agent’ [425 pp2] with more than one responsibility, which included that nurses have a responsibility to inform people about the nursing care that is available to them.
Part III: Findings
Introduction to the participants

Participants’ stories

Anne

Anne was a woman in her fifties who was living alone at the time I interviewed her. She was divorced but retained a strong friendship with her ex-husband. She was a nurse who had retired a few months prior to the study. She was a great friend with her daughter Angela and they did things together insofar as Angela’s busy work schedule allowed. Anne had been diagnosed with ‘smouldering myeloma’ 15 years earlier. Before I interviewed her, she had progressed to a stage of myeloma that required treatment. She died suddenly, four months after the interview. I had been unable to interview Anne’s daughter, Angela, before Anne died, and I decided not to approach her afterwards because I thought it would be too upsetting.

Brenda and Barry

Brenda and Barry were European immigrants who met and married in Australia. They had two young children. Barry was in his early forties. He worked as a demolition expert and was involved in property development with his family. I first interviewed Barry while he was in hospital receiving treatment. He was feeling well and was impatient to return to work. I also met Brenda in the hospital but I interviewed her at her home.

Clive and Celia

Clive and Celia were a very private and immensely resilient couple in their eighties. Clive was passionate about painting and photography and was devastated when his vision became severely impaired. They both enjoyed travelling together in their caravan and used to follow the sun with their friends. This had become increasingly difficult,
and they sold the caravan but still travelled, although not as much as before. They had two sons with whom they had limited contact. Celia was diagnosed with bowel cancer and had surgery for this during the study, but brushed this off as incidental.

David and Delia

David and Delia were a couple in their late fifties. I first met David in hospital where he was undergoing chemotherapy treatment for his myeloma. David was a Mason, holding a position of responsibility in the Lodge. He had worked in management for a large retail company for many years. He was organised, he enjoyed work and he cared about his staff and the company. Delia was a spiritualist: she believed in past lives and numerology. They had two daughters. The youngest had been diagnosed with a slow growing brain tumour some years previously. David died suddenly prior to our third interview.

Etna and Emma

Etna was a married woman in her early sixties who lived with her husband on the coast. Most of their extended family lived overseas. Etna took early retirement when she was diagnosed but found herself busy looking after grandchildren and helping her daughters. She had two daughters, one of whom was Emma. Emma was a busy woman in her thirties. She had trained as a lawyer but took time out to bring up her children. Emma had been considering returning to work when her mother was diagnosed but had not pursued employment. Emma was an energetic, articulate and passionate woman.

Fred and Fatima

Fred was in his early sixties and Fatima was in her late fifties. Fred and Fatima were married and had two adult daughters. One daughter worked with her husband in an area related to the health sciences. Fred and Fatima migrated to Australia from Europe and they maintained business and family links there. They lived in comfortable
surroundings. Fred was planning to retire from his consultancy work in the near future. Fred stopped working after he was diagnosed with myeloma, but he returned to consultancy work after an economic downturn.

*Garry and Gertie*

Garry was a 40-year-old man who worked in the transport industry. He lived with his mother, Gertie, in her house. Garry’s sister lived next door but he had little contact with her. Garry was single. He had never moved out of home and he worked long hours with very variable shifts, frequently being summoned to work overtime at short notice. Garry was proud of the fact that he had taken little sick time since his diagnosis. He managed his transplant and hospitalisation by taking long service leave and annual leave. Garry’s elderly mother, Gertie, adored her garden, and had a passion for collecting all kinds of items, particularly if they were English. She had never visited the UK, however.

*Harry and Helen*

Harry and Helen were a married couple in their early fifties who lived together in a busy home where Harry also ran his business. Helen worked elsewhere, occasionally assisting with the family business when needed. Their three adult children were described as ‘snow people’ because they travelled the globe in search of winter sports, much to Helen’s chagrin. Harry had tried to continue to work throughout his illness and treatment for the nine years since his diagnosis. He had achieved this most of the time, despite the difficulties it entailed. Despite having previously been bankrupted and losing the family home, they talked about how they had learned to be resilient and to survive.

*Ivan and Ismelda*

Ivan and Ismelda were partners and had lived together for a number of years. Ivan was in his early sixties and had been diagnosed with myeloma suddenly and dramatically 10 years previously. He used to run to keep fit and had completed the City to Surf race (an annual half-marathon) a number of times. He enjoyed spending time with his dogs and talking about sport with friends. Ismelda’s story was one of struggle and strength. Her
first two husbands both died of haematological cancers, one of lymphoma and one leukaemia. In addition, she had lost her uninsured house in a fire. Ismelda was diagnosed with a significant health problem requiring surgical intervention but dismissed this as less important than John’s health and treatment needs.

*John and Jane*

John and Jane were married and were in their late fifties. They had two adult sons. They migrated to Australia together as a young married couple. Jane gave up her work when John was diagnosed with myeloma to care for him. John, who has always undertaken hard labour-intensive work in his employment, also stopped work. This restricted his social life, which had previously revolved around his work. During the study, Jane was diagnosed with breast cancer and commenced chemotherapy.

*Kira and Kerry*

Kira was a woman in her early fifties who lived alone after divorcing her husband a number of years previously. She was a determined, articulate and reflective individual. She moved house because she had found it difficult to travel frequently to and from hospital for treatment. This had separated from her friends of many years, thus she was socially isolated. She was devastated when, because of her diagnosis, she was unable to continue her job as a personal assistant to an important public figure. She was keen to stay busy and so undertook a college course to learn new skills. Kira was the only participant to become engaged with her local myeloma support group. Her daughter Kerry, who was in her early twenties, had to juggle her job with her role as Kira’s carer (which entailed staying at her mother’s house for long periods). She also had to manage her relationship with her fiancé to whom she was soon getting married, organise her siblings, and attend to her father’s needs.
Chapter Six: Having Myeloma Is Difficult—The Illness Biography

Introduction

This chapter provides an account of what it is like to live with the symptoms and signs of myeloma, based on the content of the interviews. All of the respondents characterised the experience as a difficult one. It was difficult because of what happened to their bodies, their relationships, and their social and personal lives. The overall experience of living with myeloma was described as a complex and arduous struggle. Participants said ‘having myeloma is hard’, because the effects of myeloma permeated every facet of their lives. They all strove to make sense of their altered bodily experience, and in doing so, they relied on the medical gaze (‘the numbers’) and a set of ready-made categories that are commonly used to classify illnesses (‘acute’, ‘chronic’, or ‘terminal’). In response to the situation they found themselves in, all of the respondents strove to keep on living as best they could. Many described this as ‘getting on with it’.

Participants described the experience of myeloma as an illness rather than as a disease. The section called Somatic experience describes the subjective phenomena that were reported by all of the participants in one way or another. The following two sections, Living by numbers and Describing a category of illness, outline the means by which participants made sense of their experience.

Somatic experience

Participants described a large number of physical ailments. Pain, fatigue, peripheral neuropathy and the adverse effects of steroids were cited most frequently. Most of these ailments were described as being effects of the treatments that the participants were receiving, rather than symptoms of the disease. Kerry, for example, said that chemotherapy and the stem cell transplant caused her mother, Kira, pain, nausea, immense fatigue, anorexia, and a severely ulcerated mouth. Other participants described
the effects and complications of novel agents such as thalidomide, bortezimab and lenolidomide, as well as the effects of haematopoietic stem cell transplantation, and steroids. The full list of adverse effects included fatigue, pain, deep vein thrombosis, altered blood sugar levels, mood swings, personality changes, aggression, depression, an inability to think clearly, insomnia and osteonecrosis of the jaw, peripheral neuropathy and other (autonomic) neuropathic complications such as constipation and tinnitus. Importantly, the effects caused by the treatments were interpreted as evidence that the treatments were being effective.

Participants also described how they gained experience with different treatments and their effects. They were able to differentiate between the effects of disease and of the treatments, and between the adverse effects of different treatments. Because the treatments were evidently controlling the myeloma – the very thing that could kill them – they were able to accept the adverse effects and ‘get on with’ life despite them. Thus, even if the adverse effects of treatment were experienced as debilitating, participants rarely said they wanted to stop or change the treatment.

There were many examples of how participants just ‘got on with it’ despite the adverse effects of treatment. Harry ran his business from home, and each time I visited him, there were boxes of products piled high, colourful samples lying redundant in corners, and orders stacked neatly awaiting delivery. He sat attentively at his computer amidst a forest of towering piles of paperwork. The business was the family’s main source of income so it was imperative that it was successful. Harry told me that he was quite well at the time, but his wife, Helen, had found it distressing to watch him trying to keep the business going after his stem cell transplant:

He got every possible side effect that you could possibly get to the extreme and he got it, he stuck at it for eight months and by the time eight months came he could not function, he couldn’t think, he couldn’t hear, he couldn’t speak, he was an absolute wreck ... That was the worst eight months. He never got over the transplant. He was

6 Osteonecrosis of the jaw or ONJ has been described as occurring in approximately eight per cent of people with myeloma receiving a particular type of bone strengthening drug of the bisphosphonate group Zometa (425).
trying to work, he couldn’t, he was just like, oh, I can’t even describe the mess he was in.

Ivan described his relentless struggle to endure treatment over a period of 10 years and observed that ‘The side effects certainly have an effect on your life,… the side effects are certainly tough’. He accepted the adverse effects of treatment as the price of controlling his myeloma, but he was also curious as to whether other people with myeloma ‘did it tough’. Overall, it was apparent that there was a trade-off between living longer due to the efficacy of the newer treatments (in particular the novel agents), and tolerating their effects.

The effects of stem cell transplant, chemotherapy and novel agents were all described in the interviews. Because the participants were recruited after their first relapse or when the myeloma was progressing, the most frequently described effects were those of novel agents and steroids. Steroids have an anti-myeloma effect themselves but are frequently used along with novel agents and chemotherapy to enhance their efficacy. Half of the participants described in detail their struggle with the effects of steroids in particular. Both for participants with myeloma and for their significant others, the effects of steroids on their lives were described as invasive, debilitating and distressing.

**Living on steroids**

Steroid were said to cause mood swings, changes in personality, insomnia, weight gain, raised blood sugar and general debility. Kira and Ivan told me how they dreaded their courses of steroids because the debilitating effect lasted for days:

I dread the day that I take, or the night that I take the Dexamethasone. They’re really tough and sometimes I’m no good the second day after. Maybe I’ll pick up a little bit but tomorrow. Unless there’s a fluke, I’ll be lousy (Kira).

Some participants described personality changes that they attributed to steroids. When their partners were on steroids, carers described them as short tempered, aggressive, talkative and manic. Some carers said they had to ‘tread on egg shells’ while the person
they cared for was taking steroids, and that they struggled to deal with their partner’s hyperactivity, manic disposition and non-stop talking:

While he’s on Dexamethasone, he’s a little bit short. He’s, how would you say, short of … He’s not very patient, on a short fuse, and it just gets a bit shorter (Celia).

He’s very hyperactive when he takes the steroids, you can’t shut him up. He’s going on and on and on. On the go all the time (Jane).

When she’s on it she doesn’t stop talking and sometimes it’s frustrating. But I’m just trying to sit there and listen, but sometimes she’s like a talking machine, she won’t stop like it’ll be 10 o’clock at night, and she’s talking and I’m trying to get all relaxed, about to go to bed and she’s on fire (Kerry).

Some participants had been forewarned about potential ‘mood swings’ but the intensity and the idiosyncrasies of the steroids’ effects were learned by experience. Initially, they caused tension and distress, particularly if they were poorly understood or unexpected. Like other therapies, steroids involved a trade-off between the benefits of a potentially ‘life saving’ medication and other health problems such as diabetes.

Kira and Ivan described the debilitating effects that steroids had on them but illustrated how they accepted the effects as an accepted price to pay for treatment:

Dexamethasone now too but only once a week … the main side effects on that is quite often I’ll get nauseous, the day I take the Dex I have all this energy. The next day round about lunchtime I get very, very red, like hot and red in my face and my neck well my whole body feels hot. Then I’ll have two days of shaking and then by the next day I’m good, I’m good for two days and then I have to take them again. I have to accept it because that’s the only thing that’s brought my levels down again. I’m useless when I’m shaking like that because you know I feel like I can’t do anything. I can’t think properly, I can’t do anything properly (Kira).

One time my sugar, blood pressure, everything was perfect. Well now, they’re not. The Dexamethasone … it whacks your sugar sky high. You feel awful in the head,
terrible, so you’ve got the lack of sleep, plus the tablets themselves have knocked you around. So all I can say is they might be a lifesaver in a way, that Dexamethasone. But my God Almighty they’re tough (Ivan).

Another problem attributed to steroid medication was a lack of mental clarity. Participants described a feeling of ‘fuzziness in the head’. They were unable to think clearly, were confused at times and could neither concentrate nor remember things. Some participants attributed this to their fatigue and lack of sleep but most cited the steroids as impairing their cognitive function.

Participants found this effect even more distressing when they had insight into the fact that they were sometimes confused and forgetful. Kira had been unable to work since her diagnosis and thus had constantly looked for intellectual and creative activities whenever she felt well enough, but had been unable to maintain any activity. Harry and Fred tried to work but the effects of the steroids made this extremely difficult. Harry said his fogginess and inability to think clearly restricted his ability to process orders in his business. He described his frustration when he found it impossible to do even ‘basic paperwork’.

Another frustrating and sometimes incapacitating effect that was often attributed to steroids was a severe tremor. Fred described himself as a skilled electrician and engineer. He designed industrial equipment and continued to work occasionally as an engineering consultant. He described how his hands shook and trembled and that this made writing impossible for him and frustrated his ability to undertake skilled electrical work, which was something he had previously been able to do around both his own and his children’s houses:

I feel the physical restrictions a lot, I do, I’m an electrician as well and I did that [points to light fitting in ceiling] and then I started to get the trembles, because that’s what I do get with this treatment I’m having now.

All of the participants complained about how the steroids caused insomnia and therefore fatigue during waking hours, due to lack of sleep. This was a daily struggle for many of
them. Carers also complained about insomnia. Insomnia was blamed for exacerbating mood swings, aggression, fatigue and causing people to fall asleep during the day. Sometimes the sleeplessness was anxiety driven. Participants described a vicious cycle of worrying in advance about not sleeping, and then worrying about it while they lay awake at night:

Well I know tonight—today is my day that I have six tablets (steroids), three I’ve just had and another three about lunch time, I know I won’t sleep …… I may fluke an hour or two, but even if I have a couple of mild sleeping tablets, hardly any good at all and this has been going on for over a year (Ivan).

Seven of the dyads were partners or married and all of them had been together for a number of years. Fatima, Ismelda and Helen explained that they and their partners sometimes or always slept in separate beds and in separate rooms to avoid disturbing one another, but this added to their distress by creating a ‘private sadness’. Fatima was tearful as she told me how Fred’s sleeplessness had separated them. She said she encouraged him to stay but to no avail. This impact of myeloma on intimacy between couples was not immediately apparent, but was described in particular by two female participants as time went on. Both women were spouses of men with myeloma, and described how they no longer engaged in sexual activity and were rarely intimate, since the diagnosis led to them having separate bedrooms. They described how their husbands now distanced themselves emotionally and physically.

**Living with fatigue**

I have used the term ‘fatigue’ in the way that health care professionals use it: as a ‘catch all’ description for what participants described as exhaustion, weakness and tiredness. Participants used different descriptors for the all-consuming, relentless, extreme exhaustion but there was a marked similarity in their overall description of myeloma-related fatigue. Its relentlessness, intensity and immobilising effect struck them as extraordinary and burdensome. Anne was incredulous at her inability to perform ordinary tasks:
I think the thing that’s probably worse for me is the exhaustion, the lack of energy you know … especially when I first came home from hospital I couldn’t even lift the kettle without getting exhausted.

Celia recounted her struggle when her husband Clive, a very tall man, was so exhausted and weak that he could not walk through the hospital to his outpatient appointment:

I managed to get him to the information [point] where we were this morning, and then I got the wheelchair down to the downstairs and the wheelchair back to where I could pick him up. He knew he’d have to have it because he just wasn’t strong enough to do it.

In our second interview, a few weeks after her stem cell transplant, Etna explained that the immersive, consuming nature of her fatigue had become her only focus: ‘I can’t see anything except tired, tired’.

Harry struggled to work throughout his treatment and described his fatigue as the ‘overriding’ symptom. He said he was compelled to continue to work because he had to maintain his home business. Helen described the depth of his tiredness as she described how he could not get up in the morning without her help.

At our second interview, a few weeks after David’s stem cell transplant, Delia told me that David had recently recovered in hospital from a life-threatening episode of septic shock and pneumonia. When he returned home, he was able to maintain only the appearance of having energy and activity for short periods:

They all call him Lazarus and now he’s got to a point where he can’t get out of bed.

Participants described how the debilitating tiredness restricted their activities and was difficult and frustrating. Ivan told me that he used to enjoy catching the bus into the local shopping mall, spending the morning there, going to the local betting shop, having a beer and reading the newspaper. He went on to explain that he was rarely able to do this now and that this was a source of frustration to him:
I do get this damned tiredness. I get real tiredness and a miserable kind of a tiredness, it’s enough—I could have my bag here ready to go to Townsville. Time and again, I’m about to go … I’m getting tired, oh hang the bus, I’ll maybe get the next one and lay down, I end up not going at all, I’ll go the next day and that sort of thing, that’s how it affects me. … this horrible sort of rotten tiredness … I always had tiredness more than anything, now even but it annoys me, it annoys me this tiredness.

Since the fatigue was both unpredictable and incapacitating, participants could no longer trust their body to do things that they had previously taken for granted. This took away their ability to plan and to look forward to activities and events. Fatigue forced them to live in the present because they did not know if they would have any energy in the future. Living with constant fatigue thus contributed to their uncertainty.

Some participants interpreted their fatigue as a sign that their myeloma was active. Indeed, for three of the participants, fatigue was the only symptom that heralded the presence of myeloma. Fred described how his unprecedented exhaustion was an antecedent of his diagnosis and explained that he later used this experience to alert him to his relapse:

As soon as I started to feel tired, sit down at night, and fall asleep virtually, I thought that it was coming, the protein was building again. And that’s the only indication I’ve got, more often than not you know it’s coming because you’re getting tired.

Even though fatigue could be a cause of uncertainty, understanding the patterns of their fatigue enabled participants to anticipate calculating their capacity for activities and planning around it. However, more often, it caused frustration and struggle and was a totally immersive multidimensional experience affecting all areas of activity.

Living with neuropathy

As well as enduring fatigue, participants had to endure peripheral neuropathy (i.e. loss of sensation in the extremities of the body). Participants saw this problem as the result of some of the drugs that are used to treat myeloma and therefore accepted it as one of the trade-offs of treatment. The effects of neuropathy included pain, constipation,
dizziness, sensory loss and loss of motor function. Accommodating these effects into the activities of everyday life demanded vigilance and continuous efforts to find new ways of doing things. As was the case with fatigue, participants no longer trusted their body to perform activities that they previously took for granted.

Coping with neuropathy was a debilitating struggle for all of the participants who experienced it. In our initial interviews, they often focused on describing their symptoms whereas in subsequent interviews, they focused on how they managed their neuropathy and its impact on their daily lives.

Participants described the effects of peripheral neuropathy as debilitating. They were unable to hold a cup of tea for fear of dropping it and burning their legs. They were unable to hold a pen and write. They were reluctant to cross the road for fear of tripping. Before he was diagnosed, Ivan was an athletic and sporty person. He explained that the peripheral neuropathy in particular had changed his life. He no longer trusted his body because of the sensory loss, and this stripped his confidence and rendered him fearful:

> The feet and the numbness, and sometimes you drop things and you don’t know you’ve dropped them there in your hands. I try to ignore it as much as I can but it is really difficult with the numbness and that, it just changes your life even if you’re going along reasonable. It changes in a way … a little touch of fear at times, especially since, uh, I’m nervous a bit with my feet.

John described the unrelenting nature of peripheral neuropathy, and how he was in continual discomfort:

> The chemo damaged my nerves … It’s like my feet are in muddy water, like they’re dragging. It’s like putting your feet in muddy water here and it starts drying up, the mud—it feels like that.

When I visited Jane and John, John always sat at the back of the house in a large, comfortable recliner in an area dedicated to his interests. He enjoyed watching television and movies, listening to music and playing computer games. This was all
arranged within easy reach of his recliner. Jane tried to help John maintain his mobility as the peripheral neuropathy in his feet increased and he became increasingly incapacitated:

His feet’s getting worse, he can’t wear shoes. I had to go and look because he walks around with Ugg boots. I’ve got to go and see if I can find him something, he can’t go out with these big Ugg boots.

**Living with pain**

The third and final important element of participants’ somatic experience was pain. Pain permeated life for most of the participants who had myeloma and it was described as being present from diagnosis through remission and relapse. It was a constant companion that demanded attention. The nature and intensity of pain varied between participants and within individual illness narratives, getting better or worse at different times. It was described as sudden, acute, chronic, excruciating, out of nowhere, intense, dull, gruelling, dragging, immobilising and frightening. Pain was often described as an antecedent to diagnosis and, as Barry explained, the diagnosis of myeloma provided an explanation for otherwise inexplicable pain:

Everything was going fine until I started receiving chest and back pains. [It] took a while before they discovered that I had myeloma.

Many participants described pain as a gruelling constant in the background that was thrust into the foreground by exacerbations of sudden, severe pain. Severe pain could be brought about by a pathological event such as a fracture, or by an intervention such as a bone marrow biopsy. It could also be brought about by omitting to take regular pain medication as a result of failing to wake up when analgesia dose was due or forgetting to take it at regular intervals.\(^7\) Pain was sometimes described as being catastrophic in its onset. Ivan, a keen jogger, described his shock and sudden incapacity caused by the intense pain of the simultaneous fracture of several ribs:

---

\(^7\) With severe and/or chronic pain, analgesic medication should be taken regularly to maintain the effect. This means taking the medication when there is little or no pain.
I got on the phone there and all of a sudden my ribs snapped … Now that morning I had no pain, the only thing was I was a little bit short of breath and the previous run to that a few days, a couple of days previous—well I didn’t know what was going on and I was in pain. It wasn’t just one rib, they just went *boom*.

As myeloma makes bones brittle and fragile, the simplest and normally inconsequential action could have devastating consequences. After he presented with back and chest pains, Barry had commenced treatment with steroids and was discharged from the hospital. He told me how, one evening shortly after he was diagnosed with myeloma, he broke his back switching off the television. He got up from the sofa and leant forward to reach for the remote control. This action precipitated an intense pain in his lower back: ‘I felt something crack in my back and collapsed on the floor’. Barry went to bed and was in immense pain all night. Later, he acquiesced to his wife’s demands to call an ambulance, and was admitted to hospital the following morning.

Barry’s partner, Brenda, described how rapidly and intensely their situation changed from an ordinary evening watching television to a night of fear for Brenda and intense pain for Barry. She described her fear and uncertainty as she heard Barry’s screams. She gave him a dose of morphine, and as it took effect and Barry slept, she did not know whether she had killed him:

And we’d been watching TV and I said I want to go to sleep … and he said to me it doesn’t matter I’ll listen to the news and I’ll follow you. I fell asleep because I was so, so tired. Suddenly I heard Barry screaming. He [was] trying to go on the bed to sleep and he couldn’t. He was sweating and sweating and screaming from the pain and I’m helping to put him on the bed … I go to the fridge and get his morphine because the doctor at the hospital he gave him some morphine for pain, because he was suffering bad, bad pain. And I get him some morphine and ask me how many morphine I gave it to him—I don’t know, I don’t know maybe I kill him this night, it was really, really hard night. I give him some liquid morphine and he’s sweating, sweating so much, sweating so bad, he fell asleep, I opened all the windows, he can’t breathe any more, he couldn’t breathe. And when the day came I called an ambulance and they took him to the hospital.
Brenda’s description of events illustrates the intensity of her emotion and fear that night. Barry had previously been a strong, fit and muscular man who worked six to seven days a week in the building industry. Neither she nor Barry had previously experienced or witnessed pain of such incapacitating intensity.

It was not only the pathological effects of myeloma that were said to cause intense pain. Pain was also identified as a consequence of diagnostic tests and treatments. It could be the result of infection, neuropathy, cracking skin or painful mucosa. It was caused by invasive procedures such as the insertion of a needle to take blood or to administer medications. This is Ivan’s chilling description of a bone marrow biopsy.\(^8\)

Bone marrow … that was a Nazi style thing, that. I’ve never screamed ever in my life but this woman … well she couldn’t get the bone out properly. Someone held me down. It was excruciating pain, excruciating—oh, I’ve never—and I just yelled out one scream. She couldn’t get it out.

Pain was also the result of the effects of myeloma on bones. It causes both chronic pain and severe, acute pain. David described the intense pain he experienced in one of his feet while in hospital undergoing treatment:

Velcade, which we used, that knocked me around a bit but it did to, um, down your nose and, nails and toes and all of that sort of thing cracking open. At one stage [my toe] was so sore it just swelled up, I turned over in bed and it was like being hit by a hammer it was that sore and sensitive.

Participants explained that pain could have different meanings and was not universally undesirable. For example, pain during treatment was sometimes interpreted as a sign that the treatment was effective. Etna described severe pain throughout her body when

---

\(^8\) A bone marrow biopsy often refers to a bone marrow aspirate and/or a bone marrow trephine. In the case of an aspirate fluid only from the bone marrow is withdrawn, however, a trephine entails the removal of soft tissue from within the bone and, in adults, is usually taken from the iliac crest or back of the hip bone. A local anaesthetic is given and sometimes, sedation is also administered. A large bore needle, of sufficient diameter to obtain a piece, or trephine, of bone marrow tissue is inserted, often requiring considerable pressure into the patient’s iliac crest. A bone marrow biopsy is taken at diagnosis and repeatedly at various intervals (depending on local practice and individual treatment regimen).
she was undergoing stem cell mobilisation⁹ in preparation for her transplant. Emma explained that this pain was an indication that the bone marrow was working hard and was producing the desired stem cells: ‘pain’s good, pain’s good, it’s all worth it, it’s [the GCSF drug] all working, it’s good’.

Pain was a driver and focus of activity. Managing intense or gruelling pain usually took priority over all other activities. Participants described how, at different times in their illness, their pain determined their choice of activities, how long they could participate in them, and in what manner. For example, Fred enjoyed gardening but found he could no longer sit on his haunches to weed, thus the pain drove him to find another way of weeding.

Pain medication was prescribed to be taken at regular intervals of 12, six or four hours, and these periods determined the amount of time that was allocated to activities, especially if the activity occurred away from home or somewhere where there was no access to pain medication. The experience of pain and the schedule of pain medication frequently dictated when activities could occur, as Kira explained during our first interview:

I’m on Oxycontin [a heavy-duty pain killer] and that’s 12 hours apart, so the nine o’clock is the first time I take the morning one, nine o’clock at night is the evening one. And if I’m awake before then, which most mornings I am, mornings are pretty good for me, it’s evenings that are worse. Usually around about 6.30–7.00, I need some breakthrough [medication] at night, I’m worse at night.

If participants had visits or outings they wished to attend, they planned their medication around them, sometimes taking painkillers early and sometimes taking extra analgesia to ‘get them through’. The event had to be planned around the medication and the medication schedule had to be incorporated into the activity plan.

⁹ See chapter one, page 21
Thus far, I have discussed five aspects of the experience of myeloma: living with the effects of treatment (especially steroids), living without enough sleep, living with fatigue, living with neuropathy and living with pain. I have presented the effects of myeloma and treatment that participants talked about most frequently and in most depth, as discrete sections for clarity. However, they were not discretely experienced and participants experienced them all most, if not all, of the time. Effects were often contiguous and synergistic. For example, when Kira went to the toilet she explained that she would often fall asleep due to her fatigue and the sedative effect of thalidomide. In addition, she was oedematous as a result of the steroids, and this contributed to restricting the circulation to her feet when she sat on a hard toilet seat. She had limited feeling in her feet and lower legs because of the effect of peripheral neuropathy, which was caused by her treatment. When she awoke and attempted to stand, she would invariably fall as her feet had ‘gone to sleep’ due to the reduced circulation and she was unaware of this as she was unable to feel any sensation in her feet due to the peripheral neuropathy.

As well as describing these symptoms and side effects, participants also interpreted their experience by referring to biomedical markers or numbers.

Living by numbers

As well as describing their illness experience, participants talked about their biomedical markers or numbers. The number most frequently referred to was the level of paraprotein in the blood, but participants also talked about the protein in their urine or their white blood cell, stem cell or haemoglobin levels.

These numbers were a manifestation of the objective medical gaze [426]. The medical gaze is a way of looking into the hidden confines of the body. It takes the form of numerous tests including tests that are general in nature (e.g. blood counts) and tests that are specific to myeloma (e.g. paraprotein levels). The results of these tests are expressed as numerical values. For example, a total white cell count of $0.5 \times 10^9/L$ would inform the patient that they had a low white cell count (normal is $4.5–11 \times 10^9/L$) and were therefore at risk of infection. This information might lead them to adjust certain
aspects of their daily activities to reduce their risk. Another example is that of the paraprotein level. An individual’s paraprotein level may be less than 30g/L and treatment may reduce it to less than 10g/L. The reduction would indicate that the individual’s treatment had been effective in reducing the amount of myeloma (or ‘tumour burden’). Subsequent measurement of the level of paraprotein would indicate whether the myeloma was stable (paraprotein measure remains the same), relapsing or progressing (paraprotein measure increases), or responding further to treatment (paraprotein level continues to go down).

