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An Investigation into the Significance and Effect of Bowel and Bladder Dysfunction on Personal Burden for People Who Have Parkinson’s Disease

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RN; BAppSc (USyd); MA (Macqu); FCNA

Thesis submitted in fulfilment of the requirements for the degree of

Doctor of Philosophy

Sydney Medical School
The University of Sydney, Sydney

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Abstract

This research centres on the experiences of people with Parkinson's disease (PD) and how they perceive two autonomic non-motor symptoms, bowel and bladder dysfunction, both highly associated with PD. Many studies have addressed urinary and faecal incontinence among general populations; however, few have focused on populations of people with PD. Further, no evidence of the personal burden that is associated with the presence of these autonomic dysfunctions has been reported.

The position of this thesis is that the burden experienced by people with PD who also suffer from bowel and bladder dysfunction significantly affects their ability to fully participate in a social life and that the current clinical management used to treat either of these two symptoms fails to alleviate their burdensomeness. Using a novel mix of qualitative and quantitative research methods it was possible to identify the type, presence and legitimacy of the symptoms experienced by participants; how they searched for and used available clinical resources; and whether their search for additional personal resources alleviated or cause additional burdens and disruptions to their life quality.

The study comprised 67 people with PD who were experiencing a bowel or bladder dysfunction or a combination of both. They completed a series of quantitative surveys and answered semi-structured interview questions focused on the symptoms and their current management. Quantitative data were subjected to a range of descriptive and inferential statistical analyses and, to bring participants' perceptions to the forefront, qualitative data were converted into participant-generated quantitative burden scales that were used to statistically compare and contrast all other quantitative data sets, in gauging the severity and importance of the participants’ experiences. This process ensured the participants’ voices remained central though out the study.
This study is the first to reveal that (a) participant descriptions of their bowel and bladder dysfunctions are directly linked to their PD neuropathophysiology rather than to other influences commonly associated with older people; (b) the physical burdens these people recounted were significantly in excess of what would be considered common in non-PD populations suffering from bowel and bladder dysfunction; (c) the ability of these people to source information and assistance was significantly impaired by their own preconceived attitudes toward bowel and bladder dysfunction and their construction of what constitutes a legitimate health concern; (d) their bladder and bowel dysfunctions were psychologically burdensome and the presence of these symptoms created high levels of anxiety and emotional distress when compared to any of their other identified PD non-motor symptoms; (e) for these people common management practices widely used in clinical practice to treat chronic constipation provided scant symptom relief; (f) these people found the self-imposed social restrictions made in response to the unpredictability of their bowel and bladder dysfunction, affected their ability to participate fully in social activities and therefore negatively affected their quality of life.

The major strength of the study is its focus on the individual’s experience of PD, rather than on the more commonly investigated experience of informal and formal carers or healthcare providers. Burden highlighted in this way brings balance to the understanding of PD in terms of how it affects individuals and the challenges involved in managing this little known phenomena.
Student Declaration

I hereby declare that this submission is 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.

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Acknowledgments

I would like to extend my sincere appreciation to my supervisors, Professor Emeritus Trevor Parmenter AM, Professor Tracey McDonald AM for their never swaying patience and wise council and to Professor Richard Madden who in the early part of this study provided me with considerable support and guidance that I used to refine my research approach.

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A very big thank you goes to Mark, Joel my family and friends many of whom have not seen very much of me over the past few years. Your love, support and encouragement has given me the strength I needed to complete this important work.

Finally, yet not least I would like to extend my gratitude to the people who participated in this research. You so generously shared yourselves with me in the hope to make a difference to not only your lives, but to the many others living and sharing your experiences.

Thank you
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<thead>
<tr>
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<th>Full Form</th>
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<tbody>
<tr>
<td>ABS</td>
<td>Australian Bureau of Statistics</td>
</tr>
<tr>
<td>ADL</td>
<td>Activities of Daily Living</td>
</tr>
<tr>
<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
</tr>
<tr>
<td>ANOVA</td>
<td>Analysis of Variance</td>
</tr>
<tr>
<td>ANS</td>
<td>Autonomic nervous system</td>
</tr>
<tr>
<td>B&amp;MI</td>
<td>Brain and Mind Research Institute</td>
</tr>
<tr>
<td>BADL</td>
<td>Basic Activities of Daily Living</td>
</tr>
<tr>
<td>CAPS</td>
<td>Continence Aids Payment Scheme</td>
</tr>
<tr>
<td>CINAHL</td>
<td>Cumulative Index to Nursing and Allied Health Literature</td>
</tr>
<tr>
<td>CNS</td>
<td>Central Nervous System</td>
</tr>
<tr>
<td>DBS</td>
<td>Deep Brain Stimulation</td>
</tr>
<tr>
<td>DI</td>
<td>Double incontinence</td>
</tr>
<tr>
<td>ENS</td>
<td>Enteric Nervous System</td>
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<tr>
<td>FI</td>
<td>Faecal Incontinence</td>
</tr>
<tr>
<td>GIT</td>
<td>Gastrointestinal Tract</td>
</tr>
<tr>
<td>GP</td>
<td>General Medical Practitioner</td>
</tr>
<tr>
<td>H&amp;Y</td>
<td>Hoehn and Yahr</td>
</tr>
<tr>
<td>HREC</td>
<td>Human Research and Ethics Committee</td>
</tr>
<tr>
<td>HRQoL</td>
<td>Health Related Quality of Life</td>
</tr>
<tr>
<td>IADL</td>
<td>Instrumental Activities of Daily Living</td>
</tr>
<tr>
<td>ICC</td>
<td>Intra-class Correlation Coefficient</td>
</tr>
<tr>
<td>ICD</td>
<td>International Classification of Diseases</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
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<td>ICS</td>
<td>International Continence Society</td>
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LBP  Lewy Body Pathology  
LGP  Local General Medical Practitioner  
LUTD  Lower Urinary Tract Dysfunctions  
LUTS  Lower Urinary Tract Symptoms  
NMS  Non-motor Symptoms  
NMSS  Non-motor Symptom Severity Scale  
NSW  New South Wales  
OAB  Over Active Bladder  
OTC  Over-the-counter  
PADP  Program of Appliances for Disabled People  
PCA  Personal Care Attendant  
PD  Parkinson’s disease  
PDQ  Parkinson’s Disease Questionnaire  
PDQoL  Parkinson’s Disease Quality of Life  
PDSI  Parkinson’s Disease Summary Index Score  
PNS  Peripheral Nervous System  
PPS  Parkinson’s Problem Schedule  
PSA  Prostate-specific Antigen  
PsNS  Parasympathetic Nervous System  
PSP  Progressive Supranuclear Palsy  
PwD  People with Disabilities  
QoL  Quality of Life  
S&E  Schwab and England  
SBS  Symptom Burden Score  
SD  Standard Deviation
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td>SDAC</td>
<td>Survey of Disability, Ageing and Carers</td>
</tr>
<tr>
<td>SI</td>
<td>Summary Index</td>
</tr>
<tr>
<td>SNS</td>
<td>Sympathetic Nervous System</td>
</tr>
<tr>
<td>SPC</td>
<td>Supra-pubic Urinary Catheter</td>
</tr>
<tr>
<td>UI</td>
<td>Urinary Incontinence</td>
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<td>WHO</td>
<td>World Health Organization</td>
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Chapter 1: Introduction

1.1 Background/statement of the problem

The purpose of this study is to gain a deeper understanding of two commonly reported, yet poorly investigated non-motor symptoms (NMS); the first affects the normal function of the bowel and the second affects the bladder of people with Parkinson’s disease (PD). PD is a slowly progressive neurodegenerative disorder with a highly individualised clinical picture that affects between 1% and 2% of the 3.08 million Australians over the age of 60, although it should be noted that 20% of those diagnosed with PD are younger than 60 years (Deloitte Access Economics, 2011). This means people with PD often live and age in their communities for many years, experiencing a slow unpredictable deterioration of their abilities which diminishes their independence. Many of the individual clinical symptoms, especially those affecting the motor function of the person with PD, are well explored and documented. However, little is known about two of the most commonly occurring autonomic symptoms in PD, bowel and bladder dysfunction, beyond that of their basic pathophysiological occurrence and prevalence. These autonomic symptoms have been highlighted in recent studies as common and burdensome (Chaudhuri & Odin, 2010; Gallagher, Lees, & Schrag, 2010; Li, Zhang, Chen, Zhang, Pei, Hu, & Wang, 2010; O’Sullivan, Williams, Gallagher, Massey, Silveira-Moriyama, & Lees, 2008), yet to date no study has focused on how these symptoms burden the individual and whether they contribute to decisions by people with PD about their living arrangements or choosing care and treatment in terms of the financial, emotional or social effects these choices generate.

The prevalence of PD has been estimated in European (Lees, 2010) and American studies (Wright, Willis, Evanoff, Lian, Criswell & Racette, 2010) to affect
between one to four people per 1000 population. Parkinson’s Australia, the national peak body representing Australians with PD, estimates Australia lies midway between these American and European estimates (Access Economics, 2007). Australian prevalence estimates of 362 people over the age of 50 years per 100,000 were established by Mehta, Kifley, Wang, Rochtchina, Mitchell, & Sue, (2007) in their study of people aged 50 years and over known to be taking PD medications. PD predominantly affects people over 60 years of age and is slightly more prevalent in males than in females (Australian Bureau of Statistics [ABS], 2010; Mehta et al., 2007; Soh, McGinley, Watts, Iansek & Morris, 2012; Schapira, 2008). There is little evidence that it affects any specific racial group at higher rates than others (Chan et al., 2005; Factor, Feustel, Friedman, Comella, Goetz, C. Kurlan, … Pfeiffer, 2003; Jones, Marcantonio & Rabinowitz, 2003; Miller & Daniels, 2000; Noble, 2000; Pradilla, Vesga & Leon-Sarmiento, 2003; Sloan, Sales, Liu, Fishman, Nichol, Suzuki, & Sharp, 2003). Community healthcare providers are generally of the view that PD is a commonly occurring neurodegenerative disorder affecting community dwelling older people.

The cause of PD is a slow deterioration and eventual death of neurons within the substantia nigra, found in the midbrain of the cerebellum. No definitive aetiological factors have been identified as the trigger for this neuro-degeneration (Gómez-Esteban, Zarranz, Lezcano, Tijero, B., Luna, Velasco, … Garamendi, 2007; Peto, Jenkinson & Fitzpatrick, 1998). However, current understanding is that PD is multifactorial (Schapira, 2008). The diagnosis of PD is made on the clinical presentation of four cardinal motor symptoms together with a positive response to the drug Levodopa. These cardinal motor symptoms are involuntary resting tremors; stiffness of the muscles or
rigidity; a slowness of, or an inability to initiate, movement, known as bradykinesia; and finally, postural instability caused by disturbances in the person’s gait and balance, often with an accompanying flexion of the upper body (Calne, 1995; Hawkes, Del Tredici & Braak, 2010; Krishnan, Sarma, Sarma & Kishore, 2011; Marjama-Lyons & Koller, 2001; Pahwa & Lyons, 2010; Rahman, Griffin, Quinn, Jahanshahi, Rahman, Griffin, … Jahanshahi, 2008; Siderowf, 2001; Uitti, 1998; Vaughan & Hardie, 2002).

Most commonly, a definitive medical diagnosis of PD is made when these motor dysfunctions become apparent in the mid-stages of the disease (Gómez-Esteban et al., 2007; Tolosa, Gaig, Santamaria & Compta, 2009; Zhao, Wee, Chan, Seah, Au, Lau, … Tan, 2010). Discussions among researchers of the appropriateness of using these symptoms as a definitive diagnostic tool, revolves around the frequency of diagnostic errors found at post-mortem and the likelihood that these errors may have prevented proper clinical management (Abbott, Naismith & Lewis, 2011; Abdo, van de Warrenburg, Burn, Quinn & Bloem, 2010; Newman, Breen, Patterson, Hadley, Grosset, & Grosset, 2009; Vilariño-Güell, Ross, Wider, Jasinska-Myga, Cobb, Soto-Ortolaza, … Melrose, 2010), especially in presentations of other Parkinson-like disorders such progressive supranuclear palsy (PSP) (Williams & Lees, 2009). The prevalence of misdiagnoses is believed to be diminishing with the advent and use of genetic testing, neuro-imaging and transcranial ultrasound, all of which allow accurate and earlier detection of neuron destruction (Rahman et al., 2008).

There is some disputation regarding the benefit and usefulness of this type of early detection in non-specialised generic clinical settings as the costs of diagnostic investigations are high and any consumer benefits from early diagnosis are questionable, especially if disease prevention is not yet possible (Berg, 2008) and
disease management is not dependent on or affected by early intervention (Li et al., 2010). In more recent studies, autonomic bowel dysfunction, specifically constipation, has been identified as being a reliable early diagnostic indicator and its use in diagnosis may offer a lower cost option to accurate early detection (Rayner & Horowitz, 2013; Ross, Abbott, Petrovitch, Tanner, & White, 2012).

Abbott et al (2011) concurred with these findings and drew them closer to the issues that drive the current study by stating that Australian family medical practitioners (GP) display significant knowledge gaps around all aspects of PD. Importantly, if GPs find difficulties in diagnosing and providing management options for patients with PD focused on the four cardinal motor symptoms, then it is likely that the more obscure NMS would pose more difficulty for GPs to identify as being specifically related to PD.

1.2 Limitations of previous research

Cardinal motor symptoms continue to dominate the field of PD research while the more subtle symptoms, such as slow gut motility, depression, anxiety, mental confusion, sleep disturbances, constipation and urinary incontinence (UI), remain in the background in terms of clinical recognition and treatment, despite being acknowledged as being significantly disabling. More recently, some of these NMS symptoms have been recognised as prodromal to the onset of cardinal motor signs. In the case of constipation, there is growing acceptance by clinicians that this symptom can actually be predictive of PD (Campbell, Marbella & Layde, 2000; Hillen & Sage, 1996; Li et al., 2010; Palmer, 2009; Sakakibara, Uchiyama, Yamanishi, Shirai & Hattori, 2008; Weintraub, Moberg, Duda, Katz & Stern, 2004). Still, beyond prevalence and physiology, little evidence exists about the extent to which autonomic bowel and
bladder NMS burden the person with PD and how they manage to live their lives in ways that compensate for their condition.

1.3 Need for the study

PD is one of the most recognisable and more common neurological chronic illnesses within the over 60’s Australian community. The current generation of older adults is far less likely than previous generations to adopt a passive role in the management of their disease and it is expected that they will demand a consumer-orientated approach to healthcare services (Flynn, Smith, & Freese, 2006; Redfern & Ross, 2006). Adults with PD actively seek and share information with others about their disease through a variety of mediums including the internet and via the plethora of disease-specific community organisations and support groups, such as Parkinson’s Australia (2008). These community health services begin with GPs who are under pressure to provide cost effective clinical services that meet the needs and expectations of this literate, discerning and independent older population (Abbott, Naismith, & Lewis, 2011; Nicholson, Jackson, Marley, & Wells, 2012). However, the information available to the person with an autonomic bowel and bladder dysfunction is limited, and in many instances GPs do not provide clear guidelines for evidenced-based management (Coggrave, Wiesel, & Norton, 2009). GPs have been reported to attribute these non-motor symptoms to normal ageing processes rather than to these people’s neuropathology and provide bowel and bladder management strategies that do not incorporate neurologically focused strategies (Bennett & Gaines, 2010; Depp & Jeste, 2009; Stewart, Chipperfield, Perry & Weiner, 2012). Consequently, the strategies suggested are not in line with the health consumer’s needs, nor are they compatible with the person with PD’s social context, adding to their feelings of being a burden to
themselves and others (Cousineau, McDowell, Hotz & Herbert, 2003; McPherson, Wilson & Murray, 2007). Published research indicates that the more a person believes they are burdensome to others, the more inclined they are to make health and lifestyle choices they believe will lessen the perception that they are a burden on others, but which may not be in their own best interest (Edwards & Ruettiger, 2002; Gallagher, Lees, & Schrag, 2010; Li et al., 2010; McPherson, Wilson & Murray, 2007; McPherson, Wilson, Lobchuk, Brajtman et al., 2007; McPherson, Wilson, Murray et al., 2007; Simmons, 2007).

The available bowel and bladder research mostly originates from an ageing or gendered perspective rather than from a neurological focal point and, as such, concentrates on containing incontinence rather than treating dysfunctions (Chiarelli, Bower, Wilson, Attia & Sibbritt, 2005; Kepenekci, Keskinkilic, Akinsu, Cakir, Elhan, Erkek, & Kuzu, 2011; Macmillan, Merrie, Marshall & Parry, 2004; Slieker-ten Hove, Pool-Goudzwaard, Eijkemans, Steegers-Theunissen, Burger, & Vierhout, 2010; Teunissen, van den Bosch, van den Hoogen & Lagro-Janssen, 2004; Whitehead, Borrud, Goode, Meikle, Mueller, Tuteja, …Ye, 2009). Additionally, incontinence prevalence studies have reported that many people choose not to report their bowel and bladder symptoms to their doctors. This phenomenon was identified by an Australian continence research group who attributed symptom non-disclosure to the person with incontinence (Pearson, Tucker, Bolt, Kelly, Eastwood, Finucane, & Paterson, 2002) as:

- not seeing their incontinence as a problem
- not having an expectation beyond their current self-care
- hiding the existence of incontinence due to embarrassment
- hoping the incontinence would self-resolve
• not having the words or the opportunity to explain to others, in particular their doctors.

People with PD are known to present with higher rates of bowel and bladder dysfunction than non-affected older people, yet knowledge of how these progressive neurological disease symptoms are differentiated and managed in general medical practice settings is scant (Coggrave, Wiesel, Norton & Brazzelli, 2006; Kishi, Ogawa, Sakakibara, Tateno, Uchiyama, Yamamoto, & Yamanishi, 2011; Reimann, Schmidt, Herting, Prieur, Junghanns, Schweitzer, … Ziemssen, 2010; Sakakibara et al., 2008; Tapia, Khalaf, Berenson, Globe, Chancellor, & Carr, 2013). The importance of the current study is that it specifies neurological issues related to PD, rather than taking the more common position that normal processes of ageing are the cause of symptoms. This research addresses an existing gap between what is known about these PD symptoms and the effectiveness of interventions offered to and utilized by people with PD who experience autonomic bowel and bladder dysfunction.

1.4 Aims and purpose of the study

This study explores the effects of two poorly researched PD-specific symptoms, bowel and bladder dysfunction. While these autonomic dysfunctions have been reported to affect people with PD, the nature and extent of that influence has not been explored in any meaningful way (Bannister, 2000; Coggrave et al., 2006; Winney, 1998).

The study has three specific aims that strive to address these gaps in knowledge about autonomic bowel and bladder NMS. The first is to explore what specific bowel and bladder symptoms burden the daily lives of persons with PD, as they describe them. The results of this exploration are reported in Chapter Five of this thesis. The second aim is to investigate the ways these NMS affect people’s quality of life (QoL). The
results of this exploration are reported in Chapter Six. Finally, the study aims to investigate if principles of symptom non-disclosure as described by Pearson, Tucker, Bolt et al. (2002) are applicable to this group of people. The results of this exploration are reported in Chapter Seven.

These aims are embedded in three research questions addressed in this study:

1. What are the bio-psycho-social burdens of bowel and/or bladder dysfunction for a person with PD?
2. What specific QoL factors, as measured by the PD questionnaire (PDQ)-39, are affected by bowel and bladder dysfunction?
3. What are the therapeutic experiences of the health consumer with PD, specifically regarding their reports of bowel and bladder dysfunction?

The implications of this research lie in informing future bowel and bladder treatment design, moving attention from an acute care focus where the person with PD is seen as a recipient of care, towards a more inclusive chronic healthcare focus that regards people with PD as significant contributors to the management of their own disease. The findings of this study will also contribute clarity and depth to understanding of these two PD related NMS as well as informing other people with analogous neurological diseases, such as multiple sclerosis, where the burden of bowel and bladder dysfunction is of equal concern.

1.5 Design of study/methodology

This study has used a mixed method design to enable a more comprehensive understanding of this little explored topic, to generate a picture of the types of bowel and bladder dysfunction most commonly reported and to show how these dysfunctions challenge the individual. The study participants completed a series of quantitative
surveys; The Hoehn & Yahr, a PD specific disease staging tool; the Schwab & England, a PD specific tool that identified each participants’ ability to perform activities of daily living; the PDQ-39, a QoL survey; the Non-Motor Symptom Scale (NMSS), a survey that identifies a range of PD specific non-motor symptoms in terms of their severity and frequency; and a grouping of four numerical psychometric scales that cover areas of disability, QoL, health perception and treatment satisfaction. These data were bolstered by the qualitative data collected in the form of reflective notes used to assist researcher recall and contextualisation of participant statements made in response to open-ended questions about their bowel and bladder symptoms. These qualitative and quantitative data were reviewed as a whole, giving a depth and interpretive value to both collections.

The uniqueness of this study lies in its approach to analysis of both qualitative and quantitative data. Personal qualitative statements made by participants were categorised into symptom presentation groups before being allocated numerical psychometric ratings by the participants and then combined with reflective notes into a series of quantitative data sets. The participants’ personal qualitative statements were also explored and categorised into common themes to add a rich understanding of the emotional significance to the participants of these numerical transformations. All of the resulting quantitative data sets, comprised of the standard surveys and the participant generated ratings scales, were then statistically compared and contrasted to give a multi-dimensional picture from which a connotative meaning of this condition could be extrapolated. This complex process of data collection, data transformation and analysis is explained in more depth in Chapter Four.
1.6 Outline of the thesis

The eight chapters that comprise thesis are as follows: This chapter provides a brief overview of the study, highlighting gaps in the research literature and providing the rationale and justification for undertaking the study. Chapter Two provides a contextual critique of the bio-psycho-social aspects of Parkinson’s disease and bowel and bladder dysfunction in populations of older Australians without and with PD. This review provides insights on how taking an age-centred approach to healthcare delivery has influenced bowel and bladder management for this group of people. Chapter Three explores the literature in terms of viewing PD from a disability-centred theoretical approach as opposed to more traditional age-centred theoretical models and conceptual frameworks that currently influence the health management of many chronic diseases. Chapter Four outlines the ethical and research processes used in the study, the choice of research methods and the specific characteristics of this type of convergent research.

Chapters Five to Seven present the study’s research findings with each of these three chapters addressing one of the three research questions, allowing the information to be organised in a logical structure. Chapter Five addresses Research Question 1: What are the bio-psycho-social burdens of bowel and/or bladder dysfunction as experienced by a person with PD? This chapter presents each participants’ demographic and disability profiles and includes participant interpretations of their current health and level of disability. Chapter Six addresses Research Question 2: What specific QoL factors, as measured by the PDQ-39, are affected by bowel and or bladder dysfunction? The final results chapter is Chapter Seven, which addresses Research Question 3: What are the therapeutic experiences of the health consumer with PD, specifically regarding their reports of bowel and bladder dysfunction?
Chapter Eight provides a summary discussion of the results presented in the preceding three chapters. This chapter draws together participants’ experiences, values and priorities as they relate to the presence of these two autonomic symptoms in the form of key findings. Following the presentation of these key findings, a series of future research possibilities and clinical opportunities are recommended. These recommendations are used to promote ways that could improve the lifestyle of people with PD. Specifically, in terms of reducing the burden the participants’ state, they experience living with a bowel and bladder dysfunction. A considered account of the study’s limitations is also provided in this concluding chapter alongside a reflective discussion of the study’s significance. The findings of this study will be used to generate suitable clinical approaches, which can be employed by clinicians who wish to manage bowel and bladder dysfunction among people with PD.
Chapter 2: Contextualising the burdens experienced by older people and those with Parkinson’s disease

This chapter provides a scientific and technical context for understanding the pathophysiological cause of PD symptoms and the burdens experienced by people with a bowel or bladder dysfunction or incontinence. This is achieved by exploring the construct of non-neurological bowel or bladder dysfunction in older people before investigating bowel or bladder dysfunction as a co-morbidity in those with a neurological dysfunction commonly associated with older age. Sub-sections are used to organise this review of literature, the first addresses normal age-related bowel or bladder functional changes. The second focuses on bowel or bladder changes specifically related to the person, regardless of their age with PD. The third and final section highlights similarities and differences between expected age-related bowel or bladder changes and those specific to the neurological pathology associated with PD. The importance of distinguishing between these constructs has a bearing on the successful management of bowel or a bladder dysfunction and incontinence.

2.1 Normal age-related bowel or bladder functional decline

2.1.1 Defining normal ageing.

When referring to inanimate objects like furniture or vehicles, age as a numerical measurement is an easily understood concept. The same cannot be said when compiling a meaningful picture or profile of a person. In the human genus, a slow process of organ and cellular degradation occurs naturally throughout the lifespan and both onset and effects are experienced differently by each person (Carey, 2003).
Ageing, in general, places the person at a much higher risk of disablement and disease. However, normal age-related change in physiology should not itself be defined as a disease (Tosato, Zamboni, Ferrini & Cesari, 2007).

Before Rowe and Kahn’s seminal article in 1987, ageing definitions primarily focused on the negative degenerative aspects of ageing. They struggled to incorporate the concept of normal organ and cellular degeneration within a construct of success. Rowe and Kahn (1987) were among the first to present the older person as ageing successfully if they were able to function at a high level across three defined attributes: physical, mental and social wellbeing.

Recently, definitions have moved beyond these objectively measured attributes to include subjective personal insights generated from the older person about their lived experience, giving rise to definitions of success that include optimistic and effective styles of living, together with the person’s continued ability to participate in their social and community environs (Depp & Jeste, 2009; Jeste, Depp & Vahia, 2010; Phelan, Anderson, Lacroix & Larson, 2004). It is this perspective that guides the current study in its choices of research method and data analysis.

2.1.2 Contextual use of age in health services.

Age is an important construct that is often used to define and identify the interests, values and similarities of groups of people. Australian healthcare utilises age to prioritise funding allocations and efficiencies related to service delivery for the benefit of the largest number of persons without raising concerns of favouritism, stereotyping or discrimination (McKie, Shrimpton, Hurworth, Bell, & Richardson, 2008).
Statistical collections of information about population lifespan have enabled us to estimate an average potential length of life in years. The ABS has estimated the lifespan for those aged 50 today is for Australian women, 84 years and for men, 79 years (ABS, 2010). This shows a rise in life expectancy over the previous two decades of six years for women and four years for men, making the Australian population one of the highest ranked in terms of life expectancy in the world (ABS, 2010; 2011). However, associated with this life expectancy is the likelihood of these people experiencing some of a range of conditions that fall outside the normal physiological changes of ageing.

In 2006(a), the AIHW estimated 80% of Australians over 65 years of age experienced in excess of four chronic health concerns. The ABS (2010) also reported that this group was hospitalised at a much higher rate due to these chronic illnesses than any other age-delimited group. The array of these conditions or co-morbidities can burden the older person with a high degree of disability and poorer health outcomes (Marengoni, Von Strauss, Rizzuto, Winblad & Fratiglioni, 2009; Valderas, Starfield, Sibbald, Salisbury & Roland, 2009).

Chen, Covinsky, Cenzer, Adler and Williams (2012), Alma, Van der Mei, Groothoff and Suurmeijer (2012) and Sells, Sledge, Wieland, Walden, Flanagan, Miller, & Davidson (2009) have described the negative effect of these co-morbid conditions as extending beyond their physical manifestation to affect the older person’s ability to maintain a sense of psychological and social wellbeing; ageing them beyond their actual years and, according to Marengoni et al. (2009), contributing to their overall mortality.

2.1.3 Chronic disease states in the ageing population.

A widespread expectation within Australian society is that a longer lifespan be accompanied by one’s ability to live out these additional years in relative comfort and
good health. The unpredictable nature of biological ageing has, according to Ahan, Saderberg and Lundman (2003), Dentzer and Metz (2009), Lynn and Adamson (2003), Lunney, Lynn, Foley, Lipson and Guralnik (2003) and Waite, Broe, Creasey, Greyson, Cullen, O’Toole, & Edelbrock (1997), affected this generation of older people, causing them to confront their expectations of what 'ageing well' means. The current generation of older people are unlike previous generations in that they are mostly well educated, have higher expectations of healthcare services and are not shy about making healthcare demands (Giordano, 1988; White, 2012). These demands place pressures on health service providers and planners alike, to meet the expectations of this well-informed, consumer-rights driven group, despite healthcare services being restricted by increasing healthcare costs and access to finite resources. The tension between appropriate healthcare provision and cost allocation in chronic healthcare services has become a universally shared concern, with many developed economies now looking at better ways to manage their finite capital resources while servicing increasing demands for quantity and quality in healthcare.

In 2003, the RAND corporation, a United States (US)-based think tank, published the white paper ‘Living Well at the End of Life: Adapting Healthcare to Serious Chronic Illness in Old Age’ (Lynn & Adamson, 2003). The report outlined the need for the government to recognise and make provision within an already tight fiscal healthcare budget, for an asymmetric population shift towards an ageing society. The shift was predicted to incur higher utilisation of healthcare and affect the US’s ability to provide good healthcare services to the estimated 87 million older Americans by the year 2050 (Federal Interagency Forum on Aging-Related Statistics, 2010; Nay & Garratt, 2009; Redfern & Ross, 2006). Similar profiles have been reported by other
comparable countries, Australia included, raising concerns amongst healthcare planners as to how they will effectively meet the needs of a population that uses health services at a higher rate and over a longer period of time than the much smaller population of younger people paying tax (ABS, 2009a; AIHW, 2006a; Castles & Uhr, 2007; Curtin & Lubkin, 1995; Ironside, Scheckel, Wessels, Bailey, Powers, & Seeley, 2003; OECD, 2011).

Schoen, Osborn, How, Doty and Peugh (2009) pointed to the ineffective approach used to manage chronic disease states in a similar way to that of an acute episode of disease or injury. This approach oversimplifies chronic diseases as an extended form of an acute illness that directs medical interventions along calculated timelines for treatment and cure, many of which may neither be obtainable nor achievable. Where a false expectation of cure is promoted, the danger of frustration increases for the treating doctors and the person with a chronic illness. This does little to assist the person to adapt to any lifestyle disruptions caused by their chronic disease, and also fails to generate research interest within the medical fraternity who are widely reported as perceiving chronic health problems in the elderly to be frustratingly unresponsive as well as less profitable to treat (Carter, Walker & Furler, 2002; Higashi, Tillack, Steinman, Harper & Johnston, 2012; McWilliam, 2009; Murrow & Oglesby, 1996). Incontinence is a chronic healthcare problem frequently viewed in this manner, and Wagg, Potter, Peel, Irwin, Lowe, & Pearson (2007) and Potter, Peel, Mian, Lowe, Irwin, Pearson, & Wagg (2007) claimed that the poor management of incontinence among older people is endemic.
2.1.4 Chronic incontinence among older populations.

To be continent a person must have an “ability to store urine in the bladder or faeces in the bowel and to excrete voluntarily where and when it is socially appropriate” (Getliffe & Dolman, 2007, p. 3). UI or faecal incontinence (FI) are not normal signs of ageing, nor are they chronic diseases—they are the symptoms of underlying structural or pathological change (AIHW, 2013; Kraus, Bavendam, Brake & Griebling, 2010; Landefeld, Bowers, Feld, Hartmann, Hoffman, Ingber, … Trock, 2008; Wagg, Cardozo, Chapple, Diaz, de Ridder, Espuna-Pons, … Kirby, 2008). Chronic UI and FI develop slowly over a prolonged period that differs from an acute presentation of incontinence such as is experienced during a urinary tract infection. Chronic UI and FI are known to be prevalent in older populations, in groups of women and among people with physical disabilities or those living in institutionalised settings (AIHW, 2012a, 2012b; Chiarelli, 2010; Department of Health and Ageing, 2011; Dooley et al., 2008; Kepenekci et al., 2011; Sims, Browning, Lundgren-Lindquist & Kendig, 2011; Slieker-ten Hove et al., 2010; Tozun, Ayranci & Unsal, 2009; Whitehead et al., 2009).

Chronic incontinence is often overlooked by clinicians and sufferers alike, especially if their attitudes towards the management and treatment of incontinence are prejudiced. For instance, they may believe that nothing can be done to reverse the incontinence; or that incontinence is an inevitable part of growing older; or a normal consequence of pregnancy and birth (Chen et al., 2012; Newman, 1999, 2002; Sims et al., 2011; Slieker-ten Hove et al., 2010).

Other factors identified as persuasive in people not raising the issue of bladder or bowel dysfunction with their doctor have been explored by Horrocks, Somerset, Stoddart, and Peters (2004) in their study of barriers that prevent older people from
seeking treatment. They found that urinary dysfunction was regarded by the sufferer as shameful and embarrassing. These feelings are significant factors that impair self-confidence and limit any mention of urinary dysfunction with their doctors. A later study by Welch, Taubenberger and Tennstedt (2011) also identified that people with urinary dysfunction were inclined to overcome their embarrassment of urinary dysfunction and speak about it to their doctor only when the embarrassment of the symptom was outweighed by a need to seek treatment. They also noted that participants reported they had raised the issue of urinary dysfunction in passing during an unrelated clinical consultation, but not primary issue. The findings of these and other studies, exploring why people choose not to report urinary dysfunctions to their doctors, all concluded that it is essential that a person with urinary dysfunction feels comfortable speaking with their doctor and some assurance that their expression of concern will be taken seriously. Most importantly, the urinary symptom itself needs to be more pronounced and disturbing than any other physical symptom before the person will initiate a discussion about these symptoms with their doctors (Elenskaia, Haidvogel, Heidinger, Doerfler, Umek, & Hanzal, 2011; Pearson et al., 2002; Stenzelius, Mattiasson, Hallberg, & Westergren, 2004). There have been no similar studies conducted on bowel dysfunction, however authors writing on the prevalence of this symptom proposed that bowel dysfunction could be even more stigmatised than bladder dysfunction (Santos & Santos, 2011; Slieker-ten Hove et al., 2010; Whitehead et al., 2009). These factors, together with clinician inattention, or negative attitude and prejudices, are reported by sufferers to be a major factor inhibiting them from reporting such problems or asking for assistance (Schoen et al., 2009; St. John, Wallis, Griffiths & McKenzie, 2010). As a consequence, chronic FI and UI are significant community
issues that remain under-reported, poorly managed and misunderstood (Abrams, Manson & Kirby, 2012; Alma et al., 2012; CFA, 2010; Chen et al., 2012; Teunissen, De Jonge, Van Weel & Lagro-Janssen, 2004).

2.1.5 Definition of incontinence and dysfunction.

Of the many definitions used to describe incontinence all incorporate the concept of an unrestrained or involuntary loss from either the bowel, FI, or bladder, UI. Some definitions incorporate aspects of urinary or faecal frequency, while others focus on the negative social or hygienic consequences of this involuntary loss (Abrams, Cardozo, Khoury & Wein, 2005; AIHW, 2006b, 2012a; Getliffe & Dolman, 2007; Hannestad, Rortveit, Sandvik & Hunskaar, 2000; Sims et al., 2011). While this plethora of definitional and interpretive positions is academically interesting, such definitional diversity has the potential to undermine confidence in the reliability and usefulness of UI or FI estimates of population prevalence (AIHW, 2012a, 2013; Doughty, 2006; Getliffe & Dolman, 2007; Landefeld et al., 2008). In recognition of this problem the International Continence Society (ICS) produced a lexicon of common incontinence-related urological and urologynecological terms to ensure consensus and understanding of various aspects of bladder and bowel dysfunction. The ICS believed that by so doing they would ensure more consistent and accurate estimates of UI and FI prevalence (Abrams, Andersson, Birder, Brubaker, Cardozo, Chapple, Cottenden, Davila, de Ridder, Dmochowski, Drake, Dubeau, Fry, Hanno, Smith, 2010; Abrams, Artibani, Cardozo, Dmochowski, van Kerrebroeck, & Sand, 2006; Abrams, Cardozo, Fall, Griffiths, Rosier, Ulmsten, van Kerrebroeck, Victor, Wein, 2002).
Of particular interest to this current study is the differentiation between incontinence and dysfunction. This interest stems from the researcher’s own clinical experience of an outpatient continence clinic where people attending did not classify themselves as being incontinent, even though they had difficulties maintaining a continent state.

Dysfunctions affecting the lower urinary tract (LUTD) are categorised by the ICS into storage, voiding and post-micturition dysfunctions (Abrams et al., 2012). Dysfunctions of urinary storage are the most commonly reported clinical symptoms such as diurnal and nocturnal frequency, urge or nocturia; all of which may occur with or without an accompanying UI. Urinary bladder emptying or voiding problems primarily affect men, especially in the presence of a prostatic size change which may involve a benign or malignant growth, resulting in urethral obstruction. This produces clinical symptoms such as hesitancy in micturition and retarded urine flow. Symptoms of post-micturition dysfunctions are those that leave a person with the feeling of not fully emptying their bladder or experiencing a ‘terminal dribble’ which is a small amount of urine leakage following what they person thinks is complete bladder emptying. Such symptoms are predominantly found in prostatic disease (Higa, Lopes & D’Ancona, 2013; Maserejian, Kupelian, McVary, Doshi, Link, & McKinlay, 2011).

Dysfunctions of the lower bowel have not been able to be classified in a similar way because of the complexity of bowel neuroregulation (Awad, 2011; Vallès, Vidal, Clavé & Mearin, 2006). However, Landefeld et al. (2008) identified four cardinal physiological factors from which bowel function could be categorised: “rectal sensation; rectal storage; rectal emptying and behavioural or habitual bowel movements” (p. 449). Among older people the ability to maintain normalcy across all these functions is
compromised by factors that include: behavioural or habitual bowel habits; the use of pharmacological treatment prescribed in response to other medical conditions; changes in physical activity; diet and fluid intake; and slowing of gastric motility (Bhutto & Morley, 2008; Rayner & Horowitz, 2013).

The ICS interpretation of ‘dysfunction’ provides a neutral description of any symptom that may be slower or faster than normal, or that does not meet the extreme symptoms of incontinence (Abrams et al., 2006). Therefore unless specified, the use of ‘incontinence’ in this study should be regarded as different from the term ‘dysfunction’. In this thesis, only those terms and definitions set out by the ICS’s Scientific Committee on Terminology are used (Abrams, Andersson, Brubaker, Cardozo, Cottenden, Denis & Donovan, 2005; Abrams et al., 2010; Abrams et al., 2002; Lamontagne, Poncet, Careau, Sirois & Boucher, 2013).

2.1.6 Prevalence of incontinence in the older population groups.

The 2009 the ABS survey of UI and FI (2009a, 2009b) and the subsequent AIHW report on Disability, Ageing and Carers (2012a, 2013) identified 3 million Australians who experienced some degree of UI, 66% of whom were female. Globally, there is a strong correlation between gender, age and UI, with people over 60 years noted to have higher rates of UI than younger populations. Buckley and Lapitan (2010) reported prevalence rates for young-old females (60 to 79 years of age) at 30% to 61% and for the oldest-old (those over 80+ years of age) at 37% to 63%. For men, UI rates were lower than that for women, affecting 3% to 23% of men in the 60 to 79 age group and 8% to 22% of men aged 80+ years. In contrast to UI, FI rates between older men and women were reported by Whitehead et al. (2009) as being the same. They found
that FI occurred in less than 9% of the older (60+ years) population sampled and, unlike UI, they found no evidence to suggest a corresponding rise as people aged.

Whitehead et al. (2009) also found a strong statistical correlation between the presence of FI and UI. The occurrence of both UI and FI is known as double incontinence (DI). Apart from drawing attention to the existence of this correlation, Whitehead et al. (2009) did not further address this finding however, Shamliyan, Wyman, Bliss, Kane and Wilt (2007) found a correlation between constipation, excessive straining of stools and DI. More recently, Akbarali, Grider, Gulick, Kuemmerle, Murthy, Qiao, … Yu (2012) attributed the presence of DI in ageing individuals to hyper-stimulation of the ageing afferent (sensory) pathways that send triggering messages to the anatomically aligned bowel and bladder, causing them to become jointly agitated.

Comparable descriptions to the UI and FI definitions of weakness have been reported as occurring in epidemiological studies of incontinence. Research undertaken by Abrams et al. (2012), Abrams et al. (2010), Whitehead et al. (2009), Landefeld et al. (2008) Hawthorne (2006) and Thomas, Nay, Moore, Fonda, Hawthorne, Marosszeky, & Sansoni (2006) identified three common limiting factors that remain to be addressed in any substantive way. The first factor relates to the homogeneity and small sample sizes studied. The second is the use of specific procedures or diagnoses to select subjects, leaving little opportunity for comparisons with other research by not sharing the same diagnoses or providing the same procedures (Schmidt, Dogan, Langenbach & Zirngibl, 2009). The final factor stems from the diverse and inconsistent use of definitions and modifications of research instrumentation (AIHW, 2013).
In FI, modifications were made to data collection tools, such as the Wexner Faecal Continence Grading Scale (Jorge, Marcio & Wexner, 1993), to either include or exclude uncontrolled flatus as a form of FI, allowing more participants to be classed as having FI when flatus is included (Sansoni, Marosszéké, Sansoni & Hawthorne, 2006; Santos & Santos, 2011). In UI, the multitude of diurnal, nocturnal frequency and nocturia definitions have resulted in ambiguous data. This problem was highlighted in a study on nocturia by Yoshimura (2012) and a systematic review on this same topic by Weiss, Wein, van Kerrebroeck, Dmochowski, Fitzgerald, Tikkinen, & Abrams (2011), both noting poor differentiation between nocturnal frequency and true nocturia, resulting in skewed results.

Hawthorne (2006) and Chiarelli, et al., (2005) reported that the degree of difficulty caused by researchers choosing and then modifying instruments made it difficult for others to interpret or replicate previously completed research. The practice also contributes to the dearth of meta-analysis as researchers are unable to combine various small data sets (AIHW, 2013; Brickman, Coates & Janoff-Bulman, 1978; Coggrave, Wiesel & Norton, 2009; Getliffe & Dolman, 2007; Landefeld et al., 2008). Hawthorne (2006) concluded that “all of the measures [prevalence studies], to some degree, provided misleading estimates” (p. 69).

Despite these important methodological problems, there is consensus that UI affects more women than men; that people over the age of 60 years are more heavily burdened by UI than younger people; that UI is more commonly reported than FI by a ratio of 1:5; and that men and women with FI are equally represented (AIHW, 2013; Brickman et al., 1978).
2.2 Bowel or bladder decline specifically related to the person with PD

2.2.1 Pathogenesis of PD

PD is a common neurodegenerative disease that is widely recognised as second only to Alzheimer’s dementia (Schapira, 2008) in frequency of diagnosis. PD is not found exclusively in older people and affects individuals in early to middle adulthood as well (McCall, 2003; Mellick, 2013; Špica, Pekmezović, Svetel, & Kostić, 2013). Little is known about aetiology of PD development and there is little consensus in terms of causational theories for PD (Schapira, 2008). Over the past two decades, two areas of disease pathogenicity have emerged as likely explanations; first, that PD stems from a genetic basis and, second, that PD’s genesis is linked to environmental factors such as infections and toxins that create a neuro-inflammatory response (Corti, Lesage & Brice, 2011; Hernán, Takkouche, Caamaño-Isorna & Gestal-Otero, 2002; Hernán, Chen, Schwarzschild & Ascherio, 2003; Morley & Hurtig, 2010); however, neither has been confirmed as the primary cause of bowel and bladder decline.

2.2.1.1 Genetics

It remains unclear how genetics may play a part in the development of PD and the symptoms of bowel and bladder decline, even though more than 27 genes have been identified as contributing to PD pathogenesis. One type of early onset PD that affects less than 10% of people with the disease has been directly linked to a specific autosomal recessive gene mutation (Corti et al., 2011). The more common clinical presentation of PD has a sporadic occurrence in older people and is believed to be to be more influenced by polymorphic gene mutation(s). It is thought that these genome profiles, singly or in combination, contribute to PD development by predisposing the person to a neuro-inflammatory reaction when in contact with unspecified environmental toxins.
that are instrumental in dopamine cell death (Corti et al., 2011; Kumar, Lohmann & Klein, 2012; Schapira, 2008; Schulz, 2008). Kumar et al. (2012), Corti et al. (2011) and Morley and Hurtig (2010) asserted that knowledge of these high risk genes and their contribution to the complex pathogenesis of PD would lead to neuro-protective treatments and the development of more efficacious pharmacological agents as a response to bowel and bladder symptoms associated with PD.

2.2.1.2 Environmental factors: neuro-inflammatory response

Decline in bowel and bladder function may be explained by the aetiological theory that post viral or neuro-inflammatory responses contribute to the genesis of PD (Braak & Del Tredici, 2008; Kristensson, 2006; Mosley, Benner, Kadiu, Thomas, Boska, Hasan, … Gendelman, 2006; Ng, Lee, Cheung, Nicholls, Peiris, & Ip, 2010; Olanow & Tatton, 1999). According to Braak and Del Tredici (2008), an immune response is triggered by an unknown virus or toxin, causing a slow progressive deterioration of the entire nervous system, resulting in the death of nigral dopaminergic neurons and the laying down of Lewy bodies in their place (Kidd, 2000; Koller & Rueda, 1998; Lees, 2007; Powers et al., 2003; Weintraub, Comella & Horn, 2008). Research in this area also explored neuro-protective attributes of toxins such as caffeine and nicotine. Both are thought to inhibit the uptake of the neurotoxic agents or prevent inflammatory responses to the toxin that causes PD (Liu, Guo, Park, Huang, Sinha, Freedman … Chen, 2012; Noyce, Bestwick, Silveira-Moriyama, Hawkes, Giovannoni, Lees, & Schrag 2012; Palacios, Gao, McCullough, Schwarzschild, Shah, Gapstur, & Ascherio, 2012).
2.2.1.3 Lewy body presence in PD

Braak and Del Tredici’s (2012) work on the LBP is recognised as the key in understanding the pathogenesis of PD. The foundation of their model is based around the progressive presence of LBP across the central nervous (CNS) and peripheral nervous (PNS) systems. These scientists have traced the presence and pathways of LBP up through the enteric nervous system (ENS) and the autonomic nervous system (ANS). The ANS is of particular interest to this current study, as it comprises both the sympathetic (SNS) and parasympathetic (PsNS) systems, which control voluntary and involuntary innervation to the bowel and the bladder.

A diagnosis of PD is thought Braak and Del Tredici (2012) to be confirmed by the presence of Lewy body pathology (LBP), together with dopamine-producing cell loss within the substantia nigra. LBP is the result of an α-synucleina mutation and an incomplete clearance of protein synthesis within the cell, which ultimately prohibits normal cell functioning.

