

**An interpretative phenomenological analysis of  
spousal carers' experiences of caring for their partner  
with a long-term, indwelling urinary catheter**

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## Abstract

This thesis reports an idiographic study employing Interpretative Phenomenological Analysis (IPA) to explore the experiences of spousal carers when their partner has a long-term indwelling urinary catheter (LTIC).

A LTIC is used to manage bladder drainage for individuals with neurological damage or disease, or as a means of managing incontinence. Owing to its association with multiple recurrent problems such as infection, they are only considered when other interventions have been unsuccessful or are not deemed suitable. Experiences of a catheter from the perspective of spousal carers have been overlooked and the importance of their role is not specifically acknowledged in the literature. This thesis aims to redress this imbalance and influence future practice.

The study was conducted in two parts. In Part I, six spousal carers were interviewed about their experiences when their partner had a LTIC. To further explore carers' experiences and to consider the wider impact of the LTIC on their relationship, Part II of the study consisted of three dyad case studies. The three 'cases' included LTIC users who had Multiple Sclerosis (MS) and their spousal carers.

The findings revealed the LTIC as a *mixed blessing* that gave an initial improvement in carer's quality of life, previously dominated their partner's incontinence. They experienced a continuum of *adjusting, adapting* and *resigned acceptance over time*, with setbacks influenced by external factors such as LTIC problems and deterioration of both parties' health. The LTIC users increasingly needed their spouse's support with LTIC care over time and as part of these changes, relationships were renegotiated.

Adjusting was influenced by experiences before the LTIC and involvement with the catheter decision and were impeded by what carers perceived as poor communication from health care professionals (HCPs).

## Contents

<b>Chapter 1. Introduction to the thesis</b> .....	13
1.1 Introduction.....	14
1.2 Overview of the chapter .....	14
1.3 The research rationale .....	14
1.4 The study aims .....	16
1.5 Overview of the thesis .....	16
1.6 My voice in this study.....	17
1.7 My journey .....	18
<b>Chapter 2. Literature Review</b> .....	20
2.1 Overview of the chapter .....	21
2.2 Literature review Introduction.....	21
2.3 Terminology and explanation .....	23
2.3.1 <i>Long-term indwelling catheter - LTICs</i> .....	23
2.3.2 <i>Defining 'long' in terms of LTIC</i> .....	23
2.3.3 <i>Defining 'carer'</i> .....	23
2.3.4 <i>Intermittent Self Catheterisation (ISC) and clean intermittent catheterization (CIC)</i> .....	24
2.4 Background to LTICs .....	25
2.4.1 <i>Risks and complications associated with LTICs</i> .....	26
2.4.2 <i>Prevalence</i> .....	27
2.5 Community approach .....	29
2.5.1 <i>Management of LTICs in the community</i> .....	30
2.6 Characteristics of carers in the context of LTICs.....	31
2.7 The 'carer experience'.....	32
2.7.1 <i>Caring – a positives or a burden?</i> .....	33
2.8 The LTIC user and the spousal carer .....	34
2.9 The LTIC user.....	35
2.10 Adjustment and LTICs .....	37
2.11 Support and education .....	38
2.12 Experiences of the LTIC .....	41
2.12.1 <i>Stigma related to incontinence and LTICs</i> .....	41

2.12.2 Embodiment .....	42
2.13 Sex, intimacy and the impact of a LTIC .....	44
2.14 Literature exploring allied studies.....	45
2.14.1 Assistive technologies .....	46
2.15 Theoretical models and theories .....	49
2.15.1 Yoshida’s Pendular Reconstruction Model .....	49
2.15.2 Paterson’s Shifting Perspective Model.....	49
2.15.3 Rolland’s Chronic Illness and Life Cycle Model.....	50
2.15.4 Wilson’s Dynamic Continuum .....	50
2.16 Review of research rationale .....	51
<b>Chapter 3. Methodology .....</b>	<b>52</b>
3.1 Introduction .....	53
3.2 Overview of the chapter .....	53
3.3 My epistemological position .....	54
3.4 Study design .....	55
3.5 Interpretative Phenomenological Analysis (IPA) .....	57
3.6 Considering alternative approaches .....	57
3.6.1 Ethnography .....	58
3.6.2 Grounded Theory (GT) .....	59
3.7 Rationale behind the methodological choice of IPA .....	61
3.8 IPA theory and method .....	61
3.8.1 Examples of research using IPA .....	62
3.8.2 IPA and Phenomenology .....	63
3.8.3 IPA and hermeneutics .....	66
3.8.4 IPA and its ideographic commitment .....	67
3.9 Reflexivity and IPA .....	67
3.9.1 Reflecting on personal experience .....	68
3.10 Guide to Analysis/Stages of analysis/framework of IPA .....	69
3.10.1 IPA - Stages of Analysis .....	69
3.11 Questions of reliability and trustworthiness and IPA .....	70
3.12 IPA in practice .....	71

<b>Chapter 4. Part 1 - Spousal carers' experiences of a LTIC</b> .....	73
4.1 Overview of the chapter .....	74
4.2 Introduction .....	74
4.3 Objectives .....	75
4.4 Method .....	76
4.4.1 Ethical considerations .....	76
4.4.2 Health and safety .....	77
4.4.3 Identification and recruitment .....	77
4.4.4 Suitability of semi-structured interviews and considering alternatives.....	78
Considering structured and unstructured interview .....	78
The semi-structured interviews.....	79
4.4.5 Interviewing about a sensitive topic .....	80
4.4.6 Developing an interview guide.....	81
4.5 The participants.....	82
4.6 Analysis .....	84
4.6.1 Framework of analysis .....	85
4.7 Results Part I - The experiences of spousal carers .....	86
4.7.1 Introduction and overview of the results .....	86
4.7.2 Theme 1 - The phenomenology of the environment .....	88
Sub-ordinate themes - 1a Decision to downsize - 'the right thing to do' ...	89
1b Adaptions - but still difficulties.....	92
1c Relocating and loneliness.....	93
4.7.3 Theme 2 - The LTIC experience - as a 'mixed blessing' .....	94
Sub-ordinate themes - 2a Lead up to the LTIC and the LTIC decision.....	94
2b Positive about the LTIC.....	97
2c Managing LTIC problems.....	98
4.7.4 Theme 3 - The caring experience .....	103
Sub ordinate themes - 3a Making decisions for them both.....	104
3b Impact of their changing relationship.....	108
3c Competing needs.....	115
3d What will be will be.....	123
4.7.5 Theme 4 - Experience of support with a LTIC.....	124

Sub-ordinate themes – 4a Negative experiences.....	124
4b Positives experiences.....	127
4c Impact on the family members.....	128
4.8 Summary Part I .....	131
4.9 Justification informing for Part II .....	134
<b>Chapter 5. Part II Living together with a LTIC - Three dyad case studies..</b>	<b>137</b>
5.1 Overview of the chapter .....	137
5.2 Introduction .....	137
5.2.1 The challenges and limitations of managing interviews over a different time frame.....	139
5.3 Focus on MS .....	140
5.3.1 Multiple Sclerosis (MS) .....	141
5.3.2 Impact on carers .....	143
5.4 Review of objectives following Part I.....	144
5.5 Method .....	144
5.5.1 Case study research .....	144
5.5.2 Recruitment criteria .....	145
5.5.3 Data collection .....	146
5.6 Analysis.....	146
5.6.1 Re-analysis of LTIC user interviews and analysis of the LTIC carer.....	146
5.6.2 Creating the dyad studies .....	147
5.7 Dyad case study 1 - Hilary and Mike .....	148
5.7.1 Theme 1 - Before the LTIC and making the decision .....	149
5.7.2 Theme 2 - Adjusting .....	153
5.7.3 Theme 3 - Support .....	155
5.7.4 Theme 4 - Impact on their relationship .....	160
5.8 Dyad case study 2 - Mavis and Peter .....	162
5.8.1 Theme 1 - The LTIC decision .....	165
5.8.2 Theme 2 - Adjustment and ‘trade-off’ .....	169
5.8.3 Theme 3 - Impact on their relationship .....	172
5.8.4 Theme 4 - The future .....	179
5.9 Dyad case study 3 - Brian and Margaret .....	180

5.9.1 Theme 1 - 'It's a godsend - and it has its problems'	182
5.9.2 Theme 2 - Brian taking control and Margaret's dilemma	187
5.9.3 Theme 3 - Adjusting to the LTIC	192
5.9.4 Theme 4 - 'So I tell him - 'do not die''	197
5.10 Summary	199
5.10.2 The limitations of the research design	202
5.11 The LTIC users' experiences	202
5.11.1 The long-term condition and the LTIC	202
5.11.2 Embarrassment and stigma	203
5.11.3 Becoming more dependent on their spouse	205
5.11.4 Unpredictability	206
<b>Chapter 6. Discussion</b>	<b>207</b>
6.1 Overview of the chapter	208
6.2 Study aims	208
6.3 Overview of the findings	208
6.4 The long-term condition and the LTIC	210
6.5 Drawing together key findings of the thesis and considering aims	211
6.6 The shared experiences of carers and the LTIC users	214
6.7 Identifying core themes underpinning their experiences	215
6.8 Adapting, adjusting, acceptance and resigned acceptance	216
6.8.1 Models and frameworks related to adjustment	218
6.8.1.1 Paterson's Shifting Perspective Model of Chronic Illness	219
6.8.1.2 Rolland's Chronic Illness and the Life Cycle	220
6.8.2 Pivotal moment	222
6.8.3 Influences on adjustment	223
6.8.3.1 The impact of the environment	223
6.8.3.2 Pre-catheter experience	224
6.8.3.3 Expectations of the LTIC	225
6.8.3.4 Adjusting over time	226
6.8.3.4 Complexity of their caring role	226
6.9 Support	227
6.9.1 Communication	228

6.9.2 Support from HCPs.....	229
6.9.3 Family support.....	231
6.9.4 Coping strategies.....	231
6.9.4.1 ‘Trade-off’ .....	232
6.9.4.2 Time out/respite.....	234
6.9.5 The carer’s health .....	235
6.10 Relationship change and dependency.....	236
6.10.1 Positive experiences of caring.....	237
6.10.2 Feeling alone.....	238
6.10.3 Conflict within their relationship .....	239
6.10.4 End of their physical relationship.....	239
6.11 Loss .....	240
6.11.1 Personal loss.....	240
6.11.2 Time short and their competing needs.....	241
6.11.3 Loss and uncertainty about the future.....	242
6.12 Summary .....	244
<b>Chapter 7. Limitation and Implications for Practice .....</b>	<b>246</b>
7.1 Overview of the chapter .....	247
7.2 Introduction to the chapter .....	247
7.3 Contribution to knowledge.....	247
7.4 The implications of theories and models of adjusting.....	250
7.5 Considerations for improving practice.....	251
7.6 Limitations of the study .....	256
7.7 Reflecting on the methodology .....	257
7.8 Reflecting on the method.....	260
7.9 Reflecting on Part II, considering the use of case study.....	262
7.10 Carers knowledge and experiences being acknowledged .....	262
7.11 Future direction for research .....	263
7.12 Reflecting on my PhD journey .....	263
7.13 Conclusion .....	264
References .....	266
Appendices .....	295



## Figures and Tables

Figure 1 Phases of the PhD study .....	14
Figure 2 Stages of IPA .....	70
Figure 3 Phases of PhD study – Carer interviews .....	76
Figure 4 Phases of PhD study - Dyad Case studies .....	138
Figure 5 Dyad interviews – time-line.....	139
Figure 6 Pen portrait Part II – Hilary and Mike .....	148
Figure 7 Pen portrait Part II – Mavis and Peter .....	162
Figure 8 Pen portrait Part II – Brian and Margaret .....	180
Figure 9 Identifying core themes underpinning experiences.....	216
Figure 10 Influences on time .....	241
Table 1 Participant demographics Part I .....	83
Table 2 Carer themes - Part I .....	87
Table 3 Dyad demographics Part II .....	145
Table 4 Table of themes – Part II Hilary and Mike .....	149
Table 5 Table of themes – Part II Mavis and Peter .....	163
Table 6 Table of themes – Part II Brian and Margaret .....	182

## Appendices

Appendix 1 Literature search strategy .....	296
Appendix 2 Detailed stages of IPA analysis .....	297
Appendix 3 Ethical approval documents including approval letter.....	299
Appendix 4 Participant and Healthcare Professional Information Sheet .....	305
Appendix 5 Pen portraits of six carers in Part I .....	311
Appendix 6 Interview prompts .....	317
Appendix 7 Example of entry in reflective diary .....	318
Appendix 8 Example of IPA analysis.....	319
Appendix 9 Example of IPA exploratory comments.....	320
Appendix 10 Part I Super-ordinate/sub-ordinate themes and objectives.....	322
Appendix 11 Part II Super-ordinate/sub-ordinate themes and objectives.....	323
Appendix 12 Article: Fowler <i>et al</i> (2014) Living with a long-term indwelling urinary catheter: Catheter users' experience.....	325

## **Abbreviations**

CAUTI	Catheter Associated Urinary Tract Infection
CIC	Clean Intermittent Catheterisation
DoH	Department of Health
DN	District Nurse
GP	General Practitioner
HCP	Health Care Professional
IPA	Interpretative Phenomenological Analysis
ISC	Intermittent Self Catheterisation
LTC	Long-term condition
LTIC	Long-term, indwelling catheter
LUTS	Lower Urinary Tract Symptoms
MRSA	Methicillin-resistant Staphylococcus Aureus
MS	Multiple Sclerosis
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
PD	Parkinson's disease
RCP	Royal College of Physicians
SCI	Spinal Cord Injury
UK.	United Kingdom
UTI	Urinary Tract Infection
QoL	Quality of Life

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## **Chapter 1**

### **Introduction to the thesis**

# Chapter 1

## Introduction to the thesis

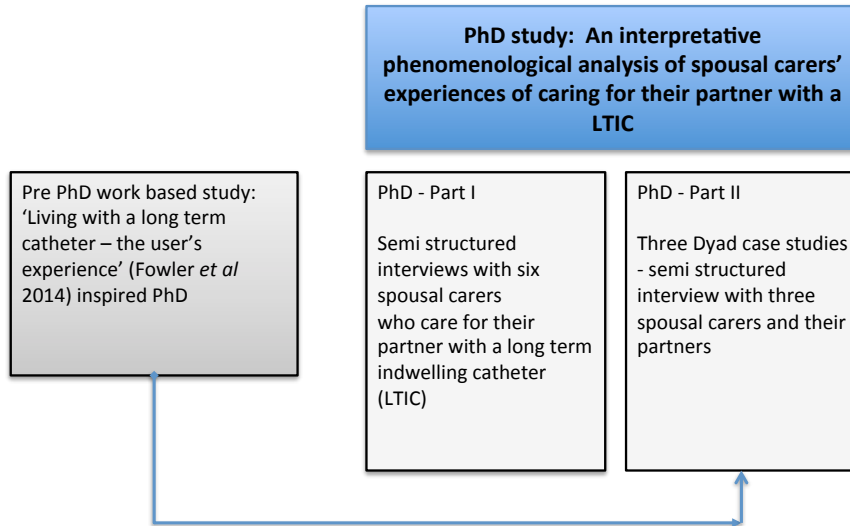
### 1.1 Introduction

The aim of exploring informal carers' personal accounts is to provide a multidimensional understanding of their experiences and to highlight their priorities for support in order to influence practice. The long-term indwelling urinary catheter (LTIC) is a medical device, provided as a means of controlling a very basic need – to enable the bladder to empty and to control continence. However, the LTIC presents challenges to the individual and those who support them.

Prior to this PhD, I had been engaged in a research study through work (Fowler *et al*, 2014); a qualitative study exploring catheter users' experiences. At that time, I met several informal carers when visiting their home to interview their partner with the catheter. The LTIC user's reliance on the support, particularly of their spouse, was apparent (Fowler, *et al*, 2014). This confirmed my anecdotal experience as a District Nurse (DN) and latterly as a community-based Continence Specialist Nurse. Little is known about the experiences of informal carers and LTICs, and it was the absence of their voice in the literature that inspired this PhD.

This thesis is in two parts. The first part focused on the experiences of spousal carers with data collected through semi-structured interviews. The second part included three dyad case studies, again using semi-structured interviews. The three additional carer interviews were with spouses of LTIC users who had taken part in the user experience study (Fowler *et al*, 2014), previously carried out by the researcher pre-PhD and included re-analysis of the original LTIC user interview. All interviews were subjected to Interpretive Phenomenological Analysis (IPA). Figure 1 outlines the phases of the study and the influence of the Fowler *et al* (2014) pre-PhD study.

Figure 1 Phases of the PhD



## 1.2 Overview of the chapter

This introductory chapter outlines the rationale for this study and the approach taken, informed by the aims and objectives. There is a brief overview of the contents of each chapter and a discussion of my epistemological and ontological perspective as the researcher on this PhD journey.

## 1.3 The research rationale

LTICS are frequently cited as the option of 'last resort' (Getliffe & Newton, 2006) owing to high probability of associated infection and complications. However, for some individuals there are currently limited treatment options when the bladder's mechanism to empty fails, resulting in urinary retention or incomplete bladder emptying. Despite the introduction of Intermittent Self Catheterisation (ISC), owing to physical limitations or personal choice, it is not a suitable

alternative for everyone (Wilde *et al*, 2015a; Sweeney, Harrington & Button, 2007) even though there are identified benefits over a long-term, indwelling catheter. In this case, their only remaining option is an indwelling device.

The work-based research study that inspired this PhD, focused on the catheter users' experiences with an initial qualitative phase and included twenty-seven, semi-structured interviews with catheter users (Fowler *et al*, 2014). This was subsequently used to inform the development of a quality of life (QoL) questionnaire specific to LTIC users (Cotterill *et al*, 2016). One of the study findings highlighted the significance and value the LTIC users placed on the practical and psychological support from their spouse.

The focus of healthcare policy promotes living with life-long conditions and co-morbidities in the community (DoH, 2004; 2005). During the time of writing this thesis, further re-structuring of community-based healthcare has resulted in a reduction in many local support services. Families, who have often filled the gap (Dingwall & McLafferty, 2006) are increasingly having to do more. Keeping up with demand continues to present a dilemma for providers and this is set to continue (Gerrish, 2015). In the context of an aging society, with life expectancy increasing at a rate not experienced before (United Nations, 2015) and more people living with long-term conditions (LTCs), the expectation is that there will be a greater need for support in the community - from someone.

The increasing use of technological interventions within healthcare can raise expectations from the public that with there will be a solution to their problems. Little has changed in the design of the catheter since first developed in 1937, despite technological advances in other areas of healthcare that often appear as more 'exciting'. LTICs remain a flawed solution because they are rarely without problems but for some individuals it is their only option (Chapel *et al*, 2016).

A review of literature highlighted the paucity of research from the perspective of informal carers when their partner has a LTIC. This, combined with the novel nature of the study related to a medical device, suggested the methodological

approach of IPA would enable a detailed examination of carers' experiences and having reviewed other qualitative approaches, IPA resonated with the epistemological position of the research aims (Smith, Flowers & Larkin, 2009).

#### **1.4 The study aims -**

- To explore carers' experiences of caring for a husband or wife, with a long-term, indwelling urinary catheter (LTIC) to inform healthcare professionals (HCPs) and improve practice
- To examine the issues carers face when caring for their partner's LTIC and how this affects their relationship.

#### **1.5 Overview of the thesis**

The thesis is presented in the following seven chapters, each chapter introducing the various components outlined below:

- **Chapter one** – introduction
- **Chapter two** – considers the study in context and presents a critical review of the literature. Owing to the limited literature about informal carers in relation to LTICs, associated literature about carers' experiences of managing stomas and medical devices at home is included. Also considered is literature about coping and devices in the context of existing models and theories that came to light during the literature review.
- **Chapter three** – presents an overview of the methodological approach, IPA, and comparisons with alternative approaches that were considered.
- **Chapter four** – details the methodological process, findings and analysis of semi-structured interviews with six spousal carers (Part I).



- **Chapter five** – presents the methodological process, findings and analysis of three dyad case studies including three LTIC user experiences (Part II). These were with the aim of exploring in more detail the carers' experiences of a LTIC on their relationship. The case studies consisted of interviews with an additional three spousal caregivers and re-analysis of interviews held with their partner who uses the LTIC (Fowler *et al*, 2014). All three LTIC users had MS.
  
- **Chapter six** – discusses and compares the findings from the whole data set (Part I and Part II) and considers if and how the thesis aims have been achieved. It identifies key and novel understandings of carers' experiences when their spouse has a LTIC and how they manage their lives.
  
- **Chapter seven** – reflects on the process and outcome, considering the strengths and limitations of this study. It concludes by considering the contribution the study makes to existing knowledge and suggests changes to improve future practice.

## 1.6 My voice in this study

I began this research project influenced by my experience of LTICs from the perspective of a DN and latterly a Continence Nurse. LTICs were frequently problematic and difficult to manage for all parties; blighted with complications such as blockage, leakage and infection. Another influence was my experience working as a research nurse on the qualitative study (Fowler *et al*, 2014) which was my first experience of research on this scale, on a study exploring LTIC users' experiences.

I was aware that in my 'nurse' role, I was always the bystander, whether as Continence Nurse or a Research Nurse, and this influenced how I chose to write this thesis. I desired the 'insider perspective' (Conrad, 1987) but as a nurse I

acknowledge I can never do this. I was aware of how my own nursing experience might influence this study and the importance of identifying any bias and attending to this during the research.

Within IPA the emphasis is on the 'sense-making' (Smith & Osborn, 2008) of both the carer and myself. The double hermeneutic aspect of the methodology means carers are trying to make sense of their world in the context of their partner and the LTIC - and in turn, I am involved in interpretation of this.

Deciding on the style of the thesis, I chose to write in both the first and third person. There were parts of the thesis written in the third person, for instance when reviewing and describing the literature. Acknowledging my outsider perspective, I chose to write predominantly in the third person when presenting the analysis of the data. The inclusion of participant quotes in the first person placed the carer's 'voice' centrally in this thesis; their experiences not previously recorded, were made more poignant by the use of 'I' and in keeping with the methodological approach.

## **1.7 My journey**

As a DN and a Continence Nurse I have always been aware of the 'taboo' and stigmatizing nature of continence and by association this includes LTICs. It is a very private topic and unlikely to be discussed outside the immediate family if at all. Over the years, I have empathized with the LTIC users and their partners as we battled with the challenges that the device imposed; spending many hours in clients' homes, attending to leaking or blocked catheters. I got to know many of the families very well. If the LTIC user's health deteriorated or affected their physical ability to manage the LTIC independently, the most common scenario was that their spouse stepped in and helped support them. They were omnipresent, helping their partner and we acknowledged this as DNs.

A personal experience of a secondment to work on a research study exploring catheter users' experiences (Fowler *et al*, 2014), presented a great opportunity

to do something proactive that might improve LTIC management. What I didn't anticipate was that it would inspire me to undertake a PhD with the realization that carers did not have a voice. It was an opportunity to record carers' experiences when their spouse has a LTIC, to inform health care professionals (HCPs), present ways to improve practice and support for the spousal carers managing at home.

**Chapter 2**  
**Literature Review**

## **Chapter 2**

### **Literature review**

#### **2.1 Overview of the chapter**

This chapter explores the literature and will draw on past research to justify the focus of the enquiry and approach with the aim of making recommendations to improve practice. Included in this chapter is an overview of LTICs, their prevalence, an explanation of their use and associated risks to health. In the absence of specific research related to spousal caregivers' experiences of LTICs, the associated literature in relation to LTICs is considered, reviewing the methodological approaches and issues that have been identified.

This literature review draws on the small number of robust studies (Polit & Beck, 2014) that explore the experiences of users living with a LTIC, considering their strengths and weaknesses and their contribution to this research. Consideration is given to the influence of embodiment, stigma and adjustment in relation to LTICs and the impact of the device on sex, physical intimacy and relationships. The current debate regarding the approach to managing LTICs in the community was reviewed in relation to caregivers and the guidance that underpins and informs the approach.

Consideration is also given to literature associated with other medical devices/technologies and carers' experiences. This included similar medical interventions such as a colostomy or ileostomy and the spousal caregiver's perspective, supporting their partner.

#### **2.2 Literature review - Introduction**

Smith, Flowers & Larkin (2009) suggest that the approach to reviewing literature is to 'widen' one's knowledge in order to convey an overview of the subject under study rather than to be overly detailed and lengthy. The focus should be on the findings, analysis and discussion of the data. Inherent to IPA is a commitment to maintain open mindedness (Smith & Osborn, 2008) and to

'suspend' or 'bracket off' any pre-conceptions in order to focus on listening with all one's attention to what the person is saying. A review of IPA, the process and literature pertaining to the methodology is detailed in Chapter 3.

A preliminary literature review demonstrated the paucity of literature specific on LTICs and carers' experiences, and reaffirmed justification for the study enquiry.

The review of literature was a continual process throughout the study following the initial review as themes and theories emerged. During the interview stage as data was collected and as themes were identified, there were further searches of the literature. As the study progressed, a comprehensive search strategy was established and the process is outlined in Appendix 1. The search was repeated at various junctures - during the analysis in Part I and again in Part II. The search was repeated again in April, 2017 and on this occasion, the assistance of a senior librarian at the hospital library was enlisted to act as an impartial 'expert', to critique my approach. The results mirrored the previous findings.

A large proportion of the literature relating to LTICs is in clinical journals documenting the medical profession's view of catheterisation (Pratt *et al*, 2007; Chapple *et al*, 2016). Papers regularly focus on technical aspects, investigating ways to reduce risk of complications that can be life threatening and improve catheter efficiency (Getliffe & Newton 2006; RCN, 2012). A problematic catheter is not only an inconvenience and costly to the user and family caregivers, but costly to the health provider (Godfrey & Evans, 2000) in terms of health professionals' time spent managing interventions.

To provide a sense of how the study developed, literature pertinent to Part II (dyad case studies) will precede Chapter 5.

## **2.3 Terminology and explanation**

### **2.3.1 Long-term indwelling catheters – LTICs**

The abbreviation 'LTIC' is chosen when referring to a Long-term Indwelling Urinary Catheter, as opposed to 'LTC', to avoid confusion and distinguish it from 'Long Term Condition', which commonly shares the same acronym. LTC is used to denote Long-Term Condition in this thesis, however, on occasions I chose not to abbreviate when the text references the catheter and their condition in close proximity.

### **2.3.2 Defining 'long' in terms of long-term indwelling urinary catheter (LTIC)**

'Long-term' implies that the catheter is an intervention for long-term management, more than three months duration (RCN, 2012; Wilde, 2002a).

### **2.3.3 Defining 'carer'**

A carer is defined as a family member who regularly looks after another and the implication is that this is in circumstances of illness or disability. However, there are various definitions of the terminology adopted in the literature, with a plethora of options used (Hagerty Lingler *et al*, 2008).

A critique of terms relating to 'carer' suggests that its use in the literature can imply one party is a recipient - particularly the term 'caregiver', which could imply a one-way action, suggestive of burden. This can be detrimental and rather the focus should be on their caring 'relationship' (Molyneaux *et al*, 2011).

The decision to predominantly use the term 'carer', followed an initial search of relevant articles to this study. The term 'carer' can imply both paid and informal caregiving in relation to LTICs, suggesting the need to be specific about the status of the carer. For the purpose of this study, spousal carer is used, abbreviated to 'carer'. It was a commonly used term to identify an informal or family carer

which is pertinent to this study. Acknowledging that 'caregiver' is also a term used to denote the same informal carer (Wilde, 2013b), I have used the term interchangeably on occasions to acknowledge its presence in the literature.

#### **2.3.4 Intermittent Self Catheterisation (ISC) and clean intermittent catheterisation (CIC)**

Although this study focuses on LTICs, catheter users often have experience of first using Intermittent Self Catheterisation (ISC) (Tenke, Jackel & Nagy, 2004) also referred as 'IC' - Intermittent Catheterisation (Robinson, 2009), particularly in the United States based literature (Newman & Wilson, 2011). ISC is considered the preferable option to a urethral or supra pubic LTIC if circumstances permit (RCN, 2012; NICE 2010; Niel-Weise *et al*, 2012; Getliffe *et al*, 2007) as it results in reduced rates of infection compared with an indwelling catheter (Patel *et al* 2001; Woodward & Rew, 2003). ISC is considered the 'Gold Standard' for urine drainage (NICE, 2006; Wyndaele *et al*, 2012). In comparison with an indwelling device, an intermittent catheter is, by definition, not permanently *insitu* but removed and disposed of after the bladder is drained of urine. It has less of a negative impact on their body image (Pellatt, 2007) as the user is free from a permanent catheter tube in their bladder or an external drainage bag. ISC offers greater freedom to have sexual intercourse (Parker, 2008), which has been reported as painful and uncomfortable with an indwelling catheter (Chapple, Prinjha & Salisbury, 2014) particularly a urethral catheter. Positives of ISC for the user are increased self-esteem (Parker, 2008) and independence from HCPs and catheter changes (NICE, 2006); an added benefit for both parties. In Shaw *et al's* (2008) QoL report, the negatives identified related to psychological aspects of stigma and anxiety.

From a clinical perspective, ISC can effectively drain the bladder (Shaw *et al*, 2008) however, not adhering to the recommended technique or frequency of use increases the risk of urinary tract infection (UTI) (Woodbury, Hayes & Askes, 2008). ISC uses a specifically designed catheter without a retaining balloon, which is inserted intermittently into the bladder to drain urine and is then



removed. Single use disposable sterile catheters are most commonly used in the United Kingdom (UK), although there are reusable designs available, referred to as 'cleaned catheters' (Wilde *et al*, 2010b). The ability to perform ISC is dependent on the willingness of the individual to use it and their physical ability to perform what is a technical procedure requiring fine motor skills (Wilde & Getliffe 2006; Gammack, 2003). If patients are unable to achieve this because of cognitive decline and/or disability (Cottenden *et al*, 2009), limited hand dexterity (Wilde & Getliffe, 2006) or personal choice (Fowler *et al*, 2014), the option is to train someone else to assist. This can be a family member such as a spouse, who is willing to undertake the procedure. There are devices developed to assist individuals with limited manual dexterity such as a catheter holder (Newman & Wilson, 2011). If ISC is not suitable, the only remaining option is often an indwelling catheter (Robinson, 2007; Pilloni *et al*, 2005).

## **2.4 Background to LTICs**

A urinary catheter enables bladder emptying when damage through injury such as spinal cord injury (SCI), or a progressive neurodegenerative disease such as Multiple Sclerosis (MS), interferes with this process (Pratt, Pellow & Wilson, 2007; Wilde & Dougherty, 2006; Wilde *et al*, 2010a). Reasons for their use also includes urinary retention associated with an enlarged prostate if surgery is deemed inappropriate. LTICs can also be used to alleviate symptoms of intractable incontinence, though not recommended clinically (RCN, 2012) but this is often associated with patient comfort, choice and palliative care (Wilde & Getliffe, 2006). The use of LTICs is more prevalent in older people (Gage *et al*, 2016) however, when used in the younger population this is often as a result of neurological damage such as spinal cord injury (SCI) or disease such as MS.

There are two possible routes of entry for a LTIC; via the urethra or the supra pubic route. The latter requires a minor surgical procedure to form an opening through the abdominal wall, approximately 2 cm above the pubic symphysis into the bladder (Sweeney, Harrington & Button, 2007). The catheter is inserted into this tract to drain urine (Getliffe & Dolman, 1997).

#### 2.4.1 Risks and complications associated with LTICs

LTICs are associated with a high risk of infection (Tew, Pomfret & King, 2005; Stickler & Feneley, 2010; Leuck *et al*, 2012). This occurs because the catheter in the bladder provides easy access for bacteria to enter via the inside and outside of the catheter. The presence of the catheter with a retaining balloon means that the bladder always contains a small amount of urine as it cannot fully drain and this acts as an ideal breeding ground for bacteria. The catheter *insitu* means the body's natural defense mechanism of urine flushing out the bladder as it empties is compromised. Trauma to the delicate bladder mucosa from the catheter also increases the risk of infection (Feneley, Kunin & Stickler, 2011).

LTICs can be challenging to manage and are rarely without problems (Wilde *et al*, 2015a). These include blockage and by-passing, causing leakage (Wilde *et al*, 2010a; RCN, 2012; Wilde *et al*, 2013b; Lawrence & Turner, 2006; Mathur *et al*, 2006) and require frequent monitoring and daily attention (Wilde *et al*, 2013b; Fowler *et al*, 2014). Indeed, some LTICs prone to frequent blockage are often referred to in the literature and described by HCPS as 'blockers' (Getliffe, 2003).

Guidance on the use of LTICs indicates that they should be avoided if possible (DoH, 2000; Godfrey, 2008a), viewed as a 'final alternative' (Sweeney, Harrington & Button, 2007) or 'last resort' (Getliffe & Newton, 2006; DoH, 2000; RCN, 2012) by the medical profession, due to the high incidence of Catheter Associated Urinary Tract infections (CAUTIs). Department of Health (DoH) guidance advocates that nurses 'always challenge the need for catheterisation and catheter usage' (DoH, 2007b). An indwelling catheter also increases the risk of life threatening bacteraemia and bladder cancer (Kunin, 2006; Pratt *et al*, 2007; Tenke *et al*, 2008; Feneley *et al*, 2011). It is recognized that the longer the catheter remains *insitu*; there is a daily rise in the risk of CAUTI by 3% - 10% per day (Jahn *et al*, 2007). Wilde's (2010a) longitudinal study over eight months with forty-three LTIC users, reported that during this period 70% had CAUTIs, 74% had blockages with 33% experiencing 'expulsion or dislodgement' of their

catheter. The failures of the LTIC added to individual's anxiety, caused stigma and embarrassment as well as frustrations for the user (Wilde & Cameron, 2003; Wilde, 2003).

If a LTIC is to be used, good practice guidance recommends this is only after a thorough assessment has been undertaken and all other methods of managing bladder drainage/incontinence have been examined and discounted as not suitable (RCN, 2012; Godfrey, 2008a). Despite all the identified problems, previous studies (Wilde & Cameron, 2003; Wilde 2002a; Fowler *et al*, 2014) acknowledge that catheter users consider LTICs can improve their quality of life and their independence in the short term.

#### 2.4.2 Prevalence

A high number of LTIC users are cared for in the community (Parkin & Keeley, 2003). This has the potential to increase as people are living longer, and with long-term conditions, which often increases the need for an indwelling catheter, typically as their condition worsens. Gage *et al* (2016) confirmed that age increases prevalence (0.732% in those over seventy years and 1.22% when aged over eighty years) and identified that male use increased with age. This suggests that the current prevalence rate is over 90,000 adults who use a LTIC. Of those using a LTIC, the reason for the device was cited as neurological (62.9%) as opposed to non-neurological (37.1%) and this group are more likely to be women (71.8% women as opposed to 56.2% men). Although the data presented by Gage *et al* (2016) offers a comprehensive overview of the characteristics of LTIC users that was previously lacking and is the largest cohort to date comprising of 583 LTIC users, the original data was obtained in 2008. This assessment of community prevalence of LTICs in England was one element of the Cotterill *et al*, (2016) ICIQ study of which the Fowler *et al* (2014) study formed the initial qualitative aspect.

The previous figure quoted for LTIC use nationally in the community was 3% of patients (McNulty *et al*, 2005; Royal College of Physicians (RCP), 2005) including those in nursing homes, where LTICs are most commonly used (Jahn *et al*, 2007);

this accounts for 450,000 people in the UK (Prinjha & Chapple, 2013). The suggestion is that LTICs are overused (Wagg *et al*, 2005) as a treatment for incontinence - or used for convenience (Inelmen, Sergi & Enzi, 2007) particularly with the elderly. There appears a variance between nursing homes with usage of 5% -17 %, suggesting that staff preference for the device might be an influencing factor (Dingwall & Malafferty, 2006; Gammack 2003). In European countries, evidence for usage varies from 0 - 23%, with higher prevalence in central and southern Europe (Sorbye *et al*, 2005) which may be a reflection on the differences in cultural approach and practice (Godfrey, 2008b).

To find a more definitive answer regarding current prevalence in the immediate vicinity to this study, two local audits were considered. In Bristol the last audit available (2007), Bristol Community Health (formally Bristol Primary Care Trust (PCT), pre 2013), recorded 428 LTIC users and described 'care overseen by GPs', in a population of 400,000. This would imply that DNs lead the day-to-day care. The second internal audit of community dwelling catheter users where I am employed as a community based Continence Specialist Nurse in Bath (February, 2013, Catheter Task Force Minutes, internal document), recorded 177 indwelling catheter users in a population of 176,005. These figures suggest that 0.1% of the population in these areas using a LTIC, with little change from 2007 to 2012. One could speculate that these statistics might imply a greater awareness of good practice guidelines (RCN, 2012) to encourage early removal of LTICs due to risks to patient health. In addition, there is the influence of initiatives such as the Catheter Passport (Codd, 2014), adopted by an increasing number of health providers, including Bath ([www.ruh.nhs.uk](http://www.ruh.nhs.uk) patient leaflet *My catheter passport*). These 'passports' are given to patients when the LTIC is first inserted as ongoing record of their catheter history and are kept by the patient. They aim to improve LTIC management as a record of the patient's catheter history for their own reference and to share with HCPs. The intended aim is to prevent unnecessary continued use of a LTIC, thus reducing the risk of complications (DoH, 2007b). The version in Bath, contains practical guidance and advice such as managing the LTIC away from home and answers questions such as 'Can I have sex with a catheter?'

## 2.5 Community approach

In recent years, chronic and long-term conditions have been a major focus of UK health policy - 'Our Health, Our Care, Our Say: A new direction for community services' (DoH, 2006). The aim was to enable people to remain living at home with complex health conditions whilst being supported within community care. A House of Commons Select Committee Report 'Ready for Aging' (March, 2013) concluded that society is 'woefully underprepared' in relation to provision of care services and an aging population both practically and financially. The emphasis of the report was social care, realistic funding for healthcare acknowledging a rapidly aging society, however the report reaffirmed the approach that people should be encouraged to live independently in their own homes, managing their long-term conditions. A report by the Care Quality Commission (CQC, 2011/12) identified that services struggle to cope with the pressures put on them. The State of Care report (2011/12) found that the increasing complexity of conditions and greater co-morbidities experienced by people was impacting on the ability of care providers to deliver person-centered care to meet individual's needs. A brief carer enquiry was included in The Royal College of Physicians (RCP) 'National Audit of Continence Care for Older People' (RCP, 2005) and subsequent re-audit a year later. This was primarily an audit of the service for HCPs and service providers. The outcome of the audit showed 'little progress' in the pursuit of truly integrated continence services as envisaged in 'Good Practice in Continence Services' (DoH, 2000).

Practical guidance in the document Excellence in Continence Care (NHS, 2015) to support commissioners and providers, health and social care staff and to provide information to the public suggests that - 'people have the right to be heard...and live the best achievable quality of life possible' (pp.8). There is specific mention of carers and families as well as the patient being treated with respect, their involvement and being '...listened to and heard' (pp.13). This guidance highlights the psychosocial effect of incontinence and impact on relationships, body image and their 'sex and romantic lives' (pp.9). There is mention of specific groups identified 'at risk' and includes those with neurological conditions such as

MS, Parkinson's disease (PD) and stroke suggesting particular support is required. All this is pertinent to this study and it reports that adjustment to incontinence 'took time' (pp.16). Many of the continence related issues could equally be made about catheters – the loss of dignity, loss of control and associated stigma.

A report Privacy and Dignity in Continence Care Project (RCP, 2009), made specific reference to carers - and caring for someone with incontinence. Although the project emphasis was to consider dignity as it related to incontinence, it has resonance with this study, although the project did not mention urinary catheters.

### 2.5.1 Management of LTICs in the community

A survey published by The Princess Royal Trust for Carers (2008) estimated that 6,000 people take on informal caring responsibilities every day and this burden of care increasingly falls on family members, as services are stretched to support an increasing aging population with longer life expectancy ([www.kingsfund.org.uk](http://www.kingsfund.org.uk), 2006).

The increased work load of DNs over the last decade has resulted in informal, family carers being encouraged by HCPs to become more involved with their relative's care, including aspects of their catheter care, often with some reluctance (Dingwall & McLafferty, 2006). The decision to catheterize was often related to clinician preference (Murphy, Prieto & Fader, 2015). Anecdotally, prior to this PhD and working in the community, I am aware that family members are often unprepared for dealing with an indwelling catheter and can feel pressured to take on a caring role because they know that services are stretched and DNs are busy.

Historically, the majority of LTIC care took place at home, supported by the DN team however policy changes affecting community care and efforts to meet the increasing demands on services (DoH, 2002; 2004; 2006), have resulted in

'Catheter Clinics'. There is an expectation that patients who are mobile and well enough, no longer need a home visit and can attend clinic (DoH, 2004) for routine catheter changes every 10 – 12 weeks (RCN, 2012). DNs are less likely to visit at home unless the patient is immobile so unable to attend clinic, or if there is a problem with the LTIC outside of GP surgery hours. Guidance on LTIC use makes recommendations regarding assessment, the importance of including both patient and their carer with education and follow on care (NICE, 2012).

The National Service Framework (NSF) for Long-Term Conditions (2005) promotes life-long care and management for people with long-term neurological conditions such as MS and PD. For many of these individuals, bladder dysfunction will be part of their condition as their health deteriorates and may necessitate use of a catheter (ISC - or a LTIC). Older patients with LTICs tend to have co-morbidities (Godfrey, 2008a). The prevalence of people living with long-term medical conditions, sometimes multiple and chronic conditions, is likely to increase. The approach to supporting people is outlined in the NHS Improvement Plan: Putting People at the Heart of Public Services' (DoH, 2004). The LTIC should therefore be viewed in the wider context of other health conditions, cultural expectations and aging.

## **2.6 Characteristics of carers in the context of LTICs**

Limited evidence suggests that similar to LTIC users, their spouses are primarily an older population (Getliffe, 1994; Wilde & Brasch, 2008) who may not find it easy to adjust to the demands of their new role and caring for the catheter. Furthermore, age increases the prevalence of bladder and bowel problems (NHS, 2015).

A small number of studies relating to LTIC users' experiences also included demographic information on marital status. Wilde, *et al* (2013b), recorded 55% LTIC users living with a partner, referred to as a 'spouse/partner' (pp.359), in a study of 202 participants. In Godfrey's (2008a) community-based study, 7 of the 13 older catheter users lived alone with the remaining living with 'a partner or

close family member' (pp.183) in the community. This information was either not included or not recorded in other studies (Sweeney, Harrington & Button, 2007; Kralik *et al*, 2007; Prinjha & Chapple, 2013).

## **2.7 The 'carer experience'**

The review of literature relating to 'carers' generally presents numerous references for 'carer' and 'caregiver', primarily in the context of long-term and chronic conditions (Paul & Rathray, 2007; Quinn *et al*, 2008). Being an informal carer is recognized as being stressful, leading to health problems such as depression and exhaustion (Raveis, Siegel & Sudit, 1989). There is an association between caregiver burden and sleep disturbances (Carter & Chang, 2000). This can be related to the long-term condition such as PD (Happe & Berger, 2002), where those with the condition experience symptoms of nocturnal pain and cramp which disturbs their partner and leads to fragmented sleep. Disturbed sleep due to the LTIC was identified by Fowler *et al* (2014) as catheter users and carers needed to attend to the LTIC during the night. This was to empty the bag, deal with leakage, and for some the catheter was more likely to block at night. Carers who are older (Rinaldi *et al*, 2005; Serrano-Aguilar *et al*, 2006), women (Thommessen *et al*, 2002; Campbell *et al*, 2008) and those who lived together were more likely to experience a greater burden compared to their younger, male counterparts who did not co-habit (Conde-Sala *et al*, 2010). If the care recipient has dementia, this also increases stress (Molyneux *et al*, 2008) and evidence suggests that living longer increases the likelihood of co-morbidities resulting in associated demands and stressors. The number of people living in the community with dementia is likely to increase as the population lives longer (Van der Roest *et al*, 2009).

Considering the effect of incontinence on a relationship in the absence of LTIC studies, evidence shows that those involved with caring for a partner with incontinence, noted it as a significant stress (Cassells & Watt, 2003) and it had a profound effect on the quality of life (QoL) for the sufferer and their relatives (Shaw, 2001). Studies exploring how urinary incontinence affected both care



recipient and carer found that as well as the negative 'burden' of caregiving (Gallagher & Pierce, 2002), carers also indicated the positive aspect of supporting their partner.

### 2.7.1 Caring – a positive experience or a burden?

Caregiver 'burden' is defined as '*a multidimensional response to physical, psychological, emotional, social, and financial stressors*' (Kasuya, Polgar-Bailey & Takeuchi, 2000).