Sometimes it was the absolute numerical value of a measure that was important (e.g. the white cell count) and sometimes it was the relationship of the level to the previous reading that was important. The latter was particularly the case with regard to the level of paraprotein. In addition to the paraprotein level and the white blood cell count, other numbers also helped participants to understand what was happening, for example, haemoglobin level, stem cell count (i.e. cells collected for haematopoietic stem cell transplant), blood glucose and the plasma cell count (which is a way of assessing the condition of someone’s bone marrow).

The numbers were important to participants with myeloma because they interpreted them in order to make sense of their experience and they were keen to learn the results of their tests. Harry was one of several participants who described the importance of the numbers for his life and his experience: ‘Every time, every time I go down and see the professor and have the blood tests here it’s an anxious week coming up to it because, depending on the results your life is going to totally change again’.

The numbers were also important to carers. Partners explained that they also needed to know what the paraprotein level was to understand how their loved one’s health really was. They also described their tensions and anxieties prior to appointments because of the meaning and implications that the next number would have for them.

\[10\] This is discussed in more depth in the section ‘risk work’ in Chapter 7: Work.
The level of paraprotein was the ‘number’ that participants referred to most frequently and they interpreted this test result several different ways.11

‘The number’ as an indicator of the quantity of myeloma in the body

Participants sometimes referred to numbers as an indicator of the quantity of myeloma in their body. In our second meeting, for example, Fred told me how he gained reassurance from being told that his level of paraprotein was static: ‘He always kept telling me that the blood test showed that my particular myeloma had halted, and that I was okay’.

Etna’s case illustrated just how much weight the paraprotein measure carried as evidence of malignant disease. Etna was asymptomatic when she was diagnosed, so both she and her daughter, Emma, had always found it difficult to believe that Etna had myeloma. In addition, neither Etna nor Emma had ever seen written test results, which further compounded their disbelief. However, Emma told me that seeing a report of paraprotein numbers would have held weight as proof despite Etna’s lack of any symptoms: ‘I’m hoping to god that someone’s looked in there to check that before we give this woman chemo she does have paraproteins’.

Similarly, for Harry, the numbers were the only evidence of disease throughout his trajectory of intermittent remissions and relapses: ‘No symptoms, as such, just the uhm, that’s always been the case virtually, that the paraprotein levels rise’.

Because the numbers signified the presence or absence of malignant disease, they indicated whether someone was in remission or whether they had ‘relapsed’. For example, John explained that he gained reassurance from his numbers to the extent that he needed his appointments to be told that he was ‘okay’: ‘I look forward to the appointments because of that. Because I can see now nothing has changed in my blood count or anything like that, it seems to be everything is alright.’

11 Living by numbers was a theme that arose early in the analysis. The schema that is applied here has been borrowed from the published work of Jordens et al (426), which built on Moore et al’s published work (427).
In other words, John could not rely on his own body to tell whether he was ‘okay’; only the medical gaze could tell him this with sufficient certainty.

‘The number’ as an indicator of treatment effectiveness

The numbers were sometimes interpreted as an indicator of whether treatments were effective or not:

They say that the reading, the blood things are quite good, so you can just go by that. Over the last two to three months of the lenolidomide, all the numbers were good.

(Celia)

The prognostic meaning of ‘numbers’

Participants accorded a prognostic meaning to the numbers. They could indicate, for example, whether one would survive until the next appointment. For Ivan, who had been living with myeloma for 10 years, finding out the number was the main reason he attended his haematology appointments, and he was evidently impatient to hear the results: ‘I feel like saying, get to the paraprotein that’s the main [thing], because you’re on edge. And if he says well it hasn’t crept up, it’s dropped a bit or something you feel like you’ve backed a winner, a big winner, it’s your life.’

In our first interview, David’s understanding of his myeloma, his health status, the success of his transplant, his prognosis, and how he was faring in relation to other survivors, were all related to the level of his paraprotein. These meanings were thus situated within a framework of numbers and ratios:

I was about six and a half originally and then it went to zero, whereas one lady that I spoke to … a few weeks back, her count was something like six and she was expecting it to come down but it went up to nine, and she was saying to me ‘What’s yours and what do you do?’ To be a success it (the transplant) had to just get [the count] down to the low single digits, but just to get it down to a minimum level that would give me that longevity of life.
Later, he explained how the numbers indicated whether he would live or die in the following weeks:

[I] had a situation last year at Easter where the protein had gone up and it was about 20, and I’m not sure if it had gone to 40, or it had gone from 20 to 40, or whatever. But it was either sitting on 20 or 40 and Dr X said well if it doubles again in the next month, I’ll give you four to six weeks to live. That’s the impact of a growing cancer count, but he knows from experience that at certain levels it’s going to kill you.

John also recounted how his life hung on a number: ‘Any time now my blood count can change. That is true. I mean I will be disappointed—no doubt about it.’

‘Numbers’ having a predictive meaning for treatment

As well as telling participants whether they would live or die, the numbers also informed about whether treatment would be commenced, stopped or changed. Rising numbers could mean that treatment was indicated because the myeloma had returned (or progressed) or, conversely, could mean that treatment needed to stop or change because it was not effective. Similarly, falling numbers could indicate that treatment could cease because it had been effective:

We’re in a situation at the moment where the protein in the blood after the transplant was down to about a reading of three and then just before Christmas it was up to 16 and last week it was up to 26. So now, we’re at a stage where they’re seriously contemplating treatment again. Just see what the protein levels are and then he’ll make a decision then.

In our second interview, Harry explained that he had recommenced treatment and described how the decision had been made: ‘The only thing that happened was that the paraprotein levels started to rise and they got up to about 36 I think. And so at that point the doctor [said] … Well it’s time [for treatment] again.’
Ivan was ‘putting off’ undergoing a second transplant and explained that the level of his paraprotein alone determined whether he would go ahead with transplant or not. Gary described the percentage of plasma cells in his marrow as the indicator that triggered the recommencement of treatment, and Clive explicitly described the numbers as something that ‘governed’ treatment decisions: ‘It depends on how my blood tests are, that’s the governing feature’.

In summary, the numbers—particularly the paraprotein levels—had several meanings for participants. They could indicate the presence or absence of disease; they could indicate whether the treatment was effective; they had a prognostic value both for life and as a predictor of treatment, and when the meaning of the numbers contradicted how participants looked or felt, a greater truth-value was accorded to the numbers.

**When the numbers and subjective experience disagree**

Sometimes the numbers told participants that they were ‘okay’ but this was contrary to how they were feeling. In other words, the numbers were not always in concordance with subjective experience. In such cases, more weight was usually given to the numbers, and participants discounted subjective experience. For example, at the time of our second interview, David had undergone a stem cell transplant two weeks previously and he was feeling extremely tired and weak. He tried to reconcile the non-concordance between how he felt and what his numbers said (in this case his full blood count): ‘I don’t know what the cause is, why I’ve got this tiredness if my counts are looking pretty good’. By questioning his tiredness rather than his blood count, David accorded more truth-value to the numbers.

Helen recounted how, at a time when Harry had been unwell with pain and severe fatigue, she had tried to resolve the non-concordance between Harry’s numbers and his apparent state of health. Like David, Helen gave more weight to the numbers than to ‘the way he [i.e. Harry] feels’:

> Just hanging on a result at the moment to see how many points he’s come down, because he had a reasonable chance. At least it was still going down, but it was only
three, and one thing I have to keep reminding myself is that just because he’s probably worse than he’s ever been, doesn’t mean, isn’t an indicator. Because you tend to think he’s not doing very well because he’s been so unwell. It could drop five points, the way he feels isn’t, and I have to keep remembering that too.

**Myeloma as a ‘category-defying’ illness**

Cancer is increasingly classified as a chronic illness and myeloma is often classified as a terminal illness. The participants operationalised conventional categories such as these in their discourse, but their experience did not conform to any one category. Myeloma was sometimes framed as a chronic illness because it was relentless and incurable, yet treatable. It was also framed as a terminal illness, because it was inevitably fatal. It was framed as an acute illness because critical (i.e. life-threatening) events could happen suddenly and without warning. Participants also sometimes said that they had no illness. They did not ascribe myeloma to any one category because their illness experience was dynamic and variable. The experience of living with myeloma thus appeared to transcend the categories that are commonly used to frame illness, and consequently myeloma was constructed as fluid, dynamic or amorphous. At any given time, it could be in several different categories, or in none. In short, Myeloma was constructed as a ‘category-busting’ illness.

**Myeloma as ‘no illness’**

Some participants were asymptomatic at diagnosis, and thereby experienced myeloma as ‘no illness’. They also experienced myeloma as ‘no illness’ when they were in remission, although most thought of themselves as ‘having myeloma’ even in periods of remission.

As mentioned above, Etna was asymptomatic when she was initially diagnosed with ‘smouldering myeloma’ and she was still asymptomatic when she was later diagnosed with ‘full blown’ myeloma. She described feeling some tiredness, but explained during our first and second interviews that she did not quite believe that there was anything wrong with her because she had no symptoms and had never seen a written report. She
also reported that she was in denial because she could not believe it: ‘I still can’t believe it, I think that’s why I said, I’m still living in denial. I cannot see really anything physical wrong with me … the kidney’s all right, the liver’s all right, and that’s everything all right.’

Etna’s daughter, Emma, also said she found it hard to believe the diagnosis, as her mother was not unwell and she had not seen any written test results either. However, the idea of her mother going through treatment without having any myeloma was too awful to contemplate. Emma explained this when I interviewed her one month after her mother’s stem cell transplant: ‘It’s still a bit weird and wonderful because mum’s never really had any side effects from it all, it’s just strange but I suppose they’re not going to make her do this if there’s nothing wrong’.

For Etna, there was clearly an ongoing tension between two truths: what her body told her and what the medical gaze told her.

David was also asymptomatic when he was diagnosed:

There was no clear indication that I had multiple myeloma or cancer. I had an annual company medical through my employer awards, there was a tiny circumvented blood in the urine, and apparently, I was slightly anaemic, not that I could tell that because I never looked at myself in the mirror to find out.

In his second interview, David explained that he no longer had myeloma: ‘the last blood count for multiple myeloma with the protein count, they found it absent, which was highly unusual to have no trace whatsoever of cancer … they’ve fixed me up now so I’ve just got to look after myself and get on’.

David also reported that he knew that myeloma was incurable. He thus framed myeloma as simultaneously ‘no illness’ and ‘terminal illness’.
Myeloma as an ‘acute’ or ‘critical’ illness

Participants described sudden, unexpected and sometimes catastrophic episodes of illness. Examples included an abrupt onset of infection or sepsis, or an unheralded fracture with no antecedent injury or event. For three participants, the experience of myeloma included sudden and dramatic yet paradoxically atraumatic fractures. Barry’s back broke one evening while he was reaching to switch off the television set. A couple of Ivan’s ribs broke suddenly and spontaneously one morning, and Kira discovered that a pleuritic pain in her chest was not due to a respiratory infection but to three fractured ribs.

Sudden overwhelming infection was another example of ‘acute’ illness experience. Anne had lived with ‘smouldering myeloma’ for 15 years and had been receiving treatment for a year when I met her. She told me that she experienced an overwhelming infection (sepsis) with a very rapid onset and course, and recounted her rapid transition from attending a writer’s festival to being critically ill in the intensive care unit (ICU):

‘Sitting on the wharf … having a pizza and a beer at two o’clock in the afternoon. Five o’clock … temperature and 12.30 that night had to call an ambulance and go to hospital … Monday morning they called my family in and said it could go either way.’

Participants often described their illness as sudden and acute episodes that occurred against a steady background of a chronic illness. They also described myeloma as chronic illness that followed an acute event.

Myeloma as a chronic illness

Myeloma was constructed as a chronic illness in four ways. It was chronic; 1) because it was relentless (it went on and on); 2) because it could be treated but not cured; 3) because death was not imminent (even though it was frequently perceived to be so at diagnosis); and 4) because participants ‘got used to it’ (i.e. living with myeloma became ordinary and familiar).
‘On and on like Burgess Paint’

Most of the participants did not know anything about myeloma when they were diagnosed, but they were soon told—or they soon found out for themselves—that it was fatal. They foresaw certain death within an uncertain but short time. However, as time went on, they came to understand myeloma as a relentless, ongoing illness rather than as a rapidly fatal one, and the prospect of more treatment filled the near future: ‘You feel you know is this what your life is going to be now forever’ (Kira).

Participants used metaphors to describe the relentlessness of myeloma:

- Just keeps on keeping on and on like Burgess Paint (Clive).
- It’s like there’s no finish line, it’s like it’s a race ongoing, it’s never-ending (Emma).

The exhausting, painful and life-altering course of myeloma contributed to its relentless nature. However, participants hoped for this to continue because the alternative was death. Ivan described his ‘mental suffering’ and the ‘toll on his nerves’ that this hope had caused him since he was diagnosed:

But you’re going for, in my case nine years and that has got to take an effect on you mentally … Of course it goes on and in my case. On and on and on. People don’t realise that your nerves have got to take some sort of an effect on that because it’s going on and on and on, what I’m saying is it goes on and on and on every day, month, year, again hopefully it keeps going.

Incurable but treatable

After a period of initial uncertainty and anxiety, living with myeloma became not only possible but also expected. All participants described myeloma as ‘incurable but treatable’ often with particular reference to newer drugs and developments in therapy,
and its treatability apparently made the incurability manageable. Brenda’s description epitomised the chronic nature of myeloma as a disease that was accommodated and managed: ‘It’s not a curable disease but we can control it, we can treat it’.

Such was the chronic nature of myeloma that Brenda, in her second interview, informed me of Barry’s relapse in a way that normalised his myeloma: ‘Actually he’s really good. I don’t know if I told you, like, the cancer [is] back again?’

_Death no longer imminent_

When they were first diagnosed, participants typically viewed myeloma as a death sentence and the anticipated death as being imminent. However, over time, they shifted from seeing it as rapidly fatal to seeing it as fatal but not in the immediate future. This contributed to their perception that it was a chronic disease. Helen described how she and Harry spent the first four years after his diagnosis waiting for him to die, and how this perception had changed: ‘I guess we finally came to the realisation that, and this is very brutal but, Harry’s not going to die now … And since we’ve been able to say that, we’ve been able to live again.’

John explained that initially, despite having pain, he had not sought pain control because he did not think that he would be alive for much longer. He later changed his mind as he realised that death was not imminent: ‘I didn’t expect to last as long, put it that way’.

_Getting used to it_

As participants ‘lived on’ with myeloma and accommodated the effects of both disease and treatment into their everyday lives, they got used to it; it became ordinary and familiar to them. As Kerry put it: ‘It just becomes a part of everyday life … It’s not—this is our lives but mum has cancer, it’s—this is our lives’.

According to Celia, the routine associated with Clive’s myeloma had rendered it ordinary and familiar. She contrasted the everydayness of myeloma with the difficulties
associated with Clive’s visual impairment: ‘With just the myeloma it wouldn’t be, it’s not the problem now, the problem is the sight. He’s got it, he’s on treatment, we follow a routine for treatments, for taking pills and stuff and coming up here and just do what has to be done that’s all.’ According to Clive, myeloma receded into the background of the ordinary and familiar so long as he felt well: ‘So as long as I’m feeling reasonably well, when I say reasonably well, as well as you can be when you’ve got the condition that I’ve got. I don’t think about it.’

Emma described myeloma as being ever present but ‘dormant’ or situated in the background rather than the foreground for experience:

> It [the treatment] may not kill it [the disease] off in its entirety. It may still be there and then it just may lay dormant.

Over the course of three interviews, Fred evidently became increasingly used to having myeloma. At our first meeting, he told me how he vacillated between thinking about it and not thinking about it, and he wondered if he would get used to it: ‘With the myeloma, I can think about it and I don’t think about it, it doesn’t really—I mean maybe you get used to that you’ve got it.’ Six months later, at our second meeting, Fred said that he was getting used to his reduced energy levels, stamina and ability to do things around the house: ‘I’m probably getting used to what I’m feeling now which is not 100 per cent. But I think I’m getting used to being that way … so therefore I feel a little bit more relaxed about the fact that I am like that.’ At our third meeting, Fred’s myeloma had faded further into the background of his life: ‘It doesn’t really come to mind to me very much anymore. I’m pretty good.’

John told me how living with myeloma was part of his life, rather than an entity to be fought. He discussed how, since he was diagnosed with myeloma, he no longer believed that there was such a thing as ‘putting up a good fight’ and that the war metaphors associated with cancer were not part of his experience: ‘I always thought that if I go

---

12 Clive’s impaired vision was due to a blood clot thought to be caused by one of his treatment medications (thalidomide).
down I will fight it … But then again you don’t have to fight it, it’s just a natural way of life I think.’

**Myeloma as a terminal illness**

Myeloma was constructed as a terminal illness in two different ways: as imminent and sudden death, and death that would occur certainly but in an uncertain time. In both cases, death was acknowledged and understood as the certain end of the myeloma trajectory—what changed was the length of the trajectory. Even if the person with myeloma had accepted their illness as a ‘terminal’ one, their partner or carer sometimes struggled to accept this.

One of the existential difficulties experienced by the participants was that of facing their mortality. The certainty of death was no longer abstract and impersonal: the diagnosis of myeloma entailed the unshakeable certainty of their own death.

*Myeloma as sudden and imminent death*

Death was constructed as an end that could occur suddenly and because of an episode of critical illness. It arrived, unforeseen, looming large on a foreshortened time horizon, with no possibility of avoiding it. Anne’s account of her episode of acute illness highlighted also how her death was suddenly an imminent and very real threat: ‘Monday morning they called my family in and said it could go either way. So that was very, very scary. And I guess that was the first real scare I’ve had … you can be here today and gone tomorrow.’

David explained that he had been critically ill during his transplant and had not remembered the events surrounding his rapid deterioration and admission to ICU. He reflected on how he felt on learning of his close brush with death during this episode of acute illness:
When he [the doctor] said I ‘did a Lazarus’, that drove it home and that threw me out a bit mentally. For the next few nights I would lay there at night thinking what’s it like to die if I was that close.

Delia described the same episode as follows:

In a couple of days, three days he was back up there right and then went down again and that particular night we were called in at about five o’clock and told no, not that he’s not going to make it but the next 24 hours, 48 hours um were critical.

Helen, Harry, John and Kerry in particular explained that when they were diagnosed with myeloma, they expected it to be fatal within a short period. Brenda described her thoughts on first hearing Barry’s diagnosis: ‘You think about my husband he’s going to die, and ‘What am I going to do with my kids?’, and ‘What am I going to do with my life?’

Helen said she spent the first four years after Harry’s diagnosis waiting for him to die. During this time, they struggled, isolated themselves from family and friends, drank and fought with each other:

So we only had each other and of course people I think assume that when something like this happens you cling on to each other, but it actually is very destructive and it does quite the opposite I think.

While the threat of death from critical illness never abated, and while death remained a certainty, it gradually ceased to be anticipated as imminent, and instead became something that would occur ‘some time’ in the future.
Myeloma as ‘certain death in uncertain time’

Fred summed up this meaning neatly as follows:

You know what you’ve got; you don’t know how long (Fred).

According to Emma, death ceased to be an abstract concept that happens to everyone, and changed into something very real that was happening to her mother. She used the metaphor of a ‘countdown’ to differentiate between these two constructions of death. Although the time of death was uncertain, it was not anticipated as being in the immediate future:

I now refer to it as a terminal disease. It will one day end her life … We all know we’re going to die but this is like the egg timer was flipped—I don’t know how to explain it, it’s like a stop-watch was started. That’s how I explained it. We can all die but we really don’t know when. But I feel like in mum’s case it was like someone turned on the stop-watch and one day it’s going to switch off. That’s the difference.

Kira and Ivan both said they knew that they would die of myeloma. The certainty of death in uncertain time was ever present, even if it resided ‘in the back of your mind’:

I try not to think about timeframe, because really you can’t with myeloma. It’s different for everybody. But that is somewhere way back in your mind it’s there, it’s a fact so you have to be realistic about it. I know for a fact that this eventually is going to kill me (Kira).

Fred and David described how the certainty of death could create a paradox. The certainty allowed Fred to organise and close his business overseas:

It gave me the chance over there to do everything I had to do. Now there’s nothing over there that the family has that’s not set, that they have to worry about. So that’s fine.

13 Having time to do things is discussed in depth in Chapter Eight.
However, for David, the certainty of death created uncertainty about how to make best use of the time he felt he had left:

I have this I suppose slight … confusion, dilemma as to whether I should be doing it, should I be thinking of retiring or carry on with life as per normal given that I’ve got inoperable cancer.

Carers described how hard it was for them to live with the knowledge that myeloma was a ‘terminal’ illness, and they described different strategies for living with this knowledge. Sometimes life was made tenable only by blocking it out:

He always says to me you’ve got to prepare me for when things happen. And I don’t want to hear about it. I just block that out (Jane).

Sometimes it’s hard because … you can see things a little bit ahead. We try and say this and what’s going to happen, and then I stop straight away, I say ‘No, I can’t deal with that, I’ll deal with that later’, you know, and I stop (Fatima).

Although Kerry understood that myeloma was treatable and that the treatment was effective in controlling her mother’s disease, she lived every day with uncertainty about her mother’s survival:

I suppose in regards to the fact that she’s gone all this way, she’s had treatment but you still don’t know, sometimes I think even though she’s been treated and she’s on medication, I sometimes think I’m going to wake up and she won’t be awake. I still think that.

Relentlessly ‘hard’

Etna, Gary, Ivan and David characterised myeloma as an experience that was hard: it was hard to keep going and it was hard to face death. Delia, Helen and Kerry told me that the experience was hard for them for three key reasons: managing changes in
relationships, managing changing priorities, and facing the prospect of losing a loved one.

During our third interview, I was at Etna’s home and the children entered the room laughing and chattering having returned from the beach with Emma. Just after this, I asked Etna if there was anything from her experience that I needed to know to understand about her experience of myeloma. She looked around and towards the door where the children has entered the room and simply told me that it was ‘hard’.

Gary continued to work shifts throughout much of his treatment and he was frequently called in to do overtime on his days off. Throughout our three interviews, he consistently told me how he could manage his myeloma and treatment and still work effectively. However, he also told me that this was a struggle: ‘To come to work all the time, trying to do things you know you take the tablets and go to work, you’re tired again, it’s hard to manage it’.

In our first interview, Ivan described how he enjoyed going to the club and occasionally to the shops. He was unable to talk to me at the time that the second interview was scheduled because talking about his myeloma put it in the foreground and he said that it was too hard to talk about. I called him again around the time that the third interview was due, and he agreed to speak to me again. At this time, things had changed and he said that he went out much less and felt trapped in a difficult situation with no escape: ‘You feel like at times that you're in the ring with a fighter who’s punching hell out of you and you can’t get out of it, you know’.

Partners of participants with myeloma described their hardship in living with myeloma. Delia explained that her relationship with David had changed. She described how David had previously always been in charge both at work and at home. She described him as a capable man who looked after his wife and family, very much as the head of the family. However, following David’s diagnosis, Delia struggled to manage both her own needs and David’s response to the changes in their relationship:
I feel there is resentment there as well. I’m going out, I’m going to work, I’m coming home, I do dinner and he just tries to do something and he’s just too tired to do it and then he feels [he’s] useless type of thing, so he thought that he can’t do anything right.

Helen explained that she hoped for an escape from the relentless toll of living with myeloma: ‘such a burden isn’t it, to go through this’. She described hoping for ‘a bit of emotional freedom’ from worrying about Harry’s health, and how he felt day-to-day, moment to moment. She explained that she needed ‘emotional freedom’ to ‘be able to function again’.

Kerry described the difficulty of managing her time to fulfil her roles as daughter, sibling and fiancée. Her roles as sibling and fiancée often took a back seat to her role as her mother’s carer:

When I’ve got free time, I’m constantly going to see my dad and then my brother and sister and trying to catch up with them, so it’s just really hard. I sometimes find that I don’t have the time to organise a wedding.

Negotiating the struggle of living with myeloma took effort and work, and this is discussed further in the Chapter Seven.
Chapter Seven: Myeloma as Work

Introduction

Living with myeloma required effort, planning and organisation. Treatment generated busy schedules that needed to be ‘fitted in’ around the demands of others, in the domains of family, job and the health care system. Activities of everyday life took more time and effort than they did before. Juggling domestic, leisure and health care activities came to require organisation and thoughtful planning to make the best use of time and energy. Starting the day was no longer a seamless flow of activities that blended one into the other; it became a series of discrete events, each of which required planning, organisation and exertion. Participants described the attention to detail and planning that was required to undertake what were—prior to myeloma—everyday, taken-for-granted activities.

Myeloma both created work and affected existing work. A great deal of work was added to the day’s activities by the demands of treatment schedules, hospital visits, and drug regimens. Since myeloma reduced the capacity of study participants to accomplish routine tasks (e.g. taking a shower), they required much more effort than they did previously. Finally, some participants left their employment and thus work in this sense was reduced.

As well as expending more effort on the activities of daily life, participants explained how they constantly had to remain vigilant about threats to their well-being. They described how they ceaselessly evaluated and managed risks. This self-surveillance was incorporated into their everyday activities and into the processes of organising and planning them. Over time, participants gained experience and expertise managing the symptoms of myeloma and complications of its treatment, and they integrated these efforts and achievements into their way of living. This is particularly apparent with regard to the effects of fatigue, immune suppression and peripheral neuropathy.
Living with myeloma required emotional and physical effort, and managing emotions demanded exertion. Participants told me how they managed their own emotions, and the emotions of others, to maintain their own sense of wellbeing and close relationships.

Living with myeloma also required organisational skills. Participants described how busy their days and weeks became. They frequently needed to consult with a range of different specialists. Each consultation generated appointments for different diagnostic tests and treatments, and these appointments needed to be organised to optimise use of both time and energy by minimising the number of trips to the hospital. Participants learned to navigate efficiently, how to travel to different treatment centres, where to park when they arrived, and how and where to obtain information. This all required organisational skills that can be characterised as essential competencies for living with myeloma.

The definition of ‘work’ in the Oxford English Dictionary aptly describes how participants constructed their lives with myeloma:

Work maybe defined as noun in reference to any action requiring effort or difficult to do or described by the verb labour as to exert oneself, strive (for some end); to endeavour strenuously (to accomplish or bring about something) [427].

The ‘something’ that participants were striving to attain was to live with the restrictions, uncertainties, impositions, disruptions, adjustments, insights and innovations demanded by myeloma. In my analysis I found it useful to distinguish between four broad categories of work: knowledge work, health work, emotion work and organisation work.

Knowledge work involved obtaining information, evaluating information and disclosing information. Informing others about diagnosis or relapse were tasks that required particularly careful planning.

Health work was work relating specifically to the body. It comprised work relating to risk and mitigation of the impact of myeloma. Risk work entailed evaluating and
managing the risk of three different types of harm: infection, injury, and anything that might compromise the ability of a significant other to continue in their caring role. Mitigation work refers to work that was undertaken to both mitigate and manage present and potential complications of treatment and disease. Mitigation work was what participants did to allay the impact of complications and potential future complications and integrate restrictions and limitations into daily life.

Emotion work was the third major type of work and it concerned both the participant’s own emotions and the emotions of other people. Participants tried to manage what they felt and they tried to manage how others felt.

Finally, organisation work was undertaken primarily by the person providing support. It included organising and coordinating appointments, which often involved juggling multiple treatments, specialist consultations and other appointments in the day or across the week and in the context of family and social life together with the complexities of new demands in financial management. Figure 5 provides an overview and illustrates the relationships between the four kinds of work.
Knowledge work

Knowledge work had three foci: obtaining and evaluating information, filtering information, and disclosing information. Information became knowledge to participants as they evaluated, synthesised and contextualised it. This enabled them to make sense of their own situation.

Most participants endeavoured to obtain information and did so most frequently at diagnosis. Most participants had not heard of myeloma before they were diagnosed and some were informed of their diagnosis by general practitioners who, they said, possessed limited knowledge about the disease. Participants initially gathered information from a variety of sources including other people affected by myeloma, health care professionals, the internet, and printed information. Over time, information
was synthesised with experience to become a form of expert knowledge. Evaluating information was integral to knowledge work. Participants explained that they were discerning in their use of information and evaluated its accuracy according to whether it was supportive and concordant with their own experience, and thus accurate.

Disclosing information involved gate keeping. Sometimes the gatekeeper was the person with myeloma, who sought thereby to protect the family from threatening news. Sometimes it was the partner or significant other, who sought to protect the patient. Disclosure work was thus undertaken both by people with myeloma and by their significant others. The process was often complex and carefully considered and managed. Usually, more care was taken in interactions with extended family and acquaintances than with closer friends and immediate family members. Disclosure carried an emotional toll, thus it required emotion work as well.

**Obtaining and evaluating knowledge**

Participants learned through experience which sources of information were trustworthy and relevant to their situation. Emma described how she initially went to the internet seeking information when her mother was diagnosed, but found that the information she came across was frightening and increased her anxiety. She explained that her initial searches on the internet always listed drug company sites first and that, through experience, she learned to evaluate what she found and that she had to scroll down to find sites that she trusted, such as the Cancer Council and Myeloma Foundation sites.¹⁴

Participants explained that basic diagnostic and prognostic information provided to them by clinicians (e.g. that they had myeloma and it was life-threatening) and information gleaned from other sources such as internet sites sometimes did not correlate with their own experience. This disjunction between expert biomedical knowledge and the participant’s own experiential knowledge sometimes added to confusion and anxiety. Etna described how the information the haematologist gave her at diagnosis – that she had a life threatening diagnosis of myeloma and required

¹⁴ The Cancer Council and the Myeloma Foundation of Australia are both non-government, non-profit organisations that provide information and support for people with myeloma (and other cancers).
treatment with chemotherapy – did not fit with her own symptomless experience. In other words (as I described in the previous chapter), there was non-concordance between the evidence of her experience and the evidence of the medical gaze.