The findings have given rise to a six-staged theory of LBP progression, the Braak Staging Model (Braak & Del Tredici, 2008) which tracks the pathogenesis of disease and cellular changes that cause symptoms to occur from the ENS up to and including the CNS. This model is unlike the Hoehn and Yahr (H&Y) (1967) motor symptom staging, which is based on post-diagnostic clinically evidenced symptom presentation. When comparing these models along a disease timeline, it is evident that PD is a slowly developing insidious chronic disease that produces a range of neurologically generated prodromal and cardinal motor symptoms that are hard to separate from ordinary non-neurological symptoms such as the bowel and bladder dysfunctions that are commonly found in ageing populations.
With an understanding of the pathogenesis of PD and symptom expression, especially symptoms affecting bowel and bladder function, the progressive nature of PD is able to be further examined using clinical assessment scales and pathological stage mapping.

2.2.2 Clinical and pathological mapping of PD

PD is highly individualistic in its presentation, yet the disease seems to progress through a series of logical and predictable phases, although there is variation in the overall time involved. Forsaa, Larsen, Wentzel-Larsen and Alves (2010) estimated mortality following PD diagnosis as ranging from two to 36 years.

Hawkes, Del Tredici and Braak (2010) connected PD’s heterogeneous clinical picture with the irregularities in LBP and cell destruction to the subsequent neurological effect on internal organ function. For clinicians, the most commonly used PD trajectory model is the H&Y scale, a clinical staging system first developed in the early 1960s (Hoehn & Yahr, 1967). It focuses on clinically observable changes to motor function and then classifies them into five levels of disease severity. The person with PD may present with all or just a few of the cardinal motor symptoms used to diagnose PD which are: tremor, muscle rigidity, bradykinesia and postural instability. However, the disease does not always follow a chronological progression from one stage to the next. Reports in this research review indicate that people commonly accelerate through or completely skip these identified disease stages (Hawkes et al., 2010; Poewe & Mahlknecht, 2009; Zhao et al., 2010).

The H&Y staging tool (represented in Table 2.1) was used in the current study to provide an interpretive guide that assisted the researcher in understanding the
collected data (Lees, 2010; Post, van der Eijk, Munneke, & Bloem, 2008; Zhao et al., 2010) and grouping or categorising the data.

**Table 2.1**

<table>
<thead>
<tr>
<th>Stage one: diagnosis</th>
<th>A mild unilateral disease. The initial presentation of <em>cardinal motor symptoms</em>.</th>
<th>Mild symptoms of tremor, muscle rigidity, bradykinesia and minor postural instability.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage two:</td>
<td>A mild to moderate bilateral disease without any impairment to balance.</td>
<td>The combination of previous symptoms plus problems with swallowing, voice changes, volume and intonation and lack of facial expression.</td>
</tr>
<tr>
<td>Stage three:</td>
<td>A moderate bilateral disease with postural instability.</td>
<td>A marked deterioration of all stage two symptoms. In addition to problems with balance and postural stability. The person now requires some assistance with daily living.</td>
</tr>
<tr>
<td>Stage four:</td>
<td>A moderate to severe bilateral disease with some ability to walk or stand with assistance.</td>
<td>A noticeable deterioration in all previous mentioned symptoms. The person now has significant problems with balance and is now no longer able to mobilise independently.</td>
</tr>
<tr>
<td>Stage five:</td>
<td>A severe disease where the person is wheelchair bound or bedridden.</td>
<td>Significant deterioration in all symptoms. Now the person is confined by their motor symptoms to a bed or chair.</td>
</tr>
</tbody>
</table>

To demonstrate the pathological and clinical relationship between the Braak staging model and the H&Y disease severity staging (see Figure 2.1), Hawkes et al. (2010) formulated a chronology of disease progression across a 40-year timeline from prodromal to post-clinical status. Twenty years was chosen for each period as it covers timeline variations known to occur in PD symptom expression (Hassan, Wu, Schmidt, Malaty, Dai, Miyasaki, & Okun, 2012; Hely, Morris, Traficante, Reid, O'Sullivan, & Williamson, 1999; Ross, et al., 2012; Zhao et al., 2010). During the prodromal stage, Braak and Del Tredici (2008) identified early LBP presence along the ENS where PD
non-specific symptoms such as bowel and bladder dysfunction are detected as a result of death of 80% of dopamine cells causing the cardinal motor symptoms most commonly associated with PD and inevitably, the death of the individual (Hoehn & Yahr, 1967).

Figure 2.1. PD timeline. Abbreviations: CA2=second section of the Ammon’s horn; CN X= motor component of cranial nerve X; RF= reticular formation; CN= central subnucleus of the amygdala; Meynert’s N= basal nucleus of Meynert; PPN= pedunculopontine tegmental nucleus; TEC= transentorhinal cortex. H (Hawkes et al, 2010, p. 80).

The Baarak and Del Tredici model has relevance for the current study in particular during the first three stages where LBP is seen as affecting the ANS and progressive degeneration of bowel and bladder function (Hawkes et al., 2010), causing difficulty in emptying one’s bowel as well as slowing faecal waste movement throughout the gastrointestinal tract (GIT), resulting in constipation. The bladder is also affected by neurological changes that cause detrusor hypersensitivity and sphincter
dyssynergia (Braak & Del Tredici, 2008; Lim, Fox & Lang, 2009; Sakakibara et al., 2008; Sakakibara, Tateno, Kishi, Tsuyuzaki, Uchiyama, & Yamamoto, 2012). Chaudhuri and Odin (2010) also noted pain and generalised bodily discomforts as further evidence of ANS neural pathway damage. On this basis, early yet clinically insignificant symptoms of pain, constipation and urinary detrusor hypersensitivity and dyssynergia, could be regarded as potential early predictors of PD and contribute to early diagnosis (Abbott, Petrovitch, White, Masaki, Tanner, Curb, Grandinetti, Blanchette, Popper, Ross, 2001; Awad, 2011; Del Tredici & Braak, 2012; Krishnan et al., 2011; Ross et al., 2012).

2.2.3 Diagnosis, morbidity and mortality of PD

A medical diagnosis of PD is most often made in the mid-stages of the disease when motor dysfunctions become apparent. High rates of misdiagnosis between other Parkinson-like disorders such as Progressive Supranuclear Palsy (PSP) have been reported by Lees (2012), Corti et al. (2011), Pahwa and Lyons (2010), Williams and Lees (2009), Weintraub et al. (2008) and Rao, Hofmann, & Shakil, (2006). These revelations are usually found during post-mortems and, because it is too late to have any effect on the management of the disorder, they are noted as unremarkable (Lees, 2012). Misdiagnosis of PD is believed to be diminishing with the use of genetic testing, neuro-imaging and transcranial ultrasound, all of which enable accurate and earlier detection of neuron destruction, especially in more complex clinical presentations (Morley & Hurtig, 2010). Issues of cost and benefit are important considerations in the early diagnosis of PD, especially if disease prevention is not available and efficacious clinical management does not respond to early intervention (Marek, Jennings, Tamagnan, & Seibyl, 2008; Pahwa & Lyons, 2010).
2.2.4 Motor symptoms and NMS in PD

The causes of the four cardinal motor symptoms of tremor, muscle rigidity, bradykinesia and postural instability tend to dominate research enquiry into PD rather than the diagnosis and management of the disabling symptoms of NMS—such as depression, anxiety, mental confusion, sleep disturbances, alterations in taste and smell, constipation and urinary dysfunction which are often overlooked by primary care physicians and medical specialists (O’Sullivan et al., 2008; Gallagher, Lees & Schrag, 2010; Li et al., 2010; Mehdiratta, Garg & Pandey, 2011; Hassan et al., 2012; Noyce et al., 2012; Martinez-Martin et al., 2013).

In 2006, Chaudhuri, Martinez Martin, Schapira, Stocchi, Sethi, Odin,… MacPhee recommended that the most commonly reported NMS should be formally identified. The resulting instrument, the NMS severity scale (NMSS) grouped these NMS into nine sub-groups according to their effect on the person’s gastrointestinal tract; urinary system; cardiovascular system; sleep and fatigue; mood and cognition; perceptual problems and hallucinations; attention and memory; sexual functioning; as well as those symptoms not able to be clearly differentiated into systems or groupings such as pain, sensory deficits, weight gain and diaphoresis (Chaudhuri, et al., 2006).

Since then, the research focus related to NMS has been more on validating the tool (Chaudhuri, Martinez-Martin, Brown et al., 2007; Martinez-Martin et al., 2013; Martinez-Martin et al., 2009), rather than on investigating the influence of NMS on the life quality of those with PD (Hinnell, Hurt, Landau, Brown & Samuel, 2012; Soh, Morris & McGinley, 2011). A systematic review of QoL within the PD literature by Soh et al. (2011) suggested that motor symptoms should not be considered solely responsible for poorer QoL, even though that research did not formally clarify the
relationship between poor QoL and other NMS. They attributed this lack of research interest in NMS symptoms to the fact that they are harder to manage, a factor of particular interest to this current study, especially the area of autonomic symptoms.

Attempts to bridge the gap between specific non-motor aspects of PD and QoL were made by Shearer, Green, Counsell and Zajicek (2012), Hinnell et al. (2012), Soh et al. (2011) and Gallagher et al. (2010). Dysautonomias affecting the bowel and bladder were found to be statistically associated with poorer QoL, yet they were undervalued and poorly understood beyond that of their pathophysiology (Sakakibara et al., 2008; Sakakibara et al., 2012). This knowledge gap between knowing that bowel and bladder dysautonomias exist in this group of people and what effect they exert on a person’s life is of interest for the current study.

2.2.5 Bowel and bladder dysautonomia in PD

In PD, two of the most commonly reported NMS are constipation and lower urinary tract symptoms (LUTS) (Gallagher et al., 2010; Lim & Lang, 2010; Mehndiratta et al., 2011; Vaughan, 2012). People with PD commonly report problems with urinary storage: 60% report nocturia; 54% urinary urgency and 36% report urinary frequency; only 26% describe themselves as having UI (Kishi et al., 2011). Smaller numbers of people with PD (44%) describe their LUTS as a dysfunction of voiding, and men (70%) were more highly represented in this symptom group than women (28%) (Sakakibara et al., 2012).

An understanding of the cause of these symptoms generates insights on the challenges faced by people with PD experiencing these symptoms. Essentially, PD causes LBP disruptions along the ENS and the ANS neurological pathways, which communicate incoming messages and outgoing instructions to the bowel and the
bladder (Blumenfeld, 2002; Sakakibara et al., 2008; Sakakibara et al., 2012). The ANS incorporates the sympathetic (SNS) and parasympathetic (PsNS) nervous systems. With regard to the bowel the SNS is responsible for maintaining anal sphincter closure, while the PsNS initiate’s a relaxation of this same sphincter, allowing the person to defecate. The effective neural coordination of both these systems balances the needs and requirements of the individual so that they remain socially continent (Blumenfeld, 2002; Politis et al., 2008; Weaver et al., 2009).

Neurological control of the GIT is additionally controlled by the ENS (Lebouvier et al., 2009). The ENS coordinates the peristaltic muscle contractions that mix and move gastric contents, and regulates mucosal secretions and absorptive functions of the GIT. In PD faecal movement along the GIT is compromised due to the LBP on the neural pathways which create dyssynergy between the GIT’s ability to relax and contract, resulting in faecal expulsion difficulties (Cadeddu et al., 2005; Fowler, Sakakibara, Frohman, Brady & Stewart, 2007; Sakakibara et al., 2008).

Bladder control is also affected by the LBP, because it alters the dopamine-basal ganglia pathways that induce the detrusor muscle to become hyper-contractile and disinhibited, causing urinary urgency and frequency which is most often reported by people with PD (Braak & Del Tredici, 2008; Lim et al., 2009; Sakakibara et al., 2008; Sakakibara et al., 2012).

Constipation is reported to affect between 70% and 100% of people with PD, as compared to 0% to 30% in aged-matched populations without this disease (Gao, Chen, Schwarzschild & Ascherio, 2011; Kaye, Gage, Kimber, Storey & Trend, 2006; Rayner & Horowitz, 2013; Sakakibara et al., 2008). High levels of LUTS, between 30% to 70%, also affect people with PD (Iacovelli et al., 2010; Sakakibara et al., 2012;
Sammour et al., 2009; Vaughan, 2012). However, unlike bowel dysfunction, age-matched prevalence estimates were difficult to locate in the literature, probably because of the difficulty in differentiating between people with PD who reported LUTS conditions, and age-matched non-diseased populations with UI. It is possible that the combination of expected high prevalence of LUTS in older populations makes it difficult to determine whether PD or age is the lead aetiological factor (Sammour et al., 2009).

Findings by Iacovelli et al. (2010) that age-matched healthy subjects demonstrate lower incidence of LUTS symptoms compared to their participants with PD, are consistent with those of Kishi et al. (2011), Winge, Skau, Stimpel, Nielsen and Werdelin (2006) and Sakakibara et al. (2001), Iacovelli and colleagues (2010) who compared their research samples against non-disabled cohorts from other studies. These general community prevalence studies presented LUTS or UI rates in women older than 65 years as being between 30% and 60% and, in men, 3% to 23% (Buckley & Lapitan, 2010); a result that is considerably lower than that found in PD populations.

Reimann et al.’s (2010) study of the autonomic NMS incidence between PD and Parkinsonism syndromes also found similar rates of autonomic NMS occurring between those with PD and with PSP and importantly, the healthy neurologically intact control group were found to have frequency rates significantly different from those with PD. For those reporting constipation, a frequency of 11.1% was found in the control group as compared to 47% of the PD group. For urinary urgency, a frequency of 3.7% was reported in the control group as compared to those with PD, who reported urge at 33.3%. UI was also reported as occurring with greater frequency in the PD group (33.3%) as compared to the control group (11.1%).
In the current study, the lack of research inquiry into symptoms and the findings outlined above are used as a basis for the argument that the presence of bowel and bladder dysfunction in this group of older adults is caused by LBP damage to their neurological pathways, rather than by age or gender-related characteristics.

2.3 Bowel and bladder dysfunctions: distinguishing between ageing and PD presentations

International reports indicate that common NMSs remain clinically under-recognised and therefore under-treated in both PD specialised settings and in general medical clinical practices (Hu et al., 2011; Mehndiratta et al., 2011; Reimann et al., 2010; Tolosa et al., 2009; van der Marck et al., 2009; Vaughan, 2012); nor has this topic received attention in Australian research. Reasons given for low rates of clinical detection include: restrictive clinical consultation times; the reluctance by the person with PD to raise NMS concerns with their doctor; and the difficulties encountered by both the neurologist’s and the GP’s ability to distinguish between age-related versus autonomic bowel and bladder dysfunctions (Hawkes, 2008; Hu et al., 2011).

Difficulties in distinguishing between age and PD-related functional and physiological bowel and bladder dysfunction relate to aspects of diagnostic blurring and prejudicial attitudes held by clinicians (Bennett & Gaines, 2010; Higashi et al., 2012; Linden & Kurtz, 2010), as well as those held by persons with PD (Elenskaia et al., 2011; Hatano, Kubo, Shimo, Nishioka & Hattori, 2009; Pearson, Tucker, Bolt et al., 2002; Stewart et al., 2012). Doctors have been reported as not recognising or acknowledging the existence of PD in the management of their patients’ autonomic complaints (Hatano et al., 2009). This is consistent with people with PD complaining that their reports of NMS were either ignored or dismissed and that the much-needed
information they require to manage these NMS was not given. When Hatano et al. (2009) interviewed people with PD together with their carers, asking them about the care they received from their GP and PD neurologist, a range of unmet needs emerged, and inefficiencies in managing their autonomic dysfunctions were noted. Hatano’s study concluded that improved communication between doctors and their patients would enable them to focus on the neurological cause of the NMS rather than on the person’s age.

As mentioned above, UI or FI are not part of normal ageing and while the prevalence of incontinence is higher in the older person, it is multi-factorial (AIHW, 2012a; Jeste et al., 2010; Kraus et al., 2010; Liang et al., 2010). Discriminating between symptoms arising from normal age changes and pathological changes can be confounded by many other factors that feature among the older population. Factors such as the presence of multiple chronic conditions increase the likelihood for the older person to experience incontinence (Dmochowski & Gomelsky, 2011; Higa et al., 2013). The use of pharmaceutical agents used to manage these co-morbid states increases the likelihood of incontinence (Dmochowski & Gomelsky, 2011; Rayner & Horowitz, 2013), and older people who are more socially isolated or functionally disabled by their chronic states are more likely to suffer incontinence (Chen et al., 2012; Hatfield, Hirsch & Lyness, 2013; Liang et al., 2010).

Gerontological researchers such as Vaughan (2012) regard ageing and physical frailty as coexisting concepts and view bowel and bladder dysfunctions as linked, regardless of the pathophysiology involved. The problem with such an approach is the limitations it can place on clinician perceptions of what may be occurring for people with PD or other disease and encourage less than optimal effort in achieving a working
and accurate diagnosis that can lead to effective interventions and greater understanding of the challenges faced by those with such symptoms.

2.4 Conclusion

The paucity of clinically validated treatments for UI, urinary dysfunctions and constipation leaves people with PD at risk of having clinical treatments chosen without due regard to the symptom biological origin. The inattention to these autonomic symptoms biological aetiology by treating doctors, has contributed little to the efficient elimination of these burdensome symptoms, nor does it provide a sound rationale to the person with PD as to why these symptoms are present. The limited acknowledgment of these biologically based personal burdens reflects a major gap in current PD knowledge and in not acknowledging these biological issues the person with PD is less able to sustain a positive attitude and to remain socially connected and resilient. In response, the current study has decided to locate PD within a disability construct as it enables a focus on how people live and manage these autonomic bowel and bladder NMS without negating their diseases’ biological origins. In understanding the biological, psychological and social mechanisms and challenges faced by this group of people, the possibility emerges for more insightful and effective clinical interventions.

Clearly, PD is an unsettling and relentless disease that incorporates bowel and bladder NMS. It is poorly researched in terms of the burden facing those who have PD as well as those who care for and service them. Personal wellbeing requires competent clinical management, as well as advice and support related to living with an intrusive and unsettling chronic disease. These issues have been identified as stemming from gaps in research, which influence the clinical interventions offered to people with PD and as such are the focus of investigation in this study.
Chapter 3: Theoretical constructs underpinning quality of life and burden

This chapter locates PD within a disability construct building on the biological concepts of age and disease discussed in the previous chapter; a conceptualization found to be wanting in terms of clarifying the needs of people with PD so that they are able to adequately manage their neurologically induced bowel and bladder dysfunction. By positioning these disease generated symptoms within a disability framework, the burdensome issues as experienced by the sufferer can be re-examined and re-conceptualized. The research reviewed in this chapter explores current understanding of personal burden and disability; and identifies knowledge gaps in preparation for exploration of the following research aims to:

- identify the origin and resulting burdensomeness of PD dysfunctions;
- explore the ways these dysfunctions disrupt the subjective experience of a good life; and
- describe how the individual incorporates and manages PD related dysfunctions in their life regardless of their age.

By embedding these aims within disability, rather than a biological construct of age and disease, quality of life and burden impact are more effectively examined.

3.1 Quality of life (QoL) and health related quality of life (HRQoL)

The International Classification of Impairments, Disabilities and Handicaps (ICIDH) adopted by the World Health Organisation (WHO) in 1980 recognised the importance of environmental factors resulting in a disability becoming a handicap. Not unsurprisingly, dissatisfaction with this linear model led to several revisions culminating in the adoption of the International Classification of Functioning, Disability
and Health (ICF) in 2001 (WHO, 1980, 2001) The ICF is an innovative framework that builds upon the narrow medical or biological focus of chronic disease and disability to incorporate a broader bio-psycho-social approach. In so doing, a wider range of professionals working with people who have a disability have been engaged in considering the impact of causal factors on the person’s ability to participate in life. The ICF framework is used in this research to express a comprehensive bio-psycho-social approach to quality of life in the context of a person having a disability. The ICF model is well regarded within the disability services research community and remains at the forefront in the exploration of issues related to burden, disability and community participation.

The International Classification of Diseases (ICD-10) (WHO, 2008) a medical disease taxonomy currently under its eleventh revision, and the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) are both a part of the WHO Family of International Classifications, and are used together in this study to provide a multiple layered coverage of the topic (see Figure 3.1).

![Figure 3.1 ICF framework (WHO, 2001; Bambra, Fox & Scott-Samuel, 2005).](image-url)
The ICD categorises a ‘disability illness’ or ‘disease’ according to its aetiology. This taxonomy forms the first component of the ICF ‘health condition’, which in this study is PD. Factors, intrinsic and extrinsic to the PwD, are derived from the ‘health condition’ term and work in dynamic interaction with each other, creating influences that either inhibit or promote social inclusion, participation and the performance of daily activities. For instance, continence is a body function that, if working well, does not interfere with people’s ADL or interrupt their social participation (see Figure 3.1). However, when PD disrupts the neurological function needed for appropriate bladder management, the person perceives a need for changes to be made in their activities and participation in a range of activities and areas of life engagement. Biological dysfunctions can also influence or be influenced by personal factors (intrinsic) and environmental factors (extrinsic) (see Figure 3.1), which complicate one's ability to participate and perform daily activities while compensating for the hurdles arising from their condition. These environmental and personal factors, or barriers, stem from financial, architectural and attitudinal influences and can contribute to or inhibit the person's connectedness with others, as well affecting their ability to adequately perform daily activities. The usefulness of the ICF is that it demonstrates a link between the ability of a PwD to function in their community and the individual facilitative or inhibitive contextual factors such as body dysfunction, cultural and attitudinal variations. These in turn enable researchers to identify and individualise the origin of the ‘burden’ incurred by the PwD (Nilsson, Westergren, Gunilla & Hagell, 2010).

Being connected in positive ways with others is important in decreasing a person’s feelings that they are a burden. Poor social connectedness is reported to contribute to poor Quality of Life (QoL) experiences, which ultimately decrease an
individual’s ability to make effective changes and adaptations in response to their illness trajectory (Alma et al., 2012; Cote, Sprinzeles, Elliott & Kutscher, 2000; Gage, Hendricks, Zhang & Kazis, 2003; Garber & Friedman, 2003; Levasseur, Desrosiers & Noreau, 2004). Feelings of self-worth and optimism are also inextricably linked to the contribution a person believes they bring to a relationship with others. Alternatively, feelings of being a burden to those nearby, with no means of social reciprocity, have been linked to lower levels of life satisfaction (Olsen & Dahl, 2007; Verbrugge & Chan, 2007).

The linking of QoL to social participation and one's ability to adapt to life changes is not new. QoL researchers including Parmenter (1996), Montbriand (2004), Burton-Smith, McVilly, Yazbeck, Parmenter and Tsutsui (2009), Gallagher et al. (2010) and Alma et al. (2012) have all stressed the importance of a balanced life that includes aspects of both valued work and social activities for PwD.

It has been claimed that the presence of a bowel or bladder symptom in people with PD does not elicit negative QoL responses (AIHW, 2012; Clarke & Bennett, 2012). It is when these symptoms compromise the person’s usual, independent and safe access to a toilet, or when the symptom attracts unwanted attention, or when the person requires assistance to perform this self-care activity, that changes in QoL are reported (AIHW, 2012; Bichard & Knight, 2010; Clarke & Bennett, 2012; Khan, Pallant, Shea & Whishaw, 2009; Rahman et al., 2008; Slieker-ten Hove et al., 2010; Stenzelius, Mattiasson, Hallberg & Westergren, 2004; Vaughan et al., 2011).

FI and UI are viewed in a negative way by modern society, as are attitudes held by the individual who is suffering from incontinence (Cochran, 2000; Elenskaia et al., 2011; Keegan, 2012). Elenskaia et al. (2011) found that 60% of their study population
reported an extreme and debilitating embarrassment and shame in response to their UI. These negative feelings about incontinence are reported in the literature as affecting self-worth and creating an environment in which optimism is hard to maintain (Esbensen, Thomé & Thomsen, 2012; Fässberg et al., 2012; Haynes & Watt, 2008; Sells et al., 2009). Such feelings impede the older person’s ability to initiate or participate in social activities as they once did and they become less resilient in response to changes in their disease profile. It is at this point that a person’s QoL is reported to decrease with a concomitant increase of feelings of being a burden on others (Esbensen et al., 2012; Gallagher et al., 2010; Haynes & Watt, 2008; King, Willoughby, Specht & Brown, 2006; Sells et al., 2009).

The WHO defined QoL as an “individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHOQOL Group, 1998, p. 1). QoL and Health Related Quality of Life (HRQoL) are terms used interchangeably in the health literature. QoL is a multi-dimensional construct, which incorporates daily physical mental and social functioning (de Boer, Spruijt, Sprangers & de Haes, 1998; Fleming, Cook, Nelson & Lai, 2005). HRQoL, is a more specific QoL measure that looks at changes in an individual’s lifestyle perceptions as they relate to their health or to a specific disease (Bowling, 1995; Forsaa et al., 2008; Walsh & Bennett, 2001). HRQoL tools have been primarily used by researchers to review and support the effectiveness of a health program or a medical intervention within specific disease groupings. These tools have become important indicators providing the evidentiary justification needed in tight fiscal environments, where resource allocation is hotly contested (Gage et al., 2003).
Very little has been reported about the effect bowel and bladder symptoms have on QoL for people with PD (Gallagher et al., 2010; Hinnell et al., 2012; Jellinger, 2009), in comparison with the multitude of reports on the NMS pathophysiology (Sakakibara et al., 2012), clinical presentation, differential diagnosis and treatment options available (Vaughan, 2012; Zesiewicz et al., 2010). This is despite the fact that these symptoms are recognised as affecting the majority of people with PD and are reported as significant contributors to disturbances in QoL (Gallagher et al., 2010; Hinnell et al., 2012).

3.2 Measuring HRQoL in chronic illness: PD and bowel and bladder dysfunction

The medical fraternity have taken a great interest in HRQoL measures, viewing them as ideal tools for evaluating therapeutic interventions, unlike sociologists who emphasise the subjective experiences of the individual. There is a multitude of specifically tailored HRQoL measures used primarily to assess health outcomes and program goals, although very few were developed or stemmed from the person’s perspective of what they saw as important (Bowling, 1995; Montbriand, 2004; Parmenter, 1994). The following is a list of HRQoL tools specifically developed for people with PD (Pablo Martinez-Martin et al., 2011):

1. Belastungsfragebogen Parkinson Kurzversion (BELA-P-k) by Ellgring et al. (1993)
2. PDQ-39 by Peto et al. (1998)
3. PDQ Short Form (PDQ-8) by Jenkinson, Fitzpatrick, Peto, Greenhall and Hyman (1997b)
4. Parkinson’s Impact Scale (PIMS) by Caln, Schulzer, Mak et al. (1996)
5. PDQoL Questionnaire by de Boer, Wijker, Speelman and de Haes (1996)
6. PDQoL Scale (PDQUALIF) by Welsh, McDermott, Holloway et al. (1997)

7. Parkinson’s Problem Schedule (PPS) by Brod, Mendelsohn and Roberts (1998)


Ahan, Saderberg and Lundman (2003) Curtin and Lubkin (1995), Glueckauf and Ketterson (2004), Ironside et al. (2003) and Martire, Lustig, Schulz, Miller and Helgeson (2004) have agreed that a chronic illness has negative effects on an older person’s QoL. However, for many years QoL researchers such as Montbriand (2004), Bowling (1995) and Parmenter (1994) have warned that grouping subjects solely according to their disease states will only result in a skewed view of HRQoL and chronic illness, and endorse the negative perception held by many health professionals that all older people have a poor QoL (Hyde, Wiggins, Higgs & Blane, 2003; Montbriand, 2004). Similar views can be seen in UI and FI HRQoL studies, where subjects are narrowly selected according to their gender and their age (Heidrich & Wells, 2004). As a result, healthcare providers may come to the erroneous belief that all older females are incontinent and have a low QoL potential.

A review was undertaken of 200 PD-specific HRQoL studies published between the year 2000 and 2013 to explore their intent. It revealed that HRQoL tools were used in PD in three distinct ways:

1. To validate the effectiveness of clinical interventions or programs (Ellis et al., 2005; Slowinski et al., 2007).
2. To measure QoL disturbance, specific to a particular motor or NMS such as facial animation (Huang, 2009; Tickle-Degnen & Lyons, 2004) or restless leg syndrome (Gomez-Esteban et al., 2007), and

3. To validate or test pre-existing tools or develop new PD-specific HRQoL tools (Franchignoni et al., 2008; Johan Marinus, Visser, Martínez-Martín, van Hilten & Stiggelbout, 2003; Marinus, Visser & Stiggelbout, 2004; Martínez-Martín, Serrano-Dueñas, Forjaz & Serrano, 2007).

Only 19% of the reviewed research focused on the person living with the disease. The remaining 81% evaluated the efficacy of health practitioners’ interventions, while others focused on reviewing, trialing or validating specified HRQoL tool(s).

Table 3.1 summarises these findings in terms of the three outlined areas of HRQoL research focus.

Table 3.1  
Review of 200 PD-specific HRQoL studies published between 2000 and 2013

<table>
<thead>
<tr>
<th>Group 1: A HRQoL tool used to validate the effectiveness of clinical interventions or programs.</th>
<th>Group 2: A HRQoL tool used to measure QoL disturbance, specific to a particular motor system or NMS.</th>
<th>Group 3: A HRQoL study used to validation or test pre-existing or develop new PD-specific HRQoL tools.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total N(%)</td>
<td>52 (26%)</td>
<td>38 (19%)</td>
</tr>
</tbody>
</table>

These findings support the view that current HRQoL research does not primarily focus on the person with the chronic illness or disease, and that the multidimensionality of HRQoL research in the context of the WHO’s definition is addressed only in the simplest of ways. This is a research deficit which, according to Montbriand (2004) and Parmenter (1994), reduces the living human entity to a collection of diseased parts. It is
suggested that HRQoL research needs to be more focused on the person who interacts with their environment in a dynamic way according to their interpretations, experiences and expectations. In this way, influences thought to affect HRQoL, such as social isolation, perceptions of being a burden on others and the economic effects of living with a chronic illness, can be explored (Engstrom & Nordeson, 1995; Hagell & Nilsson, 2009; Schrag, Jahanshahi & Quinn, 2000).

People living with a chronic illness like PD and symptoms such as incontinence are less likely to participate in social activities outside their home, promoting social isolation and decreasing their perception of having a good life (Cardol et al., 2002; Gallagher et al., 2010). Whetten-Goldstein, Cutson, Zhu and Schenkman (2000) identified financial worries as a significant factor known to contribute to social isolation. The expense of buying disposable continence products could prompt a person with a chronic illness to choose between participating in a social activity and purchasing equipment that allows them to remain clean and dry. Cousineau, McDowell, Hotz and Herbert (2003) further expanded this point in their finding that in addition to direct financial factors, non-monetary worries such as fear, anxiety or the lack of social assistance and support also isolated people.

Haynes and Watt (2001), McPherson et al. (2007), McPherson, Wilson, Lobchuk and Brajman (2007) and McPherson et al. (2007) described how people with chronic illnesses feel inhibited to ask for assistance and prioritise needs like showering, eating or dressing over non-essential social activities so as not to be a burden on others. The decision by people to prioritise care requests provides an insight into the complexities of using an informal care-giver who is also a spouse, and into how those
requiring care and those providing this assistance still require some reciprocal exchange so that feelings of dependence and burden are minimised (Cousineau et al., 2003; Martinez-Martin, Forjaz et al., 2007; McPherson et al., 2007; McPherson, Wilson, Lobchuk & Brajtman, 2007).

Reports by Murray et al. (2005) and Murray and Sheikh (2008) indicated that people made end-of-life choices according to the level of burden they believed themselves to be causing. These researchers provided stories of individuals who were not considering an active suicide, but did consider other more socially acceptable means of not prolonging their lives, such as not accepting further medical intervention for an acute infection or not taking opportunities that could extend their lives. The issues surrounding reciprocity are significant and, while under-represented in the health literature, the importance of understanding what poor HRQoL scores could mean for the person with a chronic illness and the relationship between HRQoL and burden should not be disregarded.

3.3 Burden

People often discuss issues surrounding the effect their disease has on them and how each new symptom or issue, such as constipation or over active bladder (OAB) syndrome, places burden on them, affecting their physical, financial or emotional selves (Fuller, Welch, Backer & Rawl, 2005). These burdens have a negative effect on personal relationships and on the sufferer’s ability to cope and adapt to the ongoing degenerative changes encountered in disease states such as PD (Backer, 2000). Backer (2000) and Charlton and Barrow (2002) cited cases of people with PD who reported
feelings of overwhelming suffering that brought them to the view that life was intolerable.

3.3.1 Defining burden

Burden is used across diverse contexts spanning fields such as health, religion, law, politics and economics, giving rise to many opportunities for interpretations to be made. These fields share a central tenet that burden enumerates (objective) or rates (subjective) a predefined physical load that someone has to carry. To identify how ‘burden’ is used in the PD health literature, a broad review was undertaken to provide a deeper understanding of the use of the term and its effect in disability and healthcare.

The word ‘burden’ is used across many sub-specialities and sub-contexts in health services and varies widely in its conceptualisation and usage. The subjective account of ‘burden’ is used to express personal feelings and beliefs. The second use of ‘burden’ is more objective, using numerical scores; an approach used in many disease or disability prevalence studies. Rarely has any study used both subjective and objective aspects of ‘burden’ together. The utility of this conceptual separation allows health economists to differentiate quantitative data from the subjective appreciation of health issues. However, there is a danger that the more subjective or personal aspects of ‘burden’ can be overwhelmed or lost amid prevalence scores generated in healthcare and disability research using scientific positivistic methods. Quantitative representations of ‘burden’ have been in ascendancy for several decades. Allowing for the objective economic concept of disease or disablement to be measured in regard to its effect on a society. However, this objective measurement has little regard to the ‘burden’ experienced by those with a disablting chronic illness.
3.3.2 Objective accounts of burden

Quantitative estimates of ‘burden’ are needed by governments and planners of services for social community and special needs groups addressing the needs of the majority (Evans & Etienne, 2010; OECD, 2011; Garin et al., 2010; WHO, 2008). A review of the literature on ‘burden’ revealed three dominant themes (see Table 3.2):

1. The first defined a public face of burden; these articles used numbers of diseases or disabilities encountered in specified global or local communities found in the Survey of Disability, Ageing and Carers (SDAC) conducted by the ABS.

2. The second addressed objective burden in terms of numerical indices to calculate life expectancy for those living with a disability. These are commonly known as disability-adjusted life years (DALYs) (Murray et al., 2013; Polinder, Haagsma, Stein & Havelaar, 2012).

3. The final theme incorporated studies that focused on the financial cost and societal implications of supporting people with a disease or disability within their social groups, in particular the cost of care and support (Jiang & Hesser, 2012). Each of these themes placed a numerical value on ‘burden’ as a basis for the allocation of resources and social planning of health and social care services.
Table 3.2
Review of the public face of burden: studies published between 2010 and 2013

<table>
<thead>
<tr>
<th>Totals</th>
<th>Group 1: Numbers of diseases or disabilities encountered in specified communities</th>
<th>Group 2: Indices of life expectancy for those living with a disability</th>
<th>Group 3: Societal Financial costs to support people with a disease or disability within their social group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>N=3407 (100%)</td>
<td>2278 (66.8%)</td>
<td>229 (6.7%)</td>
</tr>
<tr>
<td>PD-specific</td>
<td>206 (85.1%)</td>
<td>8 (3.3%)</td>
<td>28 (11.5%)</td>
</tr>
</tbody>
</table>

The use of ‘burden’ to determine societal worth is evident within health economics literature. The utilitarian philosophy that underlies health economics evaluates the value of contributions people make against the value of the resources they use (Rhodes, Battin & Silvers, 2012). As a result, those with chronic health problems are encouraged to accept more responsibility (Porter, 2010), to be more resilient and self-reliant (Clarke & Bennett, 2012) and to show gratitude for the services provided to them (Olsen & Dahl, 2007; Verbrugge & Chan, 2007).

The WHO and the World Bank use an economic rationalist approach to produce and fund epidemiological data needed for estimating current and future global healthcare needs. Personal illness, disability and disease experiences are configured into internationally comparable statistics used to predict and make recommendations for distribution of health resources (Garin et al., 2010; OECD, 2011). On this basis, the WHO and the World Bank are able to present comparable measures and projections, used to plan for the global distribution of scarce health resources to emerging
economies. Numerical ‘burdens’ of disease ratings are also used to disseminate information to developed economies using similar measures so that they may gauge their own healthcare resource needs and plan against future trend projections (Graycar, 1983; Hillermann, 2008; Malhotra, 2008; OECD, 2011; Olsen & Dahl, 2007; Pusey, 2003; Rhodes et al., 2012).

3.3.3 Subjective accounts of burden (Personal Burden)

In contrast to objective ‘burden’ described above, the subjective dimension of burden centres on the physical, emotional or economic needs of individuals with an illness, disease or disability, their family and their informal care networks. Literature on the topic of ‘burden’ as a subjective phenomenon was found to have three themes.

1. Burden as told by the individual with the chronic disease, in this case PD.
2. Burden as experienced by others caring for the person with PD, primarily the spouse or daughters of the person with PD.
3. The public, society-based burden focused on large groups diagnosed with the disease.

The assumption that the literature would focus on subjective issues and would explore the more personal aspects of burden in as much detail and with an equal distribution across all the themes proved to be incorrect. In a similar way to literature around objective ‘burden’, subjective burden research also tended to discount the experiences of individuals with the disease. Preference was given to the voices of others, such as families and caregivers, exploring their emotional or economic hardships and disruptions. The person living with the chronic disease was often regarded as simply providing context for the ‘burden’ of those nearby (Davis, Gilliss, Deshefy-Longhi, Chestnutt & Molloy, 2011; Martinez-Martin, Rodriguez-Blazquez & Forjaz,
3.3.4 Depiction of burden in published research

The current ambiguity related to the depiction of burden by researchers is summarised in Figure 3.2, this figure illustrates the ways burden is interpreted and used in scholarly literature to date. The person with PD is depicted as a one-way contributor and as a causal factor within the larger scheme, not as a multi-dimensional participant acknowledged as being burdened by the disease. Researchers such as Martinez-Martin et al. (2012), Martinez-Martin et al. (2008), Shin et al. (2012) and Razali et al. (2011) have linked PD with the individual by describing their symptoms, physiological dysfunction or their effect on others, rather than as a person burdened or limited by their symptoms. This one-way representation is denoted by a broken line in Figure 3.2.

<table>
<thead>
<tr>
<th>Indicative of Personal Burden</th>
<th>Indicative of Public Burden</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disease</td>
<td>Epidemiological data</td>
</tr>
<tr>
<td>Effect on self</td>
<td>Economic effect of</td>
</tr>
<tr>
<td></td>
<td>the disability or disease</td>
</tr>
<tr>
<td>Effect on self</td>
<td>Effect on family or</td>
</tr>
<tr>
<td></td>
<td>carers</td>
</tr>
<tr>
<td></td>
<td>Effect on society:</td>
</tr>
<tr>
<td></td>
<td>Prioritisation of services</td>
</tr>
</tbody>
</table>

Figure 3.2
Depiction of burden in published research
A computer search using ‘burden’ as a key term in the Medline and Cumulative Index to Nursing and Allied Health Literature (CINAHL) health and medical databases for 2005 to 2013 revealed that 98% of Medline and 95% CINAHL articles that mention the issue of burden did not address burden as it is encountered by the sufferer. Most recounted a macro or society-based view to support the socio-political effect of each symptom, disability or disorder and the potential burden on the global, geographical or culturally defined community.

The search for researcher uses of burden used the word ‘burden’ as the primary or starting key search term and then new keywords generated from the literature were introduced one at a time to create a broad search lattice. Search limitations applied to all searches were that articles be based on human research, published within 2005 to 2013 and published in English. The initial ‘burden’ score of articles was, in Medline, 46,258, and in CINAHL, 11,938. The unequal ratio was expected, as CINAHL, a database primarily generated for nurses and allied health professions, is more inclined to generate less large-scale positivist research than is found in the medical database Medline.

Key words generated from within the literature were: psychological factors, coping, stress, disability and psychological adaptation. These keywords were used singly and then in combination with ‘burden’ to refine the search. Finally, the key term of PD was used to sort the most relevant articles, which were then retrieved. Twenty-two duplicate articles were recognised and removed from the searches, leaving 39 articles relevant to PD. The process and findings are summarised in Table 3.3.
<table>
<thead>
<tr>
<th></th>
<th>Burden</th>
<th>Psychological factors</th>
<th>Coping</th>
<th>Stress</th>
<th>Disability</th>
<th>Psychological adaptation</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sub-total</strong></td>
<td>46258</td>
<td>1800</td>
<td>7051</td>
<td>28013</td>
<td>131909</td>
<td>24964</td>
<td>193737</td>
</tr>
<tr>
<td>**Combined burden and ***</td>
<td>27</td>
<td>183</td>
<td>818</td>
<td>1953</td>
<td>699</td>
<td></td>
<td>3680</td>
</tr>
<tr>
<td><strong>Per cent of total burden</strong></td>
<td>1.5</td>
<td>2.59</td>
<td>2.92</td>
<td>1.48</td>
<td>2.8</td>
<td></td>
<td>1.89</td>
</tr>
<tr>
<td>**PD and burden and ***</td>
<td>0</td>
<td>1</td>
<td>8</td>
<td>0</td>
<td>6</td>
<td></td>
<td>15</td>
</tr>
</tbody>
</table>

**Total percent of combined burden and * (% of total burden)**: 0.40% (0.007%) 6 Duplicates removed Leaving 9

<table>
<thead>
<tr>
<th></th>
<th>Burden</th>
<th>Psychological factors</th>
<th>Coping</th>
<th>Stress</th>
<th>Disability</th>
<th>Psychological adaptation</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sub-total</strong></td>
<td>11938</td>
<td>669</td>
<td>11997</td>
<td>42990</td>
<td>21070</td>
<td>7831</td>
<td>84557</td>
</tr>
<tr>
<td>**Combined burden and ***</td>
<td>17</td>
<td>672</td>
<td>2838</td>
<td>737</td>
<td>233</td>
<td></td>
<td>4497</td>
</tr>
<tr>
<td><strong>Per cent of total burden</strong></td>
<td>2.54</td>
<td>5.6</td>
<td>6.6</td>
<td>3.49</td>
<td>2.97</td>
<td></td>
<td>5.31</td>
</tr>
<tr>
<td>**PD and burden and ***</td>
<td>0</td>
<td>6</td>
<td>30</td>
<td>8</td>
<td>2</td>
<td></td>
<td>46</td>
</tr>
</tbody>
</table>

**Total percent of combined burden and * (% of total burden)**: 1.02% (0.054%) 16 Duplicates removed Leaving 30
Each of the final articles was categorised according to research focus and previously established themes. These were—Group 1: The individual with PD’s experience of burden \( (N=5, 12.8\%) \), Group 2: The burden experienced by the family as informal carers \( (N=25, 64.1\%) \) and Group 3: The burden experienced by society \( (N=9, 23\%) \). A full listing of this reviewed literature is provided in Appendix A. Only 5 articles included a discussion about the burden PD places on the individual, with the other 87\% referring to the effect the disease has on others, either caring for the sufferer or accounting for the monetary or non-monetary costs encountered by the family or wider society. This finding is not unique to PD; other chronic illnesses, such as Alzheimer’s and strokes, are also noted to be similarly addressed, especially if the sufferer is an older adult (Ahan et al., 2003; Cousineau et al., 2003; Haynes & Watt, 2008; McPherson, Wilson, Lobchuk & Brajtman, 2007).

The information gathered from these searches began to frame the argument that the word ‘burden’ has been captured by health economists and researchers to objectify those with chronic illness as causes of burden on others. McGuire et al. (2002) called for the use of burden to be more consistent, stating that one of the major issues with the concept of burden is its inconsistent usage. They stated that, in the main, the lack of an agreed definition beyond that of simply “a negative impact of illness” (McGuire et al. 2002, 179) has prohibited researchers seeing burden beyond the effect on others. The everyday use of the term ‘burden’ in conversation or in the context of discussions between health consumers and their health practitioners embeds the burdensomeness of the disease for them (Davis et al., 2011; Fässberg et al., 2012; McPherson, Wilson, Lobchuk & Brajtman, 2007; McPherson, Wilson & Murray, 2007; Verbrugge & Chan, 2007).
3.4 Adaptation

Little is known about how non-disabled older adults maintain a positive QoL. A study by Hildon, Smith, Netuveli and Blane (2008) found that well older adults are more resilient to adverse or small changes if they are able to find ways to balance the disruptiveness of these adverse events with resources that offer a modicum of structure and stability. Clarke and Bennett (2012) extended discussions of structure and stability, aligning them with a person’s continued ability to perform acts of self-care, endowing them with a sense of control over their lives. Schalock and Alonso (2013) also asserted that control, dignity and self-determination for people with disabilities are primary social determinants most highly associated with reports of positive QoL. These findings are consistent with other research showing that people who believe they are well endowed in these attributes are more inclined to feel good about themselves and report higher life satisfaction. Conversely, those people who are no longer able to perform basic ADLs, such as being able to wash, dress or toilet themselves, report much lower levels of life satisfaction (Alma et al., 2012; Clarke & Bennett, 2012; Cummins, 2005; Hildon et al., 2008; King et al., 2012; Levasseur et al., 2004; Schalock, 2004).

As people age, a commonly reported concern is that they do not wish to become a burden on others. Hildon et al. (2008), in a study of elders, reported only a minor association existing between chronic illness and feelings of being a burden. According to the ABS (2009) and the AIHW (2006), most older people have more than one chronic health condition, yet these chronic conditions do not overly restrict every elderly person. Hildon and colleagues (2008) found the support structures, routines and relationships embedded in people’s lives enabled or disabled their participation in resiliently adapting to these stressful life challenges. This was interpreted to mean that
older people do not report small, yet manageable deficiencies and declines, reserving their complaints for when these deficiencies become too complex and overwhelm their adaptive strategies.

The person with PD needs to find a dynamic balance between social participation and the burden encountered so that they are able to remain in contact with their community and society at large. It is only when these peoples’ resources, support structures, relationships and routines are not available or are not sufficient to counter the burden encountered that they experience deterioration in life satisfaction levels. In the current study, it is suggested that the taboo surrounding socially disruptive bowel and bladder symptoms interferes with a person’s ability to seek out new and effective recourses needed to maintain this equilibrium and as such results in high degree of burden.

3.5 Conclusion

By reviewing the biological, sociological and psychological attributes of QoL, burden and adaptation, the contextual frameworks that have influenced the researcher’s assumptions have been clarified. This chapter began by exploring the QoL constructs used to determine what a ‘good satisfying life’ means and how clinicians and others have reinterpreted QoL constructs, focusing not on the individual’s perceptions of their QoL, but into measurable indicators of medical interventions provided. The use of these measurable indicators has reframed many QoL studies giving them a different focus from that of the original 1998 WHOQoL group’s outline of what constitutes a primary attribute of QoL.