The majority of carer studies were specific to a particular health condition such as caring for relative with incontinence following a stroke (Billings & Brown, 2006) or related to chronic illness (Rolland, 1987). Owing to the existence of co-morbidities within the catheter user group, management of incontinence is occasionally noted with the progression of illness, but the focus is on the management of their condition.

The literature frequently highlights the burden of caregiving although studies addressing benefits to carers (Aneshensel *et al*, 1995) have identified caring as a rewarding experience. There is evidence of the positive gains associated with feeling that they are doing something useful (Schulz *et al*, 1990) which had a positive effect on their relationship and their QoL (Pierce *et al*, 2007). This gives carers a degree of pride and satisfaction (Andren & Elmstahl, 2005). Whether caregiver's own well-being improves or deteriorates as a response to caring is very individual, and dependent on the relationship with the care recipient (Aneshensel *et al*, 1995). The timescale and circumstances surrounding taking on the carer role (Gaugler, Zarit & Pearlin, 2003) can have a bearing on the caregiver's health. It is recognized that caring is a constraint on the carer's life resulting in a loss of 'self' (Twigg & Atkin, 1994).

Reviewing texts for any mention of indwelling catheters, Dingwall and Mclafferty (2006) noted that in relation to gender and carer burden, nurses noticed a gender difference, that some of the wives were 'less willing to care for their

husbands' indwelling urinary catheter' (pp.38) with no further details provided. Caring, particularly for a spouse with a LTIC, can lead to isolation (Godfrey, 2008a) and a contributory factor is the additional time commitment.

## **2.8 The LTIC user and the spousal carer**

In the absence of studies that specifically considered the carer's perspective of LTICs, attention was turned to the catheter user.

*'It's possible to live a relatively normal life with a long-term urinary catheter, although it may take some getting used to at first'* (NHS Choices Website, 2018)

Their experiences are identified in a small number of studies undertaken within a community setting (Wilde, 2002; Sweeney, Harrington & Button, 2007; Kralik *et al*, 2007; Godfrey, 2008a, Prinjha & Chapple, 2013; Fowler *et al*, 2014). The limited investment in research in this field contributes to the view that continence and related topics are often known for being 'Cinderella' services (Millard & Moore, 1996). This limited number of studies were conducted in the community in the United Kingdom, United States and Australia. Carers are mentioned briefly, often as a single comment, such as in the context of support (Sweeney, Harrington & Button, 2007) which was valued by the LTIC user and assisted adjustment (Godfrey, 2008a, Fowler *et al*, 2014). They were also included when referencing a LTIC aiding management of continence (Kralik *et al*, 2007; Wilde 2002b). Prinjha & Chapple (2013) documented that they conducted four interviews with 'informal carers' but didn't include any information specific to the carers. In the context of the practicalities of caring for LTICs, there was a brief mention relating to having an easy to open drainage valve on the catheter for 'patient and caregivers' (Fiers, 1995, pp.142).

## 2.9 The LTIC user

Limited research suggests that LTIC users are a heterogeneous group of mostly older people (Wilde & Getliffe, 2006; Godfrey, 2008a) although there is a younger cohort who use a LTIC, often as a result of a spinal cord injury (SCI)(Gammack, 2003). Overall, catheter users were aware that the catheter was a 'last resort' to manage their bladder symptoms. This was in the absence of acceptable alternatives and was viewed as easier to manage than incontinence. The term 'last resort', was used by individuals (Godfrey, 2008a, Fowler *et al*, 2014) as well as by HCPs (Getliffe & Newton, 2006).

Research specifically related to catheter users' experiences first appear in a 1987 study (Roe & Brocklehurst). It was the first study to move away from the technical focus of previous studies. Data gathered from thirty-six structured interviews questioned participants about their feelings regarding their indwelling catheter. Although no mention of partners/carers was included, the findings noted that half the cohort considered the LTIC affected their social life, expressing concerns associated with bag emptying when away from home; a theme that resonated in later studies (Fowler *et al*, 2014). The findings also included concerns associated with stigma and adjustment. Identified as a 'survey', it suggested the need for research to include the user's experience. Despite being an older reference and based on structured interviews, several findings are mirrored in the later studies pertaining to the importance of the LTIC user 'understanding' their catheter, and the bold statement is made that this: '...will lead to better acceptance of the device and enable better management of the urine drainage system' (Roe & Brocklehurst 1987, pp.713). The catheter was likened to a 'prosthesis' suggesting an external attachment, not part of them. Wilde's (2002b) study adopted a phenomenological approach and opened the semi-structured interviews with catheter users by enquiring: 'What is it like living with a long-term indwelling catheter?' (pp.14). Wilde's (2002b) findings proposed LTIC users fought to adjust to the catheter, referencing the metaphor of 'living with the forces of nature'. Adjustment to the device, gaining control and feeling the catheter was 'part of them' contrasted with previous

research (Roe and Brocklehurst, 1987). Patients monitored their urine flow (Wilde & Brasch, 2008) as a proactive intervention to identify early signs of infection. Participants in Roe and Brocklehurst's (1987) study raised their concerns about the catheter bag leaking and odour. Anxiety about odour was more likely to be linked to leaking catheters (Wilde & Brasch, 2008) and incontinence.

The qualitative methodological approaches of the LTIC user studies varied, but they all used semi-structured interviews (Wilde, 2002; Sweeney, Harrington & Button, 2007; Godfrey, 2008a; Fowler *et al*, 2014). Meeting with participants was on one or more occasions. They all sought to provide a greater understanding of life with a LTIC and a perspective on the lived experience of a LTIC. Similarities in findings revealed acceptance and adjustment to the catheter was a prominent theme (Wilde, 2002b) in terms of - 'living with adjustment' (Fowler *et al*, 2014). Godfrey's (2008a) central theme of 'all about acceptance' identified the complexity users faced when living with a catheter - 'trying to understand', judging catheter performance' and 'being aware of the catheter' with older LTIC users experiencing feeling 'easy' or 'uneasy' about the catheter. (Godfrey, 2008a). Sweeney, Harrington & Button (2007) identified that LTIC users were 'not prepared' for their supra-pubic catheter. The suggestion was that their early negative experiences could have been improved with better support from HCPS, helping them with adjustment.

Godfrey's (2008a) twelve participants reported vacillating from feeling 'easy' or 'uneasy' with the LTIC. They felt psychologically and practically unprepared for the difficulties with management.

Prinjha & Chapple's (2013) study of users' experiences of living with a LTIC signposted readers to a website for video footage of the interviews, rather than evidence of analysis in the article. This presents challenges to trustworthiness with general descriptions of findings only. The results reaffirmed previous studies relating to the positives and negatives of the LTIC, finding it embarrassing and affecting their self-image. Subsequent papers by the same

team (Chapple, Prinjha & Salisbury, 2014; Prinjha *et al*, 2016), referenced data from the original study, related to sex, sexuality and catheters (Chapple, Prinjha & Salisbury, 2016) and patient information (Prinjha *et al*, 2016). Any reference from the carer's perspective was not included in this research.

## **2.10 Adjustment and LTICs**

The time scale of adjustment to a LTIC, defined as it becoming part of their life, was identified as twelve months for the catheter user in two studies (Roe & Brocklehurst, 1987; Wilde, 2002) and as a 'considerable time' (Sweeney, Harrington & Button, 2007, pp.422) for supra-pubic catheter users. The studies did not reveal any details regarding the transitional process and experiences of people as they move from pre-catheter incontinence to adjusting to life with the LTIC.

There was no reference of carer's adjustment in relation to LTICs however, there was mention of the positive impact of a catheter in a qualitative study about incontinence and the carer's perspective (Brittain & Shaw, 2007). In one interview, a wife caring for her husband with incontinence following a stroke, spoke about the positives of the catheter, making 'everything more manageable' (pp.1278), with less work for her and their ability to socialize again.

LTIC users experienced initial resistance to the indwelling catheter (Kralik *et al*, 2007) and their adjustment evolved with self-mastery to gain control. Catheter users felt psychologically unprepared for a supra-pubic catheter owing to their 'changed body' (Sweeney, Harrington & Button, 2007, pp.423) and in Godfrey's (2008a) study, participants expressed 'downbeat sentiments' which delayed adjustment. Wilde's (2002a) hermeneutic, phenomenological study (nine women and five men) noted the link between emotional well-being, the ability to carry out daily living activities and minimizing problems as a part of acceptance. The metaphor 'living with the forces of flowing water', was used to explain the vulnerability people identified in their effort to 'control' the flow of urine.

The initial reason for the LTIC impacted on adjusting to the device and their post catheter experience (Fowler *et al*, 2014). Participants in Godfrey's (2008a) study felt 'coerced' into having a catheter. Their view on the LTIC over time was influenced by whether they had experienced problems.

### **2.11 Support and education**

Godfrey's (2008a) study, using a Grounded Theory (GT) approach, explored older people's experiences of LTICs, noting the importance of interaction from others. Catheter users recognized the value of DNs but identified that they were often 'too busy' to offer more time to support, citing 'family and friends' (pp.185), not specifically a partner or spouse, with helping them cope and adjust. The suggestion was that not being alone but having support was the valued element.

A key finding of the Fowler *et al* (2014) study, using an interpretive description approach (Thorne *et al*, 1997) identified the importance of carer support. This was particularly evident for LTIC users with their difficulty, or inability to cope when their partner died ending both physical and psychological support. Sweeney, Harrington & Button's (2007) descriptive study focussed on supra pubic LTIC users whose experiences of support varied with appreciation of support from all quarters including spouses, but two of the six participants did not feel they had anyone other than the nurse for support. They did not feel confident that they could share personal concerns with the nurse, which impacted on their psychological adjustment. Sweeney, Harrington & Button (2007, pp.423) noted that people were reticent seeking support owing to embarrassment talking about the 'intimate' nature of 'elimination'. They also concluded that early negative experience of a catheter continued to influence patient's feeling about it and adjusting their life to having the device needed comprehensive preparation and support from healthcare professionals. A consistent theme for all seven participants (Sweeney, Harrington & Button, 2007) was their perception that they had been inadequately prepared by HCPs. The importance of support was associated with adapting to changes and this was also evident for patients with a colostomy (Piwonka & Mirino, 1999).

Historically, LTIC users often considered they had inadequate information and that nurses often had poor knowledge regarding catheters (Roe & Broklehurst, 1987), catheter care and selection (Bissett, 2005). A study by Wilde *et al* (2013b) in relation to support noted that spouses/family members in the USA based study, changed the catheter in 8% (n=14) of instances. The importance of appropriate training and full information about the catheter was identified, given to both the user and carer, when they were involved with changing the device. Support needs to be on going (Wilde, *et al*, 2013b), but there was little evidence in the literature regarding the nature of support individuals had suggested.

Following Godfrey's study in 2008a, the next group of studies (Prinjha & Chapple, 2013; Fowler *et al*, 2014) noted little evidence of changes to practice. More recently Wilde *et al* (2014) having identified that LTIC users frequently check their catheters (Wilde & Dougherty, 2006; Wilde *et al*, 2013a), carried out a study to teach users self-monitoring techniques, with a view to improving health outcomes (Wilde & Garvin, 2007). Self-monitoring by 'bag patting' (Fowler *et al*, 2014) was a behaviour that all twenty-seven participants used to check the catheter was draining or needed emptying. In the context of improving practice for LTIC users, Wilde (2008a; Wilde & Brasch, 2008b; Wilde & Dougherty, 2006; Wilde & Garvin, 2007; Wilde *et al*, 2015a) and colleagues have explored strategies of self-management of the LTICs regarding support and resources to monitor for catheter problems.

A randomized clinical trial of LTIC users in the community considered the effectiveness of self-management interventions in relation to improved outcomes (Wilde *et al*, 2015a) with findings included in an information booklet. It highlighted intervention strategies such as recognising early signs of infection, practical encouragement regarding adequate fluid intake and taking care not to dislodge the catheter. The study excluded LTIC users with cognitive impairment and specified participants must be able to speak but that they 'can complete the study alone or with the help of a caregiver' (pp.25). This study acknowledges the presence of a carer. The findings (Wilde *et al*, 2015a) revealed that problems such as blockage reduced in first six months but progress didn't continue for the

following six months. This suggested unknown factors, such as the health of the group, being an influence as the control group also showed some improvement.

Empowering patient involvement to self-manage has been a leading force in caring for long-term conditions generally (DoH, 2001; 2002). Greater understanding and support with self-management has been shown to improve health outcomes in certain circumstances (Coleman & Newton, 2005). Reviewing catheter related literature, it is apparent that information and support needs to be specific and identified as what they want in order for positive change to result and for this to be sustained (Godfrey, 2008a). Encouraging greater self-management can help reduce problems associated with LTICs (Wilde *et al*, 2015a). This includes monitoring urine drainage (Roe & Brocklehurst, 1987; Wilde, 2002b), and observing events such as judging the catheter performance (Godfrey, 2008a) the catheter bag filling (Fowler *et al*, 2014). A key finding of Kralik, *et al* (2004) was that people were keen to self-care as this gave them greater control.

In relation to chronic conditions, self-management strategies for diabetes (Coyle *et al*, 2013) and stroke (Lennon, McKenna, Jones, 2013) suggest that when there was a collaborative process to management, this had a positive effect for both the patient and the HCPs (Lorig & Holman, 2003). Processes identified as supporting self-management and taking responsibility for their own health, included psychological support and making modifications to daily life as part of adjustment (Schulman-Green *et al*, 2012).

Robust measuring tools incorporating QoL domains have been designed such as The International Consultation of Incontinence Questionnaire for long-term catheter users (ICIQ – LTC QoL) (Abrams *et al*, 2006), which is a series of validated assessment instruments for individuals including the LTIC user population (Cotterill *et al*, 2016). This can also be used for informal carers of patients with a LTIC, to identify the needs of this group and guide decision making for HCPs. I was part of the team that developed this tool and the Fowler *et al* (2014) study was the part of the early data gathering for the questionnaire development. These tools



are increasingly recommended (NHS England, 2015) as a means of identifying need and service development.

LTIC literature highlighted the importance of education and support in virtually every article. Godfrey (2008a) emphasized the importance of supporting the catheter user's involvement in order to deliver quality services, particularly prioritizing their needs.

## **2.12 Experiences of the LTIC**

### 2.12.1 Stigma related to incontinence and LTICs

Similarities are suggested regarding living with incontinence and living with a LTIC in part because of the concerns from patients about visibility of wet patch, wearing a pad or the catheter bag and odour, all potentially associated with stigma (Wilde, 2003).

Identified as stigmatizing (Garcia *et al*, 2005; Paterson, 2000), incontinence has connotations with being elderly and can equate to incompetence (Peake & Manderson, 2003) and an inability to control bodily function. Seen as a barrier that affects a person's ability to engage equally in society (Twigg, 2000), being wet is a visible sign of loss of control (Mittiness & Barker, 1995; Brittain & Shaw, 2007) raising concern from individuals of embarrassment that they may be ostracized (Umlauf, Goode & Burgio, 1996). Incontinence is often accompanied by fear of the smell of urine (Lagro-Janssen, Smit & van Weel, 1992) with association with having an unclean body (Elstad *et al*, 2010), which is stigmatizing (Brittain & Shaw, 2007) and offensive to others (Twigg, 2000). The negative impact on the individual's QoL is well documented (Brown *et al* 1998; Fultz & Herzog, 2001; Herzog *et al*, 1988; Johnson *et al*, 1998).

Those caring for a relative with incontinence at home can feel isolated because of anxieties related to the negative social consequences and embarrassment of leakage and odour (Brittain & Shaw, 2007). The small number of studies relating to impact of incontinence on a family caregiver, highlighted the intrusion on their

personal time (Gallagher & Pierce, 2002) and how helping their partner manage incontinence can take a toll on both their sleep (Cassells & Watt, 2003).

Studies relating to LTIC users noted the filling catheter bag could draw unwanted attention as it bulged under clothing that others might see (Fowler *et al*, 2014). This caused embarrassment and had negative implications such as stigma. Goffman (1968) noted that people adopted strategies such as avoidance of situations that might leave them vulnerable to being embarrassed in front of others, such as family. His work (Goffman, 1959; 1968) relating to stigma and embarrassment, suggests that people attempt to hide involvement with unclean tasks or 'dirty work', which has resonance with stigma and acceptance of LTICs (Wilde, 2003).

### 2.12.2 Embodiment

Based on the philosophy of Merleau-Ponty (2004), embodiment suggests we are 'body- subjects' (Busch, 2008) engaging in the world through our bodies. His perspective was linking the body to our sense of self, our world and in particular our relations with others. When reviewing literature there were examples of studies that examined the 'embodied experience' in relation to illness and disease.

Wilde's (2002b) phenomenological study of catheter users identified that embodiment had resonance for the catheter users (Wilde, 1999) as they tried to understand how their body was working since the loss of the bodily function to empty their bladder/maintain continence. Individuals with a LTIC were 'paying attention' to their bodies (Wilde's, 2002b) as they tried to make sense of their failing body and the unpredictability of the catheter.

It is suggested that we experience our body in 'an unconscious way', what has been referred to as the phenomenological absent body of everyday life (Leder, 1990; Williams & Bendelow, 1998). When the body is functioning normally or 'silently' (Osborn & Smith, 2006), we do not feel the need to acknowledge it or

pay attention to it. When there is dysfunction however, we are suddenly conscious of it, without necessarily seeing it as 'being me' and making a distinction between 'our body' and 'us' – our body being 'separate from the self' (Maclachlan, 2004).

There are cultural boundaries that exist relating to the sick or 'unbounded body' and old age (Lawton, 1998 (pp.133); Oberg, 1996), with intolerance to conditions like incontinence. When considering a theoretical perspective, Van Manen's (pp.102, 1990) viewpoint was that sickness draws attention to our bodies and is fundamental evidence of our 'being in the world'. Caring for neutral areas of the body, such as arms, are not seen as so problematic. However, when care includes the genitalia, as with the case of urethral catheters, this can be embarrassing to the extent of humiliating for the patient (Twigg, 2000). The failing body questions personhood and suggests one's decline (Brittain & Shaw, 2007) as if the individual is not able to fully and equally participate in society as a result (Twigg, 2006,).

For informal carers, providing personal care, including care of the catheter, is evidence of their partner's failing body. The indwelling catheter and particularly a urethral catheter, involves very intimate care and as a couple, the only intimacy they share may be through personal care.

Sandelowski (2002) suggests that in western cultures, 'body work'- the personal care that is performed by predominantly females and nurses - allows nurses to 'share intimacies' with their patients. There is a lack of understanding about the possible impact and effect that intimate catheter care has on couples and how it influences intimacy within a relationship. Twigg (2006) suggests that personal care, as well as being caring, can also present an opportunity for authority and control. In the past, intimate care of this kind has had a taboo status and has been described as 'dirty work' (Lawler, 1993) by HCPs. As a society, bodily function and elimination, including incontinence, is generally not talked (Wilde, 2002b).

### **2.13 Sex, intimacy and the impact of the LTIC**

The position of a LTIC has the potential to impact on sexual intercourse and may be an influence in the citing of a urethral device. A supra-pubic catheter can make sexual intercourse logistically 'easier' (Sweeney, Harrington & Button, 2007, pp.423) and for others, provided the opportunity for sexual relationships (Kralik *et al*, 2007).

An early study (Roe & Brocklehurst, 1987) which pre-dated the popularity of ISC or supra-pubic catheters, reported that HCPs didn't volunteer information about sex and a LTIC; this was reiterated in subsequent studies (Wilde 2002b; Sweeney, Harrington & Button, 2007). LTIC users were unaware that sexual intercourse was possible with a urethral catheter (Roe & Brocklehurst, 1987).

Fowler, *et al* (2014) study of catheter user's perspective confirmed previous findings (Kralik *et al*, 2007), that the catheter impacted on body image and physical relationships. Couples who had ceased having sexual intercourse and resigned themselves to this, cited the LTIC as the most common cause. Some were concerned that their partner might perceive this as their no longer loving them. The importance of sex for some participants was recorded as not having the same importance as it did when they were younger. In addition to the LTIC, reasons suggested were their older age and their health status. This later point was reference to symptoms accompanying neurological changes they were experiencing with conditions such as MS (Du Point, 1995; Speziale, 2008), as well as fatigue (Khan *et al* 2011; Drench, 2011).

The influence of treatment in the case of prostate cancer, such as hormone treatment or surgery can result in impotence or can affect libido or cause discomfort (Jakobsson, Hallberg & Loven, 2000). There is a psychological impact on body image and masculinity as a result (Chapple & Ziebland, 2002). The Royal College of Nursing (RCN) Catheter Care Guidance (2012) identifies that

sexual function can be 'compromised' (pp.18) as a result of a LTIC and altered body image may affect the user's desire for sexual intercourse.

Recommendations are that sexual needs of people with a catheter should be included and discussed when developing care and management plans. The importance of having an open discussion about this was reiterated in the literature (Wilde *et al* 2003; Sweeney, Harrington & Button, 2007; Kralik *et al*, 2007; Fowler *et al*, 2014). However, this was not always happening in practice (Gott *et al*, 2004). Lack of confidence and not wishing to offend was a reason why GPs were not initiating discussions with patients regarding sexual intercourse (Chapple *et al* 2014; Dune, 2012). There was the assumption that patients would ask if they wanted advice (Chapple *et al*, 2014) and their spouse's perspective was not recorded.

The inclusion of questions relating to a person's sexual health as part of a nursing assessment has been suggested for many years (Atkinson, 1997) with little evidence of changing practice (Evans, 2000). The consensus from HCPs was that it should be discussed (Hampton, 2005) but the limited evidence suggests they feel ill equipped to talk to patients about this and lack of training is often cited as the reason for the omission (Haboubi & Lincoln, 2003).

There is an increasing body of work using IPA in sensitive topics such as sex and sexuality. An example is Jarman *et al*, (2005) study relating to challenging perceptions in relationships whilst exploring people's identity and conflict. However, studies focus on aspects of sexuality rather than intimacy and relationship changes.

#### **2.14 Literature exploring allied studies and carers' experiences**

Allied studies were considered where caregiving includes an assistive device or where physical changes or medical intervention resulted in caregivers supporting their partner with managing elimination in the case of colostomy or ileostomy.

### 2.14.1 Assistive technologies

An assistive technology is designed to provide functional benefits and as result improve their quality of life (QoL). Literature relating to technologies and devices that had similarities with a LTICs, includes those developed to provide and assist function for the user. Besides a LTIC, an example of this is an insulin pumps, which is an external attachment requiring attention and a degree of knowledge to manage.

Literature relating to life-maintaining interventions such as ventilators was discounted even though there was evidence of family carers' experiences and similarities with caring generally. In the context of the impact on family carers, use of portable ventilators are increasingly used in the community (Noyes, 2006). Although a blocked catheter and infection can result in the LTIC user being very unwell, it does not have the immediate risk to their life or require the level of technical ability, when caring for a ventilated relative at home might.

The psychosocial impact of devices (Jutai & Day, 2002) impacts on the person's ability to adjust. Jutai & Day (2002) developed a twenty-six-item scale, self-report questionnaire (The Psychosocial Impact of Assistive Devices Scale PIADS) to assess the impact of the assistive device on QoL with the aim of improving adaptation to the device. External factors that influenced included adapting their environment. Research has shown that difficulties with devices and technologies generally can result in dissatisfaction, anxiety and feeling a of loss of control. The devices in question were originally items such as wheelchairs and hearing aids however this research is pertinent to this PhD, as this scale has been adapted to include continence related devices such LTICs (Long *et al*, 2014). Although the scale is intended to be completed with the device user and ultimately the focus is on them, there is the option to include the carer's input. Jutai & Day (2002) acknowledge the additional impact of the user's medical condition on their ability to adapt, as well as what they term 'device stigma' (pp.107) and the varying degree of the person's disability/ability.

McDonald *et al*'s (2017) GT study explores how twenty-six family carers learn to manage technical procedures at home. It indicated that their approach was 'individualized and multi-influenced, developing over time as a response to the lived experience' (pp.850). The technical procedures and interaction with technologies included a small number managing urinary catheters but also nasogastric or gastrostomy feeding, caring for a stoma, performing complicated dressing, managing a tracheostomy and intravenous therapy. Although most of the family carers supported a child (twenty of the twenty-six participants) the study also included six carers who supported a spouse, parent or grandparent but this figure was not broken down further. The overarching theme was 'wayfinding' (pp.853) as 'a learning process' the carers adopted to manage the device or procedure. McDonald *et al* (2017) recognized that the technology was part of the wider picture of family adjusting to the long-term condition or disability (pp.855). The conclusion of the study suggests the importance of carer support as ongoing and the negative consequences if this is 'insufficient' in the context of the technical skills that are needed as lay carers.

When reviewing literature related to adapting to a stoma, the importance of education and the benefit of being more informed aids easier transition to adjustment (Munoz *et al*, 2013; Cheng *et al*, 2010). This was helpful to the carer and also resulted in the care recipient being able to do more for themselves (Lopes & Decesaro, 2014).

McDonald *et al* (2015) study carried out semi-structured interviews with twenty-one female and five male carers who were supporting a family member at home with technical procedures related to elimination such as urinary catheters, bowel management including giving enemas or bowel washouts, and ileostomy management. Other procedures the carers supported were peritoneal dialysis, tracheostomy care, gastronomy feeding and care of a central venous line. Although the majority of carers were supporting their children, three were caring for a spouse. The article did not specify which technical procedure spouses were involved with. The five 'dispositions' (pp.1) to come out of this

research were: (1) embracing care, (2) resisting, (3) reluctant acceptance (4) relinquishing and (5) being overwhelmed. The research suggested HCPs providing support including psychological as well as practical support, particularly during the training phase, aided adjustment. HCPs supporting their adjustment included assessment of the carer's emotional response relating to what they were expecting them to do.

It is acknowledged that caring for a medical device, or supporting care, can sometimes involve a degree of coercion of family carers into providing support for their 'loved ones' (Israel *et al*, 2008, pp.390).

The timescale for someone adjusting to life with a colostomy was reported as a year, according to Piwonka & Merino (1999), similar to findings in relation to a LTIC (Wilde, 2002b). It was also noted that the direct involvement of the patient in care decisions following a colostomy aided adjustment.

Research related to adjustment and body image found that people who were supported or who had the perception of support, found adjustment to changes in body image easier to accept (Rumsey *et al* 2004; Piwoka & Merino, 1999). Adjustment in relation to ileostomy research found it impacted on patients and their families' lives (Sinclair, 2009) and there was a negative impact in relation to QoL following ileostomy and colostomy which was 'underestimated' by HCPs (Karadag *et al*, 2003) in a study of 43 individuals. HCP's good relationship with patients had a positive impact on adjustment, noted as improving perception of QoL scores in 4,739 patients who had a stoma (Marquis, Marrel & Jambon, 2003).

Considering caregivers' experiences when one partner has a long-term condition which includes the use of a medical device as part of the management, an insulin pump offered similarities. Johnson, E. (2011) thesis explored the psychosocial impact of an insulin pump for patients with Type I Diabetes and the experiences of their partners. Using IPA, Johnson (2011) carried out six user semi-structured interviews but also nine interviews with partners of patients who use an insulin pump. Findings included the importance of their relationship and management



experiences as a 'family disease'. Findings recommended a structured approach to providing education and support regarding specific skills needed to manage and help them adjust to the device.

## **2.15 Theoretical models and theories**

In the course of the literature review, various theoretical models and frameworks came to light in relation to experiences and the process of adjustment that might be pertinent in the context of devices, such as LTICs. Acknowledging that with an IPA approach, the emphasis is not to start with theories and models, but to explore the emerging data without pre-empting the outcome. Various models were reviewed as part of the reflective process during the literature search and put to one side for future consideration.

### 2.15.1 Yoshida's Pendular Reconstruction Model (1993)

Yoshida's model had potential relevance to this PhD in both subject area and the adaptive nature of the model. Yoshida's study considered spinal cord injured adults and their view of 'self' in the acute stage after their injury. The thirty-five adult participants were paraplegic and although it is not included in the paper, due to the nature of their injury, they would have most likely been managing their bowel evacuation and their bladder drainage (with a urinary catheter of either intermittent or indwelling design). The metaphor of a pendulum is used to signify the backward and forward movement detailed in their accounts, between their non-disabled and their disabled concept of 'self'. They identified their reconstructed view of themselves post injury as they attempted to adapt to living with their different and altered self (Yoshida, 1993).

### 2.15.2 Paterson's Shifting Perspective Model of Chronic Illness (2001)

Paterson's 'shifting' process illness to the foreground or wellness to the foreground as people conceptualized their experiences as the changing 'shift' in relation to their long-term condition. It provides a framework to develop

understanding of a process in relation to a chronic illness. The aspects that raised my initial interest at this stage were that in times of 'wellness', the disease and difficulties moved to the background. I reflected at the time that problematic LTICs were similar in their dominance and control over everyday life when they occurred and once treated, the equilibrium returned (Fowler *et al*, 2014). Patterson's Model proposed that learning about the illness, acquiring knowledge including creating a supportive environment, proved beneficial.

### 2.15.3 Rolland's Chronic Illness and the Life Cycle: A conceptual framework (1987)

Rolland identified a continuum of adjusting which had similarities to Godfrey's (2008a) study of LTIC users' experiences. Although Godfrey (2008a) had interconnected themes specific to the LTIC such as being aware of the LTIC and judging performance, the idea of a continuum of 'ease' and 'unease' initially raised my interest in Rolland's research. Rolland's eventual relevance to the findings are detailed in Chapter 6.

### 2.15.4 Wilson's Dynamic Continuum (2007)

Wilson's (2007) study exploring experiences of faecal incontinence, interviewed twenty-two participants. The dynamic continuum, again suggests a process - of feeling overwhelmed, experiencing negativity, - through to improved QoL, as patients adapted over time. This continuum towards 'approaching mastery' may have relevance to the LTIC and this can also require 'mastery' to manage the device. Over time the ability to take control and adapt was aided by a 'supportive partner', similar to findings in Fowler *et al* (2014), redressing the balance in their lives in combination with other interventions including the support of HCPs. Wilson (2007) also highlights the importance of ongoing support that was needed to adapt.

Wilson's 2013 follow-up to the original project (Wilson, 2007) considered changes including the process of adapting over the intervening years. Of the twenty-two original participants, half of them signed up again and a further in-

depth interview showed that they had 'downgraded their aspirations' and showed improvement in their ability to cope with day to day life over time.

The theoretical models and frameworks were revisited as the study progressed, and integrated with the results of the current study. These are presented and discussed in Chapter 6.

## **2.16 Review of the research rationale**

This literature review identified that the spousal perspective in relation to LTICs has been overlooked despite national guidelines supporting inclusion and confirms the research rationale. There is acknowledgement of carers' involvement with evidence related to unpaid family members, caring for medical conditions at home (George & Martin, 2016) although not specific to LTICs and their involvement with supporting care of medical devices/technologies (McDonald *et al*, 2014).

The literature identified that for patients it is preferable to be cared for at home, and realistically in cost conscious times when managing services, this is a prudent consideration. The family carer has an important, if undervalued or poorly acknowledged role supporting care in the community. Literature documents their contribution supporting their partner's adjustment to life changing conditions and the importance of their role supporting HCPs. For an individual who need to use a catheter but is unable to use an intermittent device (ISC) for whatever reason, if they have a carer who are willing and able to take on this role, this enables them to continue to live at home. The alternative, apart from an indwelling catheter, is living in a nursing home or three hourly care at home supported by paid carers proficient in performing CIC.

## **Chapter 3**

### **Methodology**

## Chapter 3

### Methodology

#### 3.1 Introduction

Chapter 2 confirmed the absence of evidence in the literature of a spouse's experience once their partner has a LTIC, and the limited research incorporating a qualitative paradigm regarding catheter users' experiences. There was a substantial body of literature relating to spousal caregivers' experiences generally of caring for a partner with a long-term condition. This was of relevance and of interest if the condition was associated with neuropathic damage due to injury, or disease, as supporting care would be more likely to require a degree of intervention with bladder and bowel management in the later stage. This could include conditions such as MS, PD or damage following stroke or spinal cord injury (SCI).

My anecdotal experience together with the limited associated literature, suggested the multifaceted nature of caregivers' experiences involving a LTIC. The decision to use an idiographic methodology (Smith, Flowers & Larkin, 2009) enabled the complexity of individual experiences and perspectives to be explored and recorded. Given the absence of research about informal caregivers' experiences of LTCS *per se* and the 'novel' (Smith, Flowers & Larkin, 2009) nature of the study; the decision to explore in depth the experiences of a small number of individuals was considered justified and appropriate for Interpretative Phenomenological Analysis (IPA) (Smith *et al*, 1999; Smith & Osborn, 2003) to answer my research questions.

#### 3.2 Overview of the chapter

This chapter documents the approach, planning and final design of the thesis and rationale for the methodological approach. As part of the process to select an appropriate analytical framework, alternative approaches were considered and comparisons with alternative methodologies are included in this chapter.

The chapter is presented in three sections. I will begin with an overview of IPA, specifically in nursing and allied fields, before going on to explain my orientation to the research process and my epistemological position. I will discuss Ethnographic and a GT approaches and outline why they were considered as potential alternatives.

Included in the second section, there is a background to IPA and a comparison of phenomenology with IPA. This is followed by the theoretical premise of IPA; the phenomenology, hermeneutics and ideography components.

Finally, in the third section, I will present an overview of the analysis framework (Smith *et al*, 2009) and reliability and validity versus trustworthiness in relation to IPA.

### **3.3 My epistemological position**

Epistemology is defined as the philosophical theory of knowledge (Garrish, 2015), and how knowledge is known through the subjective experiences of individuals (Creswell, 2013). As a conceptual issue, it has an impact and influence on what we do.

I acknowledge that my 'worldview' is shaped and influenced by my life experiences (Guba & Lincoln, 1994), particularly my nursing career over many years in various roles but also by my personal life. I acknowledge that world views change all the time, guided by new experiences. I am also aware I have a desire to find and present 'solutions' – as a HCP, it is part of my job, but as an individual I feel the personal challenge of trying to improve a patient's situation, which is not always possible.

During my nursing career, I have gradually added knowledge and experience in a specific specialty which has become my passion; supporting those with incontinence and bladder dysfunction. The empathetic approach of IPA to 'stand

in the shoes of' (Eatough & Smith, 2008, pp.189) sat well with my epistemological perspective as a nurse.

Being a nurse is such an intrinsic part of me and I consider myself a nurse first throughout this research; a nurse on a journey as a 'real world' researcher. Smith, Flowers & Larkin (2009) suggests that our experiences inform and potentially influence both how we conduct our research and the outcome of the research. I acknowledge that my perspective as a nurse will be different from the patient or caregiver's perspective. During this study my parents became ill and ironically, I had first-hand experience of being a family member negotiating the catheter management for my father. Although it was from a daughter's perspective, I experienced an empathy with the spousal caregiver's perspective, which was insightful.

The choice of IPA over other approaches was driven by the research aims. I am a curious person by nature and was aware that the attributes for researchers using IPA are considered to be - 'open-mindedness, flexibility, patience, empathy and the willingness to enter into, and respond to, the participant's world' (Smith, Flowers & Larkin, 2009, pp55). The influence of 'reflective engagement' (Smith, Flowers & Larkin, 2000 pp.80) in the IPA process as primarily an interpretative approach was also an attraction. I was also aware of that this meant engaging with a higher level of interpretation in the analysis, as a criticism of some studies which have used IPA, is that they lack the deeper level of analysis that is required and can be too descriptive (Hefferon & Gil-Rodriguex, 2011).

### **3.4 Study design**

Considering the rationale behind the methodological choice, I began with 'assumptions, a worldview [and] the possible use of a theoretical lens' (Creswell, 2007, pp.37); the research focused on how a small group of individuals attempt 'to make sense' (Denzin & Lincoln, 2005, pp.3) of the situation they find themselves in. The assumption was that the catheter experience would be as varied for the spousal caregiver as it was for the user. The reasoning for this was

because of tangibles such as age, sex, their relationship, culture, but also the added factors relating to the disease associated with the reason for the catheter, the stage of the disease and other factors such as dementia which is known to make caring more challenging. Other influences to take in to account included the carer's health and the psychological health of both parties.

My starting point was the research question which asks what the carers' experiences were when their spouse had a LTIC, and this ultimately dictates the approach and methodology (Silverman, 2010). The suitability of the dynamic process of IPA over other approaches is consistent with the epistemological position of the research question; that the data will allow a detailed examination of the experiences of spousal carers in the context of caring for their partner's LTIC and the impact, if any, on their relationship.

It is the detailed process that individuals go through and the 'sense making' that is the key issue with IPA (Brocki & Wearden, 2006, pp.88) with data analysis guided by 'self-reflection' (Smith, Flowers & Osborn, 1997). This reflects both the phenomenological and interpretative aspect of IPA (Smith, Flowers & Larkin, 2009).

Capturing 'the lived experience of being a body-in-the-world' (Smith, Flowers & Larkin, 2009, pp.19) of another is acknowledged as something that can never be entirely possible, being complicated by our own perceptions, but we have to strive to make every effort to include such an important aspect of the individual's experience. If an outcome from this research is to propose improvements to practice, this methodological choice is in keeping; seeking service users' experiences to inform future healthcare practice (DoH, 2006).

IPA acknowledges the interpretative role the researcher plays in this process, when attempting to make sense of another's experience (Smith *et al*, 1999). This interpretative aspect in research is sometimes referred to in terms of 'messiness' (Eatough & Smith, 2006, pp.187) and 'the messy chaos of the lived world' (Smith, Flowers & Larkin, 2009, pp.55). This process of making sense of the participants'



experiences continues as their accounts are probed, eliciting further interpretation. Within IPA, the researcher is directed by the experiences recounted but certain aspects are made 'salient' by the participant (Smith, Flowers & Larkin, 2009). It is only the total immersion in this 'messiness' that enables and guides the analysis (Mellor, 2007).

IPA predominantly focuses on the personal accounts that result from a small number of semi-structured interviews with a fairly homogenous group, which in this case is carers who are the primary caregiver for their spouse and their LTIC.

### **3.5 Interpretative Phenomenological Analysis (IPA)**

IPA has its origins in phenomenology (Smith, Flowers & Larkin, 2009) with a focus on how people make sense of an experience. The suggestion is that far from being a passive recipient, people - 'interpret and understand their world by formulating their own biographical stories' (Brocki & Wearden, 2006, pp.88) and this helps them to make sense of what is happening to them. Fundamental to IPA is the individual's personal account of their experiences and central to the process of analysis within IPA is an acceptance of the interaction between the participant's narrative and the interpretation which the researcher brings to the process. Smith (1996) emphasizes the importance of the researcher attempting to understand their own biases which impacts on how they interact with the data and the role of reflexivity.

### **3.6 Considering alternative approaches**

IPA was chosen over other approaches because it was consistent with my epistemological position and informed by the research question (Moule *et al* 2017), namely that the data would allow spousal caregivers' experiences to be explored from their perspective. My intention was to build an interpretive account of how they make sense of their experiences and how this affects their relationship (Smith, Flowers & Larkin, 2009).

The two alternative methodological approaches I considered were Ethnography and Grounded Theory. Both approaches, together with Phenomenology, are frequently used in nursing with traditions in anthropology, sociology and psychology (Polit & Beck, 2014). Having demonstrated that no previous studies had considered the informal caregivers' experiences of LTICs, a small number of allied qualitative research studies had explored the catheter users' perspectives and I reviewed the methodological approaches that had been adopted. This had included Phenomenology (Wilde, 2002b) and GT (Godfrey, 2008a) with other approaches characterised as descriptive or interpretative.

### 3.6.1 Ethnography

Evolved from social anthropology, ethnographic studies are carried out in the context of the study area, providing a description of participant's culture, subculture or a social group (Holloway & Galvin, 2016). Enquiries within the area of study aim to reveal social actions, beliefs and values (Wolf, 2007) and to gain an understanding of the phenomena.

As an ethnographic researcher, one needs to be part of or have access to, that culture; to be present in their world to gain insightful interpretations. This approach typically involves unstructured interviews and observations to create a 'thick description' (Holloway & Galvin 2016, pp.209) of cultural behaviour (Burns & Grove, 2011). This thick description is developed with detailed accounts and importantly it is theoretical and analytical (Gerrish & Lathlean, 2015) in exploring underlying meaning to create a clear picture of the individual's experience.

The study sample is typically purposive (Hammersley & Atkinson, 2007) and participants are usually called 'informants' in acknowledgement of their 'informing' on the phenomenon (Gerrish & Lathlean, 2015). The interview quotes are accompanied by field notes to provide further detail.

Ethnographic studies have been used in nursing to improve practice through greater understanding, particularly investigating patient experience of their world as they live and perceive it (Polit & Beck, 2014). The term 'ethno-nursing' was coined by Leininger (1978) and emerged from Leininger's Theory of Transcultural Nursing as the study of nursing culture; to describe and explain nursing phenomena and concentrating on 'observing and documenting interactions with people of how these daily life conditions and patterns are influencing human care, health, and nursing care practices' (Leininger, 1985 pp.238). An example of such a study relating to carers and technology (Happ, *et al*, 2007) is an ethnographic approach, which enabled the description and interaction between the patient and family during the process of coming off prolonged mechanical ventilation. It included a critical examination of how the family interpreted the clinician's approach (Happ *et al*, 2007).

Originally my interest in this methodology was at a time when I was working as a DN for half the week and a continence specialist nurse in the community for the other days. A large proportion of time was spent trying to help LTIC users and their families cope with the challenges of the LTIC. I was considering my methodological approach and the opportunity for an ethnographic study in the circumstances. However, around this time, I changed my job and stopped district nursing and was therefore no longer in a position to be part of their culture to observe what I was seeing and hearing.

### 3.6.2 Grounded Theory (GT)

Grounded Theory (GT) is frequently discussed as the main alternative to IPA (Smith, Flowers & Larkin, 2009) and has been used extensively in health related/nursing research since it was formulated by Glaser and Strauss (1967). Suggested as a 'style' to doing analysis (Strauss, 1987). It has its origins in sociology and is a culmination of a descriptive and explanatory approach. Similar to IPA, it is an inductive process with the aim of capturing the variation in the studied phenomena and theories are generated by discovering which hypotheses and concepts are relevant in the area of study (Strauss, 1987). It

begins with an inquiry with specific observations and data from which theory emerges (Strauss & Corbin, 1990). This is often over time, usually working in an inductive way, though as the hypotheses are developed through further observations to verify relationships within the data, it becomes a deductive approach. The process of constant comparison and reduction aims to enable the concepts to arise directly from the research (Wimprenny & Gass, 2000). Similar to IPA, it is about developing an 'intimate relationship' with the data (Strauss, 1987, pp.6). It acknowledges that the researcher as an 'active participant' (Munhall, 2012) in the formulation of the research outcome. The theory is 'grounded' in the data and usually, though not always, employs interviews to generate a substantive theory. Charmaz (2006) further developed Glazer and Strauss' (1967) original approach in the quest to explore peoples' stories in their way. This usually entailed several meetings in order to develop a relationship with the participant. There are several versions of GT with constructive GT being more widely used (Charmaz, 2006).

During analysis in GT studies, broad categories are identified and relationships between these categories or themes are developed which invoke the same sense of exploration. Having identified factors that may explain the phenomena under investigation, further participants are recruited using theoretical sampling (Grubs & Piantanda, 2010), to help refine or challenge the findings (Patton, 2015; Bryman, 2012). Similar to IPA, GT is generally used in under researched areas where little if anything is known about the research area (Holloway & Galvin, 2015).

GT differs from IPA in that the sample size is often larger (although this does not have to be the case) and recruitment continues until data saturation is reached with no new themes emerging. In contrast, IPA explores each case in greater detail, the so-called 'micro analysis' (Smith, Flowers & Larkin, pp.292) and is focused on the convergence and divergence of participants and in this instance, their lived experience. IPA can be a sole case study to explore an area not previously researched. IPA and GT share an intuitivist approach. A GT approach

draws on themes and findings in a more generalized way, to illustrate and illuminate theories grounded in the data.

Similar to IPA, the researcher's role in shaping the analysis is acknowledged. Relevant to both GT and IPA, themes 'emerge' from the data and often develop within categories or across categories and commonalities, and natural variation can be found (Polit *et al*, 2012). Central phenomenon are identified, together with exploration of the causal conditions that are influencing these (Strauss & Corbin, 1998).

### **3.7 Rationale behind the methodological choice of IPA**

IPA was chosen because it would provide a detailed exploration of caregivers' experiences through development of an 'insider's perspective' (Reid *et al*, 2005) and through its commitment to idiography, to produce an interpretive account of their personal and social world.

I wanted to find out what was significant to spousal caregivers' experiences. This involves what Smith, Flowers & Larkin (2009 pp.33) term, engaging 'in considerable "hot cognition"'. Whether as a researcher, we are ever able to access another's experience is in itself questionable, however what we are attempting to do is research 'experience close' (Smith, Flowers & Larkin, 2009).

