Exploring Self-Management of Bladder Dysfunction among People with Multiple Sclerosis in the Republic of Ireland

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ABSTRACT

Title: Exploring self-management of bladder dysfunction among people with Multiple Sclerosis in the Republic of Ireland

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Bladder dysfunction is one of the most distressing symptoms of Multiple Sclerosis (MS) and affects several important life domains. It can affect up to 75% of people with MS. As there is no cure for MS, effective symptom management is the goal of rehabilitation. Given the sensitive nature of bladder dysfunction, facilitating strategies that can be used independently may be an optimal approach to managing this disruptive symptom. The overall aim of this thesis is to inform the development of a self-management resource to enable people with MS to self-manage bladder dysfunction.

The literature review provided the background to the topic by examining current research on the prevalence, impact, current service provision, management—including self-management—of bladder dysfunction. This review demonstrated that a wide range of bladder symptoms exist among people with MS and a lack of clarity remains around current service provision for people with MS with bladder dysfunction in the Republic of Ireland.

A mixed methods approach was employed in this project involving three distinct but interlinked research strands. Each strand was built sequentially on the preceding one. Nineteen people with MS were interviewed in Strand 1. Findings demonstrated how bladder symptoms interfered with quality of life for people with MS and identified the existing barriers to accessing services. These findings informed the questioning route for a qualitative exploration of perspectives of healthcare professionals (n=14) in Strand 2. This study provided a novel insight into how the underlying beliefs of healthcare professionals may influence clinical practice and how challenging these beliefs are important in relation to bladder dysfunction. Findings from Strand 1 and 2 both guided the development of the online questionnaire (n=213) used in the final strand of the thesis. This final strand compared current approaches to assessment and management of bladder dysfunction between both people with MS and healthcare professionals. The challenges and needs around facilitating self-management of bladder dysfunction were also explored.

This project demonstrated important outcomes for people with MS, healthcare professionals and policy-makers in the Republic of Ireland. Education is needed for both people with MS and healthcare professionals to address their lack of knowledge in relation to management strategies. This research provides an evidence and theory base to inform the development of an educational resource to facilitate the self-management of bladder dysfunction among people with MS.
DECLARATION

I declare that this thesis is my own work and has not been submitted to any other university or higher education institution, for any other academic award. Citations of secondary works have been fully acknowledged and referenced.

Signed _________________________

Catherine Browne
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LIST OF ABBREVIATIONS

MS Multiple Sclerosis
NAI Neurological Alliance of Ireland
ABN Association of British Neurologists
ICF International Classification of Functioning, Disability and Health
F Female
M Male
USA United States of America
SUI Stress urinary incontinence
UUI Urinary urge incontinence
OAB Overactive bladder symptoms
UI Urinary incontinence
HSE Health Service Executive
PwMS People with Multiple Sclerosis
HCPs Healthcare Professionals
EHS Faculty of Education and Health Sciences
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CHAPTER 1 INTRODUCTION

1.1 OUTLINE OF THE CHAPTER

Often described as a social cancer, bladder dysfunction continues to isolate people from activities and society (Potts 2012). Bladder dysfunction is one of the most distressing symptoms of Multiple Sclerosis (MS); however, it has been neglected, partly because of the perceived private nature of the problem (DasGupta and Fowler 2003). In this chapter, MS will be described in terms of its known pathophysiology, epidemiology, diagnosis, signs and symptoms. Normal bladder functioning and the types of dysfunction will be described. A brief introduction to the management of bladder symptoms among people with MS including the concept of self-management will be outlined. Finally, the aims and objectives of the thesis are detailed and an overview of each chapter is provided.

1.2 OVERVIEW

1.2.1 Multiple Sclerosis

Multiple Sclerosis (MS) is an inflammatory, demyelinating and degenerative disease of the central nervous system (CNS) (Compston and Coles 2008). Most people are diagnosed with MS between 20 and 50 years of age (Milo and Kahana 2010). MS is a lifelong condition and the most common cause of neurological disability amongst young and middle-aged adults (Haussleiter et al. 2009). It has been recognized across all ethnicities. The occurrence of MS decreases proportionally with the distance from
the poles, thus it is more common in Caucasians compared to native African and Asian populations (Ebers 2008). The cause is not completely understood; however, a combination of genetic, environmental and immunological factors appear to trigger the onset of MS (Compston and Coles 2008, Cameron et al. 2013). Depending on the area of the CNS affected, MS can lead to multiple motor, sensory, visual and psychological problems (Clarke and Coote 2015).

The estimated number of people with MS has increased from 2.1 million people worldwide in 2008 to 2.3 million in 2013 (Atlas of MS 2013). While MS is a global health issue its prevalence varies greatly, being highest in North America and Europe (140 and 108 per 100,000 respectively) and lowest in Sub-Saharan Africa and East Asia, at 2.1 and 2.2 per 100,000 respectively (Atlas of MS 2013). Prevalence in Ireland rose from 184.6 per 100,000 in 2001 to 290.3 per 100,000 in 2007 in the north west of the Republic of Ireland (Lonergan et al. 2011). In the southeast, prevalence rates remain 144.8 per 100,000 (Lonergan et al. 2011). There are approximately 9,000 people living with MS in Ireland (Multiple Sclerosis Ireland 2015) with recent evidence indicating an annual incidence rate of 5.97 per 100,000, which estimates to 290 new cases being diagnosed with MS in Ireland, annually (O'Connell 2015). MS is two to three times more common in women than men and the onset of MS is on average 5 years earlier in women than in men (Orton et al. 2006).

There are four typical patterns of MS: relapsing-remitting, secondary progressive, primary progressive and progressive relapsing (Lublin et al. 2014). Approximately 80% of people have relapsing-remitting MS which is characterised by clearly defined relapses (exacerbations) followed by full or near-complete recovery of function.
(remission) (Compston and Coles 2008). Secondary progressive MS has an initial relapsing-remitting disease course followed by progression with or without occasional relapses, minor remissions or plateaus. Primary progressive MS results in disease progression from onset with occasional plateaus and temporary minor improvements may be observed. Primary relapsing MS has a progressive disease course from onset, with clear acute relapses; recovery may be complete or partial. Findings from a recent online survey of people with MS in Ireland suggest that 63% have relapsing remitting MS, 16% reported having secondary progressive MS and 11% had primary progressive disease with 6% not knowing their current course of disease (Multiple Sclerosis Ireland 2015).

Figure 1 Description of the different types of MS (Kim and Kim 2009)
As there is no cure for MS, current disease management is aimed at reducing relapses, preventing disability directly due to relapse, providing management of fixed neurological deficits, preventing disability acquired through progression and treating established progression (Compston and Coles 2008). The signs and symptoms associated with MS vary. In a global survey of MS, the most common presenting symptoms included sensory impairments (40%), motor disturbances (39%), visual (30%) fatigue (30%), balance (24%), sexual (20%), urinary (17%) pain (15%) and cognitive (10%) (Atlas of MS 2013). According to people with MS, the most disabling symptom is fatigue (93%), followed by depression (75%), urinary incontinence (74%), and pain (73%). Employment and relationship problems were also reported by over half of people with MS (Forbes et al. 2006). Other symptoms include muscle weakness, ataxia, tremor, spasticity, bowel dysfunction, disturbances, sensory impairments, cognitive disorders, dysphagia and sexual dysfunction (Compston and Coles 2008, Flachenecker 2015). Bladder symptoms can be the most socially disabling and embarrassing aspect of the disease (Nakipoglu et al. 2009).

1.2.2 Bladder Structure and Function

As there is no cure for MS, it is important to manage symptoms. This thesis explores the symptom of bladder dysfunction in MS. To understand bladder dysfunction, it is first necessary to consider normal bladder functioning. The function of the bladder is essentially to store and empty urine. The coordinated activity between the detrusor muscles and the sphincter structures make up a complex sphincter system which controls this voiding function (Fowler et al. 2009). The detrusor muscle lines the wall of the bladder. The sphincter structures are the two cylindrical muscles (internal and external) which control the exit of faeces from the body. Bladder storage and emptying
requires continual coordination of the detrusor and sphincter structures (Figure 2) both mediated by the central and peripheral nervous systems (Fowler et al. 2008). The neural pathways that control urinary function are organized as simple on–off switching circuits that maintain a reciprocal relationship between the bladder and the urethral outlet (Fowler et al. 2008). Storage reflexes are activated during bladder filling and are organized primarily in the spinal cord, whereas voiding is mediated by reflex mechanisms that are organized in the brain (Fowler et al. 2008).

Neurological conditions, lesions or trauma can cause disturbances in urinary storage and voiding resulting in bladder dysfunction (Ghezzi et al. 2011). The involvement of the centres and pathways controlling the functioning of the detrusor and sphincters of the urethra leads to dysfunction of the storage phase, due to detrusor over-activity and/or sphincter incompetence. It also leads to dysfunction of the voiding phase, due to inefficient contraction of the detrusor muscle or a lack of coordination between the contraction of the detrusor muscle and relaxation of the sphincter (detrusor–sphincter dyssynergia).

Figure 2 Bladder storage and function (Chancellor and Yoshimura 2002)
Symptoms of bladder dysfunction can therefore be related to disorders of the storage phase (also called irritative symptoms): urgency, increased frequency, stress, urge and mixed incontinence (Abrams et al. 2002, Yamanishi 2004). Involuntary bladder contractions produce the sensation of urgency despite low bladder volume; this can advance to urge incontinence when spasms are associated with urine leakage (DasGupta and Fowler 2002). Disorders of the voiding phase (also called obstructive symptoms) include hesitancy, weak stream, intermittent stream, incomplete emptying (Abrams et al. 2002, Yamanishi 2004). These bladder symptoms cause a multitude of disturbances to daily life for people with MS. However, this topic is given little attention in the literature. Only one-third of people with MS experiencing incontinence seek help (Koch et al. 2001). Suggested reasons for this include the emotional consequences of the symptom, an acceptance of bladder dysfunction in relation to the chronic nature of the illness, a desire to self-manage and lack of awareness of services available.

Social stigma of bladder dysfunction contributes to under-diagnosis and under-reporting (Wyman et al. 1990). Prior to this research, a final year project conducted
by the researcher (CB) in partial completion of a BSc in Physiotherapy explored bladder dysfunction via semi-structured interviews with people with MS (n=6). These preliminary findings suggested that people with MS were reluctant to come forward with information to healthcare professionals as they accepted bladder dysfunction as part of the disease process. Thus, participants attempted to manage their symptoms independently. This preliminary study supported existing research that people with MS self-manage their bladder symptoms (Koch et al. 2000, Koch et al. 2001). Self-management is an appropriate strategy for bladder dysfunction; however, many people with MS use detrimental management strategies such as reducing fluid intake. Therefore, more research was needed to understand how people with MS were self-managing and if they were supported by healthcare services in these approaches. Given the sensitive nature of this symptom, facilitating strategies that can be used independently may be an optimal approach to managing this disruptive symptom of MS.

Initially, the aim of this research was to develop a web and paper based self-management resource tool. However, after reviewing the relevant literature it was clear that the development phase was not immediately feasible as more information was needed regarding the impact of bladder dysfunction on quality of life and current service provision for people with MS experiencing this symptom. These components are essential to build the foundation of an evidence and theory based educational resource to facilitate self-management of bladder dysfunction. This idea forms the basis of the research question, aims and objectives which are outlined in detail below.
1.3 RESEARCH QUESTION

How can self-management of bladder dysfunction be facilitated among people with Multiple Sclerosis?

1.3.1 Aim

The overall aim of this thesis is to inform the development of a self-management resource to enable people with Multiple Sclerosis to self-manage bladder dysfunction.

This study is theoretically situated within critical disability theory (Goodley 2013) where the integration of first-person perspectives is essential. More detail of this theoretical foundation is outlined in Chapter 3.

1.3.2 Objectives

The specific objectives of this thesis are:

1. To gain an in-depth understanding of how bladder dysfunction interferes with quality of life for people with Multiple Sclerosis (MS)

2. To explore current service provision and management of bladder dysfunction among healthcare professionals working with people with MS.

3. To compare perspectives of healthcare professionals and people with MS in the Republic of Ireland on current service provision and self-management of bladder dysfunction.
1.4 RESEARCH STRANDS

To address the research question and aims, this exploratory study has three distinct but interlinked research strands. Each strand was built sequentially on the preceding one. The interviews with people with MS in Strand 1 informed the questioning route for healthcare professionals in Strand 2. Findings from Strand 1 and 2 both guided the development of the online questionnaire used in Strand 3. Each strand connects with a specific objective.

1.4.1 Strand 1

The aim of this strand was to gain an in-depth understanding of how bladder dysfunction interfered with quality of life for people with MS. Face-to-face, individual semi-structured interviews were conducted with nineteen people with MS with bladder dysfunction from the Mid-Western branch of MS Ireland.

1.4.2 Strand 2

The second strand of the thesis aimed to explore current service provision and management of bladder dysfunction among healthcare professionals working with people with MS. This involved a combination of focus groups, dyadic interviews and semi-structured interviews with fourteen healthcare professionals working with people with MS. Participants included physiotherapists, occupational therapists, nurses and clinical case managers from acute and community settings.
1.3.1 Strand 3

The final strand of this thesis involved a large scale online questionnaire. This study explored current service provision and self-management of bladder dysfunction from the perspectives of both people with MS and healthcare professionals. A total of 213 participants completed this questionnaire. Findings help to support both people with MS and healthcare professionals in facilitating effective self-management strategies.

1.5 THESIS OUTLINE

This thesis is presented in traditional chapter-based format with two chapters published as papers in peer review journals (Chapter 4 and 5) and Chapter 5 is in preparation for submission. An introduction to the topic, review of the literature, methodology and overall discussion chapters are provided to guide the reader through all aspects of this multi-stranded thesis.

Chapter 2 presents the background literature for the overall study. This traditional review centralises the person with MS in terms of the prevalence of bladder dysfunction and the personal socioeconomic impact of bladder dysfunction. This chapter also aims to contextualise current services for people with MS with bladder dysfunction and the management options available. Furthermore, it expands on the concept of self-management of this complex symptom.

Chapter 3 outlines the research methodology. The theoretical foundation and conceptual framework underpinning this research is presented first, followed by a justification for the overall type of study design employed. The three research strands
are detailed in terms of participants and recruitment strategies. Data collection methods for each strand are presented. Ethical considerations are also addressed. The following chapters 4-6 are presented as individual published or submitted papers.

Chapter 4 moves into how bladder dysfunction interferes with quality of life for people with MS. This study is published in *Disability and Rehabilitation* (Browne et al. 2015). Nineteen individual semi-structured interviews were conducted with people with MS. Findings demonstrate that bladder dysfunction imposes major disruptions on daily life for people with MS.

Chapter 5 presents the perceptions of healthcare professionals working people with MS and current service provision for people with MS in Ireland. This study is currently under review in the *Journal of MS Care*. The study involved a combination of focus groups, dyadic and individual interviews with fourteen healthcare professionals. Findings suggest that clinical reflection and reflexive practice are both vital for the development of services.

Chapter 6 is the final strand of this thesis and involved a large scale online questionnaire among people with MS (n=109) and healthcare professionals (n=104). The aim of this study was to gather information on the current state of healthcare professional practice nationally with respect to bladder dysfunction in people with MS. Furthermore, this study identified the needs of both people with MS and healthcare professionals around self-managing bladder dysfunction. This chapter will also be submitted for publication.
Chapter 7 is an overall discussion of the thesis findings. Within this chapter, key themes from each strand are presented to demonstrate how findings build on each other and connect to inform the development of an educational resource for both people with MS and healthcare professionals to facilitate self-management of bladder dysfunction. This chapter describes the implications for people with MS, healthcare professionals and healthcare policy. Future research directions are also described towards the end of the chapter.
CHAPTER 2 REVIEW OF THE LITERATURE

2.1 INTRODUCTION

Exploring how self-management of bladder dysfunction may be facilitated among people with Multiple Sclerosis (MS) is the central concern of this thesis. In order to explore this overarching research question this literature review is divided into a number of distinct but connected topics. This chapter will review the available literature on the prevalence, impact and current management of bladder dysfunction among people with MS. This traditional review will set the scene for each stage of the research process.

In keeping with the conceptual framework of this study, which will be discussed in more detail in Chapter 3, the purpose of this review was to centralise the person with MS. Therefore, to estimate the extent of bladder dysfunction among people with MS, this review will first focus on investigating the prevalence of bladder symptoms within this population. This information is helpful when considering the impact of different bladder symptoms on daily life. The impact of these symptoms from the perspectives of people with MS will be considered. Current literature exploring the personal and socioeconomic impact of bladder dysfunction will be reviewed. In terms of the management of bladder dysfunction, current service provision for people with MS with bladder dysfunction will be explored. It is necessary to understand how people with chronic conditions function in society in terms of accessing such services. Finally, existing management options will be reviewed with specific attention to the concept of self-management.
2.2 PREVALENCE OF BLADDER DYSFUNCTION AMONG PEOPLE WITH MS

There is a substantial variation in the prevalence of bladder dysfunction among people with MS. A range of 52-97% has been reported in the literature (Litwiller et al. 1999). The exact prevalence of bladder dysfunction among people with MS is difficult to quantify. This section explores this variance in terms of the methodological issues, including differences among participants and definitions of bladder dysfunction. A detailed review of the prevalence of bladder dysfunction in MS is useful to understand the impact of different bladder symptoms on daily life. It is important to understand why these ranges in prevalence exist as we begin to unravel the complexities of bladder dysfunction among people with MS. Overall prevalence of bladder dysfunction in people with MS will be reviewed, in addition to the prevalence of urinary incontinence, stress urinary incontinence, urge urinary incontinence and mixed incontinence.

An in-depth literature search yielded six studies relevant to prevalence of bladder dysfunction (Hennessey et al. 1999, Bonniaud et al. 2004, Borello-France et al. 2004, Wollin et al. 2005, Goris et al. 2010, Murphy et al. 2012). Study participants had to be 18 years or older and study participants had to have a diagnosis of MS according to the criteria of Poser et al. (1983). Any study including prevalence data was suitable for inclusion. Studies were excluded if they contained participants of other neurological disorders. The detailed search strategy is outlined in Figure 3. Articles successfully fulfilling the inclusion criteria were subsequently examined for methodological quality. Gold standards to evaluate internal and external validity of prevalence research do not exist (Sanderson et al. 2007). However, Radulescu et al.
(2009) developed a guideline for evaluating the quality of prevalence surveys. As per these guidelines the quality of each study was assessed (Appendix 1).

Figure 3 Flow chart of study selection procedure

Articles retrieved from database search (n=825)
- AMED: n=2
- CINAHL plus: n=20
- Medline: n=86
- PsycINFO: n=5
- SPORTDiscus: n=5
- Web of Science: n=155
- Science Direct: n=378
- Embase: n=174

Excluded (n=789)
- Study duplicates: n=188
- Removed after screening of title and abstract: n=474
- Unpublished Data: n=54
- Not in English Language: n=10
- Intervention studies for management of bladder dysfunction: 26
- Prevalence studies which included participants with other neurological conditions: n=7
- Guidelines and Reviews of management of MS: 20
- Prevalence of MS: 10

Articles for full text review (n=36)
- Articles which did not contain any prevalence information: n=7
- Unpublished articles, only abstract available: n=6
- Reviews which did not contain any prevalence data: n=3

Included (n=20)
- Eligible articles from citations and references of included articles (n=3)

Total included (n=23)
- Number of articles using questionnaire methods to collect data (n=6)

6 articles included in the final review
Key data was subsequently extracted from each study (Table 1). This table summarises some key aspects from these studies. The number of participants in these studies ranged from sixty to two hundred and twenty-one with ages from thirty-five to forty-nine. All studies had a majority of female participants with three studies incorporating female participants only. Two studies were based in the USA (Borello-France et al. 2004, Murphy et al. 2012); the remaining studies were from France, UK, Turkey and Australia. Only one study reported on the type of MS experienced by participants (Goris et al. 2010). Only one study reported on disease severity (Bonnaud et al. 2004). Two studies recruited participants from hospitals (Bonnaud et al. 2004, Goris et al. 2010). One study recruited from a MS care centre (Bonnaud et al. 2004) and one from a medical centre (Borello-France et al. 2004).
Table 1 Description of the studies included in the review

<table>
<thead>
<tr>
<th>Citation</th>
<th>N</th>
<th>Age (Mean)</th>
<th>Gender</th>
<th>Country</th>
<th>Type of MS</th>
<th>EDSS</th>
<th>Sampling Frame</th>
<th>Type of BD</th>
<th>Prevalence of symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Murphy 2012</td>
<td>143</td>
<td>45.8</td>
<td>F=143</td>
<td>USA</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>Purposive sampling within 1 MS Centre</td>
<td>SUI= 55.9%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>UUI=70.6%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Mixed=44.8%</td>
</tr>
<tr>
<td>Bonniaud 2004</td>
<td>197</td>
<td>46.7</td>
<td>F=129</td>
<td>France</td>
<td>-</td>
<td>4.4</td>
<td>-</td>
<td>Purposive sampling within 3 hospitals</td>
<td>Irritative= 5%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>M=68</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Obstructive= 15%</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>UUI=11%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Mixed=36%</td>
</tr>
<tr>
<td>Borello-France 2004</td>
<td>133</td>
<td>43.8</td>
<td>F=133</td>
<td>USA</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>Purposive sampling within 1 medical Centre</td>
<td>OAB=71%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>UUI=83%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>SUI=73%</td>
</tr>
<tr>
<td>Wollin 2005</td>
<td>62</td>
<td>49</td>
<td>F=46</td>
<td>Australia</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>Self-selected participants</td>
<td>UI=66%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>M=10</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>UUI=52%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>SUI=34%</td>
</tr>
<tr>
<td>Goris 2010</td>
<td>60</td>
<td>35.9</td>
<td>F=60</td>
<td>Turkey</td>
<td>RR=88.3%</td>
<td>-</td>
<td>-</td>
<td>Purposive sampling within 1 hospital</td>
<td>UI=45%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Mixed= 33.3%</td>
</tr>
<tr>
<td>Hennessey 1999</td>
<td>221</td>
<td>50.2</td>
<td>F=148</td>
<td>UK</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>Purposive sampling from MS register</td>
<td>Urgency= 71%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>M=73</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Frequency=76%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>UI=67%</td>
</tr>
</tbody>
</table>

F= Female, M= Male, USA= United States of America, SUI= Stress urinary incontinence, UUI=Urinary urge incontinence, OAB=Overactive bladder symptoms, UI=Urinary incontinence
The total prevalence of bladder dysfunction varied from 45-98% within the six studies. The ranges of specific bladder symptoms are provided in Table 2. Four studies provided information about overactive bladder. Overactive bladder is characterised by symptoms of urgency and frequency. Hennessey et al. (1999) reported that 76% of participants experienced frequency and 71% urgency. Wollin et al. (2005) reported that 62% experienced frequency and 75% experienced urgency. Borello-France et al. (2004) found that 71% experienced frequency while 83% experienced urgency. Bonniaud et al. (2004) classified urgency and frequency as “irritative” symptoms and found a prevalence of 5%.

**Table 2 Prevalence of bladder symptoms**

<table>
<thead>
<tr>
<th>Bladder Problem</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total No. with bladder symptoms</td>
<td>45-98</td>
</tr>
<tr>
<td>Overactive Bladder: Frequency/Urgency</td>
<td>5-76</td>
</tr>
<tr>
<td>UI</td>
<td>10-58</td>
</tr>
<tr>
<td>SUI</td>
<td>34-73</td>
</tr>
<tr>
<td>UUI</td>
<td>27-83</td>
</tr>
<tr>
<td>Mixed</td>
<td>6-44.8</td>
</tr>
</tbody>
</table>

SUI= Stress urinary incontinence, UUI= Urinary urge incontinence, UI= Urinary incontinence

Four studies reported prevalence data on urinary incontinence. Bonniaud et al. (2004) found 10% of participants experienced “continuous leaking”; Wollin et al. (2005) found 66% of participants to experience “leaking”. Goris et al. (2010) reported 45% of participants to have urinary incontinence and Hennessey et al. (1999) reported 58% of participants to have this symptom. Three studies provided prevalence information on stress urinary incontinence (Borello-France et al. 2004, Wollin et al. 2005, Murphy et al. 2012) with rates of 55.9%, 73% and 34% respectively. Two studies provided prevalence information about mixed incontinence. Murphy et al. (2012) reported that 44.8% of participants experienced both stress and urge incontinence. Bonniaud et al.
found 8% of participants experienced urge with irritative symptoms, 6% urge with obstructive symptoms, 9% irritative and obstructive symptoms and 36% irritative, obstructive and urinary incontinence.

A substantial variation in the estimates of bladder dysfunction in people with MS is evident. The synthesis of the published literature on the prevalence of bladder dysfunction in MS is complex because of the differences in the definitions of urinary dysfunction used, the populations used in terms of disease severity, years since diagnosis, age, gender as well as the reliability and validity of questionnaires used. Some of the methodological issues found in this review are consistent with the findings of similar reviews in other populations (Hampel et al. 2004). Four studies recruited participants from hospitals and clinics. These participants may not be representative of the general MS population. Participants within the remaining two studies were self-selected. Wollin et al. (2005) reported a response rate of 70%. However, this sample was self-selected which limits the representativeness of the data. Hennessey et al. (1999) did not provide any information on response rate.

The questionnaires used, specifically the response method, may have contributed to differences in prevalence. Two studies used the Urogenital Distress Inventory (UDI-6) (Borello-France et al. 2004, Murphy et al. 2012). Although not validated in people with neurological conditions, internal consistency, concurrent construct validity and sensitivity to change of the UDI-6 is reported (FitzGerald and Brubaker 2002). Other studies provided little information on the psychometric properties of the questionnaires used. None of the above studies offered information about disease severity, a factor that may explain the wide range in bladder symptoms.
Gender differences between studies may also contribute to the variation in findings. Three studies reported on the prevalence of stress urinary incontinence. Murphy et al. (2012) and Borello-France et al. (2004) both have female participants only and showed a prevalence of 55.95 and 73% respectively. While Wollin et al. (2005) had a smaller sample size (n=47) they included both male and female participants and reported a prevalence of 34%. However, this study did not present prevalence rates based on gender. Gender specific prevalence rates of bladder symptoms would allow future research to explore specific symptoms and how they differ among men and women. As most prevalence studies focus on women only, it is important that men remain involved in research evaluating the impact of bladder dysfunction, as it is not known to what extent men are affected by these bladder symptoms.

Furthermore, findings may differ due to cultural differences. Goris et al. (2010) stated that Turkish women experienced difficulty in expressing urinary incontinence and sexual dysfunction due to cultural factors. None of the other studies commented on this topic. Reluctance to discuss bladder symptoms was reported among people with MS (Koch et al. 2001). No studies to date discussed bladder symptoms among people with MS in Ireland.

Despite this variation, the prevalence of bladder dysfunction in MS remains higher than the general population. A review of thirteen studies by Sandvik (1996) reported a prevalence of 20-30% in young adults, 30-40% of middle aged and 30-50% in elderly people. Due to the high prevalence among people with MS, it is necessary to examine how these symptoms interfere with quality of life.
2.3 PERSONAL AND SOCIOECONOMIC IMPACT OF BLADDER DYSFUNCTION

A wide range of bladder symptoms exist among people with MS. However, there is a paucity of literature regarding the impact of these symptoms on the quality of life of people with MS. Quality of life (QOL) is a broad multidimensional concept that includes subjective evaluations of both positive and negative aspects of life (WHOQOL Group 1998). It is a ubiquitous concept that has different philosophical, political and health-related definitions (Fallowfield 1990). The concept of health-related quality of life (HRQOL) and its determinants have evolved since the 1980s to encompass those aspects of overall quality of life that affect physical or mental health (McHorney 1999, Centers for Disease Control and Prevention 2000). It is subjective and multidimensional, encompassing physical and occupational function, psychological state, social interaction and somatic sensation (Schipper et al. 1996). Both QOL and HRQOL are used interchangeably in the literature even though health-related quality of life is assessed with standardised measures (Karimi and Brazier 2016). Therefore, for the purpose of this thesis the overarching term of QOL will be used.

As one of the primary causes of neurologic disability in young adults, MS has significant implications for QOL for people living with the condition (Wu et al. 2007). Physical disability explains only part of the reduced QOL among people with MS. Bladder dysfunction was identified as a top priority among people with MS (BSRM 1993) but it has not been given as much attention in the literature compared to other symptoms of MS (Hennessey et al. 1999). This distressing symptom causes limitations in social participation, activity levels and sexual activity (Hatzichristou 1996). Bladder
dysfunction is one of the most debilitating aspects of MS and has the capacity to affect several life domains, including work, self-care and leisure activities (Minassian et al. 2003). Furthermore, bladder dysfunction can also have psychological implications in terms of stress, worry, anxiety and even depression (Melville et al. 2005, Coyne et al. 2012).

The empirical literature investigating the impact of bladder dysfunction on QOL focuses on non-MS populations, primarily middle aged and older women. Urinary incontinence has detrimental effects on QOL for women of all ages (Sinclair and Ramsay 2011, Nilsson et al. 2012). Among these other populations, bladder symptoms are associated with sexual dysfunction (Barber et al. 2002, Handa et al. 2004), relationship problems (Barber et al. 2002), withdrawal from sport and exercise, travel restrictions (Lagro-Janssen et al. 1992), major depression and social isolation (Melville et al. 2002). It also has a potential impact on working life and employment with concerns about feeling wet and smelling of urine leading to loss of concentration, loss of ability to perform physical tasks and interruption of work for toilet breaks (Fultz and Herzog 2001). Despite this body of evidence few studies have analysed the impact of bladder dysfunction among people with MS. Therefore, given the multitude of symptoms people with MS experience, it is important to explore their perspectives of the extent to which bladder dysfunction imposes on daily life.

Forty-six percent of women suffering from urinary incontinence said their symptoms negatively impacted on sexual function, thus reducing frequency of sexual intercourse. The stigma attached to bladder dysfunction results in many women withdrawing from social and recreational activities (Lagro-Janssen et al. 1992). Psychological
disturbances are common in women with urinary incontinence (Shaw 2001) and many report low self-confidence, feeling ashamed and embarrassed and feeling unattractive to others (Charalambous and Trantafylidis 2009). This can increase the strain on intimate relationships (Robens et al. 2014).

Few studies include the perspectives of men with MS. As previously mentioned the prevalence of bladder symptoms in men with MS is unclear. Most research exploring bladder dysfunction among people with MS includes only women. There seems to be an assumption that men and women have similar experiences with bladder dysfunction and only one study to date (Koch et al. 2000) specifically identified the experiences of men who live with multiple sclerosis and bladder dysfunction. Therefore, to address this gap in literature, the perspectives of both men and women with MS with bladder dysfunction must be included.

Literature exploring the impact of bladder dysfunction among people with MS is largely focused on objectively quantifying quality of life, notably with the use of questionnaires. Most studies focus on the bladder symptom urinary incontinence. Khan et al. (2009) used a range of bladder specific questionnaires and found that urinary incontinence was not only bothersome for people with MS but also resulted in substantial disability. In contrast, Forbes et al. (2006) suggested that urinary incontinence had little impact on QOL for people with MS. This study used a general health-related quality of life instrument (SP-36). Authors concluded that this general instrument may not be sensitive enough to capture the impact of urinary incontinence in populations experiencing disabling conditions. Furthermore, this questionnaire did not include any bladder or MS specific components. People with MS often experience
a number of symptoms including muscle weakness, balance and mobility problems, fatigue and sensory impairments, of which some may be more restricting than others (Compston and Coles 2008). Investigating these symptoms in isolation by means of QOL instruments may not capture the extent to which bladder dysfunction intersects with other symptoms of MS and on daily life. Thus, an in-depth qualitative exploration is needed to gain insight into living with MS and managing bladder dysfunction.

Due to the early onset of the condition and long duration, MS can impose economic burdens on people with MS, on their families, and on society as a whole. Hospital admissions are common among people with MS, resulting in the disruption of work, social and family life. High levels of absenteeism and permanent withdrawal from the workforce due have been reported among people with MS (Kobelt et al. 2006, Taylor et al. 2007). Direct costs of MS rise with increasing disability. Mean annual direct costs of MS in Ireland increased more than fourfold from €12,822 to €55,900 per person from moderate to severe disability driven by the excess cost of institutional care and provision of professional care in the home (Fogarty et al. 2014). Total annual indirect costs are estimated as being €23,750 per person with MS, extrapolated out to the national population with MS (n=9,000), provides for a total indirect cost estimate of €213.8 million (O'Connell 2015).

More than 50% of people with MS will experience bladder problems within 3-5 years of diagnosis (Nortvedt et al. 2007). Bladder dysfunction can further increase financial burden. Direct costs to the individual include the cost of incontinence pads, diagnosis and treatment costs while direct costs to the healthcare system include increased labour time for clinicians, medical appointments, surgery, medications and diagnosis and
nursing home costs (Koch et al. 2000). Indirect costs involve lost wages, loss of productivity at work due to absenteeism and presenteeism (Hu and Wagner 2000, Moore 2001). A systematic review by Milsom et al. (2014) of the global economic burden of urge urinary incontinence estimated an annual cost ranging from €2.9 billion (direct costs for five European countries in 2000) to €7 billion (direct and indirect costs for Canada and five European countries in 2005). Authors concluded that the economic burden of urge urinary incontinence is substantial and will increase markedly in the future as the population ages (Milsom et al. 2014). The management of bladder dysfunction has significant cost implications for individuals and healthcare services. Facilitating self-management of bladder dysfunction among people with MS may help to ease this financial burden.

Approximately 45% of people with MS use assistive devices such as canes, walkers and wheelchairs to facilitate mobility (Finlayson et al. 2001). Risk of injurious falls is increased in people with MS (Peterson et al. 2008, Cameron et al. 2011). Bladder symptoms that interfere with daily living activities are associated with increased risk of falling (Finlayson et al. 2006). For example, rushing to the toilet can increase falls and fall related injuries (Wagg 2011, Coote et al. 2013). In addition to this higher risk of falls, bladder dysfunction is associated with urinary tract infections, which can further increase hospital and nursing home admissions (Stewart et al. 2003, Ko et al. 2005, Nortvedt et al. 2007).

Bladder dysfunction imposes a range of personal and socioeconomic consequences for people with MS. Little is known about the extent of the impact of bladder symptoms among people with MS and whether it is similar to experiences of other populations.
Due to their underlying neurological impairments, people with MS who experience bladder dysfunction may view their symptoms differently than their otherwise healthy counterparts who experience bladder dysfunction. It is necessary to understand the unique perspective of this population in terms of living with bladder symptoms and MS, in order to implement best practice in the management of bladder dysfunction.

2.4 CURRENT NEUROLOGY SERVICE PROVISION

It is a complex task to plan services for people with MS due to the uncertainty of the disease trajectory and the unpredictability of the symptom presentation. A client-centred approach led by individual need rather than diagnosis is necessary (Williams 2012, Multiple Sclerosis Ireland 2014). This section will review current service provision in Ireland for people with MS with particular attention to bladder dysfunction including the overall structure of neurology services in Ireland with comparison to international recommendations. Furthermore, the availability of specialist and community services will be outlined, highlighting the roles of healthcare professionals working with people with MS.

It is necessary to ensure that onward referral and access to effective management strategies for bladder dysfunction among people with MS are widely available throughout Ireland. A national survey was carried out by the National Clinical Programme for neurology in collaboration with the Neurological Alliance of Ireland (NAI). This survey was circulated to the eleven neurology centres in Ireland (Neurological Alliance of Ireland 2015). Preliminary findings report deficits in staffing across all eleven neurology centres (NAI 2015). These findings represent the
subjective opinions of neurologists in Ireland. This data has not been cross checked with human resources systems within the HSE. Furthermore, these findings represent only staff employed by the HSE and does not capture privately funded neurology nurses working in the Republic of Ireland. Worldwide, Ireland ranks thirty-third in terms of access to neurologists (McGreevy 2014). The Association of British Neurologists (ABN) recommended a ratio of one consultant neurologist per 70,000 population (Royal College of Physicians 2011). No hospital group in Ireland meets this recommendation (Table 3). Furthermore, the number of specialist nurses in neurology is less than half of the recommended 27 MS nurses for the population (Table 4).