There was no evidence of published QoL research that analysed the disturbance caused by assisting people with toileting from the perspective of the person with PD.
The dearth of QoL studies, especially with reference to the symptom of constipation or UI or urge and frequency, indicates that as this topic is not regarded as clinically important and therefore not given high research priority. Alternately, toileting issues are difficult to raise and discuss in clinical settings for the client and the physician who are often unaware of the symptoms' impact on the person’s QoL and may disregard defecation and urination issues as unimportant. Such attitudes have reduced the likelihood of these symptoms being included in measures of PD burden and in QoL research. The focus of research has continued to be on the family, specifically the spouse and daughters of the person with PD, and not on the person with PD associated bowel and bladder symptoms. At no point through the review of published research were bowel and bladder symptoms given any independent status or prominence in burden or QoL studies. The lack of definitional consensus was found to be a critical factor contributing to the person with PD being undermined or depicted as insignificant in most research outputs.

There is a pressing need to obtain critical insights, previously unknown, about living with a disability that has socially embarrassing symptoms. For instance, the person with PD needs to be asked to share their story, not the caregivers’ and not the health service providers’ experiences. This study proposes to examine the factors that may reduce the person with Parkinson’s disease capacity to make adaptive changes in their life, not because they cannot make these changes, but rather because they do not want to disturb ‘others’ who are deemed more worthy of concern by the health and general community than the person with PD.
3.5.1 Research aims and questions

The research aims and questions have been constructed to facilitate this research and to further develop an understanding about burdensome symptoms experienced by adults with the neurodegenerative disease of PD.

The overall objective of this research is to explore the impact of these two under-researched NMS commonly encountered in PD, has on the sufferer. While these autonomic dysfunctions have been reported to affect many people with PD, they remain inadequately investigated from the perspective of the person with PD in a meaningful way (Bannister, 2000; Coggrave et al., 2006; Winney, 1998).

The study has three specific aims to address gaps in knowledge about autonomic bowel and bladder NMS. The first is to explore the extent of burden experienced by those with specific bowel and bladder symptoms arising from PD. The second is to investigate ways in which these NMS affect people’s quality of life (QoL). Finally, the study will investigate how people locate, obtain and manage treatment strategies.

These aims are embedded within the following research questions:

1. What are the bio-psycho-social burdens of bowel and/or bladder dysfunction for a person with PD?

2. What specific QoL factors, as measured by the PDQ-39, are affected by bowel and bladder dysfunction?

3. What are the therapeutic experiences of the health consumer with PD, specifically regarding their reports of bowel and bladder dysfunction?
Chapter 4: Research processes

The focus of this chapter centres on the research methods and procedures used to address the three research questions discussed in Chapter 3:

4. What are the bio-psycho-social burdens of bowel and/or bladder dysfunction for a person with PD?

5. What specific QoL factors, as measured by the PDQ-39, are affected by bowel and bladder dysfunction?

6. What are the therapeutic experiences of the health consumer with PD, specifically regarding their reports of bowel and bladder dysfunction?

4.1 Research design

The mixing of research data collection and analysis methods was first described by Denzin in 1970 (cf Denzin, 2009) as methodological triangulation, based on the “unobtrusive method” proposed by Webb, Campbell, Schwartz, and Sechrest, who suggested, “Once a proposition has been confirmed by two or more independent measurement processes, the uncertainty of its interpretation is greatly reduced. The most persuasive evidence comes through a triangulation of measurement processes” (2000:p.3).

Triangulation offers compelling ways in which researchers can validate social and behavioural data and add richness to focused, numerically based questionnaires. The triangulation of mixed data methods is also recognised as a rigorous way to generate and validate the personal effect of a disease beyond mere epidemiological accounts of disease (McVilly, Stancliffe, Parmenter & Burton-Smith, 2008; Plewis & Mason, 2005). This position is also supported by Brannen (2005), Flick (1992), Hoskins and Mariano (2004), Johnstone (2004) and Niglas (2004), who agreed that the mixing of subjective and objective data creates opportunities for increased richness and clarity of
understanding that is difficult to achieve when using objective accounts alone to explore social phenomena.

Mathison (1988) postulated that mixed method research is far better placed to appreciate the importance of differences within and between research approaches and data. She warned, however, that results generated can provide inconsistent and incongruent outputs, raising more questions than answers. Mathison’s concerns will be addressed in this current research in the following ways. First, bowel and bladder dysfunctions are known to be significantly associated with this disease and only those burdened by a bowel or bladder symptom will be included and interviewed. Second, the development and exploration of questions, missed or only addressed in brevity by existing tools, will be used to generate both subjective burden scores and rich spoken interview data, which will be fully integrated into the research findings. Finally, the researcher, an expert continence clinician, can draw on her experience to provide contextual validation. Applying these guidelines to this current research provides protection from a potential interpretive maze that Mathison saw as generating incongruent and mixed messages.

Mixed method typology as described by Denzin (2009) is able to accommodate a diverse range of research needs. Denzin specifically categorised the application of mixed method triangulation across four sub-groups. The first, data specific triangulation, refers to multiple sampling across time, person or situation. Second, is the use of multiple investigators, third is analysis involving interpreting data from multiple theoretical standpoints and fourth is more than one approach being used to collect and analyse data. This research is more aligned with Denzin’s fourth approach to mixed method design.
In terms of research design, combinations of mixed method research are unlimited, provided that any collective use of quantitative or qualitative procedures is acknowledged as moving into the realm of mixed method research (Boddy et al., 2007; Dusek et al., 2010; Pretzer-Aboff, Galik & Resnick, 2011). This study will incorporate quantitative survey design alongside a qualitative semi-structured interview based on an inductive principle, which generates theoretical understanding.

4.2 Qualitative Theory - Semi-structured interviews using inductive content analysis

In addition to the quantitative surveys used a series of semi-structured interviews were conducted to learn about how the participants interpret their experiences of the phenomenon under consideration and to gain insight into the participant ‘s interpretation of their day-to-day reality living with Parkinson Disease. This participant generated data is analyzed using inductive content analysis.

Content analysis is a subject-sensitive method (Krippendorff 1980) offering significant flexibility in terms of mixing research designs (Harwood & Garry 2003). Content analysis also offers more than a one-dimensional view of the data, providing the research with more than a series of unsophisticated descriptions of the spoken word. It is used to generate thoughtful meanings and to ascertain critical elements the words spoken (Vaismoradi, Turunen, & Bondas, 2013). According to Elo & Kyngäs (2008) and Vaismoradi et al. (2013) inductive content analysis is the most appropriate analytical approach for a study exploring a previously little known phenomenon. Approaching the participant’s semi-structured qualitative interview question responses in this manner enables this research to generate theoretical opinions through the
development of data driven categories. These categories will then be used to advance an interpretative insight and understanding of the contextual influence bowel and bladder dysfunction had on each participant’s lives, so that their health beliefs, attitudes and expectations can be better understood.

A secondary qualitative data collection is also generated in the form of reflective notes during the interview. Reflective notes are a well-accepted method used in qualitative data collections, where the researcher journals what they see and what they understand at that time of interview and then later, uses these notes to reflect on the conversations and experiences had with participants (Bowling et al., 2007). These reflections were used in this instance to diagnostically categorise and understand how the participants were influenced in their choices and use of health services. This information provides insights as a basis for challenging how current services are delivered and how they may be altered to meet the needs of a group of people who have PD and bowel and bladder dysfunction.

The use of a mixed method design (interpretive content analysis and statistical analysis) to study PD and the presence of bowel and bladder dysfunction enabled participants with PD to convey their experiences to the researcher in a way that promoted deep understanding of how bowel and bladder symptoms affect their life. Through this approach the researcher also acknowledges participants’ contributions by ensuring the research findings are accessible and in a form that participants can relate to and use. McVilly et al. (2008) proffered this as a significantly important consideration for people with a disability, who often believe themselves to be unheard and their complaints trivialised.
As demonstrated in Figure 4.1, this current research used a concurrent analysis of qualitative and quantitative data sets (Leech & Onwuegbuzie, 2007). Further, this type of triangulated research design provided an innovative way of converging the data by calculating a numerical value representing each participant’s voice and thereby enabling this transformed content to be included in quantitative data analysis. By approaching the analysis in such a way participants’ voices remained the central focus of this study rather than an add-on to any central quantitative calculations.

Figure 4.1. Research design flowchart
The research was designed to enable the generation of a picture, which typifies bowel and bladder dysfunction most commonly reported by this target group, and enabled exploration of how these dysfunctions challenge individuals with PD. The participants, adults diagnosed with PD, were invited to complete a series of specific PD surveys on QoL, disease staging and disability impact scales and questionnaires. These tools, commonly used in clinical neurological and general health settings, are frequently referred to in the literature and have been extensively tested for validity and reliability. The tests selected for use in this study are discussed in more depth as each instrument is introduced later within this chapter.

- NMSS (Chaudhuri, Martinez-Martin, Brown et al., 2007) (see Appendix C).
- H&Y (Hoehn & Yahr, 1967) (see Appendix D).
- Schwab and England (S&E) ADL (Gillingham & Donaldson, 1969) (see Appendix E).
- Numerical Rating Scales

With the exception of the PDQ-39, which will be self-administered and submitted prior to the interview, all other survey tools were completed at the time of the interview. The researcher read each question or statement to the participant, who was asked to give his or her answers accordingly.

In addition to the completion of these surveys, interviews were conducted using a formal schedule of questions about the participants’ bowel and bladder symptoms (see Appendix F). The interview schedule combined both psychometric numerical rating scales (NRS) and open-ended questions. The open ended questions asked participants
about their day-to-day living and how their bowel and bladder non-motor symptoms directly affect their life, whilst the NRS provided participants with an opportunity to numerically rate these experiences.

The five psychometric NRS scales used were:

The Subjective Severity Score (S3) group which consist of four simple 4 and 5 point numerical rating scales (NRS). In this research, these NRS are employed to elicit a numerical ranking of the participant’s disease severity, the participant’s wellbeing and the participants’ satisfaction with the continence service they received. The S3 response scales were grammatically altered to correspond with the specific question asked.

a. S3-Health
b. S3-Disability
c. S3-Qol
d. S3- Satisfaction

The fifth NRS scale, the Symptom Burden Score (SBS) was used to elicit a numerical ranking of the participant’s bowel and or bladder symptom severity and its impact or burden. These rankings were additionally used to organise the participant s’ spoken words into degree of burden categories.

The contemporaneous reflective notes made by the researcher assisted in the construction of a contextual framework of meaning that was then used to diagnostically categorise continence problem expressed by each participant. These reflective notes provided useful memory prompts and points of reference, together with the participant data, to generate a deeper and more inclusive interpretation of each participant’s experiences. Though the construction of these reflective notes researcher bias was able
to be identified early and mediated allowing for a more confident convergence of all participant generated evidence.

4.3 Research procedures

4.3.1 Ethical considerations

Following ethics approval from the Human Research and Ethics Committee (HREC) University of Sydney (see Appendix H), the New South Wales (NSW) Association for PD and the Brain and Mind Research Institute (B&MI) were approached and asked to disseminate information to their members. Potential participants received information about the research via an article placed in the PD newsletter and on the Association for PD website, or via a letter inviting them to participate (see Appendix G), which was included in a regular mail-out from the PD clinic held at the B&MI. Additional information was sent by PD NSW to local organisers of PD support groups, asking them to inform their members of the research. All announcements and invitations included the researcher’s contact phone number and invited people interested in finding out more about the research to contact the researcher to arrange receipt of a research pack (see Appendix G). The research pack was sent to everyone who made an enquiry about joining the research project. The research pack included a covering letter and other documents informing them:

- the purpose of the research,
- a description of the nature of the study, the type of questions that would be asked and the potential benefits and risks that may be encountered when choosing to participate,
- how to respond if there was a problem or if they had any concerns regarding the research, and
that the research involved one telephone interview.

Consent forms and a meeting schedule were also included so that people interested in becoming a participant in this research could sign and return their completed consent forms, as well as indicate their preferred contact details and the best time, morning, afternoon or evening, for the researcher to telephone.

The confidentiality of participants and their details was maintained throughout the project by ensuring that no identifying information appeared on any of the completed questionnaires, interview schedules or notes made by the researcher. The participants were all assigned a coded number, which was used on all documentation in preference to names. The researcher was the only person with the complete listings of names and corresponding code numbers. These lists and all identifiable documents were stored separately in a locked filing cupboard inside the researcher’s single occupant office that was also locked. The papers are stored in a secure research archival room where they will remain following the completion of this project. The archived questionnaires and consents will be destroyed according to the HREC protocol after seven years.

To reduce any risks each participant was informed that their involvement or non-involvement would not affect the delivery of any of their health services. The Continence Foundation helpline number was also available to be provided to any participant should it become apparent that their bowel or bladder dysfunction was causing undue distress, or if they stated they needed further information or if during the course of the interview an unexpected emotional effect was observed. If any participant was thought by the researcher to need acute medical attention for a urinary or bowel dysfunction such as an infection, there was an option for them to be referred to their
local GP for diagnosis and treatment. The name and number of the researcher, her faculty advisors and the University of Sydney HREC’s contact details were provided to all participants via the Participant Information Letter and participants were encouraged to make contact if they needed assistance or if an unexpected problem occurred.

4.3.2 Sample size

Sample size estimations in mixed method research are not well documented and, according to Collins, Onwuegbuzie and Jiao Qun (2007) and Onwuegbuzie and Leech (2007), are more often influenced by the dominant research model used; that is, larger sized samples in quantitative dominant research and smaller sample sizes in qualitative dominant research. With power of analyses calculations not available for mixed method research, recommendations have been made by expert researchers such as Creswell (2002) (cited in Onwuegbuzie & Leech, 2007) and Morse (1994) (cited in Onwuegbuzie & Leech, 2007), who advised the use of an arbitrary 30 to 50 interviews for studies classified as purely ethnographic. In deference to these expert recommendations and as this research uses a mixed concurrent equal status approach, expressed as a QUANT ⇥ QUAL research typology (Boddy et al., 2007) a slightly larger yet manageable sample of between 60 and 70 participants was chosen to ensure trustworthy data that will enable a full exploration of the topics in question, although this information will not be regarded as generalisable beyond the sample population (Collins et al., 2007; Francis et al., 2010).

4.3.3 Sample

Data were obtained from a purposive sample of between 60 and 70 people, all of whom experienced a dysfunction with either or both their bowel or their bladder. Table 4.1 itemises the inclusion and exclusion criteria used to select or reject research
participants. In particular, people were excluded from this research if unable to self-report, or had no bowel or bladder dysfunction and did not have a medical diagnosis of PD. Those meeting the inclusion criteria were invited to take part in a 45-minute telephone interview.

Table 4.1
Inclusion Criteria: Attributes and diagnosis

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>The person being recruited had been diagnosed as having idiopathic PD.</td>
</tr>
<tr>
<td>The participant be experiencing some dysfunction with either their bowel or bladder.</td>
</tr>
<tr>
<td>The person be able to converse via a telephone in English.</td>
</tr>
<tr>
<td>No male to female ratio was imposed as the main inclusion criteria was bowel or bladder dysfunction not gender.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Persons unable to participate in a telephone interview.</td>
</tr>
<tr>
<td>People without access to a telephone.</td>
</tr>
<tr>
<td>People with Parkinson’s symptoms not yet diagnosed by a medical practitioner.</td>
</tr>
<tr>
<td>People not experiencing any bowel or bladder dysfunction.</td>
</tr>
</tbody>
</table>

4.4 Quantitative ⇆ Qualitative data collection procedures

4.4.1 Semi-structured interview questions

During a 45 minute telephone interview, participants were invited to tell their story of bowel or bladder dysfunction. The researcher made extensive notes during the interview, which were read back to each participant in the form of quotations—‘you said’—and summaries—‘what you have told me is’—before moving on to the next question. This gave each participant an opportunity to validate or add information that may have been missed by the researcher. The conversations were not audio-taped, but instead conducted in accord with the principles of a clinical consultation, where the practitioner listens and makes contemporaneous notes. The interviews took, on average, 45 minutes each.
4.4.2 Instrumentation - Semi-structured interview questions.

The current study used a concurrent methodologically structured survey tool containing six questions, scored quantitatively, and six questions that were qualitatively themed (see Table 4.2). This is a novel approach in the exploration of bowel and bladder dysfunction, as it enabled the participants’ to rank their words of defence and explanation, into a unidimensional numerical rating score (NRS). The use of these NRS allows the study to generate a truly personalised quantitative numerical appreciation of each participant’s unique experience. The NRS group are used throughout this study to augment the other instruments’ data collections that specify numerical accounts. Moreover, the NRS group assisted in the categorisation of qualitative statements which were also used to explore their diagnostic origin and:

- the treatments and products the participants use to manage their bowel and bladder concerns, and
- the degree of satisfaction they obtained from the use of these treatments and products.

Psychometric rating scales are widely used to reliably measure individual’s subjective experiences in healthcare environments and in health related research. They are extensively used to lineally evaluate, pain, depression, anxiety, global improvement and satisfaction. The SBS was adapted from the commonly used pain rating scale developed by McCaffery & Beebe (1993). The scoring was in accord with McCaffery & Beebe’s original scaling. Validation of this amended tool was beyond the scope of this project but is recommended for future research. However in terms of content and face validity it is consistent with specialists in the field of PD and the participants were able to comprehend and respond to the question asked.
The two most commonly used scale types are the Visual Analogue Scale (VAS), where a person is presented with a linear visual aid on which they indicate their score and the Numerical Rating Scale (NRS), where a person is prompted to verbally indicate the level of symptom severity according to an increasing numerical value. The VAS and the NRS have been extensively evaluated for validity and sensitivity and are both preferred by clinicians, patients and researchers to measure the subjective severity of a physiological or psychological disturbance (Hjermstad et al. 2011, Ferreira-Valente, Pais-Ribeiro & Jenson. 2011). As this research involved remotely conversing with participants, the NRS was chosen as it enabled participants to rate their Health Status, Disability, QoL, Burden and Satisfaction verbally at the time of interview.

The rationale for constructing the semi-structured interviews stemmed from the non-availability of any other suitable tool. All other investigative bowel or bladder instruments specifically address the issue of incontinence, and while some people with PD have incontinence, many others do not. By focusing only on incontinence opportunities to see if other aspects, such as participants’ attitudes or burdens, evident alongside bowel or bladder symptoms, were limited. The overall strength of the data collection was improved by having a tool that would capture concurrent quantitative and qualitative data. The validity and usefulness of the semi-structured interview tool was ensured by a group of six independent continence nurse consultants who reviewed it in terms of its appropriateness prior to the study.
Table 4.2
Survey Questions

<table>
<thead>
<tr>
<th>Data type</th>
<th>Specific questions asked</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic</td>
<td>DOB</td>
</tr>
<tr>
<td></td>
<td>How long ago were you diagnosed with PD?</td>
</tr>
<tr>
<td>Quantitative</td>
<td>How would you describe the severity of your Parkinson’s symptoms?</td>
</tr>
<tr>
<td>questions</td>
<td>S3-Disability: 1=very mild; 2=mild; 3=moderately; 4=severely affected</td>
</tr>
<tr>
<td></td>
<td>What PD motor symptoms do you have? How do you rate these symptoms in terms of burden?</td>
</tr>
<tr>
<td></td>
<td>SBS: 1=no burden - 10=extreme burden</td>
</tr>
<tr>
<td></td>
<td>What bowel/bladder symptoms do you have? How do you rate these symptoms in terms of burden?</td>
</tr>
<tr>
<td></td>
<td>SBS: 1=no burden - 10=extreme burden</td>
</tr>
<tr>
<td></td>
<td>How would you describe your overall health at present?</td>
</tr>
<tr>
<td></td>
<td>S3-Health: 1=good; 2=fair; 3=poor; 4=very poor</td>
</tr>
<tr>
<td></td>
<td>How much do you think your bowel/bladder problem affects your life?</td>
</tr>
<tr>
<td></td>
<td>S3-QoL: 1=not at all; 2=a little; 3=moderately; 4=a lot</td>
</tr>
<tr>
<td></td>
<td>Have you spoken to anyone to ask for help/assistance for these bowel/bladder problem, who were they? Were you satisfied with their help/assistance?</td>
</tr>
<tr>
<td></td>
<td>1: Yes/No. ... Specify.</td>
</tr>
<tr>
<td></td>
<td>2: S3-Satisfaction: 1=very unsatisfied; 2=unsatisfied; 3=neutral; 4=satisfied; 5=very unsatisfied.</td>
</tr>
<tr>
<td>Qualitative</td>
<td>How would you describe your bowel/bladder difficulties?</td>
</tr>
<tr>
<td>questions</td>
<td>Have you spoken to anyone to ask for help/assistance for this problem?</td>
</tr>
<tr>
<td></td>
<td>What treatments/products have you tried to solve your difficulties, were they successful?</td>
</tr>
</tbody>
</table>

NB: A detailed analysis of these survey questions is presented in chapter’s 5, 6 & 7.

Two conventional diagnostic criteria were used to classify and clarify the symptoms reported by each participant in order to ensure the completeness of the qualitative data capture and to assist in theme construction. The first was, the Rome III criteria for bowel dysfunction, specifically constipation and diarrhoea (Chatoor & Emmnauel, 2009). The second was, the International Continence Society (ICS) diagnostic criteria for bladder dysfunction (Abrams et al., 2010), which specifically categorises lower urinary tract symptoms (LUTS), diurnal frequency, urgency, nocturia, retention and incontinence.
4.4.3 Quantitative Data Collection

The four tools selected for use in this research were: the PDQ-39 (Jenkinson, Fitzpatrick, Peto, Greenhall & Hyman, 1997a; Jenkinson, Fitzpatrick & Petro, 1998), the NMSS (Chaudhuri, Martinez-Martin, Brown et al., 2007), the H&Y (Hoehn & Yahr, 1967), the S&E (Gillingham & Donaldson, 1969) and a grouping of Numerical Rating Scales (Hjermstad et al. 2011, Ferreira-Valente, Pais-Ribeiro & Jenson, 2011). All are regarded as offering a gold standard insight to research about PD. Permission to use the PDQ-39 and NMSS was sought and received. The NRS, H&Y and S&E are free of copyright restrictions.

The PDQ-39 was to be completed by the majority of participants immediately prior to the scheduled interview. The reason for this is that the Brain & Mind Institute (B&MI) planned to include this study’s participation invitation in one of their own mail-outs, which was going to include the PDQ-39. The B&MI entered the returned and completed PDQ-39 into their own database and where, once this research had obtained the participants’ consent, the current researcher was provided access to the data the B&MI regularly collect. All other questionnaires, including the NRS, NMSS, the H&Y and the S&E, were completed during and coded following the interview by the researcher.

4.5 Instrumentation

The following survey instruments and interview questions were used to collect participant information on disability, QoL, symptom frequency and severity.

They are grouped as:

1. Disability, general health rating
2. QoL, burden and service satisfaction scales.

3. Specific NMS data collection tools

4. Semi-structured open-ended interview questions.

4.5.1 Disability and general health rating

The S3- Disability, the S3- Health, the H&Y and the S&E scales were used to measure the disabling impact of PD for these people. The H&Y and S&E are used extensively throughout the literature and in clinical practice to assess and score participants on their reported functional status and to allow for standardised groupings of participants to be made (Derost et al., 2007; Eng et al., 2006; Esselink et al., 2006; Forsaa et al., 2008; Kim et al., 2007; Marras et al., 2008; Martinez-Martin, Serrano-Dueñas et al., 2007; Muslimovic, Post, Speelman, Schmand & de Haan, 2008; Post et al., 2008; Weaver et al., 2009; Zhao et al., 2010).

4.5.1.1 H&Y staging of PD

The H&Y staging of PD (Hoehn & Yahr, 1967) is used to locate the progression of the disease according to the presentation of symptoms along a five stage, increasing severity scale. Zhao et al. (2010), Goetz et al. (2004) and Fahn (2003) reported on the usefulness of the H&Y in compiling the stages of clinical progression of PD as well as aiding in the categorisation of individuals with this disease, especially in research. The H&Y is widely used and most commonly administered by the clinician at the time of a physical assessment or retrospectively from the patient’s medical records. The advantage of this staging tool lies is its ease of use by both specialised and non-specialist clinicians, with a completion time of less than five minutes (Goetz et al., 2004). This tool is acclaimed as the ‘gold standard’ for staging PD (D’Amelio et al.,
2009; Diamond & Markham, 1983; Goetz et al., 2004; Li et al., 2010; Post et al., 2008; Weaver et al., 2009; Zhao et al., 2010).

As a point of clarification, this study did not use the modified H&Y which includes three more stages with ‘0’ indicating no clinical signs of the disease, the second and third additions halved the score of the first and second stages, which read 1.5 and a 2.5 (Fahn & Elton, 1987; Goetz et al., 2004). The original five stages were regarded as adequate for use in the current study to classify participants into research sub-groups.

4.5.1.2 S&E ADL

The S&E ADL scale was introduced at the Third Symposium of PD in Edinburgh, Scotland, in 1969 (Gillingham & Donaldson, 1969) and has since become one of the most widely used and recognised measures of ADL for people who have PD (Bhatia & Gupta, 2003; Brittle et al., 2008; Rejeski, Ip, Marsh, Miller & Farmer, 2008). This tool is used by both clinicians and consumers to assess functional abilities when compared with an independent person. The scale is a graduated percentage scale ending at zero with incremental rises of 10%. A total score of 100% indicates a completely independent person in all aspect of their ADLs, while a score of 0% indicates a person in a vegetative state (Gillingham & Donaldson, 1969; Martinez-Martin, Prieto & Forjaz, 2006; Muslimovic et al., 2008; Schrag, Spotte, Quinn & Dodel, 2009).

The S&E has been used extensively in many studies that assess disability and disablement in PD. This tool has not been the primary focus of studies undertaking the clinometric characteristic evaluation of PD disablement tools; however, it is used extensively as a moderator against which all other tools are rated (Carod-Artal et al., 2007; Esselink et al., 2006; Marras et al., 2008; Martinez-Martin, Serrano-Dueñas et al.,
The expert consensus of published research supports the continued use of the S&E, primarily as there is no similar tool; and it has been rated as being more sensitive to physical change than other health-related QoL measures tools. A longitudinal study conducted by Schrag et al. (2009, p. 816) found the S&E consistently rated ADL and total disability progression (change) accurately at one year post diagnosis \( [R=0.59; \ p 0.001; \ t (3.75) \ change \ 10.81 (17.5)] \) and again at four years \( [R=-1.01; \ p<0.0001; \ t (5.06) \ change \ -17.22 (22.9)] \). Moreover the S&E is also reported as having good construct validity, inter-rater reliability and validity \( [R=-0.83, \ P < 0.0001] \) (Glazener & Lapitan, 2002, 185; Ramaker, Marinus, Stiggelbout & van Hilten, 2002).

This study chose the S&E to use as a subjective indicator of functional disability as reported by the participants and to classify their statements into homogeneous groups.

### 4.5.2 QoL, burden and service satisfaction scales

#### 4.5.2.1 PDQ-39

The PDQ-39 (Fitzpatrick et al., 2004; Jenkinson, Peto, Fitzpatrick, Greenhall & Hyman, 1995) is a Parkinson disease specific health related quality of life (HRQoL) tool that was developed by the Oxford University Health Services Research Unit. As with other HRQoL tools, the specificity of this tool to PD makes it one of the most widely used HRQoL tools. It can be self-administered and is time efficient, taking only 15 minutes to complete. The PDQ-39 may be scored as a total summary index score (PDSI) of the eight PD-specific HRQoL domains, on a scale of 0=very good HRQoL through to 100=very poor HRQoL. Alternatively, each of the eight subscales can be scored separately and reported in a profile format. These scores enable information to be
classified as dependant variables, with lower scores indicative of better self-reported health status.

The psychometric properties are reported as having good internal consistency, being dependable in testing and retesting and having good face and construct validity (Franchignoni et al., 2008; Hagell & Nilsson, 2009; Peter Hagell, Whalley, McKenna & Lindvall, 2003; Leung & Schnelle, 2008; Li et al., 2010; Martinez-Martin, Serrano-Dueñas et al., 2007; Martinez-Martin et al., 2005; Pearl-Kraus, 2007; Serrano-Dueñas & Serrano, 2008). The PDQ was assessed by Luo et al. (2010) in a study for reliability using both Cronbach’s α [0.84–0.88] and intra-class correlation coefficient (ICC) [0.56–0.82]. Franchignoni et al. (2008) and Hagell and Nygren (2007) also reported a Cronbach’s alpha respectively at [0.72 and 0.72–0.95]. Luo also examined the PDQ-39 for convergent validity alongside the commonly used short-form functional health status questionnaire or SF-36 at \[r= (~0.46)– (~0.69)\] and the unified PD rating scale (UPDRS) \[r=0.44–0.68\] and was found to produce consistent agreement. More importantly, the PDQ-39 was found to significantly discriminate between people at different H&Y stages (Franchignoni et al., 2008; Hagell & Nygren, 2007; Santos & Santos, 2011).

The items on the PDQ-39 measure the following eight HRQoL domains:

- mobility
- social support
- ADL
- cognition
- emotional wellbeing
- communication
• stigma
• bodily discomfort (Peto, Jenkinson & Fitzpatrick, 2001).

As demonstrated in the Luo et al. (2010) study, the PDQ-39 psychometric properties remain valid and reliable even when altered to accommodate different cultures and languages (Fontenla & Gould, 2003; Gaudet, 2002; Krikmann, Taba, Lai & Asser, 2008; Li et al., 2010; Martinez-Martin et al., 2005; Peto et al., 2001; Serrano-Dueñas et al., 2004; Serrano-Dueñas et al., 2008). Concerns have been raised regarding the PDSI’s capacity to represent more than just a sum of scores. Hagell et al. (2003), Hagell and Nilsson (2009) and Nilsson, Westergren, Gunilla and Hagell (2010) have addressed this issue in terms of uni-dimensionality, claiming that the PDSI was not able to represent the essential characteristics of all eight domains by simply summing their sub-scores.

This current study does not rely on the PDQ-39 PDSI scores, nor on the single domain scores as standalone traditional scores, with zero being a positive score and 100 being a negative HRQoL score. Instead the study asked participants to provide a deeper context from which interpretation of their HRQoL disturbance can be made. In this way the research is able to relate people's bowel and bladder dysfunctions to how these symptoms affect their interpretations of a positive or negative HRQoL. Additionally, it also enables them to indicate their ability to adapt to physical and environmental challenges together with their attempts at remaining socially included by demonstrating this effect in their PDQ-39 scores. This approach is seen as potentially extending the usefulness of the PDQ-39 as a valid and reliable tool that is responsive to change and able to distinguish important HRQoL differences.
4.5.2.2 The symptom burden score (SBS)

This tool differs from the other S3 group in that the symptom burden score (SBS) uses a 10 point scale, lineally scored - No symptom burden (0) to extreme symptom burden (10).

The SBS 10 point response ratings, quantifies the impact of a person’s reported symptom(s) presence and severity and is the most common of all psychometric NRS tools used in healthcare environments and research. In this study, it was used to elicit a numerical ranking of the participant’s symptom severity and impact (burden). It was also used to categorise the participant qualitative statements about the symptom(s) they experience and call burdensome. However, due to the subjective nature of burden each participant’s scores could only be rudimentary compared with the experiences of other participants within the group.

4.5.3 Specific non-motor symptom data collection tools

4.5.3.1 NMSS

The NMSS (see Table 4.2) was developed in 2007 by the PD Non-Motor Group, an international, multidisciplinary group of health practitioners and academics with an interest in the NMS that effect people with PD. The NMSS is the first clinical tool that comprehensively assists in identifying NMS as they relate to PD. The NMSS was assessed by Martinez-Martin, Serrano-Dueñas et al. (2007) for reliability using both Cronbach’s $\alpha$ [0.44 to 0.85] and ICC, which was [0.90] for the total score and ranged from [0.67 to 0.91] for each of the eight domains. The NMSS was also reported to have a satisfactory reproducibility, evidenced by a Lin’s concordance coefficient [0.88], and was free of floor or ceiling effects (Slieker-ten Hove, et al., 2010, p. 1588).
Martin, Serrano-Dueñas et al. (2007) also examined the NMSS for convergent validity alongside the PDQ-39 \( r = (0.57–0.70) \) and it was found to produce a strong consistent agreement. Higher NMSS scores were found in women, those who had PD for longer periods of time and those categorised at a higher H&Y stage, all of which is in accord with current expert knowledge and expectation of PD.

This tool has gained widespread attention as it addresses a range of NMS commonly reported by people with PD that have not previously been adequately addressed. The greatest advantage reported by many researchers is how the NMSS highlights and prioritises NMS, allowing the practitioner opportunities to correctly identify areas of expressed need without fear of missing bothersome symptoms because of time pressured consultations (Brittain et al., 2006; Buchanan, Wang, Huang, Simpson & Manyam, 2002; Caremel et al., 2012; Chaudhuri, Martinez-Martin et al., 2007; Evatt et al., 2009; Gallagher et al., 2010; Leroi, 2011; Li et al., 2010; Lim & Lang, 2010; O’Sullivan et al., 2008; Sakakibara et al., 2012; Slieker-ten Hove et al., 2010; Taylor et al., 2009; Zesiewicz et al., 2010).

The NMSS uses a 30-item scale across nine domains to investigate the presence of NMS. The NMSS was suitable for this study as it is the only tool that incorporates gastrointestinal or urinary NMS frequency or severity in PD. The simplicity of the NMSS scoring and question composition also makes it an excellent tool to use during the telephone interviews.
Table 4.3
The nine NMSS domains

<table>
<thead>
<tr>
<th>Domain 1: Cardiovascular</th>
<th>Domain 6: gastrointestinal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Domain 2: Sleep/fatigue</td>
<td>Domain 7: Urinary</td>
</tr>
<tr>
<td>Domain 3: Mood/cognition</td>
<td>Domain 8: Sexual function</td>
</tr>
<tr>
<td>Domain 4: Perceptual problems</td>
<td>Domain 9: Miscellaneous</td>
</tr>
<tr>
<td>Domain 5: Attention/memory</td>
<td></td>
</tr>
</tbody>
</table>

(Chaudhuri, et al., 2007; Chaudhuri & Odin, 2010; Martinez-Martin et al., 2009)

NB: A detailed analysis of these domains are presented in chapter 5.

4.6 Analysis

The analysis of these QUANT ⇌ QUAL data sets incorporated standard qualitative content analysis, and quantitative descriptive statistical analysis before transforming the qualitative data into quantitative data sets to enable further inferential statistical testing to be done (see figure 4.2).
4.6.1 Qualitative data analysis

The qualitative data collections were categorised and themed according to content in a process is known as Content Analysis. Content Analysis provides an objective method to explore the meanings, intent, consequence and context of, in this case, the spoken word of the participant. Seminal researchers, Cavanagh 1997, Downe-Wamboldt 1992 and Lederman 1991 (cited in Elo & Kyngäs, 2008) suggest that Concept Analysis was a sound way to consider the meaning and critical processes of the
spoken word being explored. The participants’ statements (direct participant experience) alongside the reflective notes (diagnostic categories) were explored for collective threads of experience and understandings. The participants’ shared experiences and understandings together with the generated diagnostic categories, are known as basic data categorises that are used to generate the larger group of shared sub-themes which then create the overarching core themes.

4.6.2 Transformation and convergence of qualitative data

The participants’ verbal examples (basic data categories) were aligned to each of the participant’s NRS scores, to generate a numerical score that is supported by an explanatory statement providing context and meaning. In this process the study enabled statistical comparisons and to contrast findings from the standard PD questionnaires, in particular the NMSS and PDQ-39, with specificity to any bowel and bladder dysfunction reported by participants. This form of confirmatory and explanatory qualitative data organisation has been used by Arnon and Reichel (2009) in their study which explored the attributes of a good teacher according to parents of school children. Like Arnon and Reichel, content analysis was used in the current research to contextualise qualitative data prior to its numerical transformation and inclusion in the statistical analysis.

The complexity of the transformation and convergence process used in this study to interrogate the research questions is addressed in the following chapters. Chapters Five identifies and explored the bio-psycho-social burdens of bowel and/or bladder dysfunction for a person with PD. Specifically this chapter investigates the disabling effect of PD by using the H&Y and S&E scales alongside the NRS data, S3. This was then elaborated, by contrasting how the standard PD non-motor symptoms
instrument, the NMSS represents bowel and bladder dysfunction in for this group of people with PD. The SBS was used to contrast the participant generated scores given in the NMSS in relation to specific continence related interview questions captured by the SBS. Chapter Six addresses the HRQoL factors, as measured by the PDQ-39. As this questionnaire does not directly address bowel or bladder dysfunction it was augmented with the themed and categorised participant qualitative data in order to expand on the resulting PDQ-39 scores. This was done by specifically looking for elements where bowel and bladder dysfunction may have contributed to participant reported experiences of disturbed HRQoL. Chapter Seven differs from the previous results chapters, in that both the transformed and themed qualitative data inform an under-researched area, through specific analysis of bowel and bladder dysfunction as experienced by people with PD. This chapter provides a contemporary insight into the perceptions of participants in relation to the therapeutic satisfaction gained by them in managing their PD and bowel and bladder dysfunction.

4.7 Conclusion

The combined use of existing and innovative assessment tools in this study substantially adds to the current breadth and depth of knowledge about the personal experience of bowel or bladder dysfunctions associated with PD. Bowel or bladder symptoms in people with PD have, up until now, been largely ignored beyond knowing how many people with PD report these dysfunctions. This study takes the first step in exploring this new research area. The importance of gathering meaningful data to extend the current understanding of these two embarrassing and taboo subjects is acutely felt by those with PD. It is also important to overcome the current cultural attitude toward human excretory functions as a source of significant embarrassment and
discomfort, making the topic of bowel or bladder dysfunction difficult for people to talk about. This study recognises that there is a need to extend beyond a numerical accounting of these dysfunctions and brings a mixture of data and methods to reveal details of their nature; and the extent of the challenges faced by people with PD who experience bowel and bladder difficulties.
Chapter 5: The Bio-psycho-social burdens of bowel and bladder dysfunction experienced by a person with Parkinson’s Disease

This chapter presents the results related to the research question: *What are the bio-psycho-social burdens of bowel and bladder dysfunction experienced by a person with Parkinson’s disease?* It comprises of two sections; the first begins by introducing the participants at the centre of this research by focusing specifically on their generic PD symptoms, their ability to move freely and to perform everyday tasks. The participants were asked to describe and rate their health in terms of wellbeing and how disabled they believed themselves to be. The results generated from these discussions have been used to categorise participants in terms of disease staging and their level of dependence on others. The second section builds on this general overview, by more explicitly exploring the biological (physical), the psychological and social impacts directly associated with the participants’ bowel and bladder dysfunction, both of which are known to accompany this disease profile.

The following instruments were used to compile the data presented in both sections one and two:

- The NRS Group:
  
  a. S3-Disability used to quantify the impact of a person’s reported PD symptom(s)
  
  b. S3-QoL used to quantify how much the person with PD’s reported bowel and bladder symptom(s) affects their life
  
  c. S3-Health used to quantify the participants current level of physical wellness
d. SBS employed to elicit a subjective numerical ranking of the participant’s symptom severity and impact (burden).

- The Schwab and England (S&E) ADL Scale used to measure the participant’s ability to perform every day activities or ADL’s (Gillingham & Donaldson, 1969)
- The Hoehn and Yahr (H&Y) used to stage PD according to medical convention (Hoehn & Yahr, 1967).
- The Non-Motor Symptom Scale (NMSS), recognised by clinicians as the ‘gold standard’ in collecting PD specific NMS frequency and severity.
- Open and closed ended interview questions used to explore the descriptive details of the participant’s reported autonomic bowel or bladder symptom(s).
- Reflective notes, used to create diagnostic categories. To ensure researcher objectivity, the Rome III criteria for GIT dysfunction and the International Continence Society (ICS) criteria for urinary dysfunction were used to define and categorise these data according to convention.

5.1 Section One - Generic PD symptom presentation

5.1.1 Participant Profiles

Participants reported a range of between 2 and 19 years as the intervening period since they were given a medical diagnosis of PD, giving a mean of seven years since their diagnosis was made. The study’s cohort was equally divided among men (n=34; 50.7%) and women (n=33; 49.3%), with a mean age of 68.7 years, the oldest participant being 89 and the youngest 48 years of age. As discussed earlier, people who were younger than 65, an age that generally defines ageing were not excluded, as the research
focus was PD and the presence of bowel or bladder dysfunction, rather than chronological age.

Just over half of the participants (n=38; 56.7%) resided within the NSW postcode areas that make up the Eastern Australian metropolitan centres of Sydney, Wollongong and Newcastle. The remaining 29 (43.5%) participants resided in small townships within postcode areas near these metropolitan centres. No participant lived in a remote environment or in regional centres. The majority of this group (77.6%) reported they were no longer employed, although a small number (22.4%) reported that they continued to hold either part time or full time employment (see Table 5.1). Male participants reported higher levels of employment (13.4%) than did female participants (8.9%). Participants with a higher staging of PD according to the H&Y were less likely to be employed (n=3: 4.4%) than those at H&Y stages 1 (n=5: 33.3%) and 2 (n=7: 46.6%).
Table 5.1
Participant profile

<table>
<thead>
<tr>
<th>Variables</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years</td>
<td>68.6 ± 7.5 (48–89 years&lt;sup&gt;a&lt;/sup&gt;)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>34 (50.7)&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>Female</td>
<td>33 (49.3)</td>
</tr>
<tr>
<td>Residential geographic location by post code areas:</td>
<td></td>
</tr>
<tr>
<td>Metropolitan:</td>
<td></td>
</tr>
<tr>
<td>Sydney, 2000–2234 Wollongong, 2500–2534</td>
<td>38 (56.7)</td>
</tr>
<tr>
<td>Newcastle, 2265–2333</td>
<td></td>
</tr>
<tr>
<td>Regional:</td>
<td></td>
</tr>
<tr>
<td>2235–2999</td>
<td>29 (43.3)</td>
</tr>
<tr>
<td>In Paid Employment</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>15 (22.4)</td>
</tr>
<tr>
<td>Female</td>
<td>9 (13.4)</td>
</tr>
<tr>
<td>6 (8.9)</td>
<td></td>
</tr>
<tr>
<td>Breakdown of employment status according H&amp;Y staging</td>
<td></td>
</tr>
<tr>
<td>Stage 1</td>
<td>7 (10.4)</td>
</tr>
<tr>
<td>Stage 2</td>
<td>3 (4.4)</td>
</tr>
<tr>
<td>Stage 3</td>
<td>0</td>
</tr>
<tr>
<td>Stages 4 &amp; 5</td>
<td></td>
</tr>
<tr>
<td>Not-employed</td>
<td>52 (77.6)</td>
</tr>
<tr>
<td>Time since diagnosis (years)</td>
<td>7 (2–17&lt;sup&gt;a&lt;/sup&gt;; 97% CI)</td>
</tr>
</tbody>
</table>

<sup>Note</sup>. N=67 unless otherwise specified. Mean ± Standard Deviation (range) or (%)

5.1.2 Health, disease and disability

5.1.2.1 NRS: S3 - Health & S3 - Disability

The S3 - health and disability were used to rate participants’ current disease status and to rate participants’ general wellness. The categories used to express the scores were grammatically altered to correspond with the question asked, very good (1)
to very poor (4) for the health related question and mild (1) to severe (4) for the
disability related question.

The results for general health were positively skewed with 35 participants
(52.2%) rating their health as good, 23 (34.3%) rated their health as fair, and the final 9
(13.4%) rating their general health as poor or very poor. When asked to rate the severity
of their PD, disability as opposed to their general health, 25 participants (37.3%) scored
their PD as mild, 33 (49.3%) rated their PD severity as moderate, 2 people (2.9%) rated
their PD presentation as very mild and the remaining 7 (10.4%) rated their PD as severe,
producing a negative skew.

Variation in the distribution of scores between the S3-Health and S3-Disability
was interpreted as an ability to discern between general health concerns and the
disabling features of PD (see Figure 5.1).

![Graph showing distribution of scores for S3-Health and S3-PD severity.]

**Figure 5.1**
Distinction between self-perceived health and self-perceived PD severity as measured
by the S3-Health and the S3-PD Disability.
5.1.2.2 Schwab and England (S&E) ADL Scale

The S&E assesses the effect PD has on a person’s independence. A score of 100 indicates a person is ‘totally independent’, while a score of zero indicates a person is totally dependence on others for all their needs. The majority of participants (62.6%; n=42) reported an S&E ranking between 90% to 70%, indicating they were partially independent in performing their own basic personal care. However, they now required between two and four times longer to complete ADLs, as opposed to their pre-diagnostic ability to complete these same tasks (see Table 5.2).

Table 5.2
S&E ADL as reported by participants. N=67

<table>
<thead>
<tr>
<th>Rating</th>
<th>Anchor Description</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>100%</td>
<td>Completely independent. Able to do all ADLs without slowness, difficulty, or impairment.</td>
<td>3</td>
<td>4.5</td>
</tr>
<tr>
<td>90%</td>
<td>Completely independent. Able to do all ADLs with some slowness, difficulty, or impairment. May take twice as long.</td>
<td>9</td>
<td>13.4</td>
</tr>
<tr>
<td>80%</td>
<td>Independent in most ADLs. Takes twice as long. Conscious of difficulty and slowing.</td>
<td>24</td>
<td>35.8</td>
</tr>
<tr>
<td>70%</td>
<td>Not completely independent. More difficulty with ADLs. Up to three to four times longer. Some ADLs may take up a large part of day.</td>
<td>9</td>
<td>13.4</td>
</tr>
<tr>
<td>60%</td>
<td>Some dependency. Can do most ADLs, but very slowly and with much effort they made many errors and some ADLs had become impossible to do.</td>
<td>8</td>
<td>11.9</td>
</tr>
<tr>
<td>50%</td>
<td>More dependant needing assistance with half of ADLs. Difficulty doing everything.</td>
<td>9</td>
<td>13.4</td>
</tr>
<tr>
<td>40%</td>
<td>Very dependant. Can assist with all ADLs but does only a few alone</td>
<td>3</td>
<td>4.5</td>
</tr>
<tr>
<td>30%</td>
<td>With effort, now and then does a few ADLs alone. Much help needed</td>
<td>1</td>
<td>1.5</td>
</tr>
<tr>
<td>20%</td>
<td>Can do nothing alone. Severe disability.</td>
<td>1</td>
<td>1.5</td>
</tr>
<tr>
<td>10%</td>
<td>Totally dependent.</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>0%</td>
<td>Vegetative functions present, i.e., swallowing with no voluntary functioning of bladder and bowel. Bedridden.</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td></td>
<td>67</td>
<td>100</td>
</tr>
</tbody>
</table>
5.1.2.3 Hoehn and Yahr (H&Y)

The H&Y staging of PD defines and contextualises PD in relation to the three prime motor symptoms: tremor, rigidity and bradykinesia, which together provide a definitive diagnosis of PD. In particular, the H&Y focuses on postural stability as its main index of disease staging. The H&Y disease stages of progression are:

- **Stage 1**: When presenting symptoms affect one side of the body only.
- **Stage 2**: When symptoms affect both sides of the body with noticeable changes to the person’s gait but not to their balance.
- **Stage 3**: When symptoms begin to affect the person’s ability to walk or remain upright and steady.
- **Stage 4**: When the disease affects balance and walking significantly, requiring confinement to a wheelchair.
- **Stage 5**: When the person with PD is immobile and relying completely on others for any aspect of mobility (Goetz et al., 2004).