Smith (2004) suggests that IPA is useful when the research focus is multi-dimensional and relatively 'novel' and where the emphasis is upon making sense of something. The 'novel' aspect of this enquiry is the focus on experiences caring for a medical device, as opposed to the health condition that necessitates care.

### **3.8 IPA theory and method**

The theoretical perspective that underpins IPA draws on three key theoretical perspectives:

The phenomenological aspect is concerned with exploring the lived experience and the 'sense making' that participants attach to their experiences.

The hermeneutic element denotes that this will involve interpretation by the presence of the researcher.

IPA is idiographic, reflecting the participants' experiences and focusing on the particular rather than the general (Smith, 2011).

The idiosyncratic nature of IPA is acknowledged; that analysis by another would not necessarily generate the exact same findings. Rolfe (2006) suggests this should be seen for what it is - the individual interpretation as a strength of qualitative research.

### 3.8.1 Examples of research using IPA

Prevalence has increased in recent years and it is now used extensively in health research including nursing, relating to physical health and particularly relating to chronic conditions (Reynolds & Prior, 2003; Osborn & Smith, 2006; Smith & Osborne, 2007). Furthermore, IPA has been used to explore 'patient illness experiences' (Smith, 2011, pp.13) and to answer similar questions relating to the exploration of participants' perceptions (Brocki & Wearden, 2006) and meanings they attribute to their experiences. In relation to health and illness and the lived experience these have included the carer's role and SCI (Dickson *et al*, 2010; Dickson *et al*, 2011), MS (Borkoles *et al*, 2008; Reynolds & Prior, 2003) and stroke (Hunt & Smith, 2004). There was one study using IPA that was continence related (Komorowski & Chen, 2006), exploring Chinese womens' experiences of incontinence, using semi- structured interviews with fifteen women (aged 24 - 81 years). The core themes were uncertainty about urinary incontinence, self-blame, avoidance, emotional isolation and desire for treatment.

### 3.8.2 IPA and Phenomenology

Phenomenology is acknowledged as a philosophical approach to studying lived experience with all its complexities from the individual's perspective and at a particular time in their life. There are two main approaches to phenomenology which are descriptive and interpretive. Edmund Husserl first proposed a phenomenological approach (Koch, 1995; Polit *et al*, 2001) that would seek to examine human experience, the lived experience – to 'know their own experience of a given phenomenon' (Smith, Flowers & Larkin, 2009, pp.12). In addition to exploring experiences and associated meaning of a phenomenon, it also aims to search for their opinions and the essences of their experiences (Willig, 2008). Any preconceived ideas or prior knowledge are suspended or 'bracketed' (Husserl, 1913;1962, pp.103, Johnson, 2000).

To develop insights from the person's perspective, the method to obtain first person accounts is predominantly through semi-structured interviews as with IPA. Phenomenology is, first and foremost, a 'how' approach and although different methods draw on phenomenology as IPA does, the element that is consistent to all is the notion of 'experience'.

I discounted phenomenology as a methodological approach because I was not intent on generating a theoretical based account of a phenomenon and the lack of previous evidence also had a bearing. IPA however, with a small-scale enquiry, would enable me to explore participants' experiences in detail.

A phenomenological approach, further developed by Martin Heidegger, combines with hermeneutics, acknowledges that the researcher invariably brings their own experiences and understanding. This is in the sense that their interpretation is grounded in their experience. One of Heidegger's theoretical standpoints is that every perceived experience is unique. His definition of phenomenology was 'letting that which shows itself be seen from itself, in the very way in which it shows itself from itself' (Heidegger, 1962). Heidegger's hermeneutic phenomenological approach (Johnson, 2000) differed from his

teacher, Husserl, whose approach advocates 'bracketing' (Parahoo, 2006).

The idea of 'putting aside' or 'bracketing' (Harvey & Land, 2017, pp.101) one's knowledge and beliefs appears a contested concept within phenomenological research (LeVasseur, 2003). Husserl's original intention was the total exclusion of all suppositions 'to put to one side, the taken-for-granted world' this was with the intention of being able to focus on what he termed 'our perception of that world' (Smith, Flowers & Larkin, 2009, pp.13). Heidegger argued the difficulties of bracketing and whether this was in fact possible (Larkin, Watts & Clifton, 2006) – or desirable. According to Gadamer (1975) 'bracketing' is impossible since the ability to interpret is an integral part of existence in the time we are living (Annells, 1999).

Giorgi's (2009) descriptive phenomenology, is 'Husserlian' in approach however the emphasis is on description of the experience rather than interpretation; participants describing what they can put into words. IPA has the 'modest ambition' to attempt to capture experiences pertinent to the individual (Smith, Flowers & Larkin, 2009).

Bracketing is seen as assisting with demonstrating rigour, considered essential with detailed participant engagement (Giorgi, 2009). The central focus when using IPA is engaging with participants over all other things, paying 'skillful attention' (Smith, Flowers & Larkin, 2009, pp.35) to the processes of engagement and as a result there will be an element of bracketing (Smith & Eatough, 2007). Acknowledging the important influence of Husserl's work assisting IPA in relation to the process of reflection, Smith, Flowers & Larkin (2009) remark that IPA's aim is to capture the individual's experience in contrast to Husserl's more ambitious goal to uncover the 'essence' of the experience. (Smith, Flowers & Larkin, 2009, pp.16).

The importance of reflexivity is cited when adopting a phenomenological approach (Crotty, 1998) and having an awareness of ways the researcher can impact on the research process. The ability to be truly reflective is challenged by



our objectivity about our circumstances – we cannot ‘set aside’ things if we are not aware of them (Ahern, 1999).

Drawing on the descriptive and interpretative phenomenology (Smith, Jarman & Osborn *et al*, 1999) IPA should be viewed with the understanding that the resulting phenomenological analysis will be an ‘interpretation’ of the participants’ experiences owing to the influence of the researcher’s own beliefs and assumptions.

The concept of ‘worldliness’ in our existence, first explored by Heidegger and later Merleau-Ponty further developed the idea of ‘being in the world’ and the concept to describe the ‘embodied nature’ of this state (Smith, Flowers & Larkin, 2009, pp.18). Merleau-Ponty (1945, 2004) was an exponent of the association of the body to our sense of self and our world. He claimed that the world exists for us only in and through the body (1962), this is how we ‘comprehend’ it (1962, pp.235) and it becomes our view of the world. He suggested that rather than viewing time as something independent of self that happens around us, we should think instead of time as part of our ‘embodied interaction’ with the world.

Merleau-Ponty suggested it is our participatory interaction with our embodied existence that provides our knowledge of self, with time coming into being as a function of our embodied interaction with the world. This is as opposed to thinking of time being like a river, flowing independently through our lives, something we only observe. Phenomenologists often use metaphors (Polit *et al*, 2012) in their work and this use of figurative language as an analytic strategy ‘permits greater insight and understanding’ (Polit *et al*, 2012. pp.563). In Wilde’s (2002b) study exploring the embodied experiences of people living with a LTIC with reference to Merleau-Ponty’s phenomenology, she proposed the metaphor of ‘living with the forces of flowing water’ as participants experienced living with the catheter.

### 3.8.3 IPA and hermeneutics

As previously stated, a major component underpinning IPA comes from hermeneutics (Smith, Flowers & Larkin, 2009) and the theory of interpretation. Whilst the participant is attempting to make sense of their personal and social world, the researcher in turn, is attempting to make sense of the participant, making sense of their personal and social world (Smith, 2004) This is referred to as a 'double hermeneutic' (Smith & Osborn, 2003).

The three hermeneutic theorists who have influenced IPA are Heidegger, Schleiermacher and Gadamer. IPA recognizes the researcher's influence in the analysis process, influenced by Heidegger's hermeneutic phenomenology. Schleiermacher's (1998) approach was not about following rules but rather it is about interpreting and enabling an intuitive approach, as well as having a grounded approach. Engaging in the interpretation in intense detail and in a thorough way, can result in an understanding that exceeds that of the person themselves (Smith, Flowers & Larkin, 2009). This should be viewed with caution, but it raises the issue of whether as a researcher, one might uncover insight in our analysis that is not apparent to the research participant. Schleiermacher (1998) is significant to IPA - with the focus on interpretation, suggesting that an intuitive and sensitive researcher will potentially uncover a further dimension to the analysis. I am not suggesting that the researcher knows better, however they can bring an insightful element to the analysis.

In relation to hermeneutics, Gadamer (1990, 1960) writes of the backwards and forwards processes that enable 'understanding and interpretation' (Gadamer, 1990, 1960, pp.267). The understanding should relate first to the content or the text of what is being said, rather than focusing on understanding the person and another's meaning. This is an important consideration when reviewing the analysis using IPA. Smith, Flowers & Larkin, (2009) acknowledge the influence of the 'moment of interpretation' in this process.

### 3.8.4 IPA and its idiographic commitment

The third influencing factor upon IPA is idiography (Harre, 1998); the focus on the individual, the emphasis 'with the particular' (Smith, Flowers & Larkin, 2009 pp.29) and individuality rather than individualism. An idiographic approach can be a single person case study (Bramley & Eatough, 2005) or considering an individual case before progressing to other cases. In IPA, having started analysis with the emphasis on the individual, as the study builds, it progresses towards the development of themes and categories, comparing and developing these (Smith & Dunsworth, 2003; Eatough & Smith, 2006).

### **3.9 Reflexivity and IPA**

The concept of reflexivity is where the researcher consciously acknowledges their bias and experiences (Creswell, 2013) as well as their values that they bring to the study, to enable engagement with a philosophical and theoretical focus. Using IPA, the beliefs and assumptions of the researcher are not considered to be biases that should be set aside, but are viewed as being needed in order to make sense of participants' experiences.

Reflexivity is a means to acknowledge one's interpretative role, as opposed to a necessary technique for eliminating bias (Boyatzis, 1998). According to Mason (1996) 'active reflexivity' is an essential aspect of every stage of qualitative research, acknowledging that one cannot be 'neutral, objective or detached' in this process. Reflexivity is a continuous process (Parahoo, 2006), which involves acknowledging any preconceptions when involved in the research process.

Willig (2001) suggests that as a qualitative researcher, one cannot distance oneself from the subject matter and when using IPA, it is good practice to reflect on our role particularly during data analysis and findings (Brocki *et al*, 2006). Good research practice includes making one's own position 'explicit' (Hammersley & Atkinson, 1995) As researchers, we should always be aware that

interviews should be interpreted with the knowledge that sometimes people do have difficulty expressing experiences or thoughts.

The use of reflexivity becomes paramount as the researchers' perceptions of the situation are combined with trying to make sense of the participant, trying to understand their situation (previously discussed the 'double hermeneutic' element of IPA). This acknowledges the significant role the researcher plays in the process of interpreting another's experiences (Smith & Eatough, 2006) and indeed does not consider the researcher's bias as negativity, if acknowledged as their interpretation. Transparency is provided through reflexivity suggesting that we should not 'take decisions without actively recognizing that we are taking them' (Mason, 1996, pp.165)

### 3.9.1 Reflecting on personal experience

My varied clinical experience has provided a good deal of anecdotal evidence to reflect upon, relating to the impact of urinary catheters on people's lives. My 'world views' (Guba & Lincoln, 1989) related to carers is shaped by my experiences nursing in the community and part of this qualitative research involves me constantly challenging my interpretations of the data to explore and understand the caregivers attempts to understand their situation.

Reflexivity can be viewed as being a two-part process (Creswell, 2013). The first part involves considering our position in the research, which involves personal reflection on our own experiences of the phenomenon under review to identify these (Creswell, 2013). The second part of the reflexive process is the discussion, identifying how personal experiences can potentially shape findings and the 'interpretations drawn from a study' (Creswell, 2013).

Our experiences may be through various periods in our life. Most noticeably for me, this was my nursing experience, but latterly caring for both my elderly parents and particularly my father's difficulties with continence following a fall when he had an indwelling catheter. This experience during the course of the

study, provided an alternative perspective to reflect upon and an opportunity to consider the 'participant's personal world' (Conrad, 1987, pp.218).

I recognize how my own views and values could influence this research study and have attempted to be as transparent as possible and address potential personal biases (Roberts, 2013). My approach to implementing a reflexive process included keeping a reflective diary to record thoughts and ideas (Lincoln & Guba, 1985; Holloway & Wheeler, 2010) and having discussions with my supervisory team about these reflections or about the other aspects of the study as it evolved as an ongoing process.

### **3.10 Guide to the analysis/stages of analysis/framework of IPA**

The framework that guides IPA research, is not a prescriptive approach; enabling it to be adapted to suit the research question (Smith & Osborn, 2003), what Smith, Flowers & Larkin (2009) suggests is 'exploratory, not explanatory' (pp.47).

The various stages of analysis and interpretation aim to gain insight into peoples' experiences of the phenomenon under study. The iterative nature of IPA necessitates sustained immersion in the participant's account to interrogate their 'sense making' (Eatough & Smith, 2006).

#### **3.10.1 IPA – Stages of analysis**

The process of IPA to explore participants' experiences involves various stages of analysis, referred to as 'painstaking analysis' (Smith & Osborn, 2008, pp.56) of each individual 'case' before comparison across cases. The outline stages of IPA analysis are in Figure 2 (Smith, Flowers & Larkin, 2009).

Figure 2 Stages of Analysis of IPA

1. Immersion in the data of the individual interview	Reading, re-reading – becoming very familiar with the data
2. Initial note taking	Making notes and compiling a list
3. Development of emergent themes and include participants' 'voice'	Starting to identify codes and themes
4. Clustering themes – developing a table of themes	Beginning clustering, this results in various iterations (Eatough & Smith, 2008) looking for convergence and divergence, any commonalities or anything of note.
5. Each transcript completed before moving to the next	A single case is considered first (Smith, Flowers & Larkin, 2009) The process repeated for each individual transcript
6. Looking for patterns across cases	The clustering of related themes across cases, again an iterative process, until hierarchical groups of themes begin to emerge from developing sub themes.
7. Analysis continues during the writing up	The iterative process that is aided by a reflective engagement with the data

The 'process' (Smith, Flowers & Larkin, 2009) allows for flexibility within an IPA study to uncover the uniqueness of participant accounts. I have included a more detailed account of the iterative process in Appendix 2.

### 3.11 Questions of reliability and trustworthiness with IPA

There is an issue with all research strategies concerning 'the relationship between data and social reality' (Blaikie, 2000, pp.120). Acknowledging that there will inevitably be an element of researcher bias as part of the process. This is not intention but acknowledgment that we make observations in the context of our own life experience (Blaikie, 2000).

Interviews using IPA need to have a flexibility to enable the participant to explore how they are making sense of the situation and for the interviewer to interpret relevant meanings. The claims made in the research are enhanced by credibility, transferability, dependability (Lincoln & Guba, 1985) and trustworthiness (Seale, 1999). Evidence supporting the findings need to be made clear through an audit trail to give credibility to the claims (Morse & Field, 1985). IPA requires adequate evidence supporting each theme and benefits from including background information such as characteristics of the participants.

Lincoln and Guba (1985) suggest providing a sense of the emotions, perceptions and beliefs that occurred during the interview. For dependability, there needs to be consistence and accuracy demonstrated by an audit trail and transparency of decision-making process. In order to demonstrate dependability and 'confirmability' (Holloway & Wheeler, 2010), I created tables demonstrating the raw data and codes, an example is in Appendix 8.

There were regular peer debriefing meetings with my supervisor to discuss interpretation, after independently reviewing the data (May & Pope, 1995).

Using an interview guide or prompts for the semi-structured interviews assists as evidence of a consistency of approach but with the caveat that each interview was committed to an ideographic approach. The aim of this was to capture the uniqueness of the individual's experience as much as possible and provide flexibility to enable participants to lead the direction of the interview within reason.

### **3.12 IPA in practice**

IPA is often considered in under researched areas where an initial exploration of a topic is the purpose. The typically small sample size indicative of IPA enables a detailed exploration to be carried out (Smith & Osborn, 2008). This fitted well with this PhD and the sparse literature available. The research process builds a detailed and holistic picture (Creswell, 2013) to gain an understanding,

incorporating data collection including recordings, observations and field notes of peoples' experiences that are being studied in the environment where these experiences take place (Denzin & Lincoln, 2005). The data collection process will be described in Chapter 4 (Part I) and Chapter 5 (Part II).



## **Chapter 4**

### **Part 1**

#### **Spousal carers' experiences of a LTIC**

## Chapter 4

### Part 1 - Spousal carers' experiences of a LTIC

*'While we can observe and experience empathy for another, ultimately, we can never share the other's experience, because their experience belongs to their own embodied position in the world'* (Smith, Flowers & Larkin, 2009, pp.19)

#### 4.1 Overview of the chapter

This chapter begins with a brief outline of Part I and includes a description of the recruitment and data collection process. The main body of the chapter focuses on the semi-structured interview findings. The chapter concludes with an interim summary and justification for Part II of the thesis.

#### 4.2 Introduction

Part 1 aims to explore spouses' everyday experiences of caring for their partner who has an indwelling long-term catheter (LTIC). Semi-structured interviews took place with six spousal caregivers to examine the complexities of their experiences and the impact on their lives.

Although the enquiry focuses on the LTIC, being pragmatic, it should be viewed in the context of their partner's long-term condition as its presence is likely to have an influence. My approach was to acknowledge the long-term condition as part of an ongoing reflective process during the study.

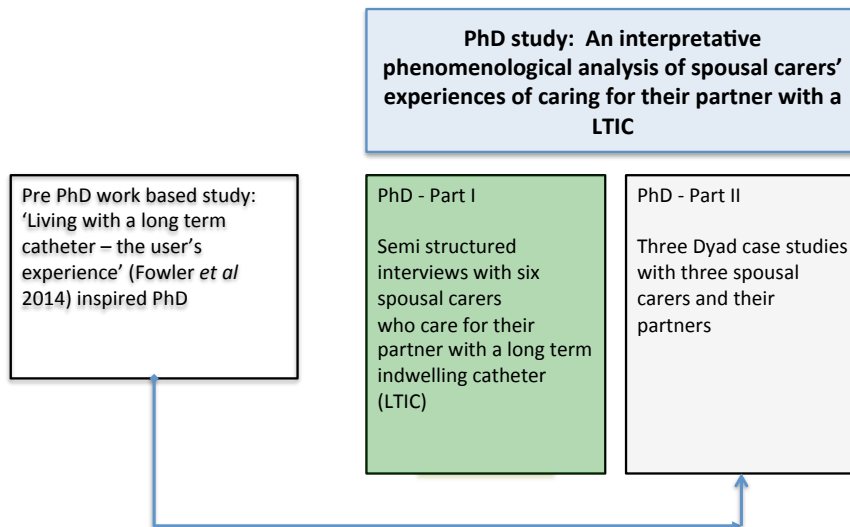
### **4.3 Objectives**

In order to achieve the study aims, the objectives of Part I were:

- To interview carers to gain an in-depth understanding of their experiences of caring for their spouse with a LTIC, to generate knowledge to inform HCPs and improve practice
- To explore how the LTIC impacts on the carer's daily life and to identify ways of coping and experiences of support.

## Part I – Carers’ Experiences

Figure 3. Phases of PhD – Carer interviews



### 4.4 Method

#### 4.4.1 Ethical considerations

Ethical approval for the study was obtained from National Health Service (NHS) Research Ethics Committee (Ref:09/H0102/44), University of West of England (UWE) Ethics Review Board Ref:09/HSC/09/53) and Avon Primary Care Research Collaborative Research and Development Department (2009-056). Appendix 3 contains evidence documents and the approval letter.

Participants were assured that their contribution remained confidential and their participation was voluntary, such that they were able to withdraw if they so wished at any stage during the process.

#### 4.4.2 Health and safety

Adhering to lone worker guidance from the University, I had an arrangement with a research nurse colleague, notifying her of my whereabouts.

Permission was granted by my employer to store the signed consent forms as the only identifiable patient information, in a locked cabinet in the secure research office at the hospital. Data stored on the computer relating to participant contact details was kept on a password protected computer and files were subsequently destroyed at the end of the study.

#### 4.4.3 Identification and recruitment

The inclusion criteria included unpaid, married carers (aged over eighteen years of age), living with, and caring for, their spouse with a LTIC (urethral or suprapubic). The indwelling catheter needed to be a 'long-term' bladder management intervention, defined as more than three months (Wilde, 2002b; RCN, 2012). The carer had to be involved with some aspect of LTIC care on a daily basis, such as changing or emptying the catheter bag.

Recruitment was via four district nurse (DN) bases in urban and semi-rural locations in the city (name). To identify the homogeneous group, purposeful selection for recruitment was with support from DNs. Their regular contact with the families meant they were aware of home circumstances and knew if they had support from a spouse. On my behalf, DNs made the initial approach with carers, providing them with the Participant Information Sheet for the study [Appendix 4] and identifying potential participants.

My initial contact was by telephone to answer questions and at that stage, if they were interested in participating, arrangements were made for a mutually convenient interview. I acknowledge the support the DNs provided was in part influenced by my previously working with them.

All participants consented for the interview to be recorded using a digital recorder. Logistically this made it easier to document data for analysis, enabling greater transparency with the IPA process. Although recording the interview had been discussed prior to the interview, I went to the interview prepared to take notes if necessary. The interviews were transcribed verbatim by the researcher. All the participants were offered a copy of the written transcript, but all declined.

#### 4.4.4 Suitability of semi-structured interviews and considering the alternatives

The appropriate method of collecting data was given careful consideration (Blaikie, 2000, pp.30). Prior to the decision to employ semi-structured interviews, alternative approaches were considered in the context of the study aims and methodology.

##### Considering structured and unstructured interviews

The alternative structured interviews were discounted as they offer little flexibility to explore the carers' experiences, as following preset questions. The research question and the choice of IPA require an in-depth, exploratory method of data collection. In contrast, the unstructured interview provides interviewees with complete freedom over the direction of the interview. Although the interviewer has a topic list, unstructured interviews can enable an experienced interviewer to direct an interview to stay within the area of the study, however the free reign can result in the interview heading too far away from the study focus. My concern was that carers might deviate to talk about their experiences of caring regarding their spouse's long-term condition which is closely aligned to the reason for the LTIC, but it is their experience of the catheter that I wished to be at the center of the interview. Other influencing factors were the limited time carers were able to give up to be interviewed, and my expertise to proficiently manage an unstructured interview with only one opportunity to interview them.

In the context of the enquiry, semi-structured interviews are revered by proponents of IPA and were my first choice. The approach is the most frequently

used method of collecting data to facilitate greater freedom and flexibility. They allow further in-depth probing as topics arise but a consideration was that as there was only going to be one interview owing to carers' commitments, semi structured interviews afforded a certain structure in a possibly limited time.

### The semi-structured interview – capturing one moment in time

These were conducted with six spousal caregivers on a single occasion; capturing one moment in time. Acknowledging the demands on their time fulfilling their caring responsibilities, recruitment for a 'one-off' interview was acceptable for this group and possibly influenced their decision to take part.

Interviews lasted between 28 – 45 minutes, averaging 35 minutes in length. The advantage of interviewing individuals at home meant that I met their spouse. This provided an additional insight in to their world, including the environment and their experiences. This supported my observational field notes and interpretation.

The initial plan had been to interview the carer without their partner with the LTIC present. This was with the intention of providing the carer with an opportunity to talk openly about their experiences in recognition that they might feel constrained or disloyal talking about their spouse in their presence. In reality this did not happen - either because logistically the layout of the house precluded this or, in case of three caregivers, they said they were happy to be interviewed with their partner present – citing they had 'no secrets'. Two of the partners who were present were unable to contribute due to dysphasia and/or cognitive decline/dementia. The interview with the one male caregiver whose wife was present, focused on his experience with occasional contributions from his spouse; although physically disabled she did not have any cognitive decline.

I was aware of the importance of establishing a good rapport with interviewees and approached the interview with particular attention to this. My experience as

a DN and Continence Nurse provided me with a good grounding in preparation for putting participants at ease and preparing for the potential unpredictability of interviewing. Part of planning and preparation included a review of the interviewing advice in relation to this methodology (Smith *et al*, 2009, pp.64), raising my awareness of potential pit falls and having a practice interview to review how effective the prompt questions were.

#### 4.4.5 Interviewing about a sensitive topic

Mindful that the interview potentially stirred up painful memories, participants appreciated a telephone call the next day to enquire after their wellbeing following the interview. This did not lead to further disclosures and suggested that a second interview would probably not have elicited additional information but reiterated the findings from the first.

There are aspects of this research that were potentially sensitive areas to consider when interviewing. Incontinence and by association the LTIC, is rarely discussed openly as a stigmatized condition (Elstad *et al*, 2010) that is considered to be private and personal. Added to this, I was asking them disclose information about their partner. I would suggest this was the reason why some caregiver's chose to have their partner with the LTIC present, not wishing to talk about them behind their back.

In exploring the LTIC in context of the complexity and dynamics of their relationship and how this might impact on their experiences, the research needed a sensitive and empathetic approach. When devising the interview guide, topics perceived to be particularly sensitive were explored later in the interview when participants were likely to be more at ease. My experience as a nurse talking about sensitive topics was again helpful to draw on. I made sure I did not end the interview with an emotionally sensitive topic (Corbin & Morse, 2003; Rogers, 2008) and in anticipation that the whole experience might evoke sadness I incorporated a 'debriefing' time at the end. I went prepared with details and information about organizations who offer advice to carers, should they find this helpful.



The positive 'therapeutic' nature (Morecroft *et al*, 2004) of interviews is evidenced in the literature; the 'unburdening' of a stressful time and having the opportunity to talk about their experiences (Corbin & Morse, 2003; Rager, 2005). Evidence from the carers in this study revealed that participants often agreed to take part knowing we would be talking about an emotive subject, but they wanted to have the opportunity to talk (Lowes & Gill, 2006) to help others in similar circumstances.

### Carer diary

The option of the carer completing a three-day diary was included if the interview had to be curtailed, as acknowledgment of the carer's restricted time and caring commitments. At the end of the interview, the carers were asked if they would like to complete a diary to record anything further following the interview. The use and result from the diaries are reviewed in Chapter 7.

### 4.4.6 Developing an interview guide

The semi-structured interviews were 'guided' by prompts [Appendix 6 Interview Prompts]. The initial interview guide was devised to answer the study question. This was informed by my past experience of interacting with patients and in conjunction with the literature review (Fowler *et al*, 2014). The guide covered key topic areas as per the study objectives. The emphasis was on encouraging participants to talk about their situation and LTIC experiences (Smith & Eatough, 2007; Smith, Flowers & Larkin, 2009), was not intended to be too explicit with questions (Smith & Osborn, 2008) and to avoid jargon (Harvey & Land, 2017). The prompts afforded flexibility to explore answers (Johnson, 2000; Baker, 2006) and not govern the course of the interview. There was an iterative process in relation to developing the interview guide which evolved and was modified as the interviews progressed, adding new elements if raised by participants.

During the interview, I was mindful not to intervene too readily when there were silences but gave participants time to think, feel at ease and not rushed to

answer (Brinkmann & Kvale 2015; Creswell, 2013). Reflecting on my previous experience of interviewing (Fowler *et al*, 2014), I concurred with Smith, Flowers & Larkin (2009, pp.67), that an interview is 'deceptively easy to do but is hard to do well'. My reflective diary was a very helpful during this time, to provide an opportunity to take stock of all the information and provide a contemplative space for myself.

Practical advice, such as memorizing the prompts for the early interviews, meant they were readily recalled (Smith & Eatough, 2007) and enabled flexibility within the approach (Kvale, 2007). I considered some degree of meandering was desirable as it elicited information such as the individual's priorities; the issues they wished to raise. I was prepared to take notes if they didn't want the interview to be recorded (Brinkmann & Kvale, 2015) however, everyone consented to being recorded and the unobtrusive recording device did not appear to hinder discussions.

Descriptive observations such as body language, participants' demeanor and the interview setting were recorded as far as practicable following the interview (Creswell, 2007). These were included as part of the interpretive process during the analysis either as an observation such as their awkwardness or as an adjunct to what they were saying such as their lowering their voice and appearing visibly embarrassed as they spoke. I also included my reflective notes, including 'hunches' (Creswell, 2007), which I made directly after the interview, and during the transcribing process.

#### **4.5 The participants**

The study sample comprised of six participants: five women and one man. They were white British aged between 58 years and 80 years (mean age was 61.5 years, median, 75 years). All were retired, one was university educated and had run her own business, the remaining five had worked in technical and clerical occupations. All five female participants cared for a spouse who was older, the one male carer was one year older than his wife. They were all the primary caregiver.

The LTIC users were aged between 59 years and 90 years (mean age 74 years, median 75 years). To maintain their anonymity, participants' names have been changed.

**Table 1 Participant demographics Part I**

Background	01 Gordon caring for Betty	02 Jenny caring for Phil	03 Beatrice caring for Clifford	04 Joyce caring for Jim	05 Mary caring for Paul	06 Judith caring for Edward
Age of carer	80 years	58 years	80 years	67 years	63 years	74 years
Age of LTIC user	79 years	59 years	80 years	68 years	66 years	90 years
Male/ Female	Male	Female	Female	Female	Female	Female
Type of LTIC	urethral	supra pubic	urethral	supra pubic	urethral	urethral
Time with LTIC	9 years	5 years	12 months	13 months	16 months	9 months
Reason for the LTIC	Surgery for spinal abscess - neuropathic damage	Multiple Sclerosis, Incontinence	Stroke, Renal disease	Parkinson's disease – urinary retention	Parkinson's disease, Incontinence	Enlarged prostate, not for surgery – retention & nocturia
Additional health conditions/ issues	Type II diabetes, obese, osteoarthritis colostomy, spinal damage, poor mobility	Immobile, dysphasia	Immobile, degree of cognitive decline	Poor mobility, degree of cognitive decline	Immobile, dysphasia, dysphasia, degree of cognitive decline	Obese Type II diabetes, immobile
Support in addition to DNs	No additional support or respite care	Employed carers x 3 times daily, occasional respite care	Employed carers x 3 times daily, plus weekly respite care	No additional support or respite care	Employed carers, no respite care	Employed carers x2 daily - week days only. Respite care on occasions
Family support	1 daughter and x2 sons, all live locally – carer considered infrequent contact	1 son living abroad x1 married daughter – lives near, has own health needs	2 married sons – one living abroad, one locally who supports	3 married sons live nearby - support from x1 daughter in law	X3 adult children - 1 daughter and x1 son living nearby, x1 abroad	2 daughters living away, x 2 sons live locally – x1 supports at weekends

Partners had their LTIC for varying lengths of time, ranging from nine months to nine years with the majority of the LTIC users having the device for a year. Only one LTIC user (Phil) had previously been using Intermittent Self Catheterization (ISC).<sup>1</sup>

In this phase of the study, there wasn't purposeful recruitment of carers who had a partner with a specific long-term condition relating to their LTIC; a decision I reviewed for the second part of the thesis. The six partners/care recipients had a LTIC due to neuropathic disease or damage and one man had an LTIC because he had an enlarged prostate which impeded his bladder emptying but as surgery was not an option on health grounds.

Pen portraits of the spousal cares are included in Appendix 5. These introduce the participants and provide contextual information to assist the reader. The pen portraits were developed from observations and the field notes I took immediately following the interview.

#### **4.6 Analysis**

This section provides an overview of the analysis using IPA (Smith, 2011). Following the verbatim transcription of the audio recordings, transcripts were re-checked for accuracy against the original recording. Understanding the value and importance of becoming as familiar as possible with the data, I found listening to recordings on the drive to and from work helpful during the analysis phase, particularly as studying part time. The aim was to keep the individuals' voices in the forefront of my mind.

The analysis of the six interviews was guided by the framework devised by Smith, Flowers & Larkin (2009). Each interview is considered individually and completed before beginning the next (Smith & Osborn, 2008).

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<sup>1</sup> \* An ISC catheter does not have a retaining balloon and it is (usually) self-inserted into the bladder to drain urine, once this is achieved, the catheter is removed.

#### 4.6.1 Framework of analysis

A detailed description of this framework is included in Appendix 2.

Each transcript was scrutinized closely to identify the individuals' experiences and impact of the LTIC, noting themes/subthemes and eventually merging themes that encapsulated their experiences. The themes to emerge were grouped together into superordinate and subordinate themes. These evolved during analysis, comparing and contrasting the themes, with some themes becoming less dominant with subsequent interviews. Initially the number overarching themes appeared large because they were frequently linked to more than one super-ordinate theme (Smith, Flowers & Larkin, 2009). I found using diagrams to visualize the development of the themes helpful, clustering the themes to form a hierarchy.

Analysis of the data extended to the language as well as the content. During this iterative process, I also considered what the participants didn't talk about, or if I had prompted a line of enquiry or they had initiated it. These issues were helpful when interpreting what might be a priority experience. An example of this relates to 'odour' which LTIC users were concerned about in previous studies (Wilde, 2008b) however, carers only mentioned it in terms of it alerting them to a possible Catheter Associated Urinary Tract Infection (CAUTI).

It was apparent that some carers had a particular agenda for the interview. There are examples where participants were vocal about one aspect of their experience. This primarily related to dissatisfaction with their partner's care or HCP's approach towards them. Others had questions to ask regarding problems with LTIC; seeing this as an opportunity to discuss queries or concerns with someone who might be able to provide an answer. On reflection this demonstrates the importance of HCPs providing the time to have a conversation with carers. Godfrey (2008a) reported that older LTIC users saw DNs as being very busy and they didn't like to bother them.

Although the analysis is presented with cross case comparisons, the ideographic

element of this approach meant that clarity of the individual's contribution remains evident through the use of quotes.

## **4.7 Results Part I - The experiences of spousal carers**

### 4.7.1 Introduction and overview of the results

When exploring carers' indepth experiences of the physical and emotional aspect of caring and the LTIC, what came to the fore was the impact of their early experiences and their transition to a 'carer' and the impact on their relationship. The interviews considered whether circumstances surrounding the catheter decision and the personal impact of their partners' pre-catheter symptoms, had a bearing on their post catheter experiences.

The home environment often proved to be a barrier and challenge for some carers in relation to their ability to carry out care. It was also the place where they increasingly spent the majority of their time since their partner rarely went out and they were not able to leave them home by themselves. A consideration for this was the LTIC.

The analysis across all six cases revealed four, inter-related, superordinate themes, concerned with aspects of the caregivers' experiences:

- The phenomenology of the environment and caring for the LTIC
- The catheter as a 'mixed blessing'
- The caring experience – which included their partner's dependency on them, changes to their relationship and their competing needs as a carer
- Their experiences of support with the LTIC

The themes were influenced by their partner's long-term condition despite my efforts to focus the interview on their experience of the LTIC. The subordinate themes, varied across the six participants' experiences. On occasions a clear hierarchy was evident within the theme for certain carers. On other occasions, what initially appeared to be a more major theme became a lower level theme or

part of a subordinate theme (Smith, Flowers & Larkin, 2009) in the final version because it only had resonance in one or two cases, all be it a strong theme for those individuals.

**Table 2 - Carer Themes**

Superordinate and subordinate themes across all six cases.

	<b>Super-ordinate Theme</b>	<b>Sub-ordinate Theme</b>
Theme 1	<b>The phenomenology of the environment</b>	<i>1a <u>Decision to downsize - 'the right thing to do'</u></i> - Adaptations – but still difficulties - Relocating and loneliness
Theme 2	<b>The catheter – as a 'mixed blessing'</b>	<i>2a <u>Lead up to the LTIC and catheter decision</u></i> <i>2b <u>Positive about the LTIC</u></i> <i>2c <u>Managing LTIC problems</u></i> - Doing the best they can
Theme 3	<b>The caring experience</b> – dependency, their changing relationship and their competing needs	<i>3a <u>Making decisions for them both</u></i> - Being fussy and feisty - Catheter changes  <i>3b <u>Impact of their changing relationship</u></i> - Sense of Loss - Care recipient's behaviour -'I live in a silent world' - Duty and marriage - Physical relationship  <i>3c <u>Competing needs</u></i> - Adjusting - Time - Respite care - Impact of carer's health  <i>3d <u>What will be will be</u></i>
Theme 4	<b>Experiences of support with the LTIC</b>	<i>4a <u>Negative experiences</u></i> <i>4b <u>Positive experiences</u></i> <i>4c <u>Impact on the family members</u></i>

Table 2 does not present themes in any hierarchy, rather they are presented in response to the study aims, apart from the first theme related to the

environment. This theme is included first as it was the opening interview question and places the carer experience in the context of their environment.

#### The opening interview question – ‘Can you describe your home?’

This broad question at the start of the interview was originally conceived to settle participants in to talking generally and provided something general and fairly innocuous to talk about. It proved to be a good ‘icebreaker’ putting participants at ease, but the replies also revealed an unexpected insight into the caregiver’s view of their home environment and the difficulties they encountered. Adopting the same opening question for all the interviews resulted in a descriptive ‘snap shot’ to accompany each interview.

#### 4.7.2 Theme I - The phenomenology of the environment

This theme related to the influence and impact the environment had on caregivers’ experiences and encompassed the difficulties posed by the physical space.

The initial ‘ice-breaker’, changed to become a sub-ordinate theme as it gained increasing prominence with each iteration. This was most noticeable when the environment had a negative impact on their ability to deliver care including managing the LTIC. Although their partner’s deteriorating long-term condition meant that carers involvement with supporting their spouse’s care needs increased, incontinence prior to the LTIC was exacerbated by decreased mobility as well as bothersome symptoms of urinary urgency and frequency. This meant that carers were often struggling to help their partner to the toilet prior to the LTIC.

I reflected that as a HCP in the community for many years, I was aware of the impact and challenges of the environment, anecdotally and from my colleagues’ comments and experiences. The home setting often has unique difficulties it places on patients, family carers and HCPs - such as confined toilets not designed for assisting someone, carpeted flooring and restricted space owing to furniture.



The general lay out wasn't designed for 'caring' as a consideration.

A further aspect of the environment was raised later in the interview when caregivers talked about having a part of the house that only they could access such as an upstairs bedroom. This 'out of bounds' area was where only they could go; something they did either consciously or subconsciously to be on their own.

Despite moving house and downsizing to make their lives easier and making alterations to accommodate their partner's needs, the challenges continued.

Adapting their home environment often created a less personal, more clinical environment with the addition of a hospital type bed and catheter related equipment such as supplies of catheters, day and night bags.

Whilst some carers were comfortable being at home for extended periods, others felt trapped, in some cases unable to leave their partner for extended periods if the LTIC bag needed attention. The 'sitter' would need to be able to deal with the LTIC such as emptying the bag if needed, similar to helping someone with incontinence. Those who had relocated to be nearer their adult children often faced isolation with the loss of social support from friends (Godfrey, 2008a) and away from the familiarity of where they used to live.

#### 1a Decision to downsize - 'the right thing to do'

The carers faced a dilemma; with their partner's health deteriorating, should they downsize and take the opportunity of moving closer to family for support, or stay where they were living? For the carers, this was the family home they had bought up their children in and enjoyed a social network of friends and neighbours.

*We down sized from a five bed-roomed house on the seaside, which I was very sorry to leave but um, Clifford worsened at that time and Colin, our eldest son, Colin only lives ten minutes away in [name of city suburb], so it was um, you know, the right thing to do to*

*come up here, but I have to say I don't like [city name]- it's like living in, um.. on the edge of London, you know...(Beatrice)*

Her unhappiness extended beyond her immediate vicinity, she felt isolated and couldn't acknowledge any redeeming qualities except that she was nearer to one of her sons. There was a transient feel to Beatrice's life, moving for practical reasons but in doing so her life was put on hold. She was still reeling from the psychological impact of her husband's failing health and moving from the home he had literally built for her and where they had raised their family. She experienced loss of two things that formed the bedrock of her life. Her life now was governed by her caring routine which included the LTIC.

The affluence of their former life was evident in their antique furniture which appeared incongruous in their current, very different house. 'The office' as she termed it was now Clifford's bedroom with a hospital bed, storage for catheter bags, continence pads and a hoist. For practical reasons there was no carpet; gone was the homely décor.

Similar to Beatrice, Joyce had moved with her husband Jim, to a housing estate in the suburbs. Joyce still felt isolated eleven years after moving:

*...[It was] all getting too much for me, so we downsized...it's just an ordinary, um small house, we moved to a smaller house because, um, before he had the Parkinson's, it started when we got here, but just because the boys had left home, I found it was getting..., not too much for me, but I was thinking, 'well when I get old, I won't want to do all that...(Joyce)*

Rationalizing the benefits of a smaller house, there was a realization that she needed to take responsibility for herself, hinting that one day she would probably be by herself. She increasingly used 'I' - 'I thought', 'I get old' and the vindication that it 'isn't much work at all', she puts a positive slant on her situation, something that continued throughout the interview.

In contrast, Judith and Edward had stayed in the family home although with some reservations on her part:

*Well we've got this enormous... (laughs) much too much space, um, because we had lots of children and we decided to stay here...ah...at...well it was too late for us to move basically when my husband became...well, disabled (sharp intake of breath), so we made it as much*

*as possible for him to live here as we can, and we have a 'Stannah' lift which goes up 2 floors and we've got a wet room and we've changed our lavatory so that....we've got a washer bottom (embarrassed voice) lavatory (laughs) so that he can get his wheelchair up and into it, and on to it, yes... so, made it as disabled friendly as possible (Judith)*

This quote illustrates the magnitude of the logistical difficulties trying to adapt a four storey Georgian house to accommodate Edward's needs.

Judith had a strained, light heartedness in her voice, attempting to mask her unease talking about the subject. Her choice of the formal word '*lavatory*', was also used by Joyce. Either this showed a generational or class difference with terminology or it was an indication of their awkwardness talking about this often 'taboo' subject for some people.

Mary also had no intention of moving from the home they had lived in for forty-one years, not because they had left it too late but through personal choice:

*We live in a four-bedroom house, there's no one here now, only Paul and myself. The children have flown the nest. One lives in Australia – our baby. So really the house is too big for us but we won't go – it's our home isn't it? Paul and mine's home...I don't want to move because none of my furniture would go in anywhere else (laughs), and I don't want new furniture at my, our time of life, and then it would cause a problem because I wouldn't be able to have all the family over for Christmas dinner and things like that. So we're quite happy here, we've got a stair lift so Paul's now upstairs – he's slept down for a year because we didn't have a stair lift in, so Paul's happy he's upstairs and can have a shower, good isn't it? (to her husband) (Mary)*

*Paul: yes (barely audible mumble)*

Mary citing her furniture not fitting as part of her reasoning for not moving was perhaps a euphemism for her being out of place. Similar to Beatrice, Mary tried to hold on to her past and good memories together in their home. Part of maintaining this was her determination to return to both sleeping in the same bed. I sensed an element of guardedness at the start of the interview, which I surmised was due to her husband Paul's presence. However, this was not so apparent as the interview progressed and, as she relaxed, her positivity also reduced. She justified remaining in the house to enable the tradition of having a family Christmas together; holding on to happier past times. She attempts to normalize their life, however Paul was totally dependent on her for all his care

and unable to move or speak. The importance of sharing a meal together as a family was a benchmark that was a measure of her QoL (Fowler *et al*, 2014; Cotterill *et al*, 2016).

### 1b Adaptations – but still difficulties

Despite alterations and adaptations to the house, difficulties were ongoing. A gradual deterioration in their partner's health and inability to assist them meant constant readjustments for the carers. At the time of the interview, all the caregivers were involved with aspects of catheter and personal care.

Adaptations such as grab rails and ramps were very visible reminders of the LTIC user's declining health and mobility. There was some variance relating to the extent of modifications they had made, many pre-dating the LTIC, relating to the long-term condition and pre-catheter bladder problems. Deterioration in their partner's mobility, unsteadiness and falls were difficult for some of the women to manage as their husbands were considerably taller as well as physically larger than them. Often with little or no outside care agency involvement to suggest equipment or support, they were still attempting to lift:

*...last week was the first time Jim had a shower for months because of course he can't stand up unaided and although we've got a seat there, I was a bit afraid of him standing up afterwards, of course I'm in there as well, getting wet through, it's a bit awkward... Oh, he doesn't go out there, he can't manage the steps ... And it was very difficult because um not being able to stand up, and at that stage we had bars and um we got these beds (profiling) you know these um...(Joyce)*

This extract gives an indication of the physical restrictions and symptoms associated with Parkinson's disease (PD); the loss of movement (Bramley & Eatough, 2005) in addition to the leaking catheter and the support needed with personal care. This passage is all about what Jim can not do. Joyce demonstrated stoicism and her interview described resigning herself to the situation, but at other times she voiced an underlying frustration. This extract is one of several where she downplayed the obstacles as - *a bit awkward* (Joyce) rather than acknowledging how unrealistic showering him was.