Table 3 Consultant Neurology Staffing in Neurology Centres compared to ABN recommended levels (NAI 2015)

<table>
<thead>
<tr>
<th>Hospital Group</th>
<th>Neurology Centres</th>
<th>Ratio neurologist: population Recommended 1:70,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dublin North-East</td>
<td>Beaumont</td>
<td>1: 181,818</td>
</tr>
<tr>
<td>1 centre. Pop 800,000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dublin Midland</td>
<td>St. James Hospital, Tallaght Hospital</td>
<td>1: 114,285</td>
</tr>
<tr>
<td>2 centres. Pop 800,000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>South/South-West</td>
<td>Cork University Hospital, Waterford Regional Hospital, Mercy University Hospital</td>
<td>1: 106, 250</td>
</tr>
<tr>
<td>3 centres. Pop 850,000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>West/North-West</td>
<td>University Hospital Galway, Sligo Regional Hospital</td>
<td>1: 185,185</td>
</tr>
<tr>
<td>2 centres. Pop 700,000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mid-West</td>
<td>University Hospital Limerick</td>
<td>1: 200,000</td>
</tr>
<tr>
<td>1 centre. Pop 400,000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>East</td>
<td>Mater Misericordiae, University Hospital, St. Vincent’s University Hospital</td>
<td>1: 147,050</td>
</tr>
<tr>
<td>2 centres. Pop 1,000,000</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 4 Current Clinical Nurse Specialist (Neurology) allocation (NAI 2015)

<table>
<thead>
<tr>
<th>Neurology Centre/Hospital Group</th>
<th>Current CNS</th>
<th>Ratio per population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beaumont/ Dublin North-East Pop 800,000</td>
<td>3</td>
<td>1:266,666</td>
</tr>
<tr>
<td>Mater St. Vincent’s/Ireland East Pop 1,000,000</td>
<td>3</td>
<td>1:200,000</td>
</tr>
<tr>
<td>Galway Sligo/North-West Pop. 700,000</td>
<td>0.4</td>
<td>1:500,000</td>
</tr>
<tr>
<td>St. James’ Tallaght/Dublin Midlands Pop. 800,000</td>
<td>1.5</td>
<td>1:266,666</td>
</tr>
<tr>
<td>Limerick; Mid-West; Pop. 400,000</td>
<td>1</td>
<td>1:400,000</td>
</tr>
<tr>
<td>Waterford Cork Mercy/ South, South-west; Pop. 850,000</td>
<td>0</td>
<td>1:283,333</td>
</tr>
</tbody>
</table>

Additionally, a critical lack of neurorehabilitation services was highlighted (NAI 2015). To ensure comprehensive care for people with MS, multi-disciplinary management including a neurologist, urologist, nurse, rehabilitation doctor, physiotherapist and occupational therapist is recommended (Motta and de Carvalho 2008). Given the shortage of specialist neurological services in Ireland, there is a need for non-specialist healthcare professionals to consider their role in MS care. In 2012, the HSE published an educational handbook for non-specialist nurses and midwives caring for people with MS. This comprehensive handbook outlines the role of each multidisciplinary team member in MS care. This team involves the nurse/midwife, physiotherapist, occupational therapist, speech and language therapist, psychologist, clinical nurse specialist, continence advisor, social worker, neurologist, GP, public health nurse and dietician. While this handbook is useful, it fails to include the role of
the urologist or detailed information regarding the management of bladder dysfunction in this population. Within this handbook, the continence advisor is the only professional to address bladder dysfunction.

When safety is of concern, bladder dysfunction falls under the scope of each member of the multidisciplinary team. Evidence suggests that overactive bladder symptoms can lead to an increase in falls and fractures since people may rush to the toilet (Chiarelli et al. 2009). Bladder symptoms can exacerbate other symptoms of MS and this link needs to be made explicit if healthcare professionals are to understand the importance of bladder management in people with MS. For example, episodes of urinary frequency with urge incontinence can conceal the presence of a urinary tract infection among people with MS (Williams 2012). Urinary tract infections can then cause neurological symptoms to worsen causing a pseudo-relapse (Fowler et al. 2009).

Evidence-based guidance and treatment algorithms are available to assist nurses and the broader multidisciplinary team in the management of people with MS (Multiple Sclerosis Trust 2007, Fowler et al. 2009, NICE 2012, Pannek et al. 2013). These should inform care planning processes in acute and community care settings. It is unclear whether these guidelines are used by healthcare professionals in Ireland to manage people with MS.

A similar situation persists in the UK, with a shortage of specialist MS nurses. However, considering current financial constraints in the NHS, it is unlikely that this national shortage will be addressed in the near future (Meikle 2011). Decline in the number of nurse specialists combined with the impact of an unpredictable debilitating neurological condition and bladder and bowel symptoms, provoke anxiety and distress among people with MS (Multiple Sclerosis Trust 2007). Specialist neurology services
are lacking in Ireland; therefore, alternative strategies are needed to increase awareness of bladder dysfunction across all healthcare professionals who work with people with MS. More research is needed to explore service provision and access to services for people with MS with bladder dysfunction in Ireland. By understanding how people with MS navigate through the healthcare system, it may be possible to identify the pivotal points for change to optimise management of bladder dysfunction within this population.

2.5 MANAGEMENT OF BLADDER DYSFUNCTION FOR PEOPLE WITH MS

It is not clear to what extent healthcare professionals in Ireland are involved in managing bladder dysfunction. A number of guidelines exist for the management of neurogenic lower urinary tract dysfunction and bladder symptoms in MS (de Sèze et al. 2007, Fowler et al. 2009, Pannek et al. 2013). NICE (2010) provides evidence-based clinical pathways for the assessment and management of lower urinary tract symptoms. These clinical guidelines suggest a stepwise approach for generalist clinicians at initial assessment. They differentiate between conservative management options and the need to refer the client for specialist assessment. Fowler et al. (2009) proposed that bladder management include testing for urine infection and measurement of the post micturition residual urine volume. A high post-void residual volume can increase the risk of urinary tract infection. Pannek et al. (2013) reported the incidence, definitions, diagnosis, therapy, and follow-up observation of neurogenic lower urinary tract dysfunction. All guidelines concur that assessment and management of bladder symptoms in people with MS are complex and multifaceted. Management of bladder dysfunction in people with MS can only be effective if an
An integrated approach is adopted by all those involved in caring for this population (Williams 2012).

Abernethy et al. (2007) reviewed the available evidence for the effectiveness of management of bladder and bowel dysfunction in people with MS. The most commonly used management methods involve pharmacological input of anticholinergic agents. However, these are found to have limited success, lack efficacy and are not tolerated well in the long term by people with MS (de Sèze et al. 2007, Tubaro et al. 2012). This is due to the many side-effects including constipation, dry mouth, dry eyes and incomplete voiding (Tubaro et al. 2012). Tubaro et al. (2012) concluded that future research priorities should include research on conservative strategies for the management of bladder symptoms.

The conservative management of bladder dysfunction described in the literature includes a wide variety of interventions: clean intermittent self-catheterisation or permanent indwelling catheters (Fowler et al. 2009), electro-acupuncture (Soe et al. 2009), dorsal penile/clitoral nerve stimulation, and percutaneous posterior tibial nerve stimulation (de Seze et al. 2011, Tubaro et al. 2012). Guidelines for the management of bladder dysfunction in MS recommend clean intermittent self-catheterisation for anyone with a raised post micturition residual volume (Fowler et al. 2009). There are multiple risks associated with catheter use including blood in the urine, bladder or renal stones in addition to the hazard of urethral erosions in the long term (Tubaro et al. 2012). Other conservative methods include bladder retraining (Burgio 2013), pelvic floor muscle training (Lúcio et al. 2011), neuromuscular electrical stimulation and electromyography (McClurg et al. 2006, McClurg et al. 2008).
Bladder retraining consists of three components; education, scheduled voiding and positive reinforcement (Fantl et al. 1991, Burgio 2013). Pelvic floor muscle training was developed by Dr. Arnold Kegel in 1948 for the management of stress urinary incontinence (Kegel 1948). Their purpose is to increase voluntary contraction of the pelvic floor muscles activities that increase intra-abdominal pressure such as coughing, sneezing or lifting to reduce urinary leakage (Bø 2004). Although pelvic floor muscle training is mainly used for the treatment of stress urinary incontinence it has been found to be beneficial in the treatment of detrusor instability and urgency (De Ridder et al. 1999). Current evidence for the effectiveness of conservative interventions in management of bladder dysfunction in people with MS suggest that pelvic floor muscle training either used alone or in conjunction with other conservative interventions can reduce urinary symptoms (Vahtera et al. 1997, De Ridder et al. 1999, McClurg et al. 2006, McClurg et al. 2008, Lúcio et al. 2011).

Neuromuscular electrical stimulation and electromyography biofeedback give visual and auditory feedback to promote control of voluntary muscle relaxation and contraction. Few studies explored electromyography biofeedback among people with MS; however, in a review of the literature Glazer and Laine (2006) found that pelvic floor muscle biofeedback was an effective treatment for urinary incontinence in healthy men and women. McClurg et al. (2008) compared the effect of active neuromuscular electrical stimulation to placebo neuromuscular electrical stimulation in a double blinded, placebo controlled randomised control trial. Findings reported that active neuromuscular electrical stimulation was beneficial for reducing bladder symptoms among people with MS. However, these findings were not sustained at follow up.
Due to the variable nature of MS and the number of conservative intervention methods, it is still not known what intervention is most suitable. Research into combined interventions to manage bladder dysfunction is in exploratory stages among people with MS. Thus, there is no single solution to managing bladder dysfunction among people with MS. Optimising self-management through a number of conservative strategies such as bladder retraining, pelvic floor muscle training and self-catheterisation may improve bladder symptoms for people with MS. Facilitating self-management of bladder dysfunction has been given little attention in the literature. It is necessary to explore the usefulness of self-management of bladder dysfunction among people with MS.

2.6 SELF-MANAGEMENT OF BLADDER DYSFUNCTION

Many people with MS attempt to manage their bladder symptoms independently (Koch et al 2000). Regardless of the consequences attached to some strategies such as poor fluid intake and social withdrawal, many participants do not seek help due to the silent nature of the problem. Through a participatory action research group, Koch et al. (2000) found that men often dehydrate themselves to avoiding the feelings of humiliation associated with leaking in public, despite understanding the potential detrimental effects this could have on their physical well-being. This stigma associated with being unable to control bodily functions and the fear of other people’s reactions, including those of health professionals is also common in older people experiencing bladder dysfunction (Shaw 2001, Horrocks et al. 2004).
Given the sensitive nature of this symptom, strategies that can be used independently may be an optimal approach to managing this disruptive symptom. Healthcare professionals may be aware of the daily challenges faced by those with bladder dysfunction, but are unsure of how to best support them in effective self-management (Wilde et al. 2014). Self-management is a critical component of self-care that involves monitoring and managing symptoms in addition to the functional, emotional, psychosocial, and physical components of a chronic illness (Richard and Shea 2011). Self-management can increase patients’ awareness of physical symptoms, empower people to monitor the effects of behavioural changes aimed at improving chronic conditions, and help them feel better equipped to cope with an illness (Wilde et al. 2014).

Self-management approaches are common in many chronic conditions; however, it is not yet common practice in relation to bladder dysfunction (Wilde et al. 2014). The principles of self-management can be applied to bladder dysfunction. Furthermore, several bladder symptoms are amenable to self-management through conservative management strategies such as bladder retraining for detrusor over-activity, pelvic floor muscle exercises for pelvic floor weakness and self-catheterisation to assist bladder emptying (Fowler et al. 2009). Many people with MS continue to attempt these strategies independently without any input from healthcare professionals, despite varying degrees of success. Therefore, in this thesis, self-management relates to optimising use of these conservative strategies to facilitate effective management of bladder symptoms for people with MS.
Computer and internet-based self-management interventions have been investigated among older adults with continence problems in a quasi-experimental study (Boyington et al. 2005) and in a single-group study (Ruiz et al. 2011). These studies found improvements in knowledge, symptoms, self-efficacy and overall management of bladder symptoms. Furthermore, a self-management risk factor modification tool was found to reduce daily leakage episodes and improve self-efficacy and incontinence-related quality of life in older women in a six-month prospective cohort study (Holroyd-Leduc et al. 2011). Although such tools exist, it is not known whether self-management of bladder dysfunction among people with MS is implemented in current practice in the Republic of Ireland. This gap between research and practice highlights the need to improve the health services provided to people with MS with bladder dysfunction. No studies to date have explored the facilitation of self-management strategies among people with MS.

To inform the development of a self-management resource for people with MS with bladder dysfunction it is necessary to explore in detail the perspectives of people with MS and healthcare professionals. This will enable further questioning of both people with MS and healthcare professionals nationwide to identify specific needs in relation to strategies used to support management of bladder dysfunction among people with MS.

2.7 CHAPTER SUMMARY

Bladder dysfunction is a distressing symptom of MS. A review of the prevalence of bladder dysfunction in MS indicates that a wide range of bladder symptoms exist
among people with MS. These symptoms affect several life domains, including work, self-care and leisure activities which can increase stress, worry, anxiety and even depression. However, much of the existing research is among non-MS populations. It is necessary to better understand the unique perspective of this population in terms of living with bladder symptoms to provide insight into how people with MS are managing bladder dysfunction. Furthermore, it is not clear to what extent healthcare professionals in Ireland are managing bladder dysfunction and if suitable self-management strategies are supported. An in-depth exploration of current service provision is necessary to improve management of this symptom. This information will guide the development of a self-management resource to enable people with Multiple Sclerosis to self-manage bladder dysfunction.
CHAPTER 3 METHODOLOGY

3.1 INTRODUCTION

The research methodology is influenced by the theoretical perspectives adopted by the researcher, and by the researcher’s philosophical stance (Gray 2013). All researchers bring a particular set of assumptions and beliefs to a study; therefore, research is naturally filtered through the researcher’s point of view, their theoretical perspective (Kilbourn 2006). The researcher must clarify their inquiry lens as his/her theoretical orientation guides the research process, from the formation of questions, the collection of data and the interpretation of data (Kilbourn 2006). This chapter opens with the theoretical foundation underpinning this project. The researcher’s views on the nature of reality and how reality is understood will be discussed. Elements of critical theory are combined with aspects of constructivism to form the basis of this research. Several shared assumptions exist between these two traditions (Guba and Lincoln 1994). These ideas informed the development of the conceptual framework, which will be detailed later in this chapter. The conceptual framework is a system of concepts, assumptions, expectations, beliefs and theories that supports the research process (Miles and Huberman 1994, Robson 2002). It provides a justification for the mixed methods approach undertaken. The methods used in the three research strands are described in this chapter. Data collection for each strand are presented with detailed description and justification for their use. Key strategies to enhance the quality of this research are described with a reflexive statement given to situate the researcher in this multi-stranded study. Ethical considerations are incorporated near the end of the chapter.
Each research strand addresses a specific thesis objective. The first strand aimed to gain an in-depth understanding of how bladder dysfunction interfered with quality of life for people with Multiple Sclerosis (MS). Strand 2 explored current service provision and management of bladder dysfunction among healthcare professionals working with people with MS. The final strand compared perspectives of healthcare professionals and people with MS in the Republic of Ireland of current service provision and self-management of bladder dysfunction.

3.2 THEORETICAL FOUNDATION

When undertaking any research, it is important to be explicit about the theoretical underpinnings of the research. A paradigm includes the philosophical assumptions relating to what is under study, the purpose and also product of the research (Hammersley 2012). The paradigm of inquiry of this research was informed by congruent elements of constructivism and critical theory. Guba and Lincoln (2005) break down paradigms into three aspects; ontology, epistemology and methodological assumptions. Each aspect will be briefly explained, with particular emphasis on how constructivism and critical theory connect within this study. As ontology and epistemology are interwoven (Breckenridge et al. 2012), they will be addressed synergistically.

Ontology describes a researcher’s stance on the nature of reality (Denzin and Lincoln 2005). In this thesis the researcher takes the position that multiple interpretations of reality exist. Both constructivism and critical theory contend that dynamic social and cultural structures, rather than certain distinguishable variables, constrain human
actions; therefore, both are open to the possibility of social change (Clark 2002). There are multiple realities, rather than a single true reality in the social world (Grix 2010). Within this confluence of paradigms, it is understood that people construct reality by ascribing meaning to certain events or actions (Bryman 2012).

When many alternative understandings of reality are brought together a greater awareness of the complexity of the phenomenon becomes available. While ontology relates to understanding what comprises reality, epistemology focuses on what it means to know (Denzin and Lincoln 2005). In other words, epistemological assumptions are concerned with how knowledge can be created, acquired and communicated (Scotland 2012). Both constructivism and critical theory presume a subjectivist epistemology that involves knowledge that is co-constructed (Guba and Lincoln 1994). Linking back to ontological foundation of multiple realities, the researcher believes there are multiple ways of knowing that include our interactions and experiences of the world. Both constructivism and critical theory assume that the researcher and participants co-create knowledge while maintaining that is is still possible to capture the essence of a phenomenon (Denzin and Lincoln 2005). Both traditions thus offer interpretations rather than proposing causal relationships (Clark 2002).

The origin of the term ‘critical theory’ dates from 1937 when Horkheimer presented his ‘critical theory of society’ in the essay Traditional and Critical Theory (Horkheimer 1972). Horkheimer’s critical theory positioned both the researcher and the phenomenon under investigation as engaged in an interactive relationship. Thus, research findings are part of an iterative process, gradually refined through interaction between the investigator and participants (Denzin and Lincoln 2005). This was
particularly evident in Strand 2 of the project where the qualitative findings from Strand 1 were used as a springboard for discussion of bladder dysfunction within the group interviews with healthcare professionals. Combining aspects of critical theory and constructivism enabled the researcher to explore the complex interaction between people with MS and living with bladder dysfunction by recognising that people with MS generate knowledge and meaning from their experiences. People with MS have unique contributions to make to bladder dysfunction literature, as they live with bladder symptoms along with a range of other MS-related impairments.

Both critical theory and constructivism presume a naturalistic set of methodological procedures (Denzin and Lincoln 2005, Guba and Lincoln 2005). This nature of inquiry requires interaction between the investigator and the subjects of inquiry. Methodology cannot be reduced to a question of methods; rather, methods employed must be aligned well with an overarching methodological approach (Guba and Lincoln 1994). Thus, in order to effectively respond to the range of research objectives while centralising the experiences of people with MS in this thesis, a mixed methods approach was deemed most appropriate (Tashakkori and Teddlie 2003). Methodological procedures are detailed later in this chapter.

A theoretical foundation is integral to research (Leshem and Trafford 2007); forming the relationship among connected concepts, assumptions and generalisations (Bloomberg and Volpe 2015). The purpose is to explain the meaning, nature and challenges of a phenomenon so that we may use that knowledge to act in more informed and effective ways (Bloomberg and Volpe 2015). Within this study, the researcher attended to ways in which the phenomenon of bladder dysfunction in MS was experienced from both people with MS and healthcare professionals, thus
shedding light on the essential aspects of the experience. To make sense of these experiences it is necessary to be guided by a conceptual framework. Conceptualisation enables the researcher to draw meaning from the world and to provide sense, order and coherence to information gathered (Bloomberg and Volpe 2015).

### 3.2.1 Conceptual Framework

A conceptual framework is a set of broad ideas and principles taken from relevant fields of inquiry (Reichel and Ramey 1987). It is more than just a set of ideas related to the topic (Bloomberg and Volpe 2015); rather, the conceptual framework offers a mechanism to help understand how people with MS and bladder dysfunction navigate within today’s society. A conceptual framework that respects the theoretical foundation is informed by three substantive bodies of work: critical disability theory (Goodley 2010), International Classification of Functioning and Disability framework (World Health Organization 2001) and self-regulatory model (Leventhal et al. 1980). This conceptual framework guided the researcher in relation to study design, data collection and analysis and facilitated a deeper understanding of the phenomenon under investigation (Denzin and Lincoln 2005).

Bladder dysfunction among people with MS has not been previously explored under this theoretical foundation. Furthermore, following the review of the literature no conceptual frameworks were made explicit throughout existing research in bladder dysfunction. The conceptual framework is a bridge between paradigms which helps to explain the research issue and the practice of investigating that issue (Leshem and Trafford 2007).
In constructing a conceptual framework, the goal is to be descriptive while simultaneously critiquing existing theories (Maxwell 2012). The framework is constructed, not found, by the researcher. The careful consideration of theories enables the researcher to understand what problems exist in previous research. For example, Critical Disability Theory and the ICF complement each other to provide a deeper insight into how people with MS with bladder dysfunction navigate within society. Furthermore, to help understand how people with MS attempt to manage their bladder symptoms it is necessary to draw from self-regulatory theory. This conceptual framework provided a mechanism in which this thesis can make an original contribution to understanding (Figure 4).
3.2.2 Critical Disability Theory

The foundation of this research lies within Critical Disability Theory (Goodley 2010) as it offers significant depth in terms of studying the body and its place within society. Disability is the space from which to think through a host of political, theoretical and practical issues that are relevant to all (Goodley 2010). Disability is created within society and through the design of the physical environment (Lang 2001). Social models of disability attempt to explain both what disability is and how an individual experiences disability (Putnam 2002). Several variations of the social model of disability exist (Lawton and Nahemow 1973, Hahn 1994, Brandt and Pope 1997). World Health Organization (2001) differentiates between disability and impairment in their definition of disability:
An umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Thus disability is a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives (World Health Organization 2001)

Thus, disability is a complex phenomenon that is evident at the level of a person's body and also presents as a socially constructed problem (Wendell 1996). Critical disability theory attempts to unravel how impairment and abnormality are generated about bodies and minds (Goodley 2013). Social structures contribute to sorting bodies into categories of “normal” or “disabled”; consequently, disabled people become “others” in the social world (Rose 2005). Disability is thus created by the interaction between the dominant group of the nondisabled or “normal” and the disabled or ‘others’ it constructs (Thomson 2002). The difference between people with disabilities and other minority groups is that every “normal” person can become disabled and this silent threat makes people avoid the subject and act awkwardly around people with disabilities (Davis 2006). Bladder dysfunction remains a taboo subject among both people with MS and healthcare professionals, thus, critical disability theory attempts to deepen understanding around this reluctance to discuss symptoms.

The history of social norms can help us to understand how social attitudes towards people with bladder dysfunction and other “leaky-bodies” are formulated in modern society. A “non-leaky body” is something that is desirable and preferable in
contemporary society as it aids functionality, reduces embarrassment and creates the illusion of control (Ogden 2013). In the context of this study and living with bladder dysfunction, leaking bodily fluids are viewed by society as the body failing to control (Ogden 2013). In the Middle Ages for example, some bodily practices (blowing one’s nose, defecation) were not met with disgust but regarded as “normal” parts of everyday life (Elias 1994). It was not until the Renaissance, that the privatisation of excreting bodily fluids was enforced by society which led to individualisation and secrecy contributing to the current beliefs around the privacy of toileting (Elias 1994). Thus, people with bladder dysfunction often experience shame and embarrassment about their bodies (Ogden 2013). People with bladder dysfunction attempt to normalise their impairment where achieving “normalcy” is the aim (Ogden 2013). Literature investigating bladder dysfunction among people with MS is largely based on urodynamic investigations involving objective measures of bladder functioning. Due to the quantitative nature of these studies, the cause of the disablement appears to lie within the nature of the disease or the inability of individuals to cope with it, rather than considering the social construction of bladder dysfunction. To build on the existing literature around bladder dysfunction in people with MS, an in-depth theoretically based inquiry is necessary to develop a better understanding of the specific factors of bladder dysfunction which reduce quality of life for people with MS. The lens of critical disability thus offers insight into the social construction of bladder dysfunction. Critical disability theory is the foundation of this conceptual framework; therefore, the perspectives of people with MS are central to each strand of the project.
3.2.3 International Classification of Functioning, Disability and Health (ICF)

A comprehensive model of disability is one that integrates both the medical and social perspectives- identifying impairment as a feature of the person while viewing disability as socially constructed (World Health Organization 2001). Critical disability provides insight into the social construction of bladder dysfunction. To further enhance this understanding, it is necessary to draw from another framework to consider how people with MS with bladder symptoms experience activities of daily living. The International Classification of Functioning, Disability and Health (ICF) provides, by this synthesis, a coherent view of different perspectives of health: biological, individual and social (World Health Organization 1980). In order to enhance the social model of disability, the ICF includes contextual factors, in which environmental factors are listed (Figure 5). These environmental factors range from physical factors such as climate and terrain, to social attitudes, institutions, and laws. Interaction with environmental factors is an essential aspect of the scientific understanding of the phenomena included under the umbrella terms 'functioning and disability'. To exist within contemporary society, people with disabilities adapt behaviour, conceal thoughts and change habits to create the illusion of normalcy (Ogden 2013). The ICF combined with Critical Disability Theory facilitates a deeper understanding of the impact of an impairment such as bladder dysfunction, the interaction between personal and environmental factors in order to understand an individual’s activities and participation.
ICF is grounded in health and functioning, rather than on disability. Previously, disability began where health ended; once you were disabled, you were in a separate category (World Health Organization 2010). The ICF aims to move away from this by instead describing functioning in society, no matter what the reason for one's impairment (WHO 2010). This approach aligns well with the aims of this multi-stranded study since it allows for exploration of the impact of bladder dysfunction among people with MS. ICF thus mainstreams the experience of disability and recognises it as a universal human experience (WHO 2010). Therefore, this framework connects well with critical disability theory in terms of the boundaries that exist between normality and disability and offers another interpretive perspective at the level of participation.
The ICF guided several key decisions over the three strands of this thesis. For example, questions asked of participants across all three strands attended to participation in daily life activities. The ICF focuses on functioning within society. This prompted the exploration of how people with MS with bladder dysfunction functioned within society and how they managed bladder symptoms. Furthermore, fitting with the constructivist roots of this research, the ICF prompted exploration of the perspectives of healthcare professionals working with people with MS, in terms of their attitudes towards managing bladder dysfunction. Within this exploration, the value of using common language of the ICF to facilitate sharing across disciplines and, across settings and geographical location when talking about bladder dysfunction became apparent. This will be discussed in more detail in Chapter 5.

### 3.2.4 Self-Regulatory Model

The ICF model helps to offer some insight into how people with MS with bladder symptoms function within contemporary society. In order to understand what people with MS are doing to respond to this disability another model is needed. A multitude of self-regulation models exist for the study of health-related behaviours (Epstein 1994, Leventhal et al. 2001, Carver and Scheier 2012). There are discrepancies between models regarding various principles of self-regulation; however, these models all share some basic principles. Most models describe self-regulation as a systematic process involving conscious efforts to modulate thoughts, emotions and behaviours in order to achieve goals within a changing environment (Zeider et al. 2000). This model assumes that people develop problem solving techniques when normal state is altered and consequently attempt to re-establish a state of normality. Therefore, this model aligns with the concepts embedded within critical disability
theory and the ICF model in that people with MS deviate from normalcy due to their “leaky bodies” and they strive to regain some sense of normality. Understanding bladder dysfunction using this model will help to identify self-management approaches.

Figure 6 demonstrates the three related processes that are basic to the self-regulatory model- interpretation, coping and appraisal (Leventhal et al. 1998). This model is a dynamic motivational system of setting goals, developing and enacting strategies to achieve these goals, appraising progress and revising strategies.

**Figure 6 Self-regulatory model (Leventhal et al. 1998)**
The first stage relates to the initial confrontation with the illness (Leventhal et al. 1998). When applied to bladder dysfunction in MS, this stage involves initial recognition of bladder symptoms. People with MS may become aware of these symptoms at any stage which is characterised by any change from normal bladder functioning. Similar to the ICF model, this stage portrays that contextual and environmental factors influence symptom perception. Understanding this confrontation stage will help to understand the reaction of people with MS and to identify their help-seeking behaviours. Without this theoretical background this aspect could easily be over-looked.

The second stage involves coping (Leventhal et al. 1998). This entails consideration and application of different coping strategies; in the context of this study these are self-management strategies. This includes both physical and emotional strategies of reacting to the symptom. This stage can be categorised into approach coping and avoidance coping (Leventhal et al. 1998). Approach coping involves reporting symptoms, seeking medical advice and treatment, information and support from others. Within this research this may include people with MS who actively seek help for their symptoms. Avoidance coping involves denial and dismissing the problem (Leventhal et al. 1998). This concept may be applied to individuals who ignore the problem and do not want to discuss the issue with anyone; they aim to keep all details private. This relates to people with MS who lived with their bladder symptoms for years without reporting to any healthcare professionals.

The third stage involves appraisal (Leventhal et al. 1998). This includes evaluating the effectiveness of self-management strategies. It is necessary to become aware of how people with MS monitor their management strategies. The self-regulatory model
centralises the person with MS, which aligns with the ontological and epistemological foundations of this research. It allows us to understand what people with MS are doing to manage their bladder symptoms at an individual level.

Self-regulation theory guides several aspects of this thesis. The aim of the latter stages of the thesis is to synthesise the needs of both people with MS and healthcare professionals to facilitate self-management of bladder symptoms from across all three strands of the study. Self-management consists of values embedded within self-regulation theory. Thus, this theory informed questions across all three strands of this thesis in relation to identifying, reporting of symptoms, managing and monitoring bladder symptoms. Therefore, if the end goal is to facilitate self-management it is necessary to draw from theories that fit and engage with this concept at the foundation of the thesis. Thus, the theory of self-regulation is embedded in this framework.

This conceptual framework informed all aspects of the research process; helped draft and refine goals, contributed to realistic and relevant research questions and was employed to identify potential validity threats to conclusions. It provided a novel insight into how this complex symptom is experienced. It supported interpretation of the emotional reactions to bladder dysfunction, physical and emotional coping, management options, behavior changes and adaptations when living with this symptom. Combined, critical disability theory, the ICF framework and the self-regulatory model (Figure 4) interact with each other to offer a multi-dimensional approach to exploring bladder dysfunction among people with MS.
3.3 REFLEXIVITY

Reflexivity is defined as a process of attending to the context of knowledge construction, especially to the effect of the researcher, at every step of the research process (Cohen and Crabtree 2006). Reflexivity is central to qualitative research in health and social science and involves finding strategies to question our own attitudes, thought processes, values, assumptions, prejudices and habitual actions (Bolton 2010). Qualitative researchers who practice reflexivity engage in a self-aware analysis of the interplay between the researcher and the researched (Finlay 2002). It opens up unconscious motivations and implicit biases in the researcher’s approach (Finlay 2002). Finally, it enables public scrutiny of the integrity of the research through offering a methodological log of research decisions (Finlay 2002). Overall, the act of reflexivity can enhance the transparency, accountability and general trustworthiness of qualitative research (Finlay and Gough 2008). This section will detail my reflexive statement and the reflexive strategies used throughout the research process.

3.3.1 Reflexive Statement

Researchers are guided by a range of factors. This includes their emotions, intuitions, experiences, meanings, values, commitments, presuppositions, prejudices, and their position as researchers (Finlay 2002). The aim of this personal piece was to acknowledge my personal beliefs, thoughts and feelings in relation to the research. It allowed me to understand how these beliefs shaped this research. It enabled identification of the biases that exist and allowed me to acknowledge them. In qualitative research the researcher is considered to be a central figure who continually influences the research process (Finlay 2002). Acknowledging how one’s views and
beliefs may influence findings adds credibility to the research and should form part of any qualitative inquiry (Jootun et al. 2009).

Similar to the work of many PhDs, it is important to situate myself in this multi-stranded study. It is common practice for the author to list a series of identifiers in an effort to demonstrate social location. Therefore, I will include a statement of gender, race, educational background, class and age range. Although these aspects of my identity clearly shape my perspective, I will go beyond these characteristics to acknowledge my work as a physiotherapist and how I came to research bladder dysfunction among people with MS.

I am an Irish woman in my mid-twenties with a Bachelor’s degree in physiotherapy. During my teens, I decided I would be a physiotherapist. Looking back, there was no distinct event that led to this career choice; my only goal was to embark on a career in which I could make a meaningful difference in the lives of others.

I began exploring the area of bladder dysfunction among people with MS in the third year of my undergraduate degree. I never had a family member with a chronic illness or indeed bladder dysfunction but there was something about both of these topics that drew me in. For a third year assignment, I completed a literature review. As I began to read around the area of urinary incontinence, the complexities around bladder dysfunction emerged. However, in discussion with experts in the area around gaps in the literature, it was identified that bladder dysfunction was particularly under-researched among people with MS. Why MS? Perhaps that there was a significant interest in my department at the time may explain my development in this area. What
if there had been significant interest in another chronic condition- would that have shaped my research question? Would I be looking at bladder dysfunction in a different population? Perhaps, but as I began to read and design my research question it became obvious that the impact of bladder dysfunction was overlooked in the literature. Therefore, I believed it was necessary to explore in depth the impact bladder dysfunction from the perspectives of people with MS.

I continued to study this topic into my fourth year where I completed my final year project exploring the impact of bladder dysfunction among people with MS. These personal insights from people with MS really struck me in terms of what people endured on a daily basis. Following my final year, I applied for and was awarded a competitive departmental scholarship from the University of Limerick to complete a Masters by Research. The aim was to further explore the impact of bladder dysfunction among people with MS. However, after six months I decided it was timely to expand this research question. I was successful in my application to the Irish Research Council for funding to complete a PhD. Simultaneously, I began working with people with MS as a physiotherapist on a part-time basis. I began to translate my research into practice as I witnessed first-hand the impact of bladder dysfunction in the lives of people with MS.

Embarking on a PhD as a newly graduated physiotherapist with no experience of disability opens the project to particular types of criticism. For example, I had a novice understanding of the real life challenges of living with a chronic condition. However, it simultaneously offered clear advantages. As I had limited clinical experience to draw from, I was heavily influenced by theory, as I began this research
journey immediately after my undergraduate degree. Looking back, I now understand that my thinking and analytical approach was shaped by a post-positivist paradigm that informed my undergraduate studies. This PhD journey gave me the opportunity to immerse myself in theory and to explore my own values, establishing a congruent paradigm of inquiry. This is a particular strength which further bolsters the theoretical foundation of this thesis.

3.3.2 Reflexive Strategies

Employing a reflexive approach throughout data collection strengthened the study. Strategies to promote reflexivity included fieldnotes and detailed discussion with supervisors. The researcher used fieldnotes to document thoughts and feelings at each step of the data collection process. The aim of these fieldnotes was to draw attention to areas of interest and to investigate why certain feelings occurred. The use of fieldnotes helped to record immediate impressions of the interview (Silverman 2010) and how individuals characterised their experience of bladder dysfunction. Key phrases that stood out during the interview were documented. Some examples included comments with increased emotion or intensity attached to them. These phrases were later explored further and informed data analysis.

Detailed discussions with supervisors took place throughout the research process. My two supervisors come from different theoretical and methodological backgrounds which stimulated discussions. Supervisors asked challenging questions which enhanced reflexivity and ultimately a greater understanding of the phenomenon being investigated. An example of this involved both supervisors reading interview transcripts. This resulted in a detailed discussion and provided me with a different
“lens” to view the data, which offered another dimension to the study. After this discussion I re-read and re-coded all the data under this new perspective and it allowed me to view concepts that I had not previously seen or acknowledged. Other examples of reflexive strategies will be discussed in more detail in the analysis section of Chapter 5 and 6.

3.4 STUDY DESIGN

Research methods are not automatically associated with particular types of study design. The key concern is not which methods are used but more so how they are used and for what purposes (Lincoln and Guba 1985). This thesis is a descriptive design using a combination of qualitative and cross-sectional studies. Mixed methods research combines the strengths of qualitative and quantitative approaches. A mixed methods approach offers a procedure for collecting, analysing and connecting components of quantitative and qualitative data, to understand a research problem more completely (Creswell and Clark 2007).

This mixed methods approach is linked back to my ontological and epistemological views of how knowledge is created. Both critical theorists and constructivists believe that knowledge is socially constructed. Both critical disability theory and the ICF model align with the premise that disability is (at least in part) a socially constructed phenomenon; that disability exists in large part due to the presence of barriers for people with disabilities in society. Combined, these theories provided the structural reference points maintaining the integrity of inquiry and the focus of investigation. Therefore, this theoretical foundation helped to elucidate the first strand of the project.
which aimed to deepen understanding of how bladder dysfunction interferes with quality of life for people with MS. The rationale for seeking participant’s perspectives is embedded within the ontological and epistemological beliefs of the researcher, in that reality is constructed by the perspectives of those within it. Thus, the views of people with MS living with bladder dysfunction were integral to the study.

Similarly, the second strand drew on the perspectives of healthcare professionals to provide an in-depth understanding of current service provision and management for people with MS. The views of healthcare professionals were necessary to understand bladder management from service providers. The final strand of this project was designed to identify the needs of both healthcare professionals and people with MS with bladder dysfunction for facilitation of self-management. This required a large scale sample and therefore survey methods were most appropriate. It was necessary to explore the needs of both people with MS and healthcare professionals and compare these findings. When used in combination, quantitative and qualitative methods complement each other (Greene et al. 1989) and may capture the depth of complex issues such as bladder dysfunction among people with MS. Methods were mixed over the three strands, but analysis of each strand remained distinct. More detail of data analysis for each strand is provided in Chapters 4, 5 and 6.

3.5 EVALUATING THIS PROJECT

There is no consensus on criteria for appraising the methodological quality of mixed methods research (O’Cathain et al. 2008). Although some criteria exist for planning, designing, reporting and globally assessing mixed methods research (Creswell and Clark 2007, O’Cathain et al. 2008), researchers need to provide specific measures for
evaluating its quality (Creswell et al. 2004). Several tools exist for the independent evaluation of quantitative and qualitative research (Letts et al. 2007, Barnett-Page and Thomas 2009, Critical Appraisal Skills Programme 2014, O'Brien et al. 2014). The division between qualitative and quantitative methods stems from differences in ontological and epistemological perspectives (Creswell and Clark 2007, Johnson et al. 2007). However, research can be viewed from a unified perspective (Onwuegbuzie and Leech 2005) in which the research question drives the methodological approaches (Tashakkori and Teddlie 2003). Therefore, it is important to evaluate a project from within its own paradigm of inquiry (Guba and Lincoln 2005). A set of questions for evaluating this research were developed based on a number of existing frameworks (Newman and Benz 1998, Creswell and Clark 2007, Pluye et al. 2009).