Figure 5.2 demonstrates that the majority of participants (n=52: 77.6%) fell within stages two and three. This staging of disease is consistent with a moderate degree of disablement in comparison to stage four (n=4: 5.9%) and five (n=0), which are both viewed as representing a severe level of PD disablement. All four participants who fell within stage four stated they needed to use a wheelchair and accessed more formal care services than did other participants at stages two and three of the disease. No participant met the criteria for stage five. Overall, 76% of participants were bilaterally affected by the disease, which indicates an impaired gait, instability and postural changes.
Correlations between the variables, ‘time since diagnosis’ and ‘H&Y staging’ were statistically significant [N=67, r (.258), p .035] confirming that the length of time since diagnosis provides a good indicator of overall disease progression (see Table 5.3).

Table 5.3
H&Y staging of participants by time since diagnosis

<table>
<thead>
<tr>
<th>H&amp;Y Stages</th>
<th>1–3 yrs</th>
<th>4–6 yrs</th>
<th>7–9 yrs</th>
<th>10–12 yrs</th>
<th>13–15 yrs</th>
<th>16+ yrs</th>
<th>Participant N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 1</td>
<td>3</td>
<td>7</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>11 (16.4)</td>
</tr>
<tr>
<td>Stage 2</td>
<td>6</td>
<td>10</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>3</td>
<td>31 (46.2)</td>
</tr>
<tr>
<td>Stage 3</td>
<td>5</td>
<td>2</td>
<td>6</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>21 (31.3)</td>
</tr>
<tr>
<td>Stage 4</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>4 (5.9)</td>
</tr>
<tr>
<td>Stage 5</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total N (%)</td>
<td>14 (20.8)</td>
<td>20 (29.8)</td>
<td>12 (17.9)</td>
<td>8 (11.9)</td>
<td>5 (5.9)</td>
<td>8 (11.9)</td>
<td>67 (100)</td>
</tr>
</tbody>
</table>

Around one in three participants (32.7%) had been diagnosed with PD at the time of data collection for at least 10 years this meant that 16.4% were diagnosed with PD in their forties (see Table 5.4).
Table 5.4
Age at diagnosis by current H&Y disease staging

<table>
<thead>
<tr>
<th>Age at diagnosis</th>
<th>Current H&amp;Y disease staging</th>
<th>Participant N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>stage 1</td>
<td>stage 2</td>
</tr>
<tr>
<td>&lt; 49</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>50 - 59</td>
<td>4</td>
<td>13</td>
</tr>
<tr>
<td>60 - 69</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>70+</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Totals</td>
<td>11</td>
<td>31</td>
</tr>
</tbody>
</table>

\(^a\) 19 years since diagnosis

The rate of PD progression and age has been discussed by both Zhao et al. (2010) and de la Fuente-Fernandez et al. (2011), with both suggesting that diagnosis at younger age is strongly associated with an overall slower disease progression and a longer duration at H&Y stages two (2) and three (3), regardless of disease management. The findings of the current study are consistent with those of Zhao et al. (2010) and de la Fuente-Fernandez et al. (2011).

The combined results of the S&E, H&Y and the S3- Disability highlighted differences between the clinical presentation of PD and how people interpret and accommodate disablement into their life. The statistical correlation between these three assessment tools was strong (p ≤0.01) and was viewed as validating the psychometric scores of the S3- Disability (see Table 5.5).
### Table 5.5 Correlation between H&Y, S3 and S&E

<table>
<thead>
<tr>
<th></th>
<th>S3- Disability</th>
<th>H&amp;Y</th>
<th>S&amp;E</th>
</tr>
</thead>
<tbody>
<tr>
<td>S3- Disability</td>
<td>Pearson Correlation</td>
<td>1</td>
<td>.396**</td>
</tr>
<tr>
<td></td>
<td>Sig. (2-tailed)</td>
<td></td>
<td>.001</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>67</td>
<td>67</td>
</tr>
<tr>
<td>H&amp;Y</td>
<td>Pearson Correlation</td>
<td>.396**</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Sig. (2-tailed)</td>
<td>.001</td>
<td>67</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>67</td>
<td>67</td>
</tr>
<tr>
<td>S&amp;E</td>
<td>Pearson Correlation</td>
<td>.443**</td>
<td>.518**</td>
</tr>
<tr>
<td></td>
<td>Sig. (2-tailed)</td>
<td>.000</td>
<td>67</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>67</td>
<td>67</td>
</tr>
</tbody>
</table>

** Correlation is significant at the 0.01 level (2-tailed).

This is further evidenced by the increases in participants S3-Disability scores alongside the H&Y and S&E scores presented in Table 5.6. The importance of the S3-Disability was that it enabled participants to incorporate a personalised representation of their everyday burdens into the analysis beyond that of a specific ADL task or the presence of specific PD symptoms, in that it represented an increase in personal difficulties encountered when in making lifestyle adjustments in response to their disease progression.

### Table 5.6
Comparison of mean scores between H&Y, S&E and S3- PD severity

<table>
<thead>
<tr>
<th></th>
<th>Very mild</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>S&amp;E (100–0)</td>
<td>11</td>
<td>25</td>
<td>29</td>
<td>2</td>
<td>3.8 (1.7)</td>
</tr>
<tr>
<td>H&amp;Y Staging (1–5)</td>
<td>16</td>
<td>31</td>
<td>18</td>
<td>3</td>
<td>2.2 (0.8)</td>
</tr>
<tr>
<td>S3- Disability</td>
<td>2</td>
<td>26</td>
<td>33</td>
<td>7</td>
<td>2.6 (0.7)</td>
</tr>
</tbody>
</table>
5.2 Section Two: Bowel and bladder bio-psycho-social aspects

Due to the complexity of generating, transforming and converging the multiple datasets, the subsequent analysis and presentation of results have been organised in the following way. The presentations of descriptive quantitative results generated from the NMSS, SBS instruments are presented first, followed by a description of the contextually analysed themes, generated by the combined quantitative and qualitative data. The qualitative collections (participants interview data & reflective notes), were themed and quantitized to facilitate the resulting converged analysis of all data sets, as described in chapter four above (Driscoll, Appiah-Yeboah, Salib, & Rupert, 2007). Convergence entailed combining all the data to find points of agreement and disagreement and to ensure symptom specificity and clarity.

The converged findings are presented in three discrete sub-sections each representing a specific symptom group: a): Bowel; b): Bladder & c) Combined Bowel and Bladder dysfunction (Double Incontinence). The combined presentation of data under each specific grouping highlights the unique approach undertaken by this convergent, parallel designed study. The outcome of which unifies each approach used and provides a holistic view of the participants’ personal burden, not only in terms of the biological presentation of symptoms, but also of the participants’ psychological and social experiences in response to these presiding biological symptom(s). The separation into symptom presentations also ensures that the commonalities and uniqueness of each symptom group are defined and maintained. The bowel and bladder dysfunction (Double Incontinence) sub-section is smaller than the two preceding single symptom sub-sections as it does not repeat previously reported data. It instead provides a
contextual comparison against which findings specific to this combined symptom group can be fully understood.

This presentation format is in keeping with other convergent research designed studies, which present results as both numerically and textually complete representations of the data (Arnon & Reichel, 2009). In regard to this study, the participants’ bio-psycho-social burdens as they relate to their bowel and bladder dysfunction are presented.

5.2.1 NMSS

The NMSS (Chaudhuri, Martinez-Martin et al., 2007) incorporates 30 questions grouped into nine domains. Each NMSS question consists of a severity score (0–3), which is multiplied by the symptoms’ frequency score (1–4) giving a possible total score of 12 for each question. The composite of question scores within each domain can then be summed to give a total domain score. Each domain score can then be further summed, giving an overall NMSS score out of 360. These domains with their respective scores are outlined in Table 5.7.

None of the participants reported difficulties in answering the 30 questions, nor did they question the relevance of the questions. The participants rated the following four domains highly: Domain 2, sleep and fatigue (10.8) and Domain 3, mood and cognition (11.1) along with the Domains 6, related to the Gastrointestinal Tract (GIT) (8.3) and Domain 7, Urinary (11.4) problems. Disruption to sleep (Chaudhuri, 2003) and mood (Heidrich & Wells, 2004; Watson, Currie, Curran, & Jarvis, 2000) are associated with the incidence and severity of urinary incontinence and as such will be included in the urinary specific symptom group sub-section.
However, as Domains 6 and 7 constitute the focus of this research the subsequent discussions will focus on the GIT and Urinary domains.

Table 5.7
NMSS Domains

<table>
<thead>
<tr>
<th>Domain</th>
<th>Domain description</th>
<th>Domain score, N=67 Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Cardiovascular: 2 questions, which address postural changes inducing falls.</td>
<td>2.7 (3.5)</td>
</tr>
<tr>
<td>2</td>
<td>Sleep and fatigue: 4 questions.</td>
<td>10.8 (9.9)</td>
</tr>
<tr>
<td>3</td>
<td>Mood and cognition: 6 questions</td>
<td>11.1 (13.8)</td>
</tr>
<tr>
<td>4</td>
<td>Perceptual problems and hallucinations: 3 questions</td>
<td>2.3 (4.8)</td>
</tr>
<tr>
<td>5</td>
<td>Attention and memory has three questions</td>
<td>7.3 (9.5)</td>
</tr>
<tr>
<td>6</td>
<td>Gastrointestinal Tract: 3 questions related to the ENS.</td>
<td>8.3 (7.3)</td>
</tr>
<tr>
<td></td>
<td>1. Excessive drooling</td>
<td>2.2 (3.3)</td>
</tr>
<tr>
<td></td>
<td>2. Swallowing difficulties</td>
<td>1.6 (2.4)</td>
</tr>
<tr>
<td></td>
<td>3. Constipation</td>
<td>4.4 (4.5)</td>
</tr>
<tr>
<td>7</td>
<td>Urinary: 3 specific questions explore the three LUTS of</td>
<td>11.4 (11.6)</td>
</tr>
<tr>
<td></td>
<td>1. Urgency</td>
<td>3.8 (4.2)</td>
</tr>
<tr>
<td></td>
<td>2. Frequency</td>
<td>3.5 (4.2)</td>
</tr>
<tr>
<td></td>
<td>3. Nocturia</td>
<td>3.8 (4.6)</td>
</tr>
<tr>
<td>8</td>
<td>Sexual function: 2 questions that address sexual interest and function</td>
<td>3.7 (6.8)</td>
</tr>
<tr>
<td>9</td>
<td>Miscellaneous, items that make up this domain are related to pain, sensory, changes in weight and excessive sweating</td>
<td>7.7 (9.2)</td>
</tr>
<tr>
<td>Total</td>
<td>NMSS score</td>
<td>The summative score of the combined domains 62.0 (46.4)</td>
</tr>
</tbody>
</table>

The individual question score*

5.2.1.1 Domain 6 NMSS - Gastrointestinal tract (GIT)

The NMSS domain 6 includes three questions that cover disorders of the upper and lower GIT. Two upper GIT questions investigated excessive drooling (Q19) and swallowing difficulties (Q20), and one lower GIT question investigates constipation (Q21). As expected, participants’ results demonstrated a strong correlation between
constipation and the total domain score \( r = 0.818, \leq p0.01 \). No relationship was found between constipation (Q21) and the swallowing difficulties (Q20). A relationship \( r = 0.048, \leq 0.05 \) was found between the excessive drooling (Q19) and the constipation (Q21). This association was interpreted as having more to do with the participants’ level of disability (H&Y) rather than having any direct relationship with constipation. This is supported by the reviewed research, which suggests that drooling is more related to muscle rigidity and bradykinesia in the jaw and face which impede the person’s ability to swallow (Kalf, Bloem, & Munneke, 2012; Leibner et al., 2010; Nobrega et al., 2008).

Table 5.8 presents the participants’ mean scores for each of the 3 NMSS GIT questions. These scores reveal that the constipation question elicits a higher frequency and severity score as compared to the two upper GIT questions.

Table 5.8
NMSS GIT Domain 6 mean scores by each question (N=67)

<table>
<thead>
<tr>
<th>NMSS GIT</th>
<th>NMSS drooling (Q19)</th>
<th>NMSS swallowing (Q20)</th>
<th>NMSS constipation (Q21)</th>
</tr>
</thead>
<tbody>
<tr>
<td>N=67</td>
<td>Mean (SD)</td>
<td>2.2 (3.3)</td>
<td>1.6 (2.4)</td>
</tr>
</tbody>
</table>

5.2.1.2 NMSS domain 7—Urinary

NMSS domain 7 consists of three lower urinary tract symptoms (LUTS) questions. These questions specifically addressed the presence and severity of urgency, frequency and nocturia. The NMSS provides a basic explanation to each stem question. The NMSS questions were: Q23: “Does the patient have difficulty holding urine?” (Urgency); Q23: “Does the patient have to void within two hours of last voiding?” (Frequency); and Q24: “Does the patient have to get up regularly at night to pass urine?” (Nocturia). The mean scores for these NMSS Domain questions revealed that the all three questions elicited similar frequency and severity scores (see Table 5.9).
Table 5.9
NMSS Urinary Domain 7 mean scores by each question (N=67)

<table>
<thead>
<tr>
<th>NMSS Urinary</th>
<th>NMSS Urgency (Q22)</th>
<th>NMSS Frequency (Q23)</th>
<th>NMSS Nocturia (Q24)</th>
<th>Total Domain 7</th>
</tr>
</thead>
<tbody>
<tr>
<td>N=67</td>
<td>Mean (SD)</td>
<td>3.8 (4.2)</td>
<td>3.5 (4.2)</td>
<td>3.8 (4.6)</td>
</tr>
</tbody>
</table>

5.2.2 The SBS

Each participant was asked to rate on the SBS their bowel or bladder symptom burden, ‘no burden (0), mild burden (1-2), moderate burden (3-5), severe burden (6-8) and extreme burden (9-10)’ (see Table 5.10). The benefit of asking the participants to score their symptom(s) experience was twofold; first the researcher was not forced to categorise or interpret the participant’s personal burden and secondly, participants were able to present their symptom(s) without the need to justify the burden they imposed. The results outlined in Table 5.10 differentiate the burden scores of the 56 participants who reported the occurrence of a bowel dysfunction from the 62 participants who reported bladder dysfunction. This table also itemises a subset of participants who reported the occurrence of both bowel and bladder dysfunction. The burden scores were further analysed via a comparison of means (M) using a paired samples t-test. This analysis indicated that bowel dysfunction (n=56, M=7.4, SD=2.5) was significantly more burdensome \([t (52) 338, p=0.023]\) for participants than was their bladder dysfunction (n=62, M=6.8, SD=2.5).
Table 5.10

<table>
<thead>
<tr>
<th>Burden Category</th>
<th>Symptoms reported</th>
<th>Bowel Burden</th>
<th>Bladder Burden</th>
<th>Bowel and Bladder Burden</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild burden (1-2)</td>
<td></td>
<td>0</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Moderate burden (3-5)</td>
<td></td>
<td>8</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Severe burden (6-8)</td>
<td></td>
<td>25</td>
<td>31</td>
<td>29</td>
</tr>
<tr>
<td>Extreme burden (9-10)</td>
<td></td>
<td>23</td>
<td>19</td>
<td>12</td>
</tr>
</tbody>
</table>

The severity and significance of the participants’ bowel or bladder dysfunction burden became even more evident when these same burden scores were contrasted against the combined burden rating of the four PD primary motor symptoms, bradykinesia, resting tremor, rigidity, and postural instability and were found to be more burdensome than any of these primary motor symptoms. To express this statistically, a paired sample t-test was conducted comparing the participants’ ratings of their motor symptom burden (IV1) with bladder (IV2) and bowel dysfunction (IV3). A significant difference in the scores for IV1 (M=4.6, SD=3.4), IV2 (M=7.2, SD=2) and IV3 (M=7.6, SD=1.9) conditions was demonstrated for bladder dysfunction [t (57) =4.93, p=.0001]. These findings were also seen in the t-test conducted for bowel dysfunction [t (55) =5.93, p=.0001], where participants again reported significantly higher rates of burden than they recorded for the primary motor dysfunctions they experienced.

5.2.3 Interview questions and reflective notes

All participants were asked about their bowel and bladder symptom(s) and how they managed them on a daily basis. Their verbal descriptions and examples were used
to construct the core, sub-themes and the basic categories. The researcher’s reflective notes were used to categorise the participant symptom statements into clinically appropriate bowel and bladder diagnostic categories. The following questions informed and guided the discussion between the participant and researcher:

- Q1: How much do you think your bladder/bowel problem affects your life?
- Q2: How would you describe your bladder/bowel difficulties?

Table 5.11 and Table 5.12 illustrate how these interview questions were contextually themed.

Table 5.11
Contextually themed qualitative data. Interview question one (N=67)

<table>
<thead>
<tr>
<th>How much do you think your bladder/bowel problem affects your life?</th>
<th>Category - Personal Burden</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Core theme</strong></td>
<td><strong>Sub-theme</strong></td>
</tr>
</tbody>
</table>
| Independence and freedom | Impact of Symptom on lifestyle, work and recreation | 1. Confidence (*I don’t go out on bowel days. I don’t trust the medicines [laxatives] they are so unpredictable.*)
2. Experience (*I cannot get too far without needing the bathroom.*) |
| Social participation | Relationships:  
- Intimate Relationships  
- Relationships with friends and family  
- Professional support relationships | 1. Burden on others (*I have had to move out of our bedroom.*)
2. Social isolation (*I do not like people coming to visit me I often feel I am very smelly, my house smells and now homecare is refusing to clean*)
3. Hiding and secreting (*I do not like talking to people about this as it is very embarrassing.*)
4. Information gathering and sharing (*So little information is given by the Drs they make assumptions that you already know*)
5. PD support groups (*He attended PD support group sessions on bladder problems and found it “enlightening and helpful”*) |
### Table 5.12
Contextually themed qualitative data. Interview question two (N=67)

<table>
<thead>
<tr>
<th>Core theme</th>
<th>Sub-theme</th>
<th>Basic Categories with examples of (verbal citations)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bowel dysfunction</td>
<td>Constipation:</td>
<td>1. &lt; 3 bowel movements per week; (I go to the toilet to open my bowels every 5 days, if I’m lucky.)</td>
</tr>
<tr>
<td></td>
<td>According to the Rome III criteria - at least 2 of the following symptoms (Basic Categories) over the preceding 3 months.</td>
<td>2. Straining at Stool. (I strain and push for long periods of time.)</td>
</tr>
<tr>
<td></td>
<td>This category includes diarrhoea attributable to excessive laxative usage and not ‘Functional Diarrhoea’</td>
<td>3. Lumpy or hard stools. (The motion (stool) is so hard that it tears my bottom)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. Sensation of anorectal obstruction. (I cannot pass any stool and I am left pushing and straining)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5. Sensation of incomplete defecation. (I do not feel as though I’m emptying my bowel out properly)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6. Manual manoeuvring required to defecate. (I have to put on rubber gloves and edge the stool out with my hand)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>7. Loose stools are rarely present without the use of laxatives. (I am taking Movicol Sachet’s to help but if I take one it does nothing if I take two or three sachets I cannot leave the house.)</td>
</tr>
<tr>
<td></td>
<td>Functional Diarrhoea:</td>
<td>1. Loose (mushy) or watery stools without pain occurring in at least 75% of stools. (I wear Tena lady pads to catch the constant faecal staining)</td>
</tr>
<tr>
<td></td>
<td>According to the Rome III criteria – symptom present over the preceding 3 months with symptom onset of at least 6months</td>
<td></td>
</tr>
<tr>
<td>Bladder Dysfunction</td>
<td>Lower Urinary Tract Symptoms (LUTS)</td>
<td>1. Urge (I have to go straight away or I will not make it.)</td>
</tr>
<tr>
<td></td>
<td>According to the ICS LUTS criteria and definitional terms (Basic Categories).</td>
<td>2. Diurnal Frequency (I have to go to the toilet every 1 - 2 hours.)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Nocturia (I wake up every 1.5 - 2 hours I have difficulty getting back to sleep.)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. Retention (It feels like my bladder has not fully emptied when I do go the toilet.)</td>
</tr>
<tr>
<td>Incontinence and Accidents</td>
<td></td>
<td>1. Incontinence. (I generally have to change my underwear and my trousers, shoes and socks 3-4 times per day.)</td>
</tr>
<tr>
<td>Combined bowel and urinary</td>
<td>Double Incontinence</td>
<td>2. Accidents. (I had very bad Urge and frequency with lots of accidents.)</td>
</tr>
<tr>
<td>concerns</td>
<td></td>
<td>1. Constipation and frequency. (I try not to drink too much but I worry, if I don’t drink my bowels will play up.)</td>
</tr>
</tbody>
</table>
The results of this content analysis enabled the basic categories to be numerically transformed. This was achieved by aligning each participants’ contextualised basic qualitative categories with their SBS score, as described in chapter four above. This numerical pairing of basic category statements with the participants’ SBS scores created a data base of statements that indicated - no burden (0), mild burden (1-2), moderate burden (3-5), severe burden (6-8) and extreme burden (9-10).

The clinical data generated from the second interview question, *how would you describe your bladder/bowel difficulties?* were diagnostically categorised into the three symptom groupings. The researcher’s reflective notes and expertise, directed by the ICS, for urinary dysfunction and the Rome III criteria for bowel dysfunction (see Appendix J) facilitated the organisation of participant symptom statements into diagnostically accurate categories. The diagnostic categories presented in Table 5.13, indicated that 56 people (83.5%) reported constipation, with a subgroup of nine identified within this same constipation grouping as also experiencing frequent bouts of diarrhoea. Their basic category statements highlight that diarrhoea was primarily due to the combinations and excessive doses of laxatives they used to relieve their constipation, more so than as a result of a large bowel blockage. These findings are developed and explored later in this chapter.

The clinical categorisation of urinary dysfunction were analysed in a similar fashion to the bowel dysfunctions described above; this time using the ICS lower urinary tract symptoms (LUTS) criteria. The clinical generation of diagnostic categories for urinary dysfunction or LUTS are also presented in Table 5.13. The most commonly reported lower LUTS in the PD literature are diurnal and nocturnal frequency, both of which are accompanied by a very strong desire to pass urine—urgency (Iacovelli et al.,
The participants’ basic category statements identified 62 participants stating they experienced diurnal frequency (n=44: 63.8%), nocturia (n=36: 52.2%) and urgency symptoms (n=46: 66.7%). These results are consistent with Iacovelli et al. findings described above. The participants also detailed the occurrence of two other urinary symptoms not frequently mentioned in the PD literature. The first of these symptoms was urinary retention, with 6 participants (8.9%) stating they were often unable to fully empty their bladder, with five of these male. The second symptom reported by a different group of six participants (8.9%), was urinary incontinence (UI) the involuntary loss or leakage of urine, with all being female. UI and retention are not identified in the scientific literature as being associated with PD.

Table 5.13
Participant-reported bowel and bladder symptoms as reported in interview (N=67)

<table>
<thead>
<tr>
<th>Bowel symptoms</th>
<th>Number of bowel symptoms reported</th>
<th>Bladder symptoms</th>
<th>Number of bladder symptoms reported</th>
</tr>
</thead>
<tbody>
<tr>
<td>No symptoms- 11 (16.4%)</td>
<td></td>
<td>No symptoms - 5 (7.4%)</td>
<td>None - 5 (7.4%)</td>
</tr>
<tr>
<td>Constipation- 56 (83.5%)</td>
<td></td>
<td>Urge - 46 (69%)</td>
<td>One - 13 (19.4%)</td>
</tr>
<tr>
<td>Diarrhoea- 9 (13.4%)</td>
<td></td>
<td>Frequency - 44 (66%)</td>
<td>Two - 26 (39%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Nocturia - 36 (54%)</td>
<td>Three - 20 (30%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>UI - 6 (8.9%)</td>
<td>Four - 3 (4.4%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Retention – 6 (8.9%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Reporting both bowel and bladder symptoms</td>
<td>Yes - 51 (76%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>No - 16 (24%)</td>
</tr>
</tbody>
</table>

Note: Participant numbers for each symptom category may not equal total sample due to counting of participants against two or more criterion.
Retention is primarily associated with prostate enlargement in males and UI is primarily a negative outcome of an underlying specific LUTS (Greer, Arya, & Smith, 2013). However, both of these symptoms are addressed in this study as the participants noted them both as producing significant levels of personal burden.

5.3 Sub-Section A: Converged analysis of all bowel dysfunction data sets

A synthesis of NMSS and data generated from the interviews (Basic Categories) revealed inconsistencies in the numbers of participants reporting constipation. This result was due to the definition for constipation used by the NMSS to guide people in answering NMSS-Q21. The criterion for constipation used by the NMSS is ‘A bowel action that occurred less than three times each week’ restricted the participants’ answers by over simplifying this complex condition. As a consequence, the NMSS excluded 14 (25%) people who, on further investigation, reported significant concerns about their constipation. The following results highlight this phenomenon in more depth.

Participants were asked during their interview to describe their bowel symptoms without any prompts or guidance from the interviewer, with all participants describing constipation in line with the Rome III criteria (R3). In that regard they defined their constipation more broadly than counting weekly bowel actions with 14 participants reporting that their stool frequency was equal to or greater than three times in one week. The following are some excerpts of the participants’ descriptions, which have been categorised according the R3 criteria for constipation. The excerpts have been labelled by participant code, gender and age.
P1(F:66): It feels to me like my bowel muscles are not strong enough to pass the stool down the back passage ... but once it starts to move to the outside, I have to put on rubber gloves and edge the stool out with my hand. [R3: straining at stool and digital evacuation]

P3(F:68): The feeling that I urgently need to go to move my bowels. However, when I go to the toilet, I cannot pass any stool and I am left pushing and straining. I am able to pass stool on an average of every second day. They are very dry and hard pebbles. [R3: straining at stool and dry, hard to pass stools]

P5(M:66): I do go every day but it is only a little amount and it takes me a lot of effort for little result. I often bleed and push a lot. It recently has become a lot worse ... I feel very full in the rectum ... I try and go twice a day with a lot of difficulty. [R3: Straining at stool; incomplete bowel emptying and sensation of anal obstruction]

P15(F:73): Constipation, I am passing stones. I have great difficulties passing stools. I bleed almost every time I go to the toilet. I do have to help them out of my bottom manually. [R3: dry, hard to pass stools, straining at stool and digital evacuation]

P30(M:67): I go a lot but with much straining and very little result. Sometimes I go four or five times in one day I get a very big urge or need to go but then I sit there for 15 minutes straining with nothing happening. Passing such hard poo often makes me tear and bleed. [R3: straining at stool and dry, hard to pass stools]
P32(F:53): It takes me up to 45 minutes to pass stool ... small hard stools that I pass with lots of effort a couple of times per week. [R3: straining at stool and dry, hard to pass stools]

P67(M:73): I like to go to the toilet in the morning but it takes me a long time, about one and half hours ... There is a lot of straining it takes me ‘sooo’ ... [sic] much effort. I do get stomach pains but I have never bled. My poo is quite soft. I think this is why I have a lot of trouble pushing it out. I have had this difficulty for many years, at least five. [R3: straining at stool and anal obstruction or blockage]

P37(M:69): Straining often [but] I don’t open my bowels for seven days. [R3: straining at stool and less than three stools per week]

P44(M:64): I have chronic constipation, I take medications ... My bowels don’t open for nine to 11 days ... I always feel uncomfortable and it is distressing. [R3: straining at stool, dry, hard to pass stools, anal obstruction or blockage and less than three stools per week]

A deeper investigation was conducted into the differences in mean scores between symptom severity or burden (SBS) and the NMSS constipation question (NMSS-Q21). A paired-samples t-test was used to compare the SBS and NMSS burden scores for constipation. A statistically significant difference \[t (66)= -3.283, p.002\] was found between the NMSS-Q21 (M=4.4, SD=4.5) and the participant reported constipation SBS score (M=6.4, SD=3.4). This result suggests that the NMSS-Q21 was not as sensitive for this group of participants as their reports of constipation burden.
reported in the SBS. The extent to which this occurs is revealed in Figure 5.3, which shows the NMSS had inferior symptom identification alongside lower score amplitudes in the extreme burden and the moderate burden categories.

![Burden comparison NMSS vs. SBS - Constipation N=56](image)

Figure 5.3 Burden Comparison NMSS vs. SBS

The participants who reported in the interviews, obstructive rather than just slower transit constipation were more inclined to be incorrectly categorised and subsequently had lower severity scores on the NMSS as they did not meet the strict criteria of a ‘Bowel action less than three times weekly’. Obstructive constipation primarily presents as straining at stool was reported by 39 (69.6%) participants reporting constipation in this study. These participants reported numerous symptoms, all associated with paradoxical contraction of the puborectalis muscle or obstructive defecation, such as extreme lower abdominal and rectal pain, difficult expulsion, excessive straining and the need to manually remove faeces.
As previously noted, nine participants (13.4%) described the occurrence of cyclical patterns of constipation followed by bouts of diarrhoea (see Table 5.13). Patterns of alternating lower GIT symptoms in neurological disease are either indicative of an obstructed bowel or an inappropriate usage of laxatives (Chatoor & Emmnauel, 2009; Coggrave et al., 2006; Harari, Norton, Lockwood & Swift, 2004; Kaye et al., 2006). However, the participants did not perceive a relationship between their reported diarrhoea and constipation and therefore did not report their occurrences to their medical practitioner.

*P6(F;65): I have asked the doctor about the constipation but not about the diarrhoea.*

The nine participants who reported the combined presence of constipation and diarrhoea also reported high burden scores. The relationship between this symptom combination and burdensomeness was verified as statistically stronger than constipation alone \[r = .357, n = 56, p = 0.006\]. The participants reported that they had not completed the NMSS or any other similar tool that identified any of their NMS prior to this study, and that their doctors rarely initiated a conversation about constipation or other bowel problems. The later statement is discussed more completely in Chapter Seven.

5.4 Sub-Section B: Converged analysis of all bladder dysfunction data sets

Similar to the NMSS Bowel, noteworthy differences were noted between the numbers of LUTS identified in the NMSS urinary domain questions and the interview collections. These differences presented earlier in Figure 5.4, were consistent across all three LUTS symptoms. The NMSS Q22 (Urgency) did not identify two people (4.8%) who on interview, were distressed about their urinary urgency. The NMSS Q23
(Frequency) missed five people (11.9%) who, during the interview, reported bothersome urinary frequency. Finally, the NMSS Q24 (Nocturia) identified an additional three people (7.14%) who on interview were found to have night-time urinary frequency, not nocturia.

**Figure 5.4 LUTS identification—NMSS vs. interview**

The numerical anomalies seen between the NMSS and the interview data collections were again a result of using a different LUTS definition from those recommended by the ICS. In the case of nocturia, the ICS defines this symptom as a “...complaint that the individual has to wake at night one or more times to void each void is preceded and followed by sleep” (van Kerrebroeck, Abrams, Chaikin et al., cited in Weiss et al., 2011, p. 700). Whilst the NMSS defines nocturia more simply, without the inclusion of any need to recommence sleep. The NMSS does not make a distinction between nocturia and nocturnal frequency, an equivalent to diurnal (daytime) urinary frequency. The following participant’s statement, that she chose not to go back to sleep even though this constituted a very early start to their day, is an example of nocturnal frequency.
The night-time bothers me as I have trouble getting back to sleep. I just give up around 4 o’clock.

A Pearson product-moment correlation coefficient was conducted to assess the strength of relationship between burden scores of the SBS and the Domain 7 (NMSS). A statistically significant correlation \( r=0.331, N=67, p = 0.006 \) between these variables was found (see Table 5.14) confirming that urinary dysfunction was a great concern among this group of people and that both instruments were able to identify this burden similarly.

Table 5.14
The identification of burden – Correlation of the SBS and the NMSS Domain 7 scores

| Identification of Burden - Correlation of the SBS and the NMSS Domain 7 (N=67) |
|-----------------|-----------------|-----------------|
| NMSS domain 7 total score | Pearson r. | \( 1 \) | \( .331^{**} \) |
| | Sig. | | \( .006 \) |
| | N | 67 | 67 |
| SBS – urinary Burden | Pearson r. | \( .331^{**} \) | \( 1 \) |
| | Sig. | \( .006 \) | |
| | N | 67 | 67 |

**Correlation is significant at the 0.01 level (2-tailed).**

Gender and the numbers of LUTS reported were also explored, the rationale being that in the scientific literature, gender differences and LUTS presentation in non-PD populations are well reported. This is not the case for people with PD where little has been reported. Figure 5.5 shows that in this group of 62 people, 32 male participants reported the presence of more individual LUTS symptoms than did the 30 female
participants and that both men and women found each additional LUTS increased their levels of burden.

**Figure 5.5 Presence of burden according to the number of LUTS reported**

Of further interest were the questions, did the increase in burden scores influence the participant in seeking of help from the doctors and was there a gender bias in this help-seeking behaviour? The data about seeking assistance had been collected as part to the interview. A paired sample test t-test was used to explore these extrapolated burden mean score differences. The first paired test was between the occurrence of burden (SBS) and seeking help from a doctor \( t(59) = -21.932 \ n=60 \ p= 0.01 \). The second pair looked at the differences between men or women when choosing to reported their LUTS to the GP, which was not significant; and a final pairing looked at burden (SBS) expression between the men and women participants \( t(59) = -22.29 \ n=60 \ p=0.01 \). These results have been interpreted as the burden of LUTS was not contributing to the likelihood that a person would seek advice and support from their doctors. That while advice seeking was not gender biased, gender did seem to play a part in the expression of burden with women expressing their LUTS as more burdensome than did the men in
This study. This difference in LUTS burden expression may indicate that a more complex relationship exists between burden (SBS) and symptom occurrences experienced by men (See Fig 5.5).

This study’s findings indicate that men may either be more resilient to or more accepting of the presentation of LUTS than are women. The following participant statement is used to support this premise. This gentleman’s reports of nocturia, together with his day time urgency and frequency, which he reported as occurring almost every hour was reported as not concerning him too much, although he said it (LUTS) drove his wife mad. He was happy with his wife sourcing information, products and services. His use of the word *we* in his statement seem to present his LUTS as a shared problem.

*P62 (M:59) It drives my wife mad, she has spoken with a Nurse Continence Advisor who suggested uridomes but we haven't tried them yet, for no particular reason. I'm happy with the pads (which his wife purchases) and have a bottle next to the bed which is very helpful.*

In studies by Iacovelli et al. (2010) and Araki and Kuno (2000), LUTS was correlated with PD motor dysfunction severity, creating a functional incontinence. That is, incontinence due to an inability to get to the toilet in time or to have the dexterity to timely remove clothing enabling voiding without wetting clothes. To establish if the participants’ LUTS presentation and burden scores corresponded with their PD severity the participants’ LUTS and SBS were explored via the H&Y disease staging (Table 5.15).
Table 5.15
Burden (SBS) and Numbers of LUTS reported according to H&Y Disease Staging (N=67)

<table>
<thead>
<tr>
<th>H&amp;Y Stage</th>
<th>Frequency</th>
<th>Mean SBS</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>SBS - bladder according to H&amp;Y</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>11</td>
<td>5.3</td>
<td>3.9</td>
</tr>
<tr>
<td>2</td>
<td>31</td>
<td>6.0</td>
<td>2.9</td>
</tr>
<tr>
<td>3</td>
<td>21</td>
<td>6.8</td>
<td>2.8</td>
</tr>
<tr>
<td>4</td>
<td>4</td>
<td>7.5</td>
<td>3.6</td>
</tr>
<tr>
<td>Total</td>
<td>67</td>
<td>6.2</td>
<td>3.1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number of LUTS according to H&amp;Y</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>11</td>
<td>1.7</td>
<td>1.1</td>
</tr>
<tr>
<td>2</td>
<td>31</td>
<td>2.3</td>
<td>.94</td>
</tr>
<tr>
<td>3</td>
<td>21</td>
<td>1.8</td>
<td>.91</td>
</tr>
<tr>
<td>4</td>
<td>4</td>
<td>1.7</td>
<td>.95</td>
</tr>
<tr>
<td>Total</td>
<td>67</td>
<td>2.0</td>
<td>.99</td>
</tr>
</tbody>
</table>

An analysis of variance (ANOVA) was used to complete this examination, however no statistically significant increases were noted between H&Y staging and LUTS burden, nor between the numbers of LUTS experienced. This was a little surprising as it was felt that the severity of these people’s disability would have had some effect on their LUTS presentation and burdensomeness.

To ensure the research had not missed any aspect of a potential relationship between LUTS and H&Y, an analysis of the length of time a person had been aware of their burdensome urinary symptom(s) was explored. This information was collected during the interview when participants were requested to describe their LUTS and when they first became aware of them (M=4yrs, SD=5.2yrs). A significant correlation [p=.003] for this group indicated that the presentation of multiple LUTS occurred at or near the time their PD was diagnosed (see Table 5.16). However, the burdensomeness of LUTS did not correlate with these symptoms’ start time.
Table 5.16
LUTS presentation according to date of PD diagnosis

<table>
<thead>
<tr>
<th></th>
<th>Bladder symptoms reported</th>
<th>Bladder burden score (SBS)</th>
<th>Symptom start date bladder</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of bladder symptoms reported</td>
<td>Pearson correlation</td>
<td>1</td>
<td>.103</td>
</tr>
<tr>
<td></td>
<td>Sig. (2-tailed)</td>
<td>.440</td>
<td>.003</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>67</td>
<td>58</td>
</tr>
<tr>
<td>Bladder burden score (SBS)</td>
<td>Pearson correlation</td>
<td>.103</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Sig. (2-tailed)</td>
<td>.440</td>
<td>.525</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>58</td>
<td>58</td>
</tr>
<tr>
<td>Symptom start date bladder</td>
<td>Pearson correlation</td>
<td>.357**</td>
<td>.085</td>
</tr>
<tr>
<td></td>
<td>Sig. (2-tailed)</td>
<td>.003</td>
<td>.525</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>67</td>
<td>58</td>
</tr>
</tbody>
</table>

** Correlation is significant at the 0.01 level (2-tailed).

A possible explanation to why these participants did not report an increase in LUTS burden according to their disease severity or the length of time these symptoms were present, was that they had already made significant life changes, which had incorporated their toileting needs through clothing modification, as well as changes made to their, environment and social expectations. The following participant statements support this position:

P14 (F, 63): *I have adjusted what I wear to give me extra access and ease in getting undressed.*

P19 (M, 75): *I am better when I am in the house. I do not travel anywhere of a long distance. So I only do things around the local area.*

P27 (M, 75): *I use a non-spill bottle that I now keep between my legs at night.*
P30 (M, 67): I am conscious of what I'm doing, where I am going and what I wear. I don’t wear lots of clothing with buttons or zippers now, they are just too hard to get off in time.

5.4.1 Specific LUTS—Urgency

Urgency is defined by the ICS as ‘a sudden need to empty the bladder which is very hard to ignore or put off till later’ (Haylen et al., 2009). Urgency has also been reported as occasionally being accompanied by urinary leakage. Urgency is rarely reported as a single symptom and, according to Irwin, Abrams, Milsom, Kopp and Reilly (2008), has not been shown to contribute in a major way to increasing levels of personal burden or decreases in QoL. Scores from the NMSS-Q22 (urgency) (n=44) recorded slightly lower rates than that established in the interviews (n=46), indicating that the NMSS missed 3% of qualified participants (see Fig 6.3). In the interviews, urgency was spoken about in terms of an ability to defer voiding or ‘hanging on’, 46 people or 67% of this population stated that the call to void was so strong that they were unable to defer without fear or risk of having an accidental urinary leakage. Participants were questioned about their ability to defer going to the toilet and asked how long they would remain dry if they did defer going to the toilet. They were also asked if they regularly experienced urinary leakage with this reported urge to void, as they made their way to the toilet or as they were removing their clothing to use the toilet. Participants reported that they were able to hold off going to the toilet on average for 10 minutes from the time they first noted the urge to void, up until they wet themselves. The majority (95%) of those reporting urgency stated the need to empty their bladder very frequently.
P1(F,66): When I get an urge I need to go. I have to go straight away or I will not make it. Most of the time I do go immediately and still don’t get there on time. I have to use incontinence pads. I generally have to change underwear and long trousers shoes and socks three to four times per day. It is so humiliating if I have an accident. I rarely go out at all to social events or even have a night out with friends and family.

P4(F,65): I have an urgent call to pass urine and I leak as I am going to the toilet.

P23(F,56): As far as the urgency goes the feeling of urgency take precedence over everything.

P28(M,65): When I get the urge ... I can put off for a little time but tends not to be too long—10 minutes at the most.

P55(F,69): I can’t ‘hang on’ for more than five minutes. I am always looking for toilets when out just in case.

Table 5.17 shows the men on interview reported 15% more incidents of urgency than did women participants as compared to the NMSS, which recorded men as reporting 3% less urgency than did the women participants.
Table 5.17
Reports of urinary urgency by gender (N=67)

<table>
<thead>
<tr>
<th>Reported diurnal urinary Urgency</th>
<th>Interview n (%)</th>
<th>NMSS n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>No</td>
<td>6 (9)</td>
<td>15 (22)</td>
</tr>
<tr>
<td>Yes</td>
<td>28 (42)</td>
<td>18 (27)</td>
</tr>
<tr>
<td>Total</td>
<td>34</td>
<td>33</td>
</tr>
</tbody>
</table>

An independent-samples t-test was conducted comparing the NMSS Q23 burden scores for urgency according to gender. A significant difference \([t (65) =1.977, p=0.052]\) was found in the scores for men (M=2.88, SD=3.51) as compared to women (M=4.90, SD=4.79). The results are interpreted that the male participants reported urinary urgency as providing for them a higher burden than did the female participants.

5.4.2 Specific LUTS—Frequency

The ICS definition asks for a subjective response based on the participant’s belief that they urinate too often during the day. The NMSS refers to a numerical count of ‘120 minutes since their last void’. Forty-four (66%) people reported at interview burdensome levels of daytime frequency (see Table 5.18). The men were found to be 25% more likely to report frequency than the women, with 26 men stating they experienced burdensome daytime frequency.

Table 5.18
Reports of diurnal urinary frequency by gender (N=67)

<table>
<thead>
<tr>
<th>Reported diurnal urinary frequency</th>
<th>Interview n (%)</th>
<th>NMSS n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>No</td>
<td>8 (12)</td>
<td>15 (31)</td>
</tr>
<tr>
<td>Yes</td>
<td>26 (39)</td>
<td>18 (27)</td>
</tr>
<tr>
<td>Total</td>
<td>34</td>
<td>33</td>
</tr>
</tbody>
</table>
Of the 44 people, 97% stated that they voided more frequently than every two hours with, a range between 30 minutes and two hours.

\[ P2(F;66): \text{I could keep the toilet busy between 6 am and 10 pm on average once an hour.} \]

\[ P3(F;68): \text{It is not uncommon for me to void three times in two hours.} \]

\[ P57(F;68): \text{My frequency symptoms vary. I can void every half hour at times.} \]

5.4.3 Specific LUTS—Nocturia

The ICS definition requires a person to report more than one awakening overnight before nocturia is diagnosed. It additionally differentiates between nocturia and nocturnal frequency in that sleep must be pre- and post-micturition (Irwin et al., 2008; Kraus et al., 2010; Wagg, Cardozo et al., 2008). The NMSS does not specify a number for nocturnal voids. However, grammatically its statement refers to multiple nocturnal awakenings rather than one, and sleep disturbance is not specifically mentioned. Consequently, the question was interpreted by participants as asking about nocturnal frequency rather than nocturia. When interviewed, the participants were able to differentiate between daytime frequency and night-time sleep disturbances with 58 participants identifying nocturnal sleep disturbances differently from diurnal disturbances. However, they found it more difficult to differentiate between night-time frequency and nocturia. The interviews identified three individuals who were actually referring to nocturnal frequency rather than nocturia.

According to interview data, true nocturia was reported by 36 (54%) participants (see Table 5.19) who stated they needed to wake more than once from their sleep to
void. The results presented in Table 5.19 show men reporting nocturia 50% more than the women did.

Table 5.19
Reports of nocturia by gender (N=67)

<table>
<thead>
<tr>
<th>Reported Nocturia</th>
<th>Interview n (%)</th>
<th>NMSS n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>No</td>
<td>10 (15)</td>
<td>21 (31)</td>
</tr>
<tr>
<td>Yes</td>
<td>24 (36)</td>
<td>12 (18)</td>
</tr>
<tr>
<td>Total</td>
<td>34</td>
<td>33</td>
</tr>
</tbody>
</table>

Burden was however harder for them to discern, with many stating that they had no trouble falling back to sleep following the nocturnal void. Those who did report difficulties getting back to sleep, stated that they persisted and mostly achieved some somnolence following the void. Many of the participants saw nocturnal wakening to void as normal or expected and had incorporated this into their lives. It was the people who were no longer sleeping with their partners, because their wakefulness disturbed them or those who found falling back to sleep more difficult, who made the disparaging comments about nocuria. This phenomenon was also noted by Weiss et al. (2011) and Yoshimura (2012), who recognised that nocturia did not seem to influence a negative QoL response.

*P1(F,66): Because I was up and down all night I disturbed [husband]. He was being woken up so much we bought two king single beds.*

*P7(M,67): [I wake up] every one and a half to two hours I have difficulty getting back to sleep. I occasionally take half a Mogadon to help me sleep ... I have had to move out of our [bed]room.*
P29(M,61): Overnight I wake up to empty my bladder three times. I go to bed at 10.30, sleep through to 2 am, then wake up at 4 am and then again at 5 am when I get up.

P40(F,75): I have to go every two hours even at night. The night-time bothers me as I have trouble getting back to sleep. It makes it difficult to go away from home. I don’t drink after 5 pm. I wear a pad at night.

P66(M,67): I sometimes have difficulties falling back to sleep, especially around 4 am. So then I get up make lunch for the boys.

P68(F,75): In the early morning I just give up and do not go back to sleep, so from 4 am after I empty my bladder I stay awake.

P69(F,82): It wakes me up at least three times per night and I have to go to the toilet My main problem is that I am having real difficulty falling back to sleep. I wake up at 9 pm, and 2.30 am, then at 4am I give up and get up for the day, which make me very tired during the day and I am back in bed by 8.30pm.

Similar to the Weiss (2011) and Yoshimura (2012) studies of nocturia, this study found that participants reported a high degree of overall acceptance and adaptation to these sleep disturbances.

P2(F,75): At night I only get up twice over night.