*... he's got a reclining chair but um, we thought it would be better for him because he finds it ever so difficult to get in and out of bed, in fact the only way he can get into bed is to, um, my son made a little platform he stands on at the end of the bed and he's got to crawl up the bed.... and ofcourse with the catheter, he can only lay on one... well with his Parkinson's he can only lay on one side anyway...so it's very difficult (Joyce)*

Joyce acknowledged the difficulties relate to his PD but also the LTIC which meant he can only lay on one side as the LTIC bag stand needs to go on the floor by the side of the bed. Joyce's approach, like all the carers, was doing the best she could under the circumstances. She refers to 'we'- 'we got' and 'best for him'. Her strategy to minimize as many difficulties as she could, meant that owing to the challenge of getting him in the car, they rarely went out *...because it's less trouble* (Joyce) and she had resigned herself to accept this.

### 1c Relocating and loneliness

Relocating contributed to loneliness for some caregivers. The loss of friends and neighbours were mentioned as well as an affiliation with the area. They were spending more time at home because it was increasingly difficult to leave their partner because the LTIC needed regular attention. This was a potential influence on their psychological wellbeing.

Since moving Joyce didn't feel she knew her neighbours:

*...because they all go out to work...they all go, we do know a few, but I mean only to say hello to, not awfully friendly with people because we're um you know, not going to work we don't see them (Joyce)*

She felt that as no one saw them as 'a couple' because of Jim's illness, even though their immediate neighbours were 'nice'. She had not made new friends and the absence of support added to her feeling isolated and unhappy about where they were living: *So it was the right thing to come here but I have to say I don't like [name of city]... (Joyce)*

This sentiment contrasted with carers Mary and Gordon who knew their neighbours and because they hadn't moved, were familiar with their neighbourhood and didn't talk about experiencing isolation. Gordon and his wife

still had the same neighbours for over forty years.

The opening question, 'Can you describe your home?' enabled many other aspects of to be explored in the context of the LTIC such as how carers managed change and their ability to problem solve and adapt.

#### 4.7.3 Theme 2 – The LTIC experience as a 'mixed blessing'

The LTIC as a 'mixed blessing' was informed by their early experiences and often evoked strong memories of the pre-catheter difficulties. Overall the LTIC was considered an improvement for managing their partner's incontinence and a positive intervention. None of the carers had any prior experience of a LTIC.

##### 2a Lead up to the LTIC and the LTIC decision

The carers recollected their partner's worsening bladder symptoms of urinary urgency and incontinence, they readily recalled the additional washing created by incontinence. Lack of sleep and exhaustion was an influencing factor in their seeking help. It was often the carer's difficulty coping that triggered a LTIC being recommended by HCPs:

*...he started off with that one (supra pubic catheter) because we thought um it would be ...less trouble (laughing)...yes, you live and learn don't you (laughing).... It was getting, we were getting up about eight, nine, ten times a night...because of course, um, they don't empty their bladders do they? (Joyce)*

Joyce understood the need for Jim to have a catheter because of incomplete bladder emptying. Overall, there was evidence of delay seeking help due to their spouse's decline over time – not in the sense of normalizing the situation but rather avoiding acknowledging the situation, despite not coping because they were so tired. Joyce acknowledged that the LTIC was, in part, to give her a night's sleep. Although she no longer had to help him to the toilet, Jim's LTIC had always leaked:

*... more so than him I think – because, ah, and I still don't get a night's sleep because I've got to get up and change the bed linen, oh it's very difficult...  
...just thought that it would be better for him because um, he wouldn't have to keep, you*

*know, keep going to the toilet and me taking him to the toilet all the time (Joyce)*

Joyce's irony demonstrates the raised expectation towards the LTIC as a 'solution'. Their experiences of disturbed nights pre-catheter were shared by others:

*...ah about a year ago, he started not being able to, ah, pee properly, he has an enlarged prostate and he's had it for a long time and it got worse and worse and worse and he used to go and sit in the loo practically all day, trying to...pee (lowers voice)  
...I was getting exhausted, being woken up to four times a night. When he discovered we were, what was happening, well he said that's no good, you need your sleep, um I think, he, um, doctor comes here now and usually we have open, you know, it's pretty...I think actually he did have an infection that minute... and I think that was one of the things the doctor... and I think he almost got him catheterised almost immediately (Judith)*

It was their doctor who 'discovered' what was happening rather than their seeking help that resulted in change; recognizing the problem, his suggestion of the catheter became the long-term solution. Their GP continued to support Judith, her stoically 'managing' rather than seeking help. Judith found it awkward talking about the topic despite her husband being in another part of the house and not able to hear our conversation.

For Mary, because of her husband's poor health, there were very few options left but an LTIC:

*...it wasn't going well, it meant a lot of washing, because I sleep with him in the bed, it means I was sleeping in it as well, so it wasn't nice (Mary)*

Similar to Joyce, Mary also struggles managing the washing generated by incontinence:

*...very frustrating because Paul couldn't tell you when... he wears continence pads, he's been wearing that for 3 years, it was very, very frustrating, not only the bowel part but the water because he can't tell you when he's going, so it's just that I do still sleep with him because I wouldn't have it no other way. I know I'm awake most of the night but that's my choice not his. He can't help it. (Mary)*

Although consoling and reasoning with herself that Paul couldn't help it, she escalates the degree of frustration relating to the time scale of his deterioration. Mary had always slept with her husband; the marital bed as a symbol of their marriage.

Although 'mixed blessing' was not a phrase used, it was the implied sentiment. From a pragmatic stance, the LTIC initially appeared the solution at a desperate time but in reality, it came with its own problems. In this example having adequate sleep is seen as the 'trade-off' for the problems of the catheter. This concept of practicing 'trade-off' became more prominent as the study developed.

### The LTIC decision

Jenny: *His bladder wasn't emptying fully... Because he was very unsteady at that time it was impossible for him to get to the toilet in time so that's why the catheter was put in originally, the urethral. We tried the...you know the 'self' one but he was getting so many infections'*

Interviewer: So, did you feel it was a decision that either of you had any input with...?

Jenny: *no, but it wasn't a decision I disagreed with ...because of the infections plus the fact that he was getting less and less able to do it (ISC), I was at work...so you know it had to be an indwelling.*

Initial attempts to manage bladder symptoms with ISC were unsuccessful. Her use of 'we', although it was Phil trying this himself, she considered it was something they were doing as a couple. Similar to five of the carers, she had been under the impression that an indwelling catheter, as recommended by HCPS, would improve their situation.

Similarly, Mary's view was from a more practical perspective, but within the context of equally bothersome symptoms associated with his PD:

*...it saves me a lot of work and a lot of pressure you know. I just wish he'd just have a bit more use in his feet to walk (Mary)*

The circumstances Gordon found himself in were slightly different as Betty, his wife, had major surgery for a spinal abscess, which resulted in spinal damage, affecting her bladder. She had been very ill and he thought she was going to die. At the time, the catheter decision was not his primary concern:

*Well I got used to the fact...I didn't have to do anything, 'cause it was...she had to have it right from the start, so the fact is, I see her in the hospital, at that time... she came out from hospital, I already knew she had the catheter...(Gordon)*



He accepted the LTIC, relieved to have her back and over the following nine years adjusted to it. Betty also had a colostomy.

Beatrice's experience of Clifford having a LTIC had involved some tenacity on her part as she saw it, plus the support of her GP:

*... in the beginning.... um I have to say in my impression of the district nurse was oh we don't want to do that....., see....., so I thought it's alright for you to say that, come and wash all my sheets you know that was my inner thought.....  
...She (her GP) said, 'oh rubbish, oh dear' she said, so what happened then on ...I don't know um, but I had a 'phone call some weeks later from the district nurse and she said, um... they'll be two of us coming in to fit his catheter...So I thought, oh thank god for that, so something the doctor must have said um, in relation to both of us, I think um set the ball rolling and we haven't looked back since.  
...So, you know it's really been a boom (Beatrice)*

She considered the DNs were unsympathetic to her situation, her use of sarcasm illustrated her exasperation. Beatrice saw her visit to the GP, who was treating her for depression and with whom she had talked to about her difficulties coping, was instrumental in the LTIC. However, no discussion had taken place about the possible negatives of the LTIC.

*Well our doctor told us about it obviously ...because like you know it was him who said you know, in the end, he (Jim) would have to have a catheter and I think the consultant, of course, I forget now, you do forget...No, I think he must have explained and we were quite agreeable to have, have them on anyways... (Joyce)*

They were very much guided by the doctor's recommendation and an assumption that he would have explained about it because they agreed to it at the time, demonstrating the trust they had in him.

### 2b Positive about the LTIC

Overall, carers perceived the LTIC as a positive intervention in the circumstances:

*It's definitely worked as far as we are concerned, well for me it has – because it's meant I've had some rest (Judith)*

Mary's initial misgivings were superseded by the practical advantages of the LTIC:

*He had one in there (hospital) then I weren't happy but then when I got home I thought 'this is easy', you know, I've got no washing and I take him down the caravan just for two nights, a weekend and I thought 'this is nice, I don't have to keep going up to the launderette....I think 'oh God', I've got no washing now – you know? And I'm getting a better night's sleep (Mary)*

Being realistic, the LTIC was an improvement on previous interventions:

*... No complaints about the catheter at all...not at all...and um I don't think, I haven't looked back...*

*... it's the best thing that's happened for Clifford and for me – because um doing condoms was absolutely hopeless (Beatrice)*

Experience of fatigue, not getting enough sleep and not coping pre-catheter, the carers were desperate to welcome something that would help:

*...and it's been, in that way, it's been fantastic because we get a brilliant night's sleep (laughs) and he doesn't sit in the loo all the time... So that's, from the point of view, it's been good...(Judith)*

### 2c Managing LTIC problems

The accounts revealed carers considered they were doing the best they could. Their accounts often suggested poor understanding of the LTIC and they were ill equipped to manage when problems such as blockage and bypassing did occur.

Phil's LTIC problems had been on going from the beginning:

*...from 4 May to 21 October there were 21 emergency changes of catheter (Jenny)*

Several considered themselves 'lucky' if they hadn't experienced any problems; which suggests that DNs had talked to some of them about the potential problems with the LTIC. Judith was empathetic towards how this must be for her husband:

*...the down side (speaking slowly) was that it started to, he started to have it changed practically every 10 days which is not a nice thing to have (Judith)*

Despite Joyce's aforementioned initial expectation for the LTIC, Jim's catheter had always leaked:

*I might have to get up and do the bed and you know, yeah – still.  
... there's nothing they can do about it because with Parkinson's, you get the um... and it's happening during the day as well - and of course during the night. He don't wear pads during the day because they're not very comfortable I shouldn't think, to wear the pads but um you don't know when it's going to happen see, so I only you know, so I've got to change him – and by the seat and everything (laughs) (Joyce)*

Joyce's fatalistic approach was to accept what was happening, justifying why he did not wear pads for the leaking LTIC, owing to possible discomfort even though it resulted in additional work for her. She justifies setting an alarm to wake herself at night to check the LTIC:

*.... that's no problem at all. I always get up once a night, I put the light on to see that it's going into the night bag... every morning when I wake up, I help him get up, like, 'oh, is the bed going to be wet? – it's not', um if the bed's going to be wet, he tells me during the night because it gets uncomfortable (Joyce)*

Since the LTIC they had separate beds but remained in the same room. Her approach was in contrast to Beatrice who slept in a different room and employed carers to put Clifford to bed. He had an alarm to call her during the night if he needed.

The initial positives that Beatrice saw had been replaced by increasing LTIC problems which meant it now needed changing every six weeks (rather than 10 – 12 weeks) and leaked, resulting in Clifford also having to wear a pad.

LTICs bypassing and leaking was also an experience for Betty and carer Gordon. Betty, the LTIC user, was present at the interview. Gordon appeared out of his comfort zone giving his opinion on his wife's LTIC: *It isn't any problem at all really...(Gordon)*

This was in contrast to Betty's comment:

*...last time I was leaking very badly, my pad absolutely soaking wet for the last couple of weeks. Well, when she (the DN) come, I said to her about it, when she took the catheter out, it was blocked half way, half the thing was blocked...and I ah, and she said like, in future if you leak like that, please ring and I'll come and change it...(Betty)*

The interview with Gordon and Betty present had a 'he said, she said' element to it. Their interaction during the interview was an additional influencing factor for Part II of this study and the dyad case studies, to capture the interaction between the couple and their experiences and relationship.

Throughout the interview, Gordon attempted to shield Betty from any potential awkwardness or embarrassment however the few comments she made were frank and open suggesting she wanted to contribute. She found the leaking difficult to manage and was looking for solutions. I suspected he did not appreciate just how much the leaking bothered her:

*Betty...yeah, yeah, I've gone about a fortnight now...my pads are quite dry aren't they? I don't like to go out without them. And several times the balloon had gone down and blocked....along the catheter*

*Gordon: (smiling voice) yes, we've had that happen a couple of times....twice it happened at night didn't it?*

This conversation finished with an exchange of laughter, which peppered much of their interview as they shared the humour of the situation they found themselves in and it released any tension.

'Doing the best you can' was a sentiment that ran through all their experiences. Beatrice saw caring as her domain and although she employed carers to support - she monitored that care. The focus of her attention was pressure area care as it was something she could do, priding herself that:

*...he hasn't had any infections.... only had a problem with it (the LTIC) once... I just make sure that he's um, comfortable at night with a change of bags and um I always cream up here, he's never had bed sores ... (Beatrice)*

The advice 'encourage drinking' is synonymous with part of the approach to prevent CAUTIs (Wilde & Galvin, 2007) with evidence promoting 'optimal fluid intake' (Wilde *et al*, 2015a). The expectation from HCPs that they should be encouraging their partner to drink more was challenging, although Joyce had a practical solution:

*...I think he did have some, um, an infection once - because we've still got the tablets. They say about drinking lots of water but he don't drink lots of water but he drinks lots of tea...which is water (laughs) And the way I make the tea, very weak, I mean it's um, you know, it's all right, so no, we've never had any trouble... (Joyce)*

Mary understood that the likelihood of CAUTIs was high, reasoning that luck had a part to play. Mary's husband Paul had dysphagia and she resorted to giving him drinks via a syringe posed a high risk of choking:

*He's been really lucky that he's only had two water infections since he's had it (LTIC), so that's quite good. But that is a problem - he had the infections because he doesn't drink, so I have to give him juice through a syringe into his mouth (Mary)*

Encouraging drinking sounds innocuous but this often loomed large for the carers. It involved a degree of insistence and persistence, often without much success:

*... ah, he has 'forced water' (laughs)...a big carafe of water on the table to help himself to...actually it doesn't work ...(Judith)*

Jenny was irritated that the DNs continued to ask her if her husband was drinking enough whenever the catheter was problematic although she kept her humour/sarcasm to herself:

*Yes, I mean he drinks a minimum of two to two and a half litres a day and I make sure of that and I would still get asked by the District Nurse how is he drinking? 'No, no, I don't bother you know!', I find that quite insulting... to accept sometimes that someone actually does do it right, that they do follow the rules to try and stop things happening (Jenny)*

She resented being questioned about Phil's care, seeing herself as doing the best she could:

*We've had such unbelievable bad luck really with the catheters. If he hadn't started off so badly, if he hadn't had MRSA immediately it would have been different I think, we might have stood a better chance (Jenny)*

Unlike Judith and Mary, Jenny's husband Phil's LTIC had always been difficult, similar to Joyce. The terminology the carers were using - 'he's been really lucky' (Mary) and Jenny's comment above that he might have 'stood a better chance' if he hadn't had an infection, reaffirms the unpredictability and problematic nature of LTICs and the external locus of control, that had nothing to do with them.

Jenny's contact with DNs reinforced her view that it was about '*bad luck*':

*Well judging by what the district nurses say, no, I don't think it's that common, I could be wrong but I don't think it's that common* (Jenny)

There was a notable contrast in Joyce's approach to dealing with problems and being more accepting, as opposed to the proactive approach that Jenny had. However, her only gauge for knowing what others were experiencing was via the DNs resulting in uncertainty about her situation. To preempt difficulties, she was very methodical and organized, educating herself about the LTIC via the Internet, asking HCPs questions and being assertive with Phil's catheter management.

Understanding of the LTIC varied across the group, as did individual involvement. The LTIC had initially improved their lives but over time it had started to block requiring interventions with some carers taking on additional care:

*...about 2 - 3 months ago, the doctor suggested that I flush it twice a week, well, he suggested the district nurse but she said actually you can do it.... which ah, so I do that twice a week...*(Judith)

Judith had been delegated this job by the DNs. It was unpleasant to do, but ever obliging, she saw the logic in her doing it:

*...well I thought it quite ridiculous for the district to come when actually I can do it (smiling voice) well, it's not, I mean, none of these things are particularly lovely are they (smiles)?* (Judith)

Although Judith complied with the suggestion, the slight reticence suggests that she had she had to comply with resigned acceptance. If Judith was obliging and understanding, Jenny was, in her own words '*feisty*'. She voiced resentment, often anger about her situation, which constantly threw up challenges as she tried her best to care for Phil:

*The catheter side is totally me, um...you know if there are any problems with the site or anything else to do with the catheter, obviously the carers are not really that capable of doing anything* (Jenny)

Jenny's involvement included a '*bit of everything*' which also included flushing the catheter. She appeared to take it in her stride but her resentment was omnipresent. She was derogatory about the capabilities of others but resentful of their expectations that she would carry out catheter 'washouts'<sup>2</sup>. She found herself in a constant struggle – she has become experienced and practiced in caring for the LTIC, on the way losing trust in HCPs ability to do anything as well as she could. Her conflict was that the more she did, the more they appeared to let her, and her role become all-consuming.

*...I'll do the wash out if I think it's blocked...because they know I can do it... I'm an easy option... (Jenny)*

Being in control of her husband's care was a reaction to the early setbacks; when she took charge frustrated by not getting appropriate help as she saw it, things improved; seeing herself as his advocate, fighting on his behalf:

*He was bypassing, there were stones in the bag, um it was just a nightmare. And all I would get from the District Nurses was they'd never known anything like it, the GP wasn't interested because she said I'm not an urologist but didn't refer me, so I rang Professor S [name] who's the MS specialist and he got us under the urologist that was working for him and he arranged another cystoscopy but in the meantime I asked the GP if they would put Phil on Augmentin because I felt a really hefty dose of Augmentin might do something. I think I've had to make all these decisions I've had to push. And I'm doing it all, I am deciding what he is medicated with and I'm not medically qualified. (Jenny)*

#### 4.7.4 Theme 3 – The caring experience

This super-ordinate theme was about their caring experience and encompassed their changing role, particularly their partner's increasing dependency on them, including LTIC care, and how this impacted on their competing needs.

Marriage vows and duty were alluded to with comments such as '*because it was my husband*' (Mary). This theme represented carers' experiences of adjusting to caring within their relationship. The influence of their partner's state of health

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<sup>2</sup> Note on terminology - Catheter irrigation involves flushing water or a solution into the catheter tube using a sterile syringe so that the liquid goes into the bladder and en route clears any blockage from the catheter tube itself. The idea is that this helps the LTIC drain and prevent blockage of the catheter.

and the challenges the LTIC raised, added complexity to managing their partner's care.

### 3a Making decisions for them both

The carers were needing to taking increasing responsibility for care and for some this eventually resulted in their partner becoming entirely dependent on them for all aspects of daily living. This change was reflected in the language they used; describing the past as 'we', in contrast with the present, they spoke about 'I'.

Taking greater responsibility affected the relationship dynamics and was accompanied by restrictions to their lives as their partner took up more of their time. Making decisions required greater self-reliance from carers; although a number of the female carers now consulted with their adult children about decisions, as the ability to communicate with their partners was affected by impaired cognition.

Beatrice saw herself as someone who coped and got on with things: *I'm not letting anything get me down...*(Beatrice). Her approach to life was more determined since a recent health scare with cancer and she was more assertive regarding her husband's care.

Joyce also saw herself as taking charge of the situation and defending her husband: *... it was definitely me, I do most of the talking anyway because Jim can't get his words out properly, it's a bit awkward* (Joyce)

She was embarrassed for him but just as she took over the care of the LTIC, she also spoke up for him, particularly if his dignity was threatened. Throughout her interview Joyce recounted her increasing confidence and felt empowered in her role. She described a time of transition, as he was able to do less including and making the decision regarding the LTIC: *...we thought it would be better for him*



(Joyce). The 'we' that had previously been her and her husband was now her and their son.

Mary wanted to do 'the right thing' for Paul's QoL as she saw it even though it might potentially be detrimental to his health:

*...I think as well they weren't happy with me because they wanted Paul to have the PEG\* while he were in [name] (Hospital), and I refused to have it, because it's my problem, not theirs, and he's got nothing left in life anymore and the only thing he's got is the food going in his mouth, which he enjoys. Until he gets a chest infection then I will consider it, apart from that, no, so, they don't like that (Mary)*

She challenged medical recommendations regarding the PEG<sup>3</sup> tube she considered eating was one of few life pleasures he had in life and his risk of choking was an acceptable trade-off.

Carers Joyce and Mary were proactive in meetings with HCPs because of their husband's inability to speak whereas Gordon assumed the lead in consultations with HCPs despite his wife Betty not having any cognitive impairment:

Gordon: *well actually I've got a lot to say anyway so I always get involved! (laughs)*

Betty: *he does all the talking, I just ... (stops)*

Gordon: *... I think the thing is we've been married so long and it happened so late in our married life, by that time you're virtually...you know, these things don't bother you do it? ...it could be a problem I suppose for young people, that, who feel, you know...*

His answer morphs into his explanation of the dynamics of their marriage; being so used to each other, that he considers he knows what Betty thinks. I suspected Gordon had always assumed the lead with decisions in their relationship however since Betty's poor health, knowing that he almost lost her, he was determined to care for her. The aspects of care that he found difficult to adjust to and acknowledge that he did, were intimate activities such as changing her pad.

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<sup>3</sup> PEG Percutaneous Endoscopic Gastrostomy – a feeding tube is passed through the abdominal wall into the patient's stomach enabling them to receive fluids and nutrients – for Paul, this was due to dysphagia

When Paul's mobility deteriorated during a hospital stay, Mary felt she had entrusted his care to the hospital but without her there to support him with mobilizing, his condition had worsened. She became increasingly angry about his care which culminated with his falling out of bed:

*'...well angry, because it was my husband, but then at the end of the day, there's not enough staff and they don't know about everyone's individual needs. That's what it's all about, isn't it?'* (Mary)

She offered an explanation that they cannot know him as she does and ultimately she believes that she is the best person to look after him. In this quote she empathizes with their difficulties caring for her husband but ultimately blames the hospital's approach to staffing.

### Being 'fussy' and 'feisty'

Mary and Jenny raised concerns for care recipients in response to their poor experiences:

*...it makes me angry for people who don't have someone like me, you know that...I can't imagine how someone on their own can fight like I've had to fight just to get care'* (Jenny)

Both described themselves as 'feisty' in their approach. Jenny illustrated this when trying to get her daughter with spina bifida the appropriate care and treatment, it was Jenny who fought for the support:

*Jenny: she's got a husband but he's not feisty like me*

*Interviewer: ... you describe yourself as feisty...?*

*Jenny: I am, I'd take anybody on, I don't care'*

Jenny's determined approach made her question her husband's care and being prepared to 'fight', mirrored Mary's sentiment, as she saw no alternative. Their choice of words to describe their approach had negative connotations which they were aware of, associated with being aggressive or, as in Beatrice's case, interfering. Beatrice saw it as her responsibility to make sure no harm came to her husband, taking her responsibility very seriously, it included checking up after the agency carers:

*No, we've never had infections but um I am paranoid about everything being washed over with disinfectant and I get through bottles of it, um, having seen, I have seen in um, a friend of mine down in Bognor, this is a long time ago, had died of it, her father, but nobody ever*

*washed over anything with a Dettol or disinfectant and I think that's very important, even the sink. When the girls have gone they leave everything beautifully tidy, but I go down there, oh, go 'round the sink - it's just how I am.*  
*...I don't want any trouble, you know so it's worth that five minutes. (Beatrice)*

Beatrice was aware of infection risk with the LTIC; the implication that infection could kill her husband. Although she downplayed what she did as being worth the additional effort, there was a sense of her anxiety that this might occur. Her reaction was to resort to something familiar and disinfection features heavily. The 'girls' she refers to were the agency carers. She was not ready to trust them, or relinquish her control: *...when they've gone, I still have a look (Beatrice)*

There were some aspects of catheter care that Beatrice preferred to do herself: *'... because, um, I'm a bit of a fuss pot, I like to do the day and night bags (Beatrice)*. The implication was that if they do not attach it correctly, it could leak resulting in work for her. She uses the term '*fuss pot*' – rather than describing herself using a positive term such as 'thorough'. Mary describes herself positively as '*up to date*', but also as '*fussy*':

*I'm very up to date, I'm one of these fussy people, I've got to have everything organized...I get on people's nerves. Like that one (folder) is all about pee ....and that one is my matron....and one's the district nurses... (Mary)*

Mary's comment that she '*gets on people's nerves*' suggests that those around her may have commented as such. She later mentions that the DNs and her daughter-in-law had suggested she had more help.

The idea of being '*fussy*' and terms used by other carers such as '*fighting*' '*fuss pot*' and '*feisty*' reflected how they saw themselves, ultimately trying to maintain control of their lives. Beatrice had her own high standards and although she acknowledges that one carer is '*extremely efficient*'; her choice of word was '*efficient*' rather than kind or caring.

### Catheter changes

These were a significant activity for carers. When DNs came to the house there was a degree of uncertainty about whether or not to be present when their partner's catheter was changed to monitor the situation:

*I watch them do it.... I would be concerned if they hurt Paul (Mary)*

Mary didn't have concerns about a different nurse catheterizing him each time. Jenny was present some of the time but very much saw LTIC changes as the DNs 'job'. Judith, similar to Mary, had recently been asked by the DNs to take over irrigating the catheter, stayed to support her husband:

*I've been there when it's been changed and I watch...you know...he doesn't really want me not to be there (smiling voice) he doesn't like it - he doesn't like having it done and it's nearly always at night which is infuriating...(Judith)*

Edward wanted Judith present for emotional support as it was most likely uncomfortable as well as being an intimate procedure.

During LTIC changes Gordon had a supportive role for Betty and the DNs:

*...um...hovering, let's put it that way - it's only...the nurse does all the technical stuff like, you know, I'm just there to take the stuff away which she doesn't want and that sort of thing, get the table and that ready - the little table there, takes this upstairs at night, they usually tell us they're coming and they usually come, um...to arrange to come in the morning, like, as she would be dressing, so ah...that way, we get all the stuff out ready - we've got a box with their, you know, equipment there ... (Gordon)*

Gordon liked to oversee proceedings with military precision. Preparation for DNs visit starts the day before. He refers to 'we' getting the 'stuff out ready' although it was only him who was doing this in reality. He focused on practical tasks he could do, such as the moving a table. A LTIC change was an intrusive procedure to observe. This quote also demonstrates Gordon's relief to talk about something which is less intimate - such as the practical preparation he does.

### 3b Impact of their changing relationship

Gordon and Betty were both present for his interview which enabled me to observe their interdependence, which was particularly evident. They shared a

camaraderie, supported each other and used humour to recount when things hadn't gone according to plan:

Gordon: ... unfortunately one day, instead of having the thing up (tap on catheter closed) there we had the thing down there (open) ...which meant to say.... (both start laughing)....I was going round the supermarket...(laughing)...

Betty: all round Tesco (Gordon laughing)...luckily I had trousers on...

Gordon: dear, dear...wondered why her feet were getting wet (chuckling)...

In reality Gordon was doing most of the caring, including Betty's personal care. Like many carers, he minimized and downplayed his contribution as a protective strategy to deflect any embarrassment and protect her dignity:

*Well yeah (matter of fact), it's just a matter of...the only thing I get involved with is, to be honest...is ...sometimes I bring a jug in, but she usually goes out herself and all I know then is, that she's used the jug and literally... It (the LTIC) doesn't really affect us...when she goes to bed of course, she has a night bag and all that means to say that I connect a bag like...so...(Gordon)*

It was apparent from the beginning of the interview that for Gordon and Betty their approach was as a partnership; Betty's health scare had amplified this further. There was great pride in Gordon's accounts of how they managed together despite the challenges, as Betty was obese and not physically able to do very much to help. Their house was small and she used a bariatric chair, wheelchair and hoist. There was little space to manoeuvre and damage to doorframes and walls was evidence of the difficulties he had moving her from the lounge to the bedroom.

### Sense of loss

Since the deterioration of their partner's health and increased dependence on them, there was a sense of loss and sadness as they tried to adjust. This was particularly evident when Judith was asked if the LTIC had affected their relationship:

*..oh yes of course (interrupts my question, preempting what I was going to ask) ...oh yes, without a doubt, I mean...(starts crying)....(pause)... We've worked together a lot like that you know. The last, I don't know....two years....we've sort of ran a small business and he doesn't do that anymore...it's one of those things...I knew you were going to ask me about (whispers) it... (Judith)*

When she agreed to take part in the study, she had psyched herself up to talk to me, aware that talking about their relationship would be likely to come up; her emotions about this time were evidently still very raw. Despite being upset, she wished to continue with the interview. I suspected she hadn't shared her thoughts and talked openly about how she felt as her reaction was immediate, having bottled up all her emotions. They had been married for forty-eight years, worked together running a business and were now facing uncertain times.

Judith was struggling to come to terms with many of the changes in her life. Edward was the most recent LTIC recipient, just nine months. Judith was trying to adapt to the practical changes first since Edward's stroke, his immobility and finally incontinence resulting in the LTIC. It was the realisation that from now on, things would be very different:

Judith: *It's one of those things about...because the person isn't the person you were with in the first place. Actually, my husband's mother lived till she was 104 – so my advice to anyone is don't get involved with someone much older than you!*

Interviewer: *I was going to say, you seem a lot younger*

Judith: *Yes, I am*

Interviewer: *Can I ask you how old you are?*

Judith: *I'm 14 years younger – I'm 76 and he's 90*

Relationship dynamics can change, roles become re-negotiated when one partner becomes a carer. Judith and Edward's partnership had been both a personal and a working relationship. Recent changes had affected their interdependence. In Judith's case, the resulting imbalance caused her to re-evaluate her life. At the end of the interview she reflected on their relationship, feeling very despondent about her future. Above is a particularly poignant extract from Judith, part of which has been to express her loss of self, as if her life was over which made her circumspect about marrying someone older and giving advice to others not to do the same. Her concern was that her life could be caring for him for years.

*Care recipient's behaviour – 'I live in a silent world'*

In addition to physical changes associated with the long-term condition, care

recipient's cognitive changes and/or dysphasia meant that for some of them there was little conversation. If their partner had reduced mobility, they became isolated: *'I'm afraid I don't talk much to people...'* (Joyce).

In some instances, care recipients chose not to talk to their partners:

*...it does get me down because I live in a silent world, Paul doesn't talk to me, but he talks to the carers – and he laughs with them. Anyone that comes... he listens to everything I say... anyone that comes he just shuts his eyes if they're talking to me... you know? He just wants me all to himself, like a child* (Mary)

Mary felt bruised that sometimes her husband purposefully chose not to talk to her. His non-verbal communication, when he closed his eyes, was his protest that he did not want visitors to talk to her. She had very little interaction with others and restricted time away from the house therefore knowing this might be his reaction if she did go out meant leaving him was even harder. She excuses her husband's behaviour as *'not him'* to hide her hurt, attempting to empathise, she explains it as *'child like'* behaviour and not wanting to share her.

*I'm fine, I'm happy to look after him. It does get me down and I do get upset. They were here yesterday, they said I've got to have more time out. Yes, I would though I know Paul to don't want me to because...but I do when his mates come in, I go on out for an hour they don't go...and then he sulks, when I come back, he doesn't normally talk. It's really...but then...(Mary)*

The DN's suggestion of *'more time out'* in response to the situation shows understanding of the situation and awareness of the added stress his behaviour caused despite all her dedication and care.

*No, I can't imagine my life without him, even though he's only sat there, and I get cross sometimes...there you go, you can bloody laugh at the carers but you can't laugh at me! don't you?* (Mary)

This quote sums up the sentiment from many of the female carers. However, I felt it was an uncomfortable conversation with him sat across the room from us, Mary talking about him not being around any more. I was aware I was only hearing one side of this experience.

Gordon and Betty were an exception, although it would have been difficult for him to voice how he felt in front of her, equally I could not imagine him doing this. He did not present any evidence as seen by other carers of this type of controlling behaviour.

On occasions carers had arranged for friends to come and sit with their spouse if they went out:

*...but then it came to a pitch where he didn't really want me to go out you know...and he didn't really want anyone in with... (Joyce)*

Similarly, Judith felt awkward about going away/respice without her husband but she too dreaded the consequences on her return:

*Well even if...I don't want to, well Cornwall's quite far, I wouldn't ...a friend of mine said to me the other day – how about coming to Istanbul for a week (laughing voice) well, I'd like to do that but I don't actually thrive on going abroad I think...*

*... I actually broached it – going to Istanbul because this friend of mine only said it two days ago, but the other...he always deteriorates when I'm away. And when I came back, he's nearly always just a bit low, he hasn't been able to do his exercises, you know, I think...that's...that's I mean a big, big deal of emotional blackmail...I try not to.... just to pick up the bits when I come back (Judith)*

Carers' horizons varied greatly – Judith was considering going away for a break and Joyce struggled to go to the nearby Sainsbury's for half an hour.

Despite carers recognising their partner could not help the way they were, they still felt annoyed by their behaviour:

*... I mean he can't help it, I know he can't help it, but it's just, it's just so annoying and sometimes you think oh dear...but I manage not to blow my top, but I do get a bit impatient sometimes because um but as I say its um it's not the catheter, twelve hours no trouble, it's his Parkinson's...that's the trouble, but it's not the um not the catheter apart from wetting the bed which you can't do anything about... (Joyce)*

Judith acknowledge that: *he finds it hard if I'm a bit grumpy (smiling voice), grumbly about something.*

Despite their efforts, carers did not always feel appreciated but it was important to her pride that he had the best care she could provide:



*... so we make sure that he's properly creamed up. The girls do all his bottom before he goes into bed, so you know I mean looking at it as an outsider, he's very well looked after, really, very well looked after, he doesn't think so sometimes, but there you go. (Beatrice)*

### Duty and marriage

Interviewees 'assumed' the role of carer over time and whilst some rose to the challenge, others experienced a degree of resentment, particularly if they did not feel they had any control over their changing situation. Views expressed related to 'marriage vows' and 'being together'.

Interviewer: *Do you think that the marriage vows have a part of play in a care situation?*

Judith: *I sometimes think he wouldn't manage it if it were the other way 'round (laughs)*

Jenny used the term 'duty' – caring out of love for her spouse: *... well he obviously can't do anything can he? I do it out of duty really (Jenny)*

Mary's devotion to her husband was influenced by a dramatic incident when she was taken seriously ill on a holiday, emergency surgery and a month in intensive care:

*...he just went to pieces, he just went to pieces...so he just couldn't live without me...(Mary)*

In addition to her strong sense of duty, Mary's interview contained a great deal of compassion:

*...it's wonderful, because of Paul...I've never wanted for anything in my life, I've done everything I wanted, he's never stopped me and he's given me everything I wanted in my life, so he's just a fantastic dad, husband, he's never been out of work, he worked for 42 years before this happened and this happened because of me...(Mary)*

The same sense of duty was also present in Gordon interview [3b] with the sentiment that they were a 'good team'.

### Their Physical relationship

Making sure they had adequate sleep in order to cope with caring was now their priority and there was an end of physical intimacy and sex with their spouse. Although they acknowledged the change in dynamics in their relationship, for the majority, not sleeping in the same bed was a symbol of their changed

relationship. When they talked about their sleeping arrangement, those that now slept separately felt it important to explain why they had moved to a different room for practical reasons. For some there was a degree of embarrassment about this as if it was a betrayal of their marriage, what Rolland (1994, pp.1) describes as '*relationship rules and sacred boundaries*'

Their role had evolved to that of carer and a more platonic relationship. Routine at night varied with the majority of carers sleeping in separate rooms though for some there was a slight unease admitting to this. Physical and intimate contact with their partner was now caring for the catheter and personal care.

Gordon interpreted my question about the impact on their relationship as if he expected that I would ask:

*Well ah, you're talking about sex aren't you?...the truth about this is, I was not in a condition anyway, as it had no effect, because it was not happening anyway. Right, so that has not been affected...to be honest on the age of people...I'm 80 years old...and ah Betty here is a little bit younger, no, I'm 80 years old and to be honest, I've gone beyond it if you like (laughs) (Gordon)*

He was visibly more relaxed talking about generalities rather than anything of a personal nature (Smith, Flowers & Larkin, 2009). As a couple, they shared a sense of togetherness and reciprocal caring.

For practical reasons Jenny and Phil slept in separate rooms and Phil had a hospital bed:

*No, I've accepted that because it's been a long time, you know I'm going back probably twenty or thirty years, so yes, I've accepted that (Jenny)*

Mary and Paul continued to sleep together but they were the exception: *...I do still sleep with him because I wouldn't have it no other way (Mary)*

Having identified the importance of adequate sleep in the lead up to the LTIC, protecting sleep remained a priority to manage their partner's care needs and they needed to be ever vigilant of the LTIC. They acknowledged their new responsibility.

*... that's the best thing that I think ever happened (the LTIC) and Clifford sleeps nightly. Its only, very occasionally he might wake up and then he presses his alarm and I go in and say, what's the matter, he says, oh I was dreaming and I think... mm yeah, well don't worry about it, it's all just a dream. Well I um, right ok - 'Would you like a warm drink?' 'yes please'. So now I'm out in the kitchen, warm drink, give him that and um let him sit up a bit, for a little while to let it go down and then I'll say, 'right you ready to go to sleep?', 'oh yes, I am' - and I think, 'so am I!' (laughter) but it works and its very occasionally, very, very not often at all. I can't grumble (Beatrice)*

When he wakes in the night, which rarely happens, her routine is to settle him quickly, giving him a drink, like a parent would to console a child. She tempers her approach to dealing effectively with his waking so that she can get back to sleep. For many of the carers, the end of sleeping together coincided with their role morphing into that of carer; their new role more like a parent/child relationship.

Judith's experience was similar in her effort to get a good night's sleep:

*...one thing I find most difficult is - I give him a sleeping pill when I go to bed, I don't want to start sitting him on the side of the bed to take his pill (smiling voice) and (laughing) he can't quite get his head round that, I said, I said to him the other day, it's one of the worse jobs (really laughing) ...but anyway, there you are...(Judith)*

Her approach was to give him his sleeping tablet in bed which he didn't find easy but she could not face sitting him up to give it to him. Seemingly small tasks were a challenge at the end of every day.

### 3c Competing needs

Several carers hoped for support and understanding from their partner in relation to their needs. This sometimes resulted in a conflict with the demands of their caring role, their partners' expectations and their competing need for time for themselves.

Carers attempted to balance the changes in their daily life whilst managing their partner's care and coping with the challenges of the LTIC. There was diminished personal control plus a time constraint, restricting what they could do. This was

influenced by the LTIC regime as well as well as meeting their partner's other care needs.

Research related to the competing needs of the carer and care recipient suggest that it can be a balancing act (Beach, 1993). There are identified 'balancing strategies' to maintain a balancing point, which are similar to coping strategies. These include managing their emotional needs, involving others so they are not so isolated and maintaining engagement in activities specifically for yourself (Shyu 2000, pp.40). Caregivers' own needs were often derogated or sidelined because of circumstances, although some managed to steal some time to themselves, particularly if they had respite care. The degree of respite care varied with some carers receiving none at all. They tended to spend this time with more mundane and often solitary activities.

The carers competing needs were influenced by the health and demands of the care recipients. There was evidence that caregiver stress was having a negative impact on their health and four of the six carers had anxiety and depression [2.7.1]. Conversation between them had changed and carers were no longer able to talk about their concerns. This impacted on the mental health of both parties - the care recipient as well as the carer (Schrag, Johanshahi & Quinn, 2001). In relation to PD, which affected Joyce's and Mary's partners, evidence (Speer, 1993) from a longitudinal study of twenty-six couples where one partner had PD, showed that less support for carers during their early adjustment equated to greater issues with depression and burden and this resulted in greater depression for the individual with PD.

Employed carers coming in to their homes meant their privacy was relinquished as well as their personal freedom, as reflected by Beatrice:

*...you think, oh ten minutes, I must start getting the tea ready for quarter to five and then he's finished by the time they (employed cares) come in.... (Beatrice).*

She found it stressful to fit in her husband's schedule of care, particularly the time it took to feed him, which she admitted got her down.

Carers also wanted to support their adult children as Jenny, whose daughter was pregnant and who had spina bifida, explained:

*...it's difficult, to try and split yourself you know because she was ill with cellulitis – I thought I've got to get to her and the only way I could get to her was as soon as the carers come at nine, I whipped out knowing I would have to be back by ten (Jenny)*

She was tied to the schedule of care for her husband with little flexibility to leave him which challenged her loyalties.

### Adjusting

The process of adjusting the carers experienced included accepting the many changes in their lives. Judith's show of raw emotion [3b] when talking about the recent changes in their lives was a poignant reminder of the context of adjustment. In comparison, Jenny was resigned to accept her life now, having given up work to care for Phil soon after he had his LTIC five years ago.

Generally, they tried to remain positive but on occasions there was an element that they were trying to convince themselves by what they were saying.

Jenny: *I live life to the full, absolutely.*

Interviewer: *Did you have a lot of interests before you had to take on such a caring role?*

Jenny: *Well I worked*

Interviewer: *So, you had that network of friends? (yes) do you miss that?*

Jenny: *I do to a certain degree, I do ... sometimes I resent being so tied that I really ... you know it's going to get worse when my daughter has a baby.*

Jenny sees herself torn between wanting to help her pregnant daughter and caring for her dependent husband – both of whom need her. She has a desire to meet all these needs because it provides her with a sense of fulfillment in her life.

Beatrice spoke of her positivity, in part this was a more recent development following her experience of cancer: *I'm a very positive person (Beatrice)*

In contrast Mary's disclosure that: *My life's dead (nervous laugh). It's the way I choose it, it's the way I choose it...* (Mary) was about her lost life but she felt she had made the choice and emotional adjustment and was prepared to make it for her husband, though she didn't say because of 'love', I quite expected her to.

Carers sometimes gave mixed messages about how they felt; the inner turmoil between their decision to care and accepting their decision (Rolland, 1994). There was the element of what they were expected to do and also being unprepared for the situation they found themselves in.

### Time

Adjustment to the LTIC was influenced by their competing needs and these were frequently cited in the context of time, including demands on their time and being ruled by time. The LTIC involved paying attention to it at regular interviews – checking drainage, and emptying the bag during the day. Getting their partner ready to go out, taking supplies, could also be time consuming:

*It takes me about a quarter of an hour, twenty minutes to get him out into the car...so therefore we don't go out...because it's less trouble' (Joyce)*

For those who did manage time away from the home by themselves, they often had to restrict their time out. Joyce's only social interaction was a trip to the shops or a visit from her daughter in law:

*...So um but I do manage to go shopping up to Sainsbury's once a week...I go as early as I can so that I'm not up there very long, I'm only up there about three quarter of an hour at the most yeah (Joyce)*

Similar to Joyce, Mary's strategy was to restrict time away:

*I don't really go that far because if I empty it before I go....so, I only really take him...oh there was once. I take him to – I haven't since October because of the weather (Mary).*

Over time, she was going out less and less, justifying it as unnecessary:

*... I'm not one to go down town buying lots of clothes – I've got clothes upstairs I don't hardly wear because I can't go anywhere now. What's the sense of spending money on lots of clothes that you're not going to wear? (Mary)*

There was an element of regret regarding this approach.

Gordon and Betty were accepting of the changes imposed on them because they had not had to make big changes their behavior. They had rarely gone on holiday during their married life, except when their children were young:

Gordon: *...we go out regularly in the car...we don't really like sleeping in any other beds...so we've never been ones to stay away ...*

Betty: *the only thing is, I leak a lot...*

For Betty, however, her leaking LTIC influenced her days out – her comment reinforces the benefit of listening to both partners.