1. Justification for a mixed methods design: Was this design appropriate to capture the breadth and depth of the research question? What examples from the thesis can support this? Are the underlying assumptions of the research method defined?

2. Description: Is the content of this research described adequately? Is enough detail given around participants and justification of sampling? Do the selected data collection methods align with the underlying theoretical foundation? Did the conceptual framework guide data analysis? Was information provided around the challenges that occurred during the research?

3. Reflexivity: How did the researcher engage in reflexive practice during each stage of the research process? Did the researcher provide a personal account
that was relevant to the research? In what ways did this reflexive statement help the reader understand the lens through which the research was interpreted?

4. Findings: Are the findings of this research meaningful? What are the implications of these findings? How do these findings connect with the experiences of people with MS not involved in the study? Whose knowledge was privileged in this thesis? Does reading the text inspire new ideas about future directions for research?

In Chapter 7, I return to these questions, inviting assessment of this mixed method research.

3.6 PARTICIPANTS

This section describes the recruitment methods and participant eligibility criteria for each strand of the study. Participants across strands were recruited through purposive sampling techniques (Patton 1990). Purposeful sampling is widely used in qualitative research and was necessary for the identification and selection of information-rich cases related to the phenomenon of interest (Palinkas et al. 2015). Specific eligibility criteria were used within each strand to ensure a range of experiences were gathered.

Qualitative studies aim to map out the different patterns observed in a data-set rather than to quantify magnitudes (Fugard and Potts 2015). The purpose is to improve understanding, not generalisability (Marshall 1996). Sandelowski (2000) claimed that the main goal is to ensure that the sample size is small enough to manage the material
and large enough to provide a deep understanding of experience and this is always a
matter of subjective judgment. Therefore, sample size is guided by the experience of
the research team and assessing the data as it is analysed in relation to the goals of the
research. Recent guidelines for thematic analysis categorise suggestions by the type
of data collection and the size of the project (Braun and Clarke 2013). The sections
below will outline the particular recruitment strategies and rationale for sample size
used within each strand.

3.6.1 Strand 1 Participant recruitment and selection criteria

Nineteen people with MS were recruited from the Mid-Western branch of the Multiple
Sclerosis Society of Ireland. Officials of the MS society acted as gatekeepers. An
information sheet (Appendix 3) was sent to officials within the branch who forwarded
the documents to people with MS who had previously attended bladder dysfunction
information evenings. Prospective participants were advised to contact the researcher
directly for further information. Participants were diagnosed with MS, aged between
37 and 64, were English-speaking and had at least one bladder dysfunction symptom.
This included any involuntary leakage of urine, voiding frequency of more than 8
times per 24-hour period, nocturia, any voiding dysfunction such as hesitancy,
straining, poor stream, increased post-void residual volume.

3.6.2 Strand 2 Participant recruitment and selection criteria

A snowballing technique was used to recruit a purposive sample of Irish healthcare
professionals. A recruitment email (Appendix 10) and information sheet (Appendix 8)
was sent to multiple branches of the Multiple Sclerosis Society of Ireland, Irish Society
of Chartered Physiotherapists, Physiotherapists in Multiple Sclerosis, The Association of Occupational Therapists of Ireland, Irish Practice Nurses Association. Representatives from these organisations acted as gatekeepers for recruitment, forwarding the recruitment email and information sheet to healthcare professionals working with people with MS known to them. Potential participants were invited to forward the recruitment email and information letter to other healthcare professionals in their network. Interested applicants contacted the researcher for further information.

Originally, a sample of 20 healthcare professionals was sought with an aim of having 4-5 participants in each focus group. However, due to a slow response rate in the first month of recruitment, changes were made to the original data collection methods to increase participation. Additional options to take part were available to facilitate participants in different areas of the country. If some participants are unable to take part in focus groups due to geographical location, they were given the option to communicate via Skype. Alternatively, they could participate in a dyadic interview or in a telephone interview. Fourteen healthcare professionals took part in Strand 2. Healthcare professionals who (1) encountered people with MS during clinical practice in any setting and (2) included assessment of bladder dysfunction in their scope of practice participated in this study. All participants were over 18 and able to communicate effectively in English.

3.6.3 Strand 3 Participant recruitment and selection criteria

Snowballing techniques were used to recruit a purposive sample (Patton 1990) of both Irish healthcare professionals and people with MS for the final strand. Potential participants were identified through professional bodies and special interest groups
(HSE Communications office, MS Ireland, Irish Society of Chartered Physiotherapists, Physiotherapists in Multiple Sclerosis, The Association of Occupational Therapists of Ireland, Irish Practice Nurses Association, Irish Medical Organisation). These organisations acted as gatekeepers of recruitment by forwarding the participant information leaflet (Appendix 15) and recruitment email (Appendix 16) to its members. Healthcare professionals presenting on the topic at conferences and known experts in the area were sent the recruitment email and information leaflet. Potential participants were recruited through media sites of MS Ireland: Twitter, Facebook (Appendix 17) and electronic newsletters (Appendix 18). Participants were invited to forward the recruitment email to both colleagues and people with MS to maximize recruitment. Interested participants directly accessed the link provided in the email. A total of 213 participants completed the questionnaire including 109 people with MS and 104 healthcare professionals.

Sample size could not be estimated as this was a pilot study and no previous studies were available to extrapolate from. There is no formal database in the Republic of Ireland with information relating to healthcare professionals working with people with Multiple Sclerosis. However, a special interest group of 78 members exists among Chartered Physiotherapists (Physiotherapists in Multiple Sclerosis-PIMS). Using this figure (78) as an estimate of the amount of physiotherapists working with people with MS in Ireland, it was estimated a similar number of physicians (78), nurses (78), and occupational therapists (78). This gives an estimated total of 312 healthcare professionals working with people with MS in the Republic of Ireland. Response rate can be as low as 25% for online questionnaires. Given this estimated response rate, a quarter of healthcare professionals working with people with MS in Ireland was aimed
to be recruited (78-100). Therefore, an equal number of people with MS was also aimed be recruited (n=100).

3.7 DATA COLLECTION

A combination of semi-structured interviews, focus groups, dyadic interviews and survey methods were used to gather data over the three strands of the project. The specific methods used within each strand are presented below with other research methods taken into consideration. In line with the conceptual framework for this project, to get to the nature of the bladder dysfunction among people with MS it was imperative that people with MS be at the core of each strand.

3.7.1 Strand 1 Individual interviews

Individual interviews were deemed the most appropriate method of data collection for this strand. The underlying theories of the conceptual framework are based on understanding the experiences of people with disabilities, therefore it was imperative to interview people with MS, as they were the ones living with this condition. There are different types of interviews that can be used in research ranging from fully structured, to semi-structured or unstructured interviews (Robson 2002). Structured interviews do not allow for deviation from the questioning route which reduces flexibility and can limit the response from the participant.

Semi-structured interviews were deemed the most appropriate for this strand as they allowed the use of open-ended questions to gather information from participants which offered a detailed exploration of the topic. They produce more in depth results than structured techniques while still following predetermined questions (Willig 2013,
With unstructured interviews, the researcher has an overarching question, but is flexible about the direction the participant takes in the discussion (Harrell and Bradley 2009). This can produce a wide range of information from different perspectives which could prove complex when seeking patterns across cases.

Face-to-face interviews were chosen over telephone interviews due to the advantage of social cues. Social cues, such as voice, intonation and body language of the participant can give the researcher extra information that can be added to the verbal answer of the participant on a question (Opdenakker 2006). Focus groups were also considered, but as outlined by the ICF (World Health Organization 2001), symptoms can vary across domains in terms of impact for different people and therefore group discussion was deemed inappropriate for this study. Participants may not share the same experiences and issues, therefore group dynamics may imply an emphasis that is misleading (Harrell and Bradley 2009). Surveys were not deemed suitable for this strand. In line with the conceptual framework, surveys would not capture the depth needed to explore fully the complex issue of bladder dysfunction among people with multiple sclerosis. A detailed exploration of the environmental and contextual factors as suggested by the ICF was simply not possible through survey methods. The methods of data collection are explained in more detail in Chapter 4.

3.7.2 Strand 2 Combined interview methods

Focus groups were the intended method for primary data collection in this strand. This method was deemed most appropriate to provide an understanding of the opinions of healthcare professionals on the topic of bladder dysfunction. The social context of a focus-group encourages the development of ideas and allows instant clarification of
how and why participants think a certain way (Kitzinger 1995). Focus groups were believed more suitable than individual interviews as group dynamics allows for the development of information-rich descriptions and ideas are generated in a non-threatening environment (Hollis et al. 2002). Unfortunately, this was not possible due to a low response rate and a nationwide dispersal of participants. The option of skype focus groups with one or two members of the focus group interacting via skype was considered. However, this raised the issue of availability and timetables of participants.

On reflection and discussion with supervisors a combination of interview methods was used for logistical purposes and to facilitate healthcare professionals given their work schedules. When a participant was unable to attend a focus group, a dyadic or individual telephone interview was offered as an alternative. In dyadic interviews, two participants interact in response to open-ended research questions. Data collection procedure is included in Chapter 5.

3.7.3 Strand 3 Online questionnaire

A cross-sectional study design by means of a self-report questionnaire was used. The questionnaire explored the perceptions of both people with MS and health care professionals working with people with MS with bladder dysfunction in the Republic of Ireland. This study design was chosen as it is built on the qualitative findings from people with MS and healthcare professionals in the first two strands.

To reach people with MS and healthcare professionals nationally, an online questionnaire was deemed most appropriate for this strand. This method enabled
collection of information from a large number of people inexpensively and reliably (De Vaus 2002). Furthermore, people with MS lead busy lives and healthcare professionals across all disciplines face time constraints; therefore, this type of study design was thought to be most time efficient and convenient for all participants. Online questionnaires have frequently been used in the literature to seek healthcare professional’s perspectives (Cho et al. 2013). Additionally, a large survey conducted by the National MS Society in the USA concluded that up to 93% of people with MS use the internet and this can be compared to 75% in a healthy population (Wardell et al. 2009). Therefore, the internet was a useful mode of delivery for this questionnaire.

Postal questionnaires, face to face structured interviews, structured telephone interviews and interviewer mediated questionnaires (face to face and telephone questionnaires) were considered for this study. However, some information may be suppressed in a face-to-face or telephone interview and answers are possibly more likely to be slanted towards an expectation of what the interviewer would like to hear (Seidman 2013). Therefore, an online questionnaire was deemed most suitable for this study. Furthermore, online questionnaires have the added advantage of providing a high level of anonymity (Coomber 1997) which may potentially reduce the risk of social desirability bias (Joinson 1999). They also have the potential of great reach, thus overcoming geographical barriers.

3.8 QUESTIONNING ROUTES AND QUESTIONNAIRE DEVELOPMENT

This project used a range of questioning routes and surveys across the three strands. The questioning routes, or flow of queries, used in the first two strands were topic
based with probes to encourage participants to expand or to move the conversation in certain directions (Boeije 2009). Consistent with the theoretical underpinnings of this research, both strands were exploratory in nature and centred around the participants. Therefore, questions within the schedules were open-ended. The questioning route (Appendix 2) for the first strand was informed by relevant literature exploring quality of life in people with MS (Vickrey et al. 1995, Hobart et al. 2001) and previously published bladder-specific questionnaires (Barry et al. 1992, Shumaker et al. 1994). This questioning route was piloted on one male and female with MS to assess suitability of questions. Minor edits were made based on their feedback. The questioning route for Strand 2 (Appendix 6) was informed by findings from Strand 1 and by other service provision questionnaires (Coote et al. 2010, Wagg 2011, Nguyen et al. 2013). This questioning route was piloted with two healthcare professionals. Changes were made to the wording to assist with the flow of questions. Finally, this questionnaire was adapted to make suitable for individual semi-structured interviews (Appendix 7).

The final strand involved two online questionnaires. A questionnaire for both healthcare professionals (Appendix 13) and for people with MS (Appendix 14) was designed specifically for this study. Both were developed based on findings of strands 1 and 2 and existing literature on bladder management among healthcare professionals in other populations (Nguyen et al. 2013). It was piloted on a group of healthcare professionals (n=4) working with people with MS and people with MS to ensure readability sequence and suitability of questions. The questions were adapted based on this feedback. Information about the study was included at the beginning of the
questionnaire, and participants were made aware that informed consent to participate was implied by completing the questionnaire.

As no study to date has explored the needs of both healthcare professionals and people with MS in relation to bladder dysfunction there was no valid and reliable questionnaire to draw from. Authors claiming to use standardised instruments were contacted but on further exploration it was found that no psychometric testing had been completed on these questionnaires apart from face validity. Therefore, to ensure reliability a number of steps were taken. These are detailed in Chapter 6.

The questionnaire inquired about background information, awareness of bladder dysfunction, confidence in assessment and management, responsibilities, access to services, barriers to management and needs to better facilitate bladder management. The questionnaire included a total of thirty-eight questions. Information was elicited via simple yes/no questions, multiple choice questions, structured questions using a Likert scale, ranking questions and some open-ended questions. Open ended questions allowed participants to share and discuss any additional ideas. The questionnaire took twenty minutes to complete and was live for a period of 3 months. This research strand is presented fully in Chapter 6.

3.9 DATA ANALYSIS

The conceptual framework guided decision making through collection and analyses of data. It helped draw attention to important features and guided key decisions in relation to data collection and analysis (Robson 1993). Qualitative data in Strand 1 and 2 was
analysed and transcribed verbatim and reviewed for accuracy. Details of the analytical process is incorporated in Chapters 4 and 5. Statistical analyses completed on the questionnaire data is described in Chapter 6.

3.10 ETHICAL CONSIDERATIONS

This research involved three distinct strands and groups of participants at different time points over the course of the thesis. Therefore, ethical approval was obtained from the University of Limerick Faculty of Education and Health Sciences Research Ethics Committee (Strand 1: Approval Number: 2011_06_09, Strand 2: Approval Number: 2013_05_09_EHS). As the final strand involved an exploration of current service provision it was necessary to recruit participants via the Health Service Executive, the main health service provider in Ireland. Therefore, ethical approval was also sought and granted from the HSE and UL (approved 26th March 2015).

Many ethical issues emerge throughout the entire research process. From the initial development to writing up stages. Therefore, instead of outlining ethical considerations in order of appearance, I will frame this section on the Beauchamp and Childress’ ethical framework (Beauchamp and Childress 2001). This framework underpins the HSE National Consent Policy (HSE 2013) and offers a broad consideration of medical ethics issues generally, not just for use in a clinical setting. The four principles include respect for autonomy, beneficence, non-maleficence and justice (Beauchamp and Childress 2001). The ethical considerations for each strand are outlined with respect to each of these four principles.
3.10.1 Strand 1

Respect for autonomy entails taking into account the decision-making capacities of autonomous person, enabling individuals to make reasoned informed choices (Beauchamp and Childress 2001). This brings to light the issue of consent. The ethical rationale behind the importance of consent is the need to ensure voluntariness while respecting the participants’ right to autonomy- their right to control their own life and to decide what happens to their own body (HSE 2013). Consent involves giving permission or agreement for an intervention, receipt or use of a service or participation in research following a process of communication about the proposed intervention (HSE 2013). To achieve informed consent all participants received information sheets at least one week before the interviews (Appendix 3). At the outset of all interviews, participants reviewed the information sheet and signed the consent form (Appendix 4) before giving permission to the researcher to switch on the audio recorder.

Non-maleficence involves avoiding harm (Beauchamp and Childress 2001). All research involves risk, even if minimal, but the harm must be balanced against the benefits of treatment (Beauchamp and Childress 2001). In this strand, there was some risk to participants in terms of discussing sensitive issues which may have caused distress. However, in terms of the second principle of beneficence this study offered participants a safe, confidential platform for discussing an important research topic that could increase awareness about how bladder dysfunction interferes with quality of life for people with MS. Furthermore, this study had potential benefit for the larger population of people with MS in Ireland through increasing understanding of living with this complex symptom. The final principle of justice emphasises fairness in the distribution of benefits and risks and equality among individuals (Beauchamp and
Childress 2001). To facilitate recruitment, participants in this strand were confined to one geographical area. Therefore, recruitment was not equitable. However, this study attended to the perspectives of people with MS, whose views are sometimes set aside because of perceptions about vulnerability. All study participants were treated equally and given the same opportunity to discuss their perspectives of bladder dysfunction.

3.10.2 Strand 2

To achieve the first principle of respect for autonomy (Beauchamp and Childress 2001), information sheets (Appendix 8) and consent forms (Appendix 9) were given and signed by all participants prior to the group interview. Within any research it is important to protect participants’ identities. Anonymity can be maintained but not confidentiality as information shared during interviews will be available to the other people involved in the session (Kaiser 2009). Therefore, although the researcher does not share the participants’ names or identifying information, their stories would be shared. Participants were encouraged to respect the privacy of others by not repeating what had been said within the focus groups. It is important for the researcher to clarify this expectation of confidentiality and respect for others within the group (Krueger and Casey 2014). Participants were advised that following the interviews, all identifiable information relating was deleted and pseudonyms would be used in any publications or presentations about the study.

The second principle of beneficence considers balancing of benefits of intervention against the risks and costs (Beauchamp and Childress 2001). No direct benefits for participants was gained through participation in this study; however, involvement in this study provided valuable information about the management of bladder
dysfunction for people with MS and current strategies used to manage this symptom in the Republic of Ireland. This study offered participants the opportunity to discuss management approaches, share ideas, trigger reflection and build their professional network with other healthcare professionals working with people with MS. Participants did not receive payment for participating in the research. Interviews were completed in the University of Limerick or in locations convenient to the participants. They travelled at their own cost to the location. It was made clear that participation was completely voluntary and no participants were coerced into taking part in this study.

In relation to the third principle of non-maleficence (Beauchamp and Childress 2001), this strand posed minimal risk of harm to participants. Participants were asked to reflect on their clinical practice and approach to assessment and management of bladder dysfunction. This may have caused some discomfort among participants who lacked confidence and expertise in this area. Therefore, participants were made as comfortable as possible during the group interviews and encouraged to share experiences as appropriate. No pressure was put on participants to divulge information. As above, all participants were treated equally in an attempt to address the final principle of justice (Beauchamp and Childress 2001). For example, all participants were given equal opportunity and time to express their opinions within the group interviews.

3.10.3 Strand 3

The four principles of respect for autonomy, beneficence, non-maleficence and justice (Beauchamp and Childress 2001) were also addressed in the final strand. However, in
terms of respect for autonomy, this strand differed from the others in relation to informed consent. As it was an online questionnaire participants were not required to sign a consent form. The first page of each online questionnaire included an information page (Appendices 13 and 14). Implied consent was obtained via acknowledgement of this page (a tick box to clarify their understanding of the paragraph). This information page included details on the voluntary nature of study, risks, benefits, and the procedures put in place to maintain confidentiality. In addition to ticking the box, participants were made aware that consent to participate was implied by completing and submitting the questionnaire.

In terms of non-maleficence this strand was also a low risk study and participants could opt out of the questionnaire at any time by simply exciting the online site. As the questionnaire software Surveymonkey (www.surveymonkey.com) records IP addresses, all were deleted immediately post data collection to ensure anonymity. If a participant chose to withdraw from the study prior to completing the questionnaire, answers were not included in the data set and any such responses were disregarded. Regarding beneficence, this study offered both people with MS and healthcare professionals the opportunity to share the perspectives around current service provision for people with MS with bladder dysfunction. This information was used to inform the development of an educational resource to facilitate the self-management of bladder dysfunction which will benefit healthcare professionals and people with MS nationally.

3.11 CHAPTER SUMMARY

This chapter described the research methodology of this thesis with particular emphasis on the theoretical foundation and conceptual framework underpinning the
research. A justification for the mixed methods approach and the data collection methods for each individual strand of the research was provided. Detailed information on data collection procedures, data analysis and findings are incorporated in the next three chapters, each presenting one strand of the study.
CHAPTER 4 STRAND 1 BLADDER DYSFUNCTION
AND QUALITY OF LIFE FOR PEOPLE WITH
MULTIPLE SCLEROSIS

4.1 INTRODUCTION

Bladder dysfunction is a worldwide problem affecting individuals of all ages and across different cultures and races (Minassian et al. 2003). It not only affects physical well-being, but also has a significant impact on the psychological and socioeconomic aspects of life (Sinclair and Ramsay 2011). Bladder dysfunction is associated with urinary tract infections, falls and fall-related injuries which can increase hospital and nursing home admissions (Stewart et al. 2003, Ko et al. 2005). Therefore, it is a multifaceted problem affecting several important domains.

Bladder dysfunction affects approximately 75% of people with Multiple Sclerosis (MS) (Nortvedt et al. 2007). This is almost three times as common when compared to other populations with the average prevalence of female urinary incontinence being 27.6% (Minassian et al. 2003). The severity of bladder symptoms in MS often correlates with the degree of spinal cord involvement (Kidd et al. 1993). However, all spectrums of bladder dysfunction can impose economic burdens on people with MS, on their families, and on society as a whole. Direct costs to the individual include the cost of pads and other appliances whilst direct costs to the healthcare system include increased labour time, nursing home costs, medical appointments, surgery, medications and diagnosis (Koch et al. 2000). Indirect costs include repercussions
from psychological distress and loss of productivity within the home and at work which may increase the risk of unemployment (Moore 2001).

Functional brain imaging studies in healthy populations show the contribution of higher centres and signal processing involved in bladder control, so that voiding can be achieved in a socially appropriate time and place (Kalsi and Fowler 2005). A complex of brain networks is involved in bladder storage (Athwal et al. 2001, Matsuura et al. 2002) and voiding (Blok et al. 1998). Lesions of the brain can interrupt or damage pathways to the bladder causing a range of bladder symptoms for people with MS (Di Benedetto et al. 2006).

Several questionnaire-based studies have shown that bladder dysfunction can be the source of significant disability and result in reduced quality of life among people with MS (Nortvedt et al. 2001, Nortvedt et al. 2007, Khan et al. 2009, Szilasiova et al. 2011, Vitkova et al. 2014). However, the meaning of quality of life varies among people making it difficult to define and measure in objective terms. The World Health Organization defines Quality of Life as 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 (World Health Organization 1997). It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment. Therefore, it is timely; to understand the perspectives of people with MS regarding how bladder dysfunction affects their quality of life.
Only one-third of people with MS experiencing incontinence seek help (Koch et al. 2001). Suggested reasons for this include the emotional consequences of the symptom, an acceptance of bladder dysfunction in relation to the chronic nature of the illness, a desire to self-manage and lack of awareness of services available. People with MS in an Australian community were reluctant to seek advice or treatment regarding incontinence even though it adversely impacted on daily life (Wollin et al. 2005). Social stigma of bladder dysfunction contributes to under-diagnosis and under-reporting (Wyman et al. 1990). Social structures have contributed to the sorting of different bodies into either “normal” or “disabled”. Leaking bodily fluids is viewed as the body failing to control (Ogden 2013). A “normal” body is something that is desirable and preferable in modern society as it aids functionality, reduces embarrassment and creates the illusion of control (Ogden 2013). Literature investigating bladder dysfunction among people with MS is largely based on urodynamic investigations. However, due to the nature of these studies the specific aspects of this symptom that interrupt daily life are not well understood. Therefore, the aim of this study is to deepen our understanding of how bladder dysfunction interferes with quality of life for people with MS.

4.2 METHODS

This qualitative study involved individual semi-structured interviews due to the intimate nature of the topic. This approach was most appropriate as the aims of the study were exploratory and inductive (Maykut and Morehouse 1994). The interview guide was informed by relevant literature exploring quality of life in people with MS (Vickrey et al. 1995, Hobart et al. 2001) and previously published bladder specific questionnaires (Barry et al. 1992, Shumaker et al. 1994). The guide prompted
participants to discuss experiences of living with bladder dysfunction and how it impacted on daily life. There was space for participants to introduce relevant topics outside this guide.

4.2.1 Participants

Participants were recruited from one branch of the Multiple Sclerosis Society of Ireland using purposive sampling techniques (Patton 1990). Officials of the MS society acted as gatekeepers. All participants were diagnosed with MS, aged between 37 and 64, were English-speaking and had at least one bladder dysfunction symptom (any involuntary leakage of urine, voiding frequency >8 per 24 hours, nocturia, any voiding dysfunction such as hesitancy, straining, poor stream, increased post-void residual volume). Participant details are provided in Table 5. The sample consisted of 11 females and 8 males, ages ranged from 37 to 64 years (mean 53.42 SD 6.99). Nine participants had relapsing remitting, 7 had secondary progressive, 2 had primary progressive and one unknown. Most participants needed assistance mobilising (n=17) with only 2 walking independently. Time since diagnosis ranged from 2 to 35 years (Mean 17.55 SD 9.59). Pseudonyms are used to protect identities of participants. Ethical approval was obtained from the University of Limerick Faculty of Education and Health Sciences Research Ethics Committee. Written informed consent was obtained from all participants before each interview.
Table 5 Strand 1 Participant Details

<table>
<thead>
<tr>
<th>Age range (Years)</th>
<th>Pseudonym</th>
<th>Gender</th>
<th>Type of MS</th>
<th>Use of assistive devices</th>
<th>Time since diagnosis (years)</th>
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</table>

4.2.2 Data Collection and Analysis

Audio-recorded interviews were conducted by three physiotherapy student researchers and lasted 40-90 minutes. At the end of the interview a verbal summary was provided to highlight key points and to allow participants to add, clarify or revise comments.
As the study progressed, topics arising in early interviews were explored among subsequent participants to allow for refinement of ongoing thematic analysis (Braun and Clarke 2013). Although outlined below as a sequential procedure, the research analysis was an iterative and reflexive process. Reflexivity can enhance the transparency, accountability and general trustworthiness of qualitative research (Finlay and Gough 2008). It prompts the researcher to critique the research process, method and outcomes. Numerous strategies were put in place to promote reflexivity throughout the research process. As the researcher is a central figure in qualitative research, a reflexive statement was formed by the first author to acknowledge personal beliefs, thoughts and feelings in relation to the research. Fieldnotes were used to capture areas of interest and allowed exploration of why certain interpretations and thoughts occurred. Another reflexive strategy employed was the use of a methodological log of research decisions (Finlay and Gough 2008). Detailed discussions between all three authors took place throughout the research process which enhanced reflexivity and ultimately produced a more nuanced understanding of the participants’ narratives. All other analytical decisions made were documented continuously throughout the process. Thematic analysis involved a process of engaging with the data and was performed in a series of steps (Braun and Clarke 2006):

(i) Becoming familiar with the transcripts: The process of analysis began with verbatim transcription of interviews followed by a check for accuracy of the text. All transcripts were then imported into Nvivo10 where they were carefully reviewed.
(ii) Generation of initial codes: preliminary codes were identified by drawing from keywords and phrases within transcripts, fieldnotes written by interviewers, and based on discussions with other authors. The code list was formed initially by all three authors and was later revised. To promote rigour, all authors read and coded two transcripts. This resulted in a detailed discussion and provided a new lens to view the data, interrupting thinking and preconceived ideas.

(iii) Searching for themes within the data: concepts were discussed among authors with codes gradually clustering into key ideas. These were examined to identify how they may combine to form an overarching theme.

(iv) Potential themes were checked across the coded extracts and a thematic map (Figure 7) of the analysis was created. This diagram representing the key concepts was discussed among authors and the strength of each concept was assessed across the dataset within the software. The concept map was then refined.

(v) Reviewing themes; at this stage all potential themes were examined in order to make sure they described a coherent pattern. Transcripts were re-read numerous and ongoing discussions between all authors took place so that clear definitions and names could be given to each category and theme. Records were kept of each discussion where key decisions were made in an analytical memo. An ongoing reflective analytical memo was kept in order to achieve “trustworthiness” in the analytical process. The
memo documents the analytical process and key decisions made in team meetings throughout the analysis process (Sandelowski 2000). Final definitions were documented for each theme. Quotes that best reflected the themes and supporting subthemes were selected to illustrate the findings in this report.

(vi) Producing the report allowed the opportunity for final analysis of the data and cohesion of themes. Member checking (Creswell 2013) was carried out with the participants by sending each a summary letter of the key points of their own interview. Participants did not request any revisions to the findings.

4.3 FINDINGS

Analysis of 19 interviews yielded two key themes: (1) Disruptions and Loss and (2) Ways of Knowing. The first theme “Disruptions and Loss” explores how bladder dysfunction can interrupt daily living activities and how these disruptions contributed to experiencing loss. The second theme “Ways of knowing” portrays the types of knowledge that exist around bladder dysfunction. Firstly, embodied knowledge represents the learning participants gained through experience about their bodies and bladder symptoms which enabled them to develop strategies to manage symptoms. A gap in knowledge became evident in relation to accessing and navigating current healthcare services creating a barrier to self-managing. Silence among healthcare professionals and perceptions of bladder dysfunction were also reported to interfere with managing symptoms. Many participants demonstrated innovative approaches to
self-managing despite these barriers. Figure 7 represents the complex interactions among these themes.

**Figure 7 How bladder dysfunction interferes with quality of life for people with MS**

![Diagram showing the relationship between bladder dysfunction, disruptions, loss, and self-management strategies]

### 4.3.1 Disruptions and Loss

Bladder dysfunction creates a clear sense of disruption and loss for people with MS, interfering with daily living activities such as sleep, routine, travel and sexual relationships. Participants discussed loss of control, security and enjoyment. Disruptions to daily living activities. This sub-theme explores the daily life activities which bladder dysfunction imposes on including sleep, routines, travel and sexual relationships. Eighteen participants discussed how their bladder symptoms interrupted
sleep. The degree of disturbance varied among participants; some reported getting up four or five times a night with a need to urinate, while others described how “once was enough” to disrupt their night’s sleep. Increased fatigue the following day and risk of falling were concerns mentioned by participants.

Well I mean getting up to the bathroom, you’re not sleeping and it’s actually the physical effort of getting in and out to the bathroom as well was taking a lot out of me and the fatigue would be aggravated throughout the day. (Luke)

Luke described his annoyance of having to get up from bed each night to pass urine. He highlighted his struggle to get out of bed and how this affected his energy levels the following day. Other participants were worried about waking up their partners at night. Elizabeth revealed that she now has “earplugs and everything” for her husband so he will not hear her constantly getting up to go to the bathroom.

The unpredictability of bladder symptoms was problematic for many participants (n=16). Lacking “rhyme or reason” (Ann) symptoms caused difficulty with daily routines. John described the contrast between good and bad days with his bladder symptoms. “Some days its murder and more days then you think there is nothing wrong with it” (John). This statement captures the intensity of the bad days while conveying his frustration with symptom variability. This inconsistency created problems with daily routines such as driving, shopping and running errands. Participants described getting sudden urges or leaking when they least expected it. Donna describes how she “often got caught out in shops” leaking urine as she never knew when her symptoms would occur. These disruptions strongly interfered with
daily life. Participants often had to leave in the middle of a task to go home to change or else cancel their plans for the day ahead. Travel disruption was also discussed. Fourteen participants described their difficulties controlling symptoms while on journeys. Complications with travel included passing urine while driving, stopping at the side of the road to urinate and carrying a bottle in the car for emergencies. Furthermore, driving long distances imposed extra anxieties for participants.

Driving for long distances, I avoid motorways, when I went there before I used to just hop in the car and drive down now I have to plan where the stops will be, where I will get off, the road, all that type of thing. (Tom)

Tom highlighted the impact his bladder had on his trips and the additional plans he made to accommodate his symptoms; turning a once simple task into a more complex chore. Ann described being unable to control urges while travelling: “I would just have to piss in my pants darling it’s as simple as that” (Ann). This quote reflects the reality of living with bladder dysfunction and what she has to endure on a regular basis. Seven participants discussed their reluctance to travel on buses without toilet facilities.

On a bus you have no control. When you are driving your own car you can nip in, you can get off the road and nip in somewhere where as with buses it’s a different story. On a train loos are no problem and planes loos are no problem. So buses are my big problem I will not get on them anymore. Never again do I want to see a bus” (John).
On a bus you cannot control the journey; therefore, it was not an option for John. The impact of bladder symptoms on sexual functioning was mentioned by several participants (n=8). Some participants described bladder dysfunction as a “passion killer” (John) due to bed wetting and leaving to urinate during intercourse. Fear of passing urine while intimate was a major concern for participants. “Are you going to do your wee’s at the wrong time. And as you know, that’s not on” (Michael). This statement conveys Michael’s worry of having to control his urgency during intercourse. This quote gives some insight into Michael’s experience of intercourse and how the fear of leaking may be as problematic as the leakage itself.

4.3.1.1 Experience of Loss

These daily disruptions created a sense of loss among participants. Many (n=16) discussed the loss of control they had over their bladder and bodies at home and within the community due to the constant interruption’s imposed by their symptoms. Despite their best efforts of planning ahead for activities, participants were frustrated by this loss.

For instance, yesterday morning I was meeting my daughter in town. I had gone to the loo three times before I left and had breakfast and I was just in town when Oh My God. When you have to go you have to go. (Teresa)

Teresa went to the bathroom three times before she left the house in an effort to control her symptoms. However, regardless of her efforts she had a sudden urge to urinate, causing frustration at this loss of bodily control. Some participants also experienced a similar sense of loss in relation to their own thoughts. They were consumed by bladder
dysfunction constantly thinking and worrying about how they will keep in control of their bodies which in turn had a detrimental effect on their symptoms.

You’re focusing too much about it and worrying about it, that in turn makes you want to go to the toilet again and just in case to be safe. (Damien)

Damien described his constant stress in relation to his bladder. He described being unable to forget about his symptoms and be free of the endless worry and anxiety. This results in a vicious cycle and worsening of symptoms. A loss of security relating to the physical environment was discussed by participants (n=15). This loss was experienced when outside the home and created fear of incontinence in public and risk of exposure. This fear impacted on numerous aspects of daily life including social activities.

The worst thing would be for it to happen in front of people, really in front of people. Like say if you were out someplace, and next thing... that would be my nightmare scenario. (Irene)

Irene feared being incontinent in public, her “nightmare scenario” which highlights the extent of her fear. Alice was afraid that unfamiliar surroundings and activities would trigger her symptoms:

Well on a few occasions, where there would have been parties, where there would have been dance out on the floor thing, I would be nervous. The movement, I would be afraid that definitely I would leak on movement. (Alice)
Alice described her lack of participation at parties due to her bladder and the fear of unfamiliar activities triggering her symptoms. Loss of security contributed to hyper-vigilance with many participants actively seeking out toilets in advance of outings in order to reduce risk of emotional distress. Participants complained about having to plan their lives around their bladder symptoms. Tom described his constant planning and how it negatively impacted on his quality of life. “I would always have to make sure that there is a toilet near so it kind of…. I won't say ruins my life but I haven't as good a life as I had” (Tom). He highlighted how seeking toilets has affected his life and compared his present situation to life before his bladder symptoms. Leaving the house was a daunting task for participants and many (n=7) became anxious in new places with the stress of novel situations increasing urgency to urinate. Fear of “unfamiliar surroundings” developed and many participants declined social outings and stayed at home where they were “comfortable”. Damien discussed his fear of leaking in public. “It’s frightening, that in turn prevents you or stops you from going out” (Damien). The powerful fear attached to leaking meant that socialising was not worth the risk for Damien. For those who socialised, enjoyment of the event was compromised due to their symptoms. To overcome the fear of leaking, participants repeatedly went to the toilet to avoid any accidents. This internal distraction would adversely affect any conversations, reducing enjoyment of social events. Other participants described how they exited early from events to avoid potential loss of bladder control. Sarah would usually “…panic and decide to give an excuse and go home”. Other participants avoided social events altogether.

Oh yeah, yeah if I was invited to weddings or something like that, you know or different parties, stuff like that and I’d say no, no I can’t, I just put it down
to not letting them know what the real problem was, I just couldn’t fancy it.

(Eamon)

Eamon avoided social events, not because of the symptoms but rather because of his reluctance to disclose to others. Fear of being judged or treated differently if he explained the “real problem” was a central concern for Eamon.

4.3.2 Ways of Knowing

Both embodied knowledge and medical knowledge are embedded within this theme. Participants described using experiential learning to self-manage symptoms. A lack of knowledge was portrayed by participants around the current healthcare service which suggests that people with MS are self-managing without professional advice from healthcare providers. A perception of limited services exists and participants do what they can to self-manage their symptoms in a fractured and inconsistent service system.

Embodied knowledge represents the learning participants gained about their bodies and their bladder symptoms through years of experience. This type of knowledge is presented by reviewing their perceived triggers and experiential knowledge. All nineteen participants expressed detailed knowledge of specific actions that exacerbated their symptoms. Triggers were both physical and emotional by participants. Physical triggers included alcohol, caffeine, walking, exercise and specific positions/movements.
I might just stagger and have to regain my balance and that would be enough to give me the sensation that I need to go and empty my bladder...simple things like that...one small thing could set me off. (Tom)

Tom described how tiny movements were enough to trigger an urge to urinate. The specificity of triggers varied among participants. Although not discussed as frequently, emotional triggers were also mentioned. “If I’m nervous or anything- the toilet is the worst thing” (Eamon). He described how being nervous worsened his bladder symptoms. Stress and anxiety were other triggers mentioned by participants. Sixteen participants had vast knowledge about symptom management. They acquired this knowledge by learning about their bodies through “trial and error”. Participants discussed their experiences of bladder retraining and trying to reduce frequent urination.