P9(M,64): I did not consider going to the toilet four times each night as excessive. I haven’t considered it a great problem.
The correlation between daytime frequency and night-time frequency, in neurological LUTS, has not been well reported (Lukacz, Whitcomb, Lawrence, Nager & Luber, 2009). A Pearson product-moment correlation coefficient was used to explore the relationship between daytime NMSS Q23, frequency and night-time frequency Q24, nocturia (see Table 5.20) and, as expected, a strong relationship between these two variables existed \( r=0.663, N=67, p=0.01 \). This finding is used to support that the presence of diurnal frequency continues overnight; a currently held clinical position that a urinary storage deficit experienced during daylight hours would continue overnight (Swit thinbank, Vestey & Abrams, 2004).

Table 5.20
The relationship between diurnal and nocturnal frequency N=67

<table>
<thead>
<tr>
<th>NMSS Q24 nocturia</th>
<th>NMSS Q23 frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pearson correlation</td>
<td>1 ( .663^{**} )</td>
</tr>
<tr>
<td>Sig. (2-tailed)</td>
<td>.000</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>NMSS Q23 frequency</th>
<th>Pearson correlation</th>
<th>NMSS Q24 nocturia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sig. (2-tailed)</td>
<td>.000</td>
<td>1 ( .663^{**} )</td>
</tr>
</tbody>
</table>

5.4.4 Participant reports of UI and urinary retention

Many of the participants stated they had frequent urinary ‘accidents’ for which they wore some form of disposable continence or menstrual pads to catch leakage events. Only six (9%) from a total group number of 67 participants interpreted these leakage events as UI; the majority of participants preferred instead to use the symptom (Frequency, Urge or Nocturia) rather than the negative outcome (UI) to describe their urinary dysfunction as incontinence.
P18(F,61): [I have] very bad urge and frequency with lots of accidents and leakage... P54(M,64): I get terrible urgency. I have lots of accidents. It is mainly due to me being so slow, you know, the PD.

Of the six people reporting UI five managed their intractable incontinence by wearing disposable incontinence pad(s), the remaining participant using an indwelling supra-pubic urinary catheter (SPC).

P1(F,66): I have no control over my bladder. I have to use incontinence pads [all of the time] and I [still] generally have to change underwear and long trousers shoes and socks three to four times per day.

P3(F,68): Before the SPC insertion, I had terrible urinary frequency and incontinence.

P16(F,67): I leak on movement. On standing, it pours down my legs.

P57(F,68): I revolve my life around bladder issues. Once I step out of bed, urine just flows out.

Retention was reported by six participants including management of the cluster of urgency, diurnal frequency and nocturia symptoms, which they also reported were often accompanied by frequent accidents (see Table 5.21).
Table 5.21
Urinary retention by gender

<table>
<thead>
<tr>
<th></th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>No retention</td>
<td>29</td>
<td>32</td>
<td>61</td>
</tr>
<tr>
<td>Retention</td>
<td>5</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Total</td>
<td>34</td>
<td>33</td>
<td>67</td>
</tr>
</tbody>
</table>

Two men in this group had been diagnosed with a slow growing prostate cancer and had made the decision to ‘watch and wait’. The woman reporting retention had a long-standing history of recurrent urinary tract infections, for which she was being treated with prophylactic antibiotics. They most often described urinary retention as a feeling of wanting to go back to the toilet not long after their last void, a diagnosis confirmed by their urologist. Therefore, their stories of retention should not be regarded as being directly caused by their PD. The following participant statements confirm the presence of urinary retention and its significance for them.

*P30(M,67):* I feel that my bladder is not emptying fully and if I go back 15 minutes later to re-empty, very little is there but it feels that there should be more.

*P53(F,68):* At times I need to go back and do another shortly after my last pee ... I had trouble with dysuria [pain on urination]. I have been on prophylactic Triprim for one year now.

*P58(M,84):* This has been checked by my urologist who said I didn’t empty properly ... I have prostate cancer, I am doing the watchful waiting for a 'slow growing cancer'.
5.4.5 Presence of OAB in this study population

Urinary urgency, diurnal and nocturnal frequency are the most common LUTS reported in general clinical practice (Iacovelli et al., 2010; Mostwin, 2002; Sakakibara et al., 2001). When these three LUTS are reported in combination, they are known as a ‘symptom syndrome’, and if urinary urgency is the central feature of this symptom syndrome, they are defined, according to the ICS, as OAB (Abrams, 2003, 2005; Temml et al., 2005). Based on participant information obtained from the interviews, 42 (63%) of this study’s population met the ICS criteria for OAB.

While the NMSS was not designed to identify OAB, the combined presence of all three LUTS, frequency, urgency and nocturia symptoms reported by 50% of the 62 participants reporting bladder dysfunction, supports the dominance of this symptom-group for these participants as compared to OAB prevalence in non-PD populations of between 7% and 31% (Irwin, et al., 2011; Shaw & Burrows, 2011). The participants’ NMSS total domain 7 score was strongly associated \( r=0.821, n=67, p<0.01 \) with each of the three participants who reported LUTS; a result, that the presence and frequency of urgency, frequency and nocturia symptoms individually created high levels of distress for the participants. In response to these findings an additional clinical category of OAB was created and populated by the participant data who, by way of the NMSS (\( n=43:64\% \)) and on interview (\( n=42:62.7\% \)), had a combination of all three LUTS.

A series of cross-tabulations were used to examine if age and gender parallels in this group could be found (see Table 5.22).
Table 5.22  
Presence of OAB Interview data: Age vs Gender (N=67)

<table>
<thead>
<tr>
<th>OAB Age into 3 groups</th>
<th>Male</th>
<th>Female</th>
<th>Total OAB n(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>45–64</td>
<td>6</td>
<td>5</td>
<td>11 (16)</td>
</tr>
<tr>
<td>65–74</td>
<td>11</td>
<td>9</td>
<td>20 (30)</td>
</tr>
<tr>
<td>+75</td>
<td>8</td>
<td>3</td>
<td>11 (16)</td>
</tr>
<tr>
<td>Total</td>
<td>25</td>
<td>17</td>
<td>42 (63)</td>
</tr>
</tbody>
</table>

Using the newly created OAB data, obtained from interview transcripts, two hypotheses were formulated to investigate its presence according to the participants’ age and gender.

1. That older participants would report higher incidence of OAB than younger participants.
2. That female participants would report higher levels of OAB incidence than male participants.

Hypothesis 1. The expectation that older aged participants would report higher levels of OAB than younger aged participants was not supported. This sample of people showed no increase in OAB symptom presentation alongside an increase in age (see Table 5.22). Neither older nor younger age groups demonstrated a relationship [ns] with the presence of OAB.

A one-way ANOVA between subject examination was conducted to explore the effect of age on the incidence of any of the LUTS identified by data obtained from the NMSS domain 7. For a second time, age was not found to be an influencing factor in any of the three LUTS questions that make up domain 7; Q22 on urgency [f (28)=16.727, p=ns]; Q23 on frequency [f (28)=19.525, p=ns]; Q24 on nocturia [f (28)=19.879, p=ns] or the total domain 7 score [f (28)=135.797, p=ns]. These findings
strongly suggest that OAB reported by this sample is more likely to be associated with the participants’ underlying neurological condition rather than with their age.

Hypothesis 2. The expectation that women participants would report higher levels of OAB than male participants was not supported. Much of what is known about gender and OAB indicates that women without PD are more affected by OAB symptoms than men. In contrast, this study found that men (n=25) reported higher rates of OAB symptoms than women (n=17). An odds ratio (OR) of 10:7 was calculated, however this finding did not reach statistical significance [n=42: OR, 0.7006: CI, 95%: Z score, 0.894: p=0.37].

5.4.6 Sub-Section 3—Double Incontinence

A high rate of combined bowel and bladder symptoms, termed in the literature as double incontinence (DI) was experienced by 48 (72%) of the participants (see Table 5.23). The high incidence of DI highlights the full effect this degenerative neurological disorder has on the participants’ lives. Only eight (12%) people in this study reported they experienced an isolated bowel difficulty and eleven (16.4%) reported an isolated bladder problem. This occurrence of DI is considerably higher than rates reported in any other prevalence studies of neurologically intact, institutionalised and non-institutionalised elders.

Table 5.23
Frequency of double incontinence (N=67)

<table>
<thead>
<tr>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>48</td>
</tr>
<tr>
<td>No</td>
<td>19</td>
</tr>
<tr>
<td>Total</td>
<td>67</td>
</tr>
</tbody>
</table>
Prevalence studies of non-institutionalised elders suffering from the combination of faecal and urinary symptoms are not plentiful, however, work conducted by Teunissen, van den Bosch, van den Hoogen and Lagro-Janssen (2004), Santos and Santos (2011), Sliker-ten Hove et al. (2010) and Stenzelius, Mattiasson, Hallberg and Westergren (2004) suggested a range of between 3% and 15%. All of these studies associate DI with older age and frailty. When this study looked for a relationship, using a Pearson’s test between the participants’ age, their gender or the level of disability, it found no statistically significant association (table 5.24). These results are viewed as supporting the basic premise of this thesis, that it is the neurological aspects of the PD which has a larger role in these people’s experiences of DI than any other factors.
<table>
<thead>
<tr>
<th></th>
<th>Gender</th>
<th>Age</th>
<th>H&amp;Y (disease progression)</th>
<th>S&amp;E (level of disability)</th>
<th>DI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender Pearson correlation</td>
<td>1</td>
<td>-.066</td>
<td>.042</td>
<td>.025</td>
<td>.043</td>
</tr>
<tr>
<td>Sig. (2-tailed)</td>
<td>.594</td>
<td>.735</td>
<td>.840</td>
<td>.733</td>
<td></td>
</tr>
<tr>
<td>N</td>
<td>67</td>
<td>67</td>
<td>67</td>
<td>67</td>
<td>67</td>
</tr>
<tr>
<td>Age Pearson correlation</td>
<td>-.066</td>
<td>1</td>
<td>-.011</td>
<td>.112</td>
<td>-.040</td>
</tr>
<tr>
<td>Sig. (2-tailed)</td>
<td>.594</td>
<td>.931</td>
<td>.367</td>
<td>.749</td>
<td></td>
</tr>
<tr>
<td>N</td>
<td>67</td>
<td>67</td>
<td>67</td>
<td>67</td>
<td>67</td>
</tr>
<tr>
<td>H&amp;Y Pearson correlation</td>
<td>.042</td>
<td>-.011</td>
<td>1</td>
<td>.518**</td>
<td>.119</td>
</tr>
<tr>
<td>Sig. (2-tailed)</td>
<td>.735</td>
<td>.931</td>
<td>.000</td>
<td>.336</td>
<td></td>
</tr>
<tr>
<td>N</td>
<td>67</td>
<td>67</td>
<td>67</td>
<td>67</td>
<td>67</td>
</tr>
<tr>
<td>S&amp;E Pearson correlation</td>
<td>.025</td>
<td>.112</td>
<td>.518**</td>
<td>1</td>
<td>.154</td>
</tr>
<tr>
<td>Sig. (2-tailed)</td>
<td>.840</td>
<td>.367</td>
<td>.000</td>
<td>.214</td>
<td></td>
</tr>
<tr>
<td>N</td>
<td>67</td>
<td>67</td>
<td>67</td>
<td>67</td>
<td>67</td>
</tr>
<tr>
<td>DI Pearson correlation</td>
<td>.043</td>
<td>-.040</td>
<td>.119</td>
<td>.154</td>
<td>1</td>
</tr>
<tr>
<td>Sig. (2-tailed)</td>
<td>.733</td>
<td>.749</td>
<td>.336</td>
<td>.214</td>
<td></td>
</tr>
<tr>
<td>N</td>
<td>67</td>
<td>67</td>
<td>67</td>
<td>67</td>
<td>67</td>
</tr>
</tbody>
</table>

** Correlation is significant at the 0.01 level (2-tailed).

Moreover, the ADL profile of the participants’ according to the S&E, provides further evidence that their reports of DI are not likely to be related to any inability to manage or maintain aspects of self-care. This finding is at odds with the cited prevalence studies above, which declare DI to be more often associated with those who are more disabled, frail and aged.
5.5 Summary of results

5.5.1 Section One

The analysis of results presented in this chapter addresses the first research question, *What are the bio-psycho-social burdens of bowel and bladder dysfunction?* The first section of this chapter presented the participants’ generic symptoms of PD, along with details of their everyday lives in terms of wellbeing and how disabled they believed themselves to be. The results were used to calculate the staging of the participants’ primary disease and how these people’s PD had impacted on their ability to perform everyday tasks. In terms of life quality and independence participants were able to differentiate between their health concerns and the disabling effects of PD.

Most of the 67 subjects lived in metropolitan areas of coastal New South Wales and had received their diagnosis of PD, on average, seven years before. The largest group were in the H&Y second stage with the next major group in the third stage. Braak and Del Tredici (2008) would describe these people’s disease as at stages four or five, where the basal ganglia are heavily depleted of dopamine-producing cells. The participants’ disease staging as opposed to the length of time since diagnosis was found to be more predictive of involvement in the workforce.

Sixty-three percent of participants reported a moderate level of disability and independence when performing personal care. They highlighted on the S&E that they now required assistance from others and took much longer to perform ADL activities than they did prior to being diagnosed with PD.

The clinical picture generated from these data is that on average participants have noticeable balance and gait deficits; difficulties with fine motor functions; and their movements were no longer smooth and well-coordinated. This impacts on their
ability to carry out their usual household and personal care activities which now takes them two or three times longer than they did previously. Despite these challenges participants’ perceptions of their own independence and social or work engagement was more positive than the H&Y and S&E assessments appeared to portray them.

5.5.2 Section Two

The second section of this chapter presented the biological occurrence experienced by 56 participants of two bowel dysfunctions, constipation and diarrhoea. Diarrhoea was outlined by a subgroup of nine participants as regularly occurring alongside their reported constipation and may be related to their choice of constipation management. Inappropriate or excessive use of laxatives are a known causative factor of loose, watery stool in people with chronic constipation (Chatoor & Emmnauel, 2009; Coggrave et al., 2006; Harari, Norton, Lockwood & Swift, 2004; Kaye et al., 2006).

Sixty-two participants identified the presence of three specific LUTS; urgency (n=28), frequency (n=26) and nocturia (n=24) with a subgroup of n=42 people stating that they experienced all three LUTS, a combination known as OAB. This symptom group was reported as occurring in this study at 63%, a much higher rate than the estimated occurrence of 7% to 31% in age and gender matched individuals without PD (Araki & Kuno, 2000; Iacovelli et al., 2010; Sammour et al., 2009).

Two additional urinary symptoms of UI (n=6) and retention (n=6) were highlighted by 12 participants. These symptoms are not commonly identified as PD specific, in the case of retention each one of the six participants had been clinically diagnosed by a urologist as not being able to fully empty their bladder. There was, however, no firm evidence presented that could be used to rule out or confirm PD as the primary cause of these participants’ reported retention. The second symptom discussed
by the other six participants was UI. This symptom was seen as a negative consequence of the three LUTS rather than as a discrete symptom itself. Many of the participants stated they experienced frequent *accidents* or episodes of UI, but they refrained from using the term UI unless their incontinence was regarded by them as amounting to an uncontrollable, constant and large leakage of urine. The collected data were used to confirm the presence of and relationship between the participants’ bowel and LUTS in the presence of a neurological disease, PD as distinct from that of an older person with non-pathological bowel and bladder changes.

The convergence of all bowel and bladder quantitative and qualitative data collections made it possible to unravel how bowel and bladder symptoms were psychologically and socially interpreted and valued by each participant. The analysis revealed that each person’s perception of what constitutes a valid PD problem was influenced their ability to generate insights of symptom validity and legitimacy. This was viewed as a critically important factor for this group of people, most of whom were unsure of the links between their PD and their presenting bladder and bowel symptoms. Without this understanding, it becomes impossible for people to confidently raise these confronting symptoms in conversation with others, family and friends. Consequently, many participants spoke of adapting their lifestyle and restricting their social activities in preference to securing treatment plans and advice even when they rated their burden highly. The burden of bowel and bladder dysfunction was well addressed in this chapter with the participants rating their bowel dysfunction as more burdensome than their bladder dysfunction, and the presence of either bowel or bladder dysfunction as more burdensome than their primary motor PD symptoms.
Chapter 6: The effects of bowel and bladder dysfunction on quality of life

The overriding objective of this chapter is to analyse the contribution of bowel and bladder dysfunction on the participants’ Quality of Life (QoL). Research published on PD has frequently indicated that QoL is negatively affected by the NMS of bowel and bladder dysfunction and that these negative effects increase with the duration of the disease. The following results and discussions explore the findings of the PDQ-39, a QoL measure specifically designed for use with people with PD, by a group of neurologists attached to Oxford University’s Public Health Unit.

The following instruments were employed to collect the data:

1. The PDQ-39, a QoL measure specifically designed for use with people with PD. As discussed in Chapter Four, the PDQ-39 is routinely used by the Brain and Mind Research Institute (B&MRI) for all their PD clients. They agreed to share their database of PDQ-39 coded results, obtained from each person who also consented to speak to this research project. In this current study, participants were asked to complete the PDQ-39 prior to undertaking the interview. Only five participants completed the PDQ-39 during the telephone interview, with all others completing the questionnaire and returning it to the PD clinic, along with other documentation unrelated to this research. All returned PDQ-39 questionnaires were collated and calculated using the coding instructions outlined in the PDQ-39 user manual (Jenkinson et al., 1998), with the scores from each dimension ... computed into a scale ranging from 0 (best, i.e., no problem at all) to 100 (worst, i.e., maximum level of problem) (Peto et al., 1998, p. S11).
2. The H&Y, the PD staging tool.

3. The S3-QoL, a psychomotor scale that requires each participant to place themselves along a numerical continuum, from 0, representing no disability, up to 4, representing a severe disability. This four-point NRS rating scale was described in Chapter Four as part of the NRS group. This NRS was used to collect data during the structured interview, specifically addressing the quality of life question: How much do you think your Bladder/Bowel problem affects your life?

6.1 Descriptive findings

Measures of central tendency and dispersion were calculated to summarise the PDQ-39 variable data. These results, shown in Table 6.1, support the interpretation and analysis that gives meaning to this group’s PDQ-39 domain and SI scores.

Table 6.1
PDQ-39 domain scores (N=67)

<table>
<thead>
<tr>
<th>Domain</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1: Mobility total score</td>
<td>48.1 (28.8)</td>
</tr>
<tr>
<td>2: ADL total score</td>
<td>47.5 (26.0)</td>
</tr>
<tr>
<td>3: Emotional wellbeing total</td>
<td>40.8 (26.1)</td>
</tr>
<tr>
<td>4: Stigma total score</td>
<td>30.3 (25.3)</td>
</tr>
<tr>
<td>5: Social support total score</td>
<td>30.3 (25.1)</td>
</tr>
<tr>
<td>6: Cognition total score</td>
<td>47.1 (25.2)</td>
</tr>
<tr>
<td>7: Communication total score</td>
<td>40.4 (26.8)</td>
</tr>
<tr>
<td>8: Bodily discomfort total</td>
<td>56.3 (24.5)</td>
</tr>
<tr>
<td>Total PDQ-39 QoL score</td>
<td>70.7 (35.4)</td>
</tr>
<tr>
<td>PDQ-39SI score</td>
<td>37.4 (17.2)</td>
</tr>
</tbody>
</table>

Note. The number of persons surveyed remains constant at N=67.
The participants’ mean scores shown in Table 6.1 fall within a mid-range from 30 to 56. On a scale between 0 and 100 this indicates low to moderate levels of QoL disruption. As well, the SD ranges between 17 and 29, indicating that these participants’ scores vary widely in each domain question. On closer examination, none of the participant raw scores showed significant outliers that could skew the results. Instead, the large SDs indicate the presence of unidentified factors that make meaningful yet important differences to participants’ individual scores.

6.1.1 Effect of PD on the lives of these people at this point in time

The PDQ-39 scores from this study were compared to the originally published validation results conducted by Jenkinson, Fitzpatrick, Petro, Greenhall and Hyman in 1997. Participant scores in the current study fell within a similar range of central tendency and dispersion to that published by Jenkinson et al. in 1997 (see Table 6.2).
Table 6.2
Comparison of PDQ-39 Scores Jenkinson vs. current study

<table>
<thead>
<tr>
<th>PDQ-39 Domain</th>
<th>Jenkinson et al. (1997, p. 355)</th>
<th>Current study Combined postal and telephone</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Postal N=201 M (SD) Clinic N=137 M (SD)</td>
<td>N=67 M (SD)</td>
</tr>
<tr>
<td>Mobility</td>
<td>66.5 (28.2) 41.7 (31.6) 48.1 (28.8)</td>
<td></td>
</tr>
<tr>
<td>ADL</td>
<td>55.8 (28.2) 40.4 (28) 47.5 (26)</td>
<td></td>
</tr>
<tr>
<td>Emotions</td>
<td>43.2 (23.8) 31.9 (22.1) 40.8 (26.1)</td>
<td></td>
</tr>
<tr>
<td>Stigma</td>
<td>34.6 (29) 30.8 (26.2) 30.3 (25.3)</td>
<td></td>
</tr>
<tr>
<td>Social</td>
<td>24.2 (24) 13.6 (20) 30.3 (25.1)</td>
<td></td>
</tr>
<tr>
<td>Cognitions</td>
<td>47.4 (23) 33.3 (22.9) 47.1 (25.2)</td>
<td></td>
</tr>
<tr>
<td>Communication</td>
<td>37.0 (24.3) 25.6 (22.9) 40.4 (26.8)</td>
<td></td>
</tr>
<tr>
<td>Bodily discomfort</td>
<td>52.1 (24) 40.7 (28.1) 56.3 (24.5)</td>
<td></td>
</tr>
<tr>
<td>PDQ-39 SI</td>
<td>44.6 (17.6) 31.6 (19) 37.4 (17.2)</td>
<td></td>
</tr>
</tbody>
</table>

It was concluded that the current study’s participant group did not appreciably differ in their QoL scores from that of Jenkinson et al. (1997), who used moderately sized sample groups. To provide insight and depth of meaning as to what these scores actually represented, an exploration between disease-staging, self-perceived severity and PDQ-39 scored QoL was generated and the qualitative data, gathered from participant interviews, were contrasted against the more noteworthy PDQ-39 domains. This gave an opportunity to examine the relationship between QoL, the severity of PD and continence-specific symptoms.

The two measures used in this study to categorise the participants’ degrees of disablement were the H&Y staging of PD and the S3-QoL, Measures of central
tendency and dispersion shown in Table 6.3 demonstrate both tools were equal and reliable measures of disease staging or severity.

Table 6.3
Measures of central tendency and dispersion (N=67)

<table>
<thead>
<tr>
<th></th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>S3-QoL</td>
<td>2.67</td>
<td>.70</td>
</tr>
<tr>
<td>H&amp;Y disease staging</td>
<td>2.27</td>
<td>.81</td>
</tr>
</tbody>
</table>

A Pearson product-moment correlation coefficient calculation was used to assess the association between participants’ disease severity and their QoL (see Appendix J). The findings demonstrated that for this group of people, a strong correlation existed between the severity of PD and their reports of a more negative QoL. A strong, positive association was noted between the H&Y and the S3-QoL \[ r=0.396, p=0.001 \text{ N=67} \]. However, the S3-QoL was demonstrably more sensitive across more of the domains and, in particular, the domains of mobility \[ r=0.439, p=0.000 \text{ N=67} \], ADLs \[ r=0.413, p=0.001 \text{ N=67} \], cognition \[ r=0.439, p=0.000 \text{ N=67} \] and body discomfort \[ r=0.439, p=0.000 \text{ N=67} \], than was the H&Y. In light of these findings and as suggested by Ward (2000), who drew attention to a weak association between disability and QoL ratings, the S3-QoL was chosen as the tool to explore in more depth the QoL changes identified in the PDQ-39.

The converged qualitative and quantitative data were used to explore participants’ reports of bowel and bladder dysfunction across each of the PDQ-39 domains that scored a mean of 44 (see Table 6.1). The score of 44 was chosen as it reflects for this group, a score in the upper 50th percentile and is more indicative of a
negative QoL. The following four domains met the inclusion criteria for this exploration.

1) Domain 1: Disturbances in mobility (M=48.1)
2) Domain 2: Interruption to ADL (M=47.5)
3) Domain 6: Changes to cognition (M=47.1)
4) Domain 7: The experiences of bodily discomfort (M=56.3)

6.1.2 Disturbances in mobility

PD is classified by the IDC-10 under ‘extrapyramidal’ and ‘movement disorder’ and, as such, disturbances in movement are viewed as diagnostically fundamental to deficits in mobility, balance and movement used to stage PD severity. It was, therefore, expected in a study exploring PD that both mobility and ADL domains would produce high mean scores. The stem question used in the PDQ-39 was: Due to having PD, how often during the last month have you …

- Q1: had difficulty doing the leisure activities which you would like to do? (M=2.3;SD=1.3)
- Q2: had difficulty looking after your home, e.g., do-it-yourself, housework, cooking? (M=2.1;SD=1.3)
- Q3: you had difficulty carrying bags of shopping? (M=2.1;SD=1.4)
- Q4: had problems walking half a mile? (M=2;SD=1.4)
- Q5: had problems walking 100 yards? (M=1.6;SD=1.3)
- Q6: had problems getting around the house as easily as you would like? (M=1.6;SD=1.3)
- Q7: had difficulty getting around in public? (M=1.8;SD=1.4)
- Q8: needed someone else to accompany you when you went out?  
  \( (M=1.7; SD=1.5) \)
- Q9: felt frightened or worried about falling over in public?  \( (M=1.8; SD=1.4) \)
- Q10: been confined to the house more than you would like\( (M=1.6; SD=1.4) \)

While the PDQ-39 separates mobility and ADL domains, most of the questions asked in the mobility domain primarily focused on ADL disturbances. A rationale for this could be that the self-administered questionnaire needs to be easily understood by the respondent, especially when there is no one available to interpret questions and, ideally, the respondent should be able to relate the questions to back to their personal situation. To achieve this, the majority of questions focused on the respondent’s ability to participate in activities rather than asking them about the action of the movement itself.

When asked, all participants believed that the combination of their physical deficits and their bowel or bladder dysfunction created their toileting difficulties, including getting to a toilet in a timely manner. The participants’ comments seemed to fit more appropriately under this first domain, mainly due to their references to gross motor movement. Almost half of this group (46%) stated that their bowel and bladder dysfunction actually accentuated their experiences of movement disruption.

\textit{P31(M;48): Having a full bladder definitely affects my gait. The urgency is often accompanied with very great gait disturbances.}

\textit{P28(M;65): Your physical limitations really affect your ability to manage things like toileting. The act of being able to undo your shorts to get your machinery}
out adds into the challenge. I have urgent urination on top of the PD, and the lack of muscle control and the muscle relaxants I take makes urination an issue.

P03: Having a SPC [catheter] has made it much easier for me. It has also made my mobility problems disappear.

Additionally, the participant group highlighted abdominal pain, emotional stress and anxiety, which they saw as directly caused by their bowel and bladder dysfunction and which had a direct influence on their ability to move freely.

P65(M;81): The [abdominal] pain has now made me resort to using a walking frame as it affects my standing and I’m leaning right over when I walk.

P57(F;68): If I’m under stress, I have frequency and lack of control. My bladder is definitely worse when the dyskinesia is bad and dyskinesia can be worse if my bladder is bad. I find that stress affects both the dyskinesia and the bladder, which both affect each other.

P51(M;79): I am able to discharge urine easier when I am relaxed. I can get into trouble when I am worried about getting [wetting] the seat, the toilet, the floor ... getting undressed and prepared causes me much aggravation.

The highest trending question within the mobility domain was Q1, which had an aggregated mean score of 2.3 (SD,1.3; n=67). As illustrated in Table 6.4, only 8 (12%) of this study’s participants stated that their disease had no effect on their leisure activities.
Table 6.4
PDQ-39 Domain: Mobility

<table>
<thead>
<tr>
<th>PDQ-39 Domain 1: Mobility</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>8</td>
<td>11.9</td>
</tr>
<tr>
<td>Occasionally</td>
<td>12</td>
<td>17.9</td>
</tr>
<tr>
<td>Sometimes</td>
<td>11</td>
<td>16.4</td>
</tr>
<tr>
<td>Often</td>
<td>19</td>
<td>28.4</td>
</tr>
<tr>
<td>Always</td>
<td>17</td>
<td>25.4</td>
</tr>
<tr>
<td>Total</td>
<td>67</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Gender differences also were also noted, with 32% of men stating that they often or always had difficulties doing leisure activities as compared to 29% of women (see Figure 6.1).

Figure 6.1. Gender differences in PDQ-39 Q1.
Q1 implied that participation in leisure activities plays an important role in maintaining a positive QoL, and 88% of this participant group believed that their participation in leisure activities was compromised. The majority of participants were aged over 65 years and 78% of this group had been noted to be no longer engaged in paid employment (see Chapter 5, Table 5.1). In this context, Q1 was seen as important by the participants who reported difficulties in keeping up, physically, emotionally and financially with their spouses or friends who were unaffected by similar limitations.

P01(F66): I rarely go out at all to social events or even have a night out with friends and family.

P03(F;68): It [catheter care] does cost me quite a bit as I am not eligible to get a pension … I purchase a PCA [Personal Care Attendant] for 12 hours per week and catheter products at $250 per month … I have very little left over for anything else.

P17(M;70): My son has complained that I go a lot. I cannot hold onto it.

P26: I use the toilet frequently … yes, over and above my peers and friends … I am sure they notice it.

Some participants spoke of their disease management as almost a full time job, which robbed them of the type of retirement that they had planned. In particular, visits to doctors, exercise clinics and medical specialists were all seen as reducing opportunities to enjoy their life in terms of recreation and socialising.
P06(F;76): I do not need to go to another specialist. I see too many already, it leaves no time for anything else.

P11(M;61): If I let it, I would be going to this doctor or that doctor and I cannot do too much else each day, so I have had to choose.

P20(M;65): If I did not put my foot down, I would be at another doctor every other day, It is just too much.

In addition to the time spent medically managing their disease, the participants spoke of an overarching fear of leaving the house, in particular the fear of having an accident. The term accident was used by this group of participants to mean the experience of a leakage event or UI or FI. These accidents were spoken of as a main obstacle to enjoying an active social life. The participants’ stories provided deeper insights into this burden and, above all, how these bowel and bladder difficulties forced them to alter their social activities to compensate. While the participants spoke of making lifestyle changes, alterations or adaptations, they rarely blamed one aspect or symptom. Instead, they pointed to the single diagnostic term, PD. This was interesting, as most participants were still more likely to blame their bowel and bladder dysfunction on getting older than on the disease itself.

P01(F;66): My lifestyle has altered so much because [a great silent pause] I used to go out all the time before I was diagnosed with PD. I was very involved in volunteer work, arts and craft, but I had to give that up because I have to stay close to the toilet.
P17(M;70): I have a lot of anxiety, this makes it worse ... we went out to dinner and during the dinner I had to go three times. It can be very annoying, especially if I am waiting in a queue, say at the football match. I even had a traffic accident as I was trying to find somewhere to stop and pass urine. [At this point, his voice changed from light and breezy to one of exhaustion and embarrassment] ... I have been that bad, that I had a small leak.

P25(F;69): I restrict my movements, stay close to home and I reduce my fluid intake, especially if I am going out.

P40(F;75): I hardly ever go out anymore to social events or even have a night out with friends and family.

P57(F;68): I revolve my life around bladder issues.

P65(M;81): I have put off going out because I do not think I will last the distance before it sneaks up on you ... I can get to the shop but may not get back.

The following participant’s statement was about faecal urgency accompanied by significant defecatory difficulties. He spoke at length about not going on holidays, because of his bowel difficulties.

P49(M;77): I plan my day’s activities around using or not using my bowels ... it makes it so hard [sic: difficult]. I do not go on holidays because of it.

Incontinence or the fear of incontinence, especially in an older population whether they have or do not have PD, is widely recognised as creating leisure activity disturbances as well as socially isolating people (Cornwell, Laumann & Schumm, 2008;
In a similar way to the first PDQ-39 mobility question, Q10 also addressed the issue of the participant being confined to their home because of mobility problems. This question focused on physically leaving the home environment, but was unlike Q1, which asked a more generalised question of leisure participation, which may or not have involved leaving the house. Despite the similarity, Q10 (N=67: M=1.6 SD=1.4) did not produce as high a mean score as did Q1.

This result may indicate that either the participants’ problems did not inhibit movement beyond their home, or that this group of people had modified their expectations about leaving their house. The latter is the most logical interpretation when considered alongside respondents’ comments about leaving the house and how they had curtailed their leisure activities. The score for this question did not seem to adequately reflect the burden reported by 49 (73.1%) participants who stated, they frequently experienced high degrees of social restrictions, more so than isolation (see Table 6.5).

Table 6.5
PDQ-39 Domain: Mobility

<table>
<thead>
<tr>
<th>PDQ-39 mobility</th>
<th>Frequency</th>
<th>Valid per cent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>18</td>
<td>26.9</td>
</tr>
<tr>
<td>Occasionally</td>
<td>21</td>
<td>31.3</td>
</tr>
<tr>
<td>Sometimes</td>
<td>8</td>
<td>11.9</td>
</tr>
<tr>
<td>Often</td>
<td>9</td>
<td>13.4</td>
</tr>
<tr>
<td>Always</td>
<td>11</td>
<td>16.4</td>
</tr>
<tr>
<td>Total</td>
<td>67</td>
<td>100.0</td>
</tr>
</tbody>
</table>
Female participants also answered this question more negatively than did the males. As a result, the men’s scores had a more normal distribution than the women’s scores (see Figure 6.2). It is possible that women participants placed a greater importance on getting out of the home than the men in this group. These gendered observations were not further explored in this research, but may warrant follow-up studies to highlight gender differences in PD and QoL expression.

Figure 6.2. PDQ-39, Q10 gender response
During the interviews, each participant indicated that any excursions away from home needed to be either well planned and geographically confined to their immediate neighbourhood, or confined to places well known to them. Personal experience was regarded by all participants as a precursor to any travel plan and any suggestion or information on new routes or places to try was seen as untrustworthy and entailing too much risk. Without reliable information or prior experience, no participant said they would leave their house for fear of bowel or bladder leakage accidents.

P19(M;75): I am better when I am in the house. I do not travel anywhere of a long distance. So I only do things around the local [area].

P26(M;64): I make sure I always know where the toilets are, especially before I leave on any journey.

P40(F;75): It makes it very difficult to go away from home.

P57(F;68): I revolve my life around my bladder issues.

P51(M;79): My bladder causes me a bit of anxiety and I have to plan trips around my bladder at times.

Participants reported that they mostly managed their bladder dysfunction by frequently using a toilet. The consequence of using the toilet often during the day was not considered a problem by any participant until they felt their use of the toilet was noticeably different from other people or it had an effect on their ability to perform daytime activities:
P26(M;64): I use the toilet frequently ... yes, over and above my peers and friends ... I am sure they notice it.

P30(M;67): I used to be able to do so much more in the day. Now, I tend to plan my day around the toilet breaks.

Participants also perceived bladder dysfunction as a problem if it disturbed their sleep. The effect of toileting habits on daytime activities is addressed within the discussion on the mobility domain, while nocturnal sleep disturbances are addressed within the cognitive domain discussion of this chapter.

A particular concern raised by participants related to their need to identify where toilets were so they could quickly access them. The issue of access extended beyond getting to the bathroom in time and included the manual dexterity needed to efficiently remove clothing. Without exception, the participants spoke about their mobility deficits as one of the most significant factors inhibiting their access to a toilet.

P01(F;66): Most of the time I don’t get there on time.

P05(M;66): I make sure I know where the toilet is and get there before I need to use it. ... as I get close to the toilet, it comes on very quickly ... at the moment, I can undress quickly, but I have had a couple of misses, you know, accidents.

P15(F;73): I’m much slower so I go to the toilet at every opportunity and approximately every two hours, but sometimes I do go just in case.

P28(M;65): The front door syndrome [the feeling of great urgency on opening the front door of the house] is a real problem. I am currently managing [this] by
discharging my bladder in the garden and always using the toilet when you see one. I always use the toilet before I leave home or a social event.

P55(F;69): Urgency, I can’t hang on for more than five minutes. I am always looking for toilets when out in case I need to go and now with Parkinson’s, well ... you know.

P56(F;66): I’m always looking for a toilet when I’m out.

P58(M;84): I tend to look for a toilet all the time. I get an urgent call to go, but only pass small amounts. I can void every 15 minutes on a bad day.

P61(F;89): At night it’s difficult to get out of bed due to stiffness and poor mobility so it’s difficult to get to a toilet. I have had to call my daughter to help me at times.

P68(F;75): During the day I go to the toilet every hour. I cannot ignore the urge and it is terrible if I turn on taps or hear water running. It is definitely much worse as I get nearer the toilet. I have frequently leaked, especially now I have difficulty undressing.

The mean scores for Q1 and Q10, when contrasted against participants’ S3-QoL scores, revealed a link between the degree of PD disability and its effect on the respondents’ ability to remain socially connected. The results, presented in Table 6.6, illustrated a coexistence of mobility disruption and isolation. Bowel and bladder dysfunction was clearly a more important factor contributing to social disruption for these people than the single aspect of mobility.
Table 6.6
Comparison of measures: S3-QoL vs. PDQ-39 (N=67)

<table>
<thead>
<tr>
<th>S3-QoL</th>
<th>PDQ-39 Q1 mobility</th>
<th>PDQ-39 Q10 mobility</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 = Very mild Mean .50 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>n 2 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SD .7 0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 = Mild Mean 2 1.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>n 25 25</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SD 1.4 1.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 = Moderate Mean 2.4 1.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>n 33 33</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SD 1.2 1.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 = Severe Mean 3.4 2.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>n 7 7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SD .7 1.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Mean 2.3 1.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>N 67 67</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SD 1.3 1.4</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

6.1.3 Interruption to ADL

The PDQ-39 ADL domain presented six questions that highlighted proficiency across the ADLs of washing, dressing, writing, cutting up food and holding a drink without spilling the contents.

Due to having PD, how often during the last month have you …

- Q11: had difficulty washing yourself? (M=1.4;SD=1.4)
- Q12: had difficulty dressing yourself? (M=2;SD=1.4)
- Q13: had problems doing up your shoe laces? (M=1.8;SD=1.5)
- Q14: had problems writing clearly? (M=3;SD=1.5)
- Q15: had difficulty cutting up your food? (M=1.8;SD=1.4)
- Q16: had difficulty holding a drink without spilling it? (M=1.6;SD=1.8)
The mean scores from each question were again recorded according to the participants’ S3-QoL rating. This was seen as an important way to understand how the participants’ degree of disability had influenced their ADL performance.

The mean scores outlined in Table 6.7 also demonstrated a concurrence with this position in all but two questions, Q15 and Q16 which demonstrated a mean score decrease indicating that the participants ADL’s were not as severely affected.

Table 6.7
Comparison of mean scores: S3-QoL vs ADL (N=67)

<table>
<thead>
<tr>
<th>S3-QoL</th>
<th>Q11 ADL</th>
<th>Q12 ADL</th>
<th>Q13 ADL</th>
<th>Q14 ADL</th>
<th>Q15 ADL</th>
<th>Q16 ADL</th>
<th>ADL total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 = Very mild</td>
<td>Mean 0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>n 2</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>SD 0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>2 = Mild</td>
<td>Mean .9</td>
<td>1.4</td>
<td>1.3</td>
<td>2.4</td>
<td>1.4</td>
<td>1.6</td>
<td>36.6</td>
</tr>
<tr>
<td></td>
<td>n 25</td>
<td>25</td>
<td>25</td>
<td>25</td>
<td>25</td>
<td>24</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>SD .9</td>
<td>1.2</td>
<td>1.4</td>
<td>1.5</td>
<td>1.1</td>
<td>1.6</td>
<td>23.7</td>
</tr>
<tr>
<td>3 = Moderate</td>
<td>Mean 1.7</td>
<td>2.3</td>
<td>2.2</td>
<td>3.3</td>
<td>2.4</td>
<td>2</td>
<td>56.8</td>
</tr>
<tr>
<td></td>
<td>n 33</td>
<td>33</td>
<td>33</td>
<td>33</td>
<td>33</td>
<td>33</td>
<td>33</td>
</tr>
<tr>
<td></td>
<td>SD 1.5</td>
<td>1.3</td>
<td>1.5</td>
<td>1.5</td>
<td>1.4</td>
<td>1.9</td>
<td>24.2</td>
</tr>
<tr>
<td>4 = Severe</td>
<td>Mean 2.4</td>
<td>2.8</td>
<td>2.4</td>
<td>3.5</td>
<td>1.2</td>
<td>.5</td>
<td>55</td>
</tr>
<tr>
<td></td>
<td>n 7</td>
<td>7</td>
<td>7</td>
<td>7</td>
<td>7</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>SD 1.3</td>
<td>1.5</td>
<td>1.5</td>
<td>.7</td>
<td>.9</td>
<td>.5</td>
<td>19.5</td>
</tr>
<tr>
<td>Total</td>
<td>Mean 1.4</td>
<td>2</td>
<td>1.8</td>
<td>3</td>
<td>1.8</td>
<td>1.6</td>
<td>47.5</td>
</tr>
<tr>
<td></td>
<td>N 67</td>
<td>67</td>
<td>67</td>
<td>67</td>
<td>67</td>
<td>67</td>
<td>67</td>
</tr>
<tr>
<td></td>
<td>SD 1.4</td>
<td>1.4</td>
<td>1.5</td>
<td>1.5</td>
<td>1.4</td>
<td>1.8</td>
<td>26</td>
</tr>
</tbody>
</table>

The score for Q15, the use of eating utensils to cut up solid food, and the score for Q16, drinking from a cup without spilling its contents, could indicate that the level of ADL difficulty had somehow been overcome and, as a consequence, allowed the participants to regain independence in performing these specific skills. This finding may
indicate that overcoming ADL deficits through the use of appropriate equipment or lifestyle modification has the propensity for increasing a person’s feelings of wellbeing and overall QoL.

The participants who scored their S3-QoL at 4 equivalent to, severely affected by their bowel and bladder symptoms scored both PDQ-39 questions in a lower range, Q15 (M 1.2: SD 0.9) and Q16 (M 0.5:SD 0.5); whist the moderately symptom disturbed group scored these same questions as providing the highest bother (Q15: M 2.4: SD 1.4; & Q16: M 2: SD 1.9). The S3-QoL mildly disturbed group demonstrated smaller yet noteworthy differences occurring in Q15 (M 1.4: SD 1.1) and Q16 (M 1.6, SD 1.6).

These results were interpreted as suggesting that forms of effective adaptation or modification had been made using specialised equipment to overcome these disruptions. No evidence was sought in the interviews to support this claim, however a logical assumption was made that participants with a more severe disability would be obtaining higher levels of assistance from carers; for example, eating foods in a way that required little cutting or using cups and bottles with lids or with drinking spouts so as not to spill their drink. This was also highlighted in the other ADL questions, not showing improvement in scores with disease severity, as they addressed skills not so easily rectified by the use of adaptive mechanical aids. The resulting interpretation is that Q11 through Q14 were in accord with the assumption that as disease severity increased, people would find it more difficult to undertake ADL’s, while Q15 and Q16 did not demonstrate this relationship.

Spector, Katz, Murphy and Fulton (1987), Holroyd-Leduc, Mehta and Covinsky (2004) and Roehrig, Hoeffken, Pientka and Wedding (2007) explained that ADLs can
be categorised into two major groupings. The first, known as basic ADLs (BADLs), measure a person’s ability to independently:

- feed or dress oneself
- maintain a good standard of personal hygiene
- urinate and defecate in the toilet
- transfer and ambulate.

The second group of ADLs, known as instrumental ADLs (IADLs), are more advanced or higher order ADLs that extend beyond BADLs into areas that are more complex. IADLs are daily activities that people do in order to live independently in the community. They focus on a person’s ability to perform:

- basic home cleaning and maintenance
- shopping using telephones and computers
- management of personal health and financial maintenance activities.

The PDQ-39 has used IADLs within its mobility domain and BADLs within its ADL domain. The ability to voluntarily defecate and urinate in a socially appropriate manner is regarded as an integral component of any sound BADL measure and their omission is a major deficit of the PDQ-39 (Aditya et al., 2003; Bradway, 2003; Chiarelli, Brown & McElдуff, 2000; Holroyd-Leduc et al., 2004; Rahman et al., 2008; Roehrig et al., 2007). However, the exclusion of toileting problems from this QoL measure may be related more to bowel and bladder dysfunction being seen as a symptom of PD than an outcome of the disabling effects of PD. Even though bowel and bladder dysfunction is widely recognised as an important factor that disrupts QoL in people with PD, it is a complex subject and, therefore, difficult to incorporate into a comprehensive QoL measure such as the PDQ-39 (Chaudhuri, Martinez-Martin et al.,
The following four ADL questions drew the highest mean scores from the six questions:

- **Q12:** Due to having PD, how often during the last month have you had difficulty dressing yourself? (M=2, SD=1.4)
- **Q13:** Due to having PD, how often during the last month have you had problems doing up your shoe laces? (M=1.8, SD=1.55)
- **Q14:** Due to having PD, how often during the last month have you had problems writing clearly? (M=3, SD=1.54)
- **Q15:** Due to having PD, how often during the last month have you had difficulty cutting up your food? (M=1.8, SD=1.4)

Being able to dress and undress independently is as significant a factor as a person’s ability to remain continent. A person who has frequent accidents or leakage due to an inability to remove clothing is considered to have a functional incontinence (Frick et al., 2009; Griebling, 2008; Hurlow, 2007; Kraus et al., 2010; Marshall & Baliey, 2008). For this participant group, their functional incontinence was made worse by urinary or faecal urgency and frequency. Kraus, Bavendam, Brake and Griebling (2010), Lord et al. (2003), Bradway (2003) and Frick et al. (2009) reported that older people with urinary symptoms such as frequency and urgency also had a higher risk of falls due in part to their haste to get to a toilet and to remove clothing. This combination was reported by the majority of participants as causing considerable concern.
Occasionally I have to be pretty quick to miss my clothes as I get undressed at the toilet or urinal.

The act of being able to undo your shorts to get your machinery out adds into the challenge. I have urgent urination on top of the PD, this makes urination an issue.

The removal of clothing was reported by this participant group to be of major importance and a source of increased stress that greatly affected excursions beyond their home.

I sometimes can’t get my pants down in time. I am finding it harder when I am in the toilet to undress.

6.1.4 Changes to cognition.

The PQD-39 cognition domain, made up of four questions, was considered by many participants to be a major area of concern.

Due to having PD, how often during the last month have you …

- Q30: unexpectedly fallen asleep during the day? (M=1.9, SD=1.5)
- Q31: had problems with your concentration, e.g., when reading or watching TV? (M=2.2, SD=1.5)
- Q32: felt your memory was bad? (M=2, SD=1.3)
- Q33: had distressing dreams or hallucinations? (M=1.4, SD=1.3)

The total mean score (M=47.1, SD=25.2) for this domain was recorded in the upper 50th percentile, indicating that the participants’ QoL was negatively affected by issues of memory, sleep, concentration and bad dream states. The contribution of bowel
and bladder dysfunction in this domain was explored by discussing sleep patterns, daytime concentration and tiredness.