Beatrice and Clifford had previously enjoyed holidays abroad, but Clifford's health eventually put paid to this. Judith and Edward had also stopped going on holiday and rarely went out, as a result the family come to them now:

*Well, he can't bear going in his wheelchair in the back of a car ...it's a horrible feeling, you feel very insecure, so we don't go out very much, in fact hardly ever (Judith)*

### 'Time out'

There was often little time for themselves with restricted respite time for those who had it. Their ability to have control over how they spent their time was an issue:

Interviewer: *... do you get any time for yourself for your interests?*

Jenny: *Not really, they give me four hours respite a week...*

Jenny's respite carer was 'Geoff': *...one of the carers, his granddad had a wheelchair car so Geoff used to borrow it and take Phil out for four hours, so I'd generally do the ironing then.*

Phil's deteriorated health due to MS meant they now stayed at home. Her 'respite' was someone else sitting with him. She chose to spend her time doing a mundane activity at home. They had never gone out or travelled very much prior to this his MS:

*... because Phil's a police officer, he worked such odd shifts that it was never part of our life to go out really and I'd never leave the children with anybody anyway. (Jenny)*

Just as she didn't like leaving the children, she hadn't left Phil in the early days of his MS '*...No, I never really left him*' - and if not for the respite, she would never leave him now. Jenny's solace and escape was tending to her garden:

*That's what I do, yes, I really enjoy the garden, I love the garden....there's peace and tranquility' (Jenny)*

She found her escape and silence in the garden and this was her respite where she can keep an eye on Phil who sits just inside the patio doors. There was little flexibility within Jenny's lifestyle for change so that she would be able to support their pregnant daughter:

*...sometimes I resent being so tied that I really....you know, it's going to get worse when my daughter has a baby...(Jenny)*

Beatrice had weekly respite: *I take him to [name] (Day) Centre..., for one day a week which is nice, so I get a day off in the middle of the week where I can more or less please myself, but its usually catching up on shopping or whatever (Beatrice)*

Similar to other carers, she spent the time doing housework but she also reflected that it was the time in her week when she had a choice about what she did and wasn't 'clock watching':

*... but um I find I enjoy that (time to self), sit and have my lunch on my own. I know it sounds silly but um you know I enjoy that, I come here, lay down with a book, cup of coffee, 'oh this is nice...'*

*... I think it's just um, no carers coming in lunchtime, so got to be ready for them, as it is we have lunch starting at 12.00, Clifford's a very slow eater and I've to be ready for 1.15, so it's, it is looking at the clock a lot. I think that um, gets on my nerves and then at 4 o'clock, we may be sitting quietly getting the tea ready for quarter to five and then he's finished by the time they come in and sat for a while, I don't want him to lay down or hoisted up when he's just had his tea (laughs). So, you know, it's looking at the clock, I think is the thing that gets on my nerves mostly. (Beatrice)*

This quote demonstrates what a prominent theme 'Time' and the control it exerted was for Beatrice. Her life is on hold caring for Clifford and a far cry from their envisaged retirement together. Agency carers visited Clifford throughout the day and their presence meant a loss of privacy in her own home.

Carers who took respite often chose solitary, mundane and contemplative activities. Joyce didn't have any official respite however she had time away from husband Jim, choosing to go in to another room:

*... I do quite a lot of reading in the evening or I play solitaire mainly on the laptop, I'm not very um...I can do a little bit but not very much, but I do...I might play about with it you know, and I do reading, as I say... (Joyce)*



Joyce's husband Jim watches television during the day, his reduced mobility means that he rarely goes in to the kitchen/diner unless she takes him. In the evening this is where Joyce often sits by herself. Over time, their world had become smaller and her interests were put to one side:

*I used to go dancing, well we both used to go dancing...sequence, and then Jim couldn't dance so I kept on going on my own because I had a partner um, but then it came to the pitch where he didn't really want me to go out you know...so I just gave it up and I've lost interest in it now quite honestly, there's um, you know, when you don't do a thing you do loose interest, don't you? (Joyce)*

Similar to other LTIC users, Jim exercised his control not wanting Joyce to go out if he couldn't. Like most of the female carers, she was being treated for depression. Joyce felt she had plenty of time but no control over how to spend it:

*... I mean we're home all day see you've got plenty of time really haven't you, apart from the cooking which you've got to do every day, which is a nuisance, I've never liked cooking much, but the housework isn't very much really (Joyce)*

There was a poignancy to her comment that it was 'a nuisance' that she didn't enjoy activities in the home such as cooking.

Respite care varied among the group. Inpatient respite was something only Mary had been offered and on one occasion:

*...um - before Paul went in hospital, not this August, the August before, to give me a break - it does get me down because I live in a silent world.....I'm happy to look after him. It does get me down and I do get upset. They (DNs) were here yesterday, they said I've got to have more time out. Yes, I would, though I know Paul don't want me too because...he says, even when his mates come in, I go on out for an hour, he says 'don't go'. (Mary)*

This is an example of displaying controlling and needy behaviour. She was under pressure not to go and he asks her directly, adding to her guilt.

The carers did not talk of seeing friends when they had respite. Judith was the only carer who left her husband at home by himself for any length of time. A 'positive' of Edward's immobility as Judith saw it, meant that he was now confined to a chair and the risk of his falling was greatly reduced since the LTIC

because he was no longer trying to get to the toilet. This made it easier for her to leave him for brief periods:

*...Well I can leave him, you know, in the afternoons, because he's quite happy to listen to the radio, he doesn't...there was a time when I couldn't leave him at all because he used to fall about...I mean, when he was a bit more mobile (smiling voice), now he's not mobile, I mean there's not really a lot that can go wrong, I can get out in the afternoon, I said to him today, I must go for a bit of walk, because I've got bad knees and if I don't I just...seize up...I don't go out in the evening really at all...which...I very occasionally if I'm...I'm a bit lucky because I've got a sister in law who lives in Bristol, we've done a lot of caring in the past and she comes in for the day or for the week and I'm quite lucky to have a day off.*

Interviewer: *So, you haven't thought about respite care?*

*...I have, in fact, I go away sometimes and get some, but all these things are really expensive, you know, I mean ah, in fact I'm going away the first week in October, going to Cornwall to see my sister, yeah, and I get someone to come and be here, a country cousin (Judith)*

### Impact on carer's health

The impact of the LTIC coupled with her partner's deteriorating health, had emotional consequences on Beatrice's health:

*... I have a monthly, no three-monthly prescription for anxiety and he (GP) likes to see me.... ...I had um, I was diagnosed, over a year ago... I'd got the start of a, um, of a cancer on my bowel...which of course, I was on the floor and thought well that's it, and then busy making arrangement for Clifford's care, um, making the wills up to date, all my finances would go for his care, blah, blah, blah. (Beatrice)*

She uses the analogy of 'on the floor' to describe how low she had become – the news had metaphorically knocked her off her feet. Despite this, she was determined to make plans for her husband's care if something happened to her. The cancer scare had been a pivotal moment for Beatrice, using two phrases with similar sentiment – 'I won't let anything beat me' and 'I'm not letting anything get me down'.

The physical demands of caring were particularly pertinent because all the LTIC users were heavier than their spouses and if the LTIC was prone to leaking, they needed changing. Judith, talked about the physical demands caring for her husband who was 90 years old, morbidly obese and immobile: *...he's quite heavy for me, he's a big man' (Judith)*. She did not have the physical strength to lift him

and being pragmatic, she knew she had to look after herself, giving herself time out in the afternoon which also provided her with a break from being home: *'I must go for a bit of walk, because I've got bad knees and if I don't I just...seize up...'* (Judith)

Following his stroke, Beatrice's husband was also immobile:

*I'm not very good with my hands as you can see, um that is the thing that I have to put up with, it's not life threatening but it's a nuisance.....arthritis in both hands and feet...* (Beatrice).

She played her difficulties down, comparing herself to her husband's condition to put it in context - *'...but we get on with it'* (Beatrice).

### 3d 'What will be, will be' (Joyce)

The loss of their 'expected' future resulted in uncertainty. For those who were having problems with their partner's LTIC, this added to feelings of unease about coping. Mary's husband Paul who had PD, was one of two LTIC users in the poorest health:

*I do panic sometimes when he's not well because I can see in his face because I just feed him with Paracetamol all the time..... I just can't imagine my life without him...(Mary)*

Their relationship has changed immeasurably; her life was for him. Mary was focused on making sure he wasn't in any discomfort to the extent of potentially overdosing him on analgesia in an effort to keep him comfortable. This minimizing strategy helps her deal with caring.

The majority of carers made a point of living in the present since there was little they could do about their situation. Joyce was philosophical when asked if she had any concerns about the future:

*...when he gets worse you mean? No, I don't...Well um I don't think so, I think what will be, will be and you can't do much about it, you can't change it so you've just got to accept it, that's what I think' (Joyce)*

Her approach was fatalistic; there is no light in her account. Judith currently had no help with care and the LTIC had always been problematic. This sentiment also expressed by other carers when asked if they contemplated the future:

*Not much...because I can't see, there isn't really a future I mean, the future is as it is now and probably getting a bit worse, I don't know. (Judith)*

Taking a day at a time became their coping strategy and they could not imagine what their future might be. The feeling of powerless and the extreme likelihood that it would get worse, made for downbeat sentiment. Jenny considered that there was 'nobody' to look out for her and she felt very much by herself: ... *I just get through every day really (Jenny)*

Beatrice's health scare with cancer had been a time for reflection and she was far more pragmatic about her life situation:

*It's not going to happen now, no I say, no, that's it, in fact um so I think I'm a very positive person...(Beatrice)*

Beatrice, was the only one to talk about her potential plans for the future:

*...if I was on my own, I would be out of here like a shot, because it's got a lot of rotten memories and I would like somewhere small, over at [name of place] where I can see green fields and that's what I would probably do, if I don't go first! (Beatrice)*

Her experience caring and coping with his health and then her cancer had all taken a toll on her.

#### 4.7.5 Theme 4 – Experience of support with the LTIC

This superordinate theme considers the positive and negative experiences of support. Although the focus was the LTIC, this was bound up in the practical and emotional support carers experienced from family and HCPS. Carers looked to HCPs with expectation of advice and support:

*... I had no idea what it meant at all...only that the doctor had prescribed it but said she thought that it was the best road to go down now...and I thought, well, I don't know what that's all about but I shall learn from the um, from the district nurses which I did (Beatrice)*

In the context of the difficulties they were experiencing with the LTIC - family, friends and HCPS helped them emotionally and provided practical support. Jenny and Mary had predominantly negative experiences of care relating to the LTIC and the HCP's involvement.

#### 4a Negative experiences

Experiences of support included being disillusioned with the HCPS, dissatisfied with care provided by agency carers and difficulty accessing appropriate support. If they perceived that care for their relative fell short, as their advocate this involved challenging decisions and approaches to get, or maintain, necessary support. Earlier experiences with HCPs that had not been a good and had impacted on their later dealings. As a result, they already had low expectations:

*A very abrupt doctor said 'is the bed wet?' and I said 'well, not always'. He said 'I'm telling you does he pee the bed?'...well you know, he's my husband and I don't deserve to be talked to like that – you know – he's just doing his job isn't he? I'm just one of a number...(Mary)*

At the time they were sharing a double bed and she was getting wet as he was incontinent. She minimized the impact of the situation commenting: *'...he can't help it'* (Mary).

Later in the interview, she was more circumspect about her situation over time: *'I can't possibly do that now because he deteriorated more...'* (Mary) - acknowledged that the catheter made life easier for her to manage.

Jenny had a similar experience and had made a formal complaint citing poor care, after Paul developed a bedsore whilst in hospital and subsequently contracted MRSA. She recounted an experience arriving on the ward:

*...nobody had informed me of anything and they said they had found him on the floor ... they hadn't put the cot-side up and in trying to get up he'd ripped out his urethral catheter.* (Jenny)

Paul was not able to tell her what happened. Following this incident Jenny was far more proactive about his care. His LTIC was bypassing and there were stones in his urine bag. She reflects back at the *'nightmare'* managing this.

*Generally, where there's a problem with the catheter, I find the District Nurses...well, their knowledge is quite limited I'm afraid; it really is quite limited.*

*...I mean, they're very honest, they say we don't know what's going on but that is then an end to it and nobody is prepared to find out what is going on. So, I'll go on the internet, I will find the answer and that's what I've done* (Jenny)

Mary had similar experiences with husband Paul's last hospital admission which included re-assessment. When she went to visit she was told:

*Paul was a bit aggressive this morning – he hurt a girl's wrist...he hit her' I said 'no I can't believe that'. I couldn't believe it, if you forced something on him and he didn't understand it or you didn't give him time because that man there you're talking about never once hit his children – you know, they just shut up then...it was only when things started moving fast when I said 'I'm sorry I've had enough of this place. I'm taking him home on Monday' and they said 'you can't manage him' and I said 'watch me' ...(Mary)*

Mary was disenchanted that he spent so much time in bed which meant that his mobility deteriorated. She felt frustrated at their lack of any understanding of his perspective and accusations that her husband was being aggressive. Her reaction to this, just as Jenny's, was to assume control of the situation and take him home.

LTIC are notoriously difficult to manage [2.4] and for the majority of the time, the carers were managing themselves:

*I don't see anyone, only when the district nurse comes...  
Nobody...do it all ourselves (Joyce)*

Joyce's partner Jim's LTIC had always leaked and she didn't consider it had been good advice from their GP to opt for a catheter: *'you live and learn don't you'* (Joyce). Her experience of follow up care was that HCPs didn't have any suggestions to improve things.

Personal care which included catheter care was supported by employed carers for half of those interviewed. Whether this was funded from social care was dependent on the needs of the care recipient. Jenny and Marys' partners received funding, in contrast to Beatrice and Judith who were not eligible for such assistance and paid a care agency direct. Even when the employed carers were involved, the spousal carers were still overseeing care and often worked together:

*...the catheter side is totally me, you know, if there are any problems with the site or anything else to do with the catheter, obviously the carers are not really that capable of doing anything... they'll put the night bag on when they put him to bed but anything like it blocking or there is a problem with the site, it comes to me (Jenny)*

Jenny had become self-reliant, very confident in her own ability.

Beatrice was very supportive of the paid carers: *I think it's very good, yeah and the carers that we have ... are excellent, um, they've been coming now, well for a year, um, prior to them we had a different set of carers which I was hoping to go back to but I didn't have a say as to who was coming in* (Beatrice).

Beatrice was grateful for their help but in her isolated existence, they were often her only daily contact. Often decisions related to care were made without consulting her. She did intervene to support the employed carers and attempts to reduce two carers attending to one, as this would impact on her husband's safety. She liked to keep a watchful eye on the proceedings, taking a lead with the smooth running of events similar to Mary:

*I have one carer who comes here who is extremely efficient and she does it, but basically when they've, I see them clearing up, I go in and I do the bags because then I'm happy, I know he's alright...* (Mary)

#### 4b Positive experiences

There were positive examples of support and often it was one particular HCP whom they valued over others. They considered the HCP had to be proficient in their job but it often had more to do with feeling comfortable with the particular person. Carer's wanted to feel confident that they would be listened to and someone who they felt was empathetic towards them.

Joyce couldn't recall having any written information about the LTIC or how to manage catheter problems:

*I just 'phone the district nurse I've always got telephone numbers of course, the district nurse um and the out of hours one is always available* (Joyce)

DNs were available round the clock and carers knew how to get help: *Whatever I ask for I just 'phone up over the surgery....*(Mary)

Over time, carers became familiar with various DN team members:

*...actually we have one or two the same... Some are better at it than others. I mean I can only tell by what he – his reaction.... it's not as if they are doing anything wrong particularly – it's just not being quite as sensitive. I mean one was very quick and actually very good – and quick – it wasn't that he was not so good.* (Judith)

Jenny's predominantly negative experience of the DNs was contrasted with other occasions when a particular DNs 'excelled'. Similar to Judith, Jenny had greater praise and trust in the out of hours team:

*The out of hours district nurses have been fantastic...they have been brilliant... he's someone I have absolute faith in, you know because I have fallen out with our District Nurse on a number of occasions to the point where I did ask them at one time not to come anymore... only when the catheter needed changing, I would say to them if necessary I would be quite happy to change the catheter myself. (Jenny)*

Jenny had belief in one DN and this was the game changer for her with regards support. Caregivers said they talked to DNs about LTIC problems but they were vague regarding information they were given. Mary acknowledged that it was difficult to give people information before the problems started:

*... I don't think anything would have been helpful. Like they give you information and they give you a book that explains it to you but until you're actually in that position doing it, I don't think you got any experience at all (Mary)*

#### 4c Impact on the family members

Carers were aware of the impact of their changed circumstance on their adult children – this was not related to LTIC but the care recipient's LTC.

All interviewees had adult children. Those who had moved to be nearer to their children (Beatrice and Joyce) had not anticipated the negative impact of moving to an unfamiliar area when their partner's health deteriorated, this restricted social interaction either as a couple or as an individual.

The most frequent interaction caregivers had, apart from HCPS, was with their children. For the three caregivers who didn't have any additional care support (Jenny, Joyce, Mary), their children were often their only face-to-face contact in a week. They tended to have support from the one who lived nearest and for Joyce, her daughter-in-law visited:

*I've got three sons as I say, and my middle son he's um, they're very good yeah, she got... I think it depends on the wife really with sons...The daughters in law because sons don't think the same as daughters...They don't, I mean although if you ask them they'll do*



*anything for you, they won't see that it wants doing but um and my middle son, his wife, the daughter in law, they come every um Wednesday, well they come once a week, during the week in the evening and they usually come on a Saturday afternoon and she brings me down a dinner once a fortnight on a Monday, so I don't have to bother to cook (smiling) Because she goes to work as well mind, so it's very good of her, she's very good [name] is, yeah (Joyce)*

Joyce mentioned her daughter-in-law, [name], several times during the interview and it was her she confided in rather than her sons:

*No, I don't say much to them, but I might say to [name] or you know the women but not the sons, they don't...um they say 'oh he's a miserable old goat', you know or 'old git', they haven't got much patience, I don't think men have. (Joyce)*

Judith and husband Edward had four grown up children – two sons and two daughters:

*... our family's very open (smiling voice) they're very, actually extremely good – I've got a lot of support, particularly from...one of my sons is in [name of city] who comes every weekend to help me put him to bed because we don't have a carer and my other son does it – but he lives outside [city] so it's a bit more...difficult for him – and my daughters, whenever they're here – they live in [name of city], whenever they're here, they always help – get him to bed  
We've always been quite open, I suppose, it (the catheter) doesn't seem to bother them very much, they know he's got it and it has to be dealt with and.... (Judith)*

Their youngest son helped at weekends to hoist Edward in to bed, as the paid carers did not come every day, with her other son helping when he can:

*....they (agency carers) come in the morning, they get him up in the morning, he has to be hoisted so, he's quite heavy for me, he's a big man (obese)...anyway um...so...they do get him up and also I do get him up...and I do have someone five nights a weeks to put him to bed but my son and I do it at the weekend – mostly – one of my sons (Judith)*

There were examples of children 'policing' parents to influence their behaviour as Judith describes:

*... actually, one of my daughters told him off the other day – for being grumpy and rude to me and he was very upset by that...Yes, she gave him a terrible telling off, perhaps... The other thing, she doesn't realize...she says I find depressing coming to see you and mum being and mum you know, being reduced... but if she's not here all the time, it's naughty to come in and say that, you know, that's what my son thinks anyway – it's all very well for her to come in and complain about how depressing it is to come and visit (smiling voice), she hardly comes to visit...once every, she works in a school so she's not – every six weeks (Judith)*

This incident caused tension within the family. Their daughter had upset the

equilibrium and made spot judgments, rather than providing practical help. Judith admitted finding caring challenging and on occasions she was short with her husband. There was a sense that she was relieved that her daughter acknowledged the difficult situation; telling her father off. However, it caused disagreement between the children and ultimately caused added pressure for Judith.

It was a role reversal situation for Judith, with adult children parenting each other. This is expressed in the language used, the word '*naughty*' that would be used about a child and some sibling pressures were being exerted.

Her daughter found it depressing to visit home – a sentiment that was shared by others. Mary and Paul's youngest son had recently emigrated. He had struggled to cope with accepting his father's illness:

*He's 30, he's lovely, he only went last year. I said 'it's your life', he said 'dad...' I said, it's your life, you go...your mum and dad have had our lives'. And I talk to him, we talk to him regularly. I never spoke to him on Skype, I don't want to, because I would cry...(Mary)*

Similar to Joyce, she had a supportive daughter in law:

*...my daughter in law, she's really lovely. I don't want them to be at my beck and call because I had that with my own mum. I felt Mum only had me and my sister, so we could look after her and I don't want that with my children. It's a bit different because my kids got their children late in life... so they haven't got time, but I 'phone, they're here, and they do call in and [name], the bigger one, the middle one, he keeps saying 'I'm sorry Mum, I'm so sorry' about his Dad. I've said to him there's nothing to be sorry about, it does happen, so... (Mary)*

Mary was keen for her children not to feel responsible for her or beholden to her '*don't want them to be at my beck and call*'. She had experience of this with her own mother and did not want the same imposition for her children. There was similar sentiment expressed by Beatrice - '*I don't want to be a burden to anybody else*' in the sense of their having to care for her as she was doing for her husband:

*...now [son's name] is in Canada, so he's out, um, but he's very supportive, there's not a week goes by that he doesn't 'phone and find out what we're like, um, [other son's name] will come if I 'phone him at any time, even from work. If I'm upset or worried about anything, so I've always got that behind me um having said that I try not to, if I've got a*

*problem, I try and get out of it myself because it's no good if I can't deal with something, I don't want to be a burden on anybody else. (Beatrice)*

Beatrice talked about this in the context of her recent cancer treatment and her son supporting her, providing an insight in to how negative she felt being a burden and not wishing it on her children. Like Mary she was mindful of her son and his wife having their own life. When she had bowel cancer he supported her, taking her to hospital for her treatment:

*... he did that for six months for me and of course after the chemotherapy, I went for trials and so and so forth and it was clear. (Beatrice)*

Similar to Mary, Jenny's daily life was built around supporting her husband's care. Jenny talked about her life being 'finished', now focused on caring for Phil. Her solitude ran through her interview:

*...we've got two children and our son walked away from the family 18 months ago because he couldn't cope with his dad being like that, I don't even know where he is. My daughter who was a great help and a great support to me is pregnant and she has spina bifida occulta anyway so obviously her pregnancy is not the easiest.....So no I'm on my own. .... so it's difficult one then to try and split yourself you know because when she was ill with Cellulitis I thought I've got to get to her and the only I could get to her was as soon as the carers came at nine I whipped out knowing I would have to be back by ten (Jenny)*

Although Jenny empathized with their son's action to leave home because he could not cope watching his dad's health deteriorate; his leaving punished her.

#### **4.8 Summary Part I**

A cross-case review of the interviews with the six spousal carers, identified superordinate and subordinate themes (Table 2)

In the context of the study objectives for Part I, to explore the spousal carers' experiences when their partner has a LTIC, the overarching themes highlighted the impact of their home environment and that the LTIC was a 'mixed blessing'. Their experience of becoming a carer for their spouse's LTIC showed an increased dependency on them, conflict with their competing needs as a carer

and the positive and negative impact of support with the LTIC and impact on their family.

The inclusion of carer's lived experience in relation to their environment demonstrated the challenges that caring at home can present, which often made practical caring more difficult even if there were adaptations to the home or they used specialist equipment.

There was evidence of the emotional impact of the pre-catheter days; watching their partner struggle with symptoms of incontinence, realizing their frailty and deterioration in their health.

The majority of caregivers had poor experiences pre-catheter as they supported their partner, as their bladder symptoms became increasingly difficult for them to manage. A poignant memory for carers was of their tiredness and for some, physical exhaustion before their partner had a LTIC and disturbed sleep due to their partner's nocturia. This informed their future concerns, knowing that tiredness/fatigue impacted on their ability to cope and as a result they guarded their sleep from then on. This aspect of caring recorded in literature links pressure of caring with fatigue and feeling tired (Hunt & Smith, 2004). It was a causative factor in their inability to cope and a constituent influence when reflecting on their partner's decision to have a LTIC.

The introduction of the LTIC was accompanied by raised expectations that it would improve their situation but in reality, was a double-edged sword as it posed problems of its own. They saw advantages initially for their partner but also for themselves, particularly with reference to less washing. However, over time reality set in and problems with the LTIC became more evident. The additional work particularly the burden of washing clothes and bedding associated with incontinence, appeared to loom large and was mentioned frequently.

In this small sample of six carers, all the LTICs presented problems such as infection, blocking and leaking. The impact of being responsible/taking responsibility as the primary carer for their partner resulted in them feeling pressure to take on further tasks. For two carers (Jenny and Judith), their role included performing regular bladder washouts, a medical procedure, to keep the catheter draining.

Considering the objective to explore the impact on their daily life, the carers experienced increased dependency on them and needing to take greater responsibility such as decision making for their partner. This included all aspects of daily care – including the catheter.

LTICs are renowned for their unpredictability and problems only increased the uncertainty in caregivers' lives. Their efforts to prevent catheter problems included encouraging their partner to have regular drinks which was an on-going challenge and like many interactions with the LTIC, it was time consuming. Although the LTIC needs to be viewed in the context of their partner's long-term condition, it was a significant burden to their caring role.

Their time was taken up with caring which included dealing with the demands dictated by the LTIC which was frequently problematic. Despite LTIC problems, they were generally positive about the LTIC in the context of this was better than before, suggestive of the LTIC as a 'mixed blessing' and no other suitable options were available.

In the context of the study objectives, considering carers' experiences in order to inform and improve management, what emerges from the data in part I was both positive and negative experiences. This included the frustration and disillusion they felt on occasions with support they received.

Respite was valued although its availability wasn't universal and it varied. Experiences and level of support varied between the carers. Support came in many guises but of importance was that the individual carer considered it of

value. This support included regular appointments with GP to review their own health, DNs who were contactable out of hours, providing practical support (e.g. when the LTIC blocked) and contact with family members. Half the carers were very much on their own because their partner's ability to communicate was affected due to their long-term condition, therefore supportive relationships were those where they felt listened to.

Many of the carers had become self-reliant with the LTIC, researching solutions to the problems in Jenny's case. Personal strengths such as being determined and proactive (Beatrice and Jenny) in managing their partner's care appeared to positively affect their ability to cope and adjust to the changes the LTIC imposed. This self-reliance became a way of coping with the LTIC and had resonance with similarities to coping with the demands of long-term conditions such as Alzheimer's disease (Claire, 2002).

The implications from the data was that the dynamics of their relationship had changed. Whilst several participants considered their caring role as doing something positive to support their partner, for others the transition to 'carer' included feelings of loss of an expected future as a couple, loss of their life and sense of self as their time was taken up caring. However, they were all trying to do the best they could for their partner. Spousal carers were reflective about how their lives had changed and recalling these times triggered sad memories for some, as with Judith who became upset when sharing previously rarely, if ever, spoken about experiences.

Their partner's dependency also altered their relationship; becoming less of a 'husband and wife' dynamic and more of a 'parent and child' dynamic for some couples. Sometimes the care recipient reacted to their partner, as if trying to maintain some semblance of self but also of control, appearing to 'punish' them if they went out without them by not speaking to them on their return. As a result, caregivers limited their time away from home either because their partner didn't like to be left alone or they had concerns about leaving them. Most carers were already isolated which increased their feelings of loneliness and loss and several

were being treated for clinical depression.

#### **4.9 Justification for Part II**

The majority of caregivers in Part I were caring for their spouse with a LTIC in the later stages of their long-term condition, requiring 'round the clock' care and attention to their needs. As a result, carers increasingly assumed responsibility for decision-making regarding LTIC care and management. Their partner's poor health and physical limitations meant that they were often not able to contribute to the care of their catheter. The changes to their relationship and how this impacted on their experience suggested deeper exploration would help inform the study aims. The inclusion of three dyad case study were included to further explore the LTIC within their relationship.

## **Chapter 5**

### **Part II**

#### **Living together with a LTIC**

##### **Three dyad case studies**



**Chapter 5**  
**Part II**  
**Living together with a LTIC:**  
**Three dyad case studies**

**5.1 Overview of the chapter**

In this chapter, Part II of the thesis, three dyad case studies are presented. I will consider the added value of the inclusion of the LTIC user's experience together with their partner who supports the care of their LTIC. These are viewed in light of the findings from Part I, considering the impact of the LTIC on their relationship.

The chapter will begin with an outline of how the participants were recruited, the rationale for focusing on LTIC users with MS and an overview of pertinent literature. As a result of Part I, the expansion and deeper exploration of the objectives will take place - to further consider the impact of their relationship on the carers' experiences. The chapter will present an outline of the method prior to presenting the three dyad case studies. The time lapse and variances of who was present at each interview and the possible impact this had on the findings will be considered. This is followed with a summary of the findings prior to the Discussion (Chapter 6), to review what additional insight the dyad case studies provided. The chapter concludes with synthesis of the LTIC users' experiences.

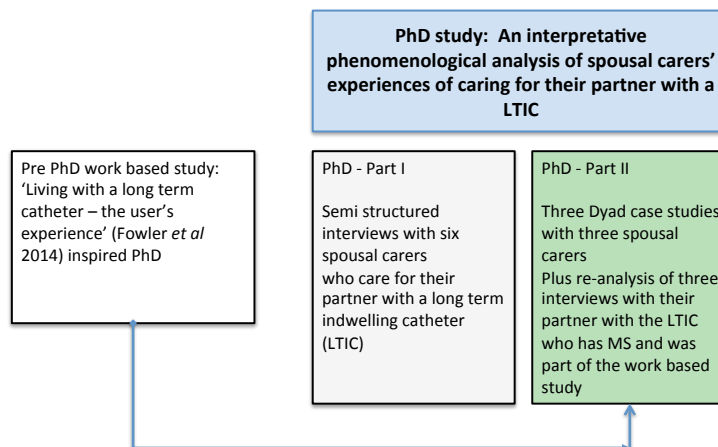
**5.2 Introduction**

Part I of the thesis left unanswered questions relating to the spousal carers' experiences. The addition of Part II enables a link with the pre-LTIC research I had been involved with, which had demonstrated the importance for LTIC users of the physical and psychological support from their spouse (Fowler *et al*, 2014) when managing the device. Part II also provided an opportunity to explore what carers considered was the impact of the LTIC on their relationship.

A key concept to emerge from Part I was in relation to adjustment and carers trying to find an equilibrium to help them cope. It was a complex issue which posed additional questions. Part II enabled further consideration of whether the carers and their partners experiences were similar.

Each 'case' begins with a pen portrait to provide background detail on the individuals. The data collection method chosen was semi-structured interviews with spousal carers whose partner had been a participant in pre-PhD LTIC study (Fowler *et al*, 2014) with the intention of triangulating it with data from the LTIC users (collected previously). All the LTIC users had MS. Each transcript was subjected to IPA.

Figure 4 Phases of the PhD study - Part II – Dyad case studies



### 5.2.1 The challenges and limitations of managing interviews over different time frames

The challenge of interviewing carers has previously been raised. They are a potentially 'hard to reach group' because they can be confined by their caring

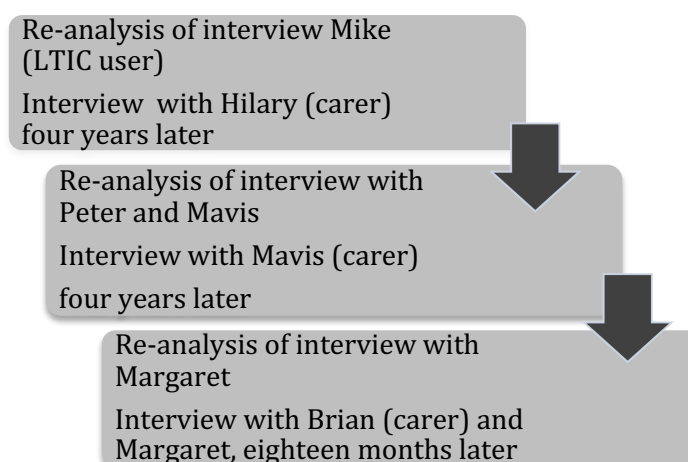
duties and responsibilities. In this study, who was present at each interview was influenced by additional factors such as limited space at home away from their partner. This was similar to Part I interviews.

The original interviews with the LTIC users (Fowler *et al*, 2014) had not been straightforward with regard to who was present. Although I was only interviewing the LTIC user at the time, for one interview their partner joined the interview and it became a dyadic interview.

Having made the decision to carry out re-analysis of interviews with three LTIC users, followed by interviews their carers, the variables of the different time frame and variation in who was present was considered when reviewing the analysis of the interviews. These semi-structured interviews had taken place four years previously with Mike and Peter and eighteen months previously with Margaret. This meant that it would not be possible to draw conclusions about how each partner experienced the LTIC at the same point in time, however the impact of their experiences will be viewed in the time frame of their interview.

The diagram below clarifies the time line and attendees at each interview.

Figure 5 - Dyad interviews – time-line



### 5.3 Focus on MS

The decision to select spousal carers whose partner had an LTIC and MS was informed initially by the fact that –

MS is a condition which results in a restricted ‘choice’ of incontinence management options and as Fowler *et al* 2015 identified the ‘choice’ in relation to LTICs appeared to affect adjustment for the user (Fowler *et al*, 2014). Guidance relating to indwelling catheters, even for short-term use, recommends they should only be used when all other options have been considered and not deemed suitable [2.2.4]. In circumstances such as managing intractable incontinence, there are several options and interventions rather than a catheter. In contrast, for those with a neurological disease such as MS, options are more limited. As a result of dysfunctional voiding, patients may have a residual urine, increased risk of infection and damage to upper urinary tract as well as other bothersome symptoms which affect QoL including incontinence.

It is a particular interest of mine, partly inspired in part by a patient I met when I first became a continence advisor in the city several years ago. I visited her at home, initially to help with continence management associated with MS. Eventually dysfunctional voiding resulted in my teaching her intermittent self-catheterisation (ISC). Each challenge presented motivated my interest to find a solution to help her manage her continence against a particularly aggressive form of MS; it was only by listening to her perspective that I was able to focus on the support she found most helpful. She faced her situation with great fortitude and resolve and managed to maintain her humour despite all that happened to her. What had particular resonance with me was she was my age, married with school age children. Each stage presented a challenge and when she could no longer cope with ISC, she eventually made the decision to have a supra-pubic LTIC. This woman, like so many people I have met through nursing, gave me a unique perspective on her experience of MS and the challenges of managing continence which I felt a passion to do something with.

### 5.3.1 Multiple Sclerosis (MS)

MS is a neurological condition affecting the central nervous system. An autoimmune attack on the myelin sheath, the coating that surrounds the nerve fibres in the brain and/or spinal cord, results in plaques or lesions forming which disrupts their ability to transmit messages. This results in disseminated, demyelination of nerve fibres of the brain and spinal cord. The range of symptoms depends upon which part of the central nervous system is affected. Symptoms are unpredictable and can vary widely for each person.

There are approximately 107,000 people in UK with MS (*MS Society website [www.mssociety.org.uk](http://www.mssociety.org.uk) - accessed 04.02.17*) and each year 5000 people are newly diagnosed, suggesting prevalence is one in every 600 people. The onset is often in young adulthood and it typically affects twice as many women as men (Mohr *et al*, 1999; Pakenham, 1999). Although severity varies greatly between individuals, many people with MS experience a steady deterioration in their condition, whilst others have few symptoms interspersed with periods of remission from symptoms lasting for many years. Treatment involves managing individuals' symptoms (NICE, 2003). The unpredictable course of the disease and the disabling symptoms mean it can be a burden for carers (Peckenham, 2002). There is limited evidence with regards to those who care for a partner with MS but the knowledge that there is no cure at present, suggests that carers face challenges adapting and coping with caring (Cockerill & Warren, 1990; Boland *et al*, 2012).

MS can affect sensation and limb movement (Lublin & Reingold, 1996) which impacts on mobility and as well as sensory-tactile and motor symptoms, there can be sexual problems and bladder and bowel function can be affected (Pakenham, 2002). Bladder symptoms vary amongst individuals depending on each relapse and remission, but it is estimated that 90% of people with MS will report lower urinary tract symptoms (LUTS) and 80% will develop some form of bladder dysfunction (Khalaf *et al*, 2015). Bladder problems include urge, stress and mixed incontinence. The loss of nerve sensation and co-ordination emptying

the bladder can cause dysfunctional voiding (difficulty emptying their bladder effectively) and a 'residual' urine can result in urinary urgency and frequency increasing the likelihood of infection because the naturally flushing of complete bladder emptying has been compromised.

There is limited reference to incontinence and MS (Murphy *et al*, 2012) and sparse literature relating to MS and indwelling catheters (Mahajan, Frasure & Marrie, 2013). The recommended management approach if bladder dysfunction is causing a residual urine, is ISC in the first instance (RCN, 2012). The progression of MS and neurological damage also impacts on the ability to manage their bladder symptoms with ISC due to hand coordination, ultimately an indwelling catheter (LTIC) may be necessary (Kalsi & Fowler, 2005; [www.mssociety.org.uk](http://www.mssociety.org.uk) accessed Dec. 2017). In addition, symptoms may include loss of balance, muscle spasm and pain, fatigue and vision can also be affected. These can in turn, impact on maintaining continence if there is a delay or difficulty getting to the toilet in time.

The most common type of catheterisation used is ISC. A study by Mahajan, Frasure & Marrie (2013) of 9,676 people with MS found that 11% of people were using a catheter at the time of the enquiry with 26% (one in four) having used one previously. Amongst those who had used a catheter, 81% were intermittent (ISC) and 43% had used an indwelling catheter (8% of these were supra pubic devices). People also reported having used more than one type of catheter. Individuals may also experience cognitive and emotional changes (Mohr *et al*, 1999), depression and latterly dementia. Over time, greater support with personal care is required.

Pakenham's (2000) study developed a measure for caregivers coping with a partner with MS. The 'coping measure' for adjustment of individuals who care for someone with MS, considered the adaption process and coping as part of caring. The study recorded data of eighty-nine carers of people with MS (57% were male, mean age was 49.87 years and 85% were married and the others were immediate family members. They faced both physical and psychosocial challenges (pp.97) and

findings reported the benefit of support and reciprocity which benefited the process of adjustment. In contrast, where carers were experiencing conflict and problems with behaviour, they were more likely to have higher levels of depression and stress. The study did not consider specific symptoms in relation to MS and there was no mention of continence or urinary catheters, however as an instrument to assess coping strategies for those caring for someone with MS, it suggested that the couple relationship influenced adjustment – linking ‘passive avoidant emotion-focused coping with poorer adjustment’ (pp113) and evidence that as health related to MS deteriorated, the caregiver offered more help which impacted on their life.

### 5.3.2 Impact on carers

Family carers experience raised levels of depression linked to the uncertainty about their partner’s MS (Gold-Spink *et al*, 2000). Similarities with long-term conditions record that intimate relationships are affected (Burman & Margolin, 1992) as MS can cause sexual dysfunction. When one partner has MS, statistically divorce is almost twice that of the general population (Brooks & Matson, 1987).

## **5.4 Review of objectives following Part 1**

An outcome of the thesis research aims is to inform practice in an area where research relating to carers supporting partners with an LTIC is sparse. In Part 1, this was achieved by addressing two main objectives:

- To interview carers to gain an in-depth understanding of carers’ experiences of caring for their spouse with a LTIC, to generate knowledge to inform HCPs and improve practice.
- Explore how the LTIC impacts on carer’s daily life and to identify ways of coping and experiences of support.

The aim of Part II was to deepen the exploration and understanding of the impact of LTIC on the spousal relationships of participants from the perspective of both carer and care recipient. The expansion of the objective was therefore:

- To further consider the impact of their relationship on the carers' experiences

## **5.5 Method**

### 5.5.1 Case study research

This second phase of the study was a natural progression to explore the interaction and impact of both carer and care recipient with the LTIC. The addition of dyad case studies enabled further examination of the complex themes in Part I and the influence on their relationship.

Case study research, whereby the uniqueness and detailed knowledge of the individual and their 'real world' (Yin, 2014) experience is respected, can be a powerful vehicle for nursing research. There is a natural affinity with nursing with the example of 'cases' to examine and explore practice (Clarke *et al*, 2015).

### 5.5.2 Recruitment criteria

The recruitment of three carers for the dyad study mirrored Part I, with the addition that their partners were LTIC users with MS and I had interviewed them previously (Fowler *et al*, 2014). As such there was a degree of 'opportunistic sampling' (Miles & Huberman, 1994) dependent on matching the spousal carer partner with the LTIC user I had previously interviewed. In the Fowler *et al* (2014) study, there had been twenty-seven LTIC users and five had MS and only four of these lived with a spouse. The first three approached agreed to take part.



**Table 3 Dyad demographics Part II**

Background	Hilary Spousal carer	Mike LTIC user	Mavis Spousal carer	Peter LTIC user	Brian Spousal Carer	Margaret LTIC user
<b>Age of carer</b>	66 years		73 years		86 years	
<b>Age of LTIC user</b>		66 years		74 years		70 years
<b>Sex</b>	Female	Male	Female	Male	Male	Female
<b>Type of catheter</b>		Supra- pubic catheter		Urethral catheter		Supra- pubic catheter
<b>Time with LTIC at carer interview</b>		6 years		5.5 years		4 years
<b>Occupation</b>	House wife	Retired carpenter and joiner	Retired social worker	Retired, managed own business	Retired university professor	Retired speech therapist
<b>Family</b>	Two married daughters with children who live near and visit parents on a daily basis		One son who died. Two daughters, one a single parent, both abroad		Two sons – one lives close and they see on a regular basis, the other lives away and they see infrequently	

### 5.5.3 Data collection

The semi-structured interviews were conducted at a mutually convenient time and all opted to be interviewed at home.

Although participants were asked to focus on their experiences of the LTIC for the purpose of this study, it is acknowledged that inevitably there would be times when MS would be talked about. To encourage a relaxed atmosphere between us and establish a good rapport (Smith, Flowers & Larkin, 2009), I wasn't unduly concerned if they deviated from talking solely about the LTIC as it might reveal what their priorities were and how much the LTIC featured in their daily life. The interview prompts, as a guide, were used as needed [Appendix 8].

### **5.6 Analysis**

The analysis was a three-step process. The first comprised of re-analysis of the existing transcripts from the care recipient with the LTIC (Fowler *et al* 2014).

The second step was analysis of the new transcript from the carer (with or without the care recipient present). The third part of the process was the intergraton of the 'paired' transcript from the first point (with LTIC users) and the second point (with the LTIC carers, with or without the LTIC user present).

#### 5.6.1 Re-analysis LTIC user interviews and analysis of the LTIC care interviews

The six semi-structured interviews were subjected to IPA; the same detailed process of analysis engaging in an 'interpretative relationship with the transcript' (Smith & Osborne, 2008) as used in Part I.

The original methodology (Fowler *et al*, 2014) followed an interpretive descriptive approach (Thorne, Kirkham & MacDonald-Emes, 1997; Thorne, Kirkham & O'Flynn-Magee, 2004).

Re-analysis of studies (Akerstrom, Jacobsson & Waterfors, 2004) involving people's experiences has practical and ethical value, particularly when working with sensitive topic areas and with hard to reach populations. Permission and consent conformed with ethical and legal guidelines.

In view of LTIC user's long-term condition and poor health, re-analysis was a practical option and enabled the impact of the LTIC to be viewed in the context of their relationship as three dyad cases. There were positives to reviewing the interviews after the passage of time, enabling a reflective view of the data and to consider the interviews from an in-depth IPA perspective.

#### 5.6.2 Creating the dyad case studies

Both individual's transcript within each dyad were examined in detail guided by the various stages of analysis (Smith, Flowers & Larkin, 2009; Smith & Osborne, 2003). Similarities and differences in their shared experiences across the cases were identified (Smith, Flowers & Larkin, 2009). The case studies highlighted the complexities of themes within the dyad. In some cases a particular superordinate

theme dominated the interview of one partner but held less significance to the other or there was a different emphasis. This recognizes the idiographic element of IPA.

The following section presents the three dyad case studies. Each dyad case study is presented in the order the caregiver interview took place.

## 5.7 Dyad case study 1 – Hilary and Mike

Figure 6 Pen portrait Hilary and Mike

'I just get on with it' [Hilary]

Hilary, aged sixty-six years, was the sole carer for her husband Mike, a year older, who had MS. They had been married forty-six years and had lived in the same three-bedroom terraced house where they had bought up their two, now married daughters. They were a close-knit family; one daughter lived opposite and their eldest daughter on the adjoining street. They saw their daughters most days and four grandchildren regularly, as well as having phone contact at least once daily. Hilary valued their frequent contact. I interviewed Mike and Hilary separately, four years apart. They were both accepting of individual interviews; the only couple who agreed to this, and the youngest couple of the three dyads.

Mike's experience

Mike was a softly spoken and unassuming man, who talked slowly, his voice slurred at times as a result of MS. On reflection, I suspected he had agreed to be interviewed because the DNs had asked him and he valued their support.

Mike was still mobile at this time though not able to walk any distance but used a mobility scooter. He had taken early retirement as a carpenter and joiner on health grounds a couple of years previously. Hilary had not worked since having their daughters who were now in their late thirties.