Harry explained that initially his sister had searched for information and provided him with reams of information from the internet, but it was not until later that he was able to read and contextualise this information about his disease and make sense of it for himself. Eventually he came to think of himself as an expert:

Talking to people in the hospital and such, I probably know more of what it’s about —the disease—than a lot of people, because initially I had a look at it and my sister did a lot of research … All these pages that she downloaded from the internet, I read the first page and then discarded it.

The timing of information delivery was important. Participants told me how it was important to control what information was delivered and when. In her first interview, Etna told me that she did not know what information she wanted. A year later during the third interview, she said that it was only then, two years after her diagnosis, that she wanted more information: ‘Before even I didn’t want to read, I didn’t want to [know] … Nothing. Now—Yes, I do want to know, I do want to know.’ Other participants also expressed confusion and uncertainty as, over time, they discovered that they wanted to know only so much and no more.

Gate keeping involved regulating what information was shared with others and for carers this included the person who was diagnosed with myeloma. It also involved evaluating that information. Gate keeping work often fell to the carer, who shouldered the bulk of the information work, which involved seeking, analysing, synthesising and transferring information:

But I know Emma does a lot of research and talks to her sister and her father but they don’t say anything to me unless I ask. But then they always say bits and pieces and that’s it (Etna).
Myeloma support groups were described as providing both support and collegiality as well as information from both health professionals and from other members of the group. Some participants talked about the role and value of support groups. One found the support group immensely beneficial and was active in her attendance. However, the majority of participants said that myeloma support groups were confronting rather than supportive. Some expressed a fear of seeing others with myeloma who may be unwell or deteriorating with more advanced disease\textsuperscript{15}. Support groups thus confronted them with the prospect of a frightening future. Jane and Fatima, who were carers, told me they would have liked to attend but felt unable to as they felt it might upset their partners. Some participants saw a support group for carers as having potential benefit.

As participants gained experience living with myeloma, they learned to live with restrictions imposed by myeloma. They synthesised and contextualised the information they obtained from various sources to turn it into knowledge that was useful and applicable to them. Figure 6 illustrates how participants combined different kinds and sources of information to produce knowledge.

\textsuperscript{15} A similar finding was recently reported in the gynae-oncology setting (428)
Participants consistently said that ‘learning to accept’ was one of the key things that enabled them to ‘get on with it’ or live with myeloma. It was seen as important to learn to accept ‘the way things are’ and to accept ‘your limits’. Understanding their limitations enabled them to develop ways to work around them. For example, Fred was a keen gardener prior to diagnosis, and at our first meeting he told me that he could no longer look after the garden and that he was unable to weed or mow the lawn. At our third meeting, 12 months later, he explained how he had ‘found other ways of doing things’. He described the change in his weeding technique:

The weeds, I manage to get the weeds … I find I don’t get down on my haunches, I actually bend over to pull the weeds, I don’t have to go down on my haunches now I can’t but I’m capable of bending over to do it still.

Harry ran his business from home, and continued to do so throughout his treatment, primarily because this was the family’s main source of income. He described how he
learned to manage his fatigue and continue to run the business by changing the way he did things:

I am doing things differently now, using the internet probably more and sending things out via couriers and such, more so than handing out samples and that sort of thing. So just changing the way I’m doing things as well.

When I first met Kira, she was struggling with pain, fatigue and neuropathy in particular, which were combining to make life extremely difficult. At her third interview, Kira explained how she had accepted the limitations of her own capacities and drawn on her experience to reduce the impact of these complications: ‘I’ve learned acceptance of everything more and probably created a little world of my own in a way that’s easy for me to live’. Experiential knowledge was a key source of knowledge in knowing how to negotiate living with myeloma as an individual, and therefore, unique experience. Information and experiential knowledge were often combined in disclosure work.

**Disclosure work**

Disclosure work involved evaluating information about the experience and health status of the person with myeloma and acting as its gatekeeper. Both carers and patients assumed this role, and it changed over time. Managing disclosure meant deciding who was told what and when they were told. Participants said that initially they could not talk about the myeloma because they did not know what to say or because the emotional toll on the discloser and the disclosee was too great, and they feared being treated differently. Some participants left disclosure to other family members because at first they found it too difficult.

Because disclosure exerted an emotional toll, it required organisation and planning. Carers frequently undertook this work. Emma told me about her reaction when her mother was first diagnosed: ‘Couldn’t even talk about it, not talking about it, not telling anyone. Mum can’t talk about it, Dad can’t talk about it. Mum just gets upset and all in a mess and Dad was in denial.’
Initially, Emma had to act as a messenger between Etna and her extended family members and as a gatekeeper and organiser of information. For example, she described how she planned to disclose her mother’s diagnosis to her aunt’s family. She intended to manage the emotional toll by speaking to her aunt in advance, on the phone:

Then [I told her] on a big hour phone call that morning before we visited and I was so glad I did that because the kids were still in bed. Her kids were doing whatever they were. They’d just gotten up. I mean, imagine trying to talk while the kids are playing about us! Then when her sister rolled up and the kids were in the pool. ‘Good’, I said I didn’t really want to have to like in front of the kids. And while the kids were in the pool I explained to her a little bit more because sometimes you don’t want hearsays, you want the full story. So, I sort of sat down and spoke to her.

At first, Etna herself was not able to talk about her myeloma: ‘like I didn’t talk to anybody, so Emma had to do all the talking’. At her third interview, though, Etna told me that she had come through depression, which she called ‘a very dark place’. Following this experience, she was able to talk about her myeloma and about how she felt:

I used to get angry and upset when somebody asked even how I was. But now, it doesn’t bother me—they just say how are you and I will be the one to tell you that this week I was such and such and you know I was better than last week, or last week was better than this week you know it depends you know how I feel. Before I couldn’t do that, I would say: ‘oh, I’m alright’, and that’s about it.

At first, Harry insisted that other people were not told about his condition, including his three children, who were all in their twenties. He that he found disclosure difficult because of the anticipated impact the news would have on them:

The hardest thing was telling other people really and we didn’t tell anybody at all, not even our kids for probably two years or so … That was more I think instigated from Helen because I thought at that stage that I was still going okay, but it seems they could see something was wrong.
When Harry finally agreed that the children should be told he had myeloma, he went away for the weekend and left Helen to tell them. Not telling the children was evidently a source of immense tension between Harry and Helen:

He said: ‘I’m going to Canberra. You can tell the kids while I’m gone.’ … He couldn’t tell them. He couldn’t tell any of them. One time he just went away for three days and didn’t come back, and it was terrible (Helen).

Clive had a very different story to tell: ‘there’s no secret—oh no, it’s pointless in making a secret of it, gee’. However, Celia, Clive’s wife, mentioned to me that they had not told members of the extended family. They had disclosed his illness to their friends, with whom they often travelled, and to their two sons.

Disclosure was difficult for all participants. It often involved planning, it always required effort, and it took an emotional toll on both the discloser and the disclosee. The burdens eased over time for most, but new bad news, such as relapse, imposed the same burdens anew. Attempts to limit the emotional toll of disclosure, however, did not always go according to plan. Kira lived alone and was divorced. She tried to disclose her diagnosis to her three children in a way that was as supportive as possible, so she planned to get them together and tell them in person. She was unable to get them together, however, so when she could wait no longer, she told them individually on the telephone:

I really didn’t want to do it that way but they were just so busy at the time without realising I had something really important to tell them. I couldn’t get them all together you know. It just didn’t work out that way. I didn’t get the opportunity so in the end I just rang them all. I told them each individually on the phone and it really was the worst thing I could have done.

When organisation and planning failed, it could add to the emotional toll of disclosure, but the participants learned from their experience about how to manage disclosure in the future.
Health work

Participants undertook two kinds of health work: reducing risk and mitigating the impact of complications and restrictions on their life due to the effects of the myeloma and its treatment.

Risk work included vigilance (or self-surveillance), risk evaluation and risk reduction. Each of these factors informed decisions about what people did, when, where and with whom. Risk evaluation also required knowledge and experience. As people gained relevant knowledge and experience, they also gained confidence in decision-making. This confidence reduced uncertainty, although never completely, and it could be torn down without notice.

Mitigating the impact of complications and restrictions often required collaborative work with health care professionals and other organisations such as those in the not-for-profit sector, specifically the Cancer Council, Myeloma Foundation of Australia (MFA) and the Leukaemia Foundation.

Reducing risk

Participants strove to reduce the risk of harms to health. The harm could be physical or emotional. Much effort was devoted to reducing the risk of infection that was posed by immunosuppression, which could be an effect of both disease and treatment. Reducing risk included evaluating and managing the risk of injury, as this was a significant feature of participants’ lives as they learned to navigate the impact of peripheral neuropathy, fatigue, sedation and fragile bones. Carers and significant others had to manage risks that were specifically pertinent to them, such as balancing their physiological and psychological wellbeing with that of the family and of the person with myeloma.
Risk of infection

Risk of infection was a constant companion because each participant’s immunity was compromised due to impaired immunoglobulin function (caused by the disease), and reduced white blood cell count and function (caused primarily by some treatment regimens). Participants were aware of the risk of infection and they made decisions accordingly, as did their families. For example, Anne, who was a nurse by profession, described the precautions she took, and how she synthesised and applied her prior learning and expertise to her new situation:

A couple of times if I’ve got a fever, it’s probably got nothing to do with the food, but I don’t think I want to eat any Asian food at the moment and I boil my water to drink. I guess the reason I did it probably more so because I was at risk of infection, but also because of the dam, and the rain, and the wall collapsing.  

As the above quote suggests, consideration of risks took external (i.e. social and environmental) factors into consideration as well as internal factors such as compromised immunity. At times, participants were categorical about the risk of infection due to their impaired immunity and acted on it by taking precautions. However, at other times, such as during or immediately post-stem cell transplant or during immunosuppressive treatment, participants also took increased preventative measures according to their degree of risk, which were proportional to their likelihood of infection.

Balancing physical and emotional risks

David was in hospital undergoing treatment with chemotherapy when I first met him. He was neutropenic at the time, and isolated in a single room in the haematology unit. He told me about how he assessed his need to see his wife against his desire to reduce life-threatening risk. In his effort to reduce risk, David prioritised the reduction of

---

16 A portion of the wall to the city’s dam collapsed a year earlier requiring city water to be drawn from alternative sources for a short period
17 Neutropenia is the state of having a greatly reduced number of neutrophils. Neutrophils are a type of white blood cell required in the body’s initial response to infection.
physical risks, which was a priority for him at that time. His decision also involved considerable emotion work as he valued her presence to support him: ‘It doesn’t help that my wife is in bed at the moment with, um, her throat is sore and coughing, she’s coughing, so she can’t come and visit me. I have to be careful, you know.’

David had previously worked in risk management for a large food retailer and he explained how he needed to understand biomedical information to be able to assess the magnitude of his risk effectively in his new situation. His efforts to reduce risk demonstrate how he assimilated the medical gaze:

As far as the blood counts go, with the white cells, because that’s your immune system, relates to the white cells and infections, well I want to know can I get out and about and not worry about picking up infections from other people. So by knowing what my counts are gives me some indication, the knowledge of where I can go and what I can be, out and about travelling on a plane or whatever.

Efforts to reduce risk were undertaken not only by those with a diagnosis of myeloma but also by those around them.

Emma told me about an occasion when her four-year-old son had a throat infection. She had no symptoms and felt well at the time, but she evaluated the potential risk to her mother, Etna, and took evasive action by isolating herself and her son:

I think he had a throat infection and I went ‘I’m not going anywhere near her’. Usually when he gets it, I get it, no one else, just him and I always seem to be prone to throat infections, so I quarantined ourselves (Emma).

I want to travel, I want to do a lot of travelling. Now in David’s position, until he’s right, he can’t travel because his immune system has got to come up, otherwise he’ll pick up everything that’s going and that will be terrible (Delia).

As the above quote from Delia suggests, partners often prioritised risk reduction over their own leisure activities. They also prioritised it over their own health problems.
During the study, one partner was diagnosed with colorectal cancer, one with breast cancer and one partner required urgent surgery for a severe intermittent claudication. All three prioritised the risk to their partner’s wellbeing over their own health needs by describing their own diagnosis and treatment as less important than that of their partners’ myeloma and by delaying surgery. Thus, the risk to their own wellbeing was accorded lower priority.

Information about how to reduce risks was gleaned from health professionals and a variety of other sources including the media, friends and family, and non-profit organisations. Barry described how, at the time of diagnosis, he had been advised by a friend to visit an alternative health practitioner who gave him a ‘bag of herbs and dead spiders’. He explained that he later changed his mind and did not return to the alternative practitioner having considered the risk that the disease would progress for want of effective treatment and the risk of harmful effects from ingesting the herbs. He said that the choice was presented to him as an either/or choice between Chinese medicine and Western medicine:

I consulted Professor [X] about them first and he goes you’re either going to leave your life in our hands or their hands. And I thought you hear more success from the hospital than what you do these herbal doctors so I just left them aside.

Perceived risk did not always correlate with biomedical evidence but it informed decisions nonetheless. Etna was asymptomatic from diagnosis. Her extended family was in Southern Europe. She felt unable to travel to see them even though she felt quite well. She told me that she wanted to travel to her homeland and visit her family but she felt that the risk (of her myeloma relapsing or progressing) was too great and explained why:

Because a lot of people keep saying when you have cancer and then you go on the plane, it will bring it back again.

---

18 A symptom of severe arterial peripheral vascular disease.
It was evident that many carers desperately wanted to reduce risk to the person with myeloma. Even though Emma had evaluated her mother’s risk of infection in the light of her individual context, and was following expert medical advice, she wanted to do more to protect her mother: ‘If I could put her in one of those little spacesuits I’d be really happy … You know those astronaut suits, like the little bubble boy. I’d be really happy if I could do that to her.’

Immune suppression and the risk of infection placed people on a tightrope of uncertainty. You could be ‘here today and gone tomorrow’ with no or very little warning, as Anne explained in her first interview. Without immunity, a taken-for-granted protective shield had been stripped away, leaving the person with myeloma feeling vulnerable to the slightest microbe. This vulnerability had a devastating impact and their families frequently felt impotent to protect them. Thus, risk evaluation, vigilance and management of reducing life-threatening risk, assumed paramount importance.

*Ordinary activities can cause extraordinary injuries*

Given the physical limitations imposed by myeloma (e.g. fragile bones) and the complications of the treatments (e.g. neuropathy), managing the risk of injury was an important task when it came to optimising quality of life. This demanded vigilance in everyday activities and, as was the case with reducing the risk of infections, knowledge gained through experience was valuable in this respect. Previous experience helped people learn what to be vigilant about. For example, Fred was a keen gardener and enjoyed using engineering skills in jobs around the house. He described how pain, weakness and sensory loss created physical impairment, which restricted his abilities. His risk work changed during the course of the study. He came to understand his limitations and learned how to live within them by drawing on expert advice, experience and, later, a synthesis of the two. In our first interview, he explained how he assessed risk with information given to him by the doctor: ‘I mean a simple thing like the lawn mower, pulling the rope, well I’ve got to be careful when I do that. As the doctor says: “be careful because it doesn’t take much for you to fracture a bone you
know”. So that’s it, I can only do a certain amount.’ Six months later, in our second interview, he told me how he had learned from his own experience of pain:

You know your bones are what they are and you feel some pain if you try to move or jerk or do things, and you sort of think about those things and say ‘jeeze’, you know you feel like doing things but you just can’t do them.

One year from when we first met, at our third interview, Fred explained how he assessed risk by synthesising biomedical information and his experience of fractures: ‘I mean, I think I’ve got a few hairline fractures as it is. I’m very careful when I step into the shower, worried about maybe slipping you know, because thinking what my bones are like I, the last thing I want is to slip over and break a bone or whatever.’

Ivan used to enjoy running to keep fit. The first indication for him that there was anything wrong was when he sustained spontaneous pathological fractures of his ribs. Following this experience, he said that he curtailed any fitness activity and became mindful of his bone strength and vulnerability.

Peripheral neuropathy posed a risk of injury, particularly to extremities such as toes and fingers. It causes a number of complications such as ataxia and instability, difficulty gripping things, and a lack of sensory perception. This set of complications was a recurring problem for Ivan. He described how his neuropathy caused him to drop a cup of hot tea, spilling the contents on his leg. He did not feel the cup drop from his hands due to the neuropathy in his fingers, so he couldn’t take evasive action to move away from the hot tea. In addition, because he lacked sensation in his feet and legs, he was also unaware that he had scalded his leg.

Partners and carers were aware of the risk of injury and took this into account in their activities. For example, Jane said she was concerned about John falling, as his balance was affected by his neuropathy. But at the same time, she wanted to help him to maintain his independence: ‘Before I go out if he wants to have a bath I’ve got to make sure I’m at home because I don’t know if he’s going to fall in the shower’.
Kira explained that she had stopped travelling by bus because unsteadiness and weakness, due to her neuropathy, made this mode of transport impractical:

Like I was having problems, absolutely terrified I was on the bus because the bus drivers will not wait for you to sit down for a start, and if I couldn’t get onto a seat where I could hold on to something, I just felt useless. I felt so scared that I was going to fall and break something that I stopped going on the bus.

This development was particularly significant for Kira, who no longer drove a car because she was concerned about falling asleep at the wheel due to the sedative effects of her medication.

Carers were also at risk

Risk was an issue for carers as well as patients. Although they prioritised the needs of the person with myeloma, they were aware of the need to manage risks that threatened their ability to provide care and support. This included getting enough sleep, managing fatigue and emotion, attending to their own health needs. Thus, carers’ work included both risk work and emotion work. Delia described how she allowed herself periods of respite:

There were times when I had to get out of it completely and either go out with my girlfriends, go to the shops, do something right and it had to be something that I wasn’t thinking about—hospitals or David or home, work.

Emma was very involved in her mother’s care and chose to spend a great deal of time with her. Initially, she fixed on the fact that myeloma is a ‘terminal’ illness, thus she was just waiting for Etna to die. Because she had previously experienced post-natal depression, however, she feared that the waiting game put her at risk of depression, so she changed the way she understood the situation. She decided to stop waiting for her mother to die, and focus instead on living with myeloma:
And I thought ‘Well whether she’s got one year, 10 years, 20 years—what? You’re going to live like this? I don’t think so.’

Carers sometimes had to make significant changes to their lives. For example, during the study, Kerry moved in with her mother for a year in order to look after her. The toll on carers was sometimes so great that it put relationships in peril. Harry was diagnosed with myeloma several years before I met him. Helen told me that they had spent the first couple of years after his diagnosis arguing, fighting and consuming alcohol because they were just waiting for him to die. Then they realised that his death was not imminent. Helen told me Harry’s reaction to this was to throw himself into his work regardless of his physical condition. Helen found this difficult and distressing to watch, and she reached a point where she felt she was unable to continue:

And I did that—Harry didn’t, he kept in this work, work, work, seven days a week, and we did actually have words over this and I said to him if you want to take that road you’ve got to take it on your own because I can’t go with you anymore.

Helen explained that she realised that if she fell apart, she would no longer be able to look after Harry. It was this realisation and assessment of the risk to her ability to continue to provide support to Harry and to her own wellbeing that enabled Helen to make changes in the way she managed her own risk.

**Mitigating the effects of both disease and treatment**

Participants strove to mitigate or reduce the adverse effects of complications of myeloma and treatment. Knowledge about how to manage such effects was gained from health care professionals, non-profit organisations, the mass media, friends and family, participants’ own experience, and the experience and expertise of others with myeloma.

Mitigation work was underpinned by risk work and by knowledge work. Combining information from a variety of sources with their own experiential knowledge enabled participants to manage and mitigate the effects of symptoms and side effects more effectively. Over time, participants became more and more skilled at this task, and it
sometimes overlapped with risk work. For example, decisions about when and how to seek professional medical help were informed by understanding and experience. David said that he had learned to try to deal with symptoms at home and then to seek professional help if needed, but he tried to avoid visiting the emergency department as a risk reduction measure:

I know that I’ve got to look after myself. If I’m not right then I go. I actually, rather than emergency, as long as it happens during the day, you go into the cancer day-care suite.

Similarly, Fred had learned to try to manage his symptoms at home and, if he could not do so, he emailed his haematologist for advice, and then visit his GP for a prescription.

Participants mitigated the impact of their disease and treatment through self-care: they strove to maintain an adequate fluid intake, eat well, exercise and manage their medications. Some found it difficult to heed expert advice to drink at least three litres of water per day to mitigate the adverse effects of myeloma on renal function:

I never drank water before, never did. At first it was hard, but now I drink it. I’ll get up in the morning, that’s the first thing I’ve got near the dressing table there and I won’t even go for the coffee. Water or green tea, that’s all I drink (Enna).

Participants who discussed their nutrition described how they had paid little attention to this issue before they were diagnosed with myeloma, but this had changed in different ways. Some ate only organic foods; some avoided processed foods, and some supplemented their diet with vitamins. They said that they attended to their nutrition and changed their eating habits in order to support their immune system and speed up its reconstitution, and thus their recovery. David also suggested that the treatments were more likely to be effective if he maintained his physical health:

We just have less preservatives and less manufactured food and most of the meat and vegetables that we have are organic, same as sugar, milk, tea and coffee which we have, the things you have regular … I think of the body being in a healthier situation
to take the medication that works on it. Whether or not that contributed towards the zero [paraprotein] count.

Ivan, John and Kira said they had to pay attention to sugar in their diet to manage high blood glucose levels that were caused by their steroid treatment. As Ivan explained, ‘the Dexamethasone does whack your sugar way up’.

Keeping physically active was seen as an important way to aid recovery, rebuild strength, reduce complications like pain and weakness, and thereby return to enjoyable activities. Emma and Kira both discussed exercise extensively as a way of promoting health and recovery. Emma organised walking companions for her mother.

Kira recounted her concerns with regard to her weight gain. She had previously been a very active person and kept reasonably fit. The impact of myeloma and treatment had affected her weight: she had fluid retention as a side effect of steroids, and had become physically inactive due to pain, neuropathy and fatigue. At our third meeting, she mentioned two major changes that allowed her to think about exercise and health promotion. She told me how she had adjusted to her new body and its limitations, and how she had more time to herself as hospital visits were slightly less frequent. Therefore, she visited the dietician with a view to commencing a rehabilitation programme: ‘It was a plan. I’d been to see the dietician and we sort of agreed, well she gave me a list of 10 exercises to do and part of the plan was yes to walk 30 minutes every day.’

Another way that participants could mitigate and manage the side effects of treatment was by manipulating their medication schedules. They sought in particular to manage the sedative effects of thalidomide and the troublesome effects of steroids. All participants were taking steroids at the time of the study or had taken them as part of their treatment regimen at some time. Sometimes steroids were taken continuously, often at a low dose, and sometimes they were taken in short courses of higher doses. The latter treatment regimen created the most difficulty for participants. The most common reason for changing a medication schedule was to reduce the impact of undesirable side effects by controlling the timing of the dose. This generally applied to
steroids. Participants sometimes sought to take advantage of a sedative or energising drug effect. Most participants told me how they felt ‘awful’ the day after their steroid regimen finished, and they had to plan to manage the effects. Ivan’s description of how dreadful he felt for two or three days when taking steroids,\textsuperscript{19} was typical.

Participants did one of two things: they planned to be ‘out of action’ for several days after coming off the steroids\textsuperscript{20} or they altered the medication schedule to fit in with their plans. If there was an event planned for a particular day, for example, they took their steroids either on the day of the event, which allowed them to feel well on that day, or they took them earlier or later than scheduled so that they did not have the effect of ‘withdrawing’ or ‘coming down’ on the day of the event:

I wanted the weekend because if it was free we could do something together and I couldn’t because I was, had the two shaky days and I’m useless when I’m shaking like that because you know I feel like I can’t do anything. I can’t think properly, I can’t do anything properly (Kira).

Ivan said that he sometimes increased the period between courses of steroids: ‘You’re supposed to take it every seven days, which is a bit wrong but sometimes I’ll pull it back one day just to give me a bit of relief’. On one occasion, he used his steroids to enable him to combat his fatigue and to watch the live cricket broadcast overnight.

The sedative effect of thalidomide was usually seen as undesirable because it caused participants to fall asleep at inconvenient times. However, Garry worked shifts and used the sedative effect of the thalidomide to his benefit by timing the dose so it helped him sleep before his next shift.

**Emotion work**

Participants had to deal with both their own feelings and those of people around them. Emotion work refers to the efforts and skill they brought to bear in these tasks. Fatima

\textsuperscript{19} See page 103
\textsuperscript{20} This aspect of time management will be discussed in Chapter Eight.
explained that she had changed the way she reacted to, and communicated with, Fred. She recounted how Fred had previously been an even-tempered man and thought that his ‘shorter fuse’ was an effect of the steroids he was taking as part of his treatment. She was clear about the effect of the treatment on Fred’s wellbeing and how important it was not to aggravate the problem:

I don’t talk about it too much with him because I’ve got to be careful that I don’t say the wrong thing, because I don’t want to upset him.

Fatima, Imelda and Jane told me similar stories. Prior to diagnosis, they used to argue back and state their feelings. Following diagnosis, they made a conscious effort to hold back, to ‘bite their tongue’ and not upset their husbands. At first, it was difficult to control their interactions to manage their partner’s emotions, but it became easier as time passed and it eventually became their ‘default’ way of responding:

I think everything is out of his system. But I think he acquired a little, how can I say, used to, because I kept quiet, don’t upset him, let him go and I think that’s where my strength really comes. Because you’re relaxing yourself and saying well you know that’s it and when we’re talking fine what I’m saying, I can see that he’s getting a little bit uptight about it, I stopped and calmed the situation straight away. I don’t go on like I used to (Fatima).

I used to give him back. But now I sort of back away, you know, I let him have his say and go ahead and do what he wants to do (Jane).

As well as changing patterns of interaction to manage their partner’s emotions, participants said that they changed the way they managed their own emotions over time. Etna told me at our first two interviews that she did not fully believe that she had myeloma. However, she gradually came to accept that she did have myeloma and her feelings changed as a result. This was not simply a change in the way that she presented herself. Etna explained that she changed how she felt about having myeloma and this enabled her to talk about it.
Clive also described how managing emotions sometimes required effort. He told me that he maintained what he described as a positive outlook. He explained that he worked to maintain a ‘positive’ emotional response and refused to ‘dwell on it’ that is, to focus on the negative aspects of having a terminal illness: ‘but you’ve got to work on it’.

David explained that time and acceptance was a key factor in changing his emotions. Initially, he was anxious, upset and scared, but over time, and with experience and information, his emotional response had changed:

But [having myeloma] doesn’t bother me too much now because as I said I have to accept that because that’s the way it is.

Fred struggled with the effects of steroids. They made him angry and caused emotional outbursts, which he found stressful. However, he learned how to manage this:

Especially going through this particular medication, you sort of feel that you have to close your eyes and you need to stay calm sometimes.

Other participants also described strategies for controlling their own emotions for the sake of their own wellbeing:

Oh it’s just if you’re not feeling too crazy just probably don’t go the way you want them so you just either clench your teeth, lock yourself in the toilet and have a cry or just have an outburst, which probably isn’t the best, but just keep it short (Celia).

I’m starting to come to grips with it again, I’m usually a pretty positive person but I said to my daughter on Friday when we got the bad news [of relapse], I sobbed a day and then it’s onwards and upwards (Anne).

Follow-up clinical appointments required an enormous amount of emotion work as the consultation reminded them of their life-limiting illness and their prognosis until the next appointment, which could be weeks or months away. Several participants described how the vacillation of emotion and anxiety around their three- or six-monthly
clinical appointments could escalate to a crescendo as the appointment approached. Ivan recounted his strategy for managing this:

I used to worry about it a week beforehand, and be a bit concerned, then you’d forget about it, then as the days got closer you’d start thinking of it more so. Now I don’t worry about it as much until a few days before or four or five days, say. I don’t get real worked up about it but a day or two beforehand (Ivan).

Kerry, who had been staying with her mother, Kira, told me at our second interview that she was going to move out of her mother’s house\(^{21}\) to reduce her own, constant anxiety about her mother’s safety, physical and emotional wellbeing:

And then I’m there and I don’t feel like I’m relaxed. So, I’m hoping that when I’m out of here the pressure won’t be as high.

**Organisation work**

The work undertaken by patients, carers and others, including health professionals, needed to be organised and coordinated. This required organisational skills and expertise to allocate time\(^{22}\) efficiently within a complex framework of competing demands. For example, organisation work was focused on coordinating multiple health care demands optimally but it also included managing activities other than those related to myeloma, such as household work and the needs of other family members. Organisation work was often a struggle, specifically when unanticipated events occurred or when there were competing demands.

Fatima’s parents became ill shortly before Fred was diagnosed and, being the only daughter, she was required to care for them as well as Fred. Fatima’s father died and then her brother became unwell. She described the competing demands and struggle she experienced in trying to organise them:

---

\(^{21}\) Kerry was engaged to be married and planned to move in with her fiancé.

\(^{22}\) The allocation of time is discussed in depth in Chapter Eight.
That changed two years ago when we, with Fred, and I had a big load and with my parents, because I used to go there, clean the house, do the washing, bring the ironing. It was just ongoing, and then of course you’ve got to let go, and then I said: ‘well, you know, this is what I can do—we cannot do this anymore’. I’m busy every hour of the day, and that’s it, you just let go, you have to.

Jane found that when Fred was hospitalised, it was harder for her to balance the competing work demands:

It used to be hard because it was only me that used to do everything, run to the hospital, come back, go back again, come home—that used to be really, really bad.