Maybe it works for some people, but putting it off, trying to build up your capacity, it just doesn’t work for me, it just ends up causing me more problems.

(John)

John explained the ineffectiveness of this technique and the negative consequences. Through this statement John displayed awareness of his body and his limitations. Ten participants displayed detailed knowledge of their bladder symptoms in terms of the relationship of fluid input and output and timing of voids. “I’ve learnt, when you think you’re finished, you’re not, Sometimes I just wait a length of time” (Damien). Damien described the process he engaged in to ensure his bladder fully emptied. He gained
this knowledge through years of experience. Timing of voids as a strategy to manage particular bladder symptoms (e.g. hesitancy) was often mentioned.

Under (work) circumstances when I would get to the toilet I would be fit to wet myself so I would have no problem, I bust away the finest. (Joe)

Joe described his ability to manage hesitancy at work by purposely delaying toilet visits so when he did urinate, he did so quickly and was able to fully empty his bladder. Through experience, Joe found a timing strategy that helps him to manage his hesitancy in the workplace and allow him to reduce overall time spent in the toilet.

4.3.2.1 Medical Knowledge

This category refers to participants understanding of treatment options for bladder dysfunction and experiences of healthcare services. There is a perception among some participants (n=5) that there is no cure for bladder dysfunction and therefore nothing can be done about it.

It is not a problem that can be fixed by surgery, it can’t. So there is nothing I can do. (Ann)

Ann believed her bladder could not be surgically repaired and was not aware of other management options. Other participants said there was no specific help available for bladder dysfunction in people with MS.

There is no major help out there because everything with MS is a problem. (Mark)
Mark mentioned the lack of support in relation to managing his bladder dysfunction. This statement brings to light the numerous symptoms people with MS have to endure and the perception that exists around availability and accessibility of services for different symptoms. Experiences of current healthcare services were discussed by those who reported bladder symptoms (n=9). Participants perceived healthcare professionals to have limited knowledge about management of bladder dysfunction.

My own GP when I went into him first about it, he used to say ‘Practise holding on to it’, I used to say I couldn’t hold it. (John)

John was instructed by his GP to practise some bladder retraining techniques but when John indicated this was not possible his GP did not offer any other options. Participants described a lack of clarity about responsibility between different healthcare professionals. “I suppose he was leaving it to the other service to take up on any concerns of the bladder” (Margaret). Margaret excused her neurologist for not offering any advice for her bladder symptoms. He referred Margaret to the urologist and the topic was never brought up again. Overall participants discussed the lack of information available about bladder dysfunction through current services.

It's (service provision) quite lacking at the moment. It is quite lacking yeah.

The information isn't there. (Teresa)

Teresa described the limited services available. This perception of services for bladder dysfunction acted as a barrier to seeking help.
A gap in knowledge became evident in relation to accessing and navigating current healthcare services which created barriers to self-managing. Barriers included silence of the issue and perceptions of bladder dysfunction yet some participants were effectively self-managing despite these barriers. Silence of bladder dysfunction exists both among people with MS and among healthcare professionals. Of these nine participants who reported symptoms, seven were never asked by any healthcare professional about bladder functioning. Participants mentioned how the issue was dismissed. They were told to monitor it for a while and if symptoms persisted they would be referred on.

And she (GP) just told me to monitor it for a while. So when I went for my check-up then after 12 months. It hadn't gotten any better so she sent me to a urologist. (Joe)

Joe reported his bladder symptoms to his GP. He was advised to monitor these symptoms but no other advice was offered. After a year when there was no improvement he was referred to the urologist. He waited another twelve months for an appointment, bringing into sharp reality the time span between reporting symptoms and receiving help. Some participants said it was the responsibility of the healthcare professional to ask about bladder dysfunction and to inform and educate people with MS about this symptom.

I say a person when they go to their doctor or neurologist no matter what they go for it should be, they should bring it up really. (Mark)
Mark mentioned that bladder dysfunction should be monitored in all routine appointments. Similarly, other participants felt that it was not a priority for healthcare professionals.

They (healthcare professionals) should make a bigger issue out of it say in comparison to everything else. (Teresa)

Teresa perceived bladder dysfunction to be a lesser priority for healthcare professionals. Nine participants did not report their bladder symptoms or concerns because of uncertainty who to turn to. “You wouldn't know who to speak to, I didn't speak to anyone” (Sarah). Sarah commented on her confusion and how this impacted on her seeking support. When healthcare professionals did not raise the issue some participants remained silent about their symptoms. Other participants found it was too embarrassing to bring up the topic. “That’s (reporting) very embarrassing. You do it (manage) yourself, you do your own thing” (Joe). Joe highlighted why people with bladder dysfunction attempt to self-manage their symptoms without expert guidance. The embarrassment attached to bladder dysfunction prompted him to independently manage his symptoms. Two participants who were asked about bladder dysfunction by their GP’s denied any symptoms as they were too embarrassed to discuss the problem. In contrast, Michael spoke about the importance of breaking the silence of bladder dysfunction and talking openly about this symptom.

If we talk about it, At least if we talk about it, you know, you'll hear other people, if you discuss it and talk to other people about it, you'll get their
Michael believed that talking to others with bladder dysfunction would be beneficial for all involved. This highlighted the need to break the silence among everyone not just healthcare professionals. Disclosure of bladder symptoms was even a problem within the home. Many participants did not disclose the problem to any family members or partners: “I kept most of it… the worse parts to myself. You know, I didn’t tell him” (Elizabeth). Elizabeth described keeping her symptoms from her husband. This emphasised the silence and privacy associated with her symptoms and as a result she remained silent about the issue. This category suggests that silence exists everywhere and is not just an issue among healthcare professionals.

### 4.3.2.2 Self-management strategies

Participants explained that their symptoms were something they were “sort of dealing with”. Through their embodied knowledge they attempted to independently manage their symptoms. Several participants (n=9) discussed their methods. These varied from pressing down on the bladder or pubic bone to stimulating the area.

> “I stimulate the bladder control sphincter that would usually get me going”

(Tom)

Tom described his method of initiating urination by stimulating the sphincter. Seven participants described various self-taught methods of bladder retraining teaching them
“how to hold it”. Other methods included measuring fluid output and pelvic floor exercises. Participants devised these strategies themselves without any professional guidance or advice.

Well, I think things are just gone lax there now. I try, like every time I sit on the toilet I do try to squeeze and hold for the couple of seconds and go again but it’s not as good as it was. (Margaret)

Margaret described her version of pelvic floor exercises- interrupting the stream by squeezing during urination. When asked if they received advice on these strategies, participants responded that they made up these strategies, learning as they went along.

Oh God no…No I wasn’t advised, I learnt the hard way I suppose. (Sarah)

She described learning the hard way suggesting that advice from healthcare professionals would aid in managing symptoms. Despite the lack of support, participants use the knowledge they gained about their bodies to attempt to manage symptoms. Some participants interpreted bladder dysfunction as a “female problem”. Female participants mentioned talking about their symptoms with daughters rather than sons and perceived men as uncomfortable discussing this symptom.

Don’t know are all men the same but a lot of men are like that anyway I think, they don’t, they think that it doesn’t exist. (Maura)
Maura’s statement explained her reasons for not sharing her worries with her husband. In today’s society bladder dysfunction is viewed as a “female problem” and therefore participants were only comfortable talking to other females and used this as a method of support.

The aim of this study was to deepen understanding of how bladder dysfunction interfered with quality of life for people with MS. The findings yielded two key themes—“Disruptions and loss” and “Ways of knowing”. The key aspects to be explored from these findings include the consequences of daily disruptions, fatigue and reduced participation, silence surrounding bladder dysfunction, self-managing symptoms and the current gap in service provision.

4.4 DISCUSSION

The numerous disruptions bladder dysfunction imposed on daily life for people with MS which created a sense of loss in their lives was a key finding. Many disruptions were expected as they are not unique to people with MS and were recently reported in a review of urinary incontinence among women (Sinclair and Ramsay 2011) including social and recreational withdrawal and psychological distress. Women living with urinary incontinence report significantly lower quality of life than continent women (Nilsson et al. 2012) in terms of sexual functioning and relationships (Sutherst 1979, Barber et al. 2002, Handa et al. 2004), exercise and travel (Lagro-Janssen et al. 1992) and emotional well-being (Melville et al. 2002). Similar disturbances to daily life have been reported in older adults with urinary incontinence (Sims et al. 2011), men following prostate surgery (Buckley et al. 2012) and people with other neurological
conditions experiencing bladder problems due to detrusor over-activity (Tapia et al. 2013).

Despite similarities with other populations, bladder dysfunction among people with MS is magnified due to other co-occurring symptoms. The physical limitations of MS heighten bladder symptoms in terms of mobility issues creating problems managing urgency and frequency. Travel and socialising become increasingly difficult resulting in restricted participation and social withdrawal which has further implications on mental health. Urinary incontinence has been associated with loneliness, depression and sadness (Dugan et al. 2000, Fultz and Herzog 2001, Felde et al. 2012). Some literature suggests a link between major depression and severe urinary incontinence in women (Melville et al. 2002, Sung et al. 2009). Findings from this research highlight the emotional consequences of bladder dysfunction and for many the fear of becoming incontinent in public is greater than the distress caused from the leakage of urine itself. Fear of leaking in public was identified as a barrier to exercise in a recent study exploring the facilitators and barriers to engagement in physical activity among people with MS (Kayes et al. 2011). This type of fear-avoidance behaviour is similar to that described in chronic pain populations where fear-avoidance beliefs have been linked to reductions in activity (Vlaeyen and Linton 2000). Therefore, the fear attached to bladder dysfunction and the repercussions on participation may reduce quality of life for people with MS. Thus, it would be useful to routinely query about the specific disruptions of bladder symptoms and the consequences on physical and emotional well-being in clinical practice.
Fatigue is one of the most common and debilitating symptoms of MS and affects over 80% of this population (Minden et al. 2006, Charvet et al. 2014). The term fatigue can encompass multiple constructs (Kluger et al. 2013). Findings of this study suggest that nocturia interrupted sleeping patterns and anecdotally increased fatigue and productivity. Another study (Stanton et al. 2006) investigated sleep disturbance among people with MS and found that nocturia is associated with “middle insomnia” (waking at least twice during the night) and this is an important factor contributing to fatigue among this population. The impact of sleep disruption in terms of both quality and quantity can negatively impact on many aspects of daily life. Several studies looked at the impact of sleep deprivation in healthy populations and found a higher incidence of reduced concentration on tasks, effectiveness at work and a decline in normal activity (Léger et al. 2001). Future research is needed to investigate if fatigue is influenced by nocturia and other symptoms of bladder dysfunction.

This paper offers novel insights in relation to the depth, intensity and scope of disruption across many important life domains. The daily disruptions and loss associated with bladder dysfunction are accentuated by the underlying silence surrounding the topic. Sexual disruption, loss of control, security, enjoyment and social withdrawal all connect back to the silence and stigma attached to bladder dysfunction. The history of social norms provide insight into how social attitudes towards people with bladder dysfunction function. In the Middle Ages bodily practices (blowing one’s nose, defecation) were considered to be regular components of daily life (Elias 1994). It was not until the Renaissance that increased discipline entered society and the privatisation of excreting bodily fluids was enforced (Elias 1994). This leads to individualisation and secrecy which contributes to misunderstanding that
informs ignorant beliefs (Elias 1994). The expectations of personal hygiene demanded today has resulted in body waste being perceived as ‘dirty’ and urinary incontinence in adults viewed as intolerable (Newman and Benz 1998). These beliefs may have influenced modern society and shaped peoples’ experiences of living with bladder dysfunction.

Because their bodies excrete differently, people with incontinence are perceived as different. Participants in this study attempted to self-manage their symptoms in an effort to normalise their impairment. Achieving normalcy is an aim for such individuals and this is a major factor contributing to their desire to self-manage (Ogden 2013). The belief that bladder dysfunction is an unavoidable result of the progression of MS has prevented many people with MS from seeking help for this problem (Goldstein et al. 1992). As a result of social norms, enduring bladder dysfunction has become the unspoken norm for many people with MS. Participants felt that healthcare professionals were not interested in bladder dysfunction. The perspectives of healthcare professionals are necessary to explore current services and existing management of this symptom. Furthermore, the attitudes and beliefs of not only people with MS and healthcare professionals but also the general public are important factors in shaping approaches to bladder dysfunction. The silence of bladder dysfunction needs to be broken to reduce the stigma surrounding the topic and the negative consequences to participation identified by participants.

Despite the many disruptions, people with MS still used strategies and learned to manage their symptoms without professional advice. Regardless of the consequences attached to some strategies such as poor fluid intake and social withdrawal, many
participants were able to maintain a satisfactory quality of life. Participants of this study displayed detailed knowledge of their bodies regarding effective techniques and specific triggers for their symptoms. This knowledge is invaluable to healthcare professionals concerned with facilitating independent management of bladder dysfunction. Future research exploring self-management strategies on a larger scale is recommended. This experiential knowledge combined with medical knowledge from health professionals could inform the development of effective resources for independent management of bladder dysfunction.

Findings from this study demonstrate a gap in service provision for people with MS with bladder dysfunction despite there are a number of published guidelines for the management of this symptom (Fowler et al. 2009). This disconnect between evidence and practice highlights the need to improve services for people with MS. An evidence-based self-management resource may be a method of overcoming the current barriers to addressing this health need. Self-management approaches are common in many chronic conditions; however, it is not yet fully appreciated with regard to bladder dysfunction (Wilde et al. 2014). Health care professionals may be aware of the daily challenges faced by those with bladder dysfunction, but unsure of how to best support them in effective self-management (Wilde et al. 2014). No self-management programmes for bladder dysfunction have been investigated among people with MS. In contrast, computer and internet based self-management interventions were investigated among older adults with continence problems (Boyington et al. 2005, Ruiz et al. 2011). These studies found improvements in knowledge, symptoms, self-efficacy and overall management of bladder symptoms. Furthermore, a self-management risk factor modification tool was found to reduce daily leakage episodes and improve self-efficacy and incontinence related quality of life in older women.
Future research needs to evaluate and implement such resources for people with MS. Given that many people with MS remain silent about their bladder symptoms, self-management strategies that can be used independently maybe a valuable initial step to effectively managing this disruptive symptom.

4.5 LIMITATIONS

The findings of this study need to be considered in the context of its limitations. For example, these findings cannot be applied universally or indeed among the MS population due to the unique, variable and unpredictable nature of the condition. This study was conducted with participants from rural settings. Findings may differ based on cultural and geographical factors. This study included self-selected participants who identified that they have bladder dysfunction; therefore, findings may not represent those who remain silent about their bladder symptoms. However, as with all qualitative research the emphasis is on improving understanding rather than generalizability (Marshall 1996).

4.6 CONCLUSION

Bladder dysfunction results in major disruptions to daily activities for people with MS which can create a sense of loss in their lives. People with MS learn about their own bodies through experience. Using this knowledge, they attempt to self-manage their bladder symptoms despite current barriers to navigating existing healthcare infrastructure. Future research is warranted to explore current service provision and the perspectives of healthcare professionals. Understanding the barriers within the
healthcare system and the individual strategies employed by people with MS are the first steps in facilitating independent management of bladder dysfunction.
CHAPTER 5 STRAND 2 HOW BELIEFS ABOUT BLADDER DYSFUNCTION AMONG HEALTHCARE PROFESSIONALS INFLUENCE CLINICAL PRACTICE DEVELOPMENT; PERSPECTIVES OF ALLIED HEALTH PROFESSIONALS, NURSES AND MANAGERS

5.1 INTRODUCTION

Bladder dysfunction affects approximately 75% of people with multiple sclerosis (MS) (Nortvedt et al. 2007). Bladder dysfunction can involve both storing and emptying difficulties which can manifest as a wide range of symptoms including urinary incontinence, overactive bladder symptoms, hesitancy, nocturia and incomplete emptying (National Multiple Sclerosis Society, 2013). Bladder dysfunction is the presenting symptom in 2-12% of people with MS, with this finding as high as 34% in some studies (DasGupta and Fowler 2003). Bladder symptoms typically appear within the 10 years following diagnosis (Perrigot et al. 1982). Bladder dysfunction is one of the most debilitating aspects of MS and affects several important life domains (Minassian et al. 2003). This includes daily activities such as work, travel, sexual functioning, social and leisure activities (Browne et al. 2015). Seventy percent of people with MS report that bladder symptoms have a “high” or “moderate” impact on daily life (Hemmett et al. 2004). In addition to physical well-being, it has a significant impact on the psychological and socio-economic aspects of life (Sinclair and Ramsay 2011).
Bladder dysfunction is associated with increased hospital and nursing home admissions in the elderly (Ko et al. 2005). Bladder symptoms that interfere with daily living activities are associated with an increased risk of falling in people with MS (Finlayson et al. 2006). Approximately 45% of people with MS use assistive devices such as canes, walkers and wheelchairs to facilitate their mobility (Finlayson et al. 2001). Risk of injurious falls is increased in people with MS (Peterson et al. 2008, Cameron et al. 2011). Evidence suggests that overactive bladder symptoms can lead to an increase in falls and fractures since people may rush to the toilet (Chiarelli et al. 2009). Thus, when safety is of concern, bladder dysfunction falls under the scope of practice of all healthcare professionals.

Despite the high prevalence of bladder dysfunction in the MS population, many people avoid discussing their symptoms with healthcare professionals (Koch and Kelly 1999, Koch et al. 2000, Wollin et al. 2005). Reluctance to discuss bladder symptoms is common across other populations with many people unaware of the available services, tests and management options (Sinclair and Ramsay 2011, Nguyen et al. 2013) and remains a substantial barrier to management (Swanson et al. 2002, Wang et al. 2015). It is common for people to develop strategies to self-manage their bladder symptoms instead of seeking care, due to the sensitive nature of the problem (St John et al. 2010). These self-management strategies can have variable success rates for people (Horrocks et al. 2004). The lack of professional guidance results in a “trial and error” approach.

There is a lack of awareness of bladder dysfunction amongst many health care professionals and care providers (Swanson et al. 2002). For example, family physicians in Canada considered urinary incontinence a difficult problem to address.
and felt ill-prepared to manage it within older populations (Nguyen et al. 2013). Lack of confidence towards management was reported due to concerns about the level of training, drug side effects, lack of support services and general embarrassment around urinary incontinence (Nguyen et al. 2013). Therefore, an in-depth exploration of the perceptions of healthcare professionals is necessary to understand how bladder dysfunction is addressed in clinical practice.

Although there is a lack of awareness of bladder dysfunction among some healthcare professionals, guidelines exist for the management of neurogenic lower urinary tract dysfunction and bladder symptoms in MS (Fowler et al. 2009, Pannek et al. 2013). Fowler et al. (2009) proposed that bladder management should include testing for urine infection and measurement of the post micturition residual urine volume. Pannek et al. (2013) reported the incidence, definitions, diagnosis, therapy, and follow-up observation of neurogenic lower urinary tract dysfunction. Asking about bladder dysfunction has become systematic in some MS clinics; however, it is not known to what extent current practice reflects the recommended guidelines. It is timely to explore the perspectives of healthcare professionals on the management of bladder dysfunction among people with MS.

Findings from an Irish review of services for people with MS reported a lack of neurologists, MS nurses with limited access to both specialist and generalist neurorehabilitation services in the community (NAI 2015). To ensure comprehensive care for people with MS, multi-disciplinary management is advised (Motta and de Carvalho 2008). Reduced access to service provision is not unique to Ireland. People with MS in Australia report restricted access to healthcare services as an
environmental barrier to activity and participation (Khan and Pallant 2007) when reporting the impact of MS according to the International Classification of Functioning, Disability and Health (ICF) (World Health Organization 2001). Following guidance from the Medical Research Council framework for the development of complex interventions (Craig et al. 2008) it is necessary to interview key stakeholders to develop a theoretical understanding of the likely process of change. Therefore, the aim of this study was to understand the perceptions of healthcare professionals around bladder dysfunction and to explore current service provision for people with MS in Ireland.

5.2 METHODS

This qualitative study includes three dyadic interviews, two focus groups and one semi-structured individual telephone interview. A conceptual framework comprised of three theories; critical disability theory (Goodley 2010), the International Classification of Functioning and Disability model (World Health Organization 1980) and the self-regulatory model (Cameron and Leventhal 2003) guided the study. These theories are all embedded within the paradigm of inquiry of the authors. These paradigms include critical theory and constructivism. Both affirm that social relations and the analyses constructed by researchers, must be acknowledged and interpreted. The rationale for using this framework is that it informed all aspects of the research process; to help assess and refine goals, to develop realistic and relevant research questions and to identify potential validity threats to conclusions (Maxwell 2012).
5.2.1 Settings and Participants

Following the recommendations of Kruger and Casey (2009) focus group methods were employed with two groups (n=7). Additionally, three dyadic interviews (n=6) were completed (Morgan et al. 2013) and one individual telephone interview was conducted. Focus groups were deemed most appropriate to provide an understanding of the opinions of healthcare professionals on the topic of bladder dysfunction. Unfortunately, this was not possible due to a low response rate and a nationwide dispersal of participants. A number of interview methods were used to facilitate participation of healthcare professionals given their work schedules. When a participant was unable to attend a focus group, a dyadic or individual telephone interview was offered as an alternative. All interviews took place during the period June to September 2014.

A snowballing technique was used to recruit a purposive sample (Patton 1990) of Irish healthcare professionals. A recruitment email and information letter were sent to the Multiple Sclerosis Society of Ireland, Irish Society of Chartered Physiotherapists, Physiotherapists in Multiple Sclerosis, The Association of Occupational Therapists of Ireland, Irish Practice Nurses Association. These groups acted as gatekeepers for participant recruitment, forwarding the recruitment email and information sheet to healthcare professionals via electronic databases. Healthcare professionals can elect to be on the emailing list of the Multiple Sclerosis Society of Ireland (MSI). This allows regular two-way communication and updates on the role and work of MSI to healthcare professionals and people with MS nationally. Potential participants were invited to forward the recruitment email and information letter to other eligible healthcare professionals in their networks. Those who were interested contacted the
first author for further information. To participate in the study, participants were over 18 and able to communicate effectively in English. All participants had contact with people with MS during clinical practice in any setting. All participants also included assessment of bladder dysfunction in their scope of practice. As all levels of experience in assessment and management of bladder dysfunction were sought, no participants were excluded based on expertise in bladder dysfunction.

Fourteen healthcare professionals participated in this study. Participants’ details are provided in Table 6. Group interviews consisted of a combination of healthcare professionals from different settings including acute hospitals, voluntary services, inpatient rehabilitation services for people with MS, primary care and community services. There was a range of 5-100% of people with MS occupying participants’ caseloads, with an average of 62%. Participants were asked before each interview to summarise their level of experience in bladder management. All three nurses had several years’ experience in the management of bladder dysfunction among people with MS. One physiotherapist was a specialist in pelvic floor dysfunction for over twenty years. The clinical case manager, two physiotherapists and one occupational therapist were experienced in working with people with MS and were confident about their respective roles in bladder management. The remaining six participants were less certain in their approach to management of this symptom.

Group details are provided in Table 7. Ethical approval was obtained from the University of Limerick Faculty of Education and Health Sciences Research Ethics Committee (Approval Number: 2013_05_09_EHS). Written informed consent was obtained from all participants.
Table 6 Strand 2 Participant Demographic Details

<table>
<thead>
<tr>
<th>P</th>
<th>S</th>
<th>Occupation</th>
<th>Work Setting</th>
<th>Years working with people with MS</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>F</td>
<td>PT</td>
<td>Acute</td>
<td>3.5</td>
</tr>
<tr>
<td>P2</td>
<td>F</td>
<td>PT</td>
<td>Acute</td>
<td>4.5</td>
</tr>
<tr>
<td>P3</td>
<td>F</td>
<td>Nurse</td>
<td>Acute</td>
<td>15</td>
</tr>
<tr>
<td>P4</td>
<td>F</td>
<td>OT</td>
<td>Acute</td>
<td>1</td>
</tr>
<tr>
<td>P5</td>
<td>F</td>
<td>Nurse</td>
<td>NPO</td>
<td>20</td>
</tr>
<tr>
<td>P6</td>
<td>F</td>
<td>PT</td>
<td>NPO</td>
<td>11</td>
</tr>
<tr>
<td>P7</td>
<td>F</td>
<td>Manager</td>
<td>NPO</td>
<td>7</td>
</tr>
<tr>
<td>P8</td>
<td>F</td>
<td>PT</td>
<td>Acute</td>
<td>12</td>
</tr>
<tr>
<td>P9</td>
<td>M</td>
<td>PT</td>
<td>NPO</td>
<td>7</td>
</tr>
<tr>
<td>P10</td>
<td>F</td>
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<tr>
<td>P11</td>
<td>F</td>
<td>PT</td>
<td>Acute</td>
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</tr>
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<td>P12</td>
<td>F</td>
<td>Nurse</td>
<td>Acute</td>
<td>12</td>
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<tr>
<td>P13</td>
<td>F</td>
<td>PT</td>
<td>Community/NPO</td>
<td>3</td>
</tr>
<tr>
<td>P14</td>
<td>F</td>
<td>OT</td>
<td>Community</td>
<td>7</td>
</tr>
</tbody>
</table>

P=participant, S=sex, F=female, M=Male, PT=Physiotherapist, OT=Occupational Therapist, NPO=Non-profit organisation
Table 7 Strand 2 Group Details

<table>
<thead>
<tr>
<th>No.</th>
<th>Type</th>
<th>No of participants</th>
<th>Participant (Occupation)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Group interview</td>
<td>2</td>
<td>P1 (Physiotherapist)</td>
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<td></td>
<td></td>
<td></td>
<td>P2 (Physiotherapist)</td>
</tr>
<tr>
<td>2</td>
<td>Group interview</td>
<td>2</td>
<td>P3 (Nurse)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>P4 (Occupational Therapist)</td>
</tr>
<tr>
<td>3</td>
<td>Focus group</td>
<td>3</td>
<td>P5 (Nurse)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>P6 (Physiotherapist)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>P7 (Clinical Case Manager)</td>
</tr>
<tr>
<td>4</td>
<td>Group Interview</td>
<td>2</td>
<td>P8 (Physiotherapist)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>P9 (Physiotherapist)</td>
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<tr>
<td>5</td>
<td>Focus group</td>
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<td>P10 (Physiotherapist)</td>
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<td></td>
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<td>P13 (Physiotherapist)</td>
</tr>
<tr>
<td>6</td>
<td>Telephone interview</td>
<td>1</td>
<td>P14 (Occupational Therapist)</td>
</tr>
</tbody>
</table>

5.2.2 Data Collection

The interview guide (Appendix 6 and 7) was informed by a previous study exploring how bladder dysfunction interfered with quality of life for people with MS (Browne et al. 2015) and by other service provision questionnaires (Coote et al. 2010, Wagg 2011, Nguyen et al. 2013). Open questions which focused on participants’ understanding of bladder dysfunction covered topics of awareness, impact of symptoms on quality of life, self-managing symptoms and current service provision.

Focus groups were moderated by the first author with support from a note-taker who recorded main points, documented group dynamics and body language (Kruger and
Both groups were audio-recorded. Focus groups consisted of either 3 or 4 participants and lasted 95 and 75 minutes respectively. Sessions concluded with a verbal summary allowing participants to add, clarify or revise comments. Debriefing sessions between the researcher and note-taker immediately followed each focus group. Group interviews (n=3) and the individual telephone interview were conducted and audio-recorded by the first author. The mean interview time of the group interviews was 70 minutes (range = 61 to 75 minutes). The telephone interview lasted 54 minutes and written consent was posted from the participant prior to the interview. Demographic details were collected before each interview. Each concluded with a summary of key points and participants were able to make any additional comments. Debriefing sessions between the researcher and other authors followed each data collection session. Key topics arising in early interviews were discussed in subsequent groups to allow for refinement of ongoing thematic analysis (Braun and Clarke 2013).

5.2.3 Data Analysis

Thematic analysis (Braun and Clarke 2006) guided the analytic process. Reflexivity enhanced the transparency, accountability and trustworthiness of the study (Finlay and Gough 2008). It opened up unconscious motivations and implicit biases in the researchers’ approach and enabled in-depth evaluation of the research process. Data analyses did not occur in an ‘‘epistemological vacuum’’ (Braun and Clarke 2006, p.84) therefore, our theoretical commitments were made explicit. This reflexive process involved detailed discussions between all authors. These regular discussions disrupted preconceptions and created space to consider beliefs at a conscious level, thus enabling critical reflection. Strategies to promote reflection were embedded in each analytical stage. For example, fieldnotes were used to document impressions
during data collection and throughout the analytical process. Analytical memos were kept to achieve trustworthiness, by clearly documenting the key analytical decisions (Sandelowski 2000).

Thematic analysis involved an iterative process of engaging with the data (Braun and Clarke 2006). This began with verbatim transcription of interviews followed by close reading after documents were imported into NVivo10. This qualitative data analysis software package aids the researcher in managing data whilst also including storage of analytical memos that create an audit trail of key decisions made throughout the research process (Welsh 2002). Initial codes were generated by drawing from keywords and phrases within transcripts and fieldnotes. All authors read and coded transcripts, strengthening the inductive coding framework. Through ongoing deliberation, the codes were gradually moved into clusters that were then explored in more detail to identify connections and contrasts. Potential themes were checked across the coded extracts and an initial diagram of the analysis was created. Tentative themes were examined to ensure they described a coherent pattern. The query tool in NVivo10 enabled the strength of these clusters and to be tested (Bassett et al. 2009). For example, when it became evident that ‘beliefs’ was an important cluster in the findings, queries were run in NVivo10 by cross-checking beliefs with other ideas such as type of healthcare professional, person with MS, and setting. This ensured that no data was missed in relation to the cluster of ‘beliefs’. Clear definitions were then developed for each theme, to uniquely set parameters and eliminate overlap between themes. The diagram (Figure 8) was adjusted to reflect these changes. Final definitions were developed for each category and theme. Representative quotes were selected to illustrate the results.
5.3 FINDINGS

Analysis yielded two key themes: (1) a model of clinical practice development in relation to bladder management and (2) facilitating change to optimise access to services for people with MS. Figure 8 represents the interaction between these themes. Theme 1 is characterised by the three cylinders labelled beliefs, practice and experiential knowledge. The large circle behind these cylinders symbolises bladder management. The model of clinical practice development focuses on the healthcare professional at an individual level. The second theme is symbolised by the brackets named “facilitating change” on both sides of the model. The first element of this theme “2a” is displayed on the left. It encompasses the interaction between clinical practice and experiential knowledge of healthcare professionals. Bracket “2b” on the right is the second element of facilitating change and incorporates how acknowledgement of individual beliefs of healthcare professionals can inform clinical practice and experiential knowledge. The arrows at the base of the diagram indicate how this model of clinical practice development in relation to bladder management may influence whether or not people with MS access services.
5.3.1 Model of clinical practice development in relation to bladder management

Theme 1 is presented here as the “model of clinical practice development”. This model captures the interaction that exists between the underlying beliefs of healthcare professionals, their current practice and experiential knowledge. Participants spoke about how their underlying beliefs regarding bladder dysfunction informed clinical practice which in turn influenced their experiential knowledge. Participants discussed beliefs about time, priorities, responsibility, the privacy associated with the topic and professional competence in relation to bladder management. Although participants mentioned beliefs about service provision at a systemic level, the findings of this study
focus on beliefs discussed at an individual level. Quotes are provided below with some phrases in parentheses to indicate clarifications by the authors.

Participants frequently reflected on the time demands associated with asking people with MS about bladder dysfunction. When asking about bladder dysfunction one must allow time for a lengthy response from clients.

If you ask that question [about bladder dysfunction] you need to give people time. Every question you ask is time-related and people [healthcare professionals] don’t have time so they avoid the questions. But in the long term that’s not effective. (Nurse P5)

This statement demonstrates the intense time demands that may result in some healthcare professionals side-stepping issues related to incontinence. Similarly, P4 commented on her beliefs about time and prioritisation of bladder questioning. She would not explore bladder dysfunction in detail during initial assessment. She explained “it wouldn’t be my top priority but I ask every single person I see in just a quick screening thing, but it probably wouldn’t be a priority in initial assessment” (Physiotherapist P4). She believed bladder dysfunction required a “quick screening.”

Time demands and pressures to prioritise reduced discussion of bladder dysfunction during assessment.

Beliefs about responsibility were also discussed. Participants stated that as healthcare professionals they focused on their own area of expertise:

Everyone tends to focus in on what they know, on what they are familiar with, on what they are good at. We might be thinking straight away we have to improve their leg strength and their walking and to improve their balance.
Maybe we are not really looking at the whole bigger picture. I suppose the doctors in clinic are probably the same. They zone in on really what they think they can work on and improve. (Physiotherapist P1)

The issue of responsibility among healthcare professionals is centralised in this statement, with P1 mapping out her typical focus as a physiotherapist. If one does not recognise professional responsibility in bladder management, then it is unlikely to translate to practice. Not only does this potentially impact upon people with MS with bladder dysfunction and their quality of life, it also limits opportunities for learning among healthcare professionals. P1 acknowledged that this narrow, discipline-specific focus may be problematic. Although in theory the person with MS is central to management, this is not evident in participants’ perspectives about current service provision. Another physiotherapist identified how she came to realise her possible role in bladder management.

I find they nearly open up more to you than they sometimes would to other professionals. I would have always kind of thought it [incontinence] was a nurse thing that needs to be done. It was only when they [people with MS] started opening up a bit more that I kind of thought that maybe we could have more of a role in it. (Physiotherapist P2)

This statement captured a shift in thinking for this physiotherapist. People with MS disclosed their bladder symptoms, thus expanding her experiential knowledge and influencing underlying beliefs about her responsibility as a healthcare professional.

A significant issue for many was the privacy associated with bladder dysfunction. Beliefs held by participants around the sensitive nature of bladder dysfunction reinforced the silence surrounding the topic. Questions about bladder dysfunction
were often not pursued with clients due to uncertainty around comfort in disclosing. For example, P10 found it difficult to ascertain whether the person might want to talk about bladder dysfunction.

Sometimes I do feel a little bit uncomfortable because a lot of these clients I would see every week and we would see for mobility problems. We would talk about a lot of things and then sometimes I’m like do they want to talk about this with me because they are going to continue seeing me afterwards and would they prefer if I didn’t know this information (Physiotherapist P10)

This uncertainty contributed to inconsistency in practice. Onward referral seems to be reliant on how comfortable the person with MS is to bring up the issue of bladder dysfunction. It is therefore likely that some people with MS may not receive onward referrals and further input around bladder dysfunction. Due to this belief around sensitivity, many participants perceived bladder dysfunction as a challenging topic. This resulted in participants struggling to decide the optimal amount of information to provide to people with MS.

For proper assessment you have to probe, but I think you kind of gauge where you are with them. Some of them are very fragile, someone was possibly diagnosed with a relapse of bladder symptoms, you don’t want to go full on “there’s catheters, there is this, that and the other”, you want to gauge it a bit as to how far you will go with it. (Physiotherapist P6)

This demonstrates P6 recognised the importance of providing suitable information at the right time. Her belief that bladder dysfunction is a sensitive topic informed how she engaged with people with MS about their symptoms. This shaped the type of relationships she developed in clinical practice. P4 stated that “you don’t want to go
barrelling in with issues about bladder control” suggesting a belief about the need to be cautious and not to overload the person with information. This underlying belief of sensitivity informed how participants discussed bladder dysfunction and their choice of language. P1 described how she asks about bladder dysfunction differently to other symptoms. She said she asks directly “How is walking going now?” or “How are you getting on?” but would never ask “How’s the bladder?” She suggested that one could not ask about bladder symptoms in the same way as other symptoms, which emphasised the influence of this belief on her clinical practice.

The final belief discussed by participants was connected to professional competence. One participant argued that healthcare professionals had the necessary skills to discuss bladder dysfunction including being open, active listening, problem solving and using a person centred approach to management.

I’m getting better at it. To be honest with you I didn’t in the beginning but now I am because it is such a huge area…and I think as occupational therapists and as healthcare professionals it is something we are very good at we are active listeners and we are problem solvers as well we can look at things you know and we are very open about things. (Occupational Therapist P14)

P14 spoke of her increased confidence in discussing bladder dysfunction. She claimed that health professional training includes all the elements needed to effectively address issues related to bladder dysfunction. However, despite this she was concerned about a perceived lack of competence among some healthcare professionals. She suggested that some may even become anxious in dealing with bladder symptoms.

You will always get somebody [a healthcare professional] who will go “Oh god, no I can’t do that. Oh god, I wouldn’t be able for it.” So then you will say
to them “ok I’m not asking you to do the job... but it’s important that you know about it. It’s important that you don’t have a panic attack-you don’t freak the person out.” If they ask you to do something, ok you can’t do it. But at the same time isn’t it better that you know about it and you are aware of what they need? (Occupational Therapist P14)

This statement suggests the importance of reassuring healthcare professionals who are not confident approaching the topic. P14 was concerned about healthcare professionals who were unable to talk about bladder dysfunction.