At the time of the interview with Mike, he'd had a supra pubic catheter for two years and was managing his catheter by himself. His MS symptoms mainly affected his bladder and mobility: *...from the waist upwards I'm fine – it's me legs and walking and things that I'm poor on ...* [Mike]

Four years later, an interview with Hilary

In the intervening years, Mike's health had deteriorated, and he now used a wheelchair all the time. He was increasingly dependent on Hilary's help to manage the catheter. They had made practical alterations to the house: *...I've had it...a stair lift, for Mike...through lounge for Mike, floorboards, easy for the wheelchair...* [Hilary] She took great pride in keeping the house nice: *I love my house, I'm always decorating...* She now did all the home maintenance jobs if she could.

Mike and Hilary came across as very private people, not used to talking about themselves. Hilary's experiences of Mike's LTIC in the early days was as something that he did. She had been aware of Mike's embarrassment of increasing incontinence and empathized with his decision to have a LTIC without talking to her, but acknowledged that this had left her unprepared. She had to overcome what she describes as her 'squeamishness' about the LTIC when he needed her support because there was nothing else she could do: *'I just cope...I have to...'* [Hilary].

**Table 4 Table of Themes – Hilary and Mike**

<b>Superordinate Themes</b>	<b>Subordinate Themes</b>
Theme 1 <b>Before the LTIC and making the decision</b>	a. The embarrassment of ' <i>water problems</i> ' b. ' <i>He just said, like, I decided</i> '
Theme 2 <b>Adjusting</b>	a. Adjusting - over time b. The LTIC always on your mind c. Long-term concerns for LTIC
Theme 3 <b>Support</b>	a. Support from DNs b. ' <i>We've got a good family</i> ' c. ' <i>I'm having...I do everything for him...</i> '
Theme 4 <b>Impact on their relationship</b>	a. Physical relationship b. ' <i>You've got to take the good with the bad</i> '

5.7.1 Theme 1 Before the LTIC and making the decision

a. The embarrassment of '*water problems*'

When Mike first had problems with urinary urgency and occasional incontinence, the DN had suggested he try a urinary sheath:

*Hilary: ...and um...to start with he had the ...tut...Convene<sup>4</sup> (hushed tones), like you know...but that was sometimes more...that was harder work...than finding a loo because condoms would come off, don't know why, but they would, and then he'd finish up with like wet patches, like you know, which was more embarrassing for him so...(exhales, clears throat)...he just felt he couldn't go on like this... (Hilary)*

She saw the situation as a bystander without being able to help him with the convene and seeing it as an unpredictable strategy (Fultz & Hezog, 2001) which made it worse for them both. He persevered for over a year using a sheath even

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<sup>4</sup> A urinary sheath or condom catheter is a continence device for men, consisting of a condom worn on the penis and attached to a catheter tube and drainage bag. 'Convene' is a trade name.

though it leaked: *I found I was getting the wrong size...using the wrong sized sheath...* (Mike). Which demonstrates he was not someone to proactively seek help when something wasn't right; his expectation, and trust, was that HCPs would suggest an alternative if there was something better.

Hilary was empathic to his embarrassment however the situation impacted on both their lives:

*Mike has been going to the hospital for quite a few years now for his ...um...water problems (voices goes quieter, clears throat), spending a penny every half an hour through the night, you know, it's much worse for him...he'd um, get...go and spend a penny, by the time he got back into bed, he'd need to go to the loo again...* (Hilary)

Her use of euphemisms such as 'water problems', 'spending a penny' and speaking in hushed tones, suggests she was uneasy discussing such things, particularly as they related to intimate details about her husband. The implication was that these subjects were not spoken about and she felt disloyal talking about his problems to someone else.

*b. 'he just said like, you know, I decided...'*

Mike recounted a poignant incident in a restaurant with his family, including grandchildren celebrating his wife's birthday, when unbeknown to him, the sheath had become detached:

*I - thought about it, thought about it for...quite a few months, I decided to a...I was in an embarrassing situation where I go out for a meal with the wife and I'd be leaking and you know you get up and you see the seat wet...things like that...quite embarrassing...yes* (Mike)

He had given the decision careful thought but the shame and embarrassment of this incident, wetting himself in front of his family including grandchildren and an affront to his manhood, was the catalyst for seeking help and the decision to have a LTIC. Going out for a meal with 'the wife' as he referred to Hilary, and his family, was an important component of his QoL (Fowler *et al*, 2014).

Mike: *'Well, um, it was (cough) - excuse me - decision, a decision in me due to the fact that it was leaking and um...I decided to have the supra pubic catheter because since I have the*

*supra pubic I found I don't leak at all...well, obviously not and I found them very ...I lived with it so far...very good'*

Mike, who was uneasy talking to start with, struggled to articulate his experiences. Initially he had endeavored to cope pre-catheter by himself with worsening and demanding bladder symptoms, attending appointments alone. He uses phrases such as: *I thinks to myself...* (Mike), as he worked through what he was going to do, reassuring himself but still choosing not to share his thoughts with Hilary. Having made the decision, Mike was very positive about the LTIC. Mike had a urethral closure procedure, hence his comment regarding not having urethral leakage.

Hilary: *so um...he'd been seeing the specialist at the BRI and they um, suggested like, you, he have this catheter, a supra pubic one (exhales) which at the time, I don't think I was there, no (answers immediately), I didn't go to the hospital with him, Mike decided this for his self (stops abruptly).*

The decision to have a supra pubic rather than a urethral catheter, was Mike's choice. The options were discussed with the urologist but the deciding factor was because they still had sex.

Hilary: *...so when he came home he just said like, you know, I decided...I can't go on like this (sighing voice), like you know, Mike felt he couldn't even go outside, you know, he was um...(clears throat), wherever we go, we were looking...for loos, like you know, so we could start (big sigh)*

Interviewer: *Did you feel as though you were included?*

Hilary: *(long pause) ...no I didn't... but I didn't mind because Mike had suffered so... That was all Mike's decision because Mike had suffered so...so much so through the years...but I was quite happy with Mike's decisions because he was the one that was suffering really*

Mike's unilateral decision was accepted by Hilary, even if reluctantly, she acknowledged it was a practical solution and 'years' had passed. She referred to him having 'suffered', using the same word on several occasions to explain and justify the decision as she reasons with his approach, but knowing the LTIC was 'easier for him'. It was an improvement on the sheath system, but it also benefited her as she was implicated in having to look for a toilet every time they went anywhere, something they had done before he had the sheath system. Hilary

was now resigned to the decision. She considered his normally contemplative decision-making was in sharp contrast to his decision regarding the LTIC. Hilary described the initial shock of the supra pubic LTIC and how she gradually adjusted to it over time:

*I was a little bit ... yes...because I'm a little bit squeamish anyway... and um...I found it...(upset voice) quite upsetting to start with, like...yeah, it's ah...(Hilary)*

Initially Mike had managed his LTIC but as his MS became more debilitating and he found it more difficult to cope, Hilary became more involved and overcame her reticence, if tentatively. By the end of the interview, she was reflective: *It didn't make any difference to me... not really...(Hilary)*

Although she said it hadn't bothered her, there was an awkwardness about her response and a forced '*not really*' that followed, as if trying to convince herself as her way of coping (Clare, 2003).

### 5.7.2 Theme 2 - Adjusting

Experiences of the LTIC suggested a continuum of adjusting over time due to changing circumstances and influences. Mike had accepted the LTIC, whereas Hilary was still in the process of adapting and coming to terms with it. His positivity about the LTIC reaffirmed its benefits as he saw them:

*I'm very happy with it (Mike) and he downplayed problems such as the frequent blockages: ... that's the only problems I've had with it, otherwise it's good...*

Mike was determined to be optimistic, but the ongoing problems did concern him:

*...so that is the only problem with the catheters if they block - I don't seem to be able to go longer than 3 weeks... (Mike)*

It emerged that his LTIC had been problematic from the start and he had problems with bladder stones, the most recent one removed had measured 4 cms in diameter.



### a. Adjusting - over time

The early days of the LTIC were a time for adjusting for them both: *I didn't know anything much about it all really....obviously, like as time goes on, you get a bit more relaxed with it...um...I'm fine with it now, I know it's um...* (Hilary)

She had not been prepared for how it looked:

*I mean when Mike first had it done...you know...it was like um, tubes and pipes and bags, you know, he used to feel...it was hard for him as well* (Hilary)

Despite some hesitancy sharing her early experiences, she acknowledged that it had had also been a shock for Mike. Many of her responses stopped abruptly and although she was given time to answer, she rarely said more. The implication was that the LTIC had come between them physically.

In contrast Mike didn't acknowledge any difficulties in the early days, instead, focusing on it being positive decision.

*Well, I think I had to cope with it more, Mike...oh no, at the start Mike was quite good like, you know, he sort of managed it himself like, emptying it and ...sorting it out like... all things he needed ....* (Hilary)

Hilary considered that adjusting to the LTIC was more difficult for her, presumably because she had not received any preparation or support with management of the catheter process but with the expectation that she would help. The comment that he '*sort of*' managed it suggested that she didn't consider he could manage it independently as he needed her assistance to help him deal with spills and/or change wet clothing.

Unpredictability of the catheter blocking made adjustment more challenging:

*I remember Mike first had it done...you know...it was ...it took a bit of time to get used to...it wasn't easy at all, for me or for him like, so um (sigh)...yeah, it's just um...and then...he had lots of trouble with it, blocking...which he still does now actually (lowers voice,) gotta keep drinking, you know, because it will block and...yeah but it's easier...I mean it's so much easier for him, you know, he's not rushing for the loo, looking for a loo everywhere we go, you know...* (Hilary)

Overtime the situation became easier despite the LTIC problems, and the catheter was viewed as a 'trade-off' for the problems Mike had been having:

*I think it took almost a year like, to feel really comfortable with it, you know, and from Mike as well, because I mean Mike used to feel, um...it was like um, (clears throat suggesting unease remembering) tubes and pipes and bags, you know, he used to feel...it was hard for him as well...(Hilary)*

The adjustment time of twelve months was consistent with Wilde's (2008) findings. However, coming to terms with it had left a long-lasting impression: *I'm fine with it now, I know it's um...yes ...(Hilary).*

At the time, she hadn't been aware of Mike having any information about the LTICs and neither of them had any previous experience or knowledge of catheters: *... I have now, I didn't at the time (laughing)...no (Hilary)*

*...he had lots of trouble with it, blocking...which he still does now actually.....Mike needs his changed more because it blocks quite often...and um...it comes down to sort of every month...he needs it changed but now he's back to six weeks because I'm trying to make him drink (Hilary)*

The DNs had tried different catheter types but the problems never resolved, resulting in regular visits from the DNs to deal with blockages. Her choice of words '*trying to make him...*' reference drinking, gives an indication of the challenges trying to encourage drinking that are frequently cited in the literature particularly in relation to LTICs.

#### b. The LTIC always on your mind

Mike's LTIC was more likely to block at night, disturbing both their sleep. Hilary described it as – '*very uncomfortable*' (Hilary) for him whilst they waited for the DN team to arrive, Hilary was helpless, unable to do anything to help him.

From a practical perspective, Mike had adjusted to wearing the catheter bag: *Well I got used to it now, it's um, at first (straps) were a bit tight, then you sort of loosen it off like and um do it to yourself for comfort (Mike)* and adapted his choice of clothing - '*...wider underpants – that's for the site*' (Mike). Because the supra pubic site was near the waist on his trousers, he now had to wear different design underwear.

When I had interviewed Mike, he had developed practical coping strategies such as knowing where the nearest toilet was to empty the bag. Being familiar with the local area gave him the confidence to continue going out independently. He monitored catheter bag filling and I noticed he had patted his bag a couple of times during the interview to assess it:

*.... I think for myself, it's getting a bit full, I must empty it (Mike)*

### c. Long term concerns with LTIC

I had asked Mike what advice he would give to someone in a similar situation to him who was considering a LTIC, his reply was:

*I would say to them 'go for it' because in that, with that um, frequency of how they go and go, I think it's ideal so I'm very happy with it...(Mike)*

However, he had concerns for the longer term:

*Well, all I'm worried about it, been having them long term – is there going to be any infections? With a foreign body in my body...but ah, hopefully no (Mike)*

There was the additional anxiety when HCPs discussed the LTIC in terms of a 'last resort' intervention, resulting in uncertainty if the LTIC is plagued with problems as Mike's was. He used the term 'foreign body' which is phrase that HCPs use when explaining why LTICs are problematic. Although Mike talked about 'sludge, mucus' when it was changed, he did not appear to understand the implication between frequent CAUTIs with blockage. Mike was very dependent on the DNs taking responsibility for the LTIC management and eventually Hilary became responsible for the day-to-day catheter care.

## 5.7.3 Theme 3 Support

### a. Support from DNs – positive experiences

They both had positive experiences of support, often individually from the DNs. The DN base was geographically close and contact was frequent. For Hilary support was an intrinsic part of helping her cope. She had been reluctant to get involved with the LTIC and had not envisaged this aspect of their life together.

When Mike had his supra pubic catheter, he also had a urethral closure procedure which meant there was an increased urgency to change it if the LTIC blocked. This was not normally a problem as the DNs were nearby and he never had to wait long for their assistance. It was, however, an added anxiety for them if they travelled any distance away from their local DN team. On one rare occasion when they travelled away from the city to his cousin's sixtieth birthday, it had blocked:

*Interviewer: What did you do that day?*

*Mike: um...wet myself...(embarrassed laugh)...so it's a problem...I phoned up...um, 'name' whoever I could...at (name of DN base) and they changed it*

The LTIC was particularly bothersome at the time of Mike's interview:

*Well, I've been having it changed every three weeks, because I been finding them blocking...and when I blocks...I'm, I'm in the process...of trying to do it myself. Because I think by watching them do it, I can do it myself... (Mike)*

His multiple use of 'I's in this quote is indicative of how he sees himself making decisions. He can be heard building himself up to suggesting it to the DNs and Hilary; convincing himself that he could do this:

*...and the only thing I'm thinking of it, um, my hoping I can achieve for myself, because you know, I've had the problems with them blocking, um ah...when I go abroad, because I might go across to Australia to see my brother...I'm hoping to go early next year... (Mike)*

Mike's pragmatic approach, realizing that unless he was able to manage the catheter himself if needed, then he would find it difficult to go on the long-haul flight to see his brother. Being independent with catheter changes would mean he wasn't exposed to uncertainty about what would happen if it blocked. He was so determined to see his brother – possibly believing that he might not have too many more opportunities owing to his health.

When I met with Hilary four years later, the whole family had made the journey to Australia to visit Mike's brother. In the end one of their daughters had learnt how to change it:

.....we've suggested that because ....were just worried like it might get blocked like you know, when we were on holiday, so it's all these things you've to think of with the catheters like, you know supra pubic you know, it's so...quite difficult really, when you go away...(sighs) so of course being abroad as well, so we asked um, dis, the nurses if, [name] our daughter could learn to change it. Which, that's what happened like you know. ... But that never came about really...that never happened because...we worked it out that Mike changed to have his catheter changed just before we went on holiday (Hilary)

Mike's LTIC had not blocked when they were away: *so that was our decision – but the nurses like, they never put any pressure on us, so...they're lovely, really helpful* (Hilary)

Hilary had built up a relationship with the DNs over the years: *I know them so well, they're so lovely anyway (smiling voice)*. When Mike was re-catheterized, she helped where she can:

*I'm not present, I mean, I just potter in cos I know them... I get everything ready for them to come...that's it really.* (Hilary)

Her comment suggested that she kept an eye on how things were going, looking out for Mike.

I asked her if there was any advice specifically that she considered would be helpful:

*I don't think there's any other advice you can give really, I mean...I just...I think as you go on, you learn to...your own way, no, I don't know...* (Hilary)

#### b. 'We've got a good family'

Hilary: *What helps me most of all is my daughters – because I've got a daughter just living opposite. (name), just come (in)...just lives top of the road from me ...(smiling)*

Hilary's ability to cope was dependent on the support from their daughters. One of the daughters had presumably called in whilst I was there and during the interview came in to the room and interrupted Hilary who was talking at the time. She talked to her mum with an insouciant flatness, as if oblivious to my presence. Hilary appeared awkward by the interruption and I wondered if as

well as supporting their mum, there was an element of control being exerted. Hilary also looked after the grandchildren on a regular basis.

The idea of going away just the two of them was something she didn't consider:

*(big sigh) no, not the catheter, I don't think... it's just.... more Mike's health in general like, you know...because we've got a good family, we're never go on our own, I couldn't manage it on my own...I just couldn't go on my own...so of course our daughters goes, we always have a week's holiday with my daughter's families, two of them like you know... (Hilary)*

*c. 'I'm having...I do everything for him...' (Hilary)*

Over the last couple of years Mike's health had deteriorated:

*Hilary: Mike's is not um...not able to...any more like, you know, I mean...if he empties his bag it sort of goes everywhere (talking in hushed tones) you know, so I ...it's very sort of ...not fiddly but (searching for the word) but it's ...just hard for him, it's just hard for him...*

She alludes to MS affecting his dexterity and ability to manage the LTIC. Hilary took great pride in her house and in her effort to keep it nice, it was easier for her to care for the LTIC these days, to avoid any mishaps which resulted in more work. Anything that could be construed as an annoyance, Hilary counteracts this with empathy and understanding: *it's just hard for him...* (Hilary)

Planning and being vigilant with the LTIC was now down to Hilary:

*...I've always got to think of – all through the day. You know, oh...I can see the bag sort of filing up, "oh I'd better empty that..." (Hilary)*

When I interviewed Mike four years previously, he had been the one to plan, thinking about finding a public convenience to empty his catheter bag if they were out: *...the loos, well I know where the ones locally are ...* By the interview with Hilary, roles had reversed and now she was doing this:

*You're always looking for a disabled loo, I mean, supermarkets are quite good, yeah...I mean, you know, we've stopped at places, you know when we've been on holiday or come off the motorway or like, petrol station, service station or something, and there's no disabled loos, and then if there is you need a key and then you've got to run and sort of look for someone and then they can't find the key. That is sometimes a problem – supermarkets are the best thing you know (Hilary)*

Being prepared gave her confidence:

*I always carry a bottle, I um...take. Um. ...carry a four pint milk container like, that's all I do, its ...just keep it in the car for a long journey because you can't always find a loo..... it wouldn't stop us, no it wouldn't stop us because...you know, we've been out for the day and um...I just take...um ...a plastic bottle like, you know, and off in a corner somewhere and empty it really, put it in a bag and soon as I can empty it, you know, in the ladies loo, perhaps anywhere (Hilary)*

These days she had little time for herself, her time taken up caring. She needed to think about the LTIC day and night: *...sometimes, I need to empty it before I go to bed, 'cos Mike will go to bed well before me (Hilary).*

She was proactive with care to try and prevent problems: *I was forever reminding Mike that you've got to drink and if you don't' drink, you'll block ... (Hilary)*

The implication was that this was a challenge as she mentioned it on two occasions:

*...I've always got a bottle of water by the side of him...you know, telling him to drink more like... (Hilary)*

The consequence of a blocked LTIC would cause her additional problems day and night:

*Sometimes through the night, the bag do get sort of full, I do sort of need to empty it...if you don't put it on really tight then it will fall off, and if that happens through the night ...then you got a sort of wet bed (smiling embarrassed voice), you know... (laughing)(Hilary)*

She had developed strategies to manage the catheter and took pride in the care she was able to give which had become such a large part of her life; sharing the knowledge she has accumulated:

*I tried a (catheter) stand but...I didn't get on with it really, I just prefers to put it in a bucket like you know... (Hilary)*

#### 5.7.4 Theme 4 Impact on their relationship

Mike and Hilarys' accounts suggested separation within their relationship. There was something she was not saying, and it was as if she was waiting for me to ask her a specific question.

### a. Physical relationship

It was not until the end of the interview, when I explained that I was drawing our meeting to a close that Hilary visibly relaxed more than at any other time. The 'prompt' topic towards the end of the interview related to the effect on physical relationship. She described how intimacy and sex had come to an end in their relationship. In the early days, their physical relationship had not changed because of the LTIC:

*...when Mike first had his catheter, sex was good, fine (hushed tones) I mean, Mike's not so well now but, it was fine – and I think that was the reason, the decision, Mike had it...in the stomach and not the penis – that was the reason. I mean, but that was Mike's decision, like you know, I would never had anything...um...but I was quite happy with Mike's decisions... (Hilary)*

His deteriorating health and disturbed nights meant that they were now sleeping separately for practical reasons and Mike had moved in to another bedroom:

*Well, at the moment, um what we've done now, cos Mike is with his MS...he um, he don't sleep well like, you know (clears throat), he's got his own television in the backroom and the television's on/off all night...I'd never get a night's sleep otherwise (Hilary)*

She had been ill at ease talking about their sleeping arrangements, feeling more comfortable suggesting it was a temporary arrangement '*at the moment*' and acknowledging that, being practical, she needed her sleep. Even though he was sleeping in another room, he had disturbed nights, moving round the house, watching television and presumably she was listening out for him in case he needed her.

### b. 'you've got to take the good with the bad' (Hilary)

Although this part of the interview gave some indication of the reason for her unease, there remained an underlying sense that all was not right. My description in my reflective notes after the interview were that she was 'guarded' and whether it was the presence of her daughter in the house or feeling disloyal talking about her husband making her feel constrained, her outward approach to



her situation was to behave how she was expected to by her family. Tellingly, the interview finished with a comment which summed up her approach:

*I always say, yeah, we've been married like 46 years like (smiling) and I just think you've got to take the good with the bad and just get on with it basically (2) (Hilary)*

Hilary and Mike were the only dyad to be interviewed separately. I never saw them together. I had put their acceptance of being interviewed alone as complying with my request but on reflection I wondered if it was because they saw themselves as separate.

Mike was resigned to the LTIC, even though it was problematic. Hilary had to accept the LTIC and Mike's MS in their relationship – like an eternal triangle – you, me and 'it' – the MS and the LTIC.

## 5.8 Dyad case study 2 – Mavis and Peter

Figure 7. Pen portrait Mavis and Peter

Mavis, aged 73, cared for her husband, Peter aged 74, who had MS. I first met them pre this PhD study when I went to their home to interview Peter about his experiences of an LTIC (Fowler *et al*, 2014) and Mavis joined the interview. Meeting her that day was a contributory factor for this PhD study as it demonstrated that carers were experiencing the LTIC but there was no evidence of their perspective. Four years later, I returned to interview Mavis in her own right, as part of this study.

Peter had been using a LTIC for six years. It had been fitted with a flip flow valve, which meant he only attached a drainage bag over night. He explained that he hadn't been diagnosed with MS until he was nearly forty-five years old by which time it became apparent that the diagnosis had been missed on two previous occasions. The first time when he was in his late twenties, his symptoms attributed to stress and bereavement following his mother's death. A period of remission followed until his late thirties and on this occasion, his doctor considered work related stress the cause of his symptoms. He took a period of sickness absence and presumably because the MS went in to remission, he was able to return to work. In retrospect, he considered it had been beneficial not knowing he had MS, as an earlier diagnosis would have affected decisions they made as a couple; they possibly might not have had three children or started his own business.

Mavis and Peter's home was a three-bedroom, detached chalet bungalow, which they had lived in for twenty-two years of their forty-six year marriage. It had a master bedroom on the ground floor. By the second interview, Mavis had moved to sleep upstairs for practical reasons as they were both getting disturbed sleep. Due to Peter's limited mobility he was no longer able to get upstairs.

Their early experience of the LTIC had been marred by a lack of discussion or involvement in the LTIC decision. The urethral catheter had signaled the end of their physical relationship and Mavis in particular, felt intense anger about this.

Peter and Mavis had three adult children, though their son had died in his early twenties. Their two daughters lived abroad – one was married and the other was a single mum. Mavis was particularly reliant on her daughters for emotional support. When she had health problems necessitating major surgery recently, their daughters had travelled to the UK to support them both, including helping with their father's care.

**Table 5 - Table of themes – Mavis and Peter**

<b>Superordinate Themes</b>	<b>Subordinate Themes</b>
Theme 1 <b>The LTIC decision</b>	a. <i>'I didn't decide. It's a bone of contention.'</i> (Peter) b. <i>'They didn't tell him it was for the rest of his life'</i> (Mavis)
Theme 2 <b>Adjustment and trade-off</b>	a. Positive about the LTIC b. <i>'I've had to fight for everything'</i> (Mavis)
Theme 3 <b>Impact on their relationship</b>	a. Mavis' health b. Loss of physical intimacy c. A part of the house that is 'out of bounds' d. Loss e. Support
Theme 4 <b>The future</b>	a. <i>'We were looking forward to having a great life'</i>

Key to identifying interviews

Interview 1 with Peter and Mavis = (1)

Interview 2 with Mavis by herself four years later = (2)

*'I'm sorry to interrupt but...'* Mavis had something to say

The first time I went to Mavis and Peter's home was to interview Peter as a LTIC user about his experiences (Fowler *et al*, 2014). Mavis was a retired social worker and appeared very confident and assertive. Although it was Peter who had agreed to be interviewed, he had passed the telephone to Mavis to make the arrangement for my visit and it was Mavis who greeted me on arrival and ushered me in to the kitchen/dining area where the interview was to take place.

On reflection, there was something almost comedic about what happened next; I had only just started talking to Peter when I became increasingly aware of Mavis' presence in the nearby kitchen – chopping vegetables with increasing fervor and eventually using a blender so that it was difficult for us to hear ourselves talk. Five minutes into the interview, she said: *'I'm sorry to interrupt but...'* Mavis had something she wanted to say. What followed was an outpouring of frustration and resentment towards HCPs for catheterizing Peter without any discussion with Peter or her. She blamed the LTIC for ending their physical relationship. I reflected that my visit to interview Peter, by himself, about his experiences of a LTIC must have reinforced her view that her opinion wasn't valued.

It was four years later when I returned to their home to interview Mavis for this PhD about her experiences of the LTIC. In the intervening years there had been a marked deterioration in Peter's health and as a result, she was carrying out all the care for the LTIC as well as his personal care.

### The environment

Although not a theme for this case study, I was mindful of the impact of the environment in Part I and recorded observational details as part of the interview which are included here as background information.

The changes they had made to their home, reaffirmed findings in Part I that the environment posed challenges for carers for managing the LTIC as well as for day-to-day care. Mavis and Peter had made practical changes to their home when Peter's MS first began to affect his mobility:

*[we]...had the bath taken out and wet room made... the local authority have been in and widened doors, so all the doors are now widened, wide enough to get wheelchair in and out, especially the front door, the local authority ramped, put a ramp in – to the front door (2)(Mavis).*

By the second interview, Peter was using an electric wheelchair all the time. He had difficulty maneuvering this as evident by the damage to walls and door frames, despite the recent redecoration.

### 5.8.1 Theme 1 - The LTIC decision

Peter tended to understate his situation and being overly optimistic was his coping mechanism. Initially he had played down his deteriorating health as an example of his difficulty coming to terms with his failing body, dismissing the significance of frequent falls:

*...after having had a fall, or two... or three falls... and I had stress fractures of the bottom three vertebrae... (1) (Peter)*

Prior to having the LTIC, he was having more frequent episodes of incontinence when he would often wet through to his outer clothing and his last fall had resulted in admission to hospital and included re- assessment of his MS:

*...well it (bladder) wasn't emptying. I don't know how much was left or what but it wasn't emptying and it was getting worse and it became worse while I was in hospital...  
...towards...the time they put they catheter in um, nothing really helped (1)(Peter)*

Residual urine was left in his bladder which increased his risk of a urinary tract infection and contributed to more frequent episodes of incontinence. Initially Mavis had appeared complicit in accepting occasional incontinence, particularly if they were at home, presumably hoping it was a transient problem. As time passed, it couldn't be ignored: *Peter, it actually had been leaking hadn't it? (1)(Mavis)*

She used the word 'leaking', rather than 'incontinence' or 'wetting' as if attempting to downplay the situation, making it less personal and removed from him with the use of the word 'it' rather than 'you'. Mavis addressed Peter in an assertive manner, contradicting him:

Interviewer: *(question to Peter): So, the problem that had arisen with your bladder before the catheter, was that over a 6 month, or shorter period, when you noticed the leaking?*

Mavis: *no years' (interrupts)*

Peter: *it was, well it was getting worse over about 2 or 3 years...*

Mavis: *and you see what happened when we were at college when Colin was a student*

Peter: *yes...*

Mavis: *that's longer than 2 or 3 years... (1)*

She was frustrated with Peter's unwillingness to acknowledge the problem – recounting a visit to see their son [name] at University when Peter had wet himself. Her retort was: *'you see what happened'* is one of several examples where she appears to chastise him; language more akin to talking to a disobedient child. Peter did not react to this or display any sign of embarrassment and I sensed this was something Mavis had brought up on previous occasions – his ambivalence as she saw it, following the incident, caused her continued frustration. Research identifies that individuals, men more commonly than women, are reluctant to seek help for incontinence (Garcia *et al*, 2005; Elstad *et al*, 2010) because of feeling awkward talking about it, often due to fear of stigmatization (Link & Phelan, 2006)

When he was in hospital, he had frequent episodes of incontinence:

*They hadn't noticed his pyjamas were wet...and I used to have to take home everything and do the washing you know and strangely I thought 'wet pyjamas' and I thought they'd notice it and would do something...but they didn't (sigh) .....when I told them that you know it had been happening at home as well and I was quite worried about it, it was a lot worse, they obviously took some notice (1) (Mavis)*

With more than a hint of sarcasm from Mavis, there was disbelief that the nurses had not thought to mention he was incontinent when there was evidence as she saw it, with the wet pyjamas. She knew he was unlikely to say anything: *Peter was denying there was a problem...and there were all sorts of reason why (2) (Mavis)*

With his impending discharge from hospital and her concerns of how she would manage at home, Mavis eventually spoke to the nurses, unbeknown to Peter, about her concerns; her broaching the subject was a plea for tangible help. This conversation appeared to precipitate Peter being catheterized with a LTIC the next day, seemingly without any discussion with Peter, a few hours before he was discharged home.

*a. Well, I didn't decide (laughter) I didn't decide. It's a bone of contention.*

(1) (Peter)

His ironic laughter veiled his embarrassment that he let this happen to him. The consequence of their lack of forewarning or involvement in the LTIC decision just prior to his discharge from hospital had a lasting impact on their adjustment process to the catheter. They felt marginalized and Mavis in particular, felt angry at the way it had been handled. She felt she had lost Peter as a husband and despite his failing body due to MS, she considered the LTIC was the catalyst for ending their physical relationship.

*Interviewer: ... there was no discussion (about the catheter) then?*

*Mavis: No discussion – at – all – not with me when I spoke to staff*

*Peter: so there! (1)*

Mavis' 'not with me' comment, seemingly aimed at Peter, the implication that he had allowed it to happen. Peter's reaction was to try and make light of the situation to hide his embarrassment. They had been married for forty-six years and there may have been an element of Peter not wishing to contradict his wife; she appeared a formidable opponent. His description of the first time he was catheterized was more like an assault than carrying out a medical procedure:

*One of the nurses in the ward and the MS nurse descended on me just before I came home and ...did it ...they'd been in and done it and they didn't tell me anything about it. The MS nurse, who knew me, didn't say anything about it and within 10 or 15 minutes they were gone. They'd done it...(1)(Peter)*

It had been a traumatic experience, which he talked about on two occasions during the interview. Peter, outnumbered, had not questioned it. The presence of this MS nurse who he knew, but who did not talk to him about it, compounded his loss of trust in HCPs generally.

Mavis' anger was not only directed at the nurses for failing to involve her with the LTIC decision after she had confided in them about his incontinence, but it was also directed at Peter:

*...and it seemed that Peter wasn't involved a great deal either...but they didn't involve me at all and I had quite a shock when I went in (2) (Mavis)*

Mavis thought Peter had not done enough to stop the LTIC being inserted:

*...and you could have told them, and I told them and then the next thing was I went in to see Peter – and – go on you can carry on from there... (1) (Mavis)*

Mavis acknowledged that her conversation with the nurses had pre-empted the LTIC, but she deflects her action in what followed by suggesting that he could have stopped them. This part of the interview became a platform for Mavis to tell Peter off – years of frustration that had built up, suddenly released. I recall feeling awkward for Peter at the time; he did not reply, except to make light of it. The consequence was, as Mavis saw it, that the urethral LTIC had put an end to their physical relationship. Their inability to talk about his incontinence and his MS suggested they were already finding it difficult to communicate as a couple. The choice of a urethral, rather than supra pubic catheter suggests poor or incomplete assessment.

b. *'...they didn't tell him it was for the rest of his life'* (Mavis)

The insertion of the LTIC: *'just before I came home'* (Peter) would have provided little opportunity to teach him or Mavis how to manage the LTIC:

*... he didn't realize he was always going to have it and it was a terrible shock ...it was a terrible, terrible shock for me too, nobody told me (ironic laughter) (1) (Mavis)*

Peter's previous experiences of health care had included the misdiagnosis of MS on two occasions. His skepticism remained fuelled by the LTIC experience and resulted in a downbeat sentiment when he talked about the care he received. A mild mannered and private person, he was ill at ease with having different DNs carrying out the intimate procedure of a urethral catheterization:

*...it's been unsatisfactory in a couple of cases because I've had a different district nurse...and sometimes it's not been done properly and I've had to call in another district nurse to put it right. You know...but um...I've coped, with it but I don't enjoy it (1)(Peter)*

Faced with no alternative and having to be stoic, the situation was not helped when the nurses had problems with the procedure. In the early days the DNs



had come to the house '*about every 10 weeks*' (1) (Peter) to change his LTIC:  
*...until they decided to have a catheter clinic at [name of venue] where I go now and have it replaced.* (1) (Peter)

The local DN service restructuring meant that his catheter changes now took place in clinic, away from the familiarity of home. The intonation in his voice conveyed a sentiment of 'yet again'- that decisions had been without consultation or consideration of his preference.

### 5.8.2 Theme 2 - Adjustment and 'trade-off'

#### a. Positive about the LTIC

From a pragmatic stance, the catheter improved their quality of life; his needing only minimal help from Mavis in the early days: '*It makes it a lot easier in so many ways*' (1) (Peter). He made light of catheter discomfort - '*only when I'm sat on it (laughter)*' (1). Despite his initial experience of the LTIC, he acknowledged the timescale of his adjustment: '*I think I got, I got used to it in no more than 6 months*' (1) (Peter) and that LTIC changes were easier:

*'I really don't know when they've finished because they say, you know, put your trousers back on, because they're so adept at it'* (1) (Peter)

The 'trade-off' for the LTIC was his ability to control his continence, despite all the problems they had with the LTIC later. The down side was that the catheter affected his comfort in bed and his sleep; restlessness and leg spasm associated with MS and his position in bed was restricted to lying on his left side only, as the catheter drainage bag he used at night had to be positioned at his side of their double bed. He could sleep on his back, but was more likely to disturb Mavis with his snoring:

*...it's a damn nuisance when I'm in bed, because I tend to turn over in the night and I'm lying on it and it's uncomfortable* (Peter) (1)

At the time of the second interview with just Mavis, she appreciated the benefits of the LTIC, acknowledging the advantages to them both:

*I mean, it is an amazing...it is a wonderful help... He hated it at first, he hated it but he's now come to realize that we can go out, we can do things... (2) (Mavis)*

Initially Peter was independently managing his LTIC and had developed a routine:

*... I change the valve once a week, that's my Tuesday morning job (laughter)... erm, no it really doesn't, it makes it a lot easier in so many ways (1) (Peter)*

He continued to use the flip flow valve and no catheter bag so the benefits of the LTIC soon became apparent to them both. In the early days of the LTIC it had enabled them to resume their social life:

*... we go to the cinema or the theatre and I haven't got the worry about getting up and missing half the film or something. We go to restaurants, I haven't got any worries like that (1) (Peter).*

This contrasted with the pre-catheter days when he would need to use the toilet at least once during a film and on occasions needed Mavis to help him to the toilet.

The positives helped their adjustment, however Peter's seemingly positive attitude to the LTIC was, I suspected, also part of his desire not to have any further interventions. When I enquired whether a supra pubic catheter had ever been discussed, he replied:*...I mean (laughing), but I really don't, I don't want to go through anymore with this (1) (Peter)*

Peter's approach to normalize any problems with the LTIC were reinforced by reassurance from Mavis: *...that's right, if it ain't broke, don't fix it (1)*. She was complicit with his approach. It was ironic that if a supra-pubic LTIC had been offered originally, the LTIC may not have been such a barrier to an intimate relationship.

At the time of the first interview, Peter had been volunteering at a local hospice, a ten-minute car journey away. This gave him social contact and it made him feel valued:

*...I mean, I'm doing an afternoon shift today, half past one 'til half past five and cups of tea and bits of cake and all sorts are offered to me. I have no problem.*

*...well, I do switchboard and reception which is out front near the entrance. Behind these is a disabled loo. No problem (1) (Peter)*

As part of the 'trade off', Peter had made adjustment to his life at the first interview when they were both present, and did not consider he was missing out on anything because of the LTIC: *... I don't swim anymore (1)*. If he was out and about, he was confident to use the flip flow valve in public toilets:

*...well I find that there are quite a few disabled loos, you know, adapted loos and that's not a problem...yeah, I've got a RADAR key (1) (Peter)*

When asked if he had any long-term concerns about the catheter his reply was: *not really, no (1)*. His ability to manage his catheter away from home meant they had the confidence to travel abroad in the early days:

*We've been to France several, twice since I came out of hospital but yeah, we go on holiday. We've just come back from Cornwall' 'no problem' (1) (Peter)*

Peter used the phrase 'no problem' several times during the interview suggesting how important it was for there not to be 'problems' which accompanied his approach of playing down potential difficulties. LTIC blockage in the early days was rare: *...it has been blocked a couple of times (1) (Peter)* and he could only remember having antibiotics on one occasion for an infection. However, it had become a 'double edged sword' by the second interview – the LTIC helped Mavis manage Peter's continence but it had started to regularly block, and she found the frequent visits by the DNs an intrusion. This included twice-weekly visits to carry out catheter irrigations and having to change his LTIC every couple of weeks.

#### b. 'I've had to fight for everything' (2) (Mavis) – experiences of support

Before retirement, Mavis had been a social worker. Her expectation was that HCPs would treat her as an equal, but her experiences fell short of her expectations. Her frustration regarding the approach and criticism of support they received extended to her GP and even the local pharmacy; she felt everyone was against her:

*I've had to fight to get everything... (2)*

*...and I told the doctor...and in fact we're going to have to change our GP I think, because I'm absolutely fed up with it...he, he finally referred him to a urologist... (2) (Mavis)*

When interacting with HCPs she saw doctors contradicting each other, fueling her feelings of cynicism and lack of trust:

*He (the urologist) was another one of those ones; he didn't talk to me or Peter, he talked...he just wrote it all down (disparaging laugh) (2) (Mavis)*

Her expectation of the meeting was informed by prior experiences of poor communication with HCPs, offering little interaction; she felt he was more intent on completing the consultation than providing individual support.

They had a letter to say that Peter had an enlarged prostate and the urologist's suggestion was that he could try a suprapubic catheter; it was their daughter she talked to about it:

*Our daughter is a nurse in Israel, well, midwife but she was a nurse, she works and she knows about these things...-she told him what it was – nobody had explained to him what it was, why it would be an advantage – and we didn't ask the nurses 'cause the nurses didn't know – they didn't know – they hadn't been told by the doctors it was one of the suggestions – we told them – we've had to tell them everything (2) (Mavis)*

### 5.8.3 Theme 3 Impact on their relationship

Although Mavis joining Peter's interview provided a greater insight into their relationship, her presence often stymied Peter's involvement:

*Peter: well he told me what it (the supra pubic catheter) ...*

*Mavis: (interrupts) he told you what it was, yes -*

*Peter: you were with me...*

*Mavis: oh yeah, I was with you, that's right - but nobody really explained and nobody asked him, I mean he's only 74 (1)*

As a counter argument, the benefit of interviewing them as a couple demonstrated the interplay between them as they talked about the LTIC. They had an understanding, even as they bickered. On occasions he stood his ground:

*Mavis: but you tuck it (the catheter) in your underpants don't you?*

*Peter: no, I don't (1)*

### a. Mavis' health

At my first meeting with Mavis and Peter, there had been an overriding sense of frustration as she felt powerless to make things 'right'. Her relationship with him had been affected by decisions made by others. In the intervening years she had felt both physically and mentally tired by her experiences. She talked about her anxiety and worry and being unable to help him when he was in distress such as if the LTIC blocked:

*It is awful when I see him in pain and it's awful if I'm around, I mean the nurses carry on as if I'm ...I mean, I find it, I find it very distressing (2) (Mavis)*

A recurring experience for Mavis was trying to maintain control. I sensed that Mavis was someone for whom being in control was important and it was her way of coping; trusting that she was the best person to do the job. Her own health problems were a watershed – a time to re-evaluate hers and their future.

She was diagnosed with cancer of the colon and needed six months of treatment, which included surgery:

*I'm very upbeat about my health and my operations but you know, everybody gets a little scared...and um...I've wondered if I'm going to come out of this (2) (Mavis)*

The emotional impact of her situation may also have been an influence on her health. Mavis admitted to putting on a brave face but was worried for herself and missed having his support: *...he can't support me in the same way (2) (Mavis)*. There was also additional tension related to the uncertainty about what would happen to her and Peter in the future:

*...it's very difficult – it's very, very difficult – I was very worried and he was much more worried than I was... (2) (Mavis)*

She suggested that Peter felt that her illness and not being able to care for him had affected their relationship: *um...it's hard...and um...I think Peter feels that's very much come between us...and it has...(2) (Mavis)*. Their relationship did not appear open and honest about problems, similar to Peter's early incontinence not being talked about.

The interval between the two interviews has been a time of great change. Her caring role had evolved to include providing personal care – something she had not envisaged. The recent problems with the LTIC blocking also meant she had to be home:

*... I know, that twice a week, twice a week we can't do things together for example because...they're very good and they come in the morning...but you never know...I mean they've got other things to do (2) (Mavis)*

Before her recent episode of poor health, Mavis used to go out socially by herself in the evening, attending quilters' meetings once a month. In the early days, Peter was critical of someone coming in to stay with him whilst she went out:

*...we had somebody coming in – we only had her once and Peter hated it – I went off for the day...he hated it ...um ...because he doesn't need anyone to do any more than give (him food), he can't cook anymore...  
He's very sociable as...he's very sociable when it's people he knows – but he feels people are doing – I won't say patronizing him...he says I don't need any help...and he doesn't really (2)(Mavis)*

She had felt pulled two ways - trying to have her own life and needing time for herself but conversely, wanting to make sure he was cared for whilst she is away. Since her illness, Peter was insecure about being left and he did not like Mavis going out. However, she had not felt like going out and had also stopped attending carers' meetings or her quilters' meeting.

#### b. Loss of physical intimacy

At the first interview with them both, Mavis talked candidly about Peter's problems, on occasions as if he wasn't there, about his incontinence and his impotence:

*... you know you couldn't have sex because of the MS and you know Peter's limited because of that...we could have cuddled, I mean... (1) (Mavis)*

It was the loss of any intimacy that she chose to talk about. He didn't answer, and I did not fully appreciate the awkwardness of the situation until I was transcribing it later.

Prior to Peter having a catheter, they had what Mavis described as a 'really good sexual relationship' (2) and by the second interview with her alone, she was far more reflective/circumspect and empathetic about his health and MS affecting their physical relationship:

*Nobody talked to me at all and we had a really good sexual relationship...and alright things had gone off, things had been difficult because of the MS...but, and sometimes penetration was not possible, but we did have a very loving relationship (2) (Mavis)*

Mavis talked very openly when given the opportunity, but her experience of not being asked for her opinion or perspective, was evident. She felt that HCPs held ageist assumptions about their sex life and their intimacy as a couple ignoring the impact of the catheter.

*Nobody had considered, nobody had talked...I can't remember how old he was, it must have been, I suppose I must have been in my 60s or 70s...and nobody thought that I was entitled to...that we were entitled to any sort of sex life, nobody has talked to me about it then, or since...or since... or to Peter (2) (Mavis)*

She acknowledged that their physical relationship had changed as his MS progressed and it was the urethral LTIC that coincided with the cessation of any physical relationship.

*I've got the memories of the husband he was, you know, and I find it very hard – I hate it – I think he's emasculated, I hate it but at least it means, it's better than it was (smile in voice) I mean, the advantages outweigh the disadvantages (2) (Mavis)*

She uses this phrase 'catheter emasculates him' on more than one occasion as her way of describing what the catheter had done to him.

*And I mean it (the urethral catheter) emasculated Peter, you know, he's very...he doesn't ...I have to say to him sometimes...I could really do with a cuddle, especially lately when I've had, the sort of...I've just wondered if I'm going to come out of this' (recent major heart surgery plus surgery for colon cancer) (2) (Mavis)*

She had resigned herself to the loss of their physical relationship: *I think he's blocked off...he's blocked off that side of his life now...(2) (Mavis)*, but found it hard not to take it personally.