Brenda found her work organisation more complex when Barry was at home, however:

When he was sick at home, I can’t [get anything done] because he’s home all day. I have to prepare the breakfast, I have to prepare the lunch, I have to keep the house hygienic for him.

Participants described how they sometimes had to find new ways of organising finances and paperwork. This sometimes required them to take on a new responsibility, which was initially a struggle:

I’m trying to claim for financial disability, but every time I go to the Centrelink they’re always asking me for more paperwork and more proof and more identity and more things. I’ve been now about four weeks, five weeks trying to fill out all the forms and bring all the proof and all identity and every time I go there they say to me this is wrong and that. That’s hard you know, that’s hard … And I feel like I’m carrying big responsibility now.

Celia kept a diary that she referred to constantly as she juggled appointments between different specialists in different hospitals, housework and her own medical appointments (she was diagnosed with colon cancer during the study). She told me that

---

23 Centrelink is the Australian Government Social Security payment and support service.
one of the criteria for a day being a ‘good day’ was that the telephone did not ring before she had completed her morning shower:

I just work his appointments on days off days you know that way, and then just do everything else, sort of set myself tasks. I suppose you could say, well tomorrow we go to the eye specialist and get another opinion from the eye specialist, which means I haven’t, because I was cleaning up on Monday. It means the vacuuming hasn’t been done, so if everything’s alright on Thursday I’ll vacuum, because you know we’re up here pretty much all day today, and we don’t know how long tomorrow will take. I think I’ve only once overlapped on an appointment which was a bit of bad judgement on my part because I didn’t look it up.

Juggling appointments included managing parking. Both Celia and Emma explained how they coordinated appointment times with availability of parking. When Etna was in hospital for her stem cell transplant, Emma coordinated a roster for the family to visit. They would meet at the car park entrance at an arranged time so they could use one parking ticket and rotate through the same parking spot.

Brenda told me that she organised documentation and biomedical information to facilitate speedy and efficient communication between different health care sectors, specifically between Barry’s GP and haematologist:

And I photocopied the whole test the family doctor done for my husband and I took them with me to the interview to see the doctor and said I think the cancer start to be active again in the body and the paraprotein goes very high, he had 75 per cent.

Participants described how they learned to organise appointments and transport, often liaising with the hospital and friends, family or transport services, such as the Leukaemia Foundation drivers, and juggle multiple different health care appointment demands to optimise their time and energy.
Illness is hard work

Characterising work as an integral component of living with myeloma echoes Corbin and Strauss’ [278, 279] argument that chronic illness requires significant amounts of work for the person with illness and those around them, particularly their spouse. As in this study, they created a taxonomy of work with three basic categories: illness work, everyday life work and biographical work. Their schema thus differentiated work according to different domains of life, which tends to fracture or compartmentalise experience. The taxonomy proposed above avoids this problem by differentiating work according to its objects—knowledge, health, emotions and organisation. Some work was imposed by the illness, some work continued despite the illness, but most work knew no boundaries according to distinct domains of life.
Chapter Eight: Living with Myeloma Changes Experiences of Time

Introduction

People experience illness within the general experiential parameters of space and time, and they recount their experiences in stories that unfold in time. Their illness narratives often referred to conventional measures of time, such as those used in calendars and clocks (e.g. years, months, days and hours). These measures were used to locate events in time (absolutely and relative to each other in a chronological sequence), and they were mutually understood—and are generally understood—because they are part of the cultural heritage shared by the participants and the interviewer.

Special days and dates such as birthdays and anniversaries, and biographical events, such as the diagnosis of myeloma or other events of major personal or familial significance, were also used to mark time in the illness narratives. Unlike conventional units, their meaning and significance was shared only within the participant’s own social networks, that is, among the participant’s own family and friends, and others who had an immediate interest in their welfare.\(^{24}\)

Sometimes biographical time was not described in terms of standardised units of conventional time but rather in terms of segments or blocks of time that were arranged into sequences that characterised the general ‘plots’ of the participants’ stories.

The subjective experience of time was not always concordant with conventional time. Participants made this point implicitly when they told me how time seemed to pass ‘slowly’ as if it was being stretched, or that it seemed to pass ‘quickly’ as if compressed or indeed, as if it seemed to ‘come to a halt’. The subjective experience of time could also be non-concordant between individuals, and this point is discussed further below.

\(^{24}\) Special days and dates are of course identified by means of conventional time: a birthday, for example, is identified by a unique date that determines its yearly recurrence. However, the exact date on which it falls each year is known only to a limited group of people.
**Conventional time**

Participants used conventional measures of time in their narratives to locate their experiences in time. This was one of the ways they conceptualised their experience to make sense of it and communicate it to the interviewer:

So I would say that the first year was pretty well bad, bad. And then on to the second year when the chemo was still being taken at a better rate, it was a good rate, you didn’t feel all that good … the last couple of weeks I’ve been feeling quite good [emphasis added]. (Fred)

Fatima also used years as place markers: ‘last year was the worst year because I really didn’t think he could pull through’.

Celia marked time with reference to Clive’s myeloma diagnosis:

And he said to me—you know how long it was—and of course I could tell him that it was coming up for the four years, I remember that.

She also marked time by referring to Clive’s future. In our first meeting, Celia explained that Clive had been given a ‘time limit’ of three years. I interviewed Celia in October, two months before the three-year ‘time limit’ was due to expire:

Celia: When he was first diagnosed the suggestion was maybe three years, and that’s what is coming up [cries]. Sorry.

Me: So is this time-line looming for you?

Celia: Well, it’s three years in December and it does bother me a bit. [Cries, takes a few deep breaths.] Control. Sorry about that.

I interviewed Celia again the following April, and I asked her about the passing of the three-year limit the previous December. She said that once Clive had ‘come through it’
she considered ‘every day to be a bonus’. Thus a segment of time that was perceived to be finite and fixed continued beyond its expiry, and time lived beyond that was considered to be ‘extra time’, and there were no expectations of more time to come. Celia did not remember the passing of the actual date of the deadline that she had so clearly anticipated beforehand, however. I asked her about this and she told me that the deadline had been lost in the busyness of Christmas, and in the heat of that summer. Thus what had seemed to be an impenetrable obstacle had faded into the background of living with myeloma as a normal part of life as other events came to the fore.

Living in segments of time

Participants often spoke about living from one segment to the next. For example, they frequently spoke of ‘living day to day’ or ‘one day at a time’. This was due to uncertainty about the future, which was often measured in days or hours. They explained that at times they could not be sure about feeling well or, on occasions, even being alive a few days or even a few hours hence. They also described living in segments of time that were defined by the health care system. These were constructed in conventional units of time (for example, three- or six-month intervals) and were defined in terms of institutional events and processes, such as ‘living from appointment to appointment’.

Whilst some participants said they ‘lived one day at a time’ or ‘lived from day to day’ because every day was a ‘bonus’, other participants related this experience to uncertainty and mistrust of their bodies:

Today is here, now and I feel like this; tomorrow I may not, and I don’t know what it may bring (Fred).

I’ll take it from there; I don’t know, I can’t predict tomorrow (Barry).

It’s really hard, it’s really, really hard because I don’t know what day I’m going to be good, what day I’m going to be bad (Kira).
That just really frightened me that I could just be having a pizza and a beer and then be nearly dead you know like 12 hours later, it was just incredible (Anne).

Living in short segments of time as a result of uncertainty became an integral aspect of participants’ experience:

You know, like, like, sometimes, like, I don’t think like what it’s going to be in the future, like I’m just living day by day (Brenda).

I just go on—today’s today. I don’t make plans any more, no plans—today is today, whatever tomorrow is tomorrow and that’s it (Fatima).

Participants lived in segments of time of varying duration, according to those defined by the health care system. Follow-up appointments were typically held at two-, three- or six-monthly intervals, and these structured participants’ expectations and their imagined futures. For some participants, the remission or plateau in their disease was said (by medical experts) to have become more ‘durable’. If the participant took this on board, they became more confident, and instead of saying that they lived ‘from one day to the next’, as they did in times of extreme uncertainty, they said they lived ‘from appointment to appointment’, which could be anything from two months to a year, as Harry explained: ‘I, you, sort of live in two or three month spans between when I’m seeing him again’.

The appointment at the hospital routinely involved an assessment of the paraprotein level to assess the quantity of myeloma in their body, and it was this result that provided prognostic information for the future two to six months. John described how the appointment, and thus the paraprotein level, structured the way both he and Jane lived: ‘we just live from day to day. So, like, now I think every few months I’ve got to go and have a test, blood test. If it’s okay they wait for the next three months.’
Marking biographical time

Conventional units of time such as days, weeks, months and years were important ways of marking time, but participants also recounted their experiences in relation to biographically significant events such as births, deaths, marriages and holidays. They also used an additional set of markers that was specific to their myeloma, such as diagnosis, transplant, progression, remission, plateau and relapse. Whereas most of the markers were also components of other haematological cancers, a plateau—referring to a steady level of paraprotein—is specific to myeloma discourse. Diagnosis was usually the most significant marker: it constituted a kind of biographical ‘faultline’ by between a life before diagnosis to which one could never return, from a life after diagnosis which was ongoing. Life before diagnosis was constructed as fundamentally, qualitatively different from life after diagnosis. After diagnosis, certain things were relinquished, certain things were taken away and things were generally different.²⁵

Brenda told me about her life before myeloma during our first meeting. She told me about their busy lives: hers was focused on caring for the children and domestic work, and her husband’s was focused on working and building for their and their children’s future. Outside of his business and his normal working hours, Barry was also acquiring land and building houses for his daughters. Brenda told me that they anticipated a future of hard work that would be followed eventually by material rewards and financial security for themselves and their children. Fred’s diagnosis changed everything, creating a ‘before’ and ‘after’. Like many participants, Brenda distinguished between these distinct periods by using terms such as ‘we used to’ suggesting a past habitude, and ‘we do’ suggesting a present habitus: ‘We used to live our daily lives every day without thinking one day my husband is going to be sick and is going to have a cancer’.

Kira’s myeloma story began with a two-year struggle with undiagnosed symptoms of fatigue and pain. This period culminated on a day when, walking from her office to her car, she found herself ‘unable to move’ because of her extreme exhaustion and pain.

²⁵ A similar kind of delineator has been described by Angela Wilkie in her autobiographical work as BC - before cancer and AD - after diagnosis (430).
She saw a doctor, had the appropriate tests and was diagnosed with myeloma. She did not return to work. For Kira, this created a clear faultline in her biography:

I was working for [a public figure] and I will say now—it was the hardest thing I’ve ever had to do, give up my job. Absolutely loved it. I still miss it. [Cries.] That was devastating for me.

Before he was diagnosed with myeloma, John had an active social life that was centred around the local pub. He was a very sociable person; he liked to drink alcohol and he took his ‘health’ for granted. However, after his diagnosis, he had to quit work and both his social life and the ‘taken-for-grantedness’ of his health disappeared:

I never, ever thought that I would resort to all these things [myeloma and diabetes] my main thing was, I don’t know, the bottle, put it that way. Well then I only used to drink like weekends, I never used to drink within the week or something like that but, but other than that I never, ever thought of my health.

The pre-diagnosis, post-diagnosis distinction was thus a critical sense-making tool for participants. The meaning of experiences differed depending on whether they belonged to the period ‘before’ or ‘after’. For example, serious threats that occurred in the ‘before’ period were sometimes constructed as ordinary or normal. This was a relative temporal judgement: compared with myeloma, previous major illnesses were judged minor and inconsequential. Fatima and Fred, for example, both spoke of their ‘normal life’ before myeloma even though Fred had undergone cardiac bypass surgery and was treated for renal calculi in an abnormal shaped kidney:

The bypass surgery went well, there’s been no problem ever since … I have kidney problems as well because I have a horseshoe kidney and I had stones in the kidney which gave me a great amount of trouble as well. Then until this got me here, everything was quite fine, had no problem (Fred).

How can I say normal life [before myeloma was diagnosed] and everything pretty much normal? (Fatima).
Diagnosis was not the only important event used by participants to mark time. For Celia and Clive, there were two major biographical markers. One was the diagnosis and the other was the day they were told that Clive ‘had three years’ left. Between these two events, there were a number of other ‘sentinel’ events such as the day they decided to sell their caravan (Clive could no longer drive due to his vision impairment and Celia was unable to reverse the caravan). This marked the beginning of a period in which they would no longer travel and take holidays in the way they always had ‘before’.

For Anne (like Kira), deciding to leave work was a major event that marked two clear periods. Despite living with ‘smouldering myeloma’ for 15 years, and then active myeloma for one year, Anne experienced fear for the first time when she became critically ill due to sepsis. It was this—the prospect of imminent death—that arguably defined the most significant fault line between the before and after in her experience: ‘It’s changed, really changed how I feel about things. It’s actually made me fearful, and I’ve never been that way.’

Participants said they sometimes experienced time as ‘slow’ (as if it were stretched), ‘fast’ (as if it were compressed) or as ‘standing still’ (as if it had stopped). This introduces the idea that the subjective experience of time can be out of step with time as it is measured objectively on clocks or calendars.

**The subjective experience of time**

**Time stopping**

Participants spoke of life being brought to a halt because of myeloma being a terminal illness. They also spoke metaphorically of time seeming to stop or be stilled. This was usually experienced with news of the initial diagnosis or of relapse. Participants frequently recounted how their life had ‘come to a halt’, or was put ‘on hold’. For example, Kira said that, since her diagnosis, life felt ‘like a pendulum and it’s stopped

26 Septic shock is a life-threatening critical event associated with immune deficiency and was a major driver in risk work related to compromised immunity.
… And that one day there’s always the hope that it’ll start swinging again. That’s how it feels.’

When Etna was diagnosed with myeloma, she did not believe it at first. She was not ill. She did have a disease, though. In her first interview, she said that she had ‘put things on hold at the moment’. She was waiting to be able to plan again. At our third interview, after she had accepted the diagnosis as true, she reflected on how the diagnosis had created a feeling that her ‘life was on hold’ and ‘held [her] in one spot’.

**Time stretching**

Time was sometimes experienced as moving ‘slowly’, as if stretched. This occurred during periods of illness, or waiting for bad news. Brenda told me about when Barry was undergoing treatment. She was caring for him, as well as caring for her two small children and managing the household. During this period, Brenda was very busy but ‘when he was home sick the time [was] very, very slow’.

Waiting for test results could stretch time, even within a consultation. Ivan recounted his frustration as he waited for the doctor to tell him his paraprotein level. He described how the doctor took ages to reach what he considered the point of the consultation—reporting the quantity of paraprotein. Similarly, Emma described how time slowed down as she anxiously waited for phone calls about test results and appointments. When I met Emma for our final interview, she commented on the non-concordance between calendar time and her experience of time: ‘it almost feels like it’s been 10 years—it’s only been one year hasn’t it?’

**Time ‘flying’**

Time was sometimes said to move quickly, as if compressed. This was usually related to being busy and occupied. Being busy was sometimes related to feeling well and undertaking more activities, but it was sometimes related to being unwell and having many appointments and treatments.
When Barry was ill, for example, time was stretched for Brenda. When he was well and in remission, time passed quickly: ‘I don’t know, maybe time is like going very fast … You feel like the time flies quickly because we enjoying the life more than before’.

Time seemed to pass quickly for Brenda because Barry was well and they were busy as a family. For Emma, time passed quickly because of the busyness of treatment. During her third interview, she reviewed what had happened since the first interview:

Oh, this year’s ridiculous. Can’t believe this year how quick, I mean … Went quick. But this year, I just lost my footing … I just think it did go quick. I must admit, especially from when she first started treatment, which was in September, October through to transplant, that sort of just went … And I think maybe because there was one thing after another—bang, bang, bang, bang, bang, and it was over—Christmas, and then kept going.

For other family members or partners, time seemed to pass ‘quickly’ as life outside myeloma went on as usual. Kerry attributed the apparent contraction of time to becoming accustomed to living with myeloma. She was also planning a wedding, moving house, and working, as well as helping her mother: ‘It just goes so fast these [last] six months I suppose just as time goes on, more time goes on you get more used to it’.

Kerry’s mother Kira commented on how her experience of the three years since her diagnosis had passed ‘rapidly’. This still seemed like a long time; however, relative to the time she might have left:

I think this has been like a very short journey but in reality [it has been] over three years now. When you think about it three years is not a short time. You know that’s a long time in your life really when you haven’t perhaps got a lot of life left.

Since time had become a scarce resource, time that passed ‘rapidly’ sometimes seemed like time that was wasted.
Interpersonal non-concordance of the experience of time

As well as being non-concordant with calendars and clocks, the experience of time was sometimes non-concordant between people who were otherwise ostensibly experiencing the same situation. For example, Delia, Fatima and Jane all told me about how their partners occasionally perceived the passage of time differently to them. This happened specifically when they had left their partner alone in the house. When they were out shopping, performing errands or socialising with friends, David, Fred and John would call to ask where they were or what time they intended to return. The men often perceived them to have been out for a long time, and this did not accord with their own experience. I asked Jane if she thought that John’s perception of time might be different to her own, and she replied: ‘Probably, yes … Sometimes he’ll say to me that was record time, because he thinks I stay away all day, but I don’t’.

In summary, a subjective viewpoint, wellness and busyness tended to ‘compress’ time while illness tended to ‘stretch’ time for partners who waited at home, and non-concordance between the temporal experience of carers and their partners with myeloma was sometimes a source of tension.

Time was constructed as a resource in two ways. Firstly, participants made sense of their illness experience using discursive resources that depended on temporal relations. Secondly, because myeloma is a ‘terminal’ illness, time became a scarce and valuable resource that that could be ‘lost’ or ‘gained’, and therefore required careful management.

Time as a discursive resource

Participants used time as a discursive resource and they did this by making social comparisons. There is an established literature on social comparisons which includes empirical studies of the comparisons that are made by cancer patients in illness narratives (for a recent example, see Morrell 2011[428]). It shows that social comparisons have a variety of parameters: speakers can compare self with others, or they can compare self with self; they can do so favourably or unfavourably,
retrospectively or prospectively; and comparisons can highlight similarities or differences. Importantly, all social comparisons presuppose the medium of time: they are either diachronic (i.e. they compare different points in time) or synchronic (i.e. they make comparisons at the same point in time). Social comparisons can thus be considered a discursive resource (because they are used to make sense of experience), and one that presupposes or depends on temporal relations.

Social comparisons were sometimes used to present the experience of myeloma in a favourable light. For example, participants sometimes compared themselves favourably to others on the basis that they had a sense of how their life might play out, and were forewarned about their death, whereas others who did not have myeloma were not forewarned and so did not have the benefit of such knowledge. Participants said that because they knew their prognosis, they were able to plan, re-prioritise and finish projects; they could plan their funeral and ‘put their affairs in order’. Those who were not forewarned, such as the hypothetical, undiagnosed ‘healthy’ person on the street who could be knocked down without notice, were robbed of such opportunities and were thereby left with ‘unfinished business. Thus participants appeared to gain ownership of a future time in which to ‘tie up loose ends’ that was theirs because of the diagnosis, not despite of it. In other words – and somewhat counter-intuitively – it is as if the stark confirmation of their own mortality, illuminated by their intimate knowledge of the terminal nature of their disease, was seen to give them time rather than deny it:

But you’re sort of brought home back to ground all the time because people who are perfectly well pass away and you think well, I’m living with this but I’m still here and going and they thought they would be as well, but they didn’t have the, the knowledge leading up to the fact that they were going. (Kira)

Similarly, Fred spoke of his prognosis as something that gave him the opportunity to secure his family’s financial security by tying up overseas business interests, and that “gave” him more time with his family:

This is a myeloma, which is not as bad as some, you know where people are virtually given death sentences more or less straight away … It gave me the chance over there
then to do everything I had to do, now there’s nothing over there that the family has
that’s not set ….. I’ve been given time to sort of hang out with my grandchildren.

Like many other participants, Kira framed this opportunity with a re-prioritisation and
re-evaluation of her life:

That’s given me a chance to do those things where a lot of people don’t have the
chance to do those things, or don’t even think about it, because most people go along
in life thinking well they’re going to go for ever until they’re an old person and
they’re going to die.

Participants also constructed favourable stories by contrasting their present self with the
past self to highlight how they had gained strength, acceptance, and/or understanding
and thereby accommodated the impact of myeloma. Onlookers sometimes made similar,
favourable comparisons. For example, during my second interview with Delia, David
was recovering from his transplant, which included a period of critical illness due to
infective complications from the treatment. Delia contrasted David’s current state of
health with his state of health as depicted in a photograph of him taken immediately
after bone marrow transplant. She said she used the comparison to reassure both herself
and David that he was improving:

I’ve got to find the magazine that they took a photograph when he’d just come out of
hospital, he’d got no hair and he looked like an old man—well he doesn’t look like an
old man now … Tremendous, yeah he really does. He doesn’t realise how far he’s
come.

Social comparisons sometimes presented the experience of myeloma in an unfavourable
light. They recreated a time when things were better by contrasting the present self
unfavourably with the self before their diagnosis. In this way, participants articulated
losses, such as loss of health, wellbeing, jobs, social status and/or quality of life. Fred
and David both described unfavourable changes since their diagnosis. They had both
ceased being employed in paid work and consequently experienced social isolation and
a loss of social status. They both reflected, as did other participants, on how this
affected their lives post-diagnosis. David illustrated this by describing how he no longer felt valued because of how he occupied his time:

You know what do I do now, I suppose I can read or I go and do whatever I’ve got something to do, but I feel as if I’m not doing anything worthwhile, whereas I was always used to be doing something.

Comparing and highlighting losses could also cause distress, as Kira told me in our first meeting:

But it stops me from doing other things that I’d like to do. Well things that I used to do, that I can’t any more like driving. I can still drive, but I’m not allowed to. So that’s one thing that really makes me angry. And not being able to work. That upsets me quite a bit.

Participants sometimes constructed unfavourable stories by contrasting their present self with a future self who had declined in health because of the myeloma. They thereby anticipated deteriorating health, relapse, further treatment and death. Comparisons like these were often implied by the expression ‘while I can’. This expression anticipated a loss of functional capacity in the future by implying that there would be a time ‘when I can’t’, and thus implied that it was important for them to ‘seize the day’:

But other than that I worked, I travelled, I did the things that I wanted to do—I thought I need to do this while I can (Anne).

The myeloma is in remission and that is the most wonderful I feel really fantastic and I want to laugh and I want to joke and I want to be, like the way it was, because this is the time to do all this, because you don’t know (Fred).

I thought let’s go to Africa, you know, with Jane. Seeing that I can still walk around and do what before they put me in a wheelchair or something like that, let’s do it (John).
Future comparisons to self could also be used to construct more optimistic stories:

The expectation I had was could I beat 12 years, which is the longest that any patient has gone with Dr [X]. The average for multiple myeloma patients is six years, so I’ve been one and a half, I’ve already had one and a half years since diagnosis, I’ve been diagnosed with it. So as I say we’ve sort of looked towards living into the seventies, into my mid-seventies and that’s the target (David).

Similarly, Kira contrasted her present self with a future self who would be as well as her cousin. She explained that she hoped to be as good as he was 10 years hence, but at the time of our conversation, she was not like him:

One day I’m hoping that that’s how I’ll feel, further down the track, like my cousin. He was in remission for 10 years, almost 10 years, and he did feel like that, he was having a life.

Participants often expressed optimism about future improvement when they were undergoing onerous treatments, such as a transplant, or recovering from their effects.

Participants sometimes described improvements that were not immediately apparent, but that occurred subtly, gradually unfolding over time. They were sometimes characterised as ‘natural’, and therefore as something that needed to be felt, and could not be forced. For example, Kerry said that the passage of time was instrumental in her accepting her mother’s diagnosis and learning to work with her mother’s myeloma. She spoke about how distressing she had found the diagnosis in the beginning. She reflected on how she had accepted it and how this had helped her to live with it. She was unable to pinpoint a specific moment in which her attitude had changed; it had shifted gradually: ‘I think it’s just happened. Yeah I don’t think anything’s just really, I think it just happens naturally like yeah, through time’.

Etna told a similar story. As I have mentioned before, when she was diagnosed, she and her daughter, Emma, questioned whether she actually had myeloma. At her third interview, Etna told me that she had accepted the diagnosis, but this had taken time. She
said that acceptance was not something that can be forced or taught. For her, it was a feeling that came gradually and with experience. Reflecting back over the previous year, she described how she had integrated the diagnosis into her life:

I think you’ve got to wait to feel it. Everybody tried to talk to me, even the doctor, and until I think until you are ready, the person is ready to accept it, not much anybody else can do, not much anybody else can do … because like I said I think that was the major thing right, that I didn’t accept it, before I was always in denial and I had no control (Etna).

Managing time as a resource

I’d rather not sleep at all, you know, that’s how I feel. Because I want to do things (Kira).

As the above quotation suggests, time became a valuable and limited resource for the participants in this study. When they were unable to function well, or when their quality of life was reduced for a short time (within a cycle of treatment, for example), they said that they had ‘lost’ time. For example, entire days were said to be lost due to the effects of steroids:

Now I feel as though I’ve got five days out of seven, instead of seven out of seven. I’ll put it that way, because tomorrow you may as well say you can cross it out, because today is my Dexamethasone day (Ivan).

Let’s say in a week we might have three, four days [out of seven] that are not bad (Fatima).

Because time was seen as valuable and limited, and as something that could be ‘lost’ or ‘wasted’, participants strove to make the best use of the time that was left. In other words, they strove to manage and allocate time efficiently. In doing so, however, they sometimes had to balance competing demands on their time. Competition came from two different sources: from the continuing needs of family and social life, and from the demands of living with myeloma. Family and social life often generated new demands,
and the demands of the disease did not arise in isolation from other, sometimes equally catastrophic, events. As a result, the tasks of prioritising and allocating time efficiently sometimes created tensions and distress.

As I showed in Chapter 7, living with myeloma was demanding in terms of effort: the disease and its treatment both created a great deal of work for participants, and this impacted on their time. Specifically, they needed more time to perform tasks than they did in the past, particularly because of the effects of pain, fatigue and neuropathy. For example, the work involved in managing pain demanded time to organise, manage, prepare and take medications. It also demanded careful attention to time, as failing to take pain medication on time could lead to severe pain, incapacity and the need for additional medication.

Both patients and carers struggled with the complex demands that myeloma placed on them. Celia worked hard to juggle and manage Clive’s many different appointments in the week:

You know the set appointments here to do that and then he sees the eye specialist and I work his appointments on days off that way, and then just do everything else, sort of set myself tasks I suppose you could say … it’s just been a matter of managing time I suppose, not always successfully but getting there.

As carers became more experienced with living with myeloma, they learned to be organised and use their time efficiently. When Emma’s mother Etna underwent her first course of chemotherapy, she went home and Emma took turns with her sister to stay there and care for her. Emma told me how she had no idea what to expect and described how she spent the day watching and waiting for ‘something to happen’:

It’s really strange, you sit there, it was almost like I was sitting there watching her, I don’t know waiting for her hair to fall off. I don’t know how to explain it, like or her head to go pop. You know I expected something to happen and nothing was happening.
In our second interview six months later, Etna had just returned home following her stem cell transplant. Emma had to juggle the demands of her family with her mother’s needs, but she had by then learned to prioritise demands on her time:

So I just found time was very limited and sometimes [daughter]’s homework didn’t always get done and sometimes the dishes were still sitting there the next morning and it was just like very, very, very hectic, but we managed it.

For some participants, managing time meant clawing it back from the health care system. In her third interview, for example, Emma recounted a battle with an appointment clerk to reclaim her mother’s time for the family:

I felt like saying she may have this disease, but it ain’t ruling our lives, get over it … You’ve had her for a month in hospital, you are not having her while we’re up the coast.

However, it was rare for participants to question the schedules set by the health care system, thus most acceded to them rather than assert their own. For example, Kira struggled to manage competing demands on her time, and tried manipulate her appointments to suit her. Even though she was an independent woman who had worked for a number of years in a senior management position, she did not question the demands of the hospital appointment system:

I try to have most of my appointments in the mornings because that’s when I’m at my best, or if I’m, if I want to do anything in the mornings … I’ve been there well, I can look at my diary, I can tell you how many times up at the hospital. I had two appointments on Monday, two appointments on Tuesday, an appointment on Wednesday, and I’ve got one tomorrow … I’m quite aware that that’s necessary and there’s not anything I can do about that.

Kira was concerned about her appointment schedule because she struggled with fatigue. Other participants described similar strategies but the constraints of hospital systems
made it impossible for them to schedule appointments according to their own priorities and energy levels.

Allocating time

Learning how to prioritise and allocate time efficiently took time and experience, and sometimes required participants to deal with competing demands on their time. Participants frequently sought to allocate more time to family, friends and loved ones and to care of the self. For example, Emma said she decided to spend more time with her mother than she used to and noted that she also took more photos of her mother than she ever did before.

Barry said he used to work seven days a week to build houses for his children and vouchsafe his family’s financial security, as these goals were of paramount importance to him at the time. His diagnosis with myeloma changed his priorities and thus the way he allocated his time:

Like before my thing was work, work, work, work, work—never thought about the family—not that I never, ignored them, but never spent time with the family as much as I have now.

Partners described how they sometimes prioritised their own needs over those of the person with myeloma. They said that this was sometimes necessary for their own wellbeing, which was important because their continuing ability to care for their partner depended on it. They allocated time to themselves by going out and meeting up with friends. Sometimes—and usually in the early years following diagnosis—this was attended by feelings of guilt or anxiety. However, as they gained experience and confidence as carers, they felt more at liberty to allocate time to themselves. In her first interview, Jane said that neither she nor John went out to purchase essentials unless they did so together:

I don’t go out, we stay at home. The only time we go out is we just take a drive to the market and shopping.
In our second interview, she told me how she was taking time out for herself: ‘sometimes you do need a bit of time out just to get away from it all’.