The mean score from the cognition domain offered very different insights into the symptomatic presentation of this disease compared to other more physical domains such as the ADL and mobility domains. In particular, participants reported the presence of disturbing cognitive changes well before they reported problematic physical disturbances. Consequently, this was the only domain where participants regarded a very mild disability as causing QoL disturbances. Using the mean and SD scores from each domain, a one-way ANOVA was used to identify if these participant reports were statistically significant. The question used to guide this examination was: Did disturbances in cognition become more severe alongside the participants’ reported S3-QoL. No statistically significant effect was noted between the participants’ reports of cognitive disturbance and their degree of S3-QoL severity [f (3,63)=1.329, p=0.273].

The results showed that while cognition appeared early in their disease profile, these cognitive disturbances did not reduce the participants’ QoL. As demonstrated in Table 6.8 this participant group reported their S3-QoL severity was more profound in the mild stage (M=48.9; SD=32) and less so in the moderate (M=47.8, SD=20) and more severely staging (M=47.4, SD=32).
Table 6.8
Comparision of measures: S3-QoL vs PDQ-39 Cognition Domain (N=67)

<table>
<thead>
<tr>
<th>S3-Qol Score</th>
<th>Q30</th>
<th>Q31</th>
<th>Q32</th>
<th>Cognition total score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1= Very mild</td>
<td>Mean</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>SD</td>
<td>0</td>
<td>1.4</td>
<td>0</td>
</tr>
<tr>
<td>2= Mild</td>
<td>Mean</td>
<td>1.8</td>
<td>2.1</td>
<td>2.1</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>25</td>
<td>25</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>SD</td>
<td>1.5</td>
<td>1.5</td>
<td>1.3</td>
</tr>
<tr>
<td>3= Moderate</td>
<td>Mean</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>33</td>
<td>33</td>
<td>33</td>
</tr>
<tr>
<td></td>
<td>SD</td>
<td>1.4</td>
<td>1.3</td>
<td>1.2</td>
</tr>
<tr>
<td>4= Severe</td>
<td>Mean</td>
<td>2.2</td>
<td>2.4</td>
<td>1.7</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>7</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>SD</td>
<td>.9</td>
<td>1.1</td>
<td>.7</td>
</tr>
<tr>
<td>Total</td>
<td>Mean</td>
<td>1.9</td>
<td>2.1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>67</td>
<td>67</td>
<td>67</td>
</tr>
<tr>
<td></td>
<td>SD</td>
<td>1.4</td>
<td>1.3</td>
<td>1.2</td>
</tr>
</tbody>
</table>

Individuals who rated themselves as being severely burdened (M=47.4: SD=16.3) reported cognitive-related QoL disruption at an intensity equal to those rating their PD disability as mild (M=48.9:SD=32.1) (see Table 6.8). This finding is diametrically opposite to those in the ADL and mobility domains, where PD progression was statistically correlated with disease severity.

The noticeably large numerical difference between the mild (M=48.9: SD=32) and very mild grouping scores (M=12.5: SD=9.1) was statistically significant at p=0.05 in t-tests. This finding revealed a point where participants recognised their cognitive changes as disease-specific symptoms rather than a cognitive change, commonly regarded by them as an occurrence of mental fatigue or age-related cognitive decline.

The interpretation of this result is that there is a demonstrable peak time where
participants’ deficits in cognition may be more noticeable than their physical changes, as compared to later stages of this disease where the participants’ physical deficits become more evident and take on a central focus.

These findings are consistent with the Braak theory of PD progression, which promotes cognitive disturbances as occurring early in stage two (Chaudhuri & Odin, 2010; Del Tredici & Braak, 2012; Hawkes et al., 2010). That stage, where dopamine-producing neurons remain adequate in number so as not to disturb a person’s gait, is known to have a greater effect on cognition, as well as on the performance of gastrointestinal and urinary systems.

Many participants lamented the loss of abilities and how the PD had robbed them of being able to use their higher order or executive thinking skills (Schneider, 2007). A participant (P9,M;64) was unable to tell his story easily, often leaving bits out and losing focus during conversation, expressed grief about not being more alert, as he stated ‘I’m just not with it any longer’. The participant’s incorporation of bowel and bladder dysfunction into this domain took the form of how much mental energy was used to manage their continence problems. The consensus among participants was that their toileting difficulties dominated their thoughts and was the main source of mental anguish and distress. While the PDQ-39 did not specifically address any aspect of bowel and bladder dysfunction, the participants’ interpretations of the cognition questions as they related to their current situation allowed them to incorporate their bowel and bladder symptoms, which they believed had stopped them thinking clearly or concentrating on tasks.
P51(M;79): I am anxious about many things. They play over in my head and leave room for nothing else ... like my bladder—it just takes over everything else.

Chaudhuri (2003) and Chaudhuri, Healy et al. (2006) have detailed the common occurrence of sleep deprivation in all people with PD as an important factor affecting a person’s cognition. Many of the participants in this study reported that they experienced very disturbed sleeping patterns, which they blamed on their nocturnal urinary frequency. Furthermore, they proposed their poor sleep pattern affected their ability to think clearly during the day, yet on examination, the number of times a participant was woken through the night was not found to be significantly associated with any of the cognitive domain questions. What follows is a deeper exploration of these relationships, warranted by the participants’ comments regarding the significance of these issues to them.

Disturbances to sleep were reported as being disturbed by the need to void more than twice each night by 36 participants (see Table 6.9).
Table 6.9
Frequency of Nocturia by PDQ-39 Domain Score (N=67)

<table>
<thead>
<tr>
<th>Nocturia</th>
<th>PDQ-39 cognition total score</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
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<tr>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

It was expected that these participants would report daytime tiredness and the need to catch up on lost sleep. Unexpected daytime sleeps were reported by 52 (77.6%) which equates to 50% of those participants answering Q30 in the affirmative, stating they often or always unexpectedly slept during the day.

While not specifically asked during interviews whether they were tired or whether they needed to sleep during the day many participants’ volunteered statements that included rising very early in the morning and, therefore, needed to sleep early in the evening.

P32(F;53): I have tried to go to sleep later but I am usually in bed by 6 or 7.
The sleep disorder clinic, they told me I did not sleep well ...I try to go to bed later. Tried not to do anything active before sleep. It makes no difference. I just gave up.
A diagrammatic view of how participants addressed each of the four cognition questions within this domain is shown in Figure 6.3 and Table 6.10 below.

**Figure 6.3: PDQ-39 Domain Six Questions on Cognition**
Table 6.10
PDQ-39 Cognition Domain Results

<table>
<thead>
<tr>
<th>Q30 (Sleep)</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>15</td>
<td>22.4</td>
</tr>
<tr>
<td>Occasionally</td>
<td>14</td>
<td>20.9</td>
</tr>
<tr>
<td>Sometimes</td>
<td>12</td>
<td>17.9</td>
</tr>
<tr>
<td>Often</td>
<td>13</td>
<td>19.4</td>
</tr>
<tr>
<td>Always (or cannot do at all, if applicable)</td>
<td>13</td>
<td>19.4</td>
</tr>
<tr>
<td>Total</td>
<td>67</td>
<td>100</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q31 (Concentration)</th>
<th>Frequency</th>
<th>Valid per cent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>9</td>
<td>13.4</td>
</tr>
<tr>
<td>Occasionally</td>
<td>16</td>
<td>23.9</td>
</tr>
<tr>
<td>Sometimes</td>
<td>15</td>
<td>22.4</td>
</tr>
<tr>
<td>Often</td>
<td>12</td>
<td>17.9</td>
</tr>
<tr>
<td>Always (or cannot do at all, if applicable)</td>
<td>15</td>
<td>22.4</td>
</tr>
<tr>
<td>Total</td>
<td>67</td>
<td>100.0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q32 (Memory)</th>
<th>Frequency</th>
<th>Valid per cent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>5</td>
<td>7.5</td>
</tr>
<tr>
<td>Occasionally</td>
<td>22</td>
<td>32.8</td>
</tr>
<tr>
<td>Sometimes</td>
<td>16</td>
<td>23.8</td>
</tr>
<tr>
<td>Often</td>
<td>13</td>
<td>19.5</td>
</tr>
<tr>
<td>Always (or cannot do at all, if applicable)</td>
<td>11</td>
<td>16.4</td>
</tr>
<tr>
<td>Total</td>
<td>67</td>
<td>100.0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q33 (Dreams &amp; Hallucinations)</th>
<th>Frequency</th>
<th>Valid per cent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never</td>
<td>15</td>
<td>22.4</td>
</tr>
<tr>
<td>Occasionally</td>
<td>31</td>
<td>46.3</td>
</tr>
<tr>
<td>Sometimes</td>
<td>6</td>
<td>9.0</td>
</tr>
<tr>
<td>Often</td>
<td>7</td>
<td>10.4</td>
</tr>
<tr>
<td>Always (or cannot do at all, if applicable)</td>
<td>8</td>
<td>11.9</td>
</tr>
<tr>
<td>Total</td>
<td>67</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Q30 and Q31 are more relevant to sleep deprivation than issues related to memory, vivid dreams and hallucinations (Marschall-Kehrel, 2004; Norlinah et al., 2009). They produced a more symmetrical score distribution compared with the other
two questions, Q33 and Q34, which were moderately and more positively skewed. These findings suggested for this group of participants that Q30 and Q31 were more indicative of a similar causal factor; in this instance possibly stemming from the participants’ reported nocturnal urinary frequency, which caused multiple sleep disturbances. Q32 ‘memory’ and Q33 ‘hallucinations’ represented different aspects of cognition and followed a trajectory that did not have diurnal tiredness or the ability to concentrate as a central feature. Both are viewed as co-dependent factors in nocturnal wakefulness.

Chaudhuri, Healy et al. (2006), Marschall-Kehrel (2004), Norlinah et al. (2009), Pal et al. (2004) and Perez-Lloret et al. (2009) asserted that sleep disturbances, while common in PD and older adulthood, seemed to have little effect on reported QoL. The cognitive domain findings together with participants’ reports were consistent with this point of view. The main references by the participants suggested that sleep disturbances were not related to the number of times the person woke up, but rather whether they had difficulty getting back to sleep. Those who stated they had little difficulty getting back to sleep also said they were untroubled by the excessive number of awakenings needed to void.

_P07_(M;67): Yes, I do have nocturnal frequency every two hours or so. No, only occasionally do I have difficulty getting back to sleep. Then I take half a Mogadon [sleeping tablet] to help me sleep._

_P09_(M;64): I did not consider going to the toilet four times each night as excessive. I haven’t considered it a great problem._
P30(M;67): I wake up three to four times overnight on average: 10 pm, 12 midnight, 2 am and 6.30 am. There is no difference in the amount I pee at night or the amount I pee during the day. Generally I have no trouble falling asleep.

Conversely, those who had more difficulty getting back to sleep were more inclined to complain that waking up to void had a negative effect on their QoL.

P25(F;69): I now wake up overnight once to empty my bladder. I do not like this at all as I have problems falling back to sleep. It makes everything else during the day so hard.

P40(F;75): The night-time bothers me as I have trouble getting back to sleep.

P41(F;73): I have difficulty going back to sleep. I hate it, it makes me so tired and irritable and I cannot think straight

Only one participant thought of discussing these disturbances with a doctor. Interestingly, the participant chose to report the sleep disturbance rather than the need to empty their bladder, the main reason they woke.

P32(F;53): I spoke with the neurologist about the sleep disturbances, not specifically the urine problems of waking up.

This complaint resulted in a referral to a sleep disorder clinic from which she gained no helpful information or assistance, adding to her frustrations.
P32(F;53): They told me I did not sleep well. They made no other suggestions or recommendations or anything. I am not really happy with the limited help offered, I am not satisfied.

6.1.5 Experience of bodily discomfort

Bodily discomfort was seen by this group of people as having a profoundly negative effect on their QoL. This domain produced the strongest participant response, as indicated by its high score compared to all other domain scores for this group of people (N=67, M=56.3: SD=24.5). The domain, bodily discomfort, encompassed three questions:

Due to having PD, how often during the last month have you …

- Q37: had painful muscle cramps or spasms? (M=2.1: SD=1.1)
- Q38: had aches and pains in your joints or body? (M=2.5: SD=1.2)
- Q39: felt unpleasantly hot or cold? (M=2.0: SD=1.4)

These domain questions drew a strong response from the participants who reported that their S3-QoL was directly related to increases in body discomforts (see Table 6.11).
Table 6.11
Comparison of domain bodily discomfort mean scores: S3-QoL vs PDQ-39

<table>
<thead>
<tr>
<th>S3-QoL</th>
<th>Q37</th>
<th>Q38</th>
<th>Q39</th>
<th>PDQ-39 bodily discomfort total score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 = Very mild</td>
<td>Mean 0</td>
<td>2</td>
<td>1.5</td>
<td>29</td>
</tr>
<tr>
<td></td>
<td>n 2</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>SD 0</td>
<td>1.4</td>
<td>0.7</td>
<td>5.7</td>
</tr>
<tr>
<td>2 = Mild</td>
<td>Mean 2</td>
<td>2.2</td>
<td>1.8</td>
<td>49.2</td>
</tr>
<tr>
<td></td>
<td>n 25</td>
<td>25</td>
<td>25</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>SD 1.1</td>
<td>1.4</td>
<td>1.7</td>
<td>24.9</td>
</tr>
<tr>
<td>3 = Moderate</td>
<td>Mean 2.3</td>
<td>2.8</td>
<td>2.3</td>
<td>61.9</td>
</tr>
<tr>
<td></td>
<td>n 33</td>
<td>33</td>
<td>33</td>
<td>33</td>
</tr>
<tr>
<td></td>
<td>SD 1.1</td>
<td>1.0</td>
<td>1.4</td>
<td>21.1</td>
</tr>
<tr>
<td>4 = Severe</td>
<td>Mean 2.6</td>
<td>2.7</td>
<td>2.3</td>
<td>63.3</td>
</tr>
<tr>
<td></td>
<td>n 7</td>
<td>7</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>SD 1.4</td>
<td>1.6</td>
<td>1.3</td>
<td>32.6</td>
</tr>
<tr>
<td>Total</td>
<td>Mean 2.1</td>
<td>2.6</td>
<td>2.1</td>
<td>56.4</td>
</tr>
<tr>
<td></td>
<td>N 67</td>
<td>67</td>
<td>67</td>
<td>67</td>
</tr>
<tr>
<td></td>
<td>SD 1.2</td>
<td>1.2</td>
<td>1.5</td>
<td>24.5</td>
</tr>
</tbody>
</table>

Many participants referred to their bodily discomfort as pervasive and disturbing numerous aspects of their life, especially their sleep, and reducing their ability to move around freely. Participants reported irregularly taking over-the-counter (OTC) pain relieving medicines such as Panadol-Osteo, which is a sustained release paracetamol. Anti-inflammatory agents, or medicines prescribed by their specialist neurologists such as Amitriptyline (Endep), an antidepressant, were also used to relieve the effects of chronic neurological pain. Minerals and vitamin supplements, such as magnesium or Coenzyme Q10, were also reported to be used to relieve the spasms and cramps experienced by the participants.
P3(F;68): The pain in my bowel for the past five years—it gets better if I use an anti-inflammatory.

P14(F;63): I have recently tried using Q10 and it seems to have helped.

P29(M;61): The Neurologist recommended Endep as the pain is significant. I really do not know whether it helps.

The participants raised issues of physical pain and bodily discomfort during the interviews, mostly within the context of continence and as a direct consequence of their constipation. However, pain was not confined to straining at stool. Participants also spoke of generalised abdominal pain, describing it in terms of spasms and cramping. These episodes were more often reported to occur prior to defecation and were interpreted by participants as the call to stool. Q37 specifically asked about spasms and cramps, though it did not specify where in the body these discomforts occurred. The participants’ answers to this question were interpreted as being in line with the bowel pain they experienced, especially as their pains, cramps and spasms were so prominent in their stories. There was no research or literature available on this topic of constipation-related pain or how this pain and cramping differs from, or is similar to, that experienced by others with and without PD.

P01(F;66): I constantly have stomach pain and cramps and I feel like I’m in labour. That pain has now made me resort to using a walking frame as it affects my standing and I’m leaning right over when I walk.
P03(F;68): Pain in my bowel for the past five years. There is an increased pain and discomfort that gives me the feeling that I urgently need to go to move my bowels.

P06(F;76): I get a pain in my tummy, which is very bad, usually in the left lower side. If I get this pain, I take Movicol (a laxative).

P15(F;73): I have to wait a long time on the toilet, up to 30 minutes. It can make you very late for appointments and it is particularly painful and debilitating.

P17(M;70): It is so bad [abdominal pain] that I perspire, it is so painful.

P20(M;65): I do need to ease the pain and stop the bleeding, that would make things better. Even my wife is not sure what to do about it.

P25(F;69): It takes so much effort, it is like having a baby again, without the end benefit.

P28(M;65): It can be a very painful experience and I can raise quite a sweat. I have found that when I am constipated it definitely affects my ability to urinate.

Bodily discomforts as reported by Abeare, Cohen et al. (2010), Kurita and de Mattos Pimenta (2009) and Rutledge, Mouttapa and Wood (2008) were also reported by each participant in terms of it being a physically and mentally exhausting experience. The participants also spoke of medicines used to minimise their pain and how these drugs affected the quality and speed of their thinking. This finding is consistent with research published by Kurita and de Mattos Pimenta (2009), who found that the use of
pain medications had considerable and detrimental effects on participants’ ability to think clearly.

The body aches and pains spoken about by this group were directly related to their bowel dysfunction and, in particular, to the peristaltic propulsion of stool from the large bowel into the rectum just prior to defecation. This phenomenon, reported by these people as affecting their movement and creating significant pain, has not been documented in the literature. This lack of knowledge about the relationship between abdominal pain, PD and bowel movements has undermined the ability of these participants to find a suitable resolution to their problem. Many participants reported that they used strong pain relieving products to manage their pain while realising that it also created the potential for further constipation as well as cognitive decline. This is an important finding, with the potential to influence clinical practice in this field.

6.1.6 Domains of emotional wellbeing, stigma and social support

As mentioned in the introduction of this chapter, the four domains covering emotional wellbeing (M=40.8), stigma (M=30.3), social support (M=30.3) and communication (M=40.4) all scored below the 50th percentile (M=44), a result taken to mean that participants did not view these domains as contributing appreciably to their reported negative QoL (see Table 6.12).
Table 6.12
Domains scoring below the 50th percentile (N=67)

Emotional wellbeing (M=40.4, SD=26.1)
Due to having PD, how often during the last month have you -

Q17: felt depressed? (M=1.6, SD=1.3)
Q18: felt isolated and lonely? (M=1.4, SD=1.2)
Q19: felt weepy or tearful? (M=1.5, SD=1.3)
Q20: felt angry or bitter? (M=1.2, SD=1.1)
Q21: felt anxious? (M=1.9, SD=1.2)
Q22: felt worried about your future? (M=1.8, SD=1.3)

Stigma (M=30.3, SD=25.3)
Due to having PD, how often during the last month have you -

Q23: felt you had to conceal your Parkinson’s from people? (M=1.2, SD=1.4)
Q24: avoided situations that involve eating or drinking in public? (M=1.4, SD=1.5)
Q25: felt embarrassed in public due to having PD? (M=1.5, SD=2.2)
Q26: felt worried by other people’s reaction to you? (M=1.2, SD=1.7)

Social support (M=30.3, SD=25.1)
Due to having PD, how often during the last month have you -

Q27: had problems with your close personal relationships? (M=1.3, SD=1.3)
Q28: lacked support in the ways you need from your spouse or partner? (M=1.2, SD=1.2)
Q29: lacked support in the ways you need from your family or close friends? (M=1.1, SD=1.3)

Yet, with the exception of communication, the areas of emotional wellbeing, stigma and social support were all raised by the participants in their interview conversations as areas of great concern. These areas are also highlighted in continence literature as providing the most stress for people with incontinence (Bradway, 2003; Fitzgerald et al., 2000; Frick et al., 2009; Khan et al., 2009; Lachowsky, 2000; Smoger et al., 2000; Weber et al., 2000). In light of this, an overview encompassing the emotional wellbeing, stigma, social support domains has been compiled. Communication (see Table 6.13) as a topic was not raised by the participants in their interviews and has, therefore, been excluded from this overview.
Table 6.13
Communication Domain (N=67)

Due to having PD, how often during the last month have you …

| Q34: had difficulty with your speech? (M=2, SD=1.3) |
| Q35: felt unable to communicate with people properly? (M=1.7, SD=1.2) |
| Q36: felt ignored by people? (M=1, SD=1) |
| Total Communication Domain Scores (M=40.4, SD=26.8) |

6.1.6.1 Emotional wellbeing

Fifty-two (85.4%) participants highlighted that they were emotionally distressed and anxious about their bowel and bladder dysfunction. Many of these participants referred to their overall disease management as being like a full time job, with no support to assist them or information to guide them. Their anxiety was reported as mainly stemming from a fear of potential or actual leakage events or accidents and the unpredictability of their bowel and bladder dysfunction was always foremost in their minds.

P49(M;77): Won’t go on holidays due to bowel issues.

P19(M;75): I sometimes don’t go out at times due to bowel concerns.

P32(F;53): This is a serious concern for me, I have to know where the next toilet is.

P57(F;68): I am afraid to go away at times.

P4(F;65): I seem to have lost any predictable bowel actions.
P17: I even had a traffic accident as I was trying to find somewhere to stop and pass urine. [At this point, his voice changed from light and breezy to one of exhaustion and embarrassment] ... I have been that bad, that I had a small leak.

The entire participant group spoke of making lifestyle changes, alterations or adaptations in relation to their bowel and bladder dysfunction. They also spoke of having to source information and products for themselves and, when asked, all reported they just did not know where to begin this search. Some participants reported using friends and spousal advice, while others listened quietly to other people’s conversations and followed their lead.

P21(M;86): I listen to my friends at the club speak and then I use what they use. I also get a lot out of the PD support group.

The participants firmly believed that no one would be interested enough to help them and they stated that they were too embarrassed to ask for any help.

P6(F;76): No, I have not asked for any help. I suppose if I thought the doctor could do anything I might.

P5(M;66): I would not speak of this to any other person, especially my friends and family, it is a little personal

Other participants felt particularly frustrated at the lack of scientific progress in the search to cure PD, as well as a lack of scientific interest in what they saw as the important issues, such as being able to go to the toilet. Participants expressed the view
that because toilet issues were not “sexy”, these symptoms were unappreciated and possibly the reason why so little research time or effort had been invested.

\[ P10(F;67): \text{Everyone assumes that everyone is able to do it (urinate or defecate) and if they cannot then it is their responsibility to find a fix.} \]

\[ P08(M;71): \text{Off the record, none of the people I spoke to seemed too particularly interested. If not for my interest, none would have asked me about it. Fifty per cent of the PD support group I attend tell me that they have problems with constipation as well and they feel the same, just helpless and frustrated.} \]

\[ P14(F;63): \text{I am very embarrassed and do not think I can speak frankly to the doctor to ask for help.} \]

### 6.1.6.2 Social support

Most participants relied very heavily on their spouse or friends to gain insight into their bowel and bladder dysfunction, with most stating they were more inclined to keep a quiet brave exterior than to bother others with this ‘embarrassing and stupidly insignificant concern’ (P21.M;86). Very few participants were aware of any social resources available to them in the form of financial assistance or specialist continence nurses working from local health services. Of the 67 participants in this study, only one had seen a continence nurse specialist and another had been signed up to the Continence Aids Payment Scheme (CAPS) by a local social worker. These two participants were the only ones who had any financial assistance or support in selecting the most appropriate continence aids. The CAPS is an Australian Commonwealth financial
payment made to all people over the age of five years who have permanent and severe incontinence due to a neurological condition. A payment of approximately $500 is indexed each year and paid directly to the eligible person’s bank account where it can be directed to a continence supplier of their choice.

P3(F;68): The continence nurses come and change my catheter and order my supplies. It still costs me quite a bit [in addition to CAPS]. As I am not eligible to get a pension, the[Personal Care Attendant-(PCA)] service costs me. I purchase a PCA for 12 hours per week as well as the catheter products at $250 per month.

P19(M;75): I know about government support to buy pads. That is why I am able to try lots of different ones, I buy them from the local chemist at $6 per packet.

The other participants using disposable continence products did so at their own cost, which they estimated to be between $50 and $100 each month.

P25: I wear Poise pads, which I buy from Coles or the local chemist. This costs me approximately $20 per week. [This participant had never heard of the CAPS scheme.]

6.1.6.3 Stigma

Stigma was deeply entrenched in the conversations. Not one participant spoke about being labelled or discriminated against based on either their PD or their incontinence, yet they had all created a protective barrier shielding them from any potential distain others may have shown towards their disease. This protection took the
form of attributing many obvious PD-related symptoms to more socially acceptable ageing frameworks. Statements like ‘well at my age I would not expect less’ were commonplace.

_P26(M;64):_ I have a weaker than average stream. Yes, I use the toilet frequently. Yes, over and above my peers and friends, but isn’t that a normal part of ageing?

It seemed likely from the tone of the participants’ voices that they concealed such information and did in fact experience embarrassment and stigma. Much of what they said was in hushed tones that included many sighs and pauses, all of which indicated the degree of difficulty they had talking to anyone, even an unmet researcher over the phone in a situation where they knew they would never be recognised.

_P3(F;68):_ I do not like talking to people about this as it is very embarrassing. Even the doctors do not feel comfortable about talking about these problems.

Each participant came into this study knowing that the research was focused on bowel and bladder dysfunction and that to be part of this study they needed to have a bowel and or bladder problem. Every interview started with the same question: ‘Tell me about your bowel/bladder problem’. It was a continual surprise that many participants would say: ‘I do not have a bowel or bladder problem’. As an experienced clinician, the researcher would then ask more specific questions that usually guaranteed a much more detailed report of their presenting problems. For example, one participant (P10:F;67) started with ‘I do not have any bowel or bladder problems’. When specifically asked about frequency—‘How often do you go to the toilet?’—the researcher was told ‘every
hour’. The participant then continued the conversation, discussing how she thought she was not able to empty her bladder fully and that she always felt full and dribbled urine constantly and this was why she was going to the toilet so much and needed to wear a pad for protection.

This pervasive and interesting feature dominated the participants’ stories and seemed to be used effortlessly by them to side-step toileting topics. Humiliation was omnipresent in the participants’ stories.

\textit{P1(F:66): It is so humiliating if I have an accident.}

The dominant rationale used was to blame their incontinence on getting older, rarely conceding that it was their PD that caused their bowel and bladder symptoms.

\textit{P57(F:68): As I’ve gotten older [a great pause and sigh, then whispered] or my PD is worse, I have noticed that if I get stressed, bowel urgency and accidents will happen, which is very distressing and horrible.}

It is quite possible that they believed problems with bowel and bladder dysfunction were more acceptable if due to ageing. As such the participants seemed to place a higher level of stigma on having PD than they did on getting older.

### 6.2 QoL concerns and participant confusion about bowel and bladder aetiology.

The study found the participants were unclear as to whether bowel and bladder dysfunction was caused by PD or whether it was more related to what they perceived as normal age-related changes. In doing so, the participants showed a great ability to compartmentalise symptoms that they did not attribute to or believed were unrelated to their PD. For the most part, participants thought of their PD as a disorder of movement,
because this was how the diagnosis had been explained to them by their doctors. The participants also stated this caused them considerable aggravation as they were not sure whom to ask for help, or how to ask the questions about their bowel and bladder dysfunction.

\[P1(F;66): \text{I am open to any suggestions that might help fix the problem.}\]

\[P6(F;76): \text{No, I have not asked for any help. I suppose if I thought the doctor could do anything I might.}\]

\[P7(M;67): \text{Bladder— Before I got PD, I did not wake up as often. I think it is a problem of getting older, you know, problems with your waterworks. Bowels well, everyone I spoke to were very unhelpful. I had to find out what the problem was and the cause.}\]

\[P8(M;71): \text{I just feel helpless and frustrated.}\]

\[P24(M;62): \text{My prostrate is of a normal size and the urologist was not relating any of my complaints to the PD. I am just going to put up with it and straighten my urethra. The doctors did not make any other recommendations.}\]

\[P32(F;53): \text{I just gave up. I am not really happy with the limited help offered. I am not satisfied.}\]

**6.3 Summary**

This chapter presented data which highlighted bowel and bladder symptoms as contributing significantly to these participants’ expression of a negative QoL. Despite the fact that the PDQ-39 does not specifically identify bowel and bladder symptoms, the
participants’ interpretations and expressions of QoL concern were directly linked to the answers they gave, especially across the four most disturbed PDQ-39 QoL Domains of; Bodily Discomfort, Mobility, ADL and Cognition.

This was especially evident when the participants spoke of the pain directly associated with the constipation they experienced. Domain Eight, bodily discomfort with a mean score of 56.3 addressed aches, pains, spasms and changes in body temperature. The participants spoke of severe abdominal griping pain and discomfort associated with their constipation, as well as not being able to clear the contents of the rectum without physically damaging themselves. They also related bladder fullness and the discomfort it caused as having a direct influence on their ability to mobilise. The participant group, without exception, related strongly to this domain, detailing the very significant and disturbing bowel and bladder related aches, pains and spasms. Pain so severe that they stated it affected their ability to mobilise to be able to dress and undress themselves, and to be able to construct sensible thoughts and understandings, which in turn decreased their feelings of wellbeing.

The second most disrupted domain of the PDQ-39 was Domain One, Mobility with a mean score of 48.1. This domain was identified by the participants as either, being affected by their bowel and bladder dysfunction or having an effect on their ability to get to a toilet safely to empty their bowel or bladder. The participants themselves raised the issue of mobility in their interviews, stating that their ability to move freely was severely compromised when they had a full bowel or a full bladder. This allowed further opportunities for aligning and interpreting bowel and bladder dysfunction alongside this domain as both addressed social restriction. This imposed social restriction also resulted in lower levels of lifestyle satisfaction.
The third most disrupted domain was ADL, with a mean score of 47.5. The participants’ stories and accounts of bowel and bladder dysfunction highlighted a difference between this and all other domains. The difference stemmed from the participants’ inability to independently perform ADL’s which in-turn created difficulties for these people in managing their bowel and bladder dysfunctions. These ADL performance difficulties accentuated the rate of functional incontinence experienced by participants, which in turn decreased their confidence and contributed to their social restrictions both of which intensified their reports of a poor QoL.

The final domain with a high mean score of 47.1, was Domain Six, Cognition. This domain was less physically orientated than the three previously discussed PDQ-39 domains. Unlike the previous three domains it was more difficult to ascertain if bowel and bladder dysfunction in this group of people had contributed to their cognitive domain scores. The primary symptoms viewed as potentially contributing to these people’s cognitive deficits were; nocturia and the pain associated with constipation. Nocturia was reported as disturbing many of this study’s participants; however many of these people stated they were not overly bothered by these nocturnal awakenings even when they also reported significant daytime somnolence and poor ability to concentrate. The experience of being in pain as well as the drugs used by this participant group to relive their pain are both known to effect a person’s ability to concentrate and may account for this domain being so highly scored. However, like the effects of nocturia on both concentration and sleep pattern disturbance the experience of chronic and episodic bowel and bladder pain in PD remains poorly understood in terms of their impact on a person’s QoL and warrant further investigation.
These findings have highlighted how bowel and bladder dysfunction has affected these people’s interpretation of what makes a good QoL. The bowel and bladder attributes identified and addressed in this chapter begin to shed light on their impact and on the context these participants’ report quality of life satisfaction. Of great importance is that these findings, presented throughout this chapter, have highlighted the interpretive possibilities of what QoL means to people with PD.
Chapter 7: The therapeutic experiences of people with Parkinson’s Disease in the context of their bowel and bladder dysfunction

The relationship between the participant and their doctor was identified in Chapter Six, as an essential element in maintaining a positive QoL for people with PD. In particular, participants who believed that they had control over their disease presented as having a more positive outlook about their future than those participants who felt overwhelmed by their PD. A major source of discontent identified in the participants’ interview statements stemmed from the lack of information or a perceived lack of support received in their attempts to manage their bowel or bladder dysfunction. This chapter examines more closely the relationship between the participant and their primary health practitioners; for this group, their GP and the medical specialists they were referred to, such as neurologists, gastroenterologists, urologists or urogynaecologists. Chapter Seven differs from the previous results chapters in that the voice of the participant is centralised with the quantitative data used to provide interpretive direction and confirmation.

7.1 Instrumentation used to collect data

7.1.1 Qualitative instruments

During the interview participants were asked to discuss their therapeutic experiences through the following open-ended questions:

1. Have you spoken to anyone to ask for help or assistance for this problem?

2. What treatments/products have you tried to solve your difficulties? Were they successful?

The interviewer took opportunities to elicit further clinical and general information by using inquiry stems such as ‘tell me more about …’ When asking for
clarification, participants were asked ‘What did you mean when you said …’ and to verify their statements, ‘Is this what you meant when you said …’.

### 7.1.2 Quantitative instruments

The NRS SBS was used by the participants to rate the burden they experienced and the NRS S3-Satisfaction was used by participants to rate their level of satisfaction regarding the help or assistance they received in this chapter.

### 7.2 Results for interview Question One:

The interview question one asked, “Have you spoken to anyone to ask for help or assistance for your bowel or bladder problem?” From the total group of 67 participants, 56 reported they experienced a bowel dysfunction and 62 reported bladder dysfunction. From within these two subgroups, 36 participants (54%) with bladder dysfunction and 45 participants (67%) with bowel dysfunction reported that they had at least once, expressed concerns about their bowel or their bladder to their medical practitioner (see Figure 7.1).

![Figure 7.1 Reports of bowel or bladder dysfunction to a GP](image)

Participants were asked to describe their experiences in seeking this help. They were additionally asked to rate the usefulness of the help they received on the S3-
Satisfaction NRS (see fig. 7.2 & 7.3). The participants identified their local general medical practitioners (LGP) as the main source for all their medical advice.

Figure 7.2
GP satisfaction rating—Bladder.

<table>
<thead>
<tr>
<th>Category</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>did not report</td>
<td>26</td>
</tr>
<tr>
<td>very satisfied</td>
<td>0</td>
</tr>
<tr>
<td>satisfied</td>
<td>5</td>
</tr>
<tr>
<td>neutral</td>
<td>9</td>
</tr>
<tr>
<td>not satisfied</td>
<td>13</td>
</tr>
<tr>
<td>very unsatisfied</td>
<td>9</td>
</tr>
</tbody>
</table>

Figure 7.3
GP satisfaction rating—Bowel

A neutral response was recorded by nine (15%) participants reporting bladder problems and 14 (25%) reporting bowel problems, meaning that they were neither satisfied nor dissatisfied with the help they received. These participants indicated they had expected very little help from their doctors and when they received very little help, it did not bother them too much, as one participant clearly affirms:

"P27 (M;75): I do not expect any help in that department"
The 11 (16%) participants with bowel complaints and 26 (39%) participants with a bladder complaint had not discussed these symptoms with their doctor. They all gave reasons that either related to their own, or their doctors’ prioritisation of health problems or because they perceived it would embarrass either themselves or their doctor. Statements from 22 participants (33%) reporting bowel concerns, indicated that they were so dissatisfied with their doctor’s response that they would not to raise the subject of toileting difficulties with their doctor or anyone else ever again.

*P5*(M;66): *I will not ask the GP again and I would not speak of this to any other person, especially my friends and family.*

*P15*(F;73): *I am sure doctors do not realise what you go through. I have given up.*

*P8*(M;71): *The neurologist just fobbed me off. I get the impression that they [doctors] lack interest [in constipation]. 50% of the PD support group I attend tell me they feel the same, just helpless and frustrated.*

Participants with bladder symptoms were found to be less likely (n=36, 53.7%) than those with a bowel dysfunction (n=45, 67.2%) to raise concerns about their symptoms with their doctor. The participants’ gender, age or length of diagnostic time did not contribute or influence help-seeking behaviours. The major reasons given by participants in defence of not raising their bowel or bladder concerns with their doctors ranged from not seeing their bowel or bladder symptoms as a legitimate health concern or that they made an assumption that bowel or bladder symptoms were beneath their doctor’s level of interest or expertise.
P14(F;63): I did not know this was important, I know it is embarrassing, the doctor has never asked me about my bowels... he has not raised it with me as an issue.

P18(F;61): None of the Dr. ’s seemed particularly interested, they never raise the issue about bowels at any time.

The participants indicated that if they had tried to broach the subject of bowel or bladder dysfunction and had felt dismissed, they concluded their doctors were disinterested.

P9(M;64): I told my doctor I was having difficulties... But he was not really very interested.

P32 (F;53): Just gave up, I am not really happy with the limited help offered, I am not satisfied.

The participants were also critical of the management options offered to them, reporting that their doctors had offered such basic information, usually in the form of ‘eat more vegetables and drink more water ’, that they were left believing that there was nothing more that could be learnt or achieved from further discussions. Moreover, the participants also viewed their doctor’s level of understanding as quite low.

P6 (F;76): No I have not asked for any more help, I suppose if I thought the doctor could do anything I might. But I am not confident that he would know what to do.

P7 (M;67): I had to find out what the problem was and the cause. I do not blame the doctor they cannot know everything. They are not God’s in everything

P8 (M;71): I sent the GP a book so she would learn about PD.
P9 (M;64): I told my doctor I was having difficulties, he told me to keep drinking and eating your veg’s. But he was not really very interested.

[Reflective notes: This participant added, that his diet was good and that he did eat and drink well]

P29(M;61): I do! I try to eat a good amount of fibre, fruit Grains and pulses and 5 cups of fluid per day; 2 x water 2 x coffee and 1 x fruit juice.

The participants also stated that medical practitioners would wait for the participant to raise the issue of toileting dysfunction and that they were rarely proactive in asking the participant if they had any concerns in this area.

P14 (F;63): The LGP has never asked me about my bowels.

For the participants, this confirmed that bowel or bladder dysfunction was not important to doctors. The rationale used by the participants to reach this a conclusion was, if these symptoms were important or related to PD, the doctor would have asked about them, just as they always did for other important ailments like high blood pressure. By LGP not actively following up on the bowel or bladder dysfunctions reported, the participants formed the view that bowel or bladder dysfunction was not important.

P16(F;67): He is more concerned about my angina and cardiac problems.

Participants also anticipated that conversations about bowel or bladder dysfunction would increase their already high levels of anxiety and distress.

P57 (M;84): If I’m under stress I have frequency and lack of control. I revolve my life around bladder issues.

P18 (F;61): I tried to speak to my Dr about having troubles (passing stool) but I did not push it as I felt embarrassed and stressed by it all.
P30(M;67): I have not spoken to my LGP, it has not come up even though it is not an insignificant thing in my life.

P9(M;64): My Dr. took blood tests and urine tests and told me nothing was wrong. I don’t think he considers it a great problem. [Reflective notes: This participant could not get through the 45 minute interview without having to go to the toilet, once before we started talking and again halfway through the interview].

P4(F;65): I spoke with my gynaecologist, he was not too interested. I have not spoken to my LGP. I am not too sure what is meant by normal any more.

Another participant used the following example to highlight an interaction with her doctor about her complaint of constipation and excessive straining at stool.

P8(M;71): The neurologist just fobbed me off, saying there was plenty on the market, I may find something that suits me, if not, then come back and see me [him].

Some doctors were reported as attempting to open up channels of communication by enquiring very generally about their patient’s health. However, most of these enquires were regarded by their patients as closing statements, instead of their using this as an opportunity to express unaddressed concerns. The participants reported they usually decided not to engage in further questions or comments.

P16 (F;67): My LGP occasionally asks how I’m going.
**P61(F;89):** When my GP asks how I’m going. I tell him I’m fine, I do not want to whinge as he is just so busy and he’s really not too interested.

Both men and women participants reported that the relationship between themselves and their doctors was at times difficult to negotiate, further inhibiting their attempts to raise a discussion about bowel and bladder symptoms.

**P6(F;76):** I think I smell, I often feel I am very smelly. I do not talk to my LGP about this; he is so busy taking BP and eye drops and sorting out your other things... I know he can smell me!

**P10(F;67):** I get the impression that LGPs do not like PD as they tend not to get involved, they lack interest. They just refer you on and never ask again.

**P25(F;69):** I have very slow delivery [urine] with lots of leakage, but [I’ve been told] my prostrate is a normal size. The doctor did not make any other recommendations. He never does.

Three sub-themes became evident within the participants’ conversations about their bowel and bladder symptoms: disgust, embarrassment and insignificance. They used these themes as a lens through which they defined and interpreted their doctor’s responses and advice. This may account for the overabundance of doctors’ initial responses being interpreted by participants as stemming from disgust, embarrassment or disinterest; the participants’ used these interpretations to justify and forgo further enquiry making or assistance seeking.

**P3 (F;68):** Even the doctors do not feel comfortable talking about these problems.
P36(M;63): Even though I had mentioned it previously, I think they are also 
embarrassed, they have lots of things on their minds.

Prioritisation of symptoms and their management were most evident in 
participants’ comments about bowel dysfunction, which appeared to generate a higher 
degree of discomfort for the participants than did their bladder symptoms.

P14(F;63): When I am with my Dr. there are so many other things that are more 
important to discuss.

The participants accepted their bladder and bowel symptoms as being related 
primarily to ageing and not to their chronic disease, PD. Participants therefore found it 
difficult to choose whom to speak to about their problem. They spoke of their friends, 
without PD who were also having difficulties maintaining a continent state. This 
seemed to confound participants who found it difficult to differentiate their problem 
from their friends’ problem.

P26(M;64): I have a weaker than average stream but isn't that a normal part of 
ageing. Yes I use the toilet frequently yes over and above my peers/friends.

Participants seemed to be confused about the pathological changes that had 
created their bowel or bladder incontinence. Some thought it might be due to their age, 
their limited ability to exercise, the drugs they were taking or changes to their food and 
fluid intake. It is quite possible that these pre-conceptions contributed to the disparate 
reporting patterns demonstrated in Figure 7.1, between bowel (67%) and bladder (54%) 
dysfunctions.

P5(M;66): [Bladder] I think it is age-related.
P26(M;64): [Bladder] I have a weaker than average stream, but isn’t that a normal part of ageing?

P7(M;67): [Bladder] I think it is a problem of getting older, you know, problems with your waterworks. [Bowel] I have had these problems for 6 years it started with the PD symptoms, I believe that it is the weak PD muscles which affect all of the body.

P8(M;71): [Bowel] It started very slowly getting worse then it really kicks in just like PD slow & gradual. I had not seen anyone before as I had not related the constipation to PD.

P14(F;63): [Bowel] I was not sure whether it had anything to do with PD.

P57(F;68): [Bowel] As I’ve gotten older I have noticed that if I get stressed, bowel urgency and accidents will happen, which is very distressing and horrible.

P59(F;60): [Bowel] I think bowel issues are related to my medications I take?

The GPs were reported as adopting an integrative approach when the topic of bowel or bladder dysfunction was raised; this approach being seen by the participants to have an ageing or gendered focus. Not once did any participant talk about a neurological bowel or bladder dysfunction or a neurological investigation. Rather, participants’ stories of bowel or bladder investigations focused around gerontological prostate enlargement or pelvic floor damage caused by multiparity. As these age and gendered associated causes were eliminated, through a process of differential diagnosis,
other investigations or treatments, which would have focused on the neurological dysfunction prevalent in PD were not initiated. Primarily, the participants viewed these initial normal results, as final diagnostic outcomes for which nothing more could be done and as such did not return to their doctor for follow-up. GPs were reported to readily make referrals to other medical specialist such as gastroenterologists and urogynaecologists, yet no participant reported a referral to other multidisciplinary services, such as a continence nurse specialist or a dietician. When the participants were asked in interview if they had seen a continence nurse advisor, they stated that they did not know of or had not been directed to this service.

*P06(F;76): No, I have not asked for any help ... he usually sends me off to a specialist for women’s problems and I do not need to go to another specialist. I see too many already. No, I am not aware of any continence service.*

Of those referred to medical specialists, five participants complaining of constipation with excessive straining at stool were referred to a gastroenterologist. These people underwent a colonoscopy, which entailed a complete bowel wash-out and all were told that their now clean bowel looked very normal. None was given any advice or management options to assist them with their constipation and excessive straining at stool.

*P19(M;75): I went to a gastroenterologist. He did a colonoscopy but he was not interested in the constipation.*

*P23(F;56): The doctor did a colonoscopy and said that the colon looked more normal than he expected.*
P52(M;78): I had colonoscopy and was told to eat prunes, bran and increase water to help move things through.

A participant who described their bowel dysfunction as intractable FI was offered and chose to have a colostomy performed.

P48(F;67): I had such severe FI, it was awful, I had no control. The doctor said it would help and it is much easier to handle. I only have problems if the bag leaks. But I am much happier with the colostomy as I have more control.

Many of the participants raised issues around the value of service and advice from their doctors, with some claiming that speaking with their doctor was not useful. They described the information given as not educative or informative and nor did it take into account their existing knowledge level.

P4(F;65): So little information given by the doctors ... they make assumptions that you know what they are looking for.

P18(F;61): The doctor did not tell me the deep brain stimulation (DBS) will improve my urinary frequency. He only spoke about dyskinesia and ability to walk. Since the DBS, I still have some urgency and I still do not trust my bladder but I have noticed that it is a lot better.

P27(M;75): I saw [a continence nurse] four months ago at Para Quad. I found her on the internet and referred myself to her. I have not spoken to my LGP. I do not expect any help in that department.
P8(M;71): In Feb, I went to a PD group seminar, then to my local chemist, then I spoke to my GP. I had not seen anyone before that ... 50% of the PD support group I attend told me they have problems with constipation.

P18(F61): I was told to increase my use of prunes, dietary fibre and fluid... none of these things have ever worked for me.

Participants did not understand the network of medical co-referrals and became frustrated with what they perceived as doctors not understanding their PD and not knowing what was causing their bowel or bladder dysfunction. Participants identified activities associated with their medical management, such as travelling, waiting and numerous consultations as interfering with their life, and being particularly burdensome. In the following example participant 22 (M;68) alleged his doctors seemed to be confused by his symptoms he referred to his urinary frequency and urgency as being like ‘a hot coal that no one wanted to catch’.

P22(M;68): I am very disappointed. The neurologist told me everyone blames PD. The urologist looked at my prostate he told me that my problem was related to my PD. Not much else was offered by the GP, who leaves it all up to the specialists.

Other participants assumed that their symptoms must be related to normal ageing and nothing else, as they had been to a specialist who could not resolve their problems.

P5(M;66): I have had my prostate checked by the GP. He said that there was nothing wrong.
P4(F;65): My specialist (gynaecologist) checked me out for a prolapse, I suppose I didn’t have one because he did not refer me for any other treatments.

P12(M;66): I did have a PSA test and everything was ok.