Her recent poor health was a time for personal change and resignation that their relationship had changed:

*...I've taken to sleeping, I've given up – I've take to sleeping upstairs because he does wake in the night and he gets very anxious, terribly anxious about the catheter. I wake up and he's fiddling about down by the side of the bed and I'm "what you are doing Peter?... "I'm just checking..." (2) (Mavis)*

*... I don't like it but then I snore Peter tells me...I'm, I'm conscious of the fact that I snore as well...(2) (Mavis)*

There was resignation in Mavis' voice with her comment, 'I've given up' about their sleeping arrangement. She had eventually moved out of their room and the resigned herself to sleeping away from him for practical reasons. She suggested the move was for his benefit because she was keeping him awake but in reality he kept her awake by anxiously checking catheter drainage. The separate rooms were a visible sign and symbolic of the end of any physical intimacy.

#### c. A part of the house that is 'out of bounds'

At the time of my second visit to the house to interview Mavis, there were areas of the house that Peter could not access because of his wheelchair:

*...all the living area that he accesses is downstairs...the house is mostly accessible for Peter, except there is one part where the passage is quite narrow...it can't be widened, it's impossible to widen... (2) (Mavis)*

The practical move to a separate bedroom upstairs was also an area of the house that he was unable to access as there was no stair lift. The physical barrier of the stairs re-enforced the barrier that now existed between them. That part of the house also provided a private space for her where she could be by herself; a 'time out' space.

#### d. Loss – like a bereavement

Her sense of loss was like a bereavement; loss of her husband as he was. For Peter, the MS and the negative impact effect of the LTIC affected his self-esteem. By the time of the interview with Mavis alone, the hospice where Peter volunteered had:



*Actually they, they asked him to stop – because the new administrator....said she didn't, she couldn't really have him – too much of a risk.....it knocked Peter for six – it really caused, it caused quite a deterioration – because he felt his worth, you know, he lost (sigh), he lost his place, useful place in society really (2) (Mavis)*

Loss, as well as relating to the loss of their physical relationship, also related to lost time and their expectations of their retirement together:

*I've got the memories of the husband he was, you know, and I find it very hard – I hate it (2) (Mavis)*

Her greater involvement with caring meant her time was regimented by the demands of care:

*It is time consuming, I am always rushing backwards and forwards to the chemist and ringing up the GPs (2)(Mavis)*

Her previous social work role involved problem solving and she adopted the same approach to managing Peter's care. By the second interview, Mavis supported all his care needs as he was able to do less and less. His catheter had started blocking and leaking and the district nurses visited a couple of times a week to irrigate the catheter.

*Peter can't get to the door...it takes him forever to get out of his armchair and in to the wheelchair and then over to – it's not far – but it takes him a long time. By this time, some people have gone...the district nurses would know and they'd wait but you know I still feel that I have to be here. (2) (Mavis)*

Even when being empathetic, there was frequently a twinge of frustration in her voice - on this occasion because he was unable to help her. The problematic catheter was controlling their lives.

Peter had gone into a nursing home when she had been in hospital and Mavis had arranged for friends to visit him - 'so he was well covered' (2). When Peter came home from the nursing home, his mobility had deteriorated and he had several falls:

*'...fell three times and hurt himself and...because I wasn't here and because Polly (their daughter) had to call the ambulance service to pick him up... (2) (Mavis).*

Mavis blamed herself for this, imposing pressure on herself, feeling guilty for leaving him. Since her cancer surgery she subsequently had a coronary. This was a poignant time for the both. Since then, Peter had become more accepting of going in to a nursing home, which he had previously been vehemently against, initially to give Mavis a respite:

*He says that lately, I think that he's just been very worried – he's better now I'm better. He was very frightened, he was frightened who was going to look after him if anything happened to me (2) (Mavis)*

She had an understanding about their changed partnership – *'he's better, now I'm better'* (2) (Mavis) but *'...if anything happened to me'* - highlights her uncertainty of their situation and voicing an anxiety they shared. Over time they had adjusted to their situation to support each other:

*...we share everything and also because his memory isn't very good...in the same way that I usually try to take, well if I can, take somebody with me who has a decent memory – and a note book (laughs)(2) (Mavis)*

#### e. Feeling confident with support

Until this point, Mavis had not felt confident with the support they had received but since her recent health problems affecting her ability to care for Peter, they had been assigned a social worker. It was a role she understood and she appreciated the support.

At the suggestion of her social worker, they now had a cleaner for a few hours a week and they were going to help Mavis apply for financial assistance to help with caring:

*... my social worker's going to help me appeal again because the fact they've put him on rapid response and that, and she's going to arrange respite care...(2) (Mavis)*

There were positive experiences of the DNs, particularly since they were visiting more frequently: *...some of the district nurses are absolutely super and they really, they talk to him about it (LTIC) (Mavis)*. Mavis had support from their friends whom she was able to call upon. When Peter had refused to have a pendant

alarm because of the cost, she had asked friends for help to try and persuade him:

*I got friends to come and talk to him about it...I said I could never go anywhere ...without...and anyway, he agreed to have it back (2) (Mavis)*

Mavis was more able to see the positives of support now.

Their daughters had supported them both when Mavis was ill; visiting their dad in the nursing home and their mum in hospital. With the support of the social worker, Mavis now had respite care for Peter and she was able to arrange a trip to friends in [city in the north of England] for a couple of days. They were both planning to visit their daughter abroad.

Spontaneity was now a thing of the past and travelling now involved planning and preparation by Mavis. Their desire to travel was only happening because it was an important occasion, their granddaughter's Bar Mitzvah, and they wanted to reciprocate and support their daughter. Also, their daughter would be able to help them during their stay.

#### 5.8.4 Theme 4 The future

##### *a. 'We were looking forward to having a great life'*

This sub theme linked with adjusting and accepting her life now.

Although Peter had retired early aged 52 years as a result of MS, because he had been astute with investments, they were financially secure:

*... we were looking forward to having a great life...and travelling a little (2)(Mavis)*

Mavis reflected on their previous retirement expectations and coming to terms with an unexpected future where health issues dictated their plans. Her recent ill health had been a pivotal time for them. The irritation and frustration she

displayed during the first interview had been replaced by concern and a pervasive sense of uncertainty about both of their futures:

*I know it's an awful thing to say but I hope he goes first, because he couldn't exist, couldn't manage without...(2) (Mavis)*

### 5.9 Dyad Case Study 3 - Brian and Margaret

Figure 8 Pen Portrait Brian and Margaret

*'The way we work on important things is that 'it's us' [Brian] (2)*

Brian, aged 86, a retired university professor, was the sole carer for his wife Margaret, aged 70, who had MS. Margaret had a supra pubic LTIC for eight years. They had been married for 44 years and had two sons they adopted as babies. They saw their eldest son more frequently as he lived near, with his wife and two young daughters. Brian described him as *'incredibly helpful'*.

They lived in a large detached property in an affluent part of the city and had made substantial structural alterations to enable wheelchair access throughout, including a through floor lift. Margaret had been adamant she was not going to sleep downstairs, even though they slept in separate rooms; *'so all together, we cannot imagine a more perfect house'* Brian (2)

#### Brian

A retired university professor, Brian came across as very confident. He approached caring in the same cerebral way he appeared to approach most things - as problems that required a solution. He had been resolutely against an indwelling catheter when it had been first suggested but having investigated the risks, he latterly considered it was *'an absolute godsend'* and now they wouldn't be able to manage without it.

Supporting LTIC care included changing Margaret's catheter. Initially learning how to do this was to enable them to continue to stay in their remote holiday cottage in Wales so they could be self-reliant should the LTIC block. Over time, Margaret's catheter had become more problematic with increasing infections so he was also changing it when they were at home. Brian had his own way of catheterizing: *'I don't obey all the rules I'm afraid'* (Brian). This put Margaret at greater risk of CAUTIs: *'...he won't use the sterile pack...drives me crazy...or wash your hands!'* (Margaret)

Brian fiercely maintained his independence and when Margaret's mobility deteriorated, he increasingly took trips away without her which she had to accept.

### Margaret

Margaret, a speech therapist before she married, was diagnosed with MS in her mid thirties. She attributed early symptoms of tiredness but over time she began to suspect that it was more than this: *'Well, you've got two small children, of course you're tired...and so... time went on and I knew something was wrong...and really for a long, long time'*

When she lost vision in one eye, she recounted in a *laissez faire* manner, she didn't go to her GP, but she mentioned it at a dinner party with a GP friend who sent her to Moorfield's Eye Hospital, London, the following day. The subsequent diagnosis of optic neuritis she was told, would clear within six months – which it did. She didn't find out until later that her GP queried MS at the time. Reflecting, she wishes she had been told about the possible diagnosis earlier:

*'I just got tireder and tireder and it's not the normal kind of tiredness and I didn't know why'... I would have preferred to have been told'* (Margaret)

Margaret had become increasingly dependent on Brian for all her care needs, but she also acknowledged that he needed time to himself. She was concerned about the increased number of CAUTIs and concerned that these were exacerbated by his lack of adherence to the recommended technique to changing the LTIC. He wouldn't change his approach. She was grateful for his support but was concerned that he increasingly struggled with the physical aspects of caring.

**Table 6 - Table of themes – Brian and Margaret**

<b>Superordinate Theme</b>	<b>Subordinate Theme</b>
Theme 1 <b><i>'It's a godsend – and it has it's problems'</i></b>	a. The LTIC decision b. <i>'I mind all the infections'</i>
Theme 2 <b>Brian taking control and Margaret's dilemma</b>	a. Involvement with the LTIC b. The practical solution c. Self-reliance and maintaining control
Theme 3 <b>Adjusting to the LTIC</b>	a. Regret, loss and adjustment b. Intimate relationship c. About not being embarrassed d. Looking out for yourself e. Maintaining their life style
Theme 4 <b><i>'So I tell him – do not die!'</i></b>	a. Uncertain future

Key to identifying interviews –

Interview with Margaret by herself = (1)

Interview with Brian and Margaret, twelve months later = (2)

5.9.1 Theme 1 - 'It's a godsend - and it has its problems'

a. The LTIC decision

Prior to having an indwelling catheter, Margaret had learnt how to self-catheterize using ISC:

*I can't remember her name now, I spoke to whatever continence person, who said I was her expert – brilliant! (laughter) (2) (Margaret).*

She was keen to acknowledge that she had mastered the technique.

Initially, Brian's involvement regarding her catheter had been minimal: *...I remember you having to use a mirror... (2) (Brian)* and it wasn't until she

increasingly needed his assistance with transfers on and off the toilet that he became more aware of the difficulties she was experiencing:

*I mean, with MS you might need to go to the loo, every 2 hours, ah, and that means, transferring, I mean, we've got a downstairs loo, but the transferring we did... and you fell in there once, you know...so the present system, although it is a bit of a bind, and it's particularly a bind at 3 o'clock in the morning when it blocks... (2) (Brian)*

He was empathic to Margaret's difficulties however he found the increasing time commitment and physical nature of the support she needed more challenging. Previously he had been used to spending large proportions of his day in his study and to a large extent he pleased himself with his time. Assisting Margaret to transfer on the toilet at least two-hourly, significantly impacted on his life.

Brian was very self-assured and liked to be organized. His way of coping was to approach caring for the LTIC as a problem to be solved to maintain control. He demonstrated resilience, almost fighting spirit, when faced with setbacks, he would analyze any problem encountered, proactively seeking solutions. He referred to the indwelling catheter as the '*the present system*' (2) - systems implied a process which was familiar territory from his engineering and academic stance. He never appeared to doubt that he couldn't find a solution.

Margaret's deteriorating mobility resulted in several falls: *...it was very soon after moving here that I was in a wheelchair* (2) (Margaret). On one occasion when she fell during a toilet transfer, Brian had to ask their neighbours for assistance as he was unable to get her up from the toilet floor by himself. His pragmatic approach had always been to pre-empt problems and if something went wrong, he was intent on finding a solution. The undignified and embarrassing episode for Margaret precipitated her decision to have an indwelling catheter.

When I asked whether Brian had been included in the catheter decision, his reply was that: *I didn't give them any choice!* (2) (Brian). Their GP had suggested the LTIC and Margaret viewed this as something positive that would make life easier for them both. Brian on the other hand, was reticent, initially:

*When the catheter came up, I was quite strongly against it.... It did dawn on me that cutting a hole in one's tummy directly in to the bladder is, in the end, quite major to do and of course it's where you get the infections from as well, so that's what worried me... (2) (Brian)*

Brian had embarked on his own research and he had particular concerns about increased risk of infection. Brian paid for a private consultation with a urologist to obtain what he would have considered as an expert opinion:

*...after a lot of questions, um in fact, if we hadn't had the catheter put in, I'm not sure how we could cope, it's been an absolute godsend and it has its problems but my goodness, it's nothing like the problems you'd had (2) (Brian)*

Brian talked about 'we', acknowledging that they were in this together. Margaret had to manage her bladder urgency and frequency in addition to bothersome MS symptoms such as leg spasm. His expression 'Godsend' (2), implies a level of relief he felt; the LTIC literally being an answer to his prayers.

When making major decisions, Brian was keen to explain that they made these together as a couple:

*...the way we work on important things is that it's us – I mean, I can't imagine Margaret saying – I'm not going to have it and I don't care what you say (laughs) it's...we've been married too long... (2) (Brian)*

He used the term 'married too long', to describe how complicit they were in their decision-making - although he still took the lead. The implication was that they were united when it came to big decisions. Importantly for Margaret, the consultation with a urologist reaffirmed her opinion that an indwelling catheter was a sensible way forward in the circumstances; aware of Brian's reticence, it gave gravitas to her wishes. The implication was that ultimately it was her decision but he wanted to be thorough considering the options:

*But I think in the end...you were quite determined to have it weren't you?.....it seemed the obvious thing to do... (2) (Brian)*

The LTIC made life easier to manage: *... well, I'm glad I have had this put in (2) (Margaret)* but recently the trade-off had been an increasing number of CAUTIs.



Margaret recalled the consultant's unrealistic claims about the benefits of the catheter prior to the first insertion:

*...he said, "I've managed to get it in very well, so you're have no more problems" – which is the most (sigh)...ridiculous old fool! (laughs) (1) (Margaret)*

b. 'I mind all the infections'

*At the moment, it does block literally every 7 days and that is a bit of pain (2) (Brian)*

Recent infections resulted in uncertainty about when and where this might happen, particularly for Margaret who voiced concern for her health: '*I mind all the infections*' (Margaret).

Brian was more likely to consider problems from his perspective as additional upheaval and the impact on their daily life. The regime of care for the catheter extended beyond emptying the bag and changing the catheter, Brian found the routine demanding and time consuming: '*I spend hours every day filtering water – it takes me at least 5 minutes...* (2) (Brian)

What sounded like sarcasm was his view that filtering water loomed large – feeling like 'hours' though he knew it only took five minutes. He filtered water in the belief that it would be more palatable, so Margaret would drink more. The DNs had emphasized the importance of drinking to help prevent infection and blockage and he saw this as something positive.

The irony for Margaret was that the LTIC reduced transfers on to the toilet but she still needed some assistance to change her pad because she continued to leak urine from her urethra (she had a supra pubic catheter) and needed to wear an incontinence pad day and night:

*I've got a bag here and so it goes in my pants the same time it goes in the bag...(1) (Margaret)*

Margaret's experience with the LTIC was overshadowed by her more bothersome symptoms of MS:

*well I've been cursing recently, I get spasm in my leg and...the district nurse or whoever, said why you've got bladder spasm, you don't realize you have, you can't feel it, but you can feel your legs, ...so that's... (1) (Margaret)*

Brian admitted that aged 86 he struggled to cope with disturbed sleep when the LTIC blocked:

*... it's particularly a bind at 3 o'clock in the morning when it blocks... (2) (Brian)*

*.... well bladder infections are a blight...Margaret has a permanent bladder infection because the microbes are always there. But just occasionally, it's more severe...and um...as you probably know, sometimes it causes the patient to be confused – I don't use that word, I use the word 'nuts' – because she does actually go completely nuts...I mean, I lose her, ah, and the first time, I was very frightened...the second and third time, it's happened a few times, I know what it is, I ring up the doctor and I say, that's what it is and can you come and last time he came round and gave her some antibiotics and when, one at 5 o'clock, one at 10 o'clock and by the next morning she was completely sane again. (2) (Brian)*

The initial experience of CAUTIs made him feel powerless to help her. He had no experience to draw on and described feeling 'very frightened' (2), as Margaret became confused, and he talked of 'losing her' (2) (Brian)

What bothered Margaret the most was she that became confused and disorientated very quickly and this loss of control caused her anxiety:

*...they call it confused but what they mean is totally loopy (laughs) (1) (Margaret)*

She recalled an occasion when she had a CAUTI, Brian and their GP were talking over her as if she wasn't there:

*I was in bed and the doctor was here and Brian, and they were talking to each other...and I was thinking...excuse me, and they more or less said but you're bats! (laughs) (2) (Margaret)*

Brian's approach was to do what was required as he saw it, he acknowledged this involved making decisions on her behalf when her competence was challenged:

*Margaret occasionally says, it's my bladder we're talking about...(2) (Brian)*

After a recent cystoscopy, there was evidence of debris in her bladder: '...a hell of a lot of gunge in there' (1) (Margaret)

While the DNs had inserted a larger gauge catheter, Margaret was aware that they were running out of management options. She was frustrated that they hadn't tried this before as she felt it had improved things. She used the term 'foreign body' to describe the catheter:

*'...and they don't like to keep on changing it because it's a foreign body going in'*  
(1) (Margaret).

### 5.9.2 Theme 2 - Brian taking control and Margaret's dilemma

This theme demonstrates the different perspective of the LTIC for each individual partner. As part of the process of IPA, this theme was prominent for Brian and Margaret. As the study progresses, this eventually becomes part of an overarching 'mixed blessing' theme.

#### a. Involvement with the LTIC

Over time, Brian had gradually taken on all the care of Margaret's catheter. He played down the impact it was having on his life:

*Brian: I just do the night bag every morning, um...I empty the leg bag about twice in the day...and...at night-time, I attach the night bag to the leg bag...* (2) (Brian)

The routine he described, in terms of the mundane tasks that he lists, didn't include the additional care that would have been necessary such as help with personal care, ordering and collecting prescriptions, care of the supra pubic site, hospital appointments and so forth. He did not mention that he also changed Margaret's LTIC until she interjected with: *well, he does it...* (2) (Margaret)

In the early days the DNs carried out routine catheter changes every ten weeks. However, if the LTIC was bypassing or blocked, it meant summoning the DN to change it. If 'out of hours', it often meant an unfamiliar DN instead of their familiar nurse and they experienced waiting hours for an emergency visit with Margaret in discomfort.

Brian, being proactive, decided he would learn to change the LTIC himself:

*'I knew I had to do it... (2) (Brian)*

There was evidence that the balance in their relationship had changed recently as Margaret had become more dependent on Brian, he was increasingly making more of the decisions. She showed signs of cognitive decline, which may have been an additional pressure on him to take greater responsibility for her care.

Brian admitted he didn't use the recommended sterile technique:

*Well he swears he doesn't need the sterile gloves...but he's a man (stresses word) and it's a man thing' (1) (Margaret)*

His attitude to this was in sharp contrast to concerns regarding risk of infection prior to Margaret having a LTIC. His decision not to abide by 'safe' practice when changing her catheter, potentially exposed her to a higher risk of infection.

Brian's approach to Margaret's catheter care was that he would change it but on his terms. Her reaction, besides being 'cross' was to also say, when interviewed by herself - *'I am really...we're so lucky'* – grateful for his caring for her, empathizing how hard it was for him.

Margaret's dilemma was that she needed his support to care for her and if he was able to change the LTIC, it meant they could go away together. For her, the dilemma – and her tradeoff – was the increased risk of infection:

Brian: *well, I don't think it would pass health and safety but I do think, from a hygiene point of view*

Interviewer: *but you wear gloves?*

Margaret: *No, you don't! or wash your hands!*

He refused to change his approach and the consequence of him not continuing might restrict her being able to stay away – or he would go away more often without her. This was a trade-off that she was currently considering.

#### b. The practical solution

Over time, Brian had come to realize just how important the catheter had become:

*Brian: If we hadn't had the catheter put in, I'm not sure how we would cope*

*Brian: I wouldn't live without it...I really couldn't cope without it, I really couldn't, all this business...*

*Margaret: what?*

*Brian: (interrupts) well, getting you to the loo*

*Margaret: I know darling- but what would the alternative...you know...*

*Brian: well, I'm just saying, it's absolutely wonderful thing this catheter (2)*

Brian was out of his comfort zone helping her with 'all this business' - her personal care and changing her pad – the unexpected role he hadn't envisaged – he was much more comfortable with more academic and less menial tasks.

### c. Self-reliance and maintaining control

Brian asserted his knowledge about the LTIC and was dismissive of professionals. He talked about current research he had read and was interested to know if I was aware of this:

*Apparently, there's a lot of research going on to make the inside of the catheter even more slippery, rather like, um nonstick pans, it's the same sort of thing... (2) (Brian)*

He appeared genuinely interested to discuss this rather than just making conversation. I reflected after the interview that it would not be an easy conversation for the DNs to challenge him on his non-sterile technique for changing Margaret's catheter.

Brian was optimistic in the face of adversity; aware that he was not adhering to suggested guidance but he did not change his approach, not even when Margaret expressed concern. From his perspective, having the ability to be self-reliant changing Margaret's supra pubic catheter was necessary to maintain his lifestyle:

*Brian: well, it's unusual.... we have a cottage in North Wales...and it happens to be...very isolated...and it's literally miles from the road and it's extremely rough and there's no roman road...ah and there's no way we can get nurses in there'*

*Margaret: well they would if they had to*

*Brian: well I think it would be quite a major thing to do and it would take them...they could come next day in daylight (both laugh) (2)*

Margaret was not quite as resolute as Brian about the remoteness of the cottage as a reason for justifying his actions. The opportunity to be independent and not have the intrusion of the DNs in their life, initiated his decision:

*So, um, I knew that I had to do it and um in fact it's extremely easy...' (2) (Brian)*

He assured himself that this was a practical solution and it being '*extremely easy*' was part of his justification that what he was doing was ok. However, he acknowledged that the down side was that it tended to block at night, which meant he had to deal with it.

*I watch them change it and I now I do it and I don't obey all the rules I'm afraid!  
I did watch very carefully what they did...  
...so, so from my point of view, it's much easier for me to change it than to get the nurses out. But I have to say that at 3 o'clock in the morning, I do find it very difficult (2) (Brian)*

Supra-pubic catheterisation has the benefit for the recipient that it is less intimate than a urethral catheterization, however it is a procedure requiring specific skills.

Brian: *I'm very, very careful... ah, the catheter is about that long and it's in a plastic bag and the catheter is in another plastic bag as well and so I get everything ready and use an analgesic where the hole is um and then I take, I clip the plastic so I know I can get the catheter out quickly but I don't take it out because of the hygiene ah, and then take the old one out and then immediately take that and slip it straight in, so I think from a hygiene point of view it's as good as using the ...*

Margaret: *sterile...*

Brian: *The sterile pack has a large plastic I suppose, it's got gloves, it's got a little box to take in urine if it's necessary, which it's not...*

Margaret: *(laughing)*

Brian: *..you know...(2)*

Brian's self-approved actions and his 'my way, my rules' approach was a self-limiting strategy. He was aware that continuing to ignore the recommended procedure, the DNs suggested there was an increased risk of Margaret getting a CAUTI. If infections continued, the DNs suggested that she would have to go to hospital for catheter changes. This was their way of safeguarding Margaret and encouraging Brian to comply with their technique.

Brian was very self-assured:

*I think it's just probably down to being a bit independent...and it's partly because I am basically very practical...and...um...it's not a difficult operation but some people would find it difficult (2) (Brian)*

When asked what helped him cope, he answered: *because I'm so clever really (laughter) (2) (Brian)*

Beyond the humour, the confidence of his reply suggested that he believed there was an element of truth in this. He saw his actions as borne out of necessity and he wasn't going to change. He did not see the procedure as difficult, however he considered himself more able than others. There was also an element of arrogance in his approach as he considered his intellect gave him the ability to take the actions he did. His use of the word '*operation*' which implied how invasive the supra pubic procedure was perceived, as the catheter is inserted through the abdominal wall into the bladder (Sweeney, Harrington & Button, 2007). He may have considered himself to have skills similar to a doctor/surgeon.

Having financial stability enabled them to make choices such as the private referral to the urologist. Brian acknowledged this and he also considered that his education and social class provided him an advantage when seeking help. Conversely, he felt that sometimes there was an assumption and expectation by HCPs that he could cope and there were times when they would have benefited from support and advice:

*Brian: ...it's one of those things, and I don't know how one overcomes this, but...the middle classes do better because they ask questions and go to the internet or what've but we still found it very difficult...to know...what was available and what social services would do...and we still don't know really but we've getting there...'*

*Interviewer: so, you've had to take the initiative?*

*Brian: ...find out for ourselves (2)*

Brian's approach was to be proactive to find solutions for himself, however he felt there was a lack of support for carers such as himself. In his view, he

considered that if he found it difficult, he wondered how others less assertive than him were able to manage.

### 5.9.3 Theme 3 Adjusting to the LTIC

#### a. Regret, loss and adjustment

Margaret recounted feelings of loss – loss of a future she couldn't have and with each difficulty she had to adjust to, another one surfaced. Initially it was bladder problems and the intervention of the catheter, which was meant to address these and she now struggled with catheter infections.

*I haven't got much choice with the catheter (1) (Margaret)*

Living with its unpredictability on a daily basis, she also resigned herself to the constraints caused by her failing body, unable to do what her peers did, or her husband sixteen years her senior:

*You know...I do think when I hear what others, friends, are doing and wish um...wish I could do that. We are going, for a second time on holiday to Portugal because...a man, owns a villa with a very suitable bathroom because he is paraplegic and so he really does know what he's dealing with (1) (Margaret)*

She compared herself to her expected self and experiences of a sense of loss of independence and spontaneity – making comparison with others, her MS and managing her catheter restricted her doing what she wanted to do. Although they still went for days out to the coast or to the theatre in London. Holidays were driven by Brian's desire to continue to do what they had always enjoyed, he researched the suitability of holiday accommodation – a pre-requisite was that it had a disabled bathroom and level access. Although they were relatively self-contained with catheter management, her world was shrinking.

Margaret appeared to steer the interview towards a subject matter she was more comfortable talking about such as her grandchild visiting and the social interaction, which she clearly enjoyed sharing with me. It reinforced my observation that she appeared isolated socially, rarely seeing anyone these days,



as their past social life enjoyed as a couple had waned. Now that Brian changed the catheter, she had less contact with the DNs. Margaret's poor memory at times, was more noticeable when interviewed by herself which may have been another reason why she steered the conversation to small talk as well as having someone to talk to. For Brian the LTIC was an unwelcome intrusion that disrupted 'his' life and had taken his wife.

#### b. Intimate relationship

Margaret: *Well again, we're...old so the sex thing isn't really a factor (hear Brian exhale)*

Brian: *I think, I was going to say it's not the most sexy thing...it's off putting*

Margaret: *well that's what anyone would think...*

Brian: *(to Margaret) well, you said...never mind*

Margaret: *You see married couples in all sorts of different ...(nervous laughter, 'phone rings and Brian goes to answer it). (2)*

Brian appeared relieved to leave the room and answer the telephone – quite literally saved by the bell! Margaret reasoned that age was why they no longer had a sexual relationship, rather than the LTIC or her MS. She talked openly to start with, but Brian can be heard sighing. Her reaction to Brian's comment about the catheter not being '*the most sexy thing*' and '*off putting*' (2), resulted in her reacting defensively, attempting to down play what she said, as it felt personal. This was an awkward exchange between them and Brian eventually retracts his statement with his standard pacifying comment '*never mind*' – a strategy he employed on more than one occasion. Even if he was going to explain what he meant, he wasn't going to do it in the recorded interview with me present.

#### c. About not being embarrassed

Margaret acknowledged that 'being embarrassed' about her catheter was a thing of the past - whether her catheter bag was visible under clothing or being embarrassed generally:

*well I always wear trousers...and I'm 70, I do not care (laughs) ah, if somebody said to me once 'you're a very private person' – well, not now (laughs) you know, you have to face that kind of thing ... (2) (Margaret)*

She resigned herself to accept her situation, the loss of dignity and not being embarrassed and that there was little room for being private with a LTIC, citing her age as helping her acceptance. Margaret's sense of humour was omnipresent, it was like a self-protection strategy to ease any awkwardness as she resigned herself to the changes in her life now.

She recounted a story of her four-year-old grandchild coming in to the room and seeing Brian draining her catheter bag:

*We had the whole family...so we went to the sitting room so that Brian could empty the bag and Charlie, my granddaughter, came pottering in and said 'what is that?' and I said, 'that's where Granny's pee goes', um, she says 'um....does it hurt?' 'No Charlie it doesn't hurt at all.' 'Does your poo go in there as well?' 'No, it doesn't Charlie.' 'Ok bye' – and off she went...! (Margaret)*

In the past Margaret admitted she would have been embarrassed by such things but these days she was beyond embarrassment and had to accept things as they were:

*...if you're not shy about it, and I'm totally not'...  
'well, my good friends, they do know all about it and um, it's taken as read... (1) (Margaret)*

The loss of her identity was primarily linked to the impact of MS and the loss of control over bodily function such as her bladder and now with its unpredictability the LTIC had become the embodiment of her failing body.

Margaret talked candidly about there being no place for embarrassment in her life now – being older had helped but she had to be pragmatic. Brian's decision to empty the urine bag at side of road rather than use a public toilet was something she accepted. It was for practical reasons – she was aware that the alternative would involve Brian having to take her to a disabled toilet or emptying the catheter bag in to a bottle in the car and disposing of it later:

*I suppose if you are in the middle of [name of city] one might put it in a bottle rather than on the pavement – if nobody is looking, I might use the pavement – but I'm not allowed to say that (his laughter) (2) (Brian)*

Although this approach made it easier for him it was at the expense of Margaret's dignity.

She felt it was undignified to have to travel in the back of the adapted car and stay in her wheelchair, as opposed to sitting alongside Brian in the front: '*... not really a human being – a wheelchair*' (1) (Margaret) A wheelchair was a manifestation of how Margaret could see herself becoming: '*I like to be next to Brian*' (2) Although the other motive was to protect herself because Brian was prone to falling asleep driving, particularly on their way back late from London.

Although Margaret was very open in the couple interview, she talked very candidly about Brian at our first meeting alone. She recalled an occasion when their eldest son had stayed with her on one occasion in Brian's absence. He had helped her with personal care:

*Brian was away for um...not very long and [name], our eldest son came had stayed with me but Brian says, I don't like him doing it, he shouldn't have to deal with all your, your...poops and all that, but [name] said, look when you've had a baby, all that poop... so he was very happy to do it but Brian feels it shouldn't be so...so...that's the way it is (1) (Margaret)*

He had made the decision and she respected this, despite their son's protestations.

Brian's personal aversion to doing such things himself, he protects his son, not accepting his son's explanation. The decision had been made by Brian and Margaret's time alone with her eldest son looking after her didn't happen again. The next time Brian went away without her, he arranged for a paid carer to stay instead.

#### d. Looking out for yourself

From Margaret's perspective, managing her LTIC away from the familiarity of home increasingly caused her anxiety. She had become more dependent on

Brian:

*We went, yesterday we went to Lyme Regis – long journey and spend quite a lot of time there and I was thinking what kit I take with me? And I was sort of thinking...oh..., and what will I do if it blocks and what not, and that makes me uneasy, um... (1) (Margaret)*

The unpredictability of the LTIC was a concern but also Brian's expectation that she would manage it herself when they went out as she had in the past - her use of 'I' as she tried to plan. The uncertainty when away from home meant she had to monitor her bag filling:

*I think I'm more likely to not notice when here – when I'm out I seem to keep an eye on it. If he (Brian) goes out, what I have to have is a jug and a phone – and the jug is just there or whatever and I can empty it (the catheter bag) myself (1) (Margaret)*

Margaret made light of Brian going out and leaving her for the day. For Brian having time away was self-protection:

Brian: *I'm determined to have time for myself...I go out a lot...*

*...I have a friend who um...for 6 or 8 years looked after his wife with MS, 24 hours a day, she went to respite care and he would go in to visit her twice a day, he never went away, he never played golf, um, he therefore never saw his friends and at the end, when she died, he's left, whatever you call it...*

Margaret: *Lifeless*

Brian: *...so I'm determined not to do that (2)*

He talked very frankly in front of Margaret, who supplied the missing word – 'lifeless' very poignantly. Brian was determined to maintain his sense of self to protect himself as he saw it. He acknowledged the importance of having time out from caring, determined not to be like his friend. At the time, he came across as a little heartless.

Inevitably, as her condition worsened and they aged, Brian was starting to have problems with practical tasks such as getting her in and out of the car:

*He does get very tired, and ...getting in and out of the car...with the banana board.... I think he's finding it more difficult to get me in the car, um, and we went to the DLC (Disabled Living Centre) about getting in and out of the car... (1) (Margaret)*

She knew that if it was easier for him, he might take her with him rather than leaving her at home. While accepting that Brian needed respites she down played how much it bothered her that he went out without her:

*Brian does go on tours...his um, two, twice a year, he shoves off...which is the right thing to do (1) (Margaret)*

The car gave them the ability to continue with activities they had always enjoyed such as trips to London to the theatre and they were out for a meal following my interview with them.

#### e. Maintaining their lifestyle

*The house is big enough for a spare bedroom to be made in to an additional bathroom for Margaret, exactly en suite...and I've got a study.... and Margaret's got a study and I've got a study, ah, and we've got a conservatory now in the back garden...(2) (Brian)*

Brian's study was his domain and had always been his private space. The implication was that if Margaret also had a study, she didn't need to use his.

They continued to travel abroad with Brian researching online to ensure they went somewhere with wheelchair access and facilities for someone with disabilities.

*Well I mean, I do ask, because we are going to their place - I say what are your wheelchair and disabled access to check up... (2) (Margaret)*

Margaret had reservations regarding how she, and ultimately, they would manage away from home, despite forward planning.

### 5.9.4 Theme 4 - 'So I tell him - 'do not die''

#### a. Uncertain future

Margaret needed Brian and he knew this. She needed him to carry on caring for her, which had resonance with the marriage vows: *'Til death do we part'*, as she says, and then clarifies that she only meant this in humour.

She was trying to cope with her MS and the LTIC whilst looking out for Brian, anxious about his health. She talked candidly when interviewed by herself and her concerns:

*Well um...I am...very lucky...in having Brian, he um...the trouble is...that he is now 85 and he does feel his age and so I'm telling him 'do not die' – that's not on (chuckles) but you know 85 is...' (1) (Margaret) (Brian was 86 at the time)*

Brian shared similar sentiments about her when interviewed together:

Brian: *I've to live because of my wife and there's nothing I can do about that, I'm just very lucky at my age to be very fit, um...it is ...somewhere in the back of my mind, I do know that when I die...it's going to change Margaret's life totally*

Margaret: *well yes...*

Brian: *totally...not just because of not a husband but just...I don't know how you...I mean, I don't' know how to even prepare for it.*

He was realistic about the future and the likelihood that she would out live him. Although he doesn't mention the marriage vows as such, the language he used reflects marriage and being a couple - 'wife' and 'husband' and commitment to each other. The conversation was particularly honest and open for Brian but both acknowledged that they did not dwell on this subject. Brian acknowledges with bleak realization that this is one problem that he would not be able to solve.

Brian did not know how to prepare for what lay ahead and there was a sense that he didn't feel Margaret grasped the implication. For Margaret, she did not want to dwell on the things they can do little about, she lived with uncertainty about her health:

*Well, (laughs)...we're more thinking about money and care homes...and there's no point lying here and worrying about it (2) (Margaret)*

Brian also has concerns for his own health and if something happened to him, who would take care of him:

Brian: *...and also you don't know whether there's going to be a temporary thing like flu or semi-permanent like a stroke*

Margaret: *you mean what's going...?*

Brian: *...for me, or permanent like death, you know, it's all those things can happen, and you can't ...nothing, I don't think there's much one can do about it (2)*

A poignant quote that sees Brian really open up and talk about his concerns, less guarded than at any time during the interview. He had the added anxiety that if his health deteriorated then she wouldn't be able to care for him and they would both have to be cared for. Brian admits to feeling tired and increasingly finding caring tasks getting harder:

*...well I dread that noise at 3 o'clock in the morning (Margaret ringing her bell for him)...I really dread it and I find myself...very difficult...(Brian)*

In contrast, when Brian talked frankly about his concern for the future and his attempt to be prepared, it contrasted with Margaret whose reaction was to accept that there was nothing to be done but to live each day. He appeared hurt and was taken aback by her comment:

Brian: *... it's all those things can happen, and you can't...nothing, I don't think there's much one can do about it*

Margaret: *I'll see you off to a good funeral*

Brian: *sorry?*

Margaret: *I'll see you off to a good funeral*

Brian: *oh yes, thank you, that's very kind (2)*

I presumed she had misinterpreted what he was saying, but after listening to the recording several times, she tried to make light of his comment to reduce the tension, not prepared to have this conversation or not with me present, this stops him saying anything further.

## **5.10 Summary**

In Part II, interviews with the caregiver and re-analysis of the care recipient were explored to further examine the LTIC experiences in the context of their relationship. The initial findings from Part I suggested the impact of the LTIC on the couples' relationship influenced their caring experience. Attempting to maintain a state of normalcy was the carer's approach to managing their daily life which meant accommodating change required to adapt and adjust.

In relation to the study objectives, the focus on Part II, to consider the impact and influence of their relationship, identified there were ongoing non-static elements. These included the LTIC difficulties, their health problems, or their family's needs to consider.

The normalizing force of a spousal relationship is referenced in the literature, as beneficial for care recipients following the formation of an ostomy procedure (colostomy or ileostomy), as offering stability (Nichols & Riemer, 2008). Their normalizing behavior after surgery which supported their ability to adapt was by learning strategies to cope. However, the state of the couple's relationship and 'other psychosocial factors' influenced a positive outcome. It was also noted that problems with the stoma increased psychosocial problems for the patient which had similarities with the LTIC experience (Fowler *et al*, 2014).

Considering the cross-case experiences of the three dyads (Table 3, 4 and 5), although the sub-ordinate themes were grouped under super-ordinate themes, there was a degree of crossover in to more than one super-ordinate theme for each individual dyad as well as over the three dyads.

There were also similarities between themes in Part II with the caregivers from Part I in relation to the 'mixed blessing' aspect of the LTIC. Examples of this were Hilary's comment that *'you've got to take the good with the bad'* (Theme 4b), Mavis and Peter's eventual view that *'...it has been amazing ...it's a wonderful help ...he hated it at first'* (Theme 2a) and Brian and Margaret's comment that *'It's a godsend - but it has its problems'* (Theme 1). The LTIC was viewed as a positive intervention but it presented other problems which they had to manage. Other over-arching themes related to adjustment and associated with this were the various aspects of support, whether this was from family members, DNs or their own self-reliance. These will be explored in greater detail with overall findings in Chapter 6.

The dyad case studies enabled me to return to carers Mavis, Brian and Hilary and record their 'voices', which I had not been able to do previously. Although Mavis



had been present at Peter's interview, the focus had been his LTIC user experiences.

Despite the variables of who was present at the interview, which was beyond my control owing to interviewee choice, the interviews revealed shared and unique experiences. The caregivers were at different points in their caring 'career' (Quinn *et al*, 2008), depending on other factors such as the care recipient's health and stage of their MS.

Comparing the cognitive state of LTIC users in Part I with those in Part II, it was evident that in Part I, four out of the six LTIC users were debilitated by cognitive decline and dementia with the exception of Betty and Edward. This gave the impression of added burden for the caregivers, which is suggested in the literature (Kim *et al*, 2011). In Part II, although Margaret had lapses in memory, she was practiced in disguising this and it was unclear if this was MS-related cognitive deterioration.

For the users and the carers, the LTIC was 'another challenge' to manage in addition to the long-term condition and their perspective was shaped by their experiences of their present situation (Brough, 2001).

The dyad studies highlight the individual timescales in relation to the adjusting/adjustment process for each partner. At the time of the interviews with the LTIC users, Mike and Peter were primarily self-caring with their LTIC. Four years later, they were dependent on their partners, Hilary and Mavis respectively, for all catheter care in addition to support with their day-to-day personal care needs.

There was only eighteen months between my first interview with Margaret and my subsequent interview with Margaret and Brian. There had not been the same degree of decline with her ability to manage the LTIC in the time between her interviews, however Margaret had been less physically able than

Mike or Peter at the time of the first interview, particularly in respect of her mobility.

#### 5.10.1 Limitations of the research design in Part II

The decision to include re-analysis of LTIC users' interview data from the pre-PhD study had limitations, and on reflection it presented challenges during analysis. I had met with the caregivers before, despite it being several years previously and they appeared to value the opportunity to have their perspective heard.

### **5.11 The LTIC users' experiences**

#### 5.11.1 The long-term condition (MS) and the LTIC

There were similarities in the experiences of the three catheter users associated with MS symptoms alongside bladder dysfunction. Margaret and Mike experienced leg spasm, which particularly affected Mike's sleep. Peter and Mike identified disturbed sleep and for Peter this was associated with concerns over the LTIC and drainage. All three no longer had a sexual relationship with their spouses. The symptoms that they reported, which impacted on their ability to maintain continence, were to do with altered mobility and dexterity.

The LTIC users in Part II experienced the same issues of increasing episodes of incontinence before they had the LTIC, that carers talked about their spouses having in Part I. These symptoms affected the care recipient's ability to manage independently (Mitteness, 1987) and they had employed 'toilet mapping' (Brittain & Shaw, 2007) in an effort to cope. They also reduced their social activities and interaction prior to the LTIC. These findings were similar to dealing with incontinence at home (Gallagher & Pierce, 2002); feelings of embarrassment, frustration, and burden. In the case of Gallagher & Pierce's phenomenological study (2002), 'burden' related to the toileting routine required.

The LTIC users' accounts demonstrated how pre-LTIC bladder problems in a variety of ways. Margaret had started with an ISC but after an increasing number of falls, she migrated to an indwelling catheter. Before his LTIC, Mike tried a urinary sheath, which was unsatisfactory as it leaked, presumably because it became detached. Peter was having increasing problems with incontinence, which were not addressed until a fall resulting in a hospital admission and culminated in his wife talking to nursing staff about how she was going to manage his incontinence at home.

#### 5.11.2 Embarrassment and stigma

Embarrassment was part of LTIC users' experiences. Margaret spoke of being '*beyond embarrassment*' since the LTIC. Her comment was '*not a human being...*' as she now had to sit in her wheelchair in the back of their mobility vehicle, feeling a loss of dignity as a result, feeling less of a person, more like an inanimate object. The wheelchair becoming the embodiment of how she considers she was perceived now, the objectification of her failed body (Wilde, 1999) which included the LTIC because her bladder no longer functioned as it should. Margaret's experience resonated with Wilde's (2003) observations of similar circumstances.

Pre-catheter, their embodied experience of living with the device resulting in their experiencing stigma associated with their failure to be able to maintain continence in the first instance and later related to their reliance on a LTIC to drain their bladder. The literature considering the embodied experience of catheters is primarily the work of Wilde (2002b) who noted that individuals had to 'pay attention' to the LTIC and be ever vigilant. This was an identified behavior in this study, although the LTIC users were more likely to be aware of the need to monitor their own device if their carer wasn't around. When they were no longer able to do this, their spouses took this task on.

Similarities were noted between previous research relating to the stigmatizing effect of urinary incontinence and the LTIC (Mitterness & Barker, 1995;

Paterson, 2000; Garcia *et al*, 2005; Brittain & Shaw, 2007). Elstad *et al*, 2010 identified the stigma of other bladder symptoms 'beyond incontinence' such as urinary urgency and frequency which the LTIC users experienced.

It was the potential 'visibility' aspect of the LTIC that was stigmatizing (Wilde, 2003). However, even before the LTIC, they had experienced embarrassment associated with incontinence, as experienced by Mike with the wet restaurant seat when his sheath became detached, or Peter wetting himself when he and his wife went to see their son at university.

Peter was the only one of the three to have a urethral catheter. He alluded to the awkwardness and embarrassment of the early catheter changes; an intimate procedure, as well as his first experience of being catheterized when in hospital. He had little forewarning and it was carried out by two female nurses. This experience remained a personal affront to him. To add to his feeling of awkwardness, Mavis was quick to suggest his ineptitude at not stopping them from carrying out the procedure. During the interview with them both, she talked openly about his incontinence and his impotence. Peter sat passively during Mavis' explanations of his failings, which he resigned himself to accept. My reflection afterwards was about how awkward I felt for him.