Participants expressed concerns about allocating time efficiently. They worried about ‘not wasting time’, ‘making the most of time’ and ‘planning the best use of time’. For Barry, this meant being referred straight to a medical specialist for issues that were previously handled by his GP:

I’d get him just to give me a referral to a specialist straight away. I don’t want to waste my time any more.

Due to the sedative effect of her medication, Kira needed to sleep a great deal, but in all three of her interviews, she complained about how ‘that annoys me because I’m not getting things done and I feel like I’m wasting time’.

Helen said she and Harry spent the first four years after Harry’s diagnosis just waiting for him to die, but that they had since learned to live differently. One of the choices they made was to not ‘waste time’ worrying about his myeloma:

I’m alright now because we just have learned to put it over there and when it rears its ugly head then we’re going to deal with it. Because we waste too much time worrying about it and you waste days in your life, so we don’t do that.

The desire to not waste time often created a sense of urgency:

It could be you know years away, but you have that urgency that you didn’t have before, simply because you know that you’d like to have those things finished off before you pass away you know (Kira).

You have to live in the now … Accept the urgency to do things now, let’s stop pussy-footing around and get on with life and enjoy it (Delia).
In summary, sorting out priorities and allocating time efficiently were significant concerns for the participants in this study. They gradually acquired time management skills to deal with this as they gained experience with myeloma and came to understand systems and competing demands on their time.
Part IV: Synthesis of the Findings: Discussion and Conclusion
Chapter Nine: Synthesis of the Findings: Discussion

Introduction

In the previous section, the findings of this research were organised into three chapters:

- the arduous nature of myeloma
- the work of myeloma
- the temporal landscape of myeloma.

This chapter weaves these three chapters back together to suggest a new way of understanding myeloma that is grounded in the experiences of participants in this study. It also explains the three themes using Bourdieu’s concept of *habitus* and Canguilhem’s concept of ‘normal’. In particular, I have used Bourdieu’s conceptual tools of practice, *habitus, field, capital and hysteresis* to explain how the complexity and effort demanded by living with myeloma becomes second nature. I argue that participants live with myeloma by accommodating their symptoms, the restrictions imposed by their symptoms, and the changes these restrictions demand of them, and that these symptoms, restrictions and changes thereby became part of the normal state of affairs. Participants consistently used the term ‘getting on with it’ to describe how they did this. ‘Getting on with it’ usually meant accepting myeloma and accommodating the symptoms and treatment effects so they became ordinary and familiar, and the demands of myeloma were incorporated in the routine of daily life. Participants described ‘getting on with it’ and ‘going into automatic pilot’.

Living with myeloma required participants to construct a ‘new normal’. This required adjustment at first, but they learned to ‘get on with it’ over time and with experience. The ‘new normal’ included activities that were focused on managing the symptoms of myeloma. Some required effort and planning and some became taken-for-granted everyday activities. For example, maintaining adequate hydration was an essential part of self-care from the point of diagnosis, and several participants described how they
‘didn’t even think about it’, but just automatically refilled their glass when it was empty. Participants were resourceful and described how they consistently found new ways of doing things when the need arose and this was integral in their new way of living. It was ‘a new state of normal and this state of normal is not normal, but it’s not that bad a thing to have to put up with … You do find other ways of doing it’ (Fred).

The ‘new normal’ persisted until there was a change either in treatment, symptoms or disease progression. This was followed by a new adjustment and accommodation of changes or recovery to a previous status.

**The catastrophic and the normal**

Participants who were diagnosed with myeloma and their primary support people were both catastrophically affected by the diagnosis of myeloma[^27]. The experience of living with myeloma changed their lives irrevocably. They eventually returned to a normal state of affairs that was different to that of their pre-myeloma life. This ‘new normal’ refers to the relationship between the individual and their changed or new environment. Over time, they normalised their relationship with their new environment—that is, they created new norms[^159]—as their experience and expertise grew. The term ‘environment’ is used here in its broadest sense meaning the sum total of all conditions that affect (the development of) an individual. This includes the surrounds and the intracellular and intercellular conditions of an individual. Horton’s[^160] example using HIV illustrates this point in that changes to the intracellular environment brought about by the HIV infection are tolerated:

> Progressive immunosuppression that follows infection by HIV is a normal response to that virus. ‘Health’ [normal] may be conceived as the ability to tolerate the virus despite clear evidence of infection [160 pp318]

[^27]: Throughout this chapter, both groups are referred to as ‘participants’, unless otherwise distinguished.
In other words, participants came to tolerate and live within changed conditions. The process of creating a ‘new normal’ demanded a great deal of effort including new ways of understanding time, normality, and health.

The term ‘new normal’ is used in the popular discourse of cancer survivorship and in information literature and blogs to describe life in the aftermath of cancer treatment\textsuperscript{28} [429-433]. It implies that things will one day ‘return to normal’ without implying that it is possible to restore the \textit{status quo ante} (the old normal), as this is frequently an unrealistic expectation in the context of extreme trauma or disruption. Importantly, for participants in this study, \textit{it became normal to be ill}. That is, the ‘new normal’ entailed living with the symptoms of myeloma, with the adverse effects of treatment, and both the uncertainties and certainties that myeloma brought.

The symptoms that participants described were intrusive and initially demanded a great deal of attention and work. Over time, these symptoms became an integral part of living with myeloma. Living with myeloma remained hard, but the burdens and restrictions placed on participants became the new way of life. Participants often described their symptoms as the ‘way things are’ for them, and they took them for granted despite their suffering, despite the restrictions that they imposed and despite the hard work that was required to manage them.

When they were diagnosed, most of the participants had never heard of multiple myeloma and they knew about it only through their symptoms (if indeed they had any). Later, as they gained knowledge and expertise in living with myeloma, their understanding of their illness experience became a complex matrix of symptoms and numbers, which together informed how they constructed their myeloma. In other words, they assimilated a hybrid gaze comprising elements of both a medical gaze and a subjective gaze [426].

Participants described how they traded off the adverse effects of treatment for its anti-myeloma efficacy. Fatigue and neuropathy, for example, were at times particularly hard

\textsuperscript{28} A Google search conducted on 12/10/2011 for the term ‘new normal’ and ‘cancer’ produced 2,660,000 hits
to bear and incapacitated some participants to the extent that they were unable to carry out everyday activities such as walking, making beverages or meals, socialising, showering or even getting out of bed in the morning. These effects were also accepted as a necessary trade-off for new and effective treatments. Participants were all aware that prior to the newer generation of novel agents, there was little to offer as effective treatment for most people with myeloma. Over time, they became aware of new treatments that offered the promise of reducing other symptoms or increasing life expectancy. They traded off the effects of treatment for stable or decreasing numbers (i.e. quantitative test results), which they understood as stable or improving health and better prospects of survival. If the numbers climbed or the effects became unbearable, they changed to another treatment.

Participants also expressed an enduring confidence that new treatments would be available when they needed them. This enabled them to persevere with the relentless symptoms and adverse treatment effects. Therefore, they were in a continuing state of illness, but one that, for the most part, was tolerated. Over time, this state of illness came to be experienced as a normal state of affairs and they ‘just [got] on with it’. I have called this ‘living on’. Living on is a concept that accounts for the fact that participants created new norms in a radically changed environment – one which included pathological changes, such as painful bones and impaired immunity; restrictions to mobility; work or effort required to undertake tasks; increased time required to do things; long hospital stays; and living with an uncertain future.

Living on

‘Living on’ is a translation of the German word ‘weiterleben’, which means to continue to live following extreme hardship and life-changing disruption, but in a new way. The term implies more than the mere fact of survival alone (überleben) [434, 435]. I use it to describe how living with myeloma became the norm for participants. Living on seeks to capture the ‘going-on-ness’ of participants’ lives and the way in which they accommodated the disruptions [200] and chaos created by the changes inherent in being
a myeloma patient. In other words, it explains how continuity and disruption coexist in the experience of living with myeloma. The demands of having to live with myeloma became integral components in their lives and they consistently talked about ‘getting on with it’, living with the arduous yet everyday experiences associated with myeloma. *Living on* is a dynamic process rather than a state. Participants responded to many changes over time such as multiple relapses, treatment complications, and hopes for remission, all of which were part and parcel of living and dying with myeloma. Over time, these changes to their environment became part of the everyday fabric of their lives. This notion of normality draws, most closely, upon the words of the French philosopher, Georges Canguilhem.

Canguilhem argued that ‘health’ was essentially the ability of the person to accommodate the challenges posed by a new environment by creating new norms. Good health, he argued, ‘means being able to fall sick and recover’ [159 pp199]. Disease can therefore be understood as something that reduces the margin of tolerance to change in the environment, but that ‘this reduction results in the ability to live only in another environment and not in parts of the previous one’ [159 pp199]. It is thus the *relationship* between the individual and the environment that determines what was normal:

> A living being is normal in any given environment in so far as it is the … functional solution found (by life) as a response to the demands of the environment [159 pp144]

The environment changed catastrophically for both participants with myeloma and their primary support persons. While the former frequently experienced progressive neuropathy, pain, fatigue and constant immunosupression, for example, these problems were ‘tolerable’ and became ‘part of life’. For those who had relapsed and were living with myeloma, the goal of treatment was not to achieve a ‘cure’ (it was not possible to eradicate the myeloma and returning their body to a statistically normal state) but to maintain functionality and quality of life. The functional norms they adopted were consistent with living with myeloma [159] and were different to their previous norms or the norms of others who did not have myeloma. The norms became part of the individual’s everyday life [436].
Living on is thus a normalising activity, and living on is a concept that seeks to account for the fact that participants responded to changes in their lives by tolerating ‘infractions to the norm’ [436 pp352] and by establishing new norms. Being diagnosed with myeloma demanded new responses from participants to their environment and a new relationship with it.

The ongoing struggle with symptoms changed how participants undertook tasks. Sometimes it precluded choices or activities altogether. This became an ordinary and familiar part of living on; it became the norm. Participants talked a great deal about just ‘getting on with it’ and finding it normal to struggle to get out of bed and ‘get going in the morning’, make a cup of tea or get to the bus stop. It was normal to spend a great deal of time waiting. Importantly, it was normal to know that you would die of your myeloma. In other words, it was not the mere fact that participants experienced ongoing symptoms that was of central importance to them, but the way that these symptoms transformed their lives, their relationships and their activities.

The work of living on

This ‘new normal’ state of affairs was not easy to maintain, however. Living on demanded a great deal of effort or ‘work’. Participants had to work hard to manage the hardship and accommodate the restrictions imposed by myeloma. This work became a component of everyday activities and can be differentiated into knowledge work, health work, emotion work, and organisation work. As Corbin and Strauss [201, 278] suggested in their characterisation of illness work, participants had to constantly change the way that they did things, and this demanded effort. They manipulated the home situation and reorganised domestic arrangements; they coordinated and organised treatment visits, consultations and medications. They consistently used managerial language when describing this work: they spoke of having ‘agreements’ with plans of action, and of ‘coordinating’, ‘organising’ and ‘managing’. They also worked with clinicians and sometimes used the second person plural (‘we’) when talking about treatment decisions.
**Knowledge work and organisation work**

Participants obtained information from various sources at various times and integrated this with their experiential knowledge. A number of participants said they were most active in seeking information at diagnosis, and to a lesser extent, at relapse or before a major event, such as transplant. They evaluated information in relation to their own experience and their imagined future and disclosed information accordingly. They referred to two types of information: personal information about the person with myeloma, and biomedical information about myeloma or its management. They used information to guide and inform their risk work and mitigation work. The latter two kinds of work synthesised information and experience in varying proportions. The need for a mix of information from different sources may be attributable to the need for different sources at different times. This echoes Hogan and Palmer’s findings that people with HIV and Multiple Sclerosis have different needs for different kinds of information (verbal and written) from different sources (lay and professional) [287]. Hogan and Palmer used Strauss and Corbin’s trajectory model [196] to suggest that this could be attributed to a need for different sources of information at different phases of illness. In this study, as participants gained experience, they synthesised experiential knowledge, professional health care information and their own biomedical information.

Conrad [285 pp14] argues that information work is central to ‘reducing uncertainty, biographical work, creating medication practices and developing practical strategies to manage illness’. Participants in this study demonstrated how they used their knowledge and expertise in their health work, particularly in their management of risk and of complications—notably of fatigue and neuropathy, and in their management of medication schedules. Knowledge work also included choosing doctors, considering treatment options, managing symptoms, and dealing with emotional and social aspects of illness [286, 287].

Only one participant attended a support group, stating that she gained information and support from attendance. All other participants with myeloma explained that they did
not attend, and some explained that they did not as they were fearful of what they might hear or come to know. Thus, information-seeking could increase uncertainty as well as reduce it.

The organisational work described by participants concerned how they integrated the demands of myeloma into their lives. Participants used information work together with organisational work to integrate myeloma into their biography or life course.

**Health work**

Participants undertook two kinds of work that was focused on maintaining their wellbeing: risk work and mitigation work. They described their analysis of risk in terms of what might or might not happen in the context of their personal situation; they rarely described risk in terms of statistical probability. This is in keeping with a sociological concept of risk where it is understood as relative to an individual and their social circumstances [437]. Their risk work drew variably on biomedical data such as white blood counts, symptomatic experience and experiential knowledge, professional advice, and sometimes they synthesised these information sources to evaluate risk in different situations and translate population risk into individual risk. Thus biomedical data was contextualised in the participant’s own situation, and risk work was socially situated. It always incorporated a biomedical perspective, however, because it was primarily focused on the risks of injury and infection due to compromised immunity. In short, a biomedical assessment of risk could not be made in isolation from an individual situation and their broader social and cultural situation [438, 439] and thus was co-constructed [361] in this way.

Cognitive psychologists have examined risk and choice and proposed a number of theories. While a discussion of these is somewhat outside the scope of this thesis, the preceding conclusions may contribute to our understanding of how people assess risk and make decisions. The ‘prospect’ theory proposes that most people give substantial

---

29 An exception here was that some participants used statistical probabilities when explaining their understanding of prognosis and treatment expectations.
weight to *anecdotal evidence*, so much so that it can cancel out expert evidence [440, 441]. This was evident in some participants’ assessment of risk. Risk evaluation was often an integral part of mitigation work as participants worked out how best to avert or reduce the impact of myeloma.

Participants in this study described and explained how they integrated information and experiential knowledge as they worked to reduce and manage the impact of myeloma. Medical sociologists have emphasised the importance of information work as a foundation for managing illness as it can help people to understand what is happening physiologically, situate their experience in their life, reduce fears and misunderstandings and misconceptions and to promote a sense of personal control [288].

Participants invested time and effort in adapting to and managing restrictions in the face of unpredictable and constantly changing conditions. They toiled at managing their illness and working to reduce the effects on their everyday activities, which was consistent with other studies that have also suggested that ‘being ill is hard and heavy work’ [281 pp161]. A number of studies have emphasised the processual nature of living with chronic illness, describing the experience as one that was relentless and required people to act, be vigilant, plan and learn new strategies [234].

The struggle to maintain a sense of balance required work and effort in a ‘constant juggling of time, space, energy, money, jobs, activities and identities’ [279 pp6] and thus mitigation work, as well as being built upon knowledge work, also required organisational work to juggle and successfully manage the competing demands.

*Emotion work*

Participants deliberately tried to change the way they expressed their feelings. Some participants described how, over time and with repetition, this changed the way that they actually felt. ‘Emotion work’ such as this evolved as emotions arose and had to be managed [294]. The familiar image of ‘a roller coaster of emotion’ captures the
ceaseless and unpredictable nature of emotion work, but fails somewhat to capture its relentless nature.

Because myeloma is a life-threatening cancer, it engenders a combination of isolation, liminality, and uncertainty [183, 184, 442]. Consequently, families and primary support people had little choice but to engage in difficult emotion work [290] in order to protect both significant others and themselves. Emotion work was undertaken by primary support people for their loved one with myeloma, the individuals with myeloma both for themselves [290] and for others—both family and the public [184]. These different types of work were not undertaken in isolation but were often dependent upon each other. For example:

- Emotion work required health work and organisation work to be successful and created a demand for knowledge work (i.e. a demand for more information).
- Knowledge work informed emotion work and created either an increase or decrease in demand for it.
- Knowledge work informed organisation work.
- Knowledge work reciprocally informed health work as health work informed knowledge work.
- Health work both demanded and informed organisation work and both demanded and informed emotion work.

The integration and interdependence of the different kinds of work came into sharp focus particularly as participants engaged with the health care system. For example, a hospital visit for an appointment demanded all four kinds of work to be able to negotiate a successful engagement, as Figure 8 illustrates.
Living on was a process that unfolded within a social world, but it was influenced (at times heavily) by the biomedical world, and it required skills and knowledge to negotiate both of these worlds successfully. This negotiation demanded an in-depth understanding of the complexity of the health care system and institutions that comprised it. Thus, it implicated hospitals, community health services and social services, as well as their particular discourses, organisational cultures and physical layout. This in-depth understanding enabled participants to manipulate, more or less effectively, their interactions with these institutions and the system as a whole.

This section has described how participants managed, organised and integrated the work that they did to live with myeloma. The different kinds of work have been described based on their focus of effort and management, knowledge, the body, emotions and
organisation. Some work exists because of the illness; some work continues despite the illness; but all work requires time, and this is the topic I will turn to next.

**The temporal landscape of living on**

A temporal landscape is how time is perceived, structured and organised, and these perceptions impact on the prioritisation and allocation of time [443-446]. Illness often imposes a new awareness of time, creates a new relationship to it [447], and thus creates a new temporal landscape. This was also a feature of the ‘new normal’. *Living on* gave rise to a new temporal landscape and a new perception of time [262, 443, 444] that differed from the perception of time before diagnosis, and that therefore differed from others’ perceptions of time. Participants became increasingly aware of time both as a medium in which they lived, and as a limited resource that had to be managed efficiently. Attending hospital appointments and treatments was time consuming; for example, one treatment could take all day and everyday activities such as taking a shower often took much more time to complete. When the life-limiting illness of myeloma was diagnosed, both aspects of time (i.e. time as medium and resource) came into sharp focus. Time, which is so often taken for granted as if it were a limitless resource, suddenly became finite, as the participant was confronted with the certainty of their time ending. Death, likewise, changed from an abstract notion to a very real one. Therefore, time became scarce, valuable and not to be wasted. It now had to be navigated, appropriated and allocated differently, according to the new temporal landscape.

Time can be used as a means to help individuals to understand and place their illness in a life perspective that has a past, a present and a future—but is ‘not solely limited to what has happened’ [448 pp95]. This idea, that the experience of time can be diverse and plural has been conceptualised as ‘shadow time’ [441, 448, 449]. The idea of shadow time posits that there are ‘multiple concepts of time for diverse purposes and circumstances’ [449 pp3]. It is important to pay attention to aspects of temporality that are inherent in the research project itself.
The way that participants talked about their experience and management of time suggested that it was an important and personally idiosyncratic component of their experience of living with myeloma. Participants described time both as a medium and as a resource.

Time as a medium has been described in three ways in this thesis:

- as units of conventional time segmented into periods of culturally understood units of time, such as years, months, hour and minutes
- as segments of biographical time using personal events and markers in their lives, such as birthdays, anniversaries and diagnosis of myeloma
- as a subjective experience that could be stilled, stretched or compressed and could be non-concordant with conventional time and with other’s experience of time.

Participants described time as a resource that had to be carefully managed and efficiently allocated because of its scarcity. Managing competing demands for time was often described as a struggle. Time was also featured as a prominent theme in participants’ stories as a ‘dimension’ (in the sense of an environment [450]) in which they experienced their myeloma and within which they told their story. Time underpinned evaluative comparisons that they made in order to make sense of their situation. Temporality (i.e. an individual’s relationship with time) is said to be central to our lives as individuals [253], and it has been clearly illustrated in the literature that illness disrupts anticipated experiences of lived time, such as temporal orientation [241] [200, 242-245]. The idea of markers in time [199, 267, 270] and emplotment [271, 272] were useful in exploring participants’ experiences of segmented time.

In this study, participants talked about time in terms of conventional units (such as hours), in terms of biographical ‘segments’ of time and as a subjective experience (‘inner time’).

Conventional units of time serve to impose order on activities. They are found in clocks, calendars, timetables, timelines, and time limits and the redefinition of everyday activities in terms of clock time. Myeloma creates demands on other people’s time,
through appointments and consultations for diagnostic tests and treatments. Biographical time provided markers and events through which to understand and order the lived experience.

As participants told their stories, they referred to conventional units of time such as days, weeks, months, and year. They also marked time by referring to significant events such as births, deaths, marriages, and holidays. And they also referred to an additional set of markers that related specifically to myeloma, such as diagnosis, transplant, progression, remission, plateau, and relapse.

In keeping with findings in the literature, diagnosis represented a major biographical “fault line”: there was a life before diagnosis, to which one could never return; and there was life after diagnosis, which was ongoing. Life before diagnosis was fundamentally, qualitatively different from life after diagnosis. Serious illness thus begins with a halt [451] and what was known as normal life ends. One suddenly becomes uncertain about those things one takes most for granted, such as faith in, and integrity of, one’s body; one’s role in other people’s lives and their role in one’s own life, and the future. This is the moment of biographical disruption [200]. Once the immediate shock of diagnosis and treatment has passed, the experience of time has been described as one of liminality, uncertainty and disorientation [183]. In other words, one experiences time neither as a person with cancer, nor as a person without cancer. Thus on different occasions during this study, some participants were neither people with myeloma, nor people without myeloma. Some described themselves in this liminal state when they were in remission. For Etna, it arrived at diagnosis, as she was not convinced that she had myeloma at all, even though she underwent treatment. For some participants, the uncertainty following diagnosis became a certainty in two ways. Firstly, the uncertainty became the norm: one thing that was certain was that there was now uncertainty in their lives. Secondly, participants were certain that relapse and death would occur, albeit at an unknown time.
**Place markers in time**

Participants used place markers, referenced often by time, to situate an event or experience in their chronology. In the interviews, participants frequently told me about events that had happened in the past—years, months or weeks ago. In doing so, they tied their story to a unit of reference that Roth [270] argued is a technique that helps to make sense of their story. They also described episodes of treatment and experiences such as pain in terms of their duration, and they gave time a forward direction by anticipating goals such as ‘survival until I’m 70’ or ‘for the next five years’ [270]. They created their own timetables [452] based on their beliefs and hopes about prognosis, their comparisons of their own health at different points in time, and their observation of others with the same disease. This served to reduce uncertainty by putting the passage of time into small, manageable units [270].

Participants provided many benchmarks to tell their life stories and to contextualise their illness experience within them retrospectively. Illness chronologies render ill people’s experiences more comprehensible [199] and ‘turning points’ or ‘existential coordinates’ [267] provide points of departure in a different direction.

Charmaz differentiated between time markers and turning points, and described turning points as identifying moments that are ‘telling’ and ‘existential’. They are moments of change that are ‘filled with new self-images’ [199 pp207]. A turning point or an identifying moment, for an ill person, is a point after which nothing is the same. As participants came to understand time differently, some decided to ‘appropriate’ time [243] and thereafter reprioritised and managed time differently.

So, time was used to create an order and to create relationships between events and was most commonly viewed as being linear. Participants described segments of time using both conventional units and using biographical markers. This synthesis of cultural and individual orders of time was their ‘autobiographical time’ [263].
Non-concordant experiences of time

Subjective, inner or ‘lived’ time was experienced rather than measured. Participants described subjective experiences of time that were non-concordant with clock or outer time. There were at least three disjunctions in participants’ experience of time; what I have called ‘temporal non-concordance’. One was when the experience of time was ‘altered’, that is, there was a perceptible non-concordance between time as it was subjectively experienced and time as it was objectively measured. Compared to clock time, time was experienced as being stilled or coming to a halt; it seemed to be stretched and ‘move slowly’, or alternatively, be ‘compressed’ and ‘pass very rapidly’ [264-266]. Time was also felt to be ‘lost’, and although this is qualitatively different to the first three, it is also a temporal experience.

The second manifestation of non-concordance occurred for participants when they experienced tensions between what was known and understood about time, particularly with respect to planning and scheduling changes and expectations in illness, what could be done before and what was possible after diagnosis. Charmaz described this as ‘temporal incongruence’, a mismatch between what could be achieved in a day before illness and what could be achieved now [199]. Pre-existing time structures no longer fitted; it was no longer an option to simply hop out of bed, take a quick shower, get in the car and arrive at a destination in a relatively seamless fashion within a few hours. All of this activity took planning and organisation when one was ill. For all of the participants, time use in relation to everyday activities was never the same as before they got ill. It also changed for those around the person with myeloma. Everything took much longer. Activities that were one taken for granted had to be ‘managed’ [267]. Participants effectively lost control of time both in the length of time taken to prepare to undertake the task and in the duration of the task itself [244].

The third example of a non-concordant time experience was when two people—for example, partners or a patient and their primary support person—had different experiences of the same ‘time’ as measured by the clock (e.g. when Fatima was shopping, she felt that she had barely left the house when Fred would call her expressing his dismay and anxiety that she had been out for ‘hours’). The temporal non-
concordance created tension as the experience of time passing was valid for each participant. This disjunction can only be understood by considering the subjective experience of time.

**Time – the resource**

Participants described how they used time as a resource in two ways: as a tool for evaluation and as a resource to be valued and managed. This finding is in keeping with Rasmussen and Elverdam’s findings [243] in which their participants experienced cancer as a disrupter of time and the diagnosis was the key marker of change. Similarly, their participants also had an increased awareness of time and experienced change in the tempo of time using time as a resource. Appropriating time resonated with the way that participants in this study prioritised and allocated time efficiently, that is, they tried hard not to waste time.

Participants in this study made comparisons between their present situation and their previous experiences, and also how they imagined themselves to be in the future. They sometimes compared their imagined, future self with others who had lived a significant number of years with myeloma. Thus they used goals of survival time to construct their future. Prospective comparisons have been said to ‘anchor future aspiration’ [453 pp167]; they set goals and therefore ‘anticipate mastery’ [453 pp167].

The ability to manage time efficiently and to allocate in it accordance with individual priorities was not always possible. Tensions created by demands from individuals and systems with differing expectations and experiences. There were a number of different stakeholders in the time of participants. These furnished a complexity of tensions, often pulling in different directions, which contributed to non-concordant experiences of time.

Managing time required skills that were themselves acquired over time as well as with experience of living with myeloma. Without them, managing time was a struggle. Charmaz [199] described how people with chronic illness were required to juggle, pace
themselves and order their time, as did participants in this study. Carers in particular had to manage time in order to organise and juggle the allocation of available time efficiently and optimally as described as a component of their work.

To sum up: time was simultaneously a medium in which to live and a resource to be managed. When the life-limiting illness of myeloma was diagnosed, both aspects of time came into sharp focus for participants. The importance of time, and the experience of ‘temporality’, was evident in the large number and variety of references to time. Conventional time and biographical time combined to provide a framework for order and understanding helping to make sense of events in participants’ lives. Attending to subjective time provides a basis for exploring non-concordance in time experiences. Paying attention to non-concordance both between partners and among families, and between providers and users of services, such as those between health care service providers and patients, was important in understanding illness experience.

**Waypoints for living on**

Participants used two objective points of reference to plan and navigate their new life course: measured time (clock and calendar time) and the numbers (i.e. their paraprotein level).

Shared understandings of linear time—such as clock times and calendar dates—together with social events and the demands of the health care system, provided points of reference in the past and for the future. Anticipated dates and periods of time duration provided markers for something achieved or something to anticipate. These included hospital visits for treatment and follow up or social events such as an expected birth, anniversary, wedding or funeral. One participant had been told at the time of his diagnosis that he could expect to live for five years and described approaching this date as if heading towards a wall beyond which there was nothing. There were no more points of reference to allow him to imagine a future. Hospital appointments comprised demands and activities that were created by myeloma and operationalised through health care system. Appointments segmented time and the time duration between appointments—six months or three months or one year, for example, told them that they
were ‘okay’ until a future appointment. Past events allowed evaluation, and future events provided a point of reference in the (new) imagined future.

The second point of reference was the paraprotein level or number. Participants used the medical gaze to make sense of their myeloma [426, 454]. Measures of paraprotein levels in the blood and/or urine provide a specific and sensitive measure of the quantity of disease that person has, and they are interpreted as indicating the effectiveness of therapy [132] and of participants’ wellness. This is similar to previous findings interpreting multiple meanings of test results in people with HIV [454] and with ovarian cancer [426]. They predicted their future and qualified ‘the kind of illness’ they were experiencing. The prognostic value of the numbers was in addition to the meanings reported by Jordens for the CA125 test and Moore et al. for HIV viral load [426, 454]. Participants talked about the numbers allowing them to live on until the next appointment; thus, the prognostic meaning was an indicator of life and offered a period of certainty until the next appointment.
Table 3: Comparison of multiple meanings of test results in HIV [454] and Ovarian Cancer [426]

<table>
<thead>
<tr>
<th></th>
<th>Measures of paraprotein</th>
<th>Measures of CA125</th>
<th>Measures of HIV viral load</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meaning 1</td>
<td>A human biological property</td>
<td>A human biological property</td>
<td>A human biological property (i.e. the amount of HIV in the bloodstream)</td>
</tr>
<tr>
<td>Meaning 2</td>
<td>An indicator of treatment effectiveness</td>
<td>An indicator of treatment effectiveness</td>
<td>An indicator of treatment effectiveness</td>
</tr>
<tr>
<td>Meaning 3</td>
<td>An indicator of prognosis</td>
<td>As an indicator of self-care</td>
<td>An indicator of the degree to which the patient is complying</td>
</tr>
<tr>
<td>Meaning 4</td>
<td>An indicator of wellness</td>
<td>An indicator of wellness</td>
<td>An indicator of wellness</td>
</tr>
</tbody>
</table>

Therefore, the paraprotein level was integral to their ability to make sense of their myeloma.