If you’re not able to do that then there is something wrong. If you feel that you haven’t got the confidence to say “look I need help here” you have to be able to go back and say “well why can’t I ask? What is it? Why am I embarrassed? Why am I ashamed?” (Occupational Therapist P14)

P14 conveyed the importance of personal reflection in practice and being able to seek guidance when needed. Lack of expertise on the topic can reduce self-confidence. This can impact on clinical practice and outcomes for people with MS. Bladder dysfunction is considered outside the scope of practice for many participants. They felt unable to offer any help for clients with bladder symptoms.

I would feel quite limited myself. I’m not trained in women’s health or continence. I would feel that that would be a bit of a gap and we don’t really have a very large women’s health service here so there isn’t really anybody directly I can really refer them to. (Physiotherapist P2)

This belief around individual ability in bladder management resulted in P2 avoiding this topic with clients.
This “model of clinical practice development” portrays the influence of underlying beliefs of healthcare professionals on clinical practice and their knowledge on bladder dysfunction. It highlights the importance of underlying beliefs and how they act as the foundation for clinical practice and influence the learning of healthcare professionals. The model can have consequences for people with MS in terms of accessing services. The interaction between the elements of underlying beliefs, clinical practice and experiential knowledge of healthcare professionals can steer people with MS towards successful management of symptoms but may also inadvertently divert them from services altogether.

**5.3.2 Facilitating change to optimise access to services for people with MS**

This theme focuses on how change may be implemented within the “model of clinical practice development” to optimise bladder management. These pivotal points for change include two elements. The first element (2a) involves reflecting on clinical practice and experiential knowledge. This provided participants with new insights in terms of collecting a detailed history, asking about bladder dysfunction, methods of probing for more information and providing a suitable physical environment for disclosure. The second element of change (2b) relates back to the individual beliefs of participants in relation to bladder dysfunction and how this changed practice. In addition to the potential influence of these changes for people with MS accessing services, participants discussed their development as healthcare professionals.

Many participants reflected on their clinical practice and offered examples of new knowledge gained through this process. Several participants suggested the need for a detailed history during subjective assessment.
I think from my perspective anyway it’s getting the collateral [information] from the patient. I think that is crucial and getting that history and asking the question “have you this problem and that?” Then it is amazing what comes out then. But it is getting the collateral and how one gets that collateral. (Nurse P12)

Looking back P12 learned from clinical practice that a detailed history is imperative. Methods of asking about bladder dysfunction were also regarded as important among participants. Asking one question may not suffice. P14 recognised changes in daily routines as indications of bladder symptoms. She stressed that assessment is more than just asking questions and it is necessary to observe changes in daily functions and habits. Others also investigated changes in socialising activities. For example, P6 asked people “are you going out on the bus trip today?” to see if bladder dysfunction was limiting participation. This emphasised the need to explore daily activities when assessing bladder dysfunction. P14 also highlighted the importance of explaining why bladder dysfunction is relevant to the assessment and offering reassurance.

You say “right, ok you are not alone. You’re not the first person this has happened to. You’re not going to be the last person this happens to.” Then once they are able to off-load, you can see there is a big change in the person. They kind of go “oh my god that’s grand that’s ok.” (Occupational Therapist P14)

In-depth questioning and justification of why one is asking about these symptoms was suggested. Implementing these strategies contributes to experiential learning. Knowing when to probe for more information is an important skill for healthcare professionals. Healthcare professionals must be capable of approaching those who are reluctant to offer information about their symptoms. Many participants emphasised
the importance of probing. “I guess that’s [probing] one way of making them aware—just asking them when assessing. So they are like ‘oh no problem with that’ then maybe when you keep asking ….so it depends on the way you ask” (Physiotherapist P10). This demonstrated how P10 used experiential knowledge, recognising that probes are often needed when clients dismiss bladder symptoms after just one question. This captured her learning from clinical practice about the methods of asking about bladder dysfunction which in turn influences the response of the person.

In addition to methods of questioning, the importance of creating a comfortable environment was discussed among participants. “They say it’s (bladder) not a problem but when you investigate it a little more or when they are in a little more comfortable environment they have reported it.” (Physiotherapist P1). This highlighted how people with MS may initially dismiss the problem but when they feel comfortable with their surroundings they will disclose their symptoms. P2 described how a crowded clinical environment can result in people withholding information:

I find that they are seen in clinic by the team and they could have four or five doctors in the room between medical students or registrars. Then you get a referral for them to be seen by physiotherapy and you bring them into a quiet gym and you see them one-on-one and they would tell you a lot of stuff then that they wouldn’t have told the doctor. I might go back to the doctor and say “oh she’s having a lot of sexual problems or she’s having a lot of urinary problems” and they wouldn’t have heard of it. (Physiotherapist P2)

P2 raises the importance of the environment and how it can impact on people disclosing their symptoms by comparing a one-to-one private session with a room full of healthcare professionals.
Some participants took into account their personal beliefs and how this influenced their practice. P13 reported that many of the people with MS she interacted with did not have bladder problems. Looking back, she suggested that this low prevalence may relate to her not asking enough questions on this topic.

That’s why I feel with some patients they initially come in and do the assessment and they don’t have any problems. I think it was partially as well my fault because I probably didn’t ask them enough, most of my assessment is really physical... so maybe I did not give enough time to ask about the bladder so maybe it’s them not wanting to disclose or me. (Physiotherapist P13)

This critical reflection, prompted by new ideas about bladder dysfunction disrupted P13’s typical approach, creating a new perspective around initial assessment.

The first point of contact for care for the person with MS is the healthcare professional. Each healthcare professional has a specific set of beliefs about themselves and their profession. Findings from this study demonstrate the influence of underlying beliefs on clinical practice and the experiential knowledge of the healthcare professional. Findings also display that these beliefs determine the pathway of the person seeking help. Thus, the importance of underlying beliefs of healthcare professionals should not be underestimated in relation to bladder management.

5.4 DISCUSSION

This is the first study attempting to understand the perceptions of healthcare professionals concerning bladder dysfunction and to explore current service provision for people with MS in Ireland. A “model of clinical practice development” was
presented. This model demonstrated the interaction between underlying beliefs, practice and experiential knowledge of healthcare professionals. Findings suggest that implementing change within this model may optimise access to services for people with MS. The first element of change connects practice and experiential knowledge. This is an example of reflective practice (Finlay 2008). The second element of change focuses on understanding one’s underlying beliefs and the influence of these beliefs on clinical practice and experiential knowledge. This is an example of reflexive practice (Bolton 2010). The terms reflective and reflexive practice are often used interchangeably in the literature (Heather D’Cruz et al. 2007); however, this study offers a mechanism to explore the difference between them. Reflexive practice is central to research methodologies (Alvesson and Sköldberg 2009) but its value is not yet fully appreciated within the clinical setting. As healthcare professionals we need to consider the value of both reflective and reflexive practice in optimising service provision for people with MS with bladder dysfunction. The degree of experience in assessing and managing MS-related bladder dysfunction would influence the themes identified during the study and therefore the final conclusions. However, the nature of focus groups and dyadic interviews allowed the teasing out of ideas across participants of different disciplines with varying expertise (Table 6) which reflects the clinical setting in which people with MS are seen.

According to Finlay (2008) reflective practice is understood as the process of learning through and from experience towards gaining new insights of oneself and/or practice (Mezirow 1981, Boyd and Fales 1983, Jarvis 1992). Participants in this study reflected on their practice, which deepened their initial impressions and allowed them to develop strategies to improve service provision for people with MS. They suggested
ways in which to optimise discussion of bladder dysfunction during assessment. This involved collecting a detailed history, methods of asking, linking bladder questions to daily activities, probing for more information and providing a suitable physical environment. The importance of reflection among healthcare professionals is well documented (Mann et al. 2009, Gibson et al. 2010, Whalley Hammell 2013). Reflective capacity is an essential characteristic of professional competence and is often prompted by complex clinical problems which enables learning from experience (Mann et al. 2009).

Based on reflections of participants, a set of practical recommendations are offered to address the difficulties clinicians face when subjectively assessing bladder dysfunction (Table 8). In order to centralise the person with MS and in keeping with the conceptual framework which guided the research process these recommendations are structured according to the International Classification of Functioning, Disability and Health (ICF) (World Health Organization 2001). The ICF provides an excellent framework of functioning and disability within which the topic of bladder dysfunction can be considered and allows us to frame the findings of this study to guide initial assessment and increase communication about bladder dysfunction.
Table 8 Suggestions to guide subjective assessment

<table>
<thead>
<tr>
<th>Body Functions and Structure</th>
<th>Prompts to initiate conversation: Begin with reassurance of symptoms:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bladder functioning</td>
<td>• Many other people with MS your age find they have to get up at night to go to the bathroom can you relate to this?</td>
</tr>
<tr>
<td></td>
<td>Use activities of daily living to probe for information. If a person reports disrupted sleep probe for more information:</td>
</tr>
<tr>
<td></td>
<td>Why do you think that is? What do you think contributes to that?</td>
</tr>
<tr>
<td>Bowel Functioning</td>
<td>• Is connected to needing to pass urine?</td>
</tr>
<tr>
<td></td>
<td>• Does bed wetting ever occur?</td>
</tr>
<tr>
<td>Urinary Tract Infections</td>
<td>• Does it interfere with your partner’s sleep?</td>
</tr>
<tr>
<td></td>
<td>• How is your diet? What is your typical daily fluid intake?</td>
</tr>
<tr>
<td></td>
<td>• Do you suffer from constipation? Do you have a daily bowel movement?</td>
</tr>
<tr>
<td></td>
<td>• Do you have a history of urinary tract infections?</td>
</tr>
<tr>
<td></td>
<td>• If so, how many? Were you hospitalised?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Activity and Participation</th>
<th>Consider activity and participation to begin questioning about bladder symptoms:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility</td>
<td>• Are mobility issues causing any problems? Do you have any difficulty washing or dressing yourself? Is this connected to your bladder symptoms?</td>
</tr>
<tr>
<td></td>
<td>• How are you managing your transfers? Do you have any difficulty getting in and out of bed?</td>
</tr>
<tr>
<td>Sexual functioning</td>
<td>• Do you sleep in a double or single bed?</td>
</tr>
<tr>
<td>Work</td>
<td>• Does your partner sleep in the same bed as you? Is this connected to your bladder symptoms?</td>
</tr>
<tr>
<td>Socialising</td>
<td>• Does it disturb your usual sexual activities?</td>
</tr>
<tr>
<td></td>
<td>• Describe your work environment</td>
</tr>
<tr>
<td></td>
<td>• Do you have access to nearby toilets? Can you get to the bathroom on time?</td>
</tr>
<tr>
<td></td>
<td>• Describe your social activities</td>
</tr>
<tr>
<td></td>
<td>• How often do you go out? What stops you? Is this connected to your bladder symptoms?</td>
</tr>
</tbody>
</table>

| Other Factors                | |
|------------------------------| |
| Product use                  | • Do you use any products to manage symptoms? |
| Attitude                     | • Do you have difficulty emptying your catheter? |
|                              | • How often do you empty it? how often do you check it? |
|                              | • Do your bladder symptoms bother you? |
Reflexive practice involves finding strategies to question our own attitudes, thought processes, values, assumptions, prejudices and habitual actions, to strive to understand our complex roles in relation to others (Bolton 2010). Reflexivity demands more complex critical engagement than reflective practice, in that the potential for understanding the countless ways in which one’s own presence and perspective influence the knowledge and actions which are created is potentially more problematic than the simple searching for implicit theory (Fook et al. 2006). A “model of clinical practice development” was presented in the paper. The foundation of the model incorporates the underlying beliefs of healthcare professionals. Addressing these beliefs creates an opportunity for healthcare professionals to engage in reflexive practice, questioning their attitudes and assumptions in relation to bladder management. This model demonstrates the influence of underlying beliefs on clinical practice and knowledge. Qualitative researchers who engage in reflexive practice promote a self-aware analysis of the interplay between the researcher and the researched. A reflexive process can empower by making possible a more critical consciousness (Finlay and Gough 2008). It is necessary to engage in this type of reflexive practice in the clinical setting if attitudes towards bladder dysfunction are to be challenged.

The underlying beliefs of healthcare professionals are rarely discussed in the literature. On a broader scale, there has been some recent discussion into the theoretical foundations of healthcare professions (Gibson et al. 2010, Whalley Hammell 2013). Healthcare professionals have specific assumptions and beliefs coming into practice and these assumptions need to be challenged to expose linkages between ideologies and power (Whalley Hammell 2013). Physiotherapists, occupational therapists and nurses have stated that little critical attention has been given to the conceptual
assumptions that underpin their profession or to the implications of these unspoken assumptions for their professions future (Öhlén and Segesten 1998, Gibson et al. 2010, Whalley Hammell 2013). Therefore, consideration of one’s underlying beliefs and approach to practice is a timely topic.

Challenging beliefs is vital in a perceived silent condition such as bladder dysfunction. Shaw (2001) highlighted the need to identify the attitudes and beliefs of healthcare professionals that act as barriers to effective treatment for urinary conditions. In our study participants discussed their beliefs regarding the silence surrounding bladder dysfunction which resulted in their hesitancy approaching the topic. This hesitancy is similar in other studies where healthcare professionals are reluctant to discuss urinary conditions. Family physicians, who are the primary care providers for the majority of incontinent women in Canada, frequently report that they are not adequately trained to treat incontinent people and therefore are reluctant to discuss or manage the condition (Swanson et al. 2002). Similarly, a study exploring GPs’ attitudes to urinary incontinence among elderly persons in The Netherlands gave insight into reasons why the treatment of elderly people with urinary incontinence is substandard. The most important reasons were reduced competence of the GP and the low motivation of the patient. Lack of knowledge and lack of time among GPs were also highlighted as barriers to successful management (Teunissen et al. 2006). This study added that lack of time, lack of privacy, lack of professional competency and uncertainty in relation to professional responsibility were barriers to management of bladder dysfunction in an Irish context. No study to date has explored beliefs around the silence of bladder dysfunction and whether or not this contributes to reduced discussion in clinical practice. Future research is needed to map out current service provision in Ireland and
to explore barriers to management from the perspectives of both healthcare professionals and people with MS.

5.5 LIMITATIONS

There were some limitations to this study. As with all qualitative research, findings are not intended to be generalised. To create transferability, findings of this study were compared and contrasted to the broader literature. It is acknowledged that the sample size could be identified as a limitation. Multiple methods of recruitment were used over six months. The fourteen participants represent diverse backgrounds in terms of clinical setting, discipline, number of years of clinical experience and working with people with MS. Therefore, these fourteen participants were a representative sample. There was predominance of physiotherapists in the cohort and only one nurse. This may be a reflection of the reduced number of nurses working with people with MS in Ireland. Although all healthcare professionals were recruited similarly, the leading author (CB) is a physiotherapist and a member of the special interest group PIMS: Physiotherapists in Multiple Sclerosis. Members of this group are familiar with a strong research ethos from the MS research team in Ireland and therefore may have been more inclined to participate by knowing members of this research team and familiar with how the data is used to influence policy and practice. Findings from a previous study exploring bladder dysfunction among people with MS (Browne et al. 2015) were used to inform the interview schedule. This may potentially result in confirmation bias (Gratton and Jones 2010). However, the interview schedule offered a springboard for discussion among participants to initiate conversation on the topic and therefore did not influence the findings of this study.
5.6 CONCLUSION

This is the first in-depth exploration of the perceptions of healthcare professionals concerning bladder dysfunction and service provision for people with MS in Ireland. Findings from this study suggest that as healthcare professionals we may need to consider our beliefs in relation to bladder dysfunction. Clinical reflection and reflexive practice are both vital for the development of services. Findings suggest that while reflection can essentially disrupt clinical practice and create the possibility for change, reflexive practice may offer greater scope for change. Examining beliefs about bladder dysfunction is necessary in order to challenge existing perceptions and to reduce the silence among healthcare professionals. This may influence how people with MS access health service provision for this disabling symptom.
CHAPTER 6 STRAND 3 CURRENT SERVICE

PROVISION AND SELF-MANAGEMENT OF BLADDER DYSFUNCTION IN THE REPUBLIC OF IRELAND:

PERSPECTIVES FROM PEOPLE WITH MULTIPLE SCLEROSIS AND HEALTHCARE PROFESSIONALS

6.1 INTRODUCTION

It is well documented that bladder dysfunction is prevalent among people with Multiple Sclerosis (MS) affecting up 75% of this population (Hennessey et al. 1999, Litwiller et al. 1999, Nortvedt et al. 2007). Bladder dysfunction is one of the most debilitating aspects of MS and affects several important life domains (Koch et al. 2001, Minassian et al. 2003, Browne et al. 2015). Evidence-based guidelines exist for the management of bladder dysfunction among people with MS (de Sèze et al. 2007, Fowler et al. 2009, Pannek et al. 2013). NICE (2012) provides clinical pathways for the assessment and management of urinary incontinence in neurological conditions suggesting a stepwise approach for generalist clinicians at initial assessment. This helps healthcare professionals to differentiate between conservative management options and the need to refer the patient for specialist assessment. All guidelines concur that managing bladder symptoms in this population is complex and multifaceted, however, major difficulties arise for healthcare professionals when implementing clinical guidelines into routine daily practice (Grol and Grimshaw 2003). For example, a review by Grol and Grimshaw (2003) found that 30-40% of patients across services in the USA and the Netherlands do not receive care according
to current scientific evidence, and about 20–25% of care provided is not needed or is potentially harmful. This challenge of translating research to practice is frequently reported in health service research (Bodenheimer 1999, Cochrane et al. 2007). The question remains if existing guidelines for the management of bladder dysfunction among people with MS are implemented in the Republic of Ireland.

It is timely to compare management of bladder dysfunction to existing guidelines and to seek the opinions of stakeholders on these strategies. Management of bladder dysfunction among people with MS can only be effective if an integrated approach is adopted by all those involved in caring for this client group (Williams 2012). Integration of first-person perspectives is central to critical disability theory (Goodley 2010). Therefore, including the accounts of people with MS in this exploration of current service provision will provide a better understanding of self-management from those living with bladder dysfunction. Healthcare professionals bring to their encounters a belief system that influences the way they discuss, assess and manage bladder dysfunction. Therefore, it is useful to involve both people with MS and healthcare professionals in this study. No research to date has explored the similarities and differences between perspectives of people with MS and healthcare professionals around the assessment and management of bladder dysfunction.

Most literature exploring the impact of bladder dysfunction on daily life attends to non-MS populations, primarily middle-aged and older women (Sinclair and Ramsay 2011, Nilsson et al. 2012). Bladder symptoms can interfere with work (Fultz and Herzog 2001), travel, (Lagro-Janssen et al. 1992), social activities (Melville et al. 2002), sexual functioning and intimate relationships (Barber et al. 2002) in the broader
population. However, people with MS who experience bladder dysfunction differ significantly from their counterparts with bladder dysfunction who are otherwise healthy. Firstly, the aetiology of bladder dysfunction in MS is complex due to the neurogenic component and disruptions to the neural pathways that control bladder functioning (Williams 2012). Secondly, mobility issues can intensify the impact of bladder dysfunction for this population. Almost half of people with MS use assistive devices to facilitate mobility (Finlayson et al. 2001), raising the risk of injurious falls (Finlayson et al. 2006, Cameron et al. 2011). Furthermore, risk of falling is increased with the addition of bladder symptoms (Finlayson et al. 2006). Finally, bladder dysfunction in MS is associated with frequent urinary tract infections, which can lead to hospitalisation and nursing home admissions for medical management and increased levels of care (Stewart et al. 2003, Ko et al. 2005, Nortvedt et al. 2007).

Bladder dysfunction is unique in this population, thus, it is necessary to understand perspectives of people with MS. Few studies focus on exploring the impact of bladder dysfunction in MS, hence no clear understanding exists. Without this research it is not known if healthcare professionals working with people with MS are aware of the unique daily challenges bladder dysfunction imposes.

Bladder dysfunction remains a “taboo” subject among both people with MS and healthcare professionals (Shaw 2001, Nguyen et al. 2013). Many healthcare professionals remain reluctant to discuss or manage the condition due to a lack of professional knowledge, time and adequate training (Swanson et al. 2002, Teunissen et al. 2006). Similarly, many people with MS are reluctant to seek help for their symptoms (Koch et al. 2001). A desire to self-manage bladder symptoms was reported by people with MS as a reason for this hesitation (Koch et al. 2001). Self-management
can increase patients’ awareness of physical symptoms, empower them to monitor the effects of behavioural changes aimed at improving chronic conditions, and help people feel better equipped to cope with an illness (Wilde et al. 2014). Several bladder symptoms are amenable to self-management through conservative strategies such as bladder retaining for detrusor over-activity, pelvic floor muscle training for pelvic floor weakness (Lúcio et al. 2011) and self-catheterisation for emptying dysfunction. However, people with MS in Ireland continue to attempt to self-manage bladder symptoms without the required professional input or advice (Browne et al. 2015). For example, people with MS often use harmful management strategies such as dehydrating themselves to avoid the perceived humiliation associated with leaking in public, despite understanding the potential detrimental effects this could have on their physical well-being (Koch et al. 2000, Browne et al. 2015). Exploring the perspectives of people with MS and healthcare professionals around self-managing dysfunction will improve understanding around current approaches to management.

This questionnaire study will examine current service provision for people with MS with bladder dysfunction from the perspectives of both healthcare professionals and people with MS. A comparison of responses between stakeholders will clarify what management strategies are employed by healthcare professionals, while simultaneously evaluating their real-life value for people with MS. Furthermore, this comparison will identify the specific challenges to management for both healthcare professionals and people with MS. This builds on the findings of the qualitative studies that explored the impact of bladder dysfunction among people with MS (Browne et al. 2015) and perceptions of health care professionals working with people with MS with bladder dysfunction (Chapter 5 paper under review). This study expands on these
findings to gather information on patient and healthcare professional beliefs that may promote or inhibit behavioural change (Craig et al. 2008).

6.2 AIM

The overall aim of this study was to compare perspectives of healthcare professionals and people with MS in the Republic of Ireland on current service provision for bladder dysfunction. More specifically the three objectives of this study were to compare:

1. The level of awareness of bladder dysfunction among people with MS and healthcare professionals.
2. The current approaches to assessment and management of bladder dysfunction from the perspectives of both people with MS and healthcare professionals.
3. The perspectives of people with MS and healthcare professional on self-management of bladder dysfunction. This includes the challenges and needs of both groups in facilitating self-management of bladder dysfunction.

6.3 METHODS

6.3.1 Study design

A cross-sectional study design was used. This study is the final strand of a larger mixed methods research project and involved a self-report online questionnaire. It builds on the qualitative findings from people with MS and healthcare professionals in the first two strands. An online questionnaire allowed collection of information from a large number of people efficiently (De Vaus 2002). An internet-based survey software,
SurveyMonkey™ provided the platform for this questionnaire. Two similar surveys were developed, one for healthcare professionals (Appendix 13) and another for people with MS (Appendix 14), as no validated questionnaire designed for this type of research was published. This content was informed by existing literature (Nguyen et al. 2013, Browne et al. 2015). Participants were requested to provide information about their awareness of bladder dysfunction, confidence in assessment and management, responsibilities, access to services, barriers to management and their perspectives on the development of an educational resource to facilitate self-management of bladder dysfunction. A range of question formats were used included yes/no, multiple choice, Likert scale, rank order and open-ended queries to obtain information to fulfil the aims of the study. The questionnaire was live from May 2015 to August 2015. Respondents’ implied consent was obtained via a statement on the opening page of the questionnaire requiring acceptance before accessing the survey. Respondents were not contacted, coded or identified in any way. Ethical approval was granted for the study from Health Service Executive (HSE) Research Ethics Committee (approved 26th March 2015).

The questionnaire designed for healthcare professionals was piloted with a group of clinicians (n=4) working with people with MS to ensure readability, sequence and suitability of questions. The second questionnaire was piloted with two people with MS (one male, one female) for lay-language appropriateness. The questions were then adapted based on this feedback before the survey went live.
6.3.2 Participants

To be eligible for inclusion in the study people with MS had at least one symptom of bladder dysfunction. All participants were required to be over 18 years and able to communicate effectively in English. It was necessary for healthcare professionals to encounter people with MS during clinical practice in any setting and for the assessment of bladder dysfunction to fall within their scope of practice. People with MS who did not experience any bladder symptoms were excluded. Healthcare professionals who were not involved in the management of people with MS were excluded from the study. Snowballing techniques enabled recruitment of a purposive sample of healthcare professionals and people with MS via professional organisational bodies (HSE Communications office, MS Ireland, Irish Society of Chartered Physiotherapists, Physiotherapists in Multiple Sclerosis, The Association of Occupational Therapists of Ireland, Irish Practice Nurses Association, Irish Medical Organisation). These organisations acted as gatekeepers for recruitment. Each organisation was contacted via email and agreed to forward the recruitment email and questionnaire link to relevant members. Potential participants were also recruited through media sites of MS Ireland: Twitter, Facebook and electronic newsletters. Interested participants were invited to forward the recruitment email to both colleagues and people with MS to maximize response rates.

6.3.3 Data Analysis

Data was exported from SurveyMonkey™ into SPSS version 16 for analysis. Descriptive statistics were used to report frequencies and percentages across both groups. For questions with Likert Scale options, data is described using percentages
and presented graphically using stacked bar charts. Presenting the data in this manner is seen as more appropriate than using means and standard deviations, due to the discrete nature of the data (Jamieson 2004). Chi-squared tests were carried out as appropriate to compare responses between healthcare professionals and people with MS. The chi-square test is a non-parametric test which assumes that each observation is independent of all the others (one observation per subject) and that at least 80% of cells have expected frequencies of 5 or more (Pallant 2013). When these assumptions were not met, Fisher’s exact test was used. A cut off significance value level of \( p < 0.05 \) was used. The Chi-square is a significance statistic, and should be followed with an effect size statistic (McHugh 2013). The Cramer’s V is the most common effect size statistic or measure of association when a significant chi-square result has been obtained (McHugh 2013). Therefore, level of association between variables was reported using Cramer’s V. To ensure transparency all \( p \) values and related analyses are reported in the tables below (Wasserstein and Lazar 2016).

6.4 RESULTS

Results are organised to address the three key research objectives. To begin, perspectives on the level of awareness of bladder dysfunction is discussed and compared among both groups. Secondly, assessment and management approaches are outlined. Finally, perspectives of self-management of bladder dysfunction are compared between healthcare professionals and people with MS, with particular attention to the associated challenges. To summarise responses, the categories “strongly agreed” or “agreed” are referred to as “agreed” in the text. Similarly, the categories “strongly disagreed” or “disagreed” are summarised as “disagreed” throughout. Frequencies of the individual categories are given within the tables. As
not all questions were completed by each respondent, results are reported as a percentage of responses for each individual question (Fink 2012).

A total of 213 participants completed the questionnaire, including 109 people with MS and 104 healthcare professionals. Table 9 demonstrates that the majority of respondents with MS were female (68/102; 66.7%). Over half of the people with MS in this study had relapsing-remitting MS (60/105; 57.1%). Regionally, the highest proportion of respondents with MS (37/100; 37%) were from Dublin North-East. Table 10 details healthcare professionals’ demographics. Among this cohort, most were female (67/79; 84.8%), 22-64 years in age and physiotherapists represented the largest response by discipline (28/68; 41.2%). Over one third (27/76; 35.5%) of healthcare professional respondents were from the west of Ireland.
Table 9 Strand 3 Demographics of people with MS

<table>
<thead>
<tr>
<th>People with MS =109/213 (51.2%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respondents</td>
</tr>
<tr>
<td>Gender</td>
</tr>
<tr>
<td>n=102</td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td>Age (years)</td>
</tr>
<tr>
<td>n=104</td>
</tr>
<tr>
<td>Range</td>
</tr>
<tr>
<td>Type of MS</td>
</tr>
<tr>
<td>n=105</td>
</tr>
<tr>
<td>Relapsing-remitting</td>
</tr>
<tr>
<td>Secondary Progressive</td>
</tr>
<tr>
<td>Primary Progressive</td>
</tr>
<tr>
<td>Progressive relapsing</td>
</tr>
<tr>
<td>Unknown</td>
</tr>
<tr>
<td>Mobility Status</td>
</tr>
<tr>
<td>n=106</td>
</tr>
<tr>
<td>Walk not affected</td>
</tr>
<tr>
<td>Walk affected but able to walk</td>
</tr>
<tr>
<td>independently</td>
</tr>
<tr>
<td>Unilateral support to walk</td>
</tr>
<tr>
<td>outdoors but independent</td>
</tr>
<tr>
<td>indoors</td>
</tr>
<tr>
<td>Bilateral support to walk</td>
</tr>
<tr>
<td>outdoors or unilateral</td>
</tr>
<tr>
<td>indoors</td>
</tr>
<tr>
<td>Wheelchair outdoors or bilateral</td>
</tr>
<tr>
<td>support indoors</td>
</tr>
<tr>
<td>indoors</td>
</tr>
<tr>
<td>Wheelchair outdoors</td>
</tr>
<tr>
<td>Years diagnosed with MS</td>
</tr>
<tr>
<td>n=84</td>
</tr>
<tr>
<td>Mean (SD)</td>
</tr>
<tr>
<td>Range</td>
</tr>
<tr>
<td>HSE Region</td>
</tr>
<tr>
<td>n=100</td>
</tr>
<tr>
<td>South</td>
</tr>
<tr>
<td>West</td>
</tr>
<tr>
<td>Dublin North-East</td>
</tr>
<tr>
<td>Dublin Mid-Leinster</td>
</tr>
<tr>
<td>Bladder Symptoms</td>
</tr>
<tr>
<td>n=107</td>
</tr>
<tr>
<td>Urgency</td>
</tr>
<tr>
<td>Frequency</td>
</tr>
<tr>
<td>Hesitancy</td>
</tr>
<tr>
<td>Interrupted Stream</td>
</tr>
<tr>
<td>Urinary Incontinence</td>
</tr>
<tr>
<td>Stress urinary incontinence</td>
</tr>
</tbody>
</table>
Table 10 Strand 3 Demographics of healthcare professionals

<table>
<thead>
<tr>
<th>Healthcare professionals =104/213 (48.8%)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Respondents</strong></td>
<td><strong>n (%)</strong></td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>n=79</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>12 (15.2%)</td>
</tr>
<tr>
<td>Female</td>
<td>67 (84.8%)</td>
</tr>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
</tr>
<tr>
<td>n=81</td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>22 - 64</td>
</tr>
<tr>
<td><strong>Working profession</strong></td>
<td></td>
</tr>
<tr>
<td>n=68</td>
<td></td>
</tr>
<tr>
<td>GP</td>
<td>3 (4.4%)</td>
</tr>
<tr>
<td>Neurologist</td>
<td>3 (4.4%)</td>
</tr>
<tr>
<td>Nurse</td>
<td>12 (17.6%)</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>17 (25%)</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>28 (41.2%)</td>
</tr>
<tr>
<td>Unknown</td>
<td>5 (7.4%)</td>
</tr>
<tr>
<td><strong>HSE Region</strong></td>
<td></td>
</tr>
<tr>
<td>n=76</td>
<td></td>
</tr>
<tr>
<td>South</td>
<td>18 (23.7%)</td>
</tr>
<tr>
<td>West</td>
<td>27 (35.5%)</td>
</tr>
<tr>
<td>Dublin North-East</td>
<td>15 (19.7%)</td>
</tr>
<tr>
<td>Dublin Mid-Leinster</td>
<td>16 (21.1%)</td>
</tr>
<tr>
<td><strong>Highest Education Level</strong></td>
<td></td>
</tr>
<tr>
<td>n=85</td>
<td></td>
</tr>
<tr>
<td>Diploma/certificate</td>
<td>10 (11.8%)</td>
</tr>
<tr>
<td>Degree (BSc/BA)</td>
<td>46 (54.1%)</td>
</tr>
<tr>
<td>Masters</td>
<td>17 (20%)</td>
</tr>
<tr>
<td>PhD</td>
<td>6 (7.1%)</td>
</tr>
<tr>
<td>Other</td>
<td>6 (7.1%)</td>
</tr>
<tr>
<td><strong>Current work setting</strong></td>
<td></td>
</tr>
<tr>
<td>n=83</td>
<td></td>
</tr>
<tr>
<td>Acute</td>
<td>25 (30.1%)</td>
</tr>
<tr>
<td>Long term residential unit/respite home</td>
<td>2 (2.4%)</td>
</tr>
<tr>
<td>Community</td>
<td>29 (34.9%)</td>
</tr>
<tr>
<td>Voluntary Body Organisation</td>
<td>3 (3.6%)</td>
</tr>
<tr>
<td>Private Practice</td>
<td>11 (13.3%)</td>
</tr>
<tr>
<td>Other</td>
<td>5 (6%)</td>
</tr>
<tr>
<td>More than one setting</td>
<td>7 (8.4%)</td>
</tr>
</tbody>
</table>
6.4.1 Level of awareness

Many people with MS (72/98; 73.4%) and healthcare professionals (64/68; 94.1%) agreed that bladder dysfunction interfered with daily life activities. However, there was a statistically significant difference between group responses regarding quality of life, work, socialising, relationships and sexual functioning (Table 11). Only half of people with MS (49/88; 55.7%) reported that bladder dysfunction interfered with work in contrast to what most healthcare professionals (62/68; 91.2%) believed. Only 49.4% (44/89) of people with MS agreed that their symptoms interfered with intimate relationships with partner or spouse, compared to 82.4% (56/68) of healthcare professionals (p <0.01, Cramer’s V= 0.426). Furthermore, only 46.1% (41/89) of people with MS compared to 80.9% (55/68) of healthcare professionals agreed that bladder dysfunction interfered with sexual functioning (p <0.01, Cramer’s V= 0.408). The majority of both people with MS and healthcare professionals agreed that bladder dysfunction impacted on travel and sleep with no statistically significant difference between groups.
Table 11 Does bladder dysfunction interfere with daily activities?

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Unsure</th>
<th>Agree</th>
<th>Strongly agree</th>
<th>Fishers Exact Test</th>
<th>Cramer’s V</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Quality of life</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PwMS (n=98)</td>
<td>4 (4.1%)</td>
<td>11 (11.2%)</td>
<td>11 (11.2%)</td>
<td>46 (46.9%)</td>
<td>26 (26.5%)</td>
<td>p &lt;0.01</td>
<td>0.37</td>
</tr>
<tr>
<td>HCPs (n=68)</td>
<td>1 (1.5%)</td>
<td>1 (1.5%)</td>
<td>2 (2.9%)</td>
<td>23 (33.8%)</td>
<td>41 (60.3%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Work</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PwMS (n=88)</td>
<td>6 (6.8%)</td>
<td>15 (17%)</td>
<td>18 (20.5%)</td>
<td>29 (33%)</td>
<td>20 (22.7%)</td>
<td>p &lt;0.01</td>
<td>0.40</td>
</tr>
<tr>
<td>HCPs (n=68)</td>
<td>1 (1.5%)</td>
<td>1 (1.5%)</td>
<td>4 (5.9%)</td>
<td>30 (44.1%)</td>
<td>32 (47.1%)</td>
<td></td>
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</tr>
<tr>
<td><strong>Travel</strong></td>
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<td></td>
</tr>
<tr>
<td>PwMS (n=98)</td>
<td>5 (5.1%)</td>
<td>8 (8.2%)</td>
<td>9 (9.2%)</td>
<td>36 (36.7%)</td>
<td>40 (40.8%)</td>
<td>0.153</td>
<td>0.20</td>
</tr>
<tr>
<td>HCPs (n=68)</td>
<td>1 (1.5%)</td>
<td>2 (2.9%)</td>
<td>2 (2.9%)</td>
<td>27 (39.7%)</td>
<td>36 (52.9%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Socialising</strong></td>
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<td></td>
</tr>
<tr>
<td>PwMS (n=96)</td>
<td>5 (5.2%)</td>
<td>11 (11.5%)</td>
<td>11 (11.5%)</td>
<td>42 (43.8%)</td>
<td>27 (28.1%)</td>
<td>0.021</td>
<td>0.27</td>
</tr>
<tr>
<td>HCPs (n=67)</td>
<td>1 (1.5%)</td>
<td>3 (4.5%)</td>
<td>4 (6%)</td>
<td>24 (35.8%)</td>
<td>35 (52.2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Relationships</strong></td>
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</tr>
<tr>
<td>PwMS (n=89)</td>
<td>7 (7.9%)</td>
<td>23 (25.8%)</td>
<td>15 (16.9%)</td>
<td>25 (28.1%)</td>
<td>19 (21.3%)</td>
<td>p &lt;0.01</td>
<td>0.43</td>
</tr>
<tr>
<td>HCPs (n=68)</td>
<td>1 (1.5%)</td>
<td>1 (1.5%)</td>
<td>10 (14.7%)</td>
<td>21 (30.9%)</td>
<td>35 (51.5%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Sexual Functioning</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PwMS (n=89)</td>
<td>3 (3.4%)</td>
<td>22 (24.7%)</td>
<td>23 (25.8%)</td>
<td>16 (18%)</td>
<td>25 (28.1%)</td>
<td>p &lt;0.01</td>
<td>0.41</td>
</tr>
<tr>
<td>HCPs (n=68)</td>
<td>1 (1.5%)</td>
<td>0 (0%)</td>
<td>12 (17.6%)</td>
<td>21 (30.9%)</td>
<td>34 (50%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Sleep</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PwMS (n=95)</td>
<td>5 (5.3%)</td>
<td>14 (14.7%)</td>
<td>6 (6.3%)</td>
<td>42 (44.2%)</td>
<td>28 (29.5%)</td>
<td>0.055</td>
<td>0.24</td>
</tr>
<tr>
<td>HCPs (n=67)</td>
<td>1 (1.5%)</td>
<td>2 (3%)</td>
<td>8 (11.9%)</td>
<td>34 (50.7%)</td>
<td>22 (32.8%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

PwMS= People with MS, HCPs= Healthcare professionals

6.4.2 Current approaches to assessment and management of bladder dysfunction

This section will outline assessment and management strategies used by people with MS and healthcare professionals to manage bladder dysfunction. People with MS were asked how comfortable they were discussing bladder dysfunction and if healthcare professionals questioned them about their symptoms. Similarly, the healthcare professional survey explored how they approached the topic with people with MS. Both groups were questioned about current management options including self-catheterisation, medication, pelvic floor muscle training, bladder retraining, fluid control, general bladder advice, goal setting and self-monitoring. Participants reported
if they used any paper or online resources to assist bladder management and finally their satisfaction with knowledge of bladder dysfunction.