Participants also informed the researcher that there were some things that they just did not tell their doctor, family and friends. These unmentionable or taboo subjects were broached carefully and contextually because they believed that if they told anyone, they would risk not being seen as an independent individual. They believed they would risk losing the respect of others, or lose control over their own lives. In some conversations, remaining in control was emphasised, as in participant 21’s story, where he protected his secret by listening and not informing others.

P21(M;86): I have not asked my doctor. I listen to my friends at the club speak and then I use what they use.

P7(M;61): I protect them [Doctor, family and friends]. I do not tell them everything. I had to find out what the problem was and the cause..

P12(M;66): I do worry a bit about it but I have to work through it.

P31(M;48): I found things out myself, no help from any of the doctors or my family.

P51(M;79): I do not like the way doctors take control and will not let me manage my own impairments. I only need them to provide me with the information to help me manage myself. They are not in charge.
It takes me up to 45 minutes to pass stool and I bleed, but I have never spoken to my doctor about it. I just won’t.

The rationale given most often by participants in defence of not talking to their doctors about bowel or bladder dysfunction was embarrassment. Some participants reported that knowing their doctor did not reduce the degree of embarrassment they experienced.

I do not like talking to anyone about this as it is very embarrassing.

I am very embarrassed and do not think I can speak frankly to the doctor to ask for help.

I know it is embarrassing for both of us [the Dr. and I]. I do think about doing something but do not know where to start.

I have not spoken to my GP. It is just too hard, too hard.

As the interviews concluded, many participants stated that this was the first time they had ever spoken to anyone about their bowel or bladder dysfunction in such detail and they were now a lot more encouraged to talk to their LGP. The participants indicated that bowel or bladder dysfunction was a difficult topic for them to raise and discuss with their doctors.
7.3 Results for Question Two

Question two asked the participants, “What products or treatments have you tried in an effort to solve your bowel or bladder dysfunction - Were they successful?”

7.3.1 Management of bladder dysfunction—containment devices

A considerable number of participants mentioned they used disposable sanitary pads to help them contain any accidents and maintain social dignity. The exact numbers of participants using pads, or how many pads these people used during a 24-hour period, was not able to be determined from the data, as the question was not posed to all participants. Only those who raised the subject of using disposable continence pads in the interview were asked about pad usage and financial costs.

Australian residents are able to access financial support to purchase continence supplies through the federally funded and non-means-tested CAPS and, in NSW, the Program of Appliances for Disabled People (PADP) known as ENABLE NSW (CFA, 2010). ENABLE is a means-tested continence supply scheme and as such is more difficult to obtain, and has long wait lists. Three participants mentioned accessing CAPS in their interviews, with one of these people additionally accessing PADP funding. Many other participants mentioned during the interviews the financial difficulties they encountered, because they had to purchase sanitary pads for their incontinence.

The three participants who had accessed government continence-funding initiatives had all been seen by a continence nurse specialist located at their local hospitals at the suggestion of friends or family or following hospitalisation for the emergency treatment of urinary retention.
P16(F;67): The community nurses called in a continence nurse who put me onto PADP.

P19(M;75): I did know about government support to buy pads. That is why I am able to try lots of different ones. I buy from the local chemist ... at $6 per packet.

P47(F;73): [reflective notes] The nurse continence advisor signed this lady up to CAPS.

For those who had no knowledge of available financial assistance, conversations were dominated by the financial stressors of purchasing disposable continence aids.

P6(F;76): I wear a pad, you know, the ones you get at Franklins with the wings, the same ones women wear for menstruation. They are very expensive. I do not get any financial assistance.

P23(F;56): I wear pads all the time. Either I use a panty liner or Libra light or regular Poise. I purchase these pads from the local chemist and that is an expensive exercise, approximately $200 to $300 each month.

P27(M;75): I stopped using the Uridomes [condom drainage devices] and pads because they were very expensive. I did not know I was entitled to any help [CAPS]. My GP did not tell me about this.

P25(F;69): I wear Poise pads that I buy from Coles or the local chemist. This costs me approximately $40 per month

P32(F;53): I wear pads, Ultra panty liners. I usually change them twice a day.
The most commonly used continence product identified was the continence pad. There are numerous styles, shapes and absorbencies available for purchase and these pads are widely available in supermarkets and pharmacies. With so many pads available and no professional advice, many participants took the position that they should use the smallest and cheapest ones available. Consequently, many of the participants reported problems and inadequacies with the product chosen.

P1(F;66): I still cannot find the right pad yet. If I get the right shape, the absorbency isn’t right, and to get the right absorbency they are massive in size. I will have to try some other brands.

P6(F;76): I wear a pad, you know, the ones you get at Franklins, the same ones women wear for menstruation. They are very expensive. I do not get any financial assistance. They are very expensive. Once or twice a week I have a leakage over the pad, and if I need to go to the toilet urgently, I often leak on the way there.

P16(F;67): Generally, the pads catch it but often they are not effective.

P18(F;61): I wear a sanitary pad but I often leak through it. I use over three each day.

The major problem raised by participants was that the pad did not provide them with enough protection for them to feel confident enough to participate actively in all aspects of their life—in other words, being socially continent. Choosing the most efficacious product is of utmost importance, yet many participants spoke of using menstrual pads, which have very little capacity to absorb the large quantities of thin,
fast moving urine as compared to the slow, thicker menstrual blood flow they were
designed to entrap. Consequently, participants were forced to change these pads
frequently, thereby substantially increasing their continence management costs. The
following participant stories highlight the importance of correct pad choice and the cost
implication of poor product knowledge.

*P23(F;56):* I wear pads all the time. Either I use a panty liner or Libra light or
regular Poise. I purchase these pads from the local chemist and that is an
expensive exercise, approximately $200 to $300 each month.

*P25(F;69):* I wear Poise pads that I buy from Coles or the local chemist. This
costs me approximately $40 per month

Participant 23 wore a combination of continence products. The absorbent
capacities of these products ranged from a panty liner that held less than 30mls through
to the regular Poise pad, which has a capacity of up to 250mls. This participant spent
$200 to $300 dollars per month, while participant 25 reportedly spent $40 dollars per
month. Both participants predominantly used the Poise pads, purchased from their local
shop. These pads retail for about $6 per pack of 18. This calculates as participant 25
using two packs of 18 pads each week, compared to Participant 23, who used between
eight and 10 packs of pads each week.

The excessive use of pads was found to be a common problem across this
participant group, especially when using a pad that had inadequate absorbent capacity.
In this case, the participant overcame the pad’s deficiencies by using multiple pads
together, one pad on top of the other. Participant 23 reported that she used up to four
pads at one time, changing them all at least five times each day. What she failed to
consider was that each pad has a protective plastic under-layer that ensures urine does not flow through the bottom of the pad into the person’s clothing. When these pads are used in this layered manner, each pad remains independent and as the first pad’s capacity is reached, the urine spills over the top soaking the sides of each subsequent pad, making them equally unusable, although not utilising their full capacity. This participant would be financially and socially much better off buying larger capacity pads, which may be more expensive but she would need to only use three of them in a 24-hour period instead of using four pads that were changed five times each day.

Independent and reliable information about choosing appropriate continence pads is not easily accessible. Community dwelling adults rely on their LGP to advise them of other services and they are particularly disadvantaged if they not made aware of continence-specific health professionals, such as specialist continence nurses.

7.3.2 Management of bladder dysfunction—medications

The use of medications to treat neurological OAB in this participant group was not extensive. Only seven people stated that they had taken a drug to assist them in controlling their neurological OAB symptoms (see Table 7.1).

Table 7.1
Use of Drugs to Treat OAB

<table>
<thead>
<tr>
<th>Bladder drugs used</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>60</td>
<td>89.5</td>
</tr>
<tr>
<td>Yes</td>
<td>7</td>
<td>10.4</td>
</tr>
<tr>
<td>Total</td>
<td>67</td>
<td>100</td>
</tr>
</tbody>
</table>

These seven participants stated they tried to take Ditropan, Oxybutynin HCl, a drug commonly prescribed for OAB. They had all stopped taking it, because it produced a severely dry mouth, an unpleasant side effect. While other side effects are noted in the
literature such as constipation, urinary retention, increases in confusion and anxiety, as well as reports of impotence, no participant reported these occurrences of side effects. Most participants commenced on a low dose but this starting dose was unable to be graduated upwards to reduce their OAB symptoms because their dry mouth was so uncomfortable. None of the participants was offered an alternative drug or a transdermal patch of Oxybutynin HCl, which is known to have a lower dry mouth profile (Oxybutynin HCl, 2012), because none of the participants returned to their doctors to report their discomforts.

P11(M;61): [Ditropan—anticholinergic] The urologist gave me a medicine and said I could make another appointment if I needed to but I did not go back. The medicine was worse than the complaint.

P7(M;67): [Ditropan—anticholinergic] My doctor gave me some Ditropan but that did not work so I stopped taking it.

Participant 4 (F;65) was prescribed a topical hormonal cream, Ovestin, for her urinary dysfunction. She also stopped using the cream as she did not think she needed to use it long term.

P4(F;65): The gynaecologist, gave me a cream called Ovestin. I used the cream but he gave me no instructions. I wasn’t sure why he had given me the cream. I just thought that it was for an infection and did not need to use it after. When I finished using it I did not ask for another.
This woman rated her neurological OAB symptoms on the SBS as six out of 10, a moderate burden. She had never been reviewed or treated by her neurologist for neurological OAB.

7.3.3 Management of bowel dysfunction—containment devices

Compared to bladder complaints, very few participants (n=3) stated they used disposable continence pads to assist them solely with bowel accidents. A number of participants spoke about using disposable pads for their combined bowel and bladder dysfunction. This made it difficult to obtain accurate numbers of people using disposable continence products just for their bowels.

P3(F;68): I wear Tena lady pads to catch the constant faecal staining.

P40(F;75): Once activated, it purges. It is very distressing. I pass wind and then the bowels open. I have to wear pads all the time.

P56(F;66): I wear a pad just in case.

For those participants who did not mention pad usage, but talked extensively about bowel accidents, it was assumed that pads would need to be used; however, no proof of pad usage was evident.

P57(F;68): Bowel urgency and accidents will happen, which is very distressing and horrible. The stool is thick, custard like. I don’t go out at times due to bowel concerns. It is a serious concern for me.

P23(F;56): I often have accidents at least a couple of times per day due to the uncontrolled diarrhoea. I do not seem to have any nervous control and cannot
tighten my anus. I believe it to be very relaxed and overactive. I cannot seem to tell the difference between gas and solid or liquid. I pass hot fluid with no control.

7.3.4 Management of bowel dysfunction—medications

In this population group, 40 people (59.7%) reported the need to use a pharmaceutical agent to assist them with defecation and 50 people (74.6%) used two or more drugs in combination to assist them in passing stool (see Table 7.2). Twenty Seven (40%) of people were opposed to the use of any drugs to assist with defecation. These people relied on food rich in fibre, plenty of fluids and exercise. However, they were the participants to more likely to complain in the interviews of very irregular bowel movements.

Table 7.2
Number of laxatives taken per participant (n=67)

<table>
<thead>
<tr>
<th>Number of Bowel preparations used</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>27</td>
<td>40.3</td>
</tr>
<tr>
<td>1</td>
<td>15</td>
<td>22.4</td>
</tr>
<tr>
<td>2</td>
<td>14</td>
<td>20.9</td>
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<td>3</td>
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<td>7.5</td>
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<td>6.0</td>
</tr>
<tr>
<td>5</td>
<td>2</td>
<td>3.0</td>
</tr>
<tr>
<td>Total</td>
<td>67</td>
<td>100.0</td>
</tr>
</tbody>
</table>
Medications used for constipation are known as laxatives. There are four classes of laxatives commercially available, none require a medical prescription:

1. bulking agents
2. stimulant or irritative agents
3. osmotic agents
4. stool softening agents.

Suppositories and enemas are not a separate class of laxative; they differ only in the way they are administered, via the rectum and not orally. Suppositories and enemas more often sit within the stimulant or irritative laxative class. They are separated in Figure 7.4 itemising their use.

![Laxative types used](image)

Figure 7.4 Types of laxatives used by participants

*Bulking agents.* The types of bulking agent used by 19.4% this participant group were Normacol™ and Metamucil™. These two products increase the volume of insoluble fibre in the person’s alimentary system. *Osmotic laxatives.* Macrogol, Epsom salts and Lactulose were the three osmotic laxatives reported as being used by 40.2% of
the cohort. These laxatives are made of inorganic salts or sugars. *Stool softeners.*

Coloxyl\textsuperscript{TM} was reported as being used by 20.5\% of this cohort. This medicine works by drawing water and fats towards the faeces increasing the softness of the stool. *Stimulant laxatives.* Stimulants were used by 25.3\% of participants. This class of drug stimulates the motility and secretions primarily in the large bowel. Stimulants are recommended for people who have chronically infrequent bowel actions. The preparations most often cited by the participants were Nu-lax, a mix of dried fruit with Senna, Durolax, a trade name used for Bisacodyl, or Senna and Coloxyl, a combination of stimulant and stool softener.

The osmotic laxative Macrogol was the most widely used laxative, with 27 participants using this drug. All participants taking this drug reported that they had to be very careful when using it as it created very loose stools, which they found difficult to control and caused them a great deal of anxiety. They additionally reported that their doctors and pharmacists were unable to advise them on how to administer Macrogol effectively. In response the participants reported that they took this laxative predominantly on a ‘when needed’ basis. This drug was reported to be very effective, but participants stated they had to plan social engagements around its use.

The expulsion of stool from the rectum in the form of excessive straining was raised by this participant group as being an issue that gave them considerable concern. Physiologically, these difficulties indicate the presence of a series of complex innervation problems that prohibit the expulsion of stool. In clinical practice, the need to override these innervation impediments has seen Macrogol being used to over-soften faecal matter to bypass the need to strain at stool. As a consequence, the majority of
participants reported higher incidences of faecal accidents or incontinent episodes, which restricted their movement beyond their home.

Laxatives used in combinations.

Many of the participants indicated that they often had to use more than one laxative type at any one time to initiate a single bowel movement. The numbers of laxative types, independent of dosage taken, i.e., two tablets of Triphenylmethane 5mg, are itemised in Table 7.4 and show 25 (25.9%) participants used more than one laxative type in combination.

It was not possible to present a clear statistical combination of each participant’s dosing regimen, due mainly to the high variance in the doses used per participant and their inability to clearly articulate how they decided to take their medication. They often made statements along the lines of ‘I just know when I need to’ or ‘I sometimes take x-many tablets and sometimes I do not’ or ‘It just depends on ...’. However, a relationship could be demonstrated between the use of stimulant laxatives, osmotic laxatives and suppositories via a Pearson product-moment correlation coefficient. The finding was that the participants choosing to use two or more laxative types more often used a combination of stimulant and osmotic laxatives \([r=0.250, N=67, p=0.04]\) and the three participants who used a suppository did so in combination with an oral stimulant laxative \([r=0.245, N=67, p=0.04]\). These were not the only combinations used; however, these combinations were the only ones that had produced a statistically significant relationship.

As previously stated, the vast majority of participants reported they had chosen the types of laxatives they used based on their friends’ or families’ recommendations. The osmotic agent, Macrogol was the only laxative recommended by the participants
LGP and the participants used this drug at a dose high enough to overwhelm their sphincter dyssynergia. With the exception of three participants using suppositories, no participant reported that they had been advised on the benefits of using a combination of rectal laxatives or digital stimulation; a common method of relaxing the anal sphincter and allowing a more comfortable and complete lower bowel clearance without the need to excessively strain at stool.

The participants’ reliance on the combined use of osmotic and stimulant agents made them more susceptible to frequent, uncontrolled bowel accidents, which they reported as being extremely distressing.

*P40*(F;75): *It’s very distressing. Once activated, it purges. It’s very distressing.*

*I pass wind and then the bowel opens.*

*P44*(M;64): *I feel uncomfortable and it is distressing*

*P57*(F;68): *bowel urgency and accidents do happen it is very distressing and horrible.*

The combined effect of taking a combination of stimulant and osmotic laxatives was described by a woman participant who places her incontinence at the centre of their social isolation and distress. She told a distressing account of living in a dreadful mess, soaked by both urine and faecal waste. She lamented that her home was now in such a state of great disrepair that no one, including her grandchildren, came to visit her any longer. Her carers were only employed to shower her three times per week and she had a cleaner who came in once each fortnight for two hours. She reported taking her medications from a pre-packaged Webster box that included her usual two Coloxyl and
Senna tablets, a stimulant and a stool softener, taken each morning and night. She also reported taking up to two sachets of Macrogol, an osmotic agent, each day as directed by her LGP. This woman reported constant faecal leakage and bouts of uncontrollable diarrhoea. However, when she stopped taking the medications, she became very constipated and bloated.

_P16(F;67):_ I often feel I am very smelly. I am only able to have a shower three times a week—Monday, Thursday and Friday. They are the only days the carers can come and help me.

This participant reported a good relationship with her LGP, who regularly visited her in her home. From her accounts, it must have been obvious to the LGP who was visiting her that she was having difficulties with her ongoing self-care, even if she did not raise the subject of incontinence specifically with him.

_P16(F;67):_ I do not talk to my LGP about this [incontinence]. He is so busy sorting out your other things. He has not spoken about these things to me.

Laxatives were purchased from local pharmacies and were used by the participants, as they needed them and not as a scheduled regular medicine. The vast majority took laxatives on an as needed basis, with only seven participants indicating that they took a regular laxative. More importantly, laxatives were taken irrespective of their pharmaceutical action and many of the participants stated that they chose a laxative based on a recommendation from a family member or someone they knew. No one gave an account of using a laxative according to a prescribed plan of care or based on rectifying the cause of their ineffectual bowel pattern. Consequently, conversations
were peppered by concerns of uncontrolled bowel actions, which stopped their performing daily activities and prohibited any forward planning that entailed leaving the house.

\[ P19(M;75): I \textit{sometimes don't go out due to my bowel concerns.} \]

\[ P32(F;53): \textit{This is a serious concern for me, I have to know where the next toilet is.} \]

\[ P49(M;77): \textit{Won't go on holidays due to bowel issues.} \]

\[ P57(F;68): \textit{I am afraid to go away at times.} \]

The participants also spoke of concerns about laxative dependency and stated that they did not want to take any more drugs than they needed to.

\[ P21(M;86): \textit{I have not asked my doctor because I do not want to take handfuls of pills. LGPs are chemical agents.} \]

\[ P19(M;75): \textit{I'm already overloaded with medications and do not want to take any more.} \]

For the most part, the participants were very reluctant to try new bowel medications or to routinely take any laxative as they had lost confidence in any bowel medication offered primarily due to the unpredictability of the resulting bowel movements.
P1(F;66): I am taking Movicol sachets [osmotic] to help [with the constipation] but if I take one it does nothing, if I take two or three sachets I cannot leave the house. I was told that I could take up to four sachets a day if I would like.

Anti-diarrhoeals, such as Loperamide Hydrochloride (Gastro-stop), were also used by participants to help them control the frequent bouts of loose bowel motions, primarily caused by the overuse of laxatives. The following is one example of the complexity of timings and drug combinations used by the participants to ensure a bowel movement.

P3(F;68): I use Movicol, Senna with Coloxyl and Gastro-stop. If my stool becomes very explosive, then I do not take the Movicol. If I do not pass stool in three days then I use extra Senna with Coloxyl as it works quicker than the Movicol.

On their doctors’ recommendation, 22 (32%) participants used the osmotic laxative Macrogol, traded in Australia as Movicol™. However, not one of these participants reported being given dosing instructions by their doctors. In the main, they were told to take the Macrogol according to the instructions on the box.

P17(M;70): The GP gave me a script for Movicol. He told me to take it according to the instructions. He did not advise me how best to take it and the instructions [on the box] really did not tell me very much ... No, not very useful.

P19(M;75): My GP told me to take the Movicol till I get diarrhoea and then back off. I did not know what he meant by back off. I really did not want to lose control of my bowels, you know, to be so runny, so I did not take it.
7.4 Bowel and bladder dysfunction as described by people with PD

The bowel and bladder symptoms described by participants were clinically very complex and without a clinical examination that included urodynamic or anorectal studies, a primary cause and diagnosis is difficult to ascertain with any certainty. However, the clinical picture described by the participants aligns their bowel and bladder dysfunctions with neurological disease more clearly than with age, dietary decline or the side effects of pharmaceutical agents taken.

Studies on neurological constipation by Abbott et al. (2001), Kaye et al. (2006) and Sakakibara et al. (2008) and on neurological OAB by Palleschi et al. (2006) and Iacovelli et al. (2010) have all stressed that neurological dysfunction of PD should be regarded by clinicians as having aetiological dominance over all toileting difficulties, especially regarding their management. However, the clinical interventions offered to participants in this study lacked a neurological focus.

Very few participants sought assistance from allied health practitioners. The three participants who did speak to a dietician stated they too felt their PD was not taken into account; stating that this offer of health information was so basic that they felt very frustrated. Other participants referred to this information as not useful, as most of this advice had already been implemented and found to be unhelpful.

P1(F;66): I spoke to the dietician, who told me to eat foods high in fibre, which I do every day. I’ve tried unprocessed bran, Weet-Bix, bread, nuts, fresh fruit and veg. I am desperate for an answer of what else I can do.
P67(M;73): I do! I eat lots of fruit, drink water, camomile tea, green tea and coffee [and still] there is a lot of straining, it takes me so much effort. My poo is quite soft. I think this is why I have a lot of trouble pushing it out.

P9(M;64): He [LGP] told me to keep drinking and eating your vegies. It was my pharmacist who recommended Coloxyl.

P15(F;73): I was told that I need to drink plenty, I do! I drink up to 11 drinks per day ... and I take prune juice!

P17(M;70): The dietician at the hospital gave me a pamphlet on increasing my fibre, fruit and vegetables and fluid. She told me to drink more and use psyllium husk and digestive rusks as well as Sultana Bran. They actually thought I did not already know this.

The management of bowel or bladder dysfunction in PD stands in stark contrast to other neurological diseases or injuries. The clinical profile of neurological dyssynergia presents as an obstructive problem, which requires the participant to exert excessively high pressures to override the contracted outlet sphincter. Of the 56 participants reporting defecation difficulties, 91% stated their straining at stool was a considerable problem. Of the 62 participants reporting urinary dysfunction, 40% reported initiation difficulties, which required them to strain.

Based on these reports, a clinical profile of neurological outlet dysfunction fits better with the evidence than the standard clinical approach which preferences age-related, slow gut transition times, decreased bladder storage, or being a consequence of prescribed or OTC medications.
Iatrogenicly induced constipation was widely reported to have influenced the treatment and management options offered to this particular group. Participants reported being offered a very narrow range of advice and treatments related to increasing dietary fibre, to maintaining a good fluid intake and to undertaking a daily exercise regime. However, this basic advice was not expanded upon and, as a consequence, very little efficacious clinical support was obtained.

**7.5 Burden of bowel and bladder complaints**

Qualitative data collected in the interviews suggests that this participant group is resilient. Many participants demonstrated great adaptive skills used in response to the stresses imposed by their bowel and bladder symptoms. The entire group reported that bowel or bladder dysfunction was extremely harrowing to deal with and often required them to take stock, re-evaluate and redefine themselves. The participants often declared in interviews that they felt very alone, primarily as these symptoms were difficult topics to raise with other people. Several participants approached their symptoms as a challenge to be worked through in a logical way, with or without the aid of their doctors. Others described their symptoms as being so degrading and humiliating that they were unable to raise the subject at all and chose to retreat into the safety of their homes.

*P20(M;65): I have not directly spoken to my doctor [about bowel or bladder dysfunction].*

*P15(F;73): I am sure doctors do not realise what you go through. I have now stopped taking everything, I have given up.*
P14(F;63): I am very embarrassed and do not think I can speak frankly to the doctor to ask for help.

It was noted that participants explored the constructs of adaptation, adjustment and resilience in either an explicitly cogitative way or from a more philosophical or spiritual basis. Some participants used faith to assist them in dealing with the emotional effort they needed in order to get up each morning. The resulting social isolation was also reported widely by the participants.

P1(F;66): My lifestyle has altered so much. I used to go out all the time before I was diagnosed with PD. I was also very involved in volunteer work, arts and craft, but I have had to give that all up.

P2(F;75): Much more changes since PD diagnosis. Within six months of diagnosis you notice significant changes.

The participants also presented a strong argument about protecting others, shielding them from the harrowing effect their disease was creating. At other times it was not what was said, but rather the context and manner in which the dialogue took place, that prompted the researcher to draw conclusions about intent and meaning.

P10(F;67): [reflective notes] She had accepted her lot in life. She made no changes and requested no assistance.

P12(M;66): I predominantly deal with it myself. It is no good sharing it with everybody.
*P65(M;81): I do not speak to friends [about my problems] as I do not want to be a bore or worry them. I protect them; I do not tell them everything.*

The participant group generated a picture of protecting others and secreting information, because they did not think anyone could help or that people would think less of them. Some participants even spoke about shielding the doctor from the existence of their bowel and bladder symptoms. The consensus was that bowel or bladder dysfunction was not something that their LGP needed to hear about, or that their bowel or bladder dysfunction was a minor issue and the doctor needed to concentrate on much more important things.

### 7.6 Summary

This chapter has investigated the two open ended questions posed to them during the interview. The first question asked if the participant had asked anyone for help or assistance in regard to their bowel or bladder dysfunction, and the second question asked the participants about the types of treatments or products they had used in an effort to ameliorate these presiding difficulties. The main findings of this chapter were that the participants’ satisfaction of either the medical services they received, and of the medications and continence products they used, did not provide them with the level of support and social confidence they wanted or expected to receive.

The participants viewed their LGP as being their primary source of support and all had very high expectations of the type of service they required. Their stories highlighted difficulties each participant had both in initially raising the subject of bowel and bladder problems and then revisiting this same subject when the suggested
management or interventions undertaken did not resolve or reduce the burdensomeness of the symptoms.

The participants’ stories emphasised a high degree of confusion stemming from these same symptoms origin. This aetiological confusion gave rise to participants’ questioning the medical legitimacy of their bowel and bladder dysfunction, and as a result many actively withheld information, which they saw as embarrassing or unworthy of their doctors’ attention. Bowel or bladder symptoms appeared to be a difficult topic for these participants to mention to their doctors, especially when they believe that their doctors would not regard these symptoms as important when compared to their other more legitimate health issues.

Toileting difficulties and behaviours were viewed as a taboo subject that created conversational discomfort between the individual and their doctors, even when the participants stated they had an established good and trusting relationship with their LGP. The participants used the word *embarrassment* to convey numerous and strong feelings about this taboo subject. The word *embarrassment* was used by the group to convey their feelings of burden, a weight they all said was made heavier by the constant and unpredictable threat of incontinence and their realisation that they were expected to bear it alone. It was also used to convey their feelings of helplessness and frustration in not being able to manage these symptoms in the same way they knew other people without PD did.

Notably, the participants informed the study that their bowel symptoms were resistant to the basic management methods recommended to people with non-neurological chronic constipation, such as increasing fluid, fibre and exercise. The group reported that this necessitated the use of a variety of laxatives and incontinence
pads both of which created further burdens. The laxatives, mostly sourced and administered independent of medical advice, created cyclical bouts of diarrhoea, which necessitated the implementation of socially restrictive practices. The financial burden of purchasing disposable continence and menstrual pads was also spoken about by participants in this study as of major concern. A basic cost for a pack of 14 sanitary pads is currently around $6, the participants’ on averaged used between two and four pads each day. This equates to $50 each month, a substantial cost for any person on a fixed income such as a pension. The participants using pads had mentioned this to their LGP’s, yet only three people stated they were aware of the continence assistance program, a government initiative that financially supports people with neurological incontinence in making continence related purchases. The LGP’s were also noted as not referring any of their patients to continence-related allied health specialists such as dieticians, continence nurse advisors or continence physiotherapists. These continence-related allied health specialists would be more likely to have knowledge of financial schemes that assist people with the cost of purchasing products, as well as being able to offer the person with urinary incontinence and chronic constipation with a very specific range of treatment options. However, the participants stated that their PD already created a great burden on their lifestyle and that if they allowed it, their life would be consumed by attending numerous health appointments and that they would have little time left to pursue more enjoyable activities.

The unpredictability of the participants’ bowel and bladder dysfunctions and their poor access to the information and support they believed they needed was identified by this group of people as creating feelings of being overwhelmed, out of control and burdened. Participants indicated that they did not like to alert or worry other
people about their troubles and in doing so restricted their ability to obtain additional and useful information. They were hesitant to classify their bowel and bladder dysfunctions as incontinence and in not relating to the term *incontinence* could have led to them not accessing the continence information or services available on-line or through local health services. This reluctance to identify with incontinence or to talk with others about their toileting problems saw many participants retreat to their homes or well-known local venues where they felt safe and close to toilets.
Chapter 8: Discussion

This study extends current knowledge around two very common NMS, bowel and bladder dysfunction, affecting people who have the degenerative neurological disease PD. All 67 of the people who participated in this study reported that they had trouble managing their toileting needs. They identified constipation and emptying their bladder more frequently than they felt was reasonable as a particular problem to be endured and managed. The research design centralised the voices of people with PD and in so doing, revealed their concerns about the effects that bowel and bladder dysfunction have on their quality of life, regardless of their age, and the burden associated with living with these challenges. Despite the involvement of health practitioners in advising and treating people with PD, these chronic and progressive symptoms of neurological dysfunction fit more appropriately within a construct of disability rather than being conceptualised as a treatable health concern or as a degenerative process commonly associated with ageing.

The participants’ major concerns are used to guide the flow of discussion within this chapter and to continue the emphasis of this research on the primacy of their experiences since receiving their PD diagnosis. Through a synthesis of participants’ stories and the distillation of their experiences and perceptions, it has been possible to gain insights about factors that motivate or limit their approach to, and management of, their bowel and bladder dysfunction. These factors are used to illuminate the process participants used in deciding on how best to respond to the reality of their bowel and bladder symptoms. The three major concepts incorporating the factors are:

1. The presence and legitimacy of the symptoms experienced by participants
2. The participants’ use of and search for additional personal resources
3. Burdens and quality of life disruptions created by symptoms and the search for help.

Discussion of key research findings is structured around these concepts and focuses on explaining the meaning of participants’ collective wisdom and experiences. The study’s strengths, methodological effectiveness, methodological limitations and future research possibilities are also included here along with implications for practice, service provision and further study.

8.1 Presence and legitimacy of symptoms experienced by participants

8.1.1 Symptom presence

The prevalence and pathophysiology of bowel and bladder dysfunctions in PD is commonly known among health practitioners, but until recently it has not been well researched nor described (Kaye et al., 2006; Mehndiratta et al., 2011; Sakakibara et al., 2008; Sakakibara et al., 2012). Even so, attention has been focused by these researchers on the high incidence of these symptoms in populations of people with PD, citing estimates of between 45% to 90% for LUTS (Sakakibara et al., 2012), and reports of up to 80% for bowel dysfunction (Gao et al., 2011; Kishi et al., 2011; Pfeiffer, 2011).

8.1.1.1 Bowel symptoms

The bowel symptoms identified by 83% of the total participant group were diarrhoea (13%) and constipation (83%). Participants’ stories of diarrhoea suggest that this symptom exists in relation to their level of understanding of the processes involved in digestion of food and the origin of various symptoms. Many were not aware that the diarrhoea was being triggered by their use of irregular and very high doses of laxatives they used to overcome their frequently occurring constipation. All participants
identified excessive time spent straining at stool as a component of their constipation difficulties, indicating neurological dyssynergia as being the major clinical indicator rather than the length of time between bowel movements. Constipation clearly creates a significant burden for participants, with 73% rating its burden as being either high or extremely high.

8.1.1.2 Bladder symptoms

Combinations of four bladder symptoms were identified by 92.5% of the total participant group, 63% of this group had had their bladder dysfunction categorised as over active bladder (OAB) syndrome. Researchers have associated the incidence of OAB strongly with older women (Lapitan & Chye, 2001; Milsom et al., 2001; Stewart et al. 2003; Temml et al., 2005; and Sims et al., 2011). In this participant group neither gender nor age were found to be significant contributors, possibly highlighting the neuropathophysiology of PD (Iacovelli et al., 2010; Sakakibara et al., 2008; and Walter et al., 2006) as the principal catalyst for their OAB occurrence.

8.1.1.3 Combined bowel and bladder dysfunction

The majority of participants (72%) reported a combined presentation of bowel and bladder dysfunction which is also referred to as double incontinence (DI). The occurrence of DI among participants is higher than results of between 3% and 15% found in reviewed community incontinence prevalence studies of people who were over 80 years of age and who had high levels of frailty and an inability to self-care (Teunissen, van den Bosch, van den Hoogen & Lagro-Janssen, 2004; Santos & Santos, 2011; Slicker-ten Hove et al., 2010 and Stenzeliu, Mattiasson, Hallberg & Westergren, 2004). There was no evidence in the current study that functional self-care deficits or severe disability were occurring in the presence of DI among participants, a finding that
supports a conclusion that a neurological aetiology to bowel and bladder dysfunction is more likely than any other DI causal factor.

Participants reported that these bowel and bladder symptoms resulted in frequent episodes of incontinence, which they referred to as ‘accidents’. All reported that their toileting difficulties were burdensome and everyone had, in some way, altered their environment, clothing and social life to accommodate the unpredictability of their bowel and bladder events. They further reported that efforts to obtain practical and helpful information were thwarted by the added pressures of having to make time to see different doctors, trialling new products and needing to take more medications, all of which were regarded by participants as adding to their existing burdens. The frustration expressed by participants revolved around their belief that toilet problems, constipation and urinary urgency and frequency, should be an easy problem to fix, primarily because they regarded going to the toilet as a fundamental human need. They were also cognisant these symptoms are experienced by many of their peers who do not have PD, yet unlike themselves their peers did not seem to be as restricted by these same symptoms as they are.

8.2 Legitimacy of bowel and bladder concerns

The reality of experiencing bowel and bladder dysfunction is ever present for people with PD; however legitimacy of the experience can depend on acknowledgement from others who observe the person with the dysfunction. Pearson, Tucker, Bolt et al., (2002); and St. John et al., (2010) proposed that symptom legitimacy is an important factor in a person’s decision whether or not to raise discussion of its existence with a health professional. Symptom legitimacy can also be supported by accessing knowledge
about the symptom and its aetiology (Gallagher et al., 2010; Gallagher, Donoghue, Chenoweth & Stein-Parbury, 2008; and O’Sullivan et al., 2008). The participants in this study did not have access to such knowledge and attributed their bowel and bladder dysfunctions primarily to their age and gender, both of which are unchangeable key determinants of health. Some blamed their diet or prescribed PD medications as causal factors. Low levels of health literacy and understanding about PD was identified by the participants as a major reason for not raising or more actively pursuing their concerns about bowel and bladder dysfunctions with their doctors. Partly the reason for not doing so was their difficulty in finding the words to discuss this embarrassing topic, but also participants expressed concern over the ‘worthiness’ of their symptoms in relation to medical attention. This internalised debate between what constituted a ‘proper’ medical concern and what did not seems to reflect participant desires to test the importance of symptoms prior to raising the subject with their doctor.

Participants reported in Chapter Five that they were reasonably healthy even though they experienced significant disability. The participants referred to their bowel and bladder dysfunctions as disabling factors which they perceived to be commonly associated with normal ageing. Unsurprisingly, people are unlikely to raise issues of disability with their doctors and instead, voluntarily restrict conversations within this vitally important interaction to legitimate health and disease related subjects (Duggan, Bradshaw, & Altman, 2010; Frosch, May, Rendle, Tietbohl, & Elwyn, 2012). Similar findings to this research were discussed by Paul, Ayis, and Ebrahim (2007) and Rothermund and Brandtstädt (2003) who found that people were more likely to draw on their own resources to make lifestyle adaptations to disabilities, and be more willing to alter their life goals rather than seek outside help. It was found that only when a
person’s concerns incrementally increased beyond their ability to cope did they seek assistance. In accord, participants in this study reported that it was only when bowel and bladder symptoms negatively influenced their ability to actively participate in social activities, and only when they had exhausted all-available resources to deal with the symptoms, did they seek advice. All members of the participant group expressed ambivalence about their symptoms’ legitimacy as proper health concerns.

8.3 Burdens and quality of life disruptions created by bowel and bladder dysfunctions and the search for help

Throughout the study, participants reported that they had made what they believe to be significant changes to their lifestyle and personal goals. They expressed the extreme lengths to which they had gone to in making these adaptive changes, and the results in Chapters Six and Seven show that it was only when they had tried everything they could to resolve the distress caused by these symptoms, did they approach their doctors for assistance. This may explain participants’ negative satisfaction rating of medical services (see Chapter Seven for detailed results), as they believed that they had already found and tried most of the basic advice offered by their doctors or allied health services and were unwilling to pursue that line of enquiry again.

Participants stated unequivocally that they were burdened by self-imposed restrictions made in response to these symptoms and this burden seemed heavier as they were no longer able to participate in activities that they understood to be part of normal life. Participants reported that these self-imposed restrictions originated from factors in their environmental and personal context; factors identified in the ICF framework as either a limiter or enhancer of a person’s ability to manage their bodily functions and to
participate in life activities (Rejeski, Ip, Marsh, Miller, & Farmer, 2008; WHO, 2001). Environmental factors, according to the ICF, are factors beyond the individual’s locus of control. Participants acknowledged that they had a knowledge deficit, particularly in relation to finding resources that could help them to manage their symptoms; this, together with their lack of confidence in the laxatives and containment products (pads) they used were all perceived as creating higher levels of burden. These external factors were compounded by the participants’ personal attitudes towards their bladder and bowel symptoms, which they regarded as being socially embarrassing and loathsome. It is likely that these negative personal factors inhibited any effective problem solving discussions between the participants and their doctors, and reinforced participants’ evaluation of these symptoms as being unworthy of their doctor’s professional interest. Consequently, participants found they needed to draw upon their own personal resources, referred to by the ICF as personal contextual factors. Personal contextual factors are greatly influenced by the individual’s cultural and educational background and enable a person to be guided during times of adversity (Rejeski et al., 2008; WHO, 2001). The excessive efforts towards self-reliance employed by participants when choosing containment devises and laxatives were described in detail throughout Chapter Seven.

8.4 Difficulties encountered when asking for help

Participants expressed very strong opinions during their interviews and these tended to frame their expectations of health professionals. The combined influences of not wanting to disturb or burden others with what the participants regarded as socially embarrassing problems, together with their attempts at self-management, led them to instigate poorly-informed treatments that often imposed further burden and social
restrictions. Because of the taboos associated with discussing toileting difficulties and toileting behaviours participants admitted to avoiding subjects known to create conversational discomfort (Elenskaia et al., 2011) and in this study the discomfort associated with raising such topics significantly inhibited them from pursuing discussions with their doctors about ongoing bowel or bladder problems. Much of this would have occurred without their doctors realising the difficulties their patients faced.

Edwards and Jones (2001) in their UK study of older people residing in private homes also found high rates (54%) of people with faecal incontinence choosing not to discuss this problem with their doctors. This widespread reluctance to converse on bowel and bladder problems has been reported to affect the type and amount of bathroom-based research, along with a current lack of clinical attention being given to toileting dysfunction (Bradway, 2003; Landefeld et al., 2008; and Milsom, Abrams et al., 2001). Studies conducted by Ueda, Tamaki, Kageyama, Yoshimura and Yoshida (2000), Cochran (2000), Milsom, Abrams, Cardozo, Roberts, Thuroff and Wein (2001), Kaye et al. (2006) and Zesiewicz et al. (2010) on incontinence, also found high rates of medical non-involvement. However, these and subsequent studies have neglected to investigate why bowel or bladder dysfunctions remain largely unreported and under-researched, even when the evidence establishes this line of enquiry as being important. To date, there has been limited research focused on why people do not report disturbing bowel or bladder symptoms to their doctors.

The current study found that many more participants stated that they had made an initial report of their bowel (67%) or bladder (54%) difficulties to their doctors when compared to the reviewed research which estimates that only 12-35% of people with incontinence report its occurrence (Buckley & Lapitan, 2010; Fritel, Panjo, Varnoux, &
Evidence of reporting trends can be found in recent data compiled by the Australian Institute of Health and Welfare (AIHW, 2012) showing a rise of thirty thousand Medicare payments for medical specialist consultations specifying bladder incontinence between 2003 and for the year 2008-2009. Interestingly, Medicare payments for local general medical practitioner (LGP) consultations, for specified bladder incontinence, rose by a mere two thousand visits across this same five-year period. The report did not include data for bowel incontinence. The participants in the current study also talked about having been referred to multiple medical specialists for their bowel or bladder problems.

Following their consultations with these medical specialists the participants became even more ambivalent about the legitimacy of their symptoms, especially as they did not receive the response or information they had expected. Many participants talked about sourcing information from others with PD via PD support groups, from local pharmacies and three male participants spoke of using their female partners to broker information and purchase continence products on their behalf.

However, it was when these informal resources could no longer assist the participant that their level of anxiety and burden seemed to be more severe. In one participant’s report of bowel dysfunction, in which he reported his burden level as being 8 out of a possible 10, stated that he was left in a quandary as his main support person was also at a loss.
8.5 Key research findings

8.5.1 Wisdom gleaned from participants’ experiences and collective insights

From first-hand experience, the participants have pursued information and strategies and have gained considerable insights on what was happening to their bodies as a result of PD. They were able to describe in biological terms, their bladder and bowel dysfunctions in terms that align with the known PD neuropathophysiology affecting the ENS and ANS pathways. They depicted their constipation and OAB symptoms as resulting from a paradoxical dyssyneria of the pelvic floor muscles and their external anal and bladder sphincters. Their vivid descriptions of excessive straining, regardless of stool formation and their detrusor hyperreflexia, unstable bladder storage and emptying were consistent with known pathophysiological mechanisms. Participants also deduced that their episodes of dyskinesia were directly linked to their bowel and bladder dysfunction, although they were not able to discern which one caused the other. They were convinced that the abdominal discomfort they experienced when they needed to go to the toilet to empty their bowel or bladder exacerbated their gait problems. Notably, participants acknowledged that these symptoms defied the basic management methods recommended to people with non-neurological chronic constipation, such as increasing fluid, fibre and exercise, and persisted despite following this advice. Similarly, further burden was associated with managing and taking a variety of medications, laxatives or in using containment devices such as incontinence pads. All participants reported that the manifestation and management of these autonomic NMS significantly heightened their burden and distorted their quality of life. Participant insights on key biological changes and linkages between biological systems indicated that they understand what is happening and
continue to search for solutions that will relieve the burden of PD symptoms. Their contribution to understanding the specific clustering of autonomic NMS in otherwise well adults, addresses a gap in medical research where this phenomenon associated with PD is currently not well described nor acknowledged.

Significant psychological disruption was reported by study participants who described their bladder and bowel dysfunctions as creating high levels of anxiety and accentuating their emotional distress. The participants considered their concerns and lifestyle options to be dominated by disempowering and highly emotional thoughts about their bowel and bladder disturbances. Living with these NMS was likened to having a full time job, one that required them to traverse unfamiliar medical terrain populated with people they held in high regard but who spoke a different language and whose actions seemed to be governed by processes beyond their understanding. It is not surprising that participants tended to withhold information they believed to be distasteful or not really a health issue. These cultural divides were not fully understood and therefore not resolved by the patients or their doctors and this could explain the high levels of dissatisfaction expressed by participants. The consequences of not discussing symptoms with their doctor also impacted on their ability to obtain relevant resources. Australian government web sites and the Australian Continence Foundations helpline were not accessed by participants nor were continence services which are available at most local hospitals. The reason contributing to participants not accessing these resources was their refusal to accept themselves as being incontinent, preferring instead to put in place socially restrictive practices to avoid exposure.

The uncertainty and unpredictability of leakage events caused most of the social disruptions reported by participants. Because only six of them stated they were
incontinent, it is possible that the remaining participants had not accessed continence specific resources, as they did not consider their leakage events as indications of incontinence. None spoke of accessing web based material such as the Bowel and Bladder Government website or the Australian Continence Foundations helpline and the apparent meagre use of continence services could have resulted in the participants reporting burdens associated with access to financial and social resources. All participants indicated that they felt excessively burdened by the possibility of being incontinent in public, an occurrence that they viewed as appalling and intolerable. Very few reported social isolation, rather they spoke of restricting their activities to familiar, local places close to their home. Again, the insights provided through this research on psychological and social effects of incontinence, contribute to medical research by conveying an understanding not previously described or acknowledged in any form about people with PD and experience of living with these two pervasive NMS.

Throughout the interviews participants expressed their deep-seated frustration about how little they knew and how ineffectually they were managing their neurological constipation and OAB. They spoke of the difficulties in accessing appropriate information that they believed could assist them in managing their bowel and bladder dysfunctions. The information they were able to access provided them with basic dietary and fluid management information, but left them wanting more specific information on intervention options. The participants also believed that for their doctors to be able to advise and recommend management plans for them to follow, these doctors would need to be better informed as well.
8.5.2 Key findings

The first key finding is that the signs and symptoms of constipation and OAB for these people are often mistaken as consequences and influences commonly associated with biological age rather than directly linked to their PD. The review of the literature presented in Chapter Two highlighted the extent to which misunderstandings about the processes of biological ageing frames current knowledge and management of both PD and incontinence constructs and in doing so limits the approach and attitudes taken by both the sufferer and their health care provider. In identifying this as a deficit, this study contextualised both PD and incontinence within a disability construct and in doing so was able to separate age bias from its analysis of these symptom presentations.

As a result of this approach the second key finding was identified, that is, that the physical burdens of chronic constipation and incontinence as described by these people were of significantly greater concern than what would be considered usual in non-PD populations. The people in this study identified high rates of occurrence and degrees of severity in response to the presence of these symptoms as reported in Chapter Five. The exploration of how these symptoms disturbed the QoL for each participant became evident in terms of the impact of these symptoms across many more areas of the participants’ life than would normally have been expected if their causation was unrelated to their PD as reported in Chapter Six. Participants were then able to distinctly voice their concerns about the degree of physical burden these symptoms had in comparison to what they believed their peer group experienced.

The third key finding identified was that symptom relief is rarely achieved via conventional management practices employed to treat the more common, age related chronic constipation and urinary incontinence. Participants identified the treatments
they used as being similar to those used for any person with these same symptoms from any cause. The participants stated that the treatments they used did not provide them with any relief, instead they created additional burdens for them (see Chapter Seven).

This finding highlights the impact of failing to identify the neurological aetiology of PD and its resulting bowel and bladder dysfunction. The outcome of not implementing a more intensively regulated neurologically focused treatment plan caused these people to be less able to adequately resolve the negative impact of symptoms. Interestingly GPs seemed to be unaware of the ineffectiveness of these management strategies, because the participants themselves admitted that they did not raise these treatment failures with them. This situation was further complicated by the participants’ doctors who were reported as not following-up on the efficacy of their given management suggestions. Participants then incorrectly interpreted this clinical deficit as an indication that these symptoms were not medically important.