Both of these points of reference indicated the extent to which myeloma was integrated into the everyday lives of the participants. Their world had changed radically, they had learned new skills and ways of doing things, and the medical gaze as one of the ways of understanding their bodies had become part of normality.
In the following section, I use Bourdieu’s conceptual framework to explain how this devastating disease became a normal state of affairs, that is, how participants came to tolerate their environment and live with myeloma as the norm.

**Living on as habitus**

*Habitus* can help us to understand how, for participants in this study, myeloma became ‘part of life’ rather than something distinct from everyday life that needed to be ‘fought’.

As outlined in Chapter Four, *habitus* is an acquired set or scheme of dispositions that generates practices and perceptions. When *habitus* encounters a social world of which it is a product, it is like a fish in water and takes the world about itself for granted’ [334 pp127]. The concept of *habitus* is thus a way of explaining how living with myeloma can become normal or ‘second nature’. Bourdieu distinguished between two kinds of *habitus*: class *habitus* and subjective *habitus*. The former is the *habitus* as a collective phenomenon. Subjective *habitus* is embodied by individuals, whereas *living on* has a collective character. It is a shared *habitus* between people with myeloma. This study has explored the individual experience of living with myeloma, that is, the subjective *habitus*. *Living on* is the second nature that participants acquired in the field of living with myeloma, either as a primary support person or as a patient. It is important to clarify that the *habitus* was not myeloma (the disease) but *living on*, and the field in which effects occurred and experiences that unfolded I have called ‘Myelomia’. Bourdieu argued that people unconsciously develop over time (and within their social setting) beliefs, perceptions and thoughts about how to act, and these are dispositions. Whereas some elements of the *habitus* remained stable, others were constantly changing as the *habitus* was constantly reshaped by the participants [320].

The *habitus* of *living on* comprised hard work and an experience of time that was at odds with the ‘normal’ one that is experienced by those who are well, including the participants, before they were diagnosed.
Before they were diagnosed, participants all had a *habitus* as people living their lives without myeloma. When they were diagnosed with myeloma, the acquired scheme of dispositions no longer worked, and this was true for lay carers as well as for those who were diagnosed. The known world could no longer be taken for granted and they became like ‘a fish out of water’[334 pp127], suddenly aware of the necessity of health. Over time, they acquired a new set of dispositions—a new way of inhabiting their environment—which constituted a different *habitus*.

In other words, in the wake of their diagnosis, the participants’ field changed catastrophically, and their *habitus* was forced to change in order to act effectively in this new field. Their experience of living with myeloma fundamentally changed their *habitus*. When diagnosed with myeloma, participants lacked the skills and experience to understand and to manage their new and unprecedented situation. What they had previously taken for granted could no longer be taken for granted. The old *habitus*—their old dispositions and their cultural and social identity—no longer worked for them. The demands of living with myeloma prompted them to find new ways of perceiving, understanding and acting that, over time, became new dispositions. Initially, there was a disjunction between the old *habitus* and the new situation, but over time, participants became disposed to doing things in different ways that worked in their new situation. They created new norms. This did not happen immediately. It took some participants a number of years to accomplish this, but over time, they all became familiar with and immersed in their new environment and developed a new set of dispositions that fitted in with, or were attuned to, their newly familiar world [341]. In other words, their *habitus* changed to meet the demands of the new field in which they found themselves. This is consistent with the notion that *habitus* is both a structured structure and a structuring structure [326].

Participants acquired a new sense of normal as they developed a new relationship with their environment [436]. The certainties and uncertainties of living with myeloma—those associated with symptoms, death and the efficacy of treatment, for example—became familiar, and thus a certain component of their ‘new normal’, their *habitus*. Unsurprisingly, participants talked of myeloma as being part of life and not as something distinct from it, let alone something that needed to be fought off. From the
perspective of the person diagnosed with myeloma, they were not in an abnormal state and the lay carers did not see themselves as carers. They were all people for whom myeloma had become a part of everyday life, although there were times when myeloma overshadowed everything else. This happened when the disease relapsed, with the introduction of a new treatment, or when new symptoms or complications demanded attention. However, most of the time it was simply a part of normal life.

The practices of living on

Practices refer to what ‘gets done’, and how it is accomplished. For the participants in this study, practices included managing risk, managing symptoms, deciding when to call the hospital, managing fatigue to optimise the time available to socialise, and managing steroids to minimise their adverse effects. Practices such as these became ‘taken for granted’.

Using Bourdieu’s formula [455 pp101], the relationship between habitus and field, for participants in this study, can be described as follows:

\[ ((\text{Living with myeloma})(\text{health, knowledge, social & medical support and time})) + (\text{Myelomia: the community of people living with myeloma}) = \text{what individuals do to live with myeloma (myeloma work, for example)}. \]

Participants in this study described their le sens pratique or ‘logic of practice’ [218, 324]. Living with myeloma was ‘hard’ and this was a constituent of the habitus. The participants described how they struggled but they also described how they ‘got on with it’. The way that they ‘got on with it’ or struggled to ‘get on with it’ was their sens pratique. For example, Ivan experienced severe peripheral neuropathy as a side effect of one of his medications (thalidomide) but he did not report this symptom to his haematologist. This is consistent with the notion that he was living on with his myeloma. His habitus was his disposition to his myeloma and to his symptoms that had developed during the 10 years since his diagnosis. His attitude was to ‘just get on with it’, and for Ivan, this included neuropathy. He was an expert at living with myeloma and understood the rules of the game [337] in the field of Myelomia. He may not have
reported his symptoms of worsening neuropathy because he understood that this could have led to a reduction of the dose of the drug that was controlling his myeloma. Even worse, it could lead to the drug being stopped altogether. However, it is also plausible that he did not report his symptoms because they had become normal to him. He had lived with peripheral neuropathy long enough for it to become normal. It was painful and made things difficult but he had found other ways of doing things, and this had become second nature to him. The neuropathy was not something out of the ordinary; it was no longer abnormal and therefore, it was not something noteworthy to report. In short, Ivan’s new *habitus* explains an aspect of his practice.

Thus, living with myeloma was an experience that took place in a unique field—one that was different to those unaffected by myeloma, and to that of the participants before their diagnosis.

**The field of Myelomia**

A field is a network or a configuration of relationships [334] and a social space in which interactions, transactions and events take place [456 pp148]. It is a social space that both shaped and was shaped by how people live. It frequently refers to a social space where a community of individuals interact, for example, academics in the field of education (academia) [218, 337] or ballet dancers in the field of dance [331]. Every individual acts within the field and thus is capable of producing effects on it [334]. Therefore, the field is a field of forces or a force field [338] pp40–41). The field is a ‘self-contained world’ [339 pp70] and as such, the (force) field provides a boundary between inside (and insiders) and outside.

In this study, the field was the community of people living with myeloma, that is, the field of *Myelomia*. This is a social space occupied by people who are personally affected by myeloma. Members of this community included patients, primary support people and informal carers. A range of social structures shaped the field in which these participants negotiated their experience of living with myeloma.
The dominant social structure influencing this field was the health care system, which was itself a field produced and shaped by those acting within it in their own *habitus*. Those acting within this field had their own capitals and dispositions that structured and shaped the *habitus* of those *acting* within the health care system field. Examples of these included: expertise (technical, professional, cultural); technology (diagnostic tests and treatments); health care personnel (with their specialised discourses and professional cultures); institutional policies, rules and regulations; time management systems (including appointments, treatment regimens and medication times); and geography (physical access). In turn, the health care system was an important social structure that influenced the field of *Myelomia* but there were inherent tensions as some types of capital—particularly those of time and expertise—were valued differently in the two fields. The influence of the field of *Myelomia* was important in that it both constrained and gave meaning to experience by providing the context (that is, a community of people affected by myeloma).

Myeloma demanded both time and work. These factors also shaped the field, as did the meaning given to myeloma. Initially, myeloma patients interpreted their diagnosis as a ‘death sentence’ because it was a type of cancer. However, over time, they gained an understanding of the disease as something more than simply a terminal disease. They learned that it is treatable, and has both acute and chronic effects. At the same time, they also had to contend with the fact that other members of the myeloma community perceived myeloma as they initially did—as death, as pain, as finality.

*Insiders and outsiders*

Georg Simmel’s construction of the ‘stranger’ can be used to explain membership of the community that constituted this field [457, 458]. Being diagnosed with myeloma had an impact on participants’ identity [448, 459-463]. At times, this led to feelings of being different, changed, or stigmatised [238] and therefore of being ‘outside’ of the mainstream (i.e. healthy) society [182, 216, 457, 461]. Thus, participants living with myeloma were ‘strangers’ because following diagnosis, they effectively ceded membership of the general social field: ‘Their experience place[d] them outside the boundaries of those around them’ [461 pp114]. In other words their experience made
them feel changed and different or ‘deviant’ [216]. However, over time, the field inhabited by participants became the mainstream for them, and the ‘strangers’ were those not intimately affected by myeloma.

Simmel’s [458] conception of the stranger later informed Lazarsfield’s and Merton’s [464] understanding of interpersonal communication. The latter distinguished two kinds of communication: heterophily, defined as communication between two or more individuals who are dissimilar; and homophily, defined as communication between two or more individuals who are similar [464, 465]. In this study, communication and relationships changed because of changing fields as follows. What was previously homophilic communication between neighbours, friends, and work colleagues became heterophilic as the participants found themselves in a different field. People with myeloma came to understand the field of Myelomia and in the process they became more alike and no longer strangers in a social sense. Friends and neighbours often became the ‘strangers’ as they were no longer able to relate to them. This conceptualisation of outsiderseness and changes in interpersonal communication helps to explain that changed relationships were an integral part of changing fields. Participants described ‘communicative alienation’ [183] recounting how ‘others didn’t understand’ (sometimes including friends who were previously close) and how they ‘tired of explaining’. Mutual understanding within the field of Myelomia provided definition and familiarity that was normative in itself.

**Capital in the field of Myelomia**

The field is shaped by participants and by certain elements or forces that Bourdieu characterises as capital [334]. Bourdieu expanded the meaning of capital to include any kind of asset (economic or symbolic) that can be transformed and exchanged across and within different networks or fields [342, 343]. Thus, a specific type of capital presupposes the existence of a field in which the capital is valued and can be exchanged [334]. For example, experiential knowledge of myeloma may have value as cultural capital in the field of Myelomia but not in the field of professional health care.
Four different kinds of capital emerged from my analysis of the interviews: physical capital, cultural capital, social capital, and time capital. Physical capital is transient and declines and dies with its bearer [466], but it can also be converted into other forms of capital such as economic capital (money, goods or services), cultural capital (education) and social capital (social relations) through work and leisure [218, 323, 332, 466]. Cultural capital refers to the kinds of knowledge, skills and education that an individual possesses. Knowledge can be legitimated by formal qualifications within a wide social field (e.g. academic knowledge). It can also be expertise gained over time within a physical endeavour such as ballet [331]. Social capital is composed of resources that are situated in exchange-based networks of people, which could be either informal or formal (e.g. non-government organisations [NGOs]):

Social capital is the sum of resources, actual or virtual, that accrue to an individual or a group by virtue of possessing a durable network of more or less institutionalised relationships of mutual acquaintance and recognition [334 pp119]

Time has also been described in economic terms as a form of capital because it can be spent, wasted, invested, budgeted, used wisely, saved and exchanged for money [262, 467]. Therefore time can also be considered as a kind of capital.

Four kinds of capital feature in this study:

- physical capital, in the form of health (defined as functional normality)[145]
- cultural capital, in the form of expert knowledge pertaining to the mastery of risk and symptom management
- time capital, as a limited resource
- social capital, in the form of (relationships (and networks of relationships) at the individual and broader social levels that channelled support and resources.

The way that participants ‘got on with it’ or struggled to ‘get on with it’ was influenced by the acquisition or loss of these four key kinds capital in the field of Myeloma. Further, each form of capital was related to the others and their loss or gain changed the position of participants within the field. For example, if a participant started a new
treatment that created new symptoms, they lost physical capital. As they became experienced with the new treatment effects, they became knowledgeable about it and thus gained cultural capital. These capital assets shaped both the field and the habitus of living with myeloma.

Physical capital

Bourdieu understood the body as an ‘unfinished’ phenomenon, that is, as something in a constant process of becoming: ‘agents create and mould their bodies in accordance with the fields in which they are involved and the demands of those specific fields’ [468 pp107]. Bodies also have the potential to become increasingly more valuable over time as convertible capital. These ideas have been explored in studies of people who cultivate their physical being as an expression of elite status [331, 332, 469]. To be successful, ballet dancers required an unrelenting finessing of their physical capital [331 pp248]. Boxers also relentlessly forged and refined their physical capital [469]. However, when the body deteriorates, physical capital can be exchanged or transformed. Ballet dancers, for example, exchanged their declining physical capital by transforming their experience and prowess into cultural capital by becoming ballet teachers [331]. This also allowed them to extend their time in the ballet world. Aging people exchange their declining physical capital for symbolic capital such as wisdom and respect [470] and in some societies their accumulated experience brings cultural capital as they come to be regarded as wise elders.

However, for the person with myeloma, physical capital ebbed and flowed under the influence of disease (i.e. pathological processes), illness (the experience of the impact of the symptoms and pathology), technology (in the form of tests and treatment), and expertise and support (from health care professionals, primary support people and their own experience). Therefore, the body for the person with myeloma was not so much ‘becoming’ in the sense that they were developing an unfinished body project, but were responding to and tolerating changes in their body. Illness is an inability to tolerate change, but ‘health is creative and capable of surviving catastrophe’ [436 pp355]. Health and, in particular, the ability to continue to undertake activities [145], albeit in different ways, was evident in the findings as being immensely important. Health was
thus a highly valued form of physical capital that allowed participants in this study to engage in their chosen activities and to look forward with myeloma not dominating their life.

The loss of physical capital was often a component of the initial illness and therefore one of the signs that there was something wrong. Therefore, physical capital was often absent at diagnosis. Sometimes it could be gained, but usually only partially and it would be lost again with subsequent relapses or other events. The requirement of the field of Myeloma was for health as functionality [145], thus the focus was to accommodate the changes brought about by a loss of physical capital and to substitute and compensate for their loss. At diagnosis, participants were thrust into this new field and it was only later that the loss of physical capital was compensated for by a kind of cultural capital (i.e. experiential knowledge). The physical capital that participants did have, gave them symbolic power within the field because it allowed a positive comparison with others in the field—‘I am stronger/healthier than them’. Primary support people exchanged physical capital (in the form of caring labour) for symbolic capital (love, honour, duty).

* Cultural capital *

The kinds of cultural capital, in the form of legitimate knowledge, that were valuable in the field of Myeloma were emotional intelligence, experiential knowledge, practical social knowledge and biomedical knowledge. Legitimate knowledge in this field, particularly that of myeloma expertise, held different value to that in other fields (for example, the health care system field or that of medical academia).

Emotional intelligence refers to the ability to perceive, control, and evaluate emotions [471]. Participants gained this kind of cultural capital by becoming adept at perceiving, reading, understanding and managing the emotions of themselves and of others within their new field. Experiential knowledge, in particular, was accumulated over time. Participants found out what worked for them and what did not. Participants sometimes gained knowledge through their own experiences by trial and error and sometimes they learned from the experiences of others with myeloma. They found out how best to
accommodate new physical restrictions, manage risk, integrate treatment side effects and symptoms into everyday life, negotiate health care systems and rules, balance priorities and manage tensions with those holding different priorities (including health care professionals and other family members), and manage the effects of myeloma in the context of other people’s lives and events. The accumulation of practical social knowledge enabled participants to know ‘how to get things done’. In the beginning, participants did not know what was available to them in the way of practical social support—they often found out serendipitously about volunteer services, for example. Health care professionals were sometimes parsimonious with this kind of information. Accumulation of practical social support in particular could compensate for losses of physical capital. Biomedical knowledge included technical knowledge about treatments and myeloma disease and pathology, including the technical meaning of numbers. Both of these kinds of knowledge were gained through a wide variety of sources, including booklets, media (such as television), the internet, support groups, agencies such as the MFA, and from health care professionals.

The cultural capital that participants developed over time was expert knowledge of living with myeloma. Shim called this kind of knowledge ‘cultural health capital’ [346]. It was accumulated as they gained experience living with myeloma, and as they cultivated knowledge about myeloma becoming expert in their own health work (risk and mitigation work). They lacked this to begin with. Most participants had never heard of myeloma before they were diagnosed with it. They evaluated, rejected and repositioned different types of knowledge according to their own context. As they synthesised information and experience, they became experts and holders of expert knowledge in this field. This expert knowledge enabled participants to negotiate their way through the field of Myeloma. This in turn gave them power within the field and allowed them to shift their position in the field as they understood and managed their responses to diagnosis, relapse, treatment, symptoms and other events.

Participants also gained experience and knowledge about their own emotions and those of others as people responded to them differently than they did before the diagnosis. As participants gained experience and expertise, they gained more cultural capital, which compensated for their lack of physical capital. Participants learned how to manage these
events with each new (or repeated) experience and thus built cultural capital as physical capital further declined.

Social capital

Social capital consisted of the participants’ support resources, relationships and networks. Participants described a number of resources broadly categorised as support and thus social capital. There were two broad categories of social capital that could be accessed: meso and micro. Social capital at the meso level resided in hospitals, health care teams, specialist health care professionals, NGOs (such as the MFA and the Leukaemia Foundation), and access to transport and financial support (such as NGOs and Centrelink). Social capital at the micro level resided in friends and family to provide assistance with everyday activities in particular. However, resources, relationships and networks were forms of social capital only if they were aligned with the participants’ needs and there was a mutual understanding of what constituted needs and support. Participants could build their health (physical capital) through using the resources afforded by their social capital. If it was not used it, could be lost, as contacts and support networks failed or broke.

Social support usually came from family and sometimes from friends. Friends were a transient resource: they came and went but rarely featured in the accounts provided by study participants. This could have been because the data was collected from participants with myeloma and their spouse, partner or daughter, all of whom had a very close or intimate experience with the them, or, because the friends, however close they were, had become ‘strangers’, outside of their field. Health care professionals provided technological and emotional support by way of diagnosis, biomedical expertise, treatment and professional care. Participants did not describe this kind of support in their interviews in much detail. This could be because they took it for granted.

Time capital

Bourdieu did not characterise time as a form of capital but, for participants, time became a valuable, finite resource to be used wisely and not wasted. Therefore, as social
and cultural capital are rooted in economic capital but were not completely reduced to an economic form [466], so was time because it was a resource that was limited, tangible and extremely valuable. It was to be appropriated, used resourcefully and valued to its full. Time capital had a strong relationship with physical capital. If one regained physical capital, one could gain more time by being healthier for longer. For example, when a new treatment (following a relapse) reduced the amount of myeloma and put the individual into a remission, their survival was extended. It could also be gambled on an exchange for more time by being healthy enough to take on the rigours of more intensive treatment (i.e. a new treatment may be taxing in its adverse effects, but the trade-off if successful would be extended survival). If the treatment was unsuccessful (i.e. the gamble did not pay off), sometimes more physical capital was lost as the deterioration was more rapid or death was the result. With each relapse or life-threatening complication, time could be lost, that is, the time available for the future was reduced. Similarly, with a good response to treatment and being able to regain physical capital, meant that the time available may be extended again, thus gaining more time for a longer future.

Capital, power and position

Bourdieu characterised the field as the site of struggle for power between dominant and subordinate classes. Within the field, legitimacy or possession of legitimate forms of capital, are key aspects defining the dominant class.

When participants entered the field of the health care system, they found themselves subordinate to the values regarding capital in that field (particularly expertise and the use of time). Cultural capital, in the form of legitimate knowledge, was different in the field of Myeloma to that of the health care system and it shaped the two fields differently. For example, the findings of a randomised controlled trial (RCT) are held to be of high value as a form evidence for clinical practice. Clinicians thus aspire to gain funding from various funding bodies to generate legitimate knowledge and promise to undertake RCTs to gain funding that further legitimises the value of this form of knowledge. The value of this kind of knowledge is illustrated and reinforced by its position in the ‘hierarchy of evidence’, which accords little value to expert opinion and
individual experience [472]. However, in the field of Myelomia, cultural capital, in the form of knowledge and expertise, enabled participants to manage their symptoms effectively; manage risk successfully; and to understand disease, illness and treatments. Participants left their own field as normal members of their community and entered the field of the health care system as a sick person [216] but they used their skills and knowledge to negotiate this field despite having little power (position) in this field.

Time capital was also a point of difference. Time, characterised as linear time and measured and understood as clock time, is the dominant understanding of the notion of time in Western societies. The dominance of linear, measured clock time is so great that it has been described as hegemonic, rendering other understandings and experience of time invisible [262]. Linear time is commodified and thus has monetary value. This is ingrained in Western society as Benjamin Franklin’s adage ‘time is money’ suggests. Bourdieu made a distinction between ‘human time’ (subjective time experienced through action and interaction) and ‘astronomical time’ (seasons, lunar cycles and life spans) [473] and the dominant, future-orientated notions of time that organise social practices. He posited that ‘the experience of time is engendered in the relationship between habitus and the social world’ [473 pp208] thus, the experience of time was a different one within the field of Myelomia to that within the field of the health care system.

In this study, the linear time of the health care system dominated and rendered the time experiences and values of the participants invisible. Adam [262] calls this invisible time ‘shadow time’. Shadow times are times that hold value and were important sources of capital for participants but had to coexist with the dominant, clock-orientated time of the health care system. This created tensions as shadow times could not always be constrained and forced to fit clock times, especially the clock times of others [474].

Participants had experienced the dominant time culture within their pre-diagnosis field where it was the unquestioned norm. However, in their new field, everything was different and there were new norms, including an understanding of time and they valued their own time developing different ways of thinking about time—such as developing a ‘philosophy of the present’ [245, 269]. Their new experience of time was a component
of their new *habitus*. In contrast, for young men with DMD, who did not experience a disruption or sudden change, and grew up in the field where the dominant time culture was the norm, there was no catastrophic change to their relationship with their environment. They internalised commoditised linear time with ‘damaging effects’ [328]. Unable to live independently, be employed or have a normal life expectancy, these young men were resigned to being marginalised and futureless by virtue of their ‘immersion in the dominant time culture’ [328 pp565]. Paradoxically, the young men themselves did not expect to live beyond their teens as their early years were spent before the advances in technology that has extended survival for young men with DMD.

Time capital in the health care system was organised, restricted and rationed, and time capital in *Myeloma* was appropriated and valued in different ways. Time was also constructed as a valuable resource in both fields but the time capital in the health care system was seen by participants as more valuable/powerful than as capital for themselves and when a participant was acting within the field of the health care system frequently they accepted the value of the capitals therein. This was illustrated by the way in which participants organised their days around the timetabled constricting demands of the health care system rather than the other way around.

**The hysteresis effect in living with myeloma**

When a change occurs that is so catastrophic that one’s skills and understanding of the world no longer have meaning or make sense in their new situation, there is a disjunction or fracture between the field and the *habitus*. The *habitus* is suddenly unable to provide meaning or make sense of the new field. Such a fracture can occur with the diagnosis of serious illness. Bourdieu conceptualised this kind of catastrophic disjunct as the hysteresis effect [218, 324].

When participants were diagnosed with myeloma, it was catastrophic. Many of them had never heard of the disease before being told (often all on the same occasion) that they had myeloma, that it was a type of cancer, that it was incurable and that it would most likely kill them. In the face of this unprecedented new situation, there was a disjunction between the dispositions formed in the *habitus* prior to myeloma and the
new situation that included myeloma. Participants’ lives had irrevocably changed and the skills, knowledge and dispositions that worked well in their lives pre-myeloma no longer worked. It took time to acquire new dispositions and to catch up with the changes inherent in the new field into which they had been thrust.

Over time, the hysteresis effect disappeared as participants incorporated different dispositions and acquired a new habitus that worked in the new field of Myelomia. However, relapse and disease progression did not bring about such a disjunction as diagnosis and was contained within the plasticity of the habitus. A state of illness became the norm and participants talked about ‘when’ rather than ‘if’ their myeloma would progress or no longer respond to treatment.

**Conclusion**

I have described how participants accommodated, worked at, and got on with, living with myeloma as a component of their life course. The participants did not construct myeloma as something distinct from their lives but as an integral part of it. While they were initially unable to tolerate the sudden and catastrophic change brought about by their diagnosis, they accommodated the changes and established new norms (habitus) in another environment (field). Bourdieu stressed that practice is not wholly consciously organised. This ‘practical logic’ or ‘feel for the game’ works ‘outside conscious control and discourse’ [324 pp61]. In other words, as they lived on, participants came to take themselves and their new social world for granted; they did not think about it because they did not have to [347]:

> Each agent, wittingly or unwittingly, willy nilly, is a producer and reproducer of objective meaning … It is because subjects do not, strictly speaking, know what they are doing that what they do has more meaning than they know [218 pp79].

This is not to say that being affected by myeloma was not devastating, catastrophic and extraordinarily hard. There was nothing easy about it, but it became normal for them to live with the restrictions each day and undertake the hard work this entailed over time, as they became immersed in living on. It was not as if this was all they had ever known,
but it became what they knew in their day-to-day living. What they did and how they did it (their practices) became normal for them. Thus, living on was normative [159] in the sense that it created new norms for individuals living with myeloma.

This study illustrated both the complexity involved and the work that is demanded to live everyday with myeloma as a normal state of affairs. Living on is a process that demands effort and different ways of understanding time, normality and health, drawing on Canguilhem’s [159] relational concept of normality and health, and Bourdieu’s [218] concepts of habitus, field, capital and hysteresis, I have argued that the habitus of living on was one that comprised hard work and a time experience at odds both with the dominant social one and with what was previously known to participants.

The concept of living on offers theoretical traction to help account for how the complexity work and effort demanded by living with myeloma became second nature and extends what is understood about the experience of living with illness or myeloma.

The next chapter will situate the concept of living on within what is known about the experience of illness and cancer survivorship and discuss the theoretical relationships between living on and existing frameworks for understanding illness experience and survivorship.
Chapter Ten: Conclusion

Introduction

In this chapter, I will revisit the aims of this study; consider the limitations of it and situate the findings within what is known about the experience of chronic illness and cancer survivorship. I will discuss the theoretical relationships between living on and existing frameworks for understanding illness experience and survivorship. Specifically, I will discuss how Bourdieu’s concepts have been used in health and illness literature; biographical theories; and survivorship literature. Situated within these three key areas of work, I will argue that the concept of living on offers theoretical traction to help account for how complexity work and effort demanded by living with myeloma became second nature and thus a normal-state-of-affairs for participants in this study. The concept of living on extends what is understood about the experience of living with illness or myeloma by offering a framework that incorporates different ideas about biographical theories of illness (such as disruption, abruption, continuity and flow for example). I argue here that the theoretical concept of living on provides an explanation of the art of survivorship with myeloma. I will then consider the implications of this study for both research and clinical practice.

Achievement of the aims of the study

This study aimed to investigate what it is like for people to live with myeloma, after they have relapsed with their disease, in ‘the era of novel agents’. My review of the literature demonstrated that there was a clear gap in the literature about the experience of living with myeloma when the initial catastrophe of diagnosis and the initial treatments such as chemotherapy and stem cell transplant are in the past. As is evidence from incremental improvements in survival rates, people go on living with myeloma as part of their everyday life, and to date this is an experience that has not been adequately explored. I aimed to fill this gap in the literature by interviewing people affected by...
myeloma (both those diagnosed with myeloma and their carer or significant other) and analysing their stories.

Specifically, the aims of this study were:

1. to develop new knowledge about the experiences of people who are living with multiple myeloma, and their primary carers
2. to develop a new vocabulary for describing and discussing the experience of multiple myeloma based on participants’ own discourse
3. to improve care for patients and their carers with multiple myeloma by using the findings to produce and publish educational literature for both patients and health care professionals.

These first two aims were achieved in developing the concept of living on as this conceptualises living with myeloma as it became the norm for participants. The concept of living on conceptualises the ‘going-on-ness’ of participants’ lives despite the chaos for both the person with myeloma and their family that was inherent in a diagnosis of myeloma. Living on explains how the demands of living with myeloma became integral components of the participants’ everyday lives and they consistently talked about ‘getting on with it’, living with events and demands that were at the same time arduous and everyday. Participants experienced many changes over time such as multiple relapses; complications of, and responses to, treatment; and hopes for remission—all of which were part-and-parcel of living and dying with myeloma. In other words, living and dying with myeloma were threads in the everyday fabric of their lives.

The third aim has been achieved and remains ongoing. I have presented findings from this study at a number of international and national conferences, research seminars, workshops, myeloma foundation support group and educational days. Educational literature and resources produced so far include DVD and 1 article in the Myeloma Foundation Newsletters (listed in appendix 5).

My own epistemic shift from that of a clinician with a medical gaze to one of a researcher seeking to understand the lived experience of myeloma with a social gaze led
me to understand differently stories with which I thought I had been familiar. Intrinsic to the experience of living with myeloma, the illness stories, the work participants described, and their relationship with time all provided the bedrock upon which to formulate a framework of understanding. As suggested in the introduction, myeloma is many things: it is a medical problem, a social problem, a personal problem and thus for those who have it, it is a part of everyday life. The stories of the participants, analysed and viewed through the lens of Bourdieu’s conceptual tools, explained how living with myeloma became a part of everyday life. This study illustrated the complexity and work that is demanded to live every day with myeloma as a normal state of affairs. Living on is a process that demands effort and new ways of understanding time, normality and health.