6.4.2.1 Assessment

The majority of the people with MS (78/103; 75.7%) who responded to the questionnaire reported they were comfortable talking to healthcare professionals about their bladder symptoms. Similarly, 75.4% (52/69) of healthcare professional agreed they were comfortable discussing bladder dysfunction with people with MS. People with MS were then asked if healthcare professionals question them about their bladder symptoms on a routine basis. Almost half of people with MS (36/88; 40.9%) reported that they “sometimes” get asked about bladder dysfunction. Less than one third (24/88; 27.3%) reported that they never or rarely get asked, while 31.8% (28/88) reported that they often or always get asked. Over half of healthcare professionals (36/66; 54.6%) responded that they often or always ask people with MS about bladder dysfunction. A chi-squared test indicated a statistically significant difference between groups $x^2 (1, n=154), p=0.004$, Cramer’s $V= 0.314$. Figure 9 summarises these responses.
Most people with MS (78/86; 90.7%) reported their bladder symptoms to a healthcare professional. Of those that did so, most spoke with their neurologist (59/75, 78.7%) or GP (51/75, 68%) (Table 12). Over half of people with MS that reported their bladder symptoms (42/79; 53.2%) were referred to another healthcare professional. Healthcare professionals were also asked how often they referred on people with MS for specialist input who reported bladder symptoms. Almost three quarters (25/35; 71.4%) reported that they often or always make this onward referral. Participants were asked how long they had to wait to gain access to these specialised services. Responses varied equally from less than one month to over twelve months. One quarter of health care professionals (14/54; 25.9%) reported less than one month from the time of referral to date of initial contact while 42.6% (23/54) remained unsure about these waiting times.
Table 12 Who did people with MS report symptoms to:

<table>
<thead>
<tr>
<th>Healthcare professional</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurologist</td>
<td>59 (78.7%)</td>
</tr>
<tr>
<td>GP</td>
<td>51 (68%)</td>
</tr>
<tr>
<td>Urologist</td>
<td>28 (37.3%)</td>
</tr>
<tr>
<td>MS nurse</td>
<td>23 (30.7%)</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>15 (20%)</td>
</tr>
<tr>
<td>Public Health Nurse</td>
<td>10 (13.3%)</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>8 (10.7%)</td>
</tr>
<tr>
<td>Continence nurse</td>
<td>6 (8%)</td>
</tr>
<tr>
<td>Unknown</td>
<td>1 (1.3%)</td>
</tr>
</tbody>
</table>
6.4.2.2 Management Strategies

This section will outline the strategies used by people with MS and healthcare professionals in their management of bladder dysfunction. Table 13 displays the frequency of these management strategies. These findings illustrate that many people with MS (60/82; 73.2%) and over half of healthcare professionals (39/62; 62.9%) never or rarely include self-catheterisation in bladder management. More than half of people with MS never or rarely use bladder retraining (50/81; 61.7%), general bladder advice (any information read or received from a healthcare professional about bladder dysfunction) (43/77; 55.8%) or goal setting (57/77; 74%). The most frequent management options among people with MS include medication (38/85; 44.7%) and controlling fluid intake (30/82; 36.6%). There was a statistically significant difference
between groups for self-catheterisation, medication, pelvic floor muscle training, general bladder advice and goal setting. Over half of people with MS with symptoms of bladder dysfunction (42/83; 50.6%) reported they never or rarely use pelvic floor muscle training while 44.4% (28/63) of healthcare professionals said they often or always include this strategy in management programmes. There was no statistical significant difference between groups for use of bladder retraining or fluid control.
Table 13 Frequency of management strategies

<table>
<thead>
<tr>
<th>Management Strategy</th>
<th>Never (%)</th>
<th>Rarely (%)</th>
<th>Sometimes (%)</th>
<th>Often (%)</th>
<th>Always (%)</th>
<th>N/A (%)</th>
<th>Fishers Exact Test</th>
<th>Cramer’s V</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Self-catheterisation</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PwMS (n=82)</td>
<td>58 (70.7%)</td>
<td>2 (2.4%)</td>
<td>3 (3.7%)</td>
<td>5 (6.1%)</td>
<td>5 (6.1%)</td>
<td>9 (11%)</td>
<td>0.027</td>
<td>0.29</td>
</tr>
<tr>
<td>HCPs (n=62)</td>
<td>34 (54.8%)</td>
<td>5 (8.1%)</td>
<td>7 (11.3%)</td>
<td>8 (12.9%)</td>
<td>0 (0%)</td>
<td>8 (12.9%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Medication</strong></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PwMS (n=85)</td>
<td>34 (40%)</td>
<td>3 (3.5%)</td>
<td>6 (7.1%)</td>
<td>6 (7.1%)</td>
<td>32 (37.6%)</td>
<td>4 (4.7%)</td>
<td>0.006</td>
<td>0.32</td>
</tr>
<tr>
<td>HCPs (n=63)</td>
<td>29 (46%)</td>
<td>5 (7.9%)</td>
<td>7 (11.1%)</td>
<td>10 (15.9%)</td>
<td>7 (11.1%)</td>
<td>5 (7.9%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Pelvic Floor Muscle Training</strong></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PwMS (n=83)</td>
<td>33 (39.8%)</td>
<td>9 (10.8%)</td>
<td>18 (21.7%)</td>
<td>14 (16.9%)</td>
<td>6 (7.2%)</td>
<td>3 (3.6%)</td>
<td>0.005</td>
<td>0.33</td>
</tr>
<tr>
<td>HCPs (n=63)</td>
<td>10 (15.9%)</td>
<td>7 (11.1%)</td>
<td>15 (23.8%)</td>
<td>11 (17.5%)</td>
<td>17 (27%)</td>
<td>3 (4.8%)</td>
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</tr>
<tr>
<td><strong>Bladder retraining</strong></td>
<td></td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>PwMS (n=81)</td>
<td>39 (48.1%)</td>
<td>11 (13.6%)</td>
<td>11 (13.6%)</td>
<td>9 (11.1%)</td>
<td>4 (4.9%)</td>
<td>7 (8.6%)</td>
<td>0.123</td>
<td>0.25</td>
</tr>
<tr>
<td>HCPs (n=63)</td>
<td>20 (31.7%)</td>
<td>8 (12.7%)</td>
<td>12 (19%)</td>
<td>8 (12.7%)</td>
<td>11 (17.5%)</td>
<td>4 (6.3%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Fluid Control</strong></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PwMS (n=82)</td>
<td>26 (31.7%)</td>
<td>3 (3.7%)</td>
<td>17 (20.7%)</td>
<td>18 (22%)</td>
<td>12 (14.6%)</td>
<td>6 (7.3%)</td>
<td>0.215</td>
<td>0.22</td>
</tr>
<tr>
<td>HCPs (n=63)</td>
<td>14 (22.2%)</td>
<td>9 (14.3%)</td>
<td>10 (15.9%)</td>
<td>16 (25.4%)</td>
<td>11 (17.5%)</td>
<td>3 (4.8%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>General Bladder Advice</strong></td>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>PwMS (n=77)</td>
<td>34 (44.2%)</td>
<td>9 (11.7%)</td>
<td>18 (23.4%)</td>
<td>3 (3.9%)</td>
<td>9 (11.7%)</td>
<td>4 (5.2%)</td>
<td>0.001</td>
<td>0.39</td>
</tr>
<tr>
<td>HCPs (n=63)</td>
<td>12 (19%)</td>
<td>6 (9.5%)</td>
<td>12 (19%)</td>
<td>13 (20.6%)</td>
<td>18 (28.6%)</td>
<td>2 (3.2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Goal Setting</strong></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PwMS (n=77)</td>
<td>47 (61%)</td>
<td>10 (13%)</td>
<td>8 (10.4%)</td>
<td>4 (5.2%)</td>
<td>4 (5.2%)</td>
<td>4 (5.2%)</td>
<td>0.001</td>
<td>0.39</td>
</tr>
<tr>
<td>HCPs (n=63)</td>
<td>19 (30.2%)</td>
<td>12 (19%)</td>
<td>11 (17.5%)</td>
<td>8 (12.7%)</td>
<td>11 (17.5%)</td>
<td>2 (3.2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Self-monitoring</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PwMS (n=80)</td>
<td>34 (42.5%)</td>
<td>6 (7.5%)</td>
<td>14 (17.5%)</td>
<td>17 (21.3%)</td>
<td>6 (7.5%)</td>
<td>3 (3.8%)</td>
<td>0.004</td>
<td>0.34</td>
</tr>
<tr>
<td>HCPs (n=63)</td>
<td>16 (25.4%)</td>
<td>12 (19%)</td>
<td>8 (12.7%)</td>
<td>11 (17.5%)</td>
<td>13 (20.6%)</td>
<td>3 (4.8%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

PwMS = People with MS, HCPs = Healthcare professionals
Table 14 displays the use of resources to aid in bladder management. There was a statistically significant difference between groups for paper resources with more healthcare professionals stating they sometimes, often or always use such items. The majority of both people with MS (76/86; 88.3%) and healthcare professionals (48/63; 76.2%) never or rarely use electronic resources to help manage their symptoms.

**Table 14 Use of resources to aid bladder management**

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
<th>Fishers Exact Test</th>
<th>Cramer’s V</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Paper Resources</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PwMS (n=85)</td>
<td>68 (80%)</td>
<td>12 (14.1%)</td>
<td>3 (3.5%)</td>
<td>1 (1.2%)</td>
<td>1 (1.2%)</td>
<td>p &lt;0.01</td>
<td>0.425</td>
</tr>
<tr>
<td>HCP (n=63)</td>
<td>27 (42.9%)</td>
<td>13 (20.6%)</td>
<td>11 (17.5%)</td>
<td>6 (9.5%)</td>
<td>6 (9.5%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Electronic Resources</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PwMS (n=86)</td>
<td>69 (80.2%)</td>
<td>7 (8.1%)</td>
<td>8 (9.3%)</td>
<td>1 (1.2%)</td>
<td>1 (1.2%)</td>
<td>0.092</td>
<td>0.212</td>
</tr>
<tr>
<td>HCP (n=63)</td>
<td>38 (63.3%)</td>
<td>10 (16.7%)</td>
<td>11 (18.3%)</td>
<td>1 (1.7%)</td>
<td>0 (0%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

PwMS=People with MS, HCPs =Healthcare professionals

Participants were asked how satisfied they were with their level of knowledge on bladder management (Figure 11). A chi-squared test for independence indicated a statistically significant difference between groups $\chi^2 (n=150)$, p=0.022, Cramer’s V=0.227. Healthcare professionals were less satisfied with their level of knowledge compared to people with MS. There was no statistical significant difference between groups in terms of confidence in managing bladder dysfunction ($n=152$, p=0.097, Cramer’s V=0.227). Two thirds of both people with MS (56/89; 62.9%) and healthcare professionals (47/63; 74.7%) were unsure or disagreed that they were confident with management of bladder symptoms.
Over half of people with MS (39/82; 47.5%) were clear about their role in bladder management but 41.5% (34/82) remained unsure. One third of healthcare professionals (20/58; 34.5%) agreed but 36.2% (21/58) were unsure about their role as healthcare professionals in bladder management (Figure 12). There was a statistically significant difference between groups (p=0.04, Cramer’s V=0.26).
6.4.3 Self-management of bladder dysfunction

Participants were asked about the importance of self-management and the specific challenges around managing bladder symptoms. Both people with MS and healthcare professionals suggested what members of the multi-disciplinary team should be involved and shared their perspectives on the development of an educational resource to facilitate self-management of bladder dysfunction.

6.4.3.1 Perspectives on self-management

Almost three quarters of people with MS (70/97; 72.2%) and healthcare professionals (51/67; 76.1%) reported that self-management was an important strategy in addressing
bladder dysfunction. Participants provided insight into the barriers of managing bladder dysfunction. People with MS reported long waiting times for specialist services (47/77; 61%), lacking knowledge in the area of how to manage bladder symptoms (37/77; 48%) and believed that bladder dysfunction was not a top priority for healthcare professionals (32/77; 41.2%). Only half of healthcare professionals (53/104; 50.9%) responded to this question. The top barrier identified among healthcare professionals was lacking knowledge in the area of bladder management (29/53; 54.7%). Other barriers included that bladder dysfunction was not a top priority for their service provision (7/53; 13.2%), lacking confidence in asking and talking about bladder dysfunction (5/53; 9.4%) and long waiting times for specialist services (5/53; 9.4%).

Both people with MS (37/63; 58.7%) and healthcare professionals (34/60; 56.7%) agreed that the neurologist was important in facilitating self-management of bladder dysfunction. However, there was a statistically significant difference between the opinions of healthcare professionals and people with MS for other members of the multidisciplinary team (Appendix 19). The MS nurse was deemed most important in facilitating self-management among healthcare professionals (57/59; 96.6%) but the urologist was reported as most important among people with MS (40/66; 60.6%) (Table 15). Table 15 compares the order of preference of multidisciplinary involvement in bladder management between people with MS and healthcare professionals.
Table 15 Order of preference of multi-disciplinary involvement in bladder management

<table>
<thead>
<tr>
<th>People with MS</th>
<th>Combined Responses (Strongly agreed or agreed)</th>
<th>Healthcare professionals</th>
<th>Combined Responses (Strongly agreed or agreed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>MS nurse</td>
<td>32/64 (61.7%)</td>
<td>MS nurse</td>
<td>57/59 (96.6%)</td>
</tr>
<tr>
<td>Urologist</td>
<td>40/60 (60.1%)</td>
<td>Continence Nurse</td>
<td>56/59 (94.9%)</td>
</tr>
<tr>
<td>Person with MS</td>
<td>37/32 (59.7%)</td>
<td>Urologist</td>
<td>51/59 (86.5%)</td>
</tr>
<tr>
<td>Neurologist</td>
<td>37/63 (58.7%)</td>
<td>Person with MS</td>
<td>50/60 (83.4%)</td>
</tr>
<tr>
<td>GP</td>
<td>35/67 (52.2%)</td>
<td>Public Health Nurse</td>
<td>47/60 (78.3%)</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>18/60 (30%)</td>
<td>Physiotherapist</td>
<td>43/59 (72.9%)</td>
</tr>
<tr>
<td>Public Health Nurse</td>
<td>14/58 (24.1%)</td>
<td>Carer</td>
<td>33/58 (56.9%)</td>
</tr>
<tr>
<td>Continence Nurse</td>
<td>14/59 (23.7%)</td>
<td>Neurologist</td>
<td>34/60 (56.7%)</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>14/61 (23%)</td>
<td>GP</td>
<td>32/57 (56.1%)</td>
</tr>
<tr>
<td>Carer</td>
<td>11/58 (19%)</td>
<td>Occupational Therapist</td>
<td>17/59 (28.8%)</td>
</tr>
</tbody>
</table>

6.4.3.2 Educational resource

Most people with MS (78.5%) and healthcare professionals (70.7%) were interested in further education on self-management of bladder dysfunction. Table 16 illustrates the order of preferences of different types of educational resources. The majority of both groups agreed for all options. Among people with MS, an online web resource (63/69; 91.3%), paper resource (51/66; 77.3%), specific guidelines (50/65; 76.9%) and general education day (38/67; 56.7%) were most frequently reported. Although the same top four resources were found among healthcare professionals, there ranking differed slightly. Healthcare professionals were most interested in specific guidelines (48/51; 94.1%), followed by online web resource (44/49; 89.8%), paper resource (45/51; 88.2%) and general education day (44/51; 86.3%). There was a statistically significant difference between groups for general education day and specific
guidelines with more healthcare professionals interested in those mediums (Appendix 20).

Table 16 Order of preference of educational resources

<table>
<thead>
<tr>
<th>People with MS</th>
<th>Combined Responses (Strongly agreed or agreed)</th>
<th>Healthcare professionals</th>
<th>Combined responses (Strongly agreed or agreed)</th>
</tr>
</thead>
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<tr>
<td>Online web resource</td>
<td>63/69 (91.3%)</td>
<td>Specific Guidelines</td>
<td>48/51 (94.1%)</td>
</tr>
<tr>
<td>Paper resource</td>
<td>51/66 (77.2%)</td>
<td>Online web resource</td>
<td>44/49 (89.8%)</td>
</tr>
<tr>
<td>Specific Guidelines</td>
<td>50/65 (76.9%)</td>
<td>Paper resource</td>
<td>45/51 (88.3%)</td>
</tr>
<tr>
<td>General education day</td>
<td>38/67 (56.7%)</td>
<td>General education day</td>
<td>44 (86.3%)</td>
</tr>
<tr>
<td>Social media</td>
<td>36/65 (55.4%)</td>
<td>Online Podcast</td>
<td>30/47 (63.9%)</td>
</tr>
<tr>
<td>Online interactive forum</td>
<td>32/64 (50%)</td>
<td>Phone app</td>
<td>29/48 (60.5%)</td>
</tr>
<tr>
<td>Online Podcast</td>
<td>31/65 (47.7%)</td>
<td>Social media</td>
<td>23/47 (48.9%)</td>
</tr>
<tr>
<td>Phone app</td>
<td>31/66 (47%)</td>
<td>Online interactive forum</td>
<td>19/45 (42.3%)</td>
</tr>
<tr>
<td>Online blog</td>
<td>28/62 (45.2%)</td>
<td>Online blog</td>
<td>16/45 (35.5%)</td>
</tr>
</tbody>
</table>

Participants were asked about the content of such an educational resource and what should be included. Over 90% of people with MS agreed to all options (Table 17). All healthcare professionals agreed that causes of bladder dysfunction of MS, different types of bladder dysfunction, general management advice and referral advice should be included in the resource. Most healthcare professionals agreed that how to ask about bladder dysfunction (51/56; 91.1%) and visual aids (54/55; 98.2%) should be part of the proposed educational resource.
### Table 17 Content that should be included in this educational resource

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Unsure</th>
<th>Agree</th>
<th>Strongly agree</th>
<th>Fishers Exact Test</th>
<th>Cramer’s V</th>
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<td>2 (2.7%)</td>
<td>2 (2.7%)</td>
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<td>0 (0%)</td>
<td>28 (50%)</td>
<td>28 (50%)</td>
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<tr>
<td><strong>Different types of bladder dysfunction</strong></td>
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<td>29 (40.3%)</td>
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<td>0.191</td>
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<td>30 (53.6%)</td>
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<tr>
<td><strong>Visual aids</strong></td>
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<td><strong>How to ask about bladder dysfunction</strong></td>
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<td>PwMS (n=72)</td>
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<td><strong>General management advice</strong></td>
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<td>0 (0%)</td>
<td>26 (46.4%)</td>
<td>30 (53.6%)</td>
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</tbody>
</table>

_PwMS = People with MS, HCPs = Healthcare professionals_
Participants gave their perspective about who this educational resource should be designed for. Most people with MS agreed with all those listed below in Table 18. There was a statistically significant difference between groups for carer involvement (p=0.001, Cramer’s V= 0.384). Most healthcare professionals (48/53; 90.6%), agreed that this information should be targeted at the carer but only 60% (36/60) of people with MS agreed and one third remained unsure. Most healthcare professionals agreed that this educational resource should be designed for the MS nurse (50/53; 94.4%), GP (50/54; 92.6%), person with MS (48/49; 98%), physiotherapist (47/50; 94%), and public health nurse (48/50; 96%). Just over one quarter of healthcare professionals (12/46; 26.1%) were unsure if occupational therapists should be a target audience for this resource.
Table 18 Who this educational resource should be designed for

<table>
<thead>
<tr>
<th>Role</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Unsure</th>
<th>Agree</th>
<th>Strongly agree</th>
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<td>26 (43.3%)</td>
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<td>11 (19%)</td>
<td>27 (46.6%)</td>
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<td>8 (12.9%)</td>
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<tr>
<td>HCPs (n=49)</td>
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<td>6 (12.2%)</td>
<td>22 (44.9%)</td>
<td>17 (34.7%)</td>
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</tr>
</tbody>
</table>

PwMS=People with MS, HCPs=Healthcare professionals
6.5 DISCUSSION

This questionnaire study provides novel data from a cohort of health professionals and people with MS from the Republic of Ireland regarding management of bladder dysfunction. Responses highlighted the level of awareness of bladder dysfunction and current assessment and management approaches. In addition, respondents provided their perspectives on self-management of bladder dysfunction.

The first aim of this study was to identify the level of awareness of bladder dysfunction among both people with MS and healthcare professionals. The impact of bladder dysfunction from the perspectives of people with MS was previously explored in the literature (Koch et al. 2000, Koch et al. 2001, Browne et al. 2015). However, healthcare professionals’ level of awareness of bladder dysfunction among people with MS has not been identified. Findings from this study indicate a difference in perspectives between people with MS and healthcare professionals around the type of daily activities that bladder dysfunction interferes with. Most healthcare professionals agreed that bladder dysfunction interfered with all aspects of daily life compared to people with MS who were more selective. These findings suggest that healthcare professionals had difficulty differentiating between which items would interfere more than others on daily tasks. This supports the need for an in-depth questioning of bladder symptoms in clinical practice to capture the individual impact of bladder symptoms for people with MS.

Both groups reported they were comfortable talking to the other about bladder symptoms. This is an important new finding suggesting people are now more open to talking about bladder symptoms. Existing literature indicates both people with bladder
symptoms and healthcare professionals are hesitant to discuss symptoms due to the sensitive nature of the topic (Wyman et al. 1990, Koch et al. 2001, Wollin et al. 2005, Wang et al. 2015). However, when participants were further questioned; people with MS reported that they were not asked about bladder symptoms by healthcare professionals in routine practice. In contrast, healthcare professionals stated that they did ask about bladder dysfunction during assessment. Although both groups reporting being comfortable discussing bladder symptoms, this finding raises an interesting question around how bladder dysfunction is queried in clinical practice. This finding suggests a miscommunication between people with MS and healthcare professionals when discussing bladder dysfunction in clinical practice and supports previous findings that bladder symptoms may need to be explored in more detail among people with MS (Browne et al 2016). Further investigation is needed to confirm whether or not assessment of bladder dysfunction in routine practice among healthcare professionals working with people with MS.

Responses highlighted important findings in terms of management strategies used by people with MS and healthcare professionals. People with MS in the current study did not include bladder retraining in their management programmes. Bladder retraining is a therapeutic intervention which can be of benefit to people with MS with overactive bladder symptoms and is a recommended management strategy in current guidelines (Fowler et al. 2009). Bladder retraining involves voluntarily “holding on” of the bladder for increasingly longer periods, often an incremental programme supervised by specialist continence advisors or physiotherapists (Fowler et al. 2009, Pannek et al. 2013). Further research is needed to explore bladder retraining and to understand why this strategy is not recommended by healthcare professionals or used among people with MS with bladder dysfunction in the Republic of Ireland.
Furthermore, the majority of people with MS reported they never or rarely use pelvic floor muscle training and more healthcare professionals say they often or always include pelvic floor exercises in management programmes. It remains unclear whether people with MS were unaware of this management strategy or simply did not adhere to their management programme. Current evidence for the effectiveness of conservative interventions in management of bladder dysfunction in people with MS suggest that pelvic floor muscle training either used alone or in conjunction with other conservative interventions can reduce urinary symptoms (Lucio 2010, McClurg 2008a, McClurg 2008b, Vahtera 1997, De Ridder 1999). NICE (2003a) guidance recommends that people with MS who continue to have incontinence issues despite medication should consider for a course of pelvic floor muscle strengthening. Despite this, our findings report that people with MS in the Republic of Ireland are not including pelvic floor exercises in their management programmes. Further exploration of pelvic floor muscle training among people with MS with bladder dysfunction is needed, particularly in relation to intervention fidelity. Integral to interventions studies is the need to enhance intervention fidelity to ensure that the intervention was conducted as planned (Sacomori et al. 2013). Furthermore, it is necessary to explore adherence levels among people with MS with pelvic floor muscle training. Adherence to pelvic floor muscle training has been frequently cited as a challenge in the literature (Frawley et al. 2015, Hay-Smith et al. 2015). Previous studies suggest that a relationship exists between high self-efficacy and positive adherence rates to these treatments for urinary incontinence (Alewijnse et al. 2003, Messer et al. 2007). Self-efficacy is defined as a person’s belief in their capability to exercise some measure of control over their own functioning and over environmental events (Bandura 1994). Self-efficacy is an important component of self-management approaches and may be
a useful approach to the management of bladder dysfunction among people with MS. Research to date has focused on frequency, intensity, timing and prescription but we are unaware of long term effectiveness and adherence to pelvic floor muscle exercises. Future research exploring pelvic floor muscle training should include intervention fidelity strategies in their studies' designs.

The final aim was to explore the perspectives of self-management of bladder dysfunction from both people with MS and healthcare professionals. The majority of both groups agreed that self-management is important in bladder dysfunction. A number of similar challenges and needs around facilitating self-management for bladder dysfunction were highlighted among both groups. Long waiting times and lack of knowledge were reported by both people with MS and healthcare professionals. These results are consistent with other published literature that also reports lack of knowledge among people with bladder difficulties (So et al. 2012) and healthcare professionals in relation to bladder management (Teunissen et al. 2006). These findings suggest that education should be targeted at both people with MS and healthcare professionals. Both groups were interested in an educational resource to facilitate self-management of bladder dysfunction. The top two options in both groups were online web resource and paper resource. Information via the internet has been previously reported popular among people with MS. A large survey conducted by the National MS Society in the USA concluded that up to 93% of people with MS use the internet and this can be compared to 75% in a healthy population (Wardell et al. 2009). Furthermore, internet use in Ireland has increased from 63% in 2008 to 82% in 2014 (Central Statistics Office 2014). Therefore, delivering information programmes via the internet in addition to paper options may be a more comprehensive method of delivering information to people with MS in the Republic of Ireland. Both groups were
interested in further information about the cause of bladder dysfunction, types of bladder dysfunction, visual aids, how to ask about bladder dysfunction, general management advice and referral advice.

6.6 LIMITATIONS

The findings of this study need to be considered in the context of its limitations. All participants were recruited online. This may have been bias toward people already using the internet and therefore more likely to opt for online education. This study included self-selected people with MS who identified that they have bladder dysfunction; therefore, findings may not represent those who remain silent about their bladder symptoms. Similarly, healthcare professionals were self-selected and although participants were dispersed nationwide, results may not be reflective of the opinions of all healthcare professionals working with people with MS. Most people with MS in this cohort were female. This corresponds with the recent Atlas of MS (Atlas of MS 2013) stating MS is twice as common among women than men. Over half of the people with MS in this study had relapsing-remitting MS (57.1%; 60/105). This figure is lower than recent epidemiological reports of MS (Atlas of MS 2013) which state that 85% have relapsing-remitting type MS. However, the percentages of primary progressive and progressive relapsing are similar to these recent findings. It is unknown why a lower percentage of people with relapsing-remitting MS responded to the questionnaire. The current sample may be representative of people with greater disability rather than the total MS population.

The data collection tool must also be considered. The authors acknowledge that the quality of the data collected is based on the quality of the questionnaire (Brancato et
al. 2006). Although a novel, non-standardised questionnaire was used in this study, efforts were made during the development process to optimise face and content validity. Due to the number of statistical tests that were conducted, there is a risk of Type 1 statistical error.

6.7 CONCLUSION

Both people with MS and healthcare professionals agree that self-management of bladder dysfunction is important. Findings build on previous research suggesting the importance of how healthcare professionals discuss bladder dysfunction. Bladder symptoms need to be explored in detail among people with MS. People with MS are not engaging in a number of bladder management strategies. Education is needed for both people with MS and healthcare professionals to address their lack of knowledge in relation to these strategies. In a country where specialist and community neurorehabilitation services are limited, the development of an educational resource to facilitate self-management of bladder dysfunction will not only alleviate burden on healthcare professionals but also optimise quality of life for people with MS.
CHAPTER 7 DISCUSSION

7.1 OUTLINE OF THE CHAPTER

This chapter presents a conceptual synthesis of the empirical data drawing upon the conceptual framework presented in Chapter 3. The contributions of this thesis to research, theory and practice are outlined below. Future research directions are described with details about the proposed educational resource tool to address the key research question of how self-management of bladder dysfunction can be facilitated among people with MS. This thesis forms the preliminary research to inform the development of an educational resource tool for both people with MS and healthcare professionals. Such an educational resource does not exist in the Irish context. A strength of this proposed tool is that it is based on the empirical needs of those who will use it. This chapter closes with an evaluation of this project which includes overall limitations, followed by thesis conclusions.

7.2 CONCEPTUAL SYNTHESIS OF THE DATA

This project uniquely contributes to knowledge regarding bladder dysfunction among people with MS within a conceptual framework informed by three substantive bodies of work: critical disability theory (Goodley 2010), International Classification of Functioning and Disability Framework (World Health Organization 2001) and the Self-Regulatory Model (Leventhal 1980). Bladder dysfunction among people with MS has not been explored to date using any explicit conceptual framework, thus the
current project extends the philosophical foundations of research involving people with MS.

The use of this novel conceptual framework strengthened this multi-stranded study. For example, by grounding the project within Critical Disability Theory the experiences of people with MS were centralised within each strand. In Strand 1 a series of semi-structured interviews with people with MS explored how bladder dysfunction interfered with quality of life and how they self-managed their symptoms. These findings were then presented to healthcare professionals and used to generate discussion around self-management of bladder dysfunction in Strand 2. Finally, the findings from these two strands were used to develop a questionnaire for both people with MS and healthcare professionals in Strand 3. This study compared perspectives of both groups on current service provision and self-management of bladder dysfunction. Critical Disability Theory mitigated the ongoing risk that the perspectives of people with MS could be shifted into the background, with the more powerful voices of healthcare professionals and researchers dominating the findings. As such, the proposed educational resource tool is centralised on the empirical needs of those who will use it.

The ICF informed specific aspects within the questioning routes across all three strands of this research. In Strand 1, it prompted the inclusion of specific questions around activity and participation, enabling a detailed exploration of how people with MS functioned within society. The questioning route in Strand 2 was also guided by the ICF. By framing the interview schedule within the common language of the ICF, detailed discussion across disciplines and settings of healthcare professionals was facilitated. The ICF also influenced the initial code list for Strand 1 and 2. While this prompted attention to particular areas within the data, it is important to consider the
limitations of a conceptual framework. For example, using the ICF to inform the code list led to a particular focus during data analysis. An alternative framework may have prompted consideration of other aspects within the data. Furthermore, a set of practical recommendations is offered within Strand 2 as a guide for healthcare professionals when subjectively assessing bladder dysfunction. The ICF was used as a mechanism to communicate key findings which emerged from the inductive analytical approach used. Many healthcare professionals use the ICF as a communication tool. Thus, presenting the data in this manner, effectively conveys findings to service providers.

Self-regulatory theory had an important role in enabling understanding self-management of bladder dysfunction among participants in this study. Self-management consists of values embedded within self-regulatory theory, providing insight into how people with MS attempted to re-establish a state of normality. Through this theory a number of questions were developed across all three strands in relation to identifying, reporting, managing and monitoring bladder symptoms. These questions supported a more nuanced understanding about how people with MS strived to regain a sense of normality. This theory attuned the researcher to the physical and emotional aspects of coping with bladder dysfunction, making a unique contribution to the literature.

Explicitly drawing upon this conceptual framework enabled the researcher to systematically approach the complex range of data gathered across all strands of this study, establishing a strong foundation from which nuanced insights regarding this complex symptom is experienced by people with MS. As with all conceptual frameworks there are limitations to consider and alternative theories may have influenced the findings. However, this strong theoretical basis enhanced the trustworthiness of the findings across all strands and the overall quality of the work.
7.3 RESEARCH CONTRIBUTIONS

This section outlines the contributions of this thesis to research, theory and practice. The relevant key findings and their additions to current literature are summarised within each section. Future recommendations are also addressed.

7.3.1 Research

This thesis examined perceptions of self-management of bladder dysfunction among people with MS from a number of perspectives. The impact of bladder dysfunction on quality of life was explored through a series of interviews with people with MS in Strand 1. This study also identified how people with MS attempt to self-manage their symptoms and the existing barriers to accessing services for bladder dysfunction. This knowledge was used to develop an interview schedule in Strand 2 which examined healthcare professionals’ perceptions around self-management of bladder dysfunction among people with MS. The final strand involved a questionnaire study comparing perspectives of healthcare professionals and people with MS on current service provision and self-management of bladder dysfunction. The questionnaire was developed from the findings of the first two strands and relevant literature. This final strand provided information around awareness of bladder dysfunction and how it interferes with daily life, availability of support for self-management of bladder symptoms, education in relation to self-management strategies and readiness for new educational resources in the area of self-managing bladder dysfunction. No research to date has compared the perspectives between healthcare professionals and people with MS in relation to bladder dysfunction.
This research makes a novel contribution to knowledge by providing new empirical data about the management of bladder dysfunction among people with MS. Firstly, the majority of research investigating the impact of bladder dysfunction on quality of life is among non-MS populations. People with MS live with bladder dysfunction in addition to a range of other MS-related symptoms including reduced mobility and fatigue. Thus, Strand 1 provides an in-depth qualitative exploration of the unique perspectives of living with MS and managing bladder dysfunction. No research to date has explored the perspectives of healthcare professionals managing bladder dysfunction. Strand 2 provides a unique insight into the role of reflexive practice in clinical practice. Findings suggest that as healthcare professionals we may need to consider our underlying beliefs in relation to bladder dysfunction. Examining these beliefs is necessary in order to challenge existing perceptions and to reduce the silence of bladder dysfunction. Finally, little was known about current service provision and access to services for people with MS with bladder dysfunction in Ireland. Strand 3 provides new information around the challenges and needs of facilitating self-management for both people with MS and healthcare professionals. Overall, the findings of this thesis support the development of an educational resource to facilitate self-management of bladder dysfunction, to assist the translation of research to practice.

7.3.1.1 Proposal of the self-management resource

Although there is information available for people with MS with bladder dysfunction, no detailed educational resource exists for both people with MS and healthcare professionals in Ireland. The National Multiple Sclerosis Society in the USA has a web page attending to bladder dysfunction (National Multiple Sclerosis Society 2016). This web page includes information about healthy bladder function, bladder problems
in MS, bladder and overall health, management and treatment options, and managing social situations. It also summarises this information in thirty-minute video which includes patient stories, advice and education from physiotherapists, physicians and other healthcare professionals. To further enhance this existing resource, practical advice around bladder retraining and scheduled voiding may be beneficial for people with MS. Furthermore, to engage with healthcare professionals it may be useful to include specific information around assessment and management of bladder dysfunction in clinical practice.

The Multiple Sclerosis Society in the UK also has a webpage (Multiple Sclerosis Society 2014a) on their national website outlining bladder storage and emptying problems in MS with links to management options and advice about how to self-refer to a continence advisor. This page includes a link to a free downloadable evidence-based booklet about managing bladder symptoms (Multiple Sclerosis Society 2014b). This comprehensive twenty-page booklet is targeted at people with MS and includes images about bladder dysfunction outlining the different types of management options. The MS Trust organisation in the UK, also has a full webpage outlining types of bladder dysfunction and management options (MS Trust 2015). Visual information and diagrams explaining bladder dysfunction would enhance this webpage. A range of links are offered at the end of this webpage to other websites, guidelines and resources. The MS Trust also offers a resource for healthcare professionals which details the assessment of bladder and bowel dysfunction and guides management options.

Multiple Sclerosis Ireland provides a webpage with a brief overview of bladder and bowel dysfunction in MS (Multiple Sclerosis Ireland 2016), with links the Continence Foundation of Ireland and the UK MS Trust website. More detailed information in
relation to assessment and specific management strategies for both people with MS and healthcare professionals would be useful.