The physical presence of symptoms and lack of effective management strategies accessed by the participants is the fourth key finding: that the presence of constipation and OAB, as described by them, creates a substantial psychological burden. This psychological burden was expressed by the participants as causing high levels of anxiety and emotional distress, more than they experienced with any of their other PD NMS. This finding highlights the importance of disease knowledge and symptom legitimacy, both of which were raised in the review of literature and again in Chapter Seven. In particular, the importance of acknowledging the primacy of aetiological factors creating the pathophysiology is stressed, thereby legitimising the importance of the symptoms and the attention needed to manage them effectively.
The participants responded to symptom-related anxiety and emotional distress by restricting their movements beyond the home. This situation was viewed by them as the only method they could use to reduce their stressors and as such has been noted as the fifth key finding: that people with PD adopt self-imposed social restrictions in response to the unpredictable nature of their chronic constipation and OAB. They further stated that even though these self-imposed restrictions were effective, they had a dramatic effect on each person’s ability to fully participate in social and lifestyle activities and as a consequence negatively affected their quality of life.

The final and sixth key finding relates to their ability to source information and assistance. Participants’ ability to source helpful resources was significantly impaired by their preconceived attitudes toward constipation and urinary incontinence and their evaluation of what constitutes a legitimate health concern. The participants did not regard their toileting problems as incontinence and therefore did not think to utilise specialist continence services or access Internet information and material. They were also concerned about becoming dominated by the medical activities related to managing their PD, which they saw as having the potential of taking over their life similar to a full time job. The participants were also cognisant of the needs of their spouse and families and were hesitant not to over-burden them or reduce their social movements. The combination of the above factors ensured that participants remained in a state of disequilibrium that was reinforced by the continued, unpredictable nature of their bowel and bladder dysfunction.
8.6 Limitations and strengths of the study

8.6.1 Strengths

The strength of this study begins with the importance of the topic explored, not just for the scientific and clinical communities, but for the participants themselves. Without exception, each participant stated on joining the research that the daily hardships they endured were insignificant compared with the trauma of not being able to use a toilet in the manner they wished. Their only request was that the findings of this study be used to raise the profile of these symptoms and to assist others like them to find more effective ways to resolve these toileting predicaments. A further strength is the mixed method converged design that allowed the research to focus on burden as the key issue, while ensuring the voices of participants were heard at all times through the research process. Other methodological approaches were considered, but none offered the comprehensiveness and flexibility needed to explore such new ground.

The use of both quantitative and qualitative data collection methods provided significant opportunity to identify common issues associated with the physical presence of symptoms and the consequent burden they created for the individuals as they cope with various disturbed aspects of their QoL. It was only when these data sets were converged and contrasted through the conceptual framework of disability, rather than by referencing conventional health and treatment paradigms, did the true nature of participants' burden and QoL become apparent. The benefit of looking at bowel and bladder dysfunction from a disability rather from a health construct enabled the study to identify the origin of burden and how participants made lifestyle adaptations to compensate. The use of the ICF Framework enabled the study to explore participants’ bowel and bladder dysfunctions in terms of their physical presence, how these
dysfunctions affected their ability to complete self-care activities and finally, how their inability to complete self-care activities disrupted their community participation and life quality. Moreover, this conceptual framework supported the exploration of internal and external influential factors with equal importance; for instance, participants’ attitudes towards their body’s structural and functional deficits and the broader shared societal attitudes and approaches to health management, all of which shaped the participants’ perceptions of burden and interpretation of their QoL.

By asking participants to score their perception of burden, and then using that score to incorporate their personal experience, the voices of participants remained central and influential in all stages of data collection, data analysis and data interpretation.

8.6.2 Limitations

The challenges of researching a poorly understood and relatively unpopular topic with a group of people at various stages of PD were known from the outset and efforts were made at each stage to ensure research rigour. The sample was drawn from a self-selected group of individuals interested in speaking to the researcher about their bowel and bladder dysfunction; however it is not known if more participants would have provided divergent or confirming insights. By talking with people with a deep personal experience of the research topic, the research outputs focused on the expressions and concerns of these participants whose views and issues may not be the same for others with PD (Collins et al., 2007). The issue of applicability of results to a wider group of people with PD does not arise in ethnography and this may be a limitation of the study that could be overcome with a multi-site, combined data analysis.
Even so, the results of this study highlight the issues of personal burden associated with PD and therefore contribute a foundation for further investigation.

The study chose not to approach bowel and bladder dysfunction from a definitional basis of incontinence, and as such no specific incontinence outcome measurement tools were used. The rationale was that many participants refused to label their bladder and bowel dysfunction using this term and would have been disenfranchised from the study if incontinence details were more broadly addressed and data collection focused specifically on incontinence. The study’s exploratory approach to this unexplored subject required a broader initial look and the decision to collect a more personalised description of these burdensome symptoms. Useful results from the study include the discovery of an association between constipation, pain and mobility which would not have been revealed if bowel dysfunction had been explored using a standardised incontinence assessment tool.

The large amount of data collected was found to cover similar ground several times. It was felt that these aspects of similarity were important in understanding this previously under researched topic and proved valuable in confirming and validating the data collected from all possible sources.

8.7 Recommendations for future research and clinical practice

The participants raised some interesting and important issues that were outside the scope of this study’s research scope; however, they suggest opportunities for related research opportunities and the future development of clinical tools.

The study adapted a commonly used pain severity rating scale to assist participants in numerically estimating the burden severity their bowel or bladder symptom created. The participants found this tool very useful and it is suggested that
this numerical rating scale be further investigated and validated beyond that of its
current use as a pain scale.

This study’s participants together with the wider medical literature have raised
the need for further clinical research and the provision of clinical management
guidelines. The plethora of antecedent clinical management based on subjective
professional experience and small poorly designed empirical studies dominate the
medical literature and provide less than reliable bases from which neurological bowel
and bladder guidelines can be constructed. According to the most recent Cochrane
review of neurological bowel management (Coggrave, Wiesel, & Norton, 2009) and the
American Academy of Neurology review of neurological OAB (Zesiewicz et al., 2010),
it remains impossible to draw any conclusions on the best practice for managing
neurologically induced constipation and OAB as research in this area is deficient in
reducing problems in obtaining a comfortable and an effective bowel emptying. Both
of these reviews support results from the current study in that there is a need for sound
multidisciplinary research to be conducted, as currently only non-empirical practice
governs the approach to managing both of these significant autonomic non-motor
symptoms. Research such as this may also provide important information useful to
others with degenerative neurological diseases, such as multiple sclerosis. Without
evidence-based practice guidelines, health professionals and their patients will continue
to draw on their personal resources and experience to guide their approach to
management without expert advice and guidance.

In response to participants' concerns regarding symptom legitimacy, the
development of self-care planning information tools, about neurological based
constipation and OAB management for people PD are required. These tools would
ensure that these people remain independent and successful in self-care and have enough information to confidently begin conversations with their doctors about these common symptoms. Such information would need to include the types of pharmaceutical agents available, and how individuals can safely use them without risking unplanned and unpredictable episodes of incontinence. To reduce personal burdens these resources would also need to include how people with PD can access financial as well as specialist continence support.

Participant insights on the relationship between their diurnal mental alertness and focus and their sleep disturbances as they related to multiple wakes overnight to void (nocturia) also offer potential research opportunities. This study found little statistical support that enabled any inferences to be drawn between these factors, especially for those who woke multiple times to void over-night and who reported concerns about their daytime mental alertness. This relationship warrants further investigation as it remains unexplored and poorly understood.

No participant in this study raised concerns regarding intimacy within their relationships; most answered this question as part of the NMSS saying that they were no longer sexually active or that they had no problems in this area. However, in the interview their reports of moving from their marital bed as a consequence of their nocturnal wakefulness suggest that this topic was under approached by the study. While intimacy was not the focus of an examination in this study it remains a topic of interest. It is highlighted as a potential area of research interest as incontinence is known to change the way people perceive themselves sexually and therefore warrants further investigation.
8.8 Conclusions

This study explored two personally burdensome autonomic NMS, constipation and OAB reported to affect 80% of all people who have PD, a degenerative neurological disease that affects 1% of the Australian population over the age of 60 years. Through a mixed method design this research was able to explore previously under researched aspects of the life experience of people with PD. The analysis converged interview and statistical data with participant estimations of personal burden levels to ensure that views of their experiences remained the central focus. The results reveal novel and informative insights on the level of information these people have about their changing biological responses; their strategies for coping unassisted with symptom management; and the adaptive choices they made in order to maintain their dignity and demeanour within their social contexts.

The people participating in this study, prior to their PD diagnosis, led a diverse, disability free and satisfying adulthood from which they enjoyed a successful, community-based life full of family, social and vocational achievements. For the most part, the participants spoke of entering a time in their lives where they had to re-draw their life plans from that of transitioning comfortably into their ‘evening years’ made up of activities of their choosing without the financial pressures of raising young families. In contrast, they now viewed these ‘evening years’ as full of trepidation and concern.


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### Group 1: The individual with PD’s experience of burden (n5)

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<td>Hackney ME; Earhart GM; (2010)</td>
<td>Effects of dance on balance and gait in severe Parkinson disease: a case study. Disability &amp; Rehabilitation, 32 (8): 679-84</td>
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<td>Lau, Kam-Mei; Au, Alma (2011)</td>
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<td>Quality of life, caregiver burden and insurance in patients with Parkinson’s disease in Germany.</td>
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<td>McLennon SM; Habermann B; Davis LL (2010)</td>
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<td>Tokunaga S; Washio M; Miyabayashi I; Fortin E; Shin Y; Arai Y; (2009)</td>
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<td>Williams S; Keady J; (2008)</td>
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<td>Di Fazio I; Franzoni S; Frisoni GB; Gatti S; Cornali C; Stolfier PM; Trabucchi M; (2006)</td>
<td>Predictive role of single diseases and their combination on recovery of balance and gait in disabled elderly patients.</td>
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<td>Kim HJ, Park SY, Cho YJ, Hong KS, Cho JY, Seo SY, et al. (2009).</td>
<td>Nonmotor symptoms in de novo Parkinson disease before and after dopaminergic treatment.</td>
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<td>Takeda Y; Kuroiwa Y; Watabe S; Gokita K; Chuman T; Wang L; Li M; Toda H; Kamitani T; Omoto S; et al.</td>
<td><em>Journal of the Neurological Sciences</em>, 287, 200-4.</td>
<td>N=23D Carers Spouse Other</td>
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Appendix B
PDQ-39 Questionnaire

**PDQ-39 QUESTIONNAIRE**

Please complete the following

*Please tick *one* box for each question*

**Due to having Parkinson’s disease, how often during the last month have you...**

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<th>Occasionally</th>
<th>Sometimes</th>
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*Please check that you have ticked *one* box for each question* before going on to the next page
| Due to having Parkinson's disease, how often during the last month have you... | Please tick one box for each question |
|---|---|---|---|---|---|
| 14 Had problems writing clearly? | Never | Occasionally | Sometimes | Often | Always or cannot do at all |
| 15 Had difficulty cutting up your food? | | | | | |
| 16 Had difficulty holding a drink without spilling it? | | | | | |
| 17 Felt depressed? | | | | | |
| 18 Felt isolated and lonely? | | | | | |
| 19 Felt weepy or tearful? | | | | | |
| 20 Felt angry or bitter? | | | | | |
| 21 Felt anxious? | | | | | |
| 22 Felt worried about your future? | | | | | |
| 23 Felt you had to conceal your Parkinson's from people? | | | | | |
| 24 Avoided situations which involve eating or drinking in public? | | | | | |
| 25 Felt embarrassed in public due to having Parkinson's disease? | | | | | |
| 26 Felt worried by other people's reaction to you? | | | | | |
| 27 Had problems with your close personal relationships? | | | | | |
| 28 Lacked support in the ways you need from your spouse or partner? | | | | | |
| If you do not have a spouse or partner tick here | | | | | |
| 29 Lacked support in the ways you need from your family or close friends? | | | | | |

Please check that you have ticked one box for each question before going on to the next page.
<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Occasionally</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
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</thead>
<tbody>
<tr>
<td>Unexpectedly fallen asleep during the day?</td>
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<tr>
<td>Had problems with your concentration, e.g. when reading or watching TV?</td>
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<tr>
<td>Felt your memory was bad?</td>
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<tr>
<td>Had distressing dreams or hallucinations?</td>
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<tr>
<td>Had difficulty with your speech?</td>
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<tr>
<td>Felt unable to communicate with people properly?</td>
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<tr>
<td>Felt ignored by people?</td>
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<tr>
<td>Had painful muscle cramps or spasms?</td>
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<tr>
<td>Had aches and pains in your joints or body?</td>
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<tr>
<td>Felt unpleasantly hot or cold?</td>
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</tbody>
</table>

Please check that you have ticked one box for each question before going on to the next page.

Thank you for completing the PDQ 39 questionnaire.
Appendix C
Non-motor System Assessment Scale for Parkinson's Disease

Non-Motor Symptom assessment scale for Parkinson’s Disease

<table>
<thead>
<tr>
<th>Patient ID No:</th>
<th>Initials:</th>
<th>Age:</th>
</tr>
</thead>
</table>

Symptoms assessed over the last month. Each symptom scored with respect to:
Severity: 0 = None, 1 = Mild: symptoms present but cause little distress or disturbance to patient;
2 = Moderate: some distress or disturbance to patient; 3 = Severe: major source of distress or disturbance to patient.
Frequency: 1 = Rarely (<1/wk); 2 = Often (1/wk); 3 = Frequent (several times per week);
4 = Very Frequent (daily or all the time).
Domains will be weighed differentially. Yes/No answers are not included in final frequency x severity calculation.
(Bracketed text in questions within the scale is included for an explanatory aid).

<table>
<thead>
<tr>
<th>Domain 1: Cardiovascular including falls</th>
<th>Severity</th>
<th>Frequency</th>
<th>Frequency x Severity</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Does the patient experience light-headedness, dizziness, weakness on standing from sitting or lying position?</td>
<td>[ ]</td>
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<tr>
<td>2. Does the patient fall because of fainting or blocking out?</td>
<td>[ ]</td>
<td>[ ]</td>
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</tbody>
</table>

SCORE:

<table>
<thead>
<tr>
<th>Domain 2: Sleep/Fatigue</th>
<th>Severity</th>
<th>Frequency</th>
<th>Frequency x Severity</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. Does the patient doze off or fall asleep unintentionally during daytime activities? (For example, during conversation, during meals, or while watching television or reading).</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>4. Does fatigue (tiredness) or lack of energy (not slowness) limit the patient’s daytime activities?</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>5. Does the patient have difficulties falling or staying asleep?</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>6. Does the patient experience an urge to move the legs or restlessness in legs that improves with movement when he/she is sitting or lying down inactive?</td>
<td>[ ]</td>
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</tbody>
</table>

SCORE:

<table>
<thead>
<tr>
<th>Domain 3: Mood/cognition</th>
<th>Severity</th>
<th>Frequency</th>
<th>Frequency x Severity</th>
</tr>
</thead>
<tbody>
<tr>
<td>7. Has the patient lost interest in his/her surroundings?</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>8. Has the patient lost interest in doing things or lack motivation to start new activities?</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>9. Does the patient feel nervous, worried or frightened for no apparent reason?</td>
<td>[ ]</td>
<td>[ ]</td>
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</tr>
<tr>
<td>10. Does the patient seem sad or depressed or has he/she reported such feelings?</td>
<td>[ ]</td>
<td>[ ]</td>
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<tr>
<td>11. Does the patient have flat moods without the normal &quot;highs&quot; and &quot;lows&quot;?</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
</tr>
<tr>
<td>12. Does the patient have difficulty in experiencing pleasure from their usual activities or report that they lack pleasure?</td>
<td>[ ]</td>
<td>[ ]</td>
<td>[ ]</td>
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</tbody>
</table>

SCORE:

<table>
<thead>
<tr>
<th>Domain 4: Perceptual problems/hallucinations</th>
<th>Severity</th>
<th>Frequency</th>
<th>Frequency x Severity</th>
</tr>
</thead>
<tbody>
<tr>
<td>13. Does the patient indicate that he/she sees things that are not there?</td>
<td>[ ]</td>
<td>[ ]</td>
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<tr>
<td>14. Does the patient have beliefs that you know are not true? (For example, about being harmed, being robbed or being unfaithful)</td>
<td>[ ]</td>
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<tr>
<td>15. Does the patient experience double vision? (2 separate real objects and not blurred vision)</td>
<td>[ ]</td>
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</table>

SCORE:
<table>
<thead>
<tr>
<th>Domain 5: Attention/memory</th>
<th>Severity</th>
<th>Frequency</th>
<th>Frequency x Severity</th>
</tr>
</thead>
<tbody>
<tr>
<td>16. Does the patient have problems sustaining concentration during activities? (For example, reading or having a conversation)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>17. Does the patient forget things that he/she has been told a short time ago or events that happened in the last few days?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>18. Does the patient forget to do things? (For example, take tablets or turn off domestic appliances?)</td>
<td>☐</td>
<td>☐</td>
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</table>

SCORE:

<table>
<thead>
<tr>
<th>Domain 6: Gastrointestinal tract</th>
<th>Severity</th>
<th>Frequency</th>
<th>Frequency x Severity</th>
</tr>
</thead>
<tbody>
<tr>
<td>19. Does the patient dribble saliva during the day?</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>20. Does the patient have difficulty swallowing?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>21. Does the patient suffer from constipation? (Bowel action less than three times weekly)</td>
<td>☐</td>
<td>☐</td>
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</table>

SCORE:

<table>
<thead>
<tr>
<th>Domain 7: Urinary</th>
<th>Severity</th>
<th>Frequency</th>
<th>Frequency x Severity</th>
</tr>
</thead>
<tbody>
<tr>
<td>22. Does the patient have difficulty holding urine? (Urgency)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>23. Does the patient have to void within 2 hours of last voiding? (Frequency)</td>
<td>☐</td>
<td>☐</td>
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<tr>
<td>24. Does the patient have to get up regularly at night to pass urine? (Nocturia)</td>
<td>☐</td>
<td>☐</td>
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</tbody>
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SCORE:

<table>
<thead>
<tr>
<th>Domain 8: Sexual function</th>
<th>Severity</th>
<th>Frequency</th>
<th>Frequency x Severity</th>
</tr>
</thead>
<tbody>
<tr>
<td>25. Does the patient have altered interest in sex? (Vary much increased or decreased, please underline)</td>
<td>☐</td>
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<tr>
<td>26. Does the patient have problems having sex?</td>
<td>☐</td>
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<thead>
<tr>
<th>Domain 9: Miscellaneous</th>
<th>Severity</th>
<th>Frequency</th>
<th>Frequency x Severity</th>
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</thead>
<tbody>
<tr>
<td>27. Does the patient suffer from pain not explained by other known conditions? (Is it related to intake of drugs and is it relieved by antiparkinson drugs?)</td>
<td>☐</td>
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<tr>
<td>28. Does the patient report a change in ability to taste or smell?</td>
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<tr>
<td>29. Does the patient report a recent change in weight (not related to dieting)?</td>
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<tr>
<td>30. Does the patient experience excessive sweating (not related to hot weather)?</td>
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SCORE:

**TOTAL SCORE:**
Appendix D
H&Y Staging of PD

Stage One

1. Signs and symptoms on one side only
2. Symptoms mild
3. Symptoms inconvenient but not disabling
4. Usually presents with tremor of one limb
5. Friends have noticed changes in posture, locomotion and facial expression

Stage Two

1. Symptoms are bilateral
2. Minimal disability
3. Posture and gait affected

Stage Three

1. Significant slowing of body movements
2. Early impairment of equilibrium on walking or standing
3. Generalized dysfunction that is moderately severe

Stage Four

1. Severe symptoms
2. Can still walk to a limited extent
3. Rigidity and bradykinesia
4. No longer able to live alone
5. Tremor may be less than earlier stages

Stage Five

1. Cachectic stage
2. Invalidism complete
3. Cannot stand or walk
4. Requires constant nursing care
Appendix E
S&E ADL


Rating can be assigned by rater or by patient

100% Complete independence. Able to do all chores w/o slowness, difficulty, or impairment.

90% Completely independent. Able to do all chores with some slowness, difficulty, or impairment. May take twice as long.

80% Independent in most chores. Takes twice as long. Conscious of difficulty and slowing.

70% Not completely independent. More difficulty with chores. 3 to 4X along on chores for some. May take large part of day for chores.

60% Some dependency. Can do most chores, but very slowly and with much effort. Errors, some impossible.

50% More dependant. Help with half of chores. Difficulty with everything.

40% Very dependant. Can assist with all chores but few alone.

30% With effort, now and then does a few chores alone of begins alone. Much help needed.

20% Nothing alone. Can do some slight help with some chores. Severe invalid.

10% Totally dependant, helpless.

0% Vegetative functions such as swallowing, bladder and bowel function are not functioning. Bedridden.
Appendix F
Formal Interview Schedule

What impact on personal burden does bowel and bladder dysfunction have for people who have Parkinson’s disease, a degenerative neurological disorder.

Questionnaire

General Health Questions

1. How long ago were you diagnosed with Parkinson’s disease?
   0-5 years □  6-10 years □  11-15 years □  15 plus □

2. How would you describe the severity of your Parkinson’s symptoms?
   Very mild □  Mild □  Moderately affected □  Severely affected □

3. What PD symptoms do you have? How do you rate these symptoms in terms of bother? Numerical out of ten

<table>
<thead>
<tr>
<th>PD Symptoms</th>
<th>Rating</th>
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<tbody>
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313
4. Do you take any regular medicines. Prescribed & OTC?
   Yes ☐  No ☐
   If yes record: 1. Drug name. 2. Dose & Frequency of use. 3. Side effects
   For your Parkinson's disease  For bladder or bowel problems  For other reasons

   ____________________________
   ____________________________
   ____________________________
   ____________________________
   ____________________________

5. How would you describe your overall health at present?
   Good ☐  Fair ☐  Poor ☐  Very Poor ☐
Bladder Problems:

6. How much do you think your bladder problem affects your life?
Not at all ☐ A little ☐ Moderately ☐ A lot ☐

7. How would you describe your bladder difficulties?

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

Code:
Frequency ☐ Nocturia ☐ Urgency ☐ Stress ☐ Retention ☐

8. Have you spoken to anyone to ask for help/assistance for this problem?
Yes ☐ No ☐
9. What treatments/products have you tried to solve your difficulties, were they successful?

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________________________________________________________________________
Bowel Problems

10. How much do you think your bowel problem affects your life?
Not at all □    A little □    Moderately □    A lot □

11. How would you describe your Bowel difficulties?
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Code:
Diarrhoea □    Constipation □    Urgency □    Other □    ________________________

12. Have you spoken to anyone to ask for help/assistance for this problem?
Yes □    No □
Health professional:
Local General  Community Nurse  Pharmacist  Specialist Dr.  Continence Nurse
Practitioner □  □  □  □  Consultant □
Other □

Non Health professional or other
Family □  Friends □  Spouse □  Other □

15. What treatments/products have you tried to solve your difficulties, were they successful?

________________________________________________________________________
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________________________________________________________________________
Hello my name is Joanne Lawrence I am conducting a study with the Brain and Mind Institute about the problems people with Parkinson’s disease have going to the toilet.

Many people with Parkinson’s disease complain of bowel and bladder symptoms like constipation and of waking up frequently at night to pass urine to name but a few.

However very little is known about what effect these and other bowel and bladder difficulties have on your lifestyle.

IF YOU: have Parkinson’s disease and experience any bowel or bladder concerns I would really like to talk with you over the telephone.

The interview usually lasts for no more than 30 minutes. I have enclosed the questions I would like to ask you. Please read them and I will collect the information from you when I phone you.

I am sending these questions to you beforehand so that you have time to make some notes and collect your thoughts. I am also hoping that this will make it a little easier for you when I speak to you.

The questions are:

1. How long ago were you diagnosed with Parkinson’s disease (PD)?
2. How would you describe the severity of your Parkinson’s symptoms?
3. What bowel or bladder and PD specific symptoms do you have?
4. How do you rate these symptoms in terms of bother? Numerical out of ten.
5. Do you take any regular medicines? The ones prescribed by your doctor and the ones you buy without a prescription. I would like you to tell me
   - Drug name. eg: Paraoxid 500mg
   - How much and when you take this drug. eg: 2 tablets twice a day.
   - Do you experience any side effects from these medicines? eg: no side effects
6. How would you describe your overall health at present?
7. How would you describe your bladder difficulties?
8. How much do you think your bladder problem affects your life?
9. Have you spoken to anyone to ask for help/assistance for this problem?
10. What treatments/products have you tried to solve your difficulties, were they successful?
11. How would you describe your bowel difficulties?
12. How much do you think your bowel problem affects your life?
13. Have you spoken to anyone to ask for help/assistance for this problem? What treatments/products have you tried to solve your difficulties, were they successful?

To set a suitable time to telephone you would you please complete and send back the enclosed consent form to the Mind and Brain Institute. On this form there is a space to let me know the most convenient time to call.

If you have any further questions please do not hesitate to call me on (02) 9739 2367.

Thank you for your time
An investigation into the significance and impact of bowel and bladder dysfunction on personal burden for people who have Parkinson’s disease.

Participant Information Statement

You are invited to participate in a telephone survey that will ask you about any bowel and/or bladder problems you may be experiencing following a diagnosis of Parkinson’s disease. This invitation is hoping that you or someone you may know would be interested in contacting us to inform this important research with first hand information about some of the difficulties people with Parkinson’s disease have with their bowel or bladder function.

Bowel and bladder difficulties are reported widely in the Parkinson’s disease (PD) literature. Many people who have PD complain of constipation and of waking up frequently at night to pass urine to name but a few. However little is known about what affect these and other bowel and bladder difficulties have on the sufferer’s lifestyle and while bowel and bladder problems are often seen as an inevitable part of PD there is little scientific evidence which demonstrates or supports this perception.

It is expected that this study will provide scientifically rigorous evidence by gathering information that will recognise and confirm the impact of bowel and bladder difficulties on personal burden, within a population of people with PD.

If you meet the following criteria we would very much like to talk with you.
- If you have been diagnosed as having PD.
- If you are able to converse in English via a telephone line.
- If you are or have experienced some difficulties with either; your bowel or your bladder or both your bowel and bladder.

What do you need to do?
If you are interested in participating in this telephone survey please contact Joanne Lawrence on (02) 9739 2367, to arrange a suitable time to telephone you to complete the survey. The telephone survey will take about 30 minutes to complete.

Who is conducting this study?
This study is being conducted by Joanne Lawrence who is a continence nurse working in NSW. Joanne is undertaking her PhD at the University of Sydney, Faculty of Medicine. She is supervised by Professor Parineter (University of Sydney) Professor McDonald (Australian Catholic University); and Professor Madden (University of Sydney).

Your participation is voluntary and, should you decide to withdraw at any time, your decision will be respected and not challenged in any way. All people participating in this research will be allocated a unique code number that will be used only to monitor the response rate and will not allow you to be
personally identified.

All information will be stored securely and archived in accordance with the National Health and Medical Research Council recommendations. Information obtained from this survey will eventually in a research report and publications. No individual participants will be able to be identified in any of these reports or publications.

If you have any further questions, please contact Ms Joanne Lawrence on (02) 9739 2367.

This information sheet is for you to keep. It is anticipated that results from this study will help inform consumers with PD as well as their health practitioners who work in a variety of specialist and community health areas. To help them better understand the significance and impact that bowel and bladder problems have in the life of a person with Parkinson’s disease.

We hope you will agree to participate.

Yours sincerely

Ms. Joanne Lawrence  Professor Trevor Parmenter  Professor Richard Madden
Professor Tracey McDonald

The Human Research Ethics Committee at The University of Sydney has approved this study. In the event that you have any complaint or concern about the way you have been treated during the study, or if you have any query that the Investigator has not been able to satisfy, you can contact the Senior Ethics Officer, Ethics Administration, University of Sydney on (02) 9351 4811 (Telephone); (02) 9351 6706 (Facsimile) or ethics@syd.edu.au (Email).

Any complaint or concerned will be treated in confidence and will be fully investigated and the participant making the complaint will be informed of the outcome.

This information sheet is for you to keep.
PARTICIPANT CONSENT FORM

1. Name (please print) ........................................... I give consent for my participation in the research.

An investigation into the significance and impact of bowel and bladder dysfunction on personal burden for people who have Parkinson's disease.

In giving my consent I acknowledge that:

1. The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.

2. I have read the Participant Information Statement and have been given the opportunity to discuss the information and my involvement in the project with the researchers.

3. I understand that I can withdraw from the study at any time, without giving reason now or in the future.

4. I understand that my involvement is strictly confidential and no information about me will be used in any way that reveals my identity.

5. I consent to be interviewed on the phone at a mutually agreeable time.

Signed: ......................................................................................................................

Address: .......................................................................................................................

Date: ............................................................................................................................

The telephone number I wish to be contacted on is: ............................................

Please indicate with a tick (✓) the most appropriate time to contact you.

<table>
<thead>
<tr>
<th></th>
<th>Any time</th>
<th>9-12 Morning</th>
<th>13-5 Afternoon</th>
<th>6-9 Evening</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monday</td>
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<tr>
<td>Friday</td>
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</tbody>
</table>

Post back to Joanne Lawrence; 29 Torokina Ave, St Ives, NSW, 2075

Royal Rehabilitation Centre Sydney; 59 Chatswood Street, PO Box 6 RYDE, NSW 2112 Australia Telephone 02 9878 8500

In partnership with The University of Sydney, Macquarie University, Nurrungai Cancer Institute, Skin Cancer Institute, Royal Rehabilitation Centre Disability Council of NSW
Date: ______________  Time: ______________

What impact on personal burden does bowel and bladder dysfunction have for people who have Parkinson’s disease, a degenerative neurological disorder.

TELEPHONE SURVEY CHECKLIST

My name is ______________. I am conducting a research project on bowel and bladder dysfunction for people who have Parkinson’s disease. You have left this contact phone number and this time which you have nominated as most suitable for you.

Is this a convenient time? If not, is there another time that would be more convenient for you to complete this survey? [Record alternative time suggested in space below]

May I ask you a few questions regarding your permission to continue this conversation?

Have you received the Information Statement outlining the study? Yes/No

Have you had a chance to read it? Yes/No

Is the purpose of the study clear to you? Yes/No

Do you have any further questions about the study? Yes/No

Would you be prepared to participate in this study by answering questions about any bowel and/or bladder problems? Yes/No

IF THEY REFUSE TO PARTICIPATE: Thank you for taking the time to chat with me today. I appreciate there are many demands on your time.

Signed by researcher
Appendix H
Sydney University Human Ethics Committee approval 2007

16 August 2007

Professor Trevor Parmenter
Centre for Developmental Disability Studies
Faculty of Medicine
The University of Sydney
PO Box 8
RYDE NSW 1650

Dear Professor Parmenter,

Thank you for your correspondence dated 10 July 2007 addressing comments made to you by the Human Research Ethics Committee (HREC). After considering the additional information, the Executive Committee at its meeting on 9 August 2007 approved your protocol entitled "An investigation into the significance and impact of bowel and bladder dysfunction on personal burden for people who have Parkinson’s disease".

Details of the approval are as follows:

Ref No.: 08-2007/10072
Approval Period: August 2007 to August 2008
Authorised Personnel: Professor Trevor Parmenter
Ms Joanne Sara Lawrence
Professor Richard Madden
Professor Tracey McDonald

The HREC is a fully constituted Ethics Committee in accordance with the National Statement on Ethical Conduct in Research Involving Humans-March 2007 under Section 5.1.29

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 should be reported to the HREC as soon as possible.

2. All unforeseen events that might affect continued ethical acceptability of the project should 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 hcrexy@usyd.edu.au (Email).

(5) Copies of all signed Consent Forms must be retained and made available to the HREC on request.

(6) It is your responsibility to provide a copy of this letter to any internal/external granting agencies if requested.

(7) 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.

(8) 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

cc: Ms Joanne Lawrence, PO Box 583. North Sydney. NSW. 2059

Enc. Participant Information Statement
Appendix I –
International Continence Society – LUTS definitions
Rome III – criteria for GIT dysfunctions: Constipation & Diarrhea

DEFINITIONS
The consultation agreed to use the current International Continence Society definitions (ICS) for lower urinary tract dysfunction (LUTS) including incontinence, except where stated. These definitions appeared in the journal Neurology and Urodynamics (2002; 22:167–178 and 2006; 25:291) or can be viewed on the ICS website: www.ics-society.org. The following ICS definitions are relevant:

1. Lower Urinary Tract Symptoms (LUTS)
LUTS are divided into storage symptoms and voiding symptoms.
Urinary incontinence is a storage symptom and defined as the complaint of any involuntary loss of urine. This definition is suitable for epidemiological studies, but when the prevalence of bothersome incontinence is sought, the previous ICS definition of an “Involuntary loss of urine that is a social or hygienic problem” can be useful.
Urinary incontinence may be further defined according to the patient’s symptoms:
- Urgency: Urinary Incontinence is the complaint of involuntary leakage accompanied by or immediately preceded by urgency.
- Stress Urinary Incontinence is the complaint of involuntary leakage on effort or exertion, or on sneezing or coughing.
- Mixed Urinary Incontinence is the complaint of involuntary leakage associated with urgency and also with effort, exertion, sneezing and coughing.
- Nocturnal Encyst is any involuntary loss of urine occurring during sleep.
- Post-micturition dribble and continuous urinary leakage denotes other symptomatic forms of incontinence.

2. Urodynamic Diagnosis
• Overactive Detrusor Function is characterized by involuntary detrusor contractions during the filling phase, which may be spontaneous or provoked.
The overactive detrusor is divided into:
- Idiopathic Detrusor Overactivity defined as overactivity when there is no clear cause.
- Neurogenic Detrusor Overactivity is defined as overactivity due to a relevant neurological condition.

Christopher Chapple led the secretariat.
The 4th International Consultation on Incontinence was held from July 6 to 8 2008 in Paris and was organized by the International Consultation on Urogynecology, a non-governmental organization, in official collaboration with the World Continence Organization, in order to develop recommendations for the diagnosis, evaluation, and treatment of stress incontinence, fecal incontinence, pelvic organ prolapse and bladder pain syndromes. The recommendations are evidence-based following a thorough review of the available literature and the global subjective opinion of recognized experts serving on treated committees. The individual committee reports were reviewed, developed and peer reviewed by open presentation and comments. The Scientific Review Committee of all the committees then refined the final recommendations. These recommendations published in 2009 will be periodically reevaluated in the light of clinical experience, technological progress and research. Incontinence, 4th Edition 2009 ed P. Abrams, I. Cardozo, S. Khoury, A. Wein was published in 2009 by Wiley-Liss, Inc and is available on Amazon.

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Management of Pelvic Organ Prolapse (including urogenital prolapse, and rectal prolapse)

**HISTORY**
- Pelvic floor muscle training may:
  - reduce the symptoms of urogenital prolapse (Grade B), although topographic change is not expected;
  - prevent or slow deterioration of anterior urogenital prolapse (Grade B).
- Pessaries, when successfully fitted, may improve prolapse symptoms (Grade B). Regular follow-up is mandatory. Support pessaries that concurrently treat stress incontinence should be considered when appropriate.
- Local estrogens may benefit hypoestrogenic women for the prevention and/or treatment of vaginal epithelial ulceration (Grade C).
- Reconstructive surgery should aim to optimize anatomy and function (see full text for grades of recommendation for specific surgical techniques). Pre- and postoperative pelvic floor muscle training may promote quality of life and fewer symptoms after surgery for urogenital prolapse (Grade C).
- Obliterative surgery is reserved for selected women who agree to permanent vaginal closure (Grade B).

**CLINICAL ASSESSMENT**
- Observation
- Lifestyle interventions
- Pelvic floor muscle training
- Pessary
- Reconstructive surgery
- Obliterative surgery

**DIAGNOSIS**
- Urogenital prolapse with or without other pelvic symptoms
- Rectal prolapse with or without other pelvic symptoms

**MANAGEMENT**
- Observation
- Lifestyle interventions
- Transperineal surgery
- Transabdominal surgery

**Recommendations**
- Patients with known neurologic disease often need evaluation to exclude neurologic bladder, not only if symptoms occur, but as a standard diagnostic approach if neurogenic bladder has a high prevalence in this disease (for prevalence figures see chapter).
- A possible neurologic cause of “idiopathic” incontinence should always be considered. Diagnostic steps to evaluate this include basic assessments, such as history and physical examination, urodynamics and specialized tests.
- Incontinence in neurogenic patients does not necessarily relate to the neurologic pathology. Other diseases such as prostate pathology, pelvic organ prolapse, etc. might have an influence. These have to be ruled out.
- Extensive diagnostic workup seems useful and necessary only to tailor an individual treatment based on complete neurofunctional data. This may not be needed in every patient, for example, patients with suprapubic lesions or in patients where treatment will consist merely of bladder drainage due to bad medical condition or limited life expectancy.
- There is often a need to manage bladder and bowel together

**Initial management**
- Strong general recommendations (Fig. 9).

Neurourology and Urodynamics DOI 10.1002/hed
Initial Management of Neurogenic Urinary Incontinence

**History**
- Level of lesion
  - Supraspinal central lesion (e.g., Parkinson’s disease, stroke, multiple sclerosis)
  - Supraspinal infraspinal lesion (e.g., trauma, multiple sclerosis)
  - Peripheral nerve lesion (e.g., radical prostatectomy, perineal equina lesion, e.g., lumbar disc prolapse)

**Clinical Assessment**
- Further history
  - General assessment including home assessment
  - Urinary history and symptom score
  - Assessment of functional level, quality of life and desire for treatment
  - Physical examination: assessment of sensation in lumbosacral dermatomes, anal tone and voluntary contraction of anal sphincter; bulbocavernous and anal reflexes, gait
  - Urine analysis + culture (if infected, treat as necessary)
  - Urinary tract imaging, serum creatinine (if abnormal): specialised management
  - Post void residual (PVR) by abdominal examination or optional by ultrasonound

**Presumed Diagnosis**
- Stress urinary incontinence
  - Due to sphincter incompetence
- Urinary incontinence due to detrusor overactivity
  - With Poor bladder emptying (significant PVR)
  - With Negligible PVR
  - Intermittent catheterisation with or without Antimuscarinics
  - Failure
  - Continuing catheterisation

**Management**
- Behavioural modification
- External appliances
- Failure

Specialised management preferable for more “tailored” treatment

Fig. 3. Initial management of neurogenic urinary incontinence.

Producing incontinence. This can in turn depend on the site and extent of the nervous system abnormality.

- Therefore neurogenic incontinence patients can be divided into those having peripheral lesions (as after major pelvic surgery) including those with lesions of the lowest part of the spinal cord (e.g., lumbar disc prolapse), central lesions below the pons (supraspinal infraspinal spinal cord lesions), central lesions above the pons (cerebrovascular accidents, stroke, Parkinson’s disease).

III. Initial treatment

- Patients with peripheral nerve lesions (e.g., denervation after pelvic surgery) and patients with supraspinal infraspinal or spinal cord lesions (e.g., traumatic spinal cord lesions) should get specialized management (A).
- Initial treatment for patients with incontinence due to supraspinal pathology, like stroke, need to be assessed for degree of mobility and ability to cooperate. Initial recommended treatments are behavioral therapy (C) and bladder relaxant drugs for presumed detrusor overactivity (A).

Specialized management

**Assessment**
- Most patients with neurogenic urinary incontinence require specialized assessment urodynamic studies are mandatory with videourodynamics if available (Fig. 10).
- Upper tract imaging is needed in most patients and more detailed renal function studies will be desirable if the upper tract is considered in danger: high LUT pressure, LUT dilatation, recurrent or chronic upper tract infection, (major) stones, (major) reflux.
- In patients with peripheral lesions clinical neurophysiological testing may be helpful for better definition of the lesion.

**Treatment**. Also for specialized management conservative treatment is the mainstay (A). Management of neurogenic urinary incontinence has several therapeutic options. The algorithm details the recommended options for different types of neurologic dysfunction of the lower urinary tract. The dysfunction does not necessarily correspond to one type/level of neurologic lesion but must depend mostly on urodynamic findings. One should always ascertain that the patient’s management is urodynamically safe (low pressure, complete emptying).

Neurology and Urodynamics DOI 10.1002/nau
Specialized Management of Neurogenic Urinary Incontinence

**Diagnosis**
- Stress UI due to sphincteric incompetence
- Incontinence associated with poor bladder emptying due to detrusor overactivity / sphincter overactivity
- UI due to detrusor overactivity

**Conservative Treatment**
- Artifical sphincter
- Bladder neck sling
- Sub-urethral tapes
- Bulking agents
- Bladder neck closure

**Surgical Treatment**
- Artifical sphincter
- Bladder neck sling
- Sub-urethral tapes
- IC + AM
- Indwelling cath + AM
- SCA + IC
- SCA + SARS
- Botulinum toxin to detrusor
- Enterocystopyty
- Autonomic augmentation

Stoma/diversion may be an option in selected cases.

**Fig. 10. Specialized management of neurogenic urinary incontinence.**

It is recommended to look at urinary and bowel function together if both systems are affected as symptoms and treatment of one system can influence the other and vice versa (A).

**Treatment modalities (often in combination)**
- Intermittent catheterization (A).
- Behavioral treatment (C).
- Timed voiding (C).
- External Appliances (B).
- Antimuscarinics (A).
- Alpha 1 blockers (B).
- Intravesical B5 (C).
- Bladder expression (E).
- Triggered voiding (C).
- Indwelling catheter (C).

Surgical treatment
- Artifical sphincter (A).
- Bladder neck sling (B).
- Sub-urethral tapes (D).
- (Bulking agents) (D).
- (Bladder neck surgery) (D).
- (Bladder neck closure) (D).
- Intravesical stents (B).
- TIH sphincter (B).
- Botulinum toxin (C) detrusor (A).
- Sacral desecfication (B).
- Sacral anterior root stimulator (B).
- Enterocystopyty (B).
- Autonomic augmentation (D).

**Urinary Incontinence in frail Older Men and Women**

Urinary incontinence in frail older men and women. Healthy older persons should receive the similar range of treatment options as younger persons, but frail older persons require a different approach addressing the potential role of comorbid disease, current medications (prescribed, over-the-counter, and/or naturopathic), and functional and/or cognitive impairment in UI. The extent of investigation and management should take into account the degree of bother to the patient and/or caregiver, goals for care, cooperation, and overall prognosis and life expectancy. Effective management to meet the goals of care should be possible for most frail elderly (Fig.11).
Rome III
Diagnostic
Criteria for
Functional
Gastrointestinal
Disorders
C3. Functional Constipation

Diagnostic criteria:
1. Must include two or more of the following:
   a. Straining during at least 25% of defecations
   b. Lumpy or hard stools in at least 25% of defecations
   c. Sensation of incomplete evacuation for at least 25% of defecations
   d. Sensation of incomplete evacuation/blockage for at least 25% of defecations
   e. Manual maneuvers to facilitate at least 25% of defecations (e.g., digital evacuation, support of the pelvic floor)
   f. Fewer than three defecations per week
2. Loose stools are rarely present without the use of laxatives
3. Insufficient criteria for irritable bowel syndrome
   * Criteria fulfilled for the last 3 months with symptom onset at least 6 months prior to diagnosis

C4. Functional Diarrhea

Diagnostic criteria:
Loose (watery) or watery stools without pain occurring in at least 75% of stools

* Criteria fulfilled for the last 3 months with symptom onset at least 6 months prior to diagnosis

C5. Unspecified Functional Bowel Disorder

Diagnostic criteria:
Bowel symptoms not attributable to an organic etiology that do not meet criteria for the previously defined categories

* Criteria fulfilled for the last 3 months with symptom onset at least 6 months prior to diagnosis

D. Functional Abdominal Pain Syndrome

D. Functional Abdominal Pain Syndrome

Diagnostic criteria:
1. Continuous or nearly continuous abdominal pain
2. No or only occasional relationship of pain with physiological events (e.g., eating, defecation, or menses)
3. Some loss of daily functioning
4. The pain is not feigned (e.g., malingering)
5. Insufficient symptoms to meet criteria for another functional gastrointestinal disorder that would explain the pain

* Criteria fulfilled for the last 3 months with symptom onset at least 6 months prior to diagnosis
F2a.2. Unspecified Functional Anorectal Pain
Diagnostic criteria
Symptom criteria for chronic proctalgia but no tenderness during posterior traction on the puborectalis

F2b. Proctalgia Fugax
Diagnostic criteria: Must include all of the following:
1. Recurrent episodes of pain localized to the anus or lower rectum
2. Episodes last from seconds to minutes
3. There is no anorectal pain between episodes
For research purposes, criteria must be fulfilled for 3 months; however, clinical diagnosis and evaluation may be made prior to 3 months.

F3. Functional Defecation Disorders
Diagnostic criteria*
1. The patient must satisfy diagnostic criteria for functional constipation**
   a. During repeated attempts to defecate, there is at least two of the following:
      b. Inappropriate contraction of the pelvic floor muscles (i.e., anal sphincter or puborectalis) or less than 20% relaxation of basal resting sphincter pressure by manometry, imaging, or EMG
   c. Inadequate propulsive forces assessed by manometry or imaging
* Criteria fulfilled for the last 3 months with symptom onset at least 6 months prior to diagnosis
** Diagnostic criteria for functional constipation:
(a) Must include two or more of the following: (a) Straining during at least 50% of defecations, (b) Lumpy or hard stools in at least 50% of defecations, (c) Sensation of incomplete evacuation for at least 25% of defecations, (d) Sensation of anal obstruction/blockage for at least 25% of defecations, (e) Manual maneuvers to facilitate defecation, (f) Fewer than three defecations per week.
(b) Loose stools are rarely present without the use of laxatives.
(c) Insufficient criteria for irritable bowel syndrome.

F3a. Dyssynergic Defecation
Diagnostic criteria
Inappropriate contraction of the pelvic floor or less than 20% relaxation of basal resting sphincter pressure with adequate propulsive forces during attempted defecation

F3b. Inadequate Defecatory Propulsion
Diagnostic criteria
Inadequate propulsive forces with or without inappropriate contraction or less than 20% relaxation of the anal sphincter during attempted defecation
## Appendix J
### Relationship between PDQ-39 Domains and Disease Severity

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<td>.345**</td>
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<tr>
<td>Sig. (2-tailed)</td>
<td>.509</td>
<td>.000</td>
<td>.016</td>
<td>.004</td>
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<tr>
<td><strong>H&amp;Y disease staging</strong></td>
<td>N</td>
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<td>67</td>
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<td>67</td>
<td>67</td>
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<tr>
<td>Pearson R</td>
<td>-.027</td>
<td>.329**</td>
<td>.259*</td>
<td>.232</td>
<td>.396**</td>
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<tr>
<td>Sig. (2-tailed)</td>
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<td>.007</td>
<td>.035</td>
<td>.059</td>
<td>.001</td>
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</table>

**Correlation is significant at the 0.01 level (2-tailed).**

*Correlation is significant at the 0.05 level (2-tailed).*