**Limitations of the study**

The generalisability of these research findings are limited because they were generated in an exploratory qualitative enquiry from a small cohort of participants. The findings cannot therefore be generalised to all people with myeloma, or to people with other cancers or conditions. In this study I collected a lot of data from a reasonably small number of participants so I may not have been able to detect a range of variation nor make comparisons as completely as I might have with a larger number of participants. I undertook much of the analysis alone and thus had little opportunity to compare and contrast interpretations with others. This may have impacted on my ability to be reflexive in a way that gives accounts to others, however, I feedback to patient groups and gave account in this way. There was only one method of data collection – by spoken word - due to the lack of uptake in diary use. Diary use may have, been limited to more word-based data, which is a limitation. The addition of visual data, such as drawings [475] or photographs may have provided a richer data collection [476, 477] and thus opened other avenues of interpretation. Whilst this study used grounded theory methods it did not subscribe to one particular set of prescriptive rules but rather tried to be internally consistent in its approach.

Although this study was longitudinal, the data collection period of 12–14 months may have not have been long enough to fully account for the changes inherent in people’s
lives as they survived for longer periods. A period of five years or more, commencing at diagnosis and continuing on through cycles of relapse and treatment may proved explanations about how hysteresis effect gives way to a new habitus and living on, and, how living on continues.

Bourdieu’s concepts and illness experience

Bourdieu’s concepts have been used in the health and illness literature to:

- explain health-related behaviours and to theorise relationships between class, health and lifestyle [346, 347, 478]

- explain health-related behaviours and relationships between process and agency [348, 349], and

- to explain a particular kind of illness experience [336, 341, 350, 479].

Health-related behaviour per se is beyond the scope of this study, but the way that these explanations have used cultural capital, health (physical capital) and time capital, resonates with the findings in this study. A new insight in this study is that because participants were situated within the field of Myeloma (i.e. a field different to the health care system field, or to the wider social world), it was when they had to act in other fields, that their capitals changed value. Therefore, the relationship between their capital and the field in which they had to act was changed. This demonstrates Bourdieu’s point that the value of capital is relative to a particular field.

Other studies are preoccupied with how the capital of certain disadvantaged groups loses its value when they move into the wider world, or when powerful systems invade their own. Whilst this proves Bourdieu’s point that the value of capital is relative to the field, it also misses a point: that the capital possessed by a disadvantaged group retains some value within a particular field (i.e. one defined by other people who have the same diagnosis). [328, 341, 350]. This emphasis on the context of field and things holding
value only in relation to that field was illustrated in Angus et al.’s study [350] in which people receiving long-term home care found their homes disrupted and reconfigured when practices from the health care field were imposed on them in their own homes. When participants with myeloma in this study, entered the field of the health care system, they found themselves subordinate to the values of the capital in that field.

I have considered the cultural capital of participants to be legitimate knowledge and that their expertise had a health-orientated focus. However, I was not explicit in suggesting that their expertise was about a particular topic, namely health. However, the notion of cultural health capital [346] is useful because it captures the essence of the cultural capital or expertise of participants. The health knowledge and expertise of living with myeloma, together with cultural skills and competencies about how to navigate the health system, and, crucially, how to engage successfully with health care providers, were cultivated through the experience of engaging with health services [346]. By interacting repeatedly with health services and health-related practices, participants accumulated cultural health capital such as; acquiring biomedical knowledge; managing risk; and ‘exercising calculative and future-orientated approaches to decision making’ [346 pp3]. They gained expertise and the ability to act skilfully, not through a process of detached, intellectual reflection so much as by being embedded in a situation [334, 350] and learning by trial and error. Similarly, participants did not purposefully seek out knowledge and experience, but, developed ‘habitual’ ways of managing their myeloma, which was ‘rooted in their experiences and schemes of thought and ways of organising action’ [346 pp4]. Cultural capital, and specifically, cultural health capital, gave patients leverage and power when interacting with health care professionals, in the field of health care. This demonstrates that know-how (practical knowledge and biomedical language) was an asset in medical encounters. Similarly, know-how was an asset in the field of Myelomia. Participants cultivated expert knowledge as they accumulated experience of living with myeloma. This was cultural health capital of a different kind to that of Shim’s [346] as it was specific to acting within the field of Myelomia although it was also useful as participants also acted in the health care field.

The influence of the field was also illustrated in Gibson’s study of young men with DMD [341]. These young men did not have stereotypical masculine bodies; they had
‘techno-bodies’. They were often seated in wheelchairs and attached to ventilators that they took for granted and saw as extensions of themselves, even though ‘outsiders freaked at them’ [341 pp510]. In their own field (that is, members of a community with DMD) they took for granted their own normal state of affairs and were quite expert in the different kinds of work that was demanded of them. But when they went out of the home, with their ‘techno-bodies’, requiring assistance from both technology and other people, they became ‘outsiders’, ‘less than men’ and ‘disabled’ [341 pp510]. Like participants in this study, they too had to undertake a considerable amount of planning and effort to go out of the home, but they too, took this for granted as a normal state of affairs.

The new temporal landscape inherent in *living on* was an important component of it and time capital held different values in the participants’ field of *Myelomia* to that of the health care system field. Temporal disruptions were created as participants struggled to appropriate time, reorganise it, and come to grips with their new experience of time. However, the new temporal landscape was different to the enduring temporal landscape of the health care field, and (as was the case with other kinds of capital) participants relinquished their time capital to that of the dominant field. They did so only when they were acting within that field. This contrasts with the young men with DMD in Gibson et al.’s study [328]. They grew up in a field where the dominant time culture was the norm; therefore, they did not experience a catastrophic change in their relationship to their environment. The effect of change (the disruption caused by the diagnosis of myeloma) enabled participants in my study to be cognisant of the change in their temporal landscape within their field of *Myelomia* whereas, Gibson’s young men had experience of only one temporal landscape that was at odds with their personal temporal landscape.

The few studies that have used Bourdieu’s concepts to explain illness experience share a commonality in that they have examined the embodied experience—*habitus*—of individuals or groups, within the more general field of society at large. However, this study argues that following diagnosis, participants found themselves in a different field to society at large or to their previous field (prior to the diagnosis of myeloma). They were still required to act outside of their own field (i.e. the community of people
personally affected by myeloma), which created tensions and problems as I have described. Acting in their new social world that included myeloma, they took things for granted. They had plans, goals, activities and interests as they always had, but as they ‘locate[d] the source of their practice in their own experience of reality’ [325 pp60], their world view had radically changed. Thus, the hardship and work of myeloma in the new field became routine and a normal state of affairs. In other words, their health-related behaviour [347] (i.e. their myeloma work) and accommodation of the changes brought about by myeloma were not so much deliberate decisions [207], but ‘a routinised feature of everyday life, something that is woven into its very fabric’ [347 pp583].

One example of work that was undertaken was risk work. The idea of a risk environment, such as being immune compromised, may be useful in exploring the experience of living with myeloma, or any illness or context where immunity is compromised. Crawshaw and Bunton [480] sought to understand choices made by young men with regard to drug use and risk. They used the Bourdieu’s [218] theory of practice to consider their participants’ risk environment as a habitus. The young men in this study were understood to be acting within a habitus that constructs the risk of taking drugs as an ordinary event, and thus, coming from this environment, they were not active risk takers because taking drugs was a routine and ordinary thing to do. This way of framing the drug taking activities of these young men puts the findings in contrast to existing work [480]. If immunity was the field [481 pp186], living with compromised immunity became a way of living that was informed by the ‘expectations and precedents set by the habitus’ [480 pp280] and thus, risk work became a disposition. Two of the expectations and experience of people with compromised immunity were that they may become rapidly and suddenly critically ill or, that they may succumb to infection from a normally minor event such as a scratched hand while gardening. The goal of risk work was to prevent or reduce harm (such as infection or injury) and thus the work of assessing risk became a practice [324], that is, ‘a way of doing something determined by a collective history or experience within a particular group’ [480 pp279]. Over time, participants integrated risk work - together with the other kinds of work - into their everyday lives: it became part-and-parcel of living with myeloma, and thus the norm.
Illness as the norm

Living on provides an additional explanation for how myeloma (as an illness) became the norm. There are three key existing explanations for how illness can become a normal state of affairs. One is the functional view of health [146, 148], one is transition and adaptation [11, 212, 233-235, 482-490], and one is the theory of normal hardship [189, 208-210].

Functional health as the norm

An individual is said to be functionally healthy when they have the capacity to support their goals, projects, and aspirations [146]. People with chronic illness describe ‘functional health’ when they define health as ‘being able to the things [they] want to do’ [148], and they ‘do’ functional health by normalising illness and accepting it as an integral part of their everyday lives. These older individuals focused on their attitudes and activities, rather than their illnesses. This is what Antonovsky describes as ‘salutogenesis’ [156, 157] and is a component of living on in that participants in this study also focused on the impact of their symptoms and what they did to get things done. They talked about their ‘workarounds’ rather than their symptoms.

The slippery nature of the status quo

As previously discussed, normalising illness has been characterised both as a coping mechanism and as an embodied process. Sanderson et al. [240 pp618] proposed a typology of normality in illness that resonates with my study. Living on, however, explains how normalising illness is not an entirely agential process – although the work of illness is an important component – but living in a new norm becomes an unreflexive state of being. The slippery nature of the status quo was illustrated in the varying magnitude of distress associated with symptoms of myeloma [117] at different times. Sanderson’s participants with rheumatoid arthritis responded to changes in symptoms and treatment and characterised different kinds of normality according to their
experiences at the time. As with these individuals and those with motor neurone disease [223], participants in my study were required to make continual adjustments in a ‘repeating cycle of confronting each new phase of deterioration and improvement and incorporating it into normal daily life’ [240 pp9619]. Thus normality is a dynamic process rather than a static state of being [223]. Locock et al [223] conceptualised a shift from biographical disruption at diagnosis to re-establishing a sense of normalcy as ‘biographical repair’. This resonates with living on and offers a description of process, however, living on provides a theoretical explanation that transcends the tension between disruption and continuity. First, the hysteresis effect offers an explanation of how disruption becomes accommodated within the cultivation of a new habitus: Second, the notion of a habitus that includes illness or an expectation of an illness diagnosis, provides an explanation for why an illness is not always disruptive.

The ‘fluctuating’ models of living with chronic illness [211-213, 230] suggest distinct variations and phases in adjustment to illness. Living on accounts for these fluctuations within the plasticity of the (new) habitus; however, myeloma is a terminal illness, thus the fluctuations and accommodations are a ‘downward’ spiral or a continuing process of adjustment to new symptoms, treatment effects and deterioration. Possessing various capitals may enhance or hinder the kind of shift the individual is able to make. For example, patients who know about anticipated adverse effects of treatment know what to expect, and this enabled them to prepare for it (e.g., planning to do very little on the days immediately following their steroids). This tacit knowledge and planning enabled them to integrate the effects of steroids into their everyday normal lives.

Living on frames myeloma as a normal-state-of-affairs rather than as a disruption. This is different to Kelleher’s theorisation of normalisation (in relation to diabetes) as one of three ways of living: coping or being in control; agonising over it; or normalising it. Normalising it included ‘an element of denial that their diabetes caused significant problems’ [491 pp153]. This is different to findings in my study as participants were clear and very aware of the significant problems that myeloma caused, including the knowledge that it would kill them.
The ‘theory of normal hardship’ where illness is something to be expected and not out of the ordinary in the course of a life [189, 208-210] is best explained in relation to other biographical theories of illness.

**Biographical theories of illness**

The impact of illness on an individual’s assumptions about themselves, their future and their world has been conceptualised as biographical disruption [200]. This idea has been challenged as not being able to account for all experiences [220] and alternative concepts have been theorised in different chronic illness circumstances. Illness in some circumstances—namely among people who are older, already living with illness or socially marginalised—has been found not to be a ‘disruption’. ‘Biographical flow’ [209], continuity [189, 208, 226] and even biographical reinforcement [225] have been used to explain why some people’s lives are not always disrupted by illness. Concepts of biographical abruption and repair [223], fracture [224] and foreclosure of disruption [210] suggest that when there is disruption, it can change and become a part of normal life, or can continue to be disruptive as new and feared complications come to pass [230]. The theory of normal hardship [189] has been drawn on to suggest that, in hard or adverse circumstances, such as material deprivation [220 pp50] or old age [208, 209, 226], sudden illness does not disrupt personal expectations, plans and everyday activities [200]. Thus, illness does not always demand ‘a fundamental rethinking of the person’s biography’ [200 pp169].

So although biographical disruption has been used to characterise the immense changes demanded by chronic illness and it is important to consider that this may be different in terminal illnesses such as myeloma. Brown suggests that MND ‘lies astride the terminal and chronic categories’ of illness and that this is ‘an uneasy interface’ [229 pp216]. Participants in my study also sat astride these categories but with the addition of acute illness. They described existential shock and ‘biographical abruption’ when they were first diagnosed with myeloma, as this was when they learned that myeloma is an incurable and terminal disease. However, unlike the participants in Locock et al.’s [223] study, participants in my study talked about myeloma being ‘incurable but treatable’. Their biography was ongoing – for now (i.e. they experienced both disruption and
discontinuity). ‘Biographical abruption’ and existential shock were clearly features of their experience early on, and major contributing factors to the hysteresis effect. However, over time, they integrated the effects of living with myeloma into their everyday lives and thereby ‘got on with it’. This phrase is used by participants in Sinding’s [210] study who either foreclosed on the disruption or experienced it only for a short time. In addition, the characterisation of ‘biographical flow’ as an ‘overall continuity of daily life’, which is focused on ‘doing’, ‘being’ and function and the ‘significant embodied and emotional work’ [224 pp184] rather than finding meaning, resonates with findings in this study.

Living on and particularly the hysteresis effect extends current understanding of biographical disruption [200] and biographical flow [209], the relationship between biographical abruption and repair [223] and the tensions in accounts of ‘disruptive’ events in the lives of people living with and losing function due to chronic conditions over many years [230], by providing an explanation that accommodates both disruption and continuity. Over time, it became normal to live with an illness that transitioned into different states [158]—acute, chronic and terminal. This process of transformation over time can be understood, using Bourdieu’s thinking tools, as transitioning from a non-myeloma habitus (prior normality), through hysteresis to a new habitus (‘new normal’) that included living with myeloma. The resolution of the hysteresis effect through the emergence of a new habitus may be responsible for restoring a kind of balance and thus, (functional) health. The persistence of a hysteresis effect, if an individual was unable to accommodate or adapt to their new situation for whatever reasons or circumstances, may demonstrate a persistent state of biographical disruption. In short, illness disrupts biography, people work to effect repair and the concept living on offers an explanation and synthesises these two theses.

Participants differentiated between their symptoms and the disruptive impact of their symptoms on their lives and their ability to undertake everyday activities. For example, Ivan described his profound difficulty making a cup of tea or crossing the road safely when talking about his experience of peripheral neuropathy, but he mentioned the pain and numbness only briefly. When Kira told me about her pain, she did not characterise
the pain itself but talked about how it restricted her social life and how she was tied to the clock for her analgesia.

Participants struggled with their fatigue, peripheral neuropathy and pain, which in turn disrupted their everyday activities to the extent that each one of them had to alter the way that they undertook tasks or had to stop doing certain things. These changes became an ordinary and familiar component of living on. Relapse, the certainty of death, pain, fatigue, neuropathy and further treatment were components of living with myeloma that were integrated into their biographies. Thus, the degree of any disruption was ‘contextual’ [221], which is to say that its magnitude was relative to the expectations and experience of the participants.

When the impact of the symptoms was highly disruptive [226], it brought to the fore the ‘illness perspective’ [213, 492]. Similarly, Potrata et al. found that personal meaning and context attributed to symptoms were determinants of distress in people with myeloma [117].

What kind of illness that was anticipated, and when it was expected to happen, mediated whether the illness was a disruptive or normal event [228, 493]. Illness that was expected—for example, for ‘hardworking’ ‘East-enders’ [189], older people suffering cerebrovascular events [208, 209], or older women with co-morbidities and adverse social situations [210]—was not always disruptive but an accepted component of aging or of circumstance, and thus did not create biographical disruption. In other words, there was no hysteresis effect because any changes brought about by illness were accommodated within the existing habitus of the participants.

When participants in this study were initially ‘hit’ by myeloma, it was catastrophic. They had never heard of this incurable, terminal disease. At the time of diagnosis, it was in comprehensible and they lacked the life skills and experience or ‘tacit stocks of knowledge’ [220 pp43] to know how to live with this change in their life. However, they had no choice but to do just that. Over time, they became immersed in their new way of living and came to know how to live with myeloma. Although relapse or disease progression was disappointing, it did not present another catastrophic disruption; it was
expected and understood, and thus could be accommodated. In other words, at diagnosis, the disruption was not within the explanatory framework [220 pp43] normally used by participants. However, at relapse, it was.

This finding is in contrast to findings about relapse with other types of cancers where ‘shock’, devastation’ and ‘fear’ have been described [494-497]. There may be two reasons for this difference: firstly, the participants in this study had expected to relapse; and secondly, they were interviewed some time after their initial relapse (or progression of disease). Participants described that the diagnosis was catastrophic at first, but then they became used to it. They transitioned and learned new skills and became experts in their own individual illness trajectories, which then enabled them to ‘get on with it’, and they continued to experience and expect relapse and progressive disease, thus they survived with it.

Survivors, survivorship, the ‘new normal’

The concept of survivorship has been used in two ways. It has been used as a tool to frame a survivor’s experience [498] and it has been used to describe the meaning making, skill building ‘craftwork’ required by survival [182, 499, 500]. Survivorship has been characterised as living on after a cancer diagnosis [430, 501], being a life-changing experience [502-504] [500, 505-509], and as having both positive and negative aspects [430].

There is a lack of consensus in the survivorship literature as to who is a cancer survivor and when they become one [430, 505, 506, 509-511]. As discussed in Chapter Three, for the purposes of this thesis, the working definition of cancer survivors are those ‘people diagnosed with cancer and those affected by a cancer diagnosis’ [512]. Survivor definitions that require completion of treatment and an absence of symptoms clearly do not work for this population [184, 513].

Frank offers some clarification and suggests that whereas a survivor is, arguably, someone who has overcome an adversarial event, survivorship is the ‘craft activity’ [499 pp251] which he describes as an embodied skill of surviving. Thus, while the
science of survival seeks to understand the disease, the art of survival seeks to understand the human experience of the disease [514 pp1475]; thus, this study may be characterised as a study of the art of myeloma survivorship.

In the discourse on survivorship, living on is analogous to ‘new normal’. The ‘new normal’ frequently refers to a transformation in the individual following a cancer diagnosis that can be experienced in a number of domains. The embodied ‘new normal’—the way in which people experience their survivorship—comprises the realisation that returning to the old normal may not be easy or possible. Further, it includes adaptation to this fact. Little et al. [183]—referring to survivors who have completed treatment and are free of symptoms—characterised cancer survivorship in terms of ‘liminality’. In other words, individuals pass through cancer illness and treatment but cannot return to their world as it was before diagnosis. Survivorship has been described as a life-changing experience because it prompts people to re-prioritise what is important in their lives [32, 503, 504, 507, 509, 515] or may include adopting a new sense of purpose in life [500, 503-505].

Experiencing a ‘new normal’ may mean adopting a new lifestyle that is focused on health and wellness [502, 516, 517] or focused on pushing the boundaries in athletic or sporting arenas [508]. It may include living with the effects of treatment such as pain, fatigue, infertility, depression, dyspnoea, cognitive impairment or neuropathy [518-522], and it almost always includes profound existential uncertainty arising from the constant fear of recurrence [184, 185, 501, 504, 509, 515, 519, 520, 523]. A component of living on was the certainty of uncertainty. Similarly, Maher & De Vries found that for people with myeloma ‘uncertainty became a way of life’ [144 pp268]. Participants in this study talked about uncertainty as being a component of their normal world. However, they talked of relapse, recurrence and/or progression of their myeloma with certainty. They did not talk about if their myeloma would progress but when and they did not talk about if they would die of their myeloma but when. Participants could not be members of the ‘remission society’ despite having ‘troubled bodies’—the chronically ill and those who are effectively well but whose disease can never be considered cured[182], because another certainty was that they remained tied to the demands of professional health care.
Living on as a ‘new normal’

According to the idea of living on, normality is what follows hysteresis. Living with myeloma is the ‘new normal’ state of affairs—not in an agential adaptive sense, in an everyday this-is-how-it-is-now, sense. Participants did not embrace new lifestyles or describe having found a new purpose in life, nor did they use battle metaphors. They did talk a great deal about ‘getting on with it’. Their ‘new normal’ was immersion in a new way of living—one that was not chosen but imposed by necessity. Thus living on is a conceptually different kind of ‘new normal’ that perhaps has better resonance with the ‘new normal’ of the financial discourse, which refers to a state of affairs rather than a change brought about solely by a particular person’s agency. The ‘new normal’ of living on is agential in that it demands hard work but this was an integral component of the ‘new normal’ state of affairs rather than a focused effort aimed at normalisation.

Implications of the study for future research

Many types of cancer are now successfully treated and managed as an incurable but treatable condition and arguably, this has changed the way people live with their cancer. Verification of the findings in this study could be sought in other populations with cancer diagnoses. Verification could also be sought in populations who are living everyday - often for many years - with chronic conditions such as diabetes, chronic heart failure or osteoarthritis, for example.

This study extends the work of Bourdieu in the way that it uses his concepts to explain findings in this study. The implications for Bourdiesian scholarship are that the concept of living on that extended the concepts of habitus, hysteresis and field together can be used to frame studies that explore illness experience. In addition, looking at fields in relation to other fields that are relevant in living with illness as well as exploring the mechanisms of the field – incorporating the concept of doxa, for example - or additional
work examining the role and kinds of capital in illness experience, would all provide new ways of understanding illness experiences. Although this study was longitudinal, a study over five years or more, commenced at the time of the participants’ diagnosis may offer a more in-depth explanation of how the new habitus of living on came to be. In addition, using Bourdieu’s conceptual tools as a pre-ordained framework for analysis with a larger cohort of people would also extend the theoretical explanations developed in this study.

I have argued that illness disrupts biography, people work to effect repair and the concept living on offers an explanation and synthesises these two theses, therefore, this study has implications for further work in regard to the ‘biographical turn’ in the illness literature. This study provides an explanation for the tensions between disruption and continuity and therefore, further investigation and development of this notion of normality as a relationship with environment may extend conceptual development in the biographical illness literature.

There are implications for the survivorship literature. Firstly, some groups are overlooked, people with myeloma and other haematological cancers, for example. There is much biomedical research about myeloma and other haematological malignancies, but almost none exploring the personal experience of these illnesses. In the introduction and literature review I have discussed how biomedical research has fuelled important developments in treating myeloma in doing so, has enabled people to live longer. Living longer, however, comes at cost as people with myeloma have to endure repeated cycles of relapse and treatment, so they spend much of their time undergoing treatment in addition to managing the everyday work of living with myeloma. It is this group of cancer survivors that is often overlooked in the survivorship literature – those who need ongoing cycles of treatment as surviving within a spiral of acute, chronic and terminal illness, sometimes requiring treatment and sometimes not.

The work of illness has been explored, however, information work in particular has been examined in the literature with only with regard to seeking, obtaining, evaluating and assimilating it, but there is little research with regard to disclosure of information (by patients and partners) within the context of illness management. Risk work, as in
this study, and decision making within a context of immune suppression has not been explored and using the concept of a risk environment as *habitus* may offer more understanding of how decisions are made for people at significant risk of infection.

The work and experience of carers has been explored in this study as part of a dyad, in other words as a part of the whole experience of living with myeloma. The skills and work demanded of carers, and the profound changes to their lives and the way in which they accommodate them, *in addition to their other work*, has been little explored.

A final point to note is that the literature conceptualising health or illness work is focused on maintaining or improving health and on chronic illness work, and as such, does not examine work in acute illness nor terminal illness, nor illness that transcends one single category, such as myeloma.

**Implications of this study for clinical practice**

The study has a discursive aim: to generate a vocabulary that grows out of – or that is somehow appropriate for – the experience. Concepts such as *living on* and the use of Bourdieu encode the understanding that has been gained in this study, and thereby make it possible to share. One of the possible implications is that the insight gained through *living on* can be shared more readily. So instead of couples fighting and drinking for two years on the assumption that one of them is about to die from cancer, they might be able to benefit from the practical wisdom of other patients who have to endure this extraordinary and unusual confluence of certainty and uncertainty. Sharing the findings with people affected by myeloma at support group meetings and educational days for people with myeloma has been evaluated as helpful and insightful by those attending. Comments such as ‘it made me feel normal’, ‘yes, that is what it is like’ and ‘I am not alone’, suggest that sharing research findings such as these with people affected by a rare illness like myeloma has a beneficial effect. It may contribute to shortening the period of disruption, of hysteresis, by providing an illustration of living with myeloma when the dust of diagnosis has settled. In addition, sharing findings such as these acknowledges the expertise and contribution to self-management that people with illness make, in partnership with health care professionals.
I have argued that living with myeloma becomes an everyday state of affairs. This then demands a more person centred approach in clinical assessment, because symptoms that may be mitigated through pharmacological and non-pharmacological therapies, have become a part and parcel of the norm, and thus not recognised as reportable. Clinical history taking and assessment, generally, tends to be focused on areas of interest to the clinician and therefore, often come from a biomedical paradigm. For example, some symptoms, such as cancer-related fatigue, are frequently under-reported and there is wide variation between patient’s and the clinician’s perceptions of its importance and impact. Thus, questions about fatigue frequently elicit a response that this is not a problem to the patient. However, recognising that the symptoms and impact of the illness had become the norm for the patient, may change the way in which the clinical assessment is undertaken. In particular, taking a more qualitative approach with open questions may allow the patient to describe their experience, which in turn may demonstrate how the symptoms have become the norm for them, but can be relieved by effective clinical management.

An area that is paid limited attention to in the clinical setting is that of teaching carers about the skills and work demanded them, and the immense changes to their lives that living with an illness, such as myeloma, brings about. There are support resources available but less attention is focused on developing the skills – e.g. time management and organisational skills, emotion work skills – that carers and family members need to negotiate and manage illness as a component of everyday life.

This study has shown how patients and their carers have non-concordant experiences of time and how people living with illness have non-concordant experiences of time with that of the health care system. Time organisation in the health care system is organisation centric rather than taking into consideration the time needs of the people it seeks to serve. This study may also provide a way of understanding social tensions that originate from differing perspectives on time and non-concordant experiences of time, and in doing so, provide a way of addressing some of these discords.
Concluding comments

With the exception of much of the literature described in Chapter Two, a large proportion of the literature examining illness experience offers descriptions, which are equally important, rather than offering explanations or theory generation. The concept of living on, through the theoretical lenses provided by Bourdieu and Canhguilhem, offers a philosophically, sociologically and biologically refined concept of normal, which is crucial to understanding the experience of illness as a new way of life. This study contributes to what can be known about illness experience by explaining how myeloma can become a normal state of affairs rather than simply a description of how people live with it.
References


432. Kimmel Cancer Center. Navigating the New Normal – a Program to Provide Support and Education for Individuals between the Ages of 18 and 40 in the
Philadelphia Region Who Are Living with Cancer or a History of Cancer.  
Cited 12/10/11;  
http://www.kimmelcancercenter.org/kcc/clinical/patients/supportprograms/navewnornal/

http://www.runnersworld.com/article/0,7120,s6-243-588--13997-0,00.html


Appendices

Appendix 1: Table Criteria for evaluating disease response and progression in patients with multiple myeloma treated by high dose therapy and haematopoietic stem cell transplantation............................................................... Page 38

Appendix 2: Sample Interview Question Schedule. ..........................................................Page 40

Appendix 3: Participants Information Letters and Diary Guideline ..................Page 43

Appendix 4: Ethics ........................................................................................................ Page 53
Appendix 5: List of presentations and publications .............................................Page 66
Appendix 1:

Criteria for evaluating disease response and progression in patients with multiple myeloma treated by high dose therapy and haematopoietic stem cell transplantation.

<table>
<thead>
<tr>
<th>EBMT Criterion</th>
<th>EBMT Definition</th>
<th>IMWG Criterion</th>
<th>IMWG Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complete Response (CR)</td>
<td>Absence of findings of myeloma in the bone marrow or peripheral blood. The disappearance of soft tissue plasmacytomas &amp; no increase in the size or number of bone (lytic) lesions. Must be for at least 6 weeks.</td>
<td>Stringent Complete Response (sCR)</td>
<td>CR + Normal free light chain assay</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Complete response (CR)</td>
<td>Absence of clonal myeloma cells in bone marrow</td>
</tr>
<tr>
<td>Partial Response (PR)</td>
<td>At least a 50% reduction in the blood serum paraprotein and, if present, at least a 90% reduction in urinary light chain excretion, at least a 50% reduction in the size of soft tissue plasmacytomas and, in the case of non-secretory myeloma, at least a 50% reduction in plasma cells in the bone marrow. Must be for at least 6 weeks.</td>
<td>Very good partial Response (VGPR)</td>
<td>Detectable paraprotein but ≥ 90% reduction</td>
</tr>
<tr>
<td>Minimal response (MR)</td>
<td>25-49% reduction in the level of paraprotein, 50-89% reduction in urinary light chain excretion and 25-49% reduction in plasmacytoma</td>
<td>Partial Response (PR)</td>
<td>As per EBMT</td>
</tr>
<tr>
<td>No Change (NC)</td>
<td>Not meeting criteria for either MR or PD</td>
<td>Stable Disease (SD)</td>
<td>Not CR, VGPR, PR nor PD</td>
</tr>
<tr>
<td>Plateau</td>
<td>Stable values (ie within 25% above or below value at time response assessed) for at least 3 months</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relapse (progressive disease following CR)</td>
<td>Two of the following must be demonstrated: 1. reappearance of the paraprotein in serum or urine 2. more than 5% plasma cells in the bone marrow 3. development of new lytic lesion or plasmacytoma 4. development of hypercalcaemia</td>
<td>Progressive Disease (PD)</td>
<td>&gt; 25% increase in level of paraprotein</td>
</tr>
<tr>
<td>Progressive Disease (for patients not in CR)</td>
<td>Two of the following must be demonstrated: 1. Increase in serum paraprotein or urinary light chain excretion by &gt; 25% 2. Increase in plasma cells in bone marrow by &gt;25% to exceed 10% 3. Increase in size and number of plasmacytomas 4. Development of hypercalcaemia</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 2:

Sample Interview Questions
EXAMPLE QUESTIONS FOR PATIENTS/SURVIVORS

Prompt for first interview: In this interview, I’d like you to tell me the story of your illness and treatment to date [or ‘illness and diagnosis’ as appropriate]. Could you take me back to the time when you first realised there was something wrong, and bring me up to date?