Despite a number of resources available on the internet, most people with MS and healthcare professionals in the questionnaire study (Strand 3) reported that they did not use any online or paper resource available. When questioned further, both groups indicated their interest in a paper and online educational resource to help facilitate self-management of bladder dysfunction. Therefore, the existing information available on bladder dysfunction is either ineffective or not known about. Furthermore, the existing resources are not informed by a theoretical and evidence base, and as such may not be attending to the needs of people with MS in an Irish context. This research considers the needs of both people with MS and healthcare professionals in the Republic of Ireland to inform the development of an appropriate and suitable educational resource.

7.3.1.2 Development and implementation of the resource

Further research is needed around the development and implementation of this resource. To ensure this educational resource is effective, a steering committee of people with MS, in addition to specialist and generalist multi-disciplinary team members will inform and evaluate the format, layout and content of the resource from beginning to end. As the development of this educational resource was beyond the scope of this thesis, the researcher plans to apply for a knowledge translation grant which would enable development of the resource. This development phase will involve converting content to user friendly interface such as videos or interactive pieces as necessary. Once the steering committee is satisfied with the resource, a detailed evaluation will be necessary. This evaluation will take the form of a one-day workshop for both people with MS and healthcare professionals. The tool will be presented to both groups and their satisfaction with the resource will be evaluated pre
and post workshop with a questionnaire. This day would be specifically to trial the resource in terms of its acceptability and feasibility.

An educational resource could include two separate components—one directed at people with MS and the other for healthcare professionals. Both digital and traditional formats (webpage and booklet) are recommended. It would be useful to include background information about the cause of bladder dysfunction through text and visual aids and an overview of the different types of bladder dysfunction for both groups. A lack of clarity exists around the roles and responsibilities of each member of the multi-disciplinary team in relation to bladder management. This information should be detailed in an educational resource for people with MS and healthcare professionals.

Findings from this research inform a novel approach in delivering an educational resource for bladder dysfunction, particularly in relation to the interactive methods recommended for the online resource. The web resource would involve a log in system to ensure privacy of data storage and allow people with MS to monitor progress over time. For people with MS, to help with discussing symptoms, a framework based on the ICF (WHO 1980) could be provided to include examples of how to discuss bladder symptoms in relation to body structure and function, in addition to activity and participation. General management advice about controlling fluids and bladder retraining is necessary. Links to bladder diaries and voiding scheduling programmes for bladder retraining with clear step-by-step instructions on the use of each and how to progress over time would be beneficial in the educational resource. These bladder diaries could be interactive so people with MS could insert details to provide a daily log of fluid input and output, to be completed monthly to monitor changes long term and to encourage people with MS to have an active role in their bladder management.
Further information could be provided around pelvic floor muscle training with gender specific cues. For example, detailed gender specific information is necessary to ensure correct technique of pelvic floor muscle training. In women, posterior cues are necessary to encourage an optimal pelvic floor contraction (Crotty et al. 2011) while optimal engagement in men requires anterior cues (Stafford et al. 2016). This information could be provided with video instruction and a checklist for people to self-assess and how to ensure they are performing the exercises correctly.

The online resource for healthcare professionals could include a list of questions based on the ICF to facilitate assessment of bladder dysfunction, relevant across disciplines. In addition to information about management options, it would be useful to include a section to prompt reflective and reflexive practice. This would entail a series of questions for healthcare professionals to consider, with an aim to challenge underlying beliefs. Furthermore, healthcare professionals could be advised to meet with more experienced colleagues and use an independent probing facilitator to enhance reflexive practice. Step-by-step protocols around bladder retraining and pelvic floor exercises and how to progress over time would be provided for healthcare professionals. There would also be an option for people with MS to link their online details (bladder diaries, voiding schedules, pelvic floor muscle training) with their healthcare professional if appropriate. In this way, the healthcare professional could encourage use of the resource while monitoring the patient’s progress over time.

The proposed web resource could be attached to an existing website such as the MS Ireland website. This may promote long term sustainability. During the development period, it would be useful to trial an online forum with people with MS where they could share additional comments and ideas in an open and anonymous environment. Within the trial period, content would be monitored for any comments around
detrimental self-strategies. A similar forum could be available for healthcare professionals to discuss and share ideas. Other interactive elements may include webinars and short surveys. These activities could be advertised through professional bodies and counted towards Continuous Professional Development (CPD) to enhance the engagement of healthcare professionals.

A number of strategies will be put in place to ensure these findings reach people with MS and healthcare professionals nationally. Firstly, a summary of the project will be submitted for publication in the MS Ireland newsletter. Furthermore, MS Ireland organises an annual conference for people with MS. This conference would provide an optimal platform to present the research findings to people with MS. Finally, a national roadshow campaign may be beneficial to enhance engagement of both people with MS and healthcare professionals involved in bladder management. These roadshows could take place in the form of half-day workshops throughout Primary Care centres nationally. A national client led campaign is recommended to increase awareness of this educational resource among people with MS. Furthermore, it would be useful to consider a public and patient involvement (PPI) component to any future research in this area (Popay and Collins 2014). As demonstrated in this thesis, the attitudes and beliefs of not only people with MS and healthcare professionals but also the general public are important factors in shaping approaches to bladder dysfunction. This aligns with the conceptual framework underlying this project, keeping people with MS at the core of future research in bladder dysfunction.

7.3.2 Theory

The use of a novel conceptual framework to guide the empirical research adds depth to the research process and findings. The conceptual framework included three bodies
of work: critical disability theory (Goodley 2010), International Classification of Functioning and Disability framework (World Health Organization 2001) and the self-regulatory model (Leventhal 1980). This conceptual framework enabled a deeper understanding of the social construction of bladder dysfunction from the perspectives of those living with this symptom, keeping people with MS at the core of each research strand.

Using this conceptual framework adds a theoretical basis to the body of literature around bladder dysfunction. While this conceptual framework was useful for this thesis, future research may need to draw on other theories to help understand additional aspects around bladder dysfunction. For example, further exploration of gender may be useful. Most research exploring bladder dysfunction includes only women. Few studies include the perspectives of men. Therefore, men with MS were included throughout each strand of this thesis. However, more research is needed to explore gender dynamics, particularly in relation to gender matching of clients and healthcare professionals. Matching client and therapist gender has been given attention in other areas such as psychology and mental health (Flaskerud et al 1990, Gaume et al 2016) but has not been examined in relation to bladder dysfunction. Some participants in Strand 1 mentioned their gender preferences when discussing bladder symptoms. More research is needed to explore gender dynamics in clinical practice when discussing bladder dysfunction. Thus, a deeper understanding and conceptualisation of gender would be necessary in future work.

Further exploration of the power dynamic between healthcare professionals and people with MS may also be useful in future research. This thesis provided insight into the complexities around discussing bladder dysfunction. Findings of Strand 3
suggested a miscommunication between people with MS and healthcare professionals when discussing bladder dysfunction in clinical practice and supports findings from Strand 2 that bladder symptoms need to be questioned in detail among people with MS. Conversations between healthcare professionals and service users can be complex for a number of reasons, thus, future research should incorporate theory to help understand the relative imbalance of power between people with MS and healthcare professionals in relation to bladder dysfunction.

A deeper theoretical understanding of the physical environment and space would be useful for future research. Within this thesis, Critical Disability Theory helped to understand the social construction of bladder dysfunction in terms of how people with MS navigate within society and manage their bladder symptoms on a daily basis. It would be useful for future work to consider the specific environmental barriers to managing bladder dysfunction, for example environmental set up, location of toilets and access to toilets in public places. Finally, within this environment, attitudes of others in relation to bladder dysfunction, particularly the general public need to be explored as the people within this environment contribute to the social construction of bladder dysfunction.

7.3.3 Practice

Findings of this research provides a range of implications for both people with MS, and healthcare professionals.

7.3.3.1 People with MS

Findings from Strand 3 suggest that people with MS are comfortable discussing their bladder symptoms with healthcare professionals. However, the majority of
participants reported they were not asked about their bladder symptoms by healthcare professionals in routine practice. This combined with a lack of knowledge around the current healthcare service and who to discuss their symptoms can result in people with MS not disclosing information to any healthcare professionals. This information adds to existing knowledge that people with MS often feel they are a burden to others by complaining about their symptoms (Koch et al. 2001). This results in people with MS self-managing bladder symptoms without professional advice from healthcare providers (Browne et al. 2015). Therefore, it is recommended that people with MS increase discussion of their bladder symptoms with healthcare professionals by considering how bladder dysfunction interferes with their daily activities. Finally, it is necessary to encourage open dialogue about bladder dysfunction, people with MS need to know that it is safe and acceptable to talk about their bladder. This comfortable environment is important in the development of trusting relationships between healthcare professionals and clients (Bedi and Duff 2014).

People with MS need to be aware of their active role in bladder management. Specific education is required to address this lack of clarity around individual roles and this information is a key component of the proposed educational resource outlined earlier in this chapter. In the final strand of this project, most people with MS reported that they were clear about their role in bladder management, however, only 59% of people with MS ranked themselves as important in facilitating self-management of bladder dysfunction. This combined with the detrimental strategies people with MS were using to self-manage bladder symptoms emphasises the need to support people with MS through education and to use evidence-based management strategies to facilitate self-management of bladder dysfunction. Self-management is a cornerstone of empowering people with chronic conditions (Cameron 2012). Education alone is
insufficient to facilitate self-management, further approaches of engagement and empowerment are necessary (Gibson et al. 2003). This connects with existing literature focusing on the concept of self-management approaches to enhance patients’ adherence to treatment regimens and maximise therapeutic outcomes (Kelly and Jordan 2015).

7.3.3.2 Healthcare professionals

This research demonstrated the individual impact of bladder symptoms on daily life for people with MS. In line with the International Classification of Functioning, Health and Disability (WHO 1980), subjective assessment of bladder symptoms needs to be expanded to consider all aspects of daily life. Thus, it could be useful for healthcare professionals to draw from elements of the ICF such as body functions and structure and activity and participation, to specifically consider bladder dysfunction. Furthermore, this project found that healthcare professionals were less selective in delineating the impact of bladder dysfunction. Each person with MS will have a difference experience of bladder dysfunction, in addition to a range of other symptoms therefore; deep, individualised, participation driven assessment of bladder symptoms is warranted.

Although reflective practice is an important component of professional development (Ferraro 2000), healthcare professionals would benefit from a more in-depth process of reflexive practice (Finlay and Gough 2008) to explore their underlying beliefs about bladder dysfunction. The importance of reflective practice in facilitating change emerged from Strand 2. Reflective practice can be enhanced with experience, feedback and the use of a model to guide the process (Levett-Jones 2007, Mann et al. 2009).
Many models of reflection exist including Gibbs (1988) reflective cycle and the model of experiential learning by Kolb (1984), however, to have a greater impact on clinical practice underlying beliefs need to be addressed. As demonstrated in Strand 2, examining beliefs about bladder dysfunction is necessary to challenge existing perceptions and to increase discussion among healthcare professionals. This in turn, will allow people with MS to talk about their symptoms at ease. Reflexivity offers a mechanism of challenging beliefs and thus developing expertise, however, it requires a certain level of expertise to begin with (H. D’Cruz et al. 2007). Therefore, it is recommended that healthcare professionals meet with more experienced colleagues and use an independent probing facilitator such as the Model of Clinical Practice Development (Figure 8) presented in Strand 2 to engage in a deeper interrogation of beliefs that inform practice. This is a new and novel finding which adds to the literature of bladder dysfunction.

Healthcare professionals need to be explicit about their individual professional roles in bladder management when communicating with people with MS. If healthcare professionals are not aware of how they can contribute to bladder management, people with MS remain unaware of the specific roles and responsibilities of such professionals. Lack of clarity around specific roles may discourage healthcare professionals from discussing bladder symptoms. This barrier further contributes to the social construction of bladder dysfunction.
7.4 EVALUATING THIS PROJECT

A set of questions was presented in Chapter 3 to guide the reader in terms of evaluating the quality of this research. Each question is considered below in relation to the overall limitations of the project.

7.4.1 Justification for a mixed methods approach

The mixed methods approach undertaken in this project was appropriate to capture the breadth and depth of the research question. This thesis captured a coherent view of bladder dysfunction including the perspectives of both people with MS and healthcare professionals. However, this research did not address the perspectives of families and carers of people with MS. These additional insights would have added a further dimension to this project. Furthermore, this research did not include the perspectives of service managers, which may have been beneficial considering they often set priorities in service provision. However, the focus of this research was to centralise the perspectives of people with MS and therefore, it was not within the scope of this project to involve family members, carers and service managers.

It is important to consider the tension of framing this research within a constructivist paradigm when one third of the fieldwork was based on the use of quantitative methods (Strand 3). This study could have been framed under the pragmatic paradigm. Pragmatism offers a useful middle position philosophically and methodologically. Pragmatist researchers focus on the 'what' and 'how' of the research problem (Creswell, 2003, p.11). The pragmatic paradigm centralises the research problem, thus, data collection and analysis methods are chosen to provide insights into the question with
no philosophical loyalty to any alternative paradigm (Mackenzie and Knipe 2006). Quantitative and qualitative methods can be used in both constructivist and pragmatic research, but that the difference lies within the epistemological foundation. Constructivism will attempt to uncover meaning from data, whereas pragmatists would collect data in order to find solutions and solve problems. Thus, the core interest of the research was the subjective perspectives of people with MS and healthcare professionals and to deepen understanding of bladder dysfunction, providing the rationale for framing the work under a constructivist paradigm.

7.4.2 Description of study design

The specific details of each study design are described in Chapters 4, 5 and 6. One noticeable limitation is the sample size in Strand 2. The qualitative exploration included a moderate sample size of fourteen healthcare professionals who were recruited over a period of six months. A snowballing technique was used to recruit a purposive sample of Irish healthcare professionals. There was predominance of physiotherapists in the cohort and only one nurse. This study did not include the perspectives of neurologists, urologists or general practitioners. There was only one male healthcare professional within the cohort. As such, this sample is not representative of healthcare professionals working with people with MS in the Republic of Ireland. However, the fourteen participants represented diverse backgrounds in terms of clinical setting, experience with bladder dysfunction, number of years of clinical experience and working with people with MS. As such, the interactions between participants within the focus groups and dyadic interviews created interesting discussions and excellent dialogue. In future research with healthcare professionals it is important to consider funding to cover mileage for
potential participants. Furthermore, it may be necessary to contact service managers outlining the potential value of the research for clinical practice in relation to access, effectiveness and cost. Details of this specific challenge was managed is outlined in Chapter 5.

7.5.3 Reflexivity

Throughout each stage of the research process, the researcher engaged in reflexive practice. A personal account was provided in Chapter 3 to demonstrate the specific values and experiences of the researcher. This reflexive approach to data collection was a particular strength of the project and is evident throughout each strand. For example, in Strand 1, both supervisors read a sample of interview transcripts. This engagement with the data created a detailed discussion around the initial coding structure. After this discussion, the coding list was revised and I re-read and re-coded all the data under this new perspective which allowed me to view concepts that I had not previously acknowledged.

Furthermore, during data collection in Strand 2, I became drawn to a particular idea around values and beliefs of healthcare professionals that was emphasised by a participant during a telephone interview. However, these ideas were only developing at the surface and required in-depth discussions with supervisors. By actively engaging with supervisors, and collectively thinking through these particular comments around beliefs underpinning practice, greater clarity was achieved. These supervision meetings helped to articulate what this participant was eluding to and informed the distinction between reflective and reflexive practice, which is discussed in detail in Strand 2.
Finally, the survey in Strand 3 was originally designed for healthcare professionals only. However, after a detailed discussion with supervisors it became clear that an obvious link was missing - the survey for people with MS. This supervision meeting prompted consideration of the conceptual framework and allowed me to consider the importance of keeping people with MS at the core of each strand.

**7.5.4 Are the findings of this research meaningful?**

The implications of these findings for people with MS, healthcare professionals and policy-makers are clearly outlined at the beginning of this chapter. People with MS were involved in the development of the questioning routes used in this project. The first strand described the impact of bladder dysfunction on daily life from the perspectives of people with MS. These findings informed the development of the questioning schedule used in Strand 2 and the surveys used in Strand 3. The people with MS who reviewed the draft survey in Strand 3 were not surprised by the content and extent to which bladder dysfunction interfered with daily activities. This suggests the research results resonate with people with MS who were not involved in the study. This research did not include an advisory panel of people with MS and healthcare professionals, which may have been helpful to connect the findings with people with MS and healthcare professionals not directly involved in the project. However, findings were presented to healthcare professionals at national and international conferences throughout the duration of the project. Furthermore, findings were disseminated to people with MS at research day seminars organised through Multiple Sclerosis Ireland. These knowledge translation activities raised awareness of the importance of this research and provided an opportunity to discuss the findings with healthcare professionals and people with MS not directly involved in the project.
7.6 THESIS CONCLUSIONS

The overall aim of this thesis was to inform the development of a self-management resource to enable people with Multiple Sclerosis to better self-manage bladder dysfunction.

This thesis found that bladder dysfunction results in major disruptions to daily activities for people with MS which can create a sense of loss in their lives. People with MS attempted to self-manage their bladder symptoms despite current barriers to navigating existing healthcare infrastructure.

This project provided novel insights into the perspectives of healthcare professionals working with people with MS around bladder dysfunction. Findings highlighted the importance of both reflective and reflexive practice in clinical practice. It is important for healthcare professionals to challenge their underlying beliefs to optimise discussion of bladder dysfunction.

Finally, this project demonstrated the importance of self-management of bladder dysfunction among people with MS. Education is needed for both people with MS and healthcare professionals to address their lack of knowledge in relation to management strategies. These findings provide an evidence and theory base to inform the development of an educational resource to facilitate the self-management of bladder dysfunction among people with MS.
CHAPTER 8 REFERENCES


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Appendices
## Appendix 1 Quality Assessment of prevalence studies

### A. Seven criteria which should always be assessed:

<table>
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<tbody>
<tr>
<td>Was the target population specified?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Which sampling method was employed?</td>
<td>Purposive sampling</td>
<td>Purposive sampling</td>
<td>Purposive sampling</td>
<td>Self-selected</td>
<td>Purposive sampling</td>
<td>Purposive sampling</td>
</tr>
<tr>
<td>Was the sample size adequate?</td>
<td>No detail given</td>
<td>No detail given</td>
<td>No detail given</td>
<td>x</td>
<td>No detail given</td>
<td>✓</td>
</tr>
<tr>
<td>Was the response rate adequate?</td>
<td>No detail given</td>
<td>✓</td>
<td>No detail given</td>
<td>✓</td>
<td>No detail given</td>
<td>✓</td>
</tr>
<tr>
<td>Was information given on non-responders?</td>
<td>x</td>
<td>x</td>
<td>✓</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Was a valid and repeatable disease definition given?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
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<tr>
<td>Have reasonable efforts been made to reduce observer bias?</td>
<td>No detail given</td>
<td>No detail given</td>
<td>No detail given</td>
<td>No detail given</td>
<td>No detail given</td>
<td>No detail given</td>
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### B. Other factors worth looking for:

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<tbody>
<tr>
<td>Were inclusion criteria specified?</td>
<td>✓</td>
<td>✓</td>
<td>x</td>
<td>✓</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Was information on persons actually studied reported in detail?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Were known and validated instruments used for measurement of the health outcome?</td>
<td>✓</td>
<td>x</td>
<td>✓</td>
<td>x</td>
<td>✓</td>
<td>x</td>
</tr>
<tr>
<td>Were the terms “incidence” and “prevalence” correctly applied?</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Were confidence intervals or standard errors presented for the estimates of prevalence?</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
</tbody>
</table>
### Appendix 2 Strand 1 Questioning Route

<table>
<thead>
<tr>
<th>Topic</th>
<th>Main Questions</th>
<th>Probes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Background Information</strong></td>
<td>How long have you been diagnosed with MS?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>What type of MS do you have?</td>
<td></td>
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<tr>
<td></td>
<td>Do you use an aid to help you walk?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Are you working at present?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Are you married/ Have you children?</td>
<td></td>
</tr>
<tr>
<td><strong>History of Bladder Dysfunction</strong></td>
<td>Tell me when first begin to notice symptoms of bladder dysfunction.</td>
<td>If not, why not? If you did report- did you receive any help or advice?</td>
</tr>
<tr>
<td></td>
<td>Did you report this problem immediately to a health professional?</td>
<td></td>
</tr>
<tr>
<td><strong>Financial</strong></td>
<td>Are you working at present? (If currently unemployed) Do you think your bladder dysfunction a major reason you cannot work?</td>
<td>Buying products- continence pads, panty liners, etc)</td>
</tr>
<tr>
<td></td>
<td>Why?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Do you find it costly to manage your bladder dysfunction?</td>
<td></td>
</tr>
<tr>
<td><strong>Home life</strong></td>
<td>Can you tell me how it may affect your ability to perform routine household chores?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Is this a factor that may have changed your role in the household?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Do you have to get up during the night to go to the toilet?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>If so how many times? does it affect your fatigue, are you able to go back to sleep</td>
<td></td>
</tr>
<tr>
<td>Socialising</td>
<td>Tell me how it has affected your social life. Do you find yourself always checking where the toilet is in a new building?</td>
<td>Do you still go out with friends/attending family occasions? Are you embarrassed/ashamed</td>
</tr>
<tr>
<td>------------</td>
<td>-----------------------------------------------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Exercise</td>
<td>Does controlling your urine (bladder) interfere with your exercise participation? Explain. Does it stop you from taking part in activities you once enjoyed? Would you be comfortable going to a gym/attending an exercise class?</td>
<td></td>
</tr>
<tr>
<td>Sexual Function</td>
<td>Many people with MS with bladder dysfunction experience sexual dysfunction also. Is this something you can relate to? Has your sexual life changed since diagnosis?</td>
<td>Do you have a diminished sexual desire? Does this have a strain on your relationship?</td>
</tr>
<tr>
<td>Conclusion</td>
<td>If you were to spend the rest of your life with your urinary condition, just the way it is now, what part of your life do you think it may affect most? Is there anything else you would like to add that we have not discussed already?</td>
<td>Emotional/Financial/Social/Sexual Travel considerations/ choice limitation</td>
</tr>
</tbody>
</table>
Title: The impact of Bladder Dysfunction in Multiple Sclerosis

Involuntary leakage of urine, needing to urinate more frequently than normal, awakening from sleep at night to pass urine, any voiding dysfunction (hesitancy, straining, poor stream) are some symptoms of bladder dysfunction. These may seriously affect social participation, activity levels and sexual activity. This study aims to explore the impact of bladder dysfunction from a patient’s perspective.

What does this study involve?

It involves taking part in a once off, face to face interview which will take place in a private room in the University of Limerick. The interview will last for a maximum of 60 minutes. The questions asked are related to bladder dysfunction and its impact on your everyday life. Prior to the interview you will be asked to sign a consent form to confirm your participation in the study. At the end of the interview you will be provided with a summary highlighting the main points of the discussion.

To take part in the study you must have a definite diagnosis of MS, aged between 18 and 65 and have at least one bladder dysfunction symptom. No information containing your name or that can be identified as you will be presented in the research report.

Your participation in this study is completely voluntary and you may withdraw at any time without having to give any explanation. If you have any questions regarding the study, please contact any of the research team:

Catherine Browne email: 0862088@studentmail.ul.ie
Dr. Maria Garrett email: maria.garrett@ul.ie

If you have concerns regarding this study, please contact:
Chairman, Education and Health Sciences,
Research Ethics Committee,
EHS Faculty Office,
University of Limerick.
Tel (061) 234101 Email: ehsresearchethics@ul.ie
Appendix 4 Strand 1 Consent Form

Title: The effect of Bladder Dysfunction in Multiple Sclerosis

I have read and understood the participant information leaflet. I am fully aware of what my role in this study and what is involved. I know that my participation is voluntary and I can withdraw from the study at any stage without giving any reason. I give my permission to tape-record the interview and know that the results will be anonymised.

Participant’s Name (BLOCK CAPITALS): ____________________

Participant’s Signature: ____________________

Researcher’s name (BLOCK CAPITALS): ____________________

Researcher’s Signature: ____________________

Date: ____________________
I am currently looking for volunteers to participate in a study which is investigating the impact of bladder dysfunction in people with Multiple Sclerosis. This is an important area of research that has been previously unexplored. Dr Maria Garrett is the supervisor involved in this project.

You will find all the information you need in the information leaflet enclosed. I would really appreciate if you could spare some time to read this leaflet and consider volunteering.

If you would like to volunteer, please contact me by email or phone, and I will arrange a suitable interview time with you. Please do not hesitate to contact me if you require any further information.

Thank you for your time and I look forward to hearing from you.

Catherine Browne email: 0862088@studentmail.ul.ie Phone: 087-2473830

Dr. Maria Garrett email: maria.garrett@ul.ie Phone: (061) 234865

If you have concerns regarding this study, please contact:
Chairman, Education and Health Sciences,
Research Ethics Committee,
EHS Faculty Office,
University of Limerick.
Tel (061) 234101
Appendix 6 Group Interview Questioning Route

<table>
<thead>
<tr>
<th>Content</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Introduction</strong></td>
<td>2-3mins</td>
</tr>
<tr>
<td>(Introduce myself and the current setting where I see people with MS)</td>
<td></td>
</tr>
<tr>
<td>In this focus group study, we will explore the potential roles of healthcare professionals in supporting people with bladder dysfunction.</td>
<td></td>
</tr>
<tr>
<td>Before we begin I would just like to double check if everyone has signed and given me the consent form and background information.</td>
<td></td>
</tr>
<tr>
<td><strong>Opening</strong></td>
<td>5mins</td>
</tr>
<tr>
<td>I would like to begin by asking everyone to tell us their first-name and tell us about the type of setting you work in and your current role working with people with MS.</td>
<td></td>
</tr>
<tr>
<td><strong>Introductory Questions:</strong></td>
<td>10mins</td>
</tr>
<tr>
<td>What comes to mind when you consider bladder dysfunction among people with Multiple Sclerosis?</td>
<td></td>
</tr>
<tr>
<td><em>(Brainstorm: create word-cloud of suggestions made)</em></td>
<td></td>
</tr>
<tr>
<td><strong>Probes:</strong></td>
<td></td>
</tr>
<tr>
<td>• How do you approach people with MS asking people about bladder dysfunction?</td>
<td></td>
</tr>
<tr>
<td>• Some people with MS (and clinicians) consider BD to be just another symptom of MS- what do you think of this?</td>
<td></td>
</tr>
<tr>
<td><strong>Transition</strong></td>
<td>10mins</td>
</tr>
<tr>
<td>The presence of bladder dysfunction in people with MS has been well established, however, there is substantial variation in the prevalence of bladder dysfunction in this population reported in the literature with estimates ranging from 52 to 97%.</td>
<td></td>
</tr>
<tr>
<td>• Tell me about the prevalence of bladder dysfunction among your patients.</td>
<td></td>
</tr>
<tr>
<td><strong>Probes:</strong></td>
<td></td>
</tr>
</tbody>
</table>
Key Questions:
Theme 1: “Loss and Disruption”

19 semi-structured interviews were conducted with people with MS exploring the impact of bladder dysfunction on their lives. I will now present the key themes from this study.

The first theme which emerged was the “Loss and Disruption”. *(Figure 1 below will be displayed)*
Participants described the loss and disruption they experienced throughout many aspects of life:

- Physical Disruption
- Sexual Disruption:
- Family Disruption
- Home Disruption
- Community Disruption

- Do these types of disruption connect with your experiences with clients? Can you offer some examples of these?
- What other life disruptions have patients reported to you? Probe for daily routines, work life, travel, activities of daily living, relationships.

This loss and disruption increases emotional distress. People with MS are constantly worried and concerned about their bladder symptoms and how they will manage in different situations. Participants discussed how fatigue was increased due to both the physical disruption and emotional distress of having to constantly plan around their bladder symptoms.
The loss and disruption of BD and constant emotional distress results in reduced participation in society.

“*It’s frightening, that in turn prevents you or stops you from going out*” (P16)

“If I was invited to weddings or parties…I’d say no, no I can’t” (P14)

- Are you familiar with this emotional distress in relation to bladder dysfunction? Tell me about your experiences with patients.

**Probe:** How do you address this emotional distress? How does this affect your assessment/management?

<table>
<thead>
<tr>
<th><strong>Introduce Theme 2</strong></th>
<th><strong>Knowledge</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Theme 2 “Ways of Knowing” includes the knowledge participants have gained through their bodies and through experience which allows people with MS to gain a deep understanding of how their bladder symptoms affect their bodies. Participants described how they use this knowledge to self-manage their symptoms. For example:</td>
<td></td>
</tr>
</tbody>
</table>

“*I taught myself how to hold it*” (P12)

“*Sometimes if I talk to it (bladder) it helps to start the flow...*” (P3)

“*I press down on my tummy to encourage elimination...*” (P7)

- Tell me about a client who has used their knowledge about their bodies to manage their bladder symptoms. Was this method effective? How did they come up with this method?

Knowledge of current healthcare service provision highlights the lack of knowledge participants have in relation to reporting symptoms, accessing services and knowledge about management options. This lack of knowledge also suggests that people with MS are

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<td>30mins</td>
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</tbody>
</table>
self-managing without the additional expertise knowledge from the healthcare system.

- Tell me about patients reporting bladder dysfunction. Do they talk about it openly? Do you need to probe for information?
- Several participants suggested that it should be the responsibility of the HCP to raise the topic of BD. What do you think?
- Bladder dysfunction has been found to be a top priority among people with MS. As HCPs, especially in the current economy we are faced with increasing challenges and time constraints. Where does bladder dysfunction fit among our priorities as HCPs?
- What would help you as HCPs to address the issues of BD among people with MS in terms of assessment and management?

**Probes:** Do you feel you have enough knowledge to offer advice about managing their BD? What are some of the strategies/advice you offer to people with BD? What sources of information do you rely on? Who do you refer to? What HCPs play a role in the management of BD? What contribution do these HCPs make?

<table>
<thead>
<tr>
<th>Closing Question-</th>
<th>Closing remarks and opportunity to add/amend.</th>
<th>5mins</th>
</tr>
</thead>
<tbody>
<tr>
<td>Summary</td>
<td>Short summary on key points of focus group</td>
<td>5mins</td>
</tr>
</tbody>
</table>
## Appendix 7: Semi-structured Interview Questioning Route

<table>
<thead>
<tr>
<th>Content</th>
<th>Time</th>
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<tbody>
<tr>
<td><strong>Introduction</strong></td>
<td>2-3mins</td>
</tr>
<tr>
<td>(Introduce myself and the current setting where I see people with MS)</td>
<td></td>
</tr>
<tr>
<td>In this interview we will explore the potential roles of healthcare professionals in supporting people with bladder dysfunction.</td>
<td></td>
</tr>
<tr>
<td>Sign consent form and collect background information.</td>
<td></td>
</tr>
<tr>
<td><strong>Opening</strong></td>
<td>5mins</td>
</tr>
<tr>
<td>Tell me about the type of setting you work in and your current role working with people with MS.</td>
<td></td>
</tr>
<tr>
<td><strong>Introductory Questions:</strong></td>
<td>5mins</td>
</tr>
<tr>
<td>What comes to mind when you consider bladder dysfunction among people with Multiple Sclerosis?</td>
<td></td>
</tr>
</tbody>
</table>

![Figure 1. Findings of impact of bladder dysfunction among people with MS](image-url)
Here are some of the examples which participants in previous focus groups have mentioned (give some examples to stimulate ideas)

**Probes:**

- How do you approach people with MS asking people about bladder dysfunction?
- Some people with MS (and clinicians) consider BD to be just another symptom of MS- what do you think of this?

**Transition**

The presence of bladder dysfunction in people with MS has been well established, however, there is substantial variation in the prevalence of bladder dysfunction in this population reported in the literature with estimates ranging from 52 to 97%.

- Tell me about the prevalence of bladder dysfunction among your patients.

**Probes:**

- Do you find it is more prevalent in particular patients? Type of MS, disease severity, years since diagnosis, age, gender

**Key Questions:**

**Theme 1: “Loss and Disruption”**

19 semi-structured interviews were conducted with people with MS exploring the impact of bladder dysfunction on their lives. I will now present the key themes from this study.

The first theme which emerged was the “Loss and Disruption”. (Figure 1 below will be displayed) Participants described the loss and disruption they experienced throughout many aspects of life:

- Physical Disruption
- Sexual Disruption:
- Family Disruption
- Home Disruption
Community Disruption

- Do these types of disruption connect with your experiences with clients? Can you offer some examples of these?
- What other life disruptions have patients reported to you? Probe for daily routines, work life, travel, activities of daily living, relationships.

This loss and disruption increases emotional distress. People with MS are constantly worried and concerned about their bladder symptoms and how they will manage in different situations. Participants discussed how fatigue was increased due to both the physical disruption and emotional distress of having to constantly plan around their bladder symptoms.

The loss and disruption of BD and constant emotional distress results in reduced participation in society.

“It’s frightening, that in turn prevents you or stops you from going out” (P16)

“If I was invited to weddings or parties…I’d say no, no I can’t” (P14)

- Are you familiar with this emotional distress in relation to bladder dysfunction? Tell me about your experiences with patients.

Probes: How do you address this emotional distress? How does this affect your assessment/management?

Introduce Theme 2

“Knowledge”

Theme 2 “Ways of Knowing” includes the knowledge participants have gained through their bodies and through experience which allows people with MS to gain a deep understanding of how their bladder symptoms affect their bodies. Participants described how they use this
knowledge to self-manage their symptoms. For example

“I taught myself how to hold it” (P12)

“Sometimes if I talk to it (bladder) it helps to start the flow....” (P3)

“I press down on my tummy to encourage elimination...” (P7)

- Tell me about a client who has used their knowledge about their bodies to manage their bladder symptoms. Was this method effective? How did they come up with this method?

Knowledge of current healthcare service provision highlights the lack of knowledge participants have in relation to reporting symptoms, accessing services and knowledge about management options. This lack of knowledge also suggests that people with MS are self-managing without the additional expertise knowledge from the healthcare system.

Tell me about patients reporting bladder dysfunction. Do they talk about it openly? Do you need to probe for information? Several participants suggested that it should be the responsibility of the HCP to raise the topic of BD. What do you think?

Bladder dysfunction has been found to be a top priority among people with MS. As HCPs, especially in the current economy we are faced with increasing challenges and time constraints. Where does bladder dysfunction fit among our priorities as HCPs?

What would help you as HCPs to address the issues of BD among people with MS in terms of assessment and management?

Probes: Do you feel you have enough knowledge to offer advice about managing their BD? What are some of the strategies/advice you offer to people with BD? What sources of information do you rely on? Who do you refer to? What HCPs play a role in the management of BD? What contribution do these HCPs make?
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</thead>
<tbody>
<tr>
<td><strong>Closing Question</strong></td>
<td>Closing remarks and opportunity to add /amend.</td>
<td><strong>5mins</strong></td>
</tr>
<tr>
<td><strong>Summary</strong></td>
<td>Short summary on key points of the interview</td>
<td><strong>5mins</strong></td>
</tr>
</tbody>
</table>

Figure 1. Findings of impact of bladder dysfunction among people with MS
Appendix 8 Strand 2 Participant information Leaflet

The reflections of Healthcare Professional’s on managing Bladder Dysfunction among People with Multiple Sclerosis

Introduction

Bladder dysfunction is common in people with multiple sclerosis (MS) affecting approximately 75% at some stage in their lives. This distressing symptom is often overlooked and many people with MS are reluctant to talk about it. The aim of this study is to explore the potential roles of healthcare professionals in effectively supporting people with bladder dysfunction.

Participants

Physiotherapists, Occupational Therapists, General Practitioners, MS nurses, continence nurses or any healthcare professionals who encounter people with MS during regular clinical practice in any setting would be suitable to take part in this study. Participants do not need extensive experience in MS care - all perspectives are valuable.

Procedure

If you agree to participate you will attend one focus group meeting lasting up to 90 minutes. If you are unable to attend the focus group meeting will be given the option of participating via Skype. During this focus group the researcher will present the results of the pilot study to stimulate discussion. You will be encouraged to share and discuss your experiences working with people with MS. The focus group will be recorded if all participants agree. There are no right or wrong answers to the questions that are raised in the group. Your participation
within this study is completely voluntary and you can opt not to answer any question and you may withdraw at any time without giving any explanation.

If focus groups are not suitable you will be given the option to participate in a one-to-one semi-structured interview. The interview will last approx. 60 minutes and will follow the same questioning route as the focus groups. At the end of the focus group/interview you will be given a summary of the key points. During data analysis all information containing your name or identifiable information will be removed. Your consent form and background information will be stored in a locked cabinet in the Department of Clinical Therapies in the University of Limerick. Once we fully analyse the data from both focus groups we will email or post a summary to you if you wish.

**Benefits and Risks**

There are no anticipated risks to the participants. No direct benefits will be gained through participation in this study; however, your involvement will provide valuable information about the impact of bladder dysfunction in the lives of people with MS and current strategies used to manage this symptom.

**Confidentiality**

To keep your identity private, you will be assigned a code number to be used in the study. Your identity will be kept private in any presentations or papers developed. The electronic anonymised transcriptions will then be stored for a period of 7 years in the Department of Clinical Therapies in the University of Limerick. After this period the data will be permanently deleted. If you have any questions regarding the study, please feel free to contact any of the research team:

**Catherine Browne email**: Catherine.M.Browne@ul.ie

**Dr. Maria Garrett email**: Maria.Garrett@ul.ie

**Dr. Nancy Salmon email**: Nancy.Salmon@ul.ie

If you have concerns regarding this study, please contact: Chairman, Education and Health Sciences, Research Ethics Committee, EHS Faculty Office, University of Limerick.

Tel (061) 234101; Email: ehsresearchethics@ul.ie
Appendix 9 Strand 2 Consent Form

Title: The reflections of Healthcare Professional’s on the impact of Bladder Dysfunction among People with Multiple Sclerosis

I have read and understood the participant information leaflet. I am fully aware of what my role in this study and what is involved. I know that my participation is voluntary and I can withdraw from the study at any stage without giving any reason. I give my permission to tape-record the focus group/interview and know that the results will be kept anonymised. To ensure confidentiality I will not repeat information discussed during the focus group.

Please Tick accordingly:

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>I agree to keep all information discussed in this focus group/interview private.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I agree that this focus group/interview can be audio recorded</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am happy to review a summary of the results of this focus group/interview.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>If yes, I would like to receive this summary via:</td>
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<tr>
<td>• Email</td>
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<td></td>
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<tr>
<td>• Post</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I agree that the anonymised transcripts of this study may be used for secondary analysis in the future</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Participant’s Name (BLOCK CAPITALS) __________________________

Participant’s Signature: __________________________

Researcher’s name (BLOCK CAPITALS) __________________________

Researcher’s Signature: __________________________
Appendix 10 Strand 2 Recruitment Email

Dear (name),

My name is Catherine Browne and I am a PhD Student at the University of Limerick and a Chartered Physiotherapist. I am currently researching bladder dysfunction in people with Multiple Sclerosis (MS).

My study involves a focus group of healthcare professionals reflecting on bladder dysfunction among people with MS. You may also participate in this study via a one-to-one semi-structured interview. The aim of this study is to explore the potential roles of healthcare professionals in effectively supporting people with bladder dysfunction. This project has ethics approval from the University of Limerick (2013_05_09_EHS).

Focus groups/interviews will be held in a location convenient to all participants. I have attached an information leaflet to provide some further information. Please let me know if you would like more information about this study or if you would be interested in taking part.

Many thanks for taking the time to read this email,

Yours sincerely,

Catherine Browne (PhD Student University of Limerick)

Email: Catherine.M.Browne@ul.ie

Dr. Maria.Kehoe (Principal Investigator and Project Supervisor)

Email: Maria.Kehoe@ul.ie Phone: 061-234865

Dr. Nancy Salmon (Other Investigator and Project Supervisor)

Email: Nancy.Salmon@ul.ie Phone: 061-234275
Appendix 11 Strand 2 Research Fieldnote Template

FG/Participant Number:

1. **Describe the environment where the interview took place in as much detail as you can** (e.g. time, space, lighting, sound)

2. **Describe the participants in as much detail as you can** (e.g. appearance, body language, tone of voice, comfort level).

3. **Describe the interview process** (e.g. flow, depth of participant responses, rapport between interviewer and participant, change over the course of the interview).

4. **Were there any unexpected interruptions that need to be explained to the transcriber?** (e.g. loud noises, someone needing to take a phone call, the recorder being shut off for a period of time).

5. Think back over the interview. **Were there any keywords or phrases used by the participant that struck you in some way? If so, list them here.**

6. **Summarize the key points from this interview in 2-3 paragraphs.**

7. **Consider your main interview question: In what ways does this interview help you respond to that question?**

8. **Now think about the aims of your study. Describe how this interview connects to those aims.**

9. **Now turn your attention to your own experience of the interview itself. How did you respond throughout the session? Did you hear pretty much what you expected to hear? If so, explain. Did anything about the participant’s experience surprise you or make your feel uncomfortable? If so, explain.**
Appendix 12 Strand 2 Researcher Confidentiality Agreement

Before I become involved in this focus group study, I understand that I am to keep anything I read or discuss with the principal investigator or research partners completely private.

I understand that I am to keep all information discussed in this focus group completely private and I will not discuss this information with anyone outside the study. I will not disclose under any circumstances the names of anyone who participates in the focus groups.

If I do not adhere to this agreement, I understand that my work on this study may be terminated immediately.

_______________________________________
Research Assistant

_______________________________________
Principal Investigator
Appendix 13 Strand 3 Healthcare Professional Questionnaire

The aim of this questionnaire is to gather information regarding current practice and strategies used by healthcare professionals to support the management of bladder dysfunction among people with multiple sclerosis (MS). The findings of this study will identify what needs to be in place to facilitate successful self-management of bladder dysfunction.

This questionnaire will take 15-20mins to complete. You do not have to be an expert to answer these questions. There are no right or wrong answers. Participation is voluntary. You may withdraw at any time.

The questionnaire focuses on awareness of bladder dysfunction, confidence in assessment and management, roles and responsibilities, access to services, barriers to management and what you need to better support people with MS who experience bladder dysfunction.

Please tick the following statements:

- I confirm, I am a health professional _____
- I have encountered a person with MS in my clinical practice _____
- By completing this questionnaire, I acknowledge my information is submitted and will not be retrievable _______
1. **Age:** Please select an appropriate month and year:
   - Month you were born: Jan-Dec (Drop down menu)
   - Year you were born: 1940-2000 (Drop down menu)

2. **Gender:** Please tick:
   - Male
   - Female

3. **Please tick your current working profession:**
   - GP
   - Neurologist
   - Nurse
   - Occupational Therapist
   - Physiotherapist
   - Urologist
   - Other___________________

4. **Highest Level Qualification:**
   Please tick one or more:
   - Diploma
   - BSc/BA
   - MSc
   - PhD
   - Other____________
5. **Work Setting:**

Please tick one or more:

- Acute Inpatient
- Acute Outpatient
- Long term residential unit
- Respite
- Community (Domiciliary)
- Community (Primary care)
- Voluntary Body Organisation
- Private Practice
- Other

If other, please specify__________

6. **How many years since obtaining your highest level qualification?**

Number of years: __________________

7. **HSE Region:**

Please tick:

- SOUTH
- WEST
- DUBLIN NORTH EAST
- DUBLIN MID-LEINSTER

*HSE South – (County Carlow, County Cork, County Kerry, County Kilkenny, County Waterford, County Wexford and South Tipperary)*
8. How many years are you in your current job? _______

Please tick one: 0-5/6-10/11-15/15-20/20 and over

9. Please estimate what percentage of your caseload is made up of people with Multiple Sclerosis (MS): ________________

10. How many years have you been working with people with MS? ________________
Page 2:

1. Please tick your response to each statement in the table below based on your clinical judgement and perspectives of working with people with MS.

For people with MS, bladder dysfunction significantly interferes with:

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Unsure</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of life</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Work</td>
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<td>Travel</td>
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<tr>
<td>Socialising</td>
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<tr>
<td>Relationships</td>
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<td>Sexual Functioning</td>
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<td>Sleep</td>
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</tbody>
</table>

If you have additional comments about how you perceive bladder dysfunction to interfere with daily life for people with MS, please explain here:
_______________________________

2. I feel comfortable talking to people with MS about bladder dysfunction

Strongly agree/agree/unsure/disagree/strongly disagree

Please explain why this is the case: _________________________________

3. Self-management is an essential strategy in addressing bladder dysfunction among people with MS

Please tick: Strongly agree/agree/unsure/disagree/strongly disagree
If you strongly agree or agree, please explain your approach to facilitating self-management

4. From your experience please comment on any strategies you have used to promote self-management of bladder symptoms

Page 3:

Please tick accordingly for each sentence below:

1. I ask about bladder dysfunction during initial assessment.

Never/rarely/sometimes/often/always

*if “never” please skip to the next page

Please explain: _______________________

2. Please state the specific question/statement you use to ask about bladder dysfunction and to approach the topic

______________________________

3. I use a bladder questionnaire or screening tool to subjectively assess bladder dysfunction.

Never/rarely/sometimes/often/always

If sometimes/often/always, please state name of tool _____________

4. Please tick to agree with the following statements below for each bladder symptom
<table>
<thead>
<tr>
<th>Symptom</th>
<th>Strongly disagree</th>
<th>disagree</th>
<th>Not sure</th>
<th>agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am familiar with the following bladder symptom:</td>
<td></td>
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</tr>
<tr>
<td>Urgency</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Frequency</td>
<td></td>
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</tr>
<tr>
<td>Hesitancy</td>
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</tr>
<tr>
<td>Interrupted stream</td>
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<tr>
<td>Urinary Incontinence</td>
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<tr>
<td>Stress incontinence</td>
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<tr>
<td>Mixed incontinence</td>
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<tr>
<td>I probe about the following bladder symptoms during initial assessment</td>
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<tr>
<td>Urgency</td>
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<tr>
<td>Frequency</td>
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<td>Hesitancy</td>
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<tr>
<td>Interrupted stream</td>
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<tr>
<td>Urinary Incontinence</td>
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<tr>
<td>Stress incontinence</td>
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<tr>
<td>Mixed incontinence</td>
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<tr>
<td>I find the following bladder symptoms difficult to manage</td>
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<tr>
<td>Urgency</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequency</td>
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<tr>
<td>Hesitancy</td>
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<tr>
<td>Interrupted stream</td>
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<tr>
<td>Urinary Incontinence</td>
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</tr>
<tr>
<td>Stress incontinence</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mixed incontinence</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
5. How often do you engage in the strategies below to promote self-management of bladder symptoms in people with MS:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
<th>Non-applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-catheterisation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medication</td>
<td></td>
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<tr>
<td>Pelvic floor exercises</td>
<td></td>
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<td></td>
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<tr>
<td>Bladder retraining</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fluid control</td>
<td></td>
<td></td>
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<tr>
<td>General bladder advice</td>
<td></td>
<td></td>
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<tr>
<td>Self-monitoring techniques,</td>
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<tr>
<td>please specify____________</td>
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<td></td>
</tr>
<tr>
<td>Other (if not listed above</td>
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<td></td>
</tr>
<tr>
<td>please state here) _____________</td>
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</tr>
</tbody>
</table>

6. I use one or more paper resources (e.g. bladder diary or advice booklets) to help facilitate bladder management in people with MS.

Never/rarely/sometimes/often/always

If used, please explain this paper resource: ______________________

7. I use electronic/online resources (e.g. websites) to help facilitate bladder management in people with MS

Never/rarely/sometimes/often/always

If used, please explain this electronic/online resource: ___________________

8. I am satisfied with my level of knowledge on bladder management in my current position.
9. I am confident with my approach to management of bladder dysfunction.

Please tick: Strongly agree/agree/unsure/disagree/strongly disagree

Page 4:

1. If bladder dysfunction is reported to you do you refer to other healthcare professionals?

Please tick: Never/rarely/sometimes/often/always

Additional comments: ___________________

*if never please skip to question 4

2. If so, who do you refer to?

Please tick one or more:

- GP
- Neurologist
- Urologist
- Physiotherapist
- Occupational Therapist
- Public Health Nurse
- Continence Nurse
- MS Nurse
- Other ____________________
3. How long do people with MS have to wait to get an appointment for this onward referral?

Please tick:

- Unsure
- Less than 1 month
- 1-2 months
- 2-6 months
- 6-12 months
- >12 months

4. Are there specialist continence services available in your area?

(Specialist continence services include urologists, continence nurses, Women’s Health physiotherapist or any other HCP specialised in the area)

Yes/no/unsure

If yes, please explain ____________________
5. The person stated below is well placed to facilitate self-management of bladder dysfunction. Please tick for each of those listed below:

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Not sure</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Continence Nurse</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>GP</td>
<td></td>
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<tr>
<td>MS Nurse</td>
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</tr>
<tr>
<td>Neurologist</td>
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</tr>
<tr>
<td>Occupational Therapist</td>
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<tr>
<td>Person with MS</td>
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</tr>
<tr>
<td>Physiotherapist</td>
<td></td>
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<tr>
<td>Public Health Nurse</td>
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<tr>
<td>Urologist</td>
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<tr>
<td>Other (if not listed above please state here)</td>
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</tr>
</tbody>
</table>

6. Bladder management is a specialist service.

Please tick: Strongly disagree/disagree/unsure/agree/strongly agree
If you agree or strongly agree, please comment on the resources or skills these specialist services have: ____________________

7. I am clear about my role in bladder management

Please tick: Strongly disagree/disagree/unsure/agree/strongly agree

Explain your role: ____________________

8. Bladder dysfunction is managed well for people with MS in my area.

Please tick: Strongly disagree/disagree/unsure/agree/strongly agree

Additional Comments: ____________________
Page 5:

1. Please tick as appropriate each statement below:

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Not sure</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I lack confidence in the area of asking and talking about bladder symptoms.</td>
<td></td>
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<tr>
<td>I lack knowledge in the area of bladder management-strategies and advice.</td>
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<tr>
<td>I do not have time to discuss or address bladder symptoms.</td>
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<tr>
<td>Bladder dysfunction falls outside of my scope of practice.</td>
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<tr>
<td>Specialist services have long waiting times</td>
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<tr>
<td>It is not a top priority for my service provision.</td>
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<tr>
<td>People with MS are reluctant to discuss their symptoms</td>
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</tr>
</tbody>
</table>

Please provide information on any additional barriers you experience in practice that are not mentioned above: _______________________

2. I have completed additional professional development in relation to bladder dysfunction

Please tick: Yes/no

If yes please provide details (e.g. CPD units, weekend course, informal study, postgraduate work) _______________________

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3. **I am interested in taking part in additional training/courses/CPD on bladder management**

Please tick: Strongly agree/agree/unsure/disagree/strongly disagree

Please explain any particular reasons for your answer: __________

If you strongly disagree or disagree, the survey is now complete. Thank you for taking part.

4. **I would be interested in using the following education resources for bladder management. Please tick for each resource below.**

<table>
<thead>
<tr>
<th>Resource</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Not sure</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Online Podcast</td>
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</tr>
<tr>
<td>Online web resource (webpage/ website)</td>
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<tr>
<td>Online Interactive Forum</td>
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<tr>
<td>Online Blog</td>
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<tr>
<td>Phone App</td>
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<tr>
<td>Social Media with regular updates (Facebook page, Twitter feed)</td>
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<tr>
<td>Paper resource (Leaflet)</td>
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<tr>
<td>General education day</td>
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<tr>
<td>Specific Guidelines</td>
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<tr>
<td>Other (if not listed above please state here)</td>
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</tbody>
</table>

5. **What information should be included in the resource?**

Please rank 1-6 in order of preference (1 being most, 6 being least preferred method or 1-7 if using the “other” option)
• Cause of bladder dysfunction in MS
• Different types of bladder dysfunction
• Visual aids: Pictures/Diagrams
• How to ask about bladder dysfunction
• General Management advice
• Referral advice
• Other _______________

6. This information should be targeted at:

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Not sure</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer</td>
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<tr>
<td>Continence Nurse</td>
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<td>GP</td>
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<td>MS Nurse</td>
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<tr>
<td>Neurologist</td>
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<tr>
<td>Occupational Therapist</td>
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<tr>
<td>Person with MS</td>
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<tr>
<td>Physiotherapist</td>
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<tr>
<td>Public Health Nurse</td>
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<td>Urologist</td>
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<tr>
<td>Other (if not listed above please state here) _________</td>
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</tbody>
</table>

7. I have access to the internet at work.

Please tick: Yes/no
8. Please use this box to state any other suggestions or comments you may have in relation to better facilitating management of bladder dysfunction among people with MS.

This survey is now complete by submitting this page your responses will be added to the database and may not be withdrawn.

Thank you for your time.

Please contact the postgraduate researcher on the email address provided below if you wish to be sent a summary of final results.

Catherine.M.Browne@ul.ie
Appendix 14 Strand 3 Person with MS Questionnaire

The aim of this questionnaire is to gather information regarding current practice and strategies used by healthcare professionals to support the management of bladder dysfunction among people with multiple sclerosis (MS). The findings of this study will identify what needs to be in place to facilitate successful self-management of bladder dysfunction for people with MS.

This questionnaire will take 15-20mins to complete. There are no right or wrong answers. Participation is voluntary. You may withdraw at any time.

The questionnaire focuses on awareness of bladder dysfunction, assessment and management of bladder dysfunction among healthcare professionals, roles and responsibilities, access to services, barriers to management and what you need to better support you in terms of your bladder symptoms.

Please tick the following statements:

- I confirm, I have MS and am over 18 years old _____
- I have experienced some bladder symptoms_____
- By completing this questionnaire, I acknowledge my information is submitted and will not be retrievable _______
Page 1:

1. **Age:** Please select an appropriate month and year:
   - Month you were born: Jan-Dec (Drop down menu)
   - Year you were born: 1940-2000 (Drop down menu)

2. **Gender:** Please tick:
   - Male
   - Female

3. **Please state the year you were diagnosed with multiple sclerosis (MS)**
   ____________________

4. **What type of MS do you have? Please tick**
   - Relapsing-remitting MS ___
   - Secondary-progressive MS ___
   - Primary-progressive MS ___
   - Progressive-relapsing MS ___
   - Unsure___

5. **In terms of your mobility, please carefully read the following statements and tick which statement best describes you:**
   - My walking is not affected
   - My walking is affected but I am still able to walk independently
   - I usually use unilateral support (e.g. single stick or crutch, one arm) to walk outdoors, but walk independently indoors
   - I usually use bilateral support (e.g. two sticks or crutches, frame or two arms) to walk outdoors OR unilateral support (e.g. single stick or crutch, one arm) to walk indoors
- I usually use a wheelchair to travel outdoors OR bilateral support (e.g. two stick or crutches, frame or two arms) to walk indoors
- I usually use a wheelchair indoors

6. What region of the HSE do you access services in relation to your MS:

Please tick:

- SOUTH
- WEST
- DUBLIN NORTH EAST
- DUBLIN MID-LEINSTER

**HSE South** – (County Carlow, County Cork, County Kerry, County Kilkenny, County Waterford, County Wexford and South Tipperary)

**HSE West** – (County Clare, County Donegal, County Galway, County Leitrim, County Limerick, County Mayo, County Roscommon, County Sligo and North Tipperary)

**HSE Dublin North East** – (County Cavan, County Louth, County Meath, County Monaghan and North Dublin)

**HSE Dublin Mid-Leinster** – (County Kildare, County Laois, County Longford, County Offaly, County Westmeath, County Wicklow and South Dublin)

7. I experience the following bladder symptoms. Please tick one or more

<table>
<thead>
<tr>
<th>Symptom</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urgency: sudden strong urge to urinate</td>
</tr>
<tr>
<td>Frequency: needing to urinate more often usual</td>
</tr>
<tr>
<td>Hesitancy: difficulty starting a urine stream even though bladder feels full</td>
</tr>
<tr>
<td>Interrupted stream: difficulty maintaining a urine stream</td>
</tr>
<tr>
<td>Urinary Incontinence: involuntary leaking of urine</td>
</tr>
<tr>
<td>Stress incontinence: involuntary leaking of urine when coughing/sneezing</td>
</tr>
<tr>
<td>Other: Please state _________________________</td>
</tr>
</tbody>
</table>

271
Page 2:

1. Please tick your response to each statement in the table below based on your bladder symptoms.

For me, bladder dysfunction significantly interferes with:

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Unsure</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of life</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Work</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Travel</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Socialising</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Relationships</td>
<td></td>
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</tr>
<tr>
<td>Sexual Functioning</td>
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<tr>
<td>Sleep</td>
<td></td>
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</tr>
</tbody>
</table>

If you have additional comments about how your bladder symptoms interfere with daily life, please explain here: ________________________________

2. I feel comfortable talking to my family about my bladder symptoms.

Strongly agree/agree/unsure/disagree/strongly disagree

Please explain why this is the case: ________________________________

3. I feel comfortable talking to healthcare professionals about my bladder symptoms.

Strongly agree/agree/unsure/disagree/strongly disagree

Please explain why this is the case: ________________________________

4. Self-management is an essential strategy in addressing my bladder symptoms

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Please tick: Strongly agree/agree/unsure/disagree/strongly disagree

If you strongly agree or agree, please explain your approach to self-management

5. Please comment on any strategies you have used to self-manage your bladder symptoms

______________________________________________

Page 3:

Please tick accordingly for each sentence below:

1. Healthcare professionals ask me about my bladder symptoms.

Never/rarely/sometimes/often/always

Please explain: _______________________

2. Please tick to agree with the following statements below for each bladder symptom

Urgency: sudden strong urge to urinate

Frequency: needing to urinate more often usual

Hesitancy: difficulty starting urine stream even though bladder feels full

Interrupted stream: difficulty maintaining a urine stream

Urinary Incontinence: involuntary leaking of urine

Stress incontinence: involuntary leaking of urine when coughing/sneezing
<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Not sure</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
</table>

**I have been asked about the following bladder symptoms:**

- Urgency
- Frequency
- Hesitancy
- Interrupted stream
- Urinary Incontinence
- Stress incontinence

**I have been given information on how to manage the following bladder symptoms**

- Urgency
- Frequency
- Hesitancy
- Interrupted stream
- Urinary Incontinence
- Stress incontinence
3. How often do you use the strategies below to self-manage your bladder symptoms: Please tick

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
<th>Non-applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-catheterisation</td>
<td></td>
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<tr>
<td>Medication</td>
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<tr>
<td>Pelvic floor exercises</td>
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<tr>
<td>Bladder retraining</td>
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<tr>
<td>Fluid control</td>
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<td></td>
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<tr>
<td>General bladder advice</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Self-monitoring techniques, please specify</td>
<td></td>
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<tr>
<td>Other (if not listed above please state here)</td>
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</tr>
</tbody>
</table>

4. I use one or more paper resources (e.g. bladder diary or advice booklets) to help manage my bladder symptoms.

Never/rarely/sometimes/often/always

If used, please explain this paper resource: ______________________

5. I use electronic/online resources (e.g. websites) to help manage my bladder symptoms.

Never/rarely/sometimes/often/always

If used, please explain this electronic/online resource: ______________________

6. I am satisfied with my level of knowledge on how to manage my bladder symptoms

Please tick: Strongly agree/agree/unsure/disagree/strongly disagree
7. I am confident with how to manage my bladder symptoms.

Please tick: Strongly agree/agree/unsure/disagree/strongly disagree

Page 4:

1. Have you reported your bladder symptoms to a healthcare professional?

Please tick: Yes/no

Please explain your response: ______________

*if no please skip to question 6

2. If so, who have you reported your symptoms to?

Please tick one or more:

- GP
- Neurologist
- Urologist
- Physiotherapist
- Occupational Therapist
- Public Health Nurse
- Continence Nurse
- MS Nurse
- unsure
- Other ______________

3. Were you referred to another healthcare professional?

Please tick: Yes/no/unsure
*If no/unsure please skip to question 6

4. **If yes, who were you referred to?**

Please tick one or more:

- GP
- Neurologist
- Urologist
- Physiotherapist
- Occupational Therapist
- Public Health Nurse
- Continence Nurse
- MS Nurse
- Other _____________________

5. **How long did you have to wait to get an appointment for this onward referral?**

Please tick:

- Unsure
- Less than 1 month
- 1-2 months
- 2-6months
- 6-12months
- >12months

6. **Are there specialist continence services available in your area?**

(Specialist continence services include urologists, continence nurses, Women’s Health physiotherapist or any other HCP specialised in the area)

Yes/no/unsure
If yes, please explain __________________

7. The person stated below is important in self-manage my bladder symptoms. Please tick for each of those listed below:

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Not sure</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer</td>
<td></td>
<td></td>
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<tr>
<td>Continence Nurse</td>
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<tr>
<td>GP</td>
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<td>MS Nurse</td>
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<tr>
<td>Myself</td>
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<tr>
<td>Neurologist</td>
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<td>Occupational Therapist</td>
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<tr>
<td>Physiotherapist</td>
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<td>Public Health Nurse</td>
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<tr>
<td>Urologist</td>
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<tr>
<td>Other (if not listed above please state here)</td>
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</tbody>
</table>

8. Bladder management is a specialist service.

Please tick: Strongly disagree/disagree/unsure/agree/strongly agree

If you agree or strongly agree, please comment on the resources or skills these specialist services have: ____________________
9. I am clear about my role in bladder management

Please tick: Strongly disagree/disagree/unsure/agree/strongly agree

Explain your role: ________________

10. Bladder dysfunction is managed well for people with MS in my area.

Please tick: Strongly disagree/disagree/unsure/agree/strongly agree

Additional Comments: ________________

Page 5:

1. Please tick as appropriate each statement below:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Not sure</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am reluctant to discuss my symptoms</td>
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<tr>
<td>I lack knowledge in the area of how to manage my bladder symptoms.</td>
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<tr>
<td>I feel healthcare professionals do not have time to discuss and address my bladder symptoms.</td>
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<tr>
<td>I am unsure what healthcare professional to approach about my bladder symptoms.</td>
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<tr>
<td>Specialist services have long waiting times</td>
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<tr>
<td>Bladder dysfunction is not a top priority for healthcare professionals.</td>
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</tbody>
</table>
Please provide information on any additional barriers you experience in terms of managing your bladder symptoms __________________

2. I am interested in education on how to self-manage my bladder symptoms

Please tick: Strongly agree/agree/unsure/disagree/strongly disagree

Please explain any particular reasons for your answer: __________________

If you strongly disagree or disagree, the survey is now complete. Thank you for taking part.

3. I would be interested in using the following education resources to learn about bladder management. Please tick for each resource below.

<table>
<thead>
<tr>
<th>Resource</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Not sure</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
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<tbody>
<tr>
<td>Online Podcast</td>
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<td>Online web resource (webpage/ website)</td>
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<td>Online Interactive Forum</td>
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<td>Online Blog</td>
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<td>Phone App</td>
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<td>Social Media with regular updates (Facebook page, Twitter feed)</td>
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<tr>
<td>Paper resource (Leaflet)</td>
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<tr>
<td>General education day</td>
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<tr>
<td>Other (if not listed above please state here)</td>
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</tbody>
</table>
4. **What information should be included in the resource?**

Please rank 1-4 in order of preference (1 being most, 4 being least preferred method or 1-5 if using the “other” option)

- Cause of bladder dysfunction in MS
- Information on the different types of bladder dysfunction
- Visual aids: Pictures/Diagrams
- General Management advice
- Other ___________

5. **This information should be targeted at:**

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Not sure</th>
<th>Agree</th>
<th>Strongly agree</th>
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<td>Carer</td>
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<td>Continence Nurse</td>
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<td>MS Nurse</td>
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<td>Neurologist</td>
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<td>Occupational Therapist</td>
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<tr>
<td>People with MS</td>
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<tr>
<td>Physiotherapist</td>
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<tr>
<td>Public Health Nurse</td>
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<tr>
<td>Urologist</td>
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<td>Other (if not listed above please state here)</td>
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</tbody>
</table>
6. I have access to the internet at home.

Please tick: Yes/no

7. Please use this box to state any other suggestions or comments you may have in relation to better facilitating management of bladder dysfunction among people with MS

____________________________________

This survey is now complete and by submitting this page your responses will be added to the database and may not be withdrawn.

Thank you for your time.

Please contact the postgraduate researcher on the email address provided below if you wish to be sent a summary of final results.

Catherine.M.Browne@ul.ie
Appendix 15 Strand 3 Participant information Leaflet

Current practice among healthcare professionals managing Bladder Dysfunction among People with Multiple Sclerosis

Introduction

This study will gather information regarding current practice and strategies used to support management of bladder dysfunction among people with multiple sclerosis (MS). The findings of this study will identify what needs to be put in place to facilitate successful self-management of bladder dysfunction.

Participants

People with MS and healthcare professionals are invited to take part in this study. Physiotherapists, occupational Therapists, physicians, MS nurses, continence nurses or any healthcare professionals who encounter people with MS during regular clinical practice may take part. Participants do not need extensive experience in MS care - all perspectives are valuable.

Procedure

If you agree to participate you will complete an online questionnaire, which will take 15-20mins. The questionnaire focuses on awareness of bladder dysfunction, assessment and management of bladder dysfunction among healthcare professionals, roles and responsibilities, access to services, barriers to management and what needs for facilitating successful bladder management. The questionnaire includes open ended questions where you may share and discuss additional ideas. There are no right or wrong answers to the questions.

Benefits and Risks

No direct benefits will be gained through participation in this study. However, your involvement will provide valuable information about the management of bladder dysfunction for people with MS and current strategies used to manage this symptom. This information will inform the development of a resource tool to better facilitate self-management of bladder dysfunction for people with MS. There are no anticipated risks to the participants. If you feel uncomfortable with a question, you can skip that question or withdraw from the study altogether. If you decide to quit at any time before you have finished the questionnaire, your answers will not be recorded.

Confidentiality and withdrawal
All data will be anonymous and there will be no way of linking your identity to your responses. IP addresses will be deleted immediately after you submit the questionnaire. There will be no identifiable information gathered. Only the research team will have access to the anonymised data. Your participation is voluntary; you are free to withdraw from this study at any time. If you do not want to continue, you can simply exit the webpage.

**Contact information**

If you have any questions regarding the study, please feel free to contact any of the research team:

**Catherine Browne email:** Catherine.M.Browne@ul.ie

**Dr. Maria Kehoe email:** Maria.Kehoe@hse.ie

**Dr. Nancy Salmon email:** Nancy.Salmon@ul.ie
Appendix 16 Strand 3 Recruitment Email

Dear (name),

By way of introduction, my name is Catherine Browne. I am a PhD Candidate in the Department of Clinical Therapies at the University of Limerick and a Chartered Physiotherapist. I am currently researching bladder dysfunction among people with Multiple Sclerosis (MS). The aim of my thesis is to develop a self-management resource tool to better facilitate the management of bladder dysfunction among people with MS.

As part of this thesis, we are conducting a study to gather valuable information regarding current practice and strategies used to support management of bladder dysfunction among people with multiple sclerosis (MS). The findings of this study will identify what needs to be put in place to facilitate successful self-management of bladder dysfunction. People with MS and healthcare professionals are invited to take part in this study.

This study involves an online questionnaire, which will take 15-20 mins to complete. The questionnaire will inquire about awareness of bladder dysfunction, confidence in assessment and management, roles and responsibilities, access to services, barriers to management and needs to better facilitate bladder management.

I have attached an information leaflet to provide some further information and the link to the survey is provided below. Please consider sharing this email with your colleagues and people with MS throughout your professional network so that the conclusions reached are reflective of current practice.

Do not hesitate to contact me or the HSE research ethics committee if you require any additional information.

Many thanks for taking the time to read this email and for considering our request,

Yours sincerely,

Catherine Browne (PhD Student University of Limerick)
Email: Catherine.M.Browne@ul.ie

Dr. Nancy Salmon (Primary Investigator and Project Supervisor)
Email: Nancy.Salmon@ul.ie Phone: 061-234275

Dr. Maria.Kehoe (Co-Investigator and Project Supervisor)
Email: Maria.Kehoe@hse.ie

HSE Mid-Western Regional Hospital Research Ethics Committee, Patient Safety & Quality Directorate, 3rd Floor Nurses Home, University Hospital Limerick, Dooradoyle, Limerick. E-Mail: joanne.oconnor@hse.ie Tel: 061 482519
Appendix 17 Strand 3 Social Media posts

Twitter post:

- “Are you a #healthcare professional #HCP #nurse #physio #physiotherapist #GP #doctor #OT #Occupationaltherapist working with people with #MS in Ireland? Please take part in our study on #bladder management” (link to questionnaire) @@tag professional bodies

- “Do you have #MS #multiplesclerosis and experience #bladder dysfunction in Ireland? Please take part in our study on #bladder management” (link to questionnaire)

Facebook post

- Are you a healthcare professional working with people with #MS in Ireland? Please take part in this study on bladder management and current service provision (link to questionnaire)

- Do you have #MS and experience #bladder dysfunction? Please take part in our study on #bladder management” in Ireland (link to questionnaire)
Appendix 18 Strand 3 Electronic Newsletter post

**Current practice among healthcare professionals managing Bladder Dysfunction among People with Multiple Sclerosis (MS): questionnaire study**

This study will gather information regarding current practice and strategies used to support management of bladder dysfunction among people with MS.

Physiotherapists, Occupational Therapists, General Practitioners, MS nurses, continence nurses or any healthcare professionals who encounter people with MS during regular clinical practice in any setting would be suitable to take part in this study. If you agree to participate you will complete an online questionnaire, which will take 15-20mins. All data will be anonymous. Your participation is voluntary; you are free to withdraw from this study at any time.

Please contact [Catherine.M.Browne@ul.ie](mailto:Catherine.M.Browne@ul.ie) for additional information. Alternatively, you may access the detailed information leaflet and questionnaire directly on the following link: _________
Appendix 19 Multi-disciplinary involvement in facilitating self-management of bladder dysfunction

<table>
<thead>
<tr>
<th>Role</th>
<th>Strongly Agree</th>
<th>Disagree</th>
<th>Unsure</th>
<th>Agree</th>
<th>Strongly agree</th>
<th>Fishers Exact Test</th>
<th>Cramer’s V</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer</td>
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</tr>
<tr>
<td>PwMS (n=58)</td>
<td>25 (43.1%)</td>
<td>4 (6.9%)</td>
<td>18 (31%)</td>
<td>8 (13.8%)</td>
<td>3 (5.2%)</td>
<td>p&lt;0.01</td>
<td>0.543</td>
</tr>
<tr>
<td>HCPs (n=58)</td>
<td>1 (1.7%)</td>
<td>6 (10.3%)</td>
<td>18 (31%)</td>
<td>19 (32.8%)</td>
<td>14 (24.1%)</td>
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<tr>
<td>Contiinece Nurse</td>
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</tr>
<tr>
<td>PwMS (n=59)</td>
<td>20 (33.9%)</td>
<td>7 (11.9%)</td>
<td>18 (30.5%)</td>
<td>12 (20.3%)</td>
<td>2 (3.4%)</td>
<td>p&lt;0.01</td>
<td>0.772</td>
</tr>
<tr>
<td>HCPs (n=59)</td>
<td>0 (0%)</td>
<td>1 (1.7%)</td>
<td>2 (3.4%)</td>
<td>19 (32.2%)</td>
<td>37 (62.7%)</td>
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<tr>
<td>GP</td>
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<tr>
<td>PwMS (n=67)</td>
<td>13 (19.4%)</td>
<td>8 (11.9%)</td>
<td>11 (16.4%)</td>
<td>26 (38.8%)</td>
<td>9 (13.4%)</td>
<td>0.042</td>
<td>0.277</td>
</tr>
<tr>
<td>HCPs (n=57)</td>
<td>2 (3.5%)</td>
<td>6 (4.8%)</td>
<td>17 (29.8%)</td>
<td>26 (45.6%)</td>
<td>6 (10.5%)</td>
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<tr>
<td>MS nurse</td>
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<tr>
<td>PwMS (n=63)</td>
<td>13 (20.6%)</td>
<td>7 (11.1)</td>
<td>11 (17.5%)</td>
<td>24 (49%)</td>
<td>8 (12.7%)</td>
<td>p&lt;0.01</td>
<td>0.577</td>
</tr>
<tr>
<td>HCPs (n=59)</td>
<td>0 (0%)</td>
<td>0 (0.0%)</td>
<td>2 (3.4%)</td>
<td>25 (42.4%)</td>
<td>32 (54.2%)</td>
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<td>Neurologist</td>
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</tr>
<tr>
<td>PwMS (n=63)</td>
<td>9 (14.3%)</td>
<td>4 (6.3%)</td>
<td>13 (20.6%)</td>
<td>22 (34.9%)</td>
<td>15 (23.8%)</td>
<td>0.078</td>
<td>0.258</td>
</tr>
<tr>
<td>HCPs (n=60)</td>
<td>1 (1.7%)</td>
<td>6 (10%)</td>
<td>19 (31.7%)</td>
<td>22 (36.7%)</td>
<td>12 (20%)</td>
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<tr>
<td>Occupational Therapist</td>
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<tr>
<td>PwMS (n=61)</td>
<td>16 (26.2%)</td>
<td>9 (14.8%)</td>
<td>22 (36.1%)</td>
<td>10 (16.4%)</td>
<td>4 (6.6%)</td>
<td>0.009</td>
<td>0.322</td>
</tr>
<tr>
<td>HCPs (n=59)</td>
<td>2 (3.4%)</td>
<td>11 (18.6%)</td>
<td>29 (49.2%)</td>
<td>13 (22%)</td>
<td>4 (6.8%)</td>
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<tr>
<td>Person with MS</td>
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</tr>
<tr>
<td>PwMS (n=62)</td>
<td>10 (16.1%)</td>
<td>4 (6.5%)</td>
<td>11 (17.7%)</td>
<td>20 (32.3%)</td>
<td>17 (27.4%)</td>
<td>0.006</td>
<td>0.344</td>
</tr>
<tr>
<td>HCPs (n=60)</td>
<td>1 (1.7%)</td>
<td>0 (0%)</td>
<td>9 (15%)</td>
<td>25 (41.7%)</td>
<td>25 (41.7%)</td>
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<tr>
<td>Physiotherapist</td>
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</tr>
<tr>
<td>PwMS (n=60)</td>
<td>17 (28.3%)</td>
<td>5 (8.3%)</td>
<td>20 (33.3%)</td>
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PwMS = People with MS, HCPs = Healthcare professionals
### Appendix 20 Educational resource tools needed to promote self-management of bladder dysfunction

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