[Below are examples of the kinds of questions that will be asked in follow-up interviews. They are drawn from a similar study of recurrent lymphoma. The exact questions may be modified in light of any unforeseen issues that emerge in the first round of interviews, and which may warrant following up. This is in accordance with qualitative research methodology.]

Last time we spoke, I did not have a list of questions, but there are some particular areas I would us to top cover today. Please let me know if I ask a question that you do not feel comfortable answering, and we can just skip that one.

Last time we spoke, [describe briefly where they were up to in the process of diagnosis/treatment]. Could you please bring me up to date by telling me what has happened since then?

[interviewer prompts]

[experience of any treatment]
[any new test results, and reactions to test results]
How did you cope?
How did your carer cope? Was this what you expected?
How did those around you cope?

Did things turn out as you expected?

Do you think you were prepared for what was to come
Physically?
Emotionally?

What effect has illness and treatment had on your relationships?
Who helped? [How did they help?]
What helped? What was your main support?
What made it harder?
Is there anything else that might have helped you?

How do you feel about the future?
[If they mentioned any plans in previous interviews, explore whether they have been able to realise them, how plans have changed etc.]

Do you think about the myeloma returning/progressing [as appropriate]?

What do you think you would do if it did return/progress [as appropriate]?

Has your view of the world changed since you became ill? [If so, how?]

Is there anything else you would like to talk about that hasn’t come up or that you think is important for us to know about the experience of having myeloma?
Appendix 3:

Participant Information and Participant Diary Guideline
RESEARCH STUDY INTO THE EXPERIENCE OF MULTIPLE MYELOMA

PARTICIPANT INFORMATION STATEMENT for patients

Investigators: Dr Chris Jordens, Univ. of Sydney
                Assoc. Prof. Ian Kerridge, Univ. of Sydney/Westmead Hospital
                Dr Stacy Carter, Univ. of Sydney
                Moira Stephens, Researcher and PhD student, Univ. of Sydney

Associate investigators: Prof. Doug Joshua, Sydney South West Area Health Service
                         Associate Prof Joy Ho, Sydney South West Area Health Service
                         Tracy King, Myeloma Foundation of Australia Nurse

Introduction

You are invited to take part in a research study into the experience of multiple myeloma. The purpose of the study is to increase knowledge and understanding about the experiences of patients with multiple myeloma, and their close friends and relatives.
who provide support. The findings of the study will be used for educational purposes, and to help to improve the services that are provided to people with myeloma and their carers.

The study is being conducted by Moira Stephens who is a researcher at the Centre for Values, Ethics and the Law in Medicine (VELiM) at the University of Sydney. The study will form the basis for Moira’s PhD degree at the University of Sydney under the supervision of Associate Professor Ian Kerridge, who is the Director of VELiM.

**Study Procedures**

If you agree to participate in this study, you will be asked to sign the Participant Consent Form and you will then be asked to do three in-depth interviews. In the first interview you will be asked to tell the story of your illness, diagnosis and treatment to date, and answer some questions about treatment decisions and your expectations. We will seek a follow-up interview 6-9 months later, and a second follow-up interview after a further 6-9 months have passed. In the follow-up interviews you’ll be asked to give an update about what has happened since the previous interview. You’ll also be asked questions that arise during the course of the study.

We expect the interviews will last about an hour on average. They will be conducted at a time and place convenient for you. The interviewer is a nurse who has experience working in cancer medicine. She is also an experienced interviewer. We’ll invite you to keep a diary between interviews to record your experiences and observations. We’ll ask to take a copy of the diary entries, but you can choose to keep the diary private if you prefer.

As well as interviewing you, we would also like to interview a person who is close to you and who provides support (e.g. a spouse, close friend or relative). We’ll ask you to nominate someone as your main “carer”, and we’ll ask your permission to approach him or her for an interview. After the second interview, we’ll also ask if there is someone else who you think would be informative about the experience of myeloma, whom we could interview.

**Confidentiality**

All of the interviews will be recorded and transcribed (typed up). You will be given a pseudonym (a false name) to help protect your confidentiality. Recordings and
transcripts will be stored securely at the University of Sydney. The recordings and any printed transcripts will be destroyed at the end of the study. Computer files containing the interview transcripts will be kept for seven years and then destroyed.

All aspects of the study, including results, will be strictly confidential and only the investigators named above will have access to the interviews and other information on participants. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

There are no additional medical tests required as part of this research, and we will not require access to your medical records.

**Risks**

Some people may become upset during or between interviews. The interviewer is very aware that the wellbeing of the participants is the major concern and that interviews may need to be interrupted or stopped altogether if they are causing anxiety or distress. If this happens, the interviewer can put you in contact with an appropriate service at the hospital where you are being treated.

**Benefits**

Some people involved in interview-based research say they benefit from talking things over. While we intend that this research study furthers medical knowledge and may improve services and care of people with Myeloma in the future, it may not be of direct benefit to you.

**Costs**

Participation in this study will not cost you anything, nor will you be paid.

**Voluntary Participation**

Participation in this study is entirely voluntary. You do not have to take part in it. If you do take part, you can withdraw at any time without having to give a reason. Whatever your decision, please be assured that it will not affect your medical treatment or your relationship with the staff who are caring for you.

Of the people treating you, no one will be aware of your participation or non-participation.
When you have read this information, Moira Stephens will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact Moira (the researcher) on 9036 3427 or Chris Jordens (chief investigator) on 9036 3406. This information sheet is for you to keep.

**Ethics Approval**

Any person with concerns or complaints about the conduct of a research study can contact the Senior Ethics Officer, Ethics Administration, University of Sydney on (02) 9351 4811 (Telephone); (02) 9351 6706 (Facsimile) or gbriody@usyd.edu.au (Email).

This study has been approved by the Ethics Review Committee (RPAH Zone) of the Sydney South West Area Health Service. Any person with concerns or complaints about the conduct of this study should contact the Secretary on 02 9515 6766 and quote protocol number X07-0085.
RESEARCH STUDY INTO THE EXPERIENCE OF MULTIPLE MYELOMA

PARTICIPANT INFORMATION STATEMENT for carers

Investigators: Dr Chris Jordens, Univ. of Sydney
Assoc. Prof. Ian Kerridge, Univ. of Sydney/Westmead Hospital
Dr Stacy Carter, Univ. of Sydney
Moira Stephens, Researcher and PhD student, Univ. of Sydney

Associate investigators: Prof. Doug Joshua, Sydney South West Area Health Service
Associate Prof Joy Ho, Sydney South West Area Health Service
Tracy King, Myeloma Foundation of Australia Nurse

Introduction

You are invited to take part in this study because you have been nominated as a person who is close to and provides support for someone with a diagnosis of multiple myeloma.

The purpose of the study is to increase knowledge and understanding about the experiences of patients with multiple myeloma, and their close friends and relatives who
provide support. The findings of the study will be used for educational purposes, and to help to improve the services that are provided to people with myeloma and their carers.

The study is being conducted by Moira Stephens who is a researcher at the Centre for Values, Ethics and the Law in Medicine (VELiM) at the University of Sydney. The study will form the basis for Moira’s PhD degree at the University of Sydney under the supervision of Associate Professor Ian Kerridge, who is the Director of VELiM.

**Study Procedures**

If you agree to participate in this study, you will be asked to sign the Participant Consent Form and you will then be asked to do three in-depth interviews. In the first interview you will be asked to tell the story of your relative/friend’s illness, diagnosis and treatment to date, and answer some questions about treatment decisions and your expectations. We will seek a follow-up interview 6-9 months later, and a second follow-up interview after a further 6-9 months have passed. In the follow-up interviews you’ll be asked to give an update about what has happened since the previous interview. You’ll also be asked questions that arise during the course of the study.

We expect the interviews will last about an hour on average. They will be conducted at a time and place convenient for you. The interviewer is a nurse who has experience working in cancer medicine. She is also an experienced interviewer. We’ll invite you to keep a diary between interviews to record your experiences and observations. We’ll ask to take a copy of the diary entries, but you can choose to keep the diary private if you prefer.

**Confidentiality**

All of the interviews will be recorded and transcribed (typed up). You will be given a pseudonym (a false name) to help protect your confidentiality. Recordings and transcripts will be stored securely at the University of Sydney. The recordings and any printed transcripts will be destroyed at the end of the study. Computer files containing the interview transcripts will be kept for seven years and then destroyed.

All aspects of the study, including results, will be strictly confidential and only the investigators named above will have access to the interviews and other information on participants. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.
There are no additional medical tests required as part of this research, and we will not require access to your medical records.

**Risks**

Some people may become upset during or between interviews. The interviewer is very aware that the wellbeing of the participants is the major concern and that interviews may need to be interrupted or stopped altogether if they are causing anxiety or distress. If this happens, the interviewer can put you in contact with an appropriate counselling service at the hospital.

**Benefits**

Some people involved in interview-based research say they benefit from talking things over. While we intend that this research study furthers medical knowledge and may improve services and care of people with Myeloma in the future, it may not be of direct benefit to you.

**Costs**

Participation in this study will not cost you anything, nor will you be paid.

**Voluntary Participation**

Participation in this study is entirely voluntary. You do not have to take part in it. If you do take part, you can withdraw at any time without having to give a reason. Whatever your decision, please be assured that it will not affect the medical treatment of your relative/friend or relationship with the staff who are caring for them.

Of the people treating you, no one will be aware of your participation or non-participation.

When you have read this information, Moira Stephens will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact Moira (the researcher) on 9036 3427 or Chris Jordens (chief investigator) on 9036 3406. This information sheet is for you to keep.
Ethics Approval

Any person with concerns or complaints about the conduct of a research study can contact the Senior Ethics Officer, Ethics Administration, University of Sydney on (02) 9351 4811 (Telephone); (02) 9351 6706 (Facsimile) or g briody@usyd.edu.au (Email).

This study has been approved by the Ethics Review Committee (RPAH Zone) of the Sydney South West Area Health Service. Any person with concerns or complaints about the conduct of this study should contact the Secretary on 02 9515 6766 and quote protocol number X07-0085.
RESEARCH STUDY INTO THE EXPERIENCE OF MULTIPLE MYELOMA

Experience of living with Myeloma study – Diary

How to use the Diary

This diary is for you to use or not to use.

You may write down thoughts or ideas or use it remember appointments and treatment details or to write how you feel – it is up to you.
You don’t have to write every day – some days you may feel like it and others not.
You may want to use it to describe how you feel on a good day, or how you feel on a bad day .. or how you feel in between.
You may want to write how you felt after an appointment, or what the doctor said.
You may want to write things that you remember in between interviews about your experience with myeloma and how it affects your life.

On completion of the study – you may keep the diary yourself or you may return it to me so that I can include your diary thoughts in the study to better understand the experience of living with myeloma and these diary entries will be made non identifiable , as your interviews have been.

If you have any questions about the diary, please do not hesitate to contact me.
Moira

Moira Stephens RN, MSc
Research Academic
Centre for Values, Ethics and Law in Medicine
Medical Foundation Building (K25)
University of Sydney , NSW 2006, Australia
Phone:  +61 2 9036 3427
Mobile:  +61 422468233
Fax :  +61 2 9036 3436
Email :m.stephens@med.usyd.edu
Appendix 4:

Ethics
22 March 2007

Dr C F C Jordens  
Centre for Values, Ethics and the Law in Medicine  
Medical Foundation Building – K25  
The University of Sydney

Dear Dr Jordens

I am pleased to inform you that the Human Research Ethics Committee (HREC) at its meeting on 20 February 2007 approved your protocol entitled "A qualitative study of the experience of multiple myeloma".

Details of the approval are as follows:

Ref No.: 02-2007/9899  
Authorised Personnel:  
Dr C F C Jordens  
Associate Professor I H Kerridge  
Dr S M Carter  
Ms M Stephens  
Professor D Joshua  
Ms T King  
Emeritus Professor M Little

The HREC is a fully constituted Ethics Committee in accordance with the National Statement on Ethical Conduct in Research Involving Humans-June 1999 under Section 2.8.

The approval of this project is conditional upon your continuing compliance with the National Statement on Ethical Conduct in Research Involving Humans. We draw to your attention the requirement that a report on this research must be submitted every 12 months from the date of the approval or on completion of the project, whichever occurs first. Failure to submit reports will result in withdrawal of consent for the project to proceed.

Chief Investigator / Supervisor's responsibilities to ensure that:

(1) All serious and unexpected adverse events are to be reported to the HREC as soon as possible.

(2) All unforeseen events that might affect continued ethical acceptability of the project are to be reported to the HREC as soon as possible.
(3) The HREC must be notified as soon as possible of any changes to the protocol. All changes must be approved by the HREC before continuation of the research project. These include:

- If any of the investigators change or leave the University.
- Any changes to the Participant Information Statement and/or Consent Form.

(4) All research participants are to be provided with a Participant Information Statement and Consent Form, unless otherwise agreed by the Committee. The Participant Information Statement and Consent Form are to be on University of Sydney letterhead and include the full title of the research project and telephone contacts for the researchers, unless otherwise agreed by the Committee and the following statement must appear on the bottom of the Participant Information Statement. Any person with concerns or complaints about the conduct of a research study can contact the Senior Ethics Officer, University of Sydney, on (02) 9351 4811 (Telephone); (02) 9351 6706 (Facsimile) or ethics@sydney.edu.au (Email).

(5) The HREC approval is valid for four (4) years from the Approval Period stated in this letter. Investigators are requested to submit a progress report annually.

(6) A report and a copy of any published material should be provided at the completion of the Project.

Yours sincerely

[Signature]

Associate Professor J D Watson
Chairman
Human Research Ethics Committee
SYDNEY WEST AREA HEALTH SERVICE (Westmead Campus)

HUMAN RESEARCH ETHICS COMMITTEE

Research Office, Clinical Sciences
Westmead Hospital Campus
Westmead NSW 2145

In reply please quote: JHTG HREC2007/2/4.15(2572)

30 March 2007

Dr Christopher F C Jordens
Centre for Values, Ethics and the Law in Medicine
Medical Foundation Bldg (K2S)
University of Sydney 2006

Dear Dr Jordens

Research Proposal: 'A qualitative study of the experience of multiple myeloma'

Thank you for submitting the above project which was considered by the Sydney West Area Health Service Human Research Ethics Committee at its meeting held on 27 March 2007. The HREC is constituted and operates in accordance with the National Health and Medical Research Council's National Statement on Ethical Conduct in Research Involving Humans (June 1999) and the GMP/RCH Note for Guidance on Good Clinical Practice.

I am pleased to advise that the Committee has granted ethical approval of the above project conditional upon the amendments as listed below being made to the Participant Information and Consent Forms Version 01 dated 5 March 2007:

- On Page 1 of 7 the title of the study and the chief investigator’s name and affiliation appear twice and one should be removed.
- On Page 2 of 7 under the heading Are there any risks? fourth line the word ‘to’ should be deleted.

The following documentation has been reviewed by the HREC:

- Scientific Study Protocol
- Interview script dated 29 January 2007 for Patients/Survivors
- Interview script dated 29 January 2007 for Carers

Please note the following conditions of approval:

- The approval of this research proposal applies to the ethical content of the study and individual arrangements should be negotiated with heads of departments in those situations where the use of their resources is involved (e.g. nursing etc).
- The HREC has the delegated authority to approve the commencement of this research on behalf of Sydney West Area Health Service.
- The Principal Investigator must immediately report anything which might warrant review of ethical approval of the project in the specified format, including any serious or unexpected adverse events and any unforeseen events that might affect continued ethical acceptability of the project.
2.

- The Principal Investigator must report proposed changes to the research protocol, conduct of the research, or length of HREC approval to the HREC for review.
- The Principal Investigator must notify the HREC of the date of commencement of the study and recruitment of subjects.
- The Principal Investigator must inform the HREC, giving reasons, if the study is discontinued before the expected date of completion.
- The Principal Investigator must provide an annual report to the HREC and a final report at completion of the study, in the specified format. HREC approval is valid for 12 months from the date of final approval and continuation of the HREC approval beyond the initial 12 month approval period, is contingent upon submission of an annual report each year. A copy of the Annual / Final Research Report Form is attached and can be obtained electronically from the Research Office on request.
- It should be noted that compliance with the ethical guidelines is entirely the responsibility of the researcher.
- A copy of the HREC’s Standard Operating Procedures is attached.

Please return the attached copy letter, signed and dated in acknowledgement, to the Research Office, together with the Participant Information and Consent Forms revised as above, ensuring all amendments are **highlighted** and an updated version number and date appears at the foot of each page. The study may not begin until final approval is given and the revised forms are returned to you marked ‘Approved’.

Should you have any queries about your study, please contact the HREC Executive Officer or the HREC Secretary through the Research Office on 9845 8183. The HREC membership details and standard forms are available by telephoning the Research Office or emailing researchoffice@westgate.whs.usyd.edu.au.

In all future correspondence concerning this study, please quote your approval number HREC2007/3/4.15(2572).

Yours sincerely

Dr Jim Hazel
Secretary
Sydney West Area Health Service
Human Research Ethics Committee

I accept, acknowledge and will comply with the conditions of approval for this project and acknowledge that compliance with the ethical guidelines is my responsibility.

__________________________  __________
Chief Investigator          Date
17 May, 2007

Ms Moira Stephens
Level 1 Medical Foundation Building K25
University of Western Sydney NSW 2006

Dear Ms Stephens

Research Proposal: A qualitative study of the experience of multiple myeloma

Thank you for your letter dated 27 April 2007 together with the following documentation for the above study, which were reviewed and approved by the SWAHS HREC Sub Committee at its meeting on 15 May 2007:

- Protocol Amendment, Version 2 dated 27/4/07
- Amended PIS Version 3 dated 27/4/07 for Patients and Carers

An approved copy of amended Participant Information and Consent Sheets Version 3 dated 27/4/07 for ‘Patients’ and ‘Carers’ are attached for your records.

Would you please ensure that any further amendments to this study are brought to the attention of the Human Research Ethics Committee.

Yours sincerely

Ms Rada Kusic
Secretary
Sydney West Area Health Service
HREC Sub Committee
17 May 2007

Dr C Jordens
Centre for Values, Ethics and Law in Medicine, K25
UNIVERSITY OF SYDNEY NSW 2006

Dear Dr Jordens,

Re: Protocol No X07-0085 - “A qualitative study of the experience of multiple myeloma”

The Executive of the Ethics Review Committee, at its meeting of 26 April 2007, considered Ms M Stephens’ undated correspondence (received on 23 April 2007), and subsequently reviewed her correspondence of 27 April 2007. In accordance with the decision made by the Ethics Review Committee, at its meeting of 11 April 2007, approval is now granted to proceed.

This approval includes the following:

- Inclusion of A/Professor P Joy Ho as a study investigator
- Change of time of recruitment from ‘at diagnosis’ and ‘prior to transplant’ to ‘at first relapse’
- Participant Information Statement (for patients) (Version 2, 18 April 2007)
- Participant Information Statement (for carers) (Version 2, 18 April 2007)
- Participant Consent Form (undated)

You are asked to note the following:

- This approval is valid for four years, and the Committee requires that you furnish it with annual reports on the study’s progress beginning in May 2008.
This approval relates to the ethical content of the study only, and you are responsible for the following:

- negotiating individual arrangements with the Heads of service departments in those situations where the use of their resources is involved,
- arranging an identity pass for any researcher who is not employed by the Sydney South West Area Health Service. You should contact the Ethics Officer on 02 9515 7899 for advice on this matter, and
- if appropriate, informing the study sponsor that the membership and procedures of the SSWAHS Ethics Review Committee (RPAH Zone) comply with the National Statement on Ethical Conduct in Research Involving Humans.

- If you or any of your co-investigators are University of Sydney employees or have a conjoint appointment, you are responsible for informing the University’s Risk Management Office of this approval, so that you can be appropriately indemnified.

Yours sincerely,

Lesley Townsend
Secretary
Ethics Review Committee (RPAH Zone)

HERO/EXCOR97-05
Dear Dr Jordens,

Project No 2008/007 (noting only) - A qualitative study of the experience of multiple myeloma

The SSWAHS Human Research Ethics Committee wishes to acknowledge receipt of your application with regards to the above project. As the Study has already been approved by SSWAHS (RPAH Zone) (Approval No X07-0065) the Human Research Ethics Committee (Western Zone) notes the study administratively.

I am pleased to advise that approval is hereby granted for this study to proceed as a Category A Project at Liverpool Hospital, on the same terms and conditions as granted by the Human Research Ethics Committee (RPAH Zone), and the HREC (Western Zone). Please note that documentation approved by the HREC RPAH Zone is to be utilised within the study at Liverpool. The Patient Information Sheets and Consent forms may only be amended to reflect the contact details for the Liverpool site.

Ethics clearance is granted for periods of up to twelve months. This project will be due for renewal on 31st January, 2008 and you must provide a Progress Report (attached) or final report by this date. If no report is supplied, ethics clearance for this project may be cancelled.

Your attention is drawn to the attached document Guidelines for Investigators which sets out not only the principles under which research should be conducted, but also the conditions under which ethics approval is granted by the Committee. Also enclosed for your information, is a copy of the document Guidelines for Responsible Practice in Research and Dealing with Problems of Research Misconduct.

Please note that the Committee must be notified IMMEDIATELY of any untoward or unexpected complications or side effects arising during the project or of any ethical or medico-legal problems that may arise. Also, any changes to the original protocol must be submitted to the Committee for approval.

Would you please quote the above project number in all future correspondence relating to this project.

Yours sincerely,

[Signature]

PROFESSOR MICHAEL FROMMER
Chairperson
SSWAHS Human Research Ethics Committee

Cc Ms Leeley Townsend, Research Development Office
Dear xxxx,

I am writing on behalf of a research team from Liverpool, Royal Prince Alfred and Westmead Hospitals and the University of Sydney to request your permission to telephone you regarding possible participation in a research project we are currently undertaking. We have previously spoken with your Doctor who felt that it would be appropriate for us to contact you.

The aim of the project is to examine the experience of having myeloma and the experiences, values and needs of people dealing with this disease and with its treatment. The focus of this project will be a series of three interviews with people who have been diagnosed with myeloma and three interviews with a chosen person or carer, over a period of twelve to eighteen months.

With your permission we would like to contact you by telephone to discuss whether you would be interested in being involved in the study. However, if you feel, for any reason, that you would rather not be contacted to discuss the study, you should complete the enclosed Objection to Further Contact Form and return it in the reply paid envelope, or contact our research officer, Ms Moira Stephens, directly by email, mstephens@med.usyd.edu.au or telephone, 02 9036 3427 or 0422 468 233.
If you are happy to be contacted and do not return the Objection to Further Contact Form Moira Stephens will telephone you within the next fortnight. The focus of this telephone call will be to give you further information about the study and to answer any questions you may have. Having received this additional information you will be given the opportunity to consent to participation in the study. You should not feel obligated to participate in this study or to continue your involvement should you wish to withdraw at any stage.

Enclosed is a three page Participant Information sheet with further details about the project and what your involvement would entail. If you have any further questions please do not hesitate to contact one of us or Moira Stephens, or we can discuss your questions when we contact you.

Thank you for considering our request. Sincerely,

Moira Stephens RN, MSc,
Centre for Values, Ethics and the Law in Medicine, University of Sydney

For the research team:

Associate Professor Ian Kerridge     Staff
Haematologist, Westmead Hospital and
Director, Centre for Values, Ethics and the Law in Medicine,

Professor Doug Joshua              Clinical
Professor in Medicine, University of Sydney,
Head of Haematology, Royal Prince Alfred Hospital

Associate Professor Joy Ho            Clinical
Professor in Medicine, University of Sydney, Staff Haematologist, Royal Prince Alfred Hospital

Dr David Rosenfeld
Head of Haematology, Liverpool Hospital

Dr Christopher Jordens
Centre for Values, Ethics and the Law in Medicine
Dr Stacey Carter
Centre for Values, Ethics and the Law in Medicine
Ms Tracy King
Myeloma Foundation of Australia Nurse
PARTICIPANT CONSENT FORM

The experience of multiple myeloma

I ………………………………………………………………………………………………….[name]
of
………………………………………………………………………………………………..[address]

have read and understood the Information for Participants on the above named research study and have discussed the study with
………………………………………………………………………………………………..

I have been made aware of the procedures involved in the study, including any known or expected inconvenience, risk, discomfort or potential side effect and of their implications as far as they are currently known by the researchers.

I freely choose to participate in this study and understand that I can withdraw at any time.

I also understand that the research study is strictly confidential.

I hereby agree to participate in this research study.

NAME:
………………………………………………………………………………………………..
Appendix 5:

Publications and Presentations
The following lists the articles and presentations that arose from this thesis or were part of the background for this thesis. The list includes public seminars and workshops that were undertaken during the course of this study with the Myeloma Foundation of Australia. Additional manuscripts involving the findings are being prepared for submission to peer-reviewed journals.

Publications directly related to this thesis

Peer Reviewed Publications


Peer Reviewed Abstract Publications


Non-Peer Reviewed Publications


Publications Indirectly Related to this Thesis


Professional Presentations

Conference Presentations

International
2011 Stephens M. How do I Transform My Niggling Question into a study and then Share it With the World? Invited Speaker. HAA Annual Scientific Meeting, Sydney


2010 Stephens M. Haematology Education the Wikiway: A Constructivist Approach to Learning, HAA Annual Scientific Meeting, Auckland

2010 Stephens M, Kerridge I, Jordens C, Carter S, McKenzie H, The work of living with myeloma. ICCN meeting, Atlanta, Georgia, USA

2009 Stephens M, Kerridge I, Jordens C, Carter S, McKenzie H, Joshua D, Ho J, Rosenfeld D, King T, Little M Habitus; the experiences of people living with myeloma HAA Annual Scientific Meeting, Adelaide

2008 Stephens M. What can Qualitative Research do for me? Invited Speaker, HAA Annual Scientific Meeting, Perth


2007 Stephens M. The changing experience of living with Myeloma. HAA Annual Scientific Meeting Gold Coast

National (Australia)


Research Seminars, Presentations, Public Workshops

68
26/3/2011  The Silent Work of Myeloma: 20 minute presentation at HSANZ Queensland State Meeting

22/9/2010  From theory to practice: Moving research findings into the clinic. Study findings presented followed by a facilitated discussion with expert panel (Consumer, Myeloma Nurse Consultant, Clinical Psychologist and a Social Worker) and the audience. Royal Prince Alfred Hospital (SSWAHS/University of Sydney),

01/9/2010  HSANZ Nurses Group Myeloma Nurses Education day, Dubbo, 60 minute lectures – Haematopoeis and Oncological emergencies

10/9/2009  Cancer Institute NSW Allied Health Haematology Education Day, 60 minute lecture (heamatopoesis) and facilitator of case discussion with actor and expert panel

25/3/2008  The Experience of Living with Myeloma: a Grounded Theory study. 30 minute presentation to Faculty of Nursing Research Group, University of Sydney

22/2/2008  Myeloma and the segway between pathology and people. 15 minute presentation linking scientific and patient experience speakers at HSANZ NG Education Meeting, North Ryde, Sydney

5/12/2007  Myeloma in the 21st Century: Living longer, living differently. 1 hour presentation, BMTNSW nurses education day

Myeloma Foundation of Australia Public Presentations


4/11/09   The Experience of living with Multiple Myeloma, research findings. 45 minute presentation to Myeloma Foundation Australia members and public, Dubbo Base Hospital
03/8/2009  Myeloma in the 21st Century: Living On. 45 minute presentation to Myeloma Foundation Australia members and public, Gosford

04/6/2009  Myeloma in the 21st Century: Living On. 45 minute presentation to Myeloma Foundation Australia members and public, St Leonards, Sydney

10/11/2008 The Experience of Living with Myeloma; Research findings. 30 minute presentation to Myeloma Foundation Australia members, Camperdown Support Group, Sydney


3/12/07 Managing Fatigue with Myeloma 45 minute presentation and Managing Immunity with Myeloma. 45 minute presentation to Myeloma Foundation Australia members and public. The Burns Club, Kambah, Canberra

16/5/07 Managing Fatigue with Myeloma 45 minute presentation and Managing Immunity with Myeloma. 45 minute presentation to Myeloma Foundation Australia members and public. Dubbo Base Hospital

Patient Resources and Literature

Stephens M Myeloma in the 21st Century: Living On. DVD recording of Myeloma Foundation of Australia (Myeloma Foundation Australia (MFA)) presentation, St Leonards, 4 June 2009. [Patient Information DVD, distributed by MFA]

Stephens M The work of Myeloma. Myeloma Foundation News Issue 18 Spring 2010 p12,13