Margaret accepted the undignified catheter bag emptying at the side of the road by Brian. This practice had been noted in the literature (Fowler *et al*, 2014) by LTIC users.

Carer Mavis and her husband Peter found that once he had the LTIC, their ability to go out as a couple returned as his continence was controlled. This was also evidenced in the Brittain & Shaw (2007) study on incontinence which recorded a spousal carer's view that the LTIC was the 'best thing that had happened' (pp.1287) following a spouse's stroke. This aspect of LTIC users' experiences was shared with their spousal caregivers as part of their adjustment to the device. Overall, they were positive about the LTIC in the sense of there being nothing better.

MS is not considered life limiting if the disease is managed (Leary & Thompson, 2000) which has implications for whoever is involved with their care and support, as they may need this for some time. Although this was not mentioned during the interview, my interpretation was that Brian and Margaret were aware of this. In view of the age gap between them, their exchange relating to her care after he dies was poignant because the probability of this was high. This adds an additional 'burden' for carers to consider and plan for.

The impact on carer's QoL, such as their social life, has been identified in MS studies (Cockrill & Warren, 1990). Topcu *et al* (2016) identified 17 qualitative studies demonstrating the positive and negative aspects of caring, themes that were identified by carers included: loss and change, demands of caring, future concerns and their experiences of support. These themes had resonance with this study specific to the dyad study.

### 5.11.3 Becoming more dependent on their spouse

There are aspects of disability fluctuations associated with MS (Wilde, 2002b) which are a further challenge to manage with the unpredictability associated with LTIC infections. In the context of the catheter, this can result in demands on carer time, observing for infection, monitoring that it is draining and checking when the bag needed emptying. At the time of the interviews with the LTIC users (Fowler *et al*, 2014) they were regularly observing and checking the catheter. By the carer interview in Part II, only Margaret was taking the lead with this, although Brian supported this at home. The altered mobility and dexterity of the LTIC user made the task of emptying the catheter bag more difficult, resulting in mishaps which caused carers Mavis and Hilary a degree of annoyance.

### 5.11.4 Unpredictability

Similarities were identified in the literature with unpredictability associated with incontinence, suggesting that this aspect can be more problematic than incontinence itself (Cotterill *et al*, 2008) as it is more difficult to manage. The

LTIC unpredictability related to problems of blocking and leaking which was felt to be more of a disturbance if it happened during the night when they had to wait for DNs to attend. If away from home, as Mike and Hilary experienced on a rare day out, it curtailed their time out, returning home in order to see their familiar DN team. Whilst the problems with LTICs are well documented (Wilde, 2015a), it was the leaking of urine (bypassing) that caused the greatest issue. This was an ongoing problem for LTIC users Mike and Margaret. Peter also had LTIC problems with blockage.

This chapter has enabled further consideration of the influence of relationship on adjustment to LTIC. It provided an insight into the intertwining of individual needs that exist and how support for one person in a partnership in instances such as the introduction of a LTIC needs to include similar and/or different support for their partner. Drawing from the theory (Rolland, 1987) that long-term conditions impact on those other than the person with the condition, this resonates with the LTIC being imposed on spouses.

**Chapter 6**  
**Discussion**

## **Chapter 6**

### **Discussion**

#### **6.1 Overview of the chapter**

This discussion chapter draws together findings from Part I and Part II of the thesis, to consider the core themes that reflect the carers' experiences when their partner has a LTIC.

The chapter will consider findings from Part I and II in relation to the study aims and whether the aims have been met. The chapter then moves on to the integration of the findings into a 'wider picture' message of the findings of the thesis. This is followed by discussion on how findings, in the context of the literature relating to management of other devices by carers, can provide insight into the management of catheters.

#### **6.2 Study Aims**

The aims of the study were -

- To explore carers' experiences of caring for a husband or wife, with a long-term, indwelling urinary catheter (LTIC), to inform healthcare professionals (HCPs) and improve practice.
- To examine the issues carers face when caring for their partner's LTIC and how this affects their relationship.

#### **6.3 Overview of the findings**

This is the first study that has focused on the experiences of a LTIC from the perspective of informal spousal carers. The power of the personal accounts from the caregivers provided an insight in to the complex nature of the impact of the LTIC for those supporting care. It also added to the small number of studies



exploring the perspectives of LTIC users (Roe & Brocklehurst, 1987; Wilde, 2002; Sweeney, Harrington & Button, 2007; Kralik *et al*, 2007; Godfrey, 2008a; Prinjha & Chapple, 2013; Fowler *et al*, 2014).

Part II of the study served to clarify and reiterate many of the findings in Part I for caregivers and suggests their experiences of the LTIC were as a 'mixed blessing'. The introduction of the LTIC impacted on their lives in different ways. Initially it was an improvement for spousal carers and LTIC users by relieving bothersome bladder symptoms that impacted on their daily lives. The arrival of the LTIC enabled some of them to resume a previous life style. However, over time the LTIC became more problematic, often at a time when the LTIC user needed increasing support from their partner to manage it due to their long-term condition.

Their individual experiences presented as a continuum of adjusting, as a back and forth process, adapting to changes over time or resigned adjustment and re-adjusting to their life as a carer in the context of the LTIC. As part of adjusting, they negotiated the challenges they faced in their new role caring and dealing with the LTIC. A number of strategies that aided adjusting were evident in their accounts, such as 'trade-off', time out/respite and receiving the support they identified as valued, often for its empathetic approach.

This study acknowledges that the arrival of the LTIC impacted on their relationship over time. They experienced loss, which was a multifaceted theme, including loss of their expected future as a couple and conflict with their own needs due to their circumstances. The carers were already experiencing a time of change in the context of their personal experiences of adapting and adjusting to their partner's long-term condition. The LTIC proved an additional challenge because of its unpredictability and problems associated with infection and bypassing.

Spouses caring for a LTIC showed similarities with family carers managing technical health procedures at home (McDonald *et al*, 2017) as they developed

skills but very much self-navigated problems. They too were trying to do the best they could to care for their loved ones. In the case of caring for similar technologies, the importance of on-going support and education was seen as a vital component. The objectives of the study are considered in the context of the cross-case themes in Appendix 10 and 11.

#### **6.4 The long-term condition and the LTIC**

The impact of the long-term condition on participants in this study has been a presence throughout and I acknowledge the influence on the findings. In Chapter 7, Limitations (7.7) I critically discuss the use of IPA to deliver the answer to the research question. I consider the limitations associated with concluding that the carers' experiences related to the LTIC only, if they had difficulty separating their experiences of the LTIC from their partner's long-term condition.

At the start of the interview, I had asked carers to try and put to one side their caring experiences in relation to the partner's long-term condition and focus on the LTIC. I had initial reservations that participants might not be able to extricate themselves from their 'carer' role *per se*. I acknowledge that this was not always possible particularly as their partner's health was a dominating presence in their lives. However, for some carers, owing to the problems they were experiencing with the LTIC, this was easier to do. The interview prompts were helpful to draw the focus back on the LTIC.

The impact of a chronic illness or disease affected them both and meant that they needed to adjust and redefine their life. They were concerned for their partner (Cheung & Hocking, 2004) and were trying to cope with the demands of caring as well as trying to maintain their sense of self.

Reflecting on the LTIC in the context of the care recipient's long-term condition and their shared experience, carers were already experiencing various stages of adjustment to their partner's long-term condition as well as the existence of co-morbidities. An example of this is Judith's description of caring for her 90-year-

old husband: *'I mean, his legs don't work anymore, he's got Diabetes, he's got no use in his legs really'*. Judith was 76 years old, caring for her morbidly obese husband who had Type II Diabetes and had a LTIC due to an enlarged prostate but surgical intervention was considered inappropriate at the time.

In order to consider the experiences of the LTIC overall, the device needed to be considered in the context of the care recipient's long-term condition but other influences such as the home environment and the challenges it presents, impacts on their lives, their ability to deliver care and the adjustment process.

## **6.5 Drawing together key findings of the thesis and considering the aims of study**

The findings have increased understanding of the challenges for caregivers when their partner has a LTIC and this thesis provides an insight in to their experiences. The study confirms that early experiences of the LTIC were similar, with the majority of carers aware of their partners' pre-catheter bladder symptoms and the difficulties that their partners faced trying to manage urinary urgency, frequency and incontinence. The majority of carers had no, or minimal involvement with the LTIC decision, despite being their married partner, however they supported their partner with care of the LTIC because they were married. LTICs presented carers with many practical challenges and some catheters, in the case of Jim's (and caregiver Betty), had always been problematic and leaked. Their experiences of care encompassing both the LTIC and the long-term condition sometimes became difficult to separate.

Although the focus of the thesis is ultimately the caregiver, the state of marriage meant that they shared the intervention of the LTIC in the sense of the impact it had. Their altered relationship happened gradually over time and they had already had to adjust to the long-term condition. The arrival of the LTIC focused the loss of their physical relationship in some cases.

This following section integrates the findings from Part I and Part II to present a wider picture of carers' experiences.

**Table 2 – Carers' Themes from Part I**

**Part I – Carers' experiences**

	<b>Super-ordinate Theme</b>	<b>Sub-ordinate Theme</b>
Theme 1	<b>The Phenomenology of the environment</b>	1a <u>Decision to downsize - 'the right thing to do'</u> - Adaptations – but still difficulties - Relocating and loneliness
Theme 2	<b>The catheter – as a 'mixed blessing'</b>	2a <u>Lead up to the LTIC and catheter decision</u>  2b <u>Positive about the LTIC</u>  2c <u>Managing LTIC problems</u> - Doing the best they can
Theme 3	<b>The caring experience – dependency, their changing relationship and their competing needs</b>	3a <u>Making decisions for both</u> - Being fussy and feisty - Catheter changes  3b <u>Impact of their changing relationship</u> - Sense of Loss - Care recipient's behaviour - <i>'I live in a silent world'</i> - Duty and marriage - Physical relationship  3c <u>Competing needs</u> - Adjusting - Time - Respite care - Impact of carer's health 3d <u>What will be will be</u>
Theme 4	<b>Experiences of support with the LTIC</b>	4a <u>Negative experiences</u> 4b <u>Positive experiences</u> 4c <u>Impact on the family</u>

## Dyads Part II Tables of themes

**Table 3 Hilary and Mike**

<b>Superordinate Themes</b>	<b>Subordinate Themes</b>
Theme 1 - <b>Before the LTIC and making the decision</b>	a. The embarrassment of <i>'water problems'</i> b. <i>'He just said, like, I decided'</i>
Theme 2- <b>Adjusting</b>	a. Adjusting - over time b. The LTIC always on your mind c. Long-term concerns for LTIC
Theme 3 - <b>Support</b>	a. Support from DNs b. <i>'We've got a good family'</i> c. <i>'I'm having...I do everything for him...'</i>
Theme 4 - <b>Impact on their relationship</b>	a. Physical relationship b. <i>'You've got to take the good with the bad'</i>

**Table 4 Mavis and Peter**

<b>Superordinate Themes</b>	<b>Subordinate Themes</b>
Theme 1 - <b>The LTIC decision</b>	a. <i>'I didn't decide. It's a bone of contention.'</i> (Peter) b. <i>'They didn't tell him it was for the rest of his life'</i> (Mavis)
Theme 2 <b>Adjustment and trade-off</b>	a. Positive about the LTIC b. <i>'I've had to fight for everything'</i> (Mavis)
Theme 3 - <b>Impact on their relationship</b>	a. Mavis' health b. Loss of physical intimacy c. A part of the house that is 'out of bounds' d. Loss e. Support
Theme 4 - <b>The future</b>	a. <i>'We were looking forward to having a great life'</i>

**Table 5 Brian and Margaret**

<b>Superordinate Theme</b>	<b>Subordinate Theme</b>
Theme 1 - <b><i>'It's a godsend - and it has its problems'</i></b>	a. The LTIC decision b. <i>'I mind all the infections'</i>
Theme 2 - <b>Brian taking control and Margaret's dilemma</b>	a. Involvement with the LTIC b. The practical solution c. Self-reliance and maintaining control
Theme 3 - <b>Adjusting to the LTIC</b>	a. Regret, loss and adjustment b. Intimate relationship c. About not being embarrassed d. Looking out for yourself e. Maintaining their life style
Theme 4 - <b><i>'So I tell him - do not die!'</i></b>	a. Uncertain future

## **6.6 The shared experiences of carers and the LTIC users**

Overall, Part II built on themes identified in Part I, but in the context of their partners' accounts and re-analysis of previously collected data (Fowler *et al*, 2014). Despite the LTIC user interviews being several years earlier and the variance of who was present during the interviews in Part II, the caregivers' and LTIC users' shared experiences.

The carers faced many of the same experiences and challenges as their partner with the LTIC evidenced by the literature (Wilde, 2002; Sweeney, Harrington & Button, 2007; Kralik *et al*, 2007; Godfrey, 2008a; Fowler *et al*, 2014). However, there was a different emphasis or perspective – as the carer was experiencing an increase in responsibility for care of catheter, in contrast to the LTIC user who was becoming more dependent on their partner for care.

The individual experiences specific to the LTIC user are included Chapter 5 [5.11].

## **6.7 Identifying the overall findings underpinning their experiences**

To capture carers' experiences in Part 1 and Part II, the same approach of IPA was applied as outlined in Chapter 3, considering the shared superordinate/subordinate themes, the recurrence of themes and connections between themes. Consideration was given to the 'dual quality' of themes as part of IPA (Smith, Flowers & Larkins, 2009, pp.101), in order to illuminate and retain the idiosyncratic elements of the caregivers' experiences and still present the overall findings. Grouping related themes necessitated relabeling themes as in the example of Mixed Blessing. This was an emergent theme in Part I, which took on a superordinate status and eventually became the overall theme capturing carers' experiences of the LTIC.

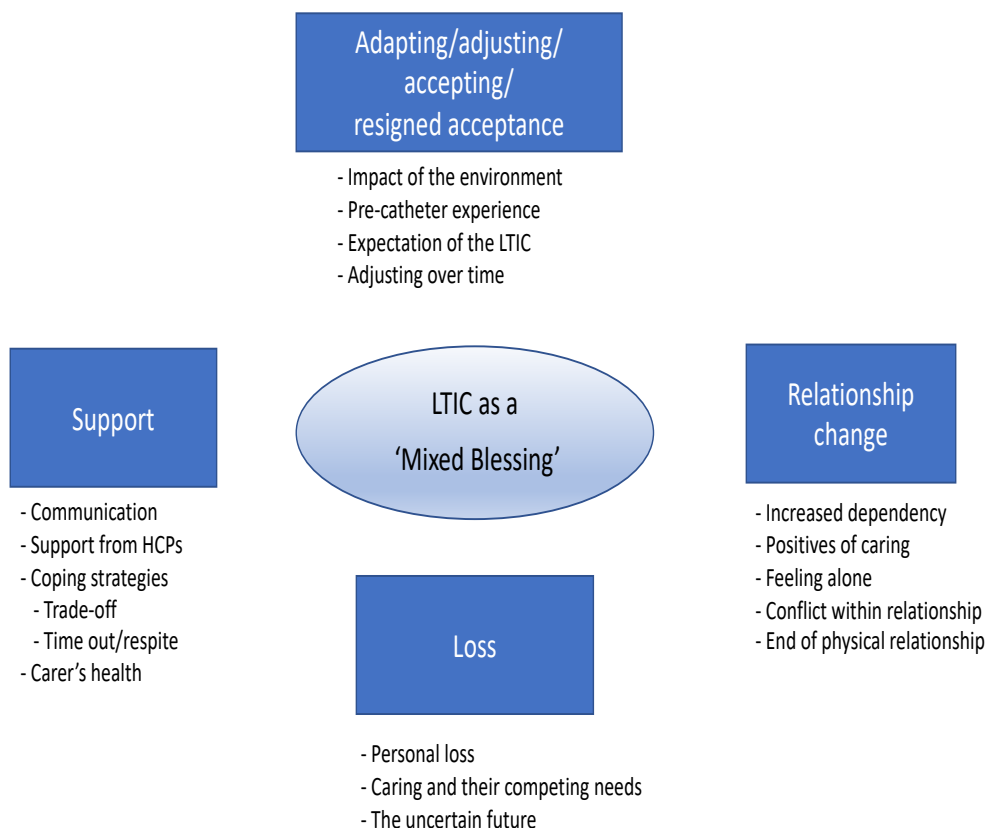
The core themes in addition to Mixed Blessing, that underpin carers' experiences are presented diagrammatically in Figure 9 (pp.216) and these are: Relationship

Change, Adapting and Adjusting, Loss, and Support. Figure 9 shows the associated influences and factors as part of the core themes.

The LTIC as a mixed blessing reflected the positive and negative impact of the LTIC from the spousal carer's perspective. It offered a solution, although not ideal, it provided an opportunity to normalise their lifestyle in the early days, as it made their partner's bladder symptoms less intrusive and dominating in their daily life. The catheter continued to require regular attention and there were problems they had to manage. Over time carers became more adept at meeting the challenges and crucially the LTIC meant carers were less fatigued as they had undisturbed sleep. Some caregivers found adapting and adjusting easier than others, depending on the various influences and factors that helped or hindered with the process of adjusting.

Changes to their relationship occurred as the LTIC user became increasingly dependent on them for care of their catheter. Support they received varied and over time they developed individual coping strategies. Carers experienced a sense of loss as they made compromises in their life in order to support their partner with the LTIC. The arrival of the LTIC in the context of their partner's deteriorating health, meant there were often blurred boundaries between the two when talking about their experiences.

Figure 9 Identifying core themes underpinning experiences in Part I and Part II



### 6.8 Adapting, adjusting, acceptance, and resigned acceptance

The term 'adjusting' suggests changes are still occurring or there is a process over time (Sharpe & Curran, 2006). In contrast, 'adjustment' suggests a state has been reached and misconceptions can exist that this is the end point and everything is now fine. However, an alternative description is that the state of adjustment may exist, but it is a continuous state of flux and if not maintained then it will change.

Adapting suggests an ongoing phase and has practical connotations which reflects the physical aspects to adapting, or practical adaptations, with the implication of a change in behaviour. The inclusion of 'resigned' acceptance as



part of the carer's experience was adopted in response to the blurring of this process and definition.

Resignation suggests more of a state of mind than a practical issue or change in behavior. This was particularly for the LTIC users; their resignation was acknowledging that there was no other alternative – they had MS and the LTIC was their only solution.

Carers attempted to adapt and adjust to the changes in their lives as part of coming to terms with their life now, both as a carer and adjusting to the changes imposed by the LTIC. Adjusting was one element of a larger picture. Influences on the adjustment process included: the influence of care environment, their partner's pre-catheter symptoms and support they received (emotional and practical). Their ability to adjust was also influenced by effective communication and involvement with decisions relating to the LTIC. Their raised expectations of the LTIC were following early improvements when their partner first had the catheter. This aided the adjustment process as they regained aspects of their previous life that had been disrupted, such as the ability to socialize because their lives were no longer dominated by their partner's bladder symptoms.

Their ability to adjust their lives to incorporate caring for their partner and the LTIC was affected by their health, aging and their need to have adequate sleep; these were considerations that concerned them. In addition to problems with the LTIC that they all experienced, the study confirmed the value of ongoing support and communication to overcome and prevent negative experiences. There were also influencing factors relating to adjusting that were pertinent to individuals - such as Brian's unconventional approach to the catheterization procedure, which was his way of adjusting to life caring for this wife since she had a LTIC. It was also his way of maintaining control over his life.

The introduction of the LTIC for many of the carers led an improvement in their lives, often enabling the LTIC user to take more responsibility for their continence in the short term.

In this study, there was a degree of adjustment to enable some positive improvement and this was the case with the majority of LTIC users and their partners. The elements of adjusting to a LTIC are within a continuum that carers move through - back and forth, as they attempt to adjust. The literature had identified Wilde's (2002b; 2003) phenomenological study with LTIC users, which explored their 'dialectical swing' between accepting the catheter in their lives and feeling the stigma that it represented. These findings had resonance with LTIC users in this study.

Various adjustment scales exist specific to conditions such as MS (Pakenham, 1999) that can support assessment. However, their adjustment does not necessarily mean that their pre-illness state will return or their life will be as it was previously. Sharpe & Curran (2006) suggests a scaling back of activities occurs as part of adjustment, which has resonance in this PhD study – with the adoption of coping strategies such as 'trade-off'.

Altering the carers' perspectives and coming to terms with the LTIC involved incorporating change. Although not everyone managed to do this, for those who did, this helped them deal more effectively with the situation they found themselves in. Finding 'meaningfulness' in their situation through accommodating what had happened, Sharpe & Curran (2006) suggested this was part of adapting to illness; the idea of integrating changes in to daily life.

#### 6.8.1 Models and frameworks related to adjustment

The initial literature review had identified various models to enable greater understanding of carers' experiences and these were discussed in Chapter 2. The associated models of adjusting, adapting and resigned acceptance to the device were considered but the following two offered a supporting explanation in relation to this study.

### 6.8.1.1 Paterson's Shifting Perspective Model of Chronic Illness

Paterson's Shifting Perspective Model of Chronic Illness (2001) was considered relevant in relation to LTIC users in Part II who had a chronic illness and it could equally be applied to the LTIC and to carers. It suggests a framework to explore LTIC users' experiences and also carers' experiences, and is helpful to enhance understanding of adjustment. Central to the model is the shifting and changing process of illness or wellness to the foreground.

Paterson's model (2001) suggests that 'acceptance' can be a final or eventual stage, for the individual with the condition. The findings suggest that the carers follow a similar shifting process. The state of acceptance was not seen for the carers, apart from Gordon, although there were elements of acceptance suggested by carers such as Jenny, Mary and Joyce who were gradually accepting aspects of their life now, even if they had times when things weren't going according to plan. Viewing Patterson's model in this study in the context of their experiences, the suggestion is that eventually, after many years, if acceptance is reached it is with the understanding that it is a process with regressive steps along the way.

Wilde (2003) highlighted the LTIC users' experiences of 'vacillating back and forth' (pp.1201) from the positives and negatives of the LTIC, which had resonance with The Shifting Perspective Model of Chronic Illness (Patterson, 2001) and the 'shift' that brings illness-to-the-fore or wellness-to-the-fore. The Shifting Perspectives Model (Paterson, 2001) proposes that illness and wellness are part of the individual's condition. These aspects come to the fore at different times as a changing process. An example would be the early experiences of the LTIC – there was an improvement in symptoms for the LTIC user, they are not constantly experiencing bladder problems and wellness is to-the-fore.

When the LTIC user had an infection or a relapse in their health, this positioned illness to-the-fore. They could be very ill at this time as Margaret experienced

when she had CAUTIs. This affected their ability to cope and became all-consuming.

When considering the three LTIC users within this model, Mike and Peter were accepting of their condition and their LTIC, but in the sense of resignation to their health and predicament in the face of no alternative. Margaret however was not at this juncture; her MS problems were to the fore and she was experiencing frequent CAUTIs.

The carers' lives were affected by the fluctuating nature of their partner's health, their own health, LTIC problems and outside influences such as their family. This meant they were constantly trying to balance their lives. This study showed that carers were under a degree of stress as part of their caring experience. This is mirrored in the literature of allied studies which considered the demands of caring when this involves medical intervention and dealing with a device (Israel, *et al*, 2018). The concept of change and adjusting 'over time' was particularly pertinent to this thesis. The re-analysis of the interviews with LTIC users had captured one moment in time however the return to their home to interview their carer and meet them again, was an opportunity to view changes over time.

#### 6.8.1.2 Rolland's Chronic Illness and the Life Cycle: A Conceptual Framework (1987)

This was pertinent to this study, in particular the variables that relate to families adapting to chronic illness. Rolland (1987) included a case study example of MS, citing the family's 'level of adaptability' (pp.12) through difficult stages. Rolland (1987) identifies various phases as a continuum or time line, with a crisis point, initial adjustment and resolution of loss, but also includes their expectations and anticipations. There was resonance with the carers' experiences in this study linked to the progressive nature of the long-term condition. The 'crisis' or pivotal moment, which had resulted in the arrival of the LTIC, required further adjustment and was accompanied with raised expectations as already discussed.

Rolland's (1987) 'competency, mastery, control and participation' components of the family-illness paradigm can be applied to many of the LTIC carers in this study, where 'mastery' over the catheter was seen as a pre-requisite to coping with the device. In the case of Brian and Jenny, they both became 'experts' in their own way, while others, such as Judith, took on an extended role, flushing the catheter in an attempt to manage the problem of blockage. Attempting mastery, initially for the LTIC users and later the LTIC carers, was a way of maintaining control over their lives.

Rolland (1987) suggests considering the family and patient as a unit in relation to coping with chronic conditions. Within the realms of this study, as a married couple, they already considered themselves a 'unit'. They wished to be involved in conversations and discussions regarding care and while some carers considered they were included, others felt marginalized. Rolland (1987) extols the benefit of the family's knowledge that they are able to provide, in combination with the care recipient in their 'life cycle' (pp.13). This supports adapting and 'flexibility within the family and the health-provider system' and is an intrinsic factor in 'optimal family functioning' (Rolland, 1987, pp.510)

The study identified experiences of loss relating to a physical relationship - sexual intercourse and/or physical intimacy. Mavis considered the LTIC responsible for ending her intimate/sexual relationship with her husband Peter. He was given a urethral catheter, without being provided any information about having sex when fitted with a urethral catheter or a plan for a supra-pubic catheter. Mavis had not considered their changed sexual relationship in the context of the possible effect of MS as a contributory factor on Peter's libido. All three LTIC users and carers no longer had a sexual relationship but owing to the isolation of each carer and the taboo nature of continence, catheters and sex, they had accepted this and for Mavis, although she was resigned to this, it was with resentment.

In relation to illness experience, Rolland (1994) advocates encouraging couples to talk openly and acknowledging that both physical and mental health

influences the situation. He cited the benefits of this approach when diseases are progressive such as MS.

### 6.8.2 Pivotal moment

There was often a pivotal moment or 'crisis' (Rolland, 1987), which influenced or hastened the LTIC decision. The catheter decision, once taken, was made with the expectation of improvement often at a time of desperation and exhaustion attempting to cope with incontinence. The process towards the decision varied in timescale but with the exception of Gordon and Betty, they all shared experiences of their partner's loss of control of continence in some form, influenced by deteriorating physical health.

The LTIC users and their spouses recounted particular moments of embarrassment (Peter, Margaret and Mike), affecting their decision to accept the catheter for LTIC users Margaret and Mike. A particularly poignant moment for Mike related to his shame and embarrassment in front of his family, noticing he had leaked urine on the seat in a restaurant. Hilary had shared his embarrassment. Margaret's awareness that husband Brian was finding it increasingly difficult physically, to help her to the toilet and the fall in the toilet when he was unable to help her up, was a pivotal moment for them both.

Considering pivotal moments with reference to Rolland (1987), the early pre-catheter experiences related to the difficulties coping with incontinence. The mid-phase of their experiences, were the personal impact of adapting and adjusting their lives to coping with the LTIC. At this stage, it was often a time of transition, as they became 'caregiver' and their partner became more dependent on them. Many of the carers in Part I, such as Jenny, Beatrice, Mary and Joyce were in the 'long haul' stage (Rolland, 1987, pp.4).

### 6.8.3 Influences on adjustment

Carers experienced various influences and factors that either helped or hindered their ability to adapt and adjust.

#### 6.8.3.1 The impact of the environment

The environment set the scene for the study. Over the course of the study, the issues they had with the environment impacted on their experiences. Adapting and adjusting to their changed circumstances was influenced by the lived space of the couple's home.

I acknowledged that working in the community for many years, I have become acclimatized, almost accepting, of the challenges of the home environment. Carers did their best to cope with small bathrooms, narrow doorways and restricted space, making practical changes, such as Hilary and Mike having carpets removed to make his wheelchair use easier. During the analysis the environment was identified as a recurring theme, as it presented difficulties that impacted on all participants to some degree.

The Essence of Care Benchmarks for the Care Environment (DoH, 2007) as part of general guidance (DoH, Essence of Care, 2003), relates to the environment where care takes place, including the home. Incorporating feedback from 'patients' (pp.5) it offers best practice indicators, taking in to account the needs of the individual and offering solutions. However, peoples' homes are unique, and the guidance is more suited to institutional settings.

This study found that similar to the problems the catheter added to caring, the challenges of the home environment and equipment was 'one more challenge'. The context of 'home' was where carers spent an increasing amount of time as their partner's health deteriorated. In an effort to make their life easier and have 'less work', couples had 'downsized' to what they considered a more manageable space. Joyce and Beatrice had moved to be closer to adult children for support.

There was sadness having left homes with happy memories; a reminder also of the changing and uncertain times they found themselves in. Moving had made them more isolated and they missed their friends and the 'connectedness or familiarity' (Van Dijkhuizen, Clare & Pearce, 2006, pp.83) that their network of support provided. Those who had moved to the suburbs found accessing services more difficult which added to their isolation. Carers Gordon, Mary and Jenny who had not moved, mentioned their neighbours being supportive, even if they were not close friends.

Circumstances dictated spending increasing amounts of time at home and several turned their hand to decorating and minor home improvements, not only in response to damaged door frames in Hilary's case, because Mike wasn't very adept with the wheelchair, but also because it was an activity they could do at home and it helped maintain a sense of purpose.

All carers had been pragmatic in their approach and making changes to the house. These physical adaptations were often very visible and included major structural changes such as a stair lift or through floor lift. Brian and Margaret had completely redesigned their house, reconfiguring the rooms to accommodate her needs. There was evidence of homes becoming 'medicalized' with equipment such as hoists, hospital beds, toilet adaptations and commodes.

#### 6.8.3.2 The pre-catheter experience

Adjusting was a long-term and shifting process (Paterson, 2001) as carers tried to re-establish normality in their lives. An impact on adjusting to the LTIC was influenced by the pre-catheter experience, how problematic their partners' bladder symptoms were and the manner of the catheter decision. A poor experience influenced their future view of the LTIC.

Carers recounted that the original decision relating to the LTIC was their partners', was not always the case and HCPs [carers: 4.7.2(2a) and dyads: 5.8.3] and carers had not always been included in the decision. Experiences of poor



communication, emerged more strongly as the analysis continued and as a result carers felt disempowered.

The importance of positive communication between spouses and family members has been identified as an important contributor in relation to adapting to, and coping with, a long-term health condition (Rolland, 1999). This had resonance with the carers in this study.

#### 6.8.3.3 Expectations of the LTIC

Both carers and LTIC users were generally positive about the catheter despite initial misgivings. This presents a dichotomy for HCPs as the LTIC is considered a 'last resort' strategy because it is fraught with problems. Carer's positivity was influenced by their pre-catheter experiences, empathy for their partner's struggle and their shared experience of coping with incontinence. It seemed the most practical solution for them at the time.

The LTIC heralded an immediate improvement in their QoL with a 'honeymoon period' when continence was managed more effectively and incontinence was controlled. Mavis and Peter were able to resume their social life, going out to the cinema and restaurants. For others, it meant the end of dealing with incontinence particularly at night.

Their raised hopes and expectations were short lived as the inevitable infection related problems of a LTIC presented themselves. They both faced physical challenges over-time, however the psychosocial impact of the LTIC was also far reaching and complex, presenting different challenges.

Similarities in the trajectory for LTIC users can be found with regard to adjusting to long-term conditions. In Reichsman & Levy (1972) longitudinal study of patients with End Stage Renal Disease (ESRD), patients were likely to experience three stages, which includes an initial 'honeymoon' phase, which was a short-term phase of up to six months after starting dialysis when initially symptoms

improved. This mirrored the improvement once an LTIC is first used. The later two stages were when treatment became challenging and patients experienced 'disenchantment' before finally, the last phase, and their acceptance of 'long-term adjustment' in their lives.

#### 6.8.3.4 Adjusting over time

Carers experienced a continuum of adjusting over time. The circumstances of Gordon's interview with his wife present in Part I, showed how their 'togetherness' supported the adjusting and the coping process, and this was further explored in Part II.

Timescale was highlighted as an important predictor in the adjustment process with LTICs (Kralik *et al*, 2007; Fowler *et al*, 2014). It is suggested that a caregiver's ability to cope is challenged less when they have experience of caring for a longer length of time (McKeen *et al*, 1997). There appeared a 'critical period', when carers found it particularly difficult to cope, often in the early days. This appears to have resonance with the adjustment process (Motenko, 1989; Kralik *et al*, 2007) and the LTIC. Linked with adjustment, Motenko (1989) also suggests that the impact and influence on the carer's life is more likely to cause them distress, more than their partner's condition and diagnosis.

#### 6.8.3.5 Complexity of their caring role

Carers had feelings of being useful and caring for their partner as well as doing the 'best they could' and being a dutiful partner. However, there were other times when they were overwhelmed by their situation, feeling trapped, tired and depressed.

Adapting and adjusting, or resigned acceptance of their life now, varied with each individual (Jablonski, 2004). Being responsible for their partner's care had personal implications, such as the impact on their own health and this influenced

their ability to cope. In the context of naturally aging together, they were more likely to express concern for each other at this time.

There were similarities related to a 'reluctant acceptance' in the literature (McDonald *et al*, 2015) in relation to caring for a technology as part of the carers' role. The carer's relationship had changed over time and was no longer the relationship they once had. At times this evolved in to a nurse-patient relationship and in certain instances it was similar to a parent-child relationship particularly for caregivers in Part I.

## **6.9 Support**

'Support' was a multifaceted experience covering the physical, practical and psychological aspects, and a need for this increased over time. The psychosocial issues carers raised were helpful in identifying the type of support they would find useful. There were positive and negative experiences of support. The level of social support influences adjustment and is associated with depression (Dickson *et al*, 2011).

Spousal carers and their partners were ill prepared for the inevitable problems that result the longer the LTIC remains *in situ*. The level and type of support was an influence on adjustment and coping. By the time the problems with the LTIC started, the assumption on their part was that a solution would be found. This was not always the case and the LTIC problems required the carer's support, similar to the pre LTIC days. If users had been informed about potential problems, there was often limited information or preparation for such an event and even less for the carer if they had not been involved with the pre-catheter discussion.

Spouses were taking responsibility for the LTIC on a day-to-day basis often with limited support. The importance of their role can be over-looked as I am anecdotally aware, there is often an expectation by HCPs that as a spouse, they will support LTIC care. The spousal carer may not have been involved with

decisions about the LTIC or included when instructions for care were given, but the expectation remains. It is suggested that this contributes to future difficulties. The literature highlighted the importance of extending practical training and support when carers are involved with a technology or procedures at home (McDonald *et al*, 2015) and also to include emotional and psychological support. The reaction to the LTIC was often a shock to some of the carers such as Hilary who had found the adjustment to seeing her husband Mike's supra-pubic catheter difficult to come to terms with in the early days.

The thesis highlights how crucial it is for spouses to be part of the decision-making process unless the LTIC user specifically requests that they are not. Their interdependence as a couple was identified and maintaining the equilibrium was influenced by their relationship before, as well as the support from those around them. Being a carer for one's spouse suggests facing relationship changes and competing needs within their own lives. Gordon and Betty approached most things they did as a couple and their interdependence was part of their relationship.

### 6.9.1 Communication

Experiences of support from HCPs were both positive and negative. When contact with the DNs on a regular basis was reduced, they missed their support. In relation to adjustment, the importance of a spouse's emotional support was found with similar interventions such as post colostomy (Piwonka & Merino, 1999). It raised the question that if there was more individualized support would catheter users and their carers be more adept at self-managing or have more confidence to self-manage.

This PhD study identified that decisions were often made without consultation as noted by others (Wilde *et al*, 2010a, pp.1258). The carers had certain people they turned to – family, DNs or GP. All carers valued involvement and being included – although individuals acknowledged why this might not have happened if the

LTIC was a personal decision for their partner. This had been the case with Mike who wanted to resolve his problems himself and shield Hilary. Ultimately the LTIC decision affected them both, if not at the beginning, then later as carers became more involved and responsible for managing the LTIC.

### 6.9.2 Support from HCPs

This was a theme that ran through many caregivers' experiences (McCann, Lubman & Clark, 2011). It highlights the changes within the health service particularly in the community, with patients expected to take greater responsibility for their health and to initiate asking help if required.

When Mary's husband had fallen out of bed in hospital and pulled his catheter out; not being contacted left her sidelined and angry. Her reaction was to discharge him from hospital. This set the tone for her future resentment of HCPs. This raises the issue of the importance of effective communication. It is acknowledged that there is no HCP voice in this study.

Those who perceived they had poor support were left feeling overwhelmed and negative about their experiences. In some instances, such as Mary in Part I or Mavis in Part II, they had very little interaction generally with HCPs. They relied on coping by themselves until eventually appropriate help was found - from a community matron and a social worker respectively. This was similar to studies of MS patients with decisions being forced upon them (DuPont, 1995; Murray, 1995; Knight, Devereux, Godfry, 1997).

The detailed analysis presented an opportunity to consider what was provoking their reaction or behaviour. It was often underpinned by being tired and feelings of sadness and loss. On occasions HCPs' recommendations competed with the carer's idea of what the approach should be, adding further tension. An example of this was Mary choosing to feed her husband despite the choking risk.

The carer's priority was having support from someone who was empathetic to their perspective and situation, and who listened to them. This could be a specific HCP who helped them and provided what they perceived as the appropriate support. On occasions it appeared that the only support they required was someone to reaffirm that they were doing a good job caring. Their levels of caregiver stress were not solely influenced by their experiences with the LTIC, but their daily lives overall (Shaw, Patterson, Semple, 1997; Schulz, Newsom, Mittelmark, 1997).

The study established that carers had certain people they turned to. Support came in different guises, for instance several mentioned DNs for practical support but it was their GP they went to for health-related support. Research suggests empowering people through information (Harkness *et al*, 2004) and although information was important, it was not enough on its own. For the carers, it was the personal contact that was important. The perceived value of support seemed influenced as much by carers' feelings about the people involved as by their skills and abilities.

When practical problems with the LTIC occurred, this often involved seeing their partner in pain or distress and feeling powerless to help. Many of the caregivers in Part I had become more confident and proficient with the LTIC over time and learnt strategies to lessen the distress for their partner and proactively manage these problems.

The study highlights a desire for spousal carers in these circumstances to be informed and involved; acknowledgment that they are taking on this role often unprepared. There was some good evidence of collaborative working when caregivers eventually found what they considered good support. Carers having sufficient opportunity to talk to HCPs and identifying that they were 'self-managing' (Paterson *et al* 1999) was positive.

### 6.9.3 Family support

There was evidence of the influence of the LTIC on adult children, particularly as they supported their 'caring' parent. Hilary's support from her daughters was fundamental to her coping so when there was a problem, she wasn't dealing with it alone.

The multiple role (Penning, 1998) for carers of dealing with family (Stone, Cafferata, Sangl, 1987; Stoller & Pugliesi, 1989) and their desire to have the ability to care for other family members (Beach, 1993) created a conflict of interests on occasions. The needs of their grown-up children competing with the needs of their partner were present with several participants. Jenny wanted to support her daughter having a baby, Mavis wanted to support her single parent daughter and granddaughter. The challenge they faced that gave them additional stress was trying to balance everyone's needs as well as their own. (Carmack, 1997; Beach, 1993). The family dynamics and relationship had been affected when there was an ill parent.

### 6.9.4 Coping strategies

Coping was defined as how we respond when we perceive that a demand exceeds the resources that we have available to deal with it. Coping related strategies link to adjustment, often in an attempt to maintain the equilibrium. Coping with a long-term condition required a multifaceted approach. The ability to adapt (Cheng, 2003) and assume a flexible approach depending on the situation (Kato, 2012), enabled people to cope more effectively. Carers often avoided challenging their partner to maintain the equilibrium.

Piwoka & Merino's (1999) study related to colostomy formation. It found that the ability to adapt was influenced by 'self-care skills' to enable them to cope with the colostomy. The importance of the family providing support was acknowledged and the importance of including spouses at each stage of the process.

Several carers demonstrated flexible coping skills and were very adept at using problem solving strategies to overcome difficulties such as those used by carers Brian and Jenny. However, despite their seeming self-reliance, they voiced that they would have valued additional support.

Carers used practical strategies with the LTIC such as planning ahead and taking a bottle to drain the catheter bag into. Margaret, a LTIC user, had to plan for herself when going out because of Brian's expectation that she would manage her LTIC herself, although she struggled with this without his support. LTIC users had lots of changes forced upon them as a result of their MS (DuPont, 1995; Murray, 1995) and many of these were shared with their spouse (Knight, Devereux & Godfry, 1997).

Carers coping strategy was primarily to take one day at a time and avoid looking too far ahead. The value of respite, or time away for themselves, was identified by carers as experiencing a break (Chappell *et al*, 2001) and rest. Considering it in these terms rather than the more conventional view of respite, suggested it could be something they do regularly (Stoltz, Willman & Uden, 2006). Carers were already doing this to some extent, in their choice of activities that took them away from caring as much as they could.

#### 6.9.4.1 'Trade-off'

'Trade-off' is the ability to consider or weigh up the benefits over the negatives which may involve losing one thing but gaining another in compensation. It can be helpful to justify a situation and it can enable individuals to cope more readily. Carers were adopting 'trade-off' to assist their adjustment process, without necessarily identifying that they were doing this.

Considering experiences of caring and adjusting, 'trade-off' was identified as a coping strategy. I have been aware of the concept of 'trade-off' for many years in a nursing context, often to justify a treatment/management approach with the



idea of taking an action that would have a beneficial outcome despite negatives for a downside. An example related to 'traded-off sex life, for longer life' (Jakobsson, Hallberg & Lowen, 2000, pp.62) in relation to surgery for prostate cancer that left patients impotent.

'Trade-off' has been previously mentioned as part of the realignment that carers and partners attempt (Carpenter, 1994; Morse, 1997) in relation to restructuring their approach to managing health. Examples of 'trade-off' included considering the LTIC preferable to their life before with continence problems – despite all the catheter difficulties they were experiencing. Another example was the importance of sharing a marital bed but over time they accepted the move to their own bed/room and their need for sleep.

Margaret had a personal dilemma related to 'trade-off' and whether to allow Brian to continue to change her catheter and thus expose her to increased risk of infection or accept that the DNs do this. The latter, would most likely mean that Brian would continue to go away but without her.

In the literature there are examples of similar sentiments to 'trade-off' such as 'balancing strategies' which included caregivers 'maintaining the balance point' (Shyu, 2000). This was associated with justification of a situation or course of action and balancing strategies. Shyu (2000) noted several facets to 'maintaining a balancing point' which required physical intervention and strategies to manage the emotional side of caring.

All three LTIC users in Part II showed resigned acceptance of the device. The 'trade-off' for the LTIC being easier to manage than incontinence was accepting the loss of privacy and embarrassment such as when their partner emptied the LTIC over a drain at the side of the road (Margaret). They acknowledged their current life with restrictions and limitations related to MS and the LTIC, and their reliance on their partner. Integrating the LTIC into their life in order to manage their bladder involved elements of self-adjustment and accepting staying closer to home (Mike), no longer having holidays abroad (Mike and Peter) or only going

where they can cater for your needs (Margaret). They had to adapt to change in order to have a quality of life.

#### 6.9.4.2 Time out/respice

Those who had respite valued it and findings were acknowledged in research specific to MS (O'Brien, 1993; McQueen 1992). Carers mentioned the importance of sleep and not being tired to support their ability to cope effectively. Increasing amounts of time were taken up as the level of their partner's disability increased (Aronson *et al*, 1996).

'Respite' as a break from caring responsibility came in various forms, from the traditional day center visit, which Clifford attended, or someone coming in to sit with their partner, which Jenny received for Phil. The value of 'time out' was acknowledged.

Taking 'time-out' was often part of the carer's day - Jenny loved to garden, and Brian had his study which he would retreat to - as well as having his 'days out'. This study showed that that carers chose various ways and means to have time away from their partner.

Some of the carers also had places in the house where their partner was not able to physically go. Mavis had her bedroom upstairs, which Peter could not access because there was no stair lift. She also talked of a narrow passageway to the kitchen, which only she could use. Mary spent time in the kitchen/diner which husband Jim could not get to because of the step he was unable to negotiate. Edward was restricted to only two rooms because of the wheelchair. Judith, Edward's wife, said she went out walking in the afternoon on the pretense that it was for her 'knees' as physiotherapy, but in reality, it was because she wished to have time away. All of these 'escapes' were part of the carer's coping strategy (Ashworth & Baker, 2000) whether they acknowledged it or not, and part of their way of managing their caring duties (Piercey & Dunkley, 2004).

### 6.9.5 The carer's health

The impact of their health, aging and their ability to cope and support with the LTIC was compounded by an already fragile situation as a result of their spouses' health demands and long-term condition. Carers are known to neglect their own health (Weitzenkamp *et al*, 1997) and these findings are found in similar circumstances associated with the burden of caregiving.

This study evidenced that carers were allowing their own health problems to take second place to their caring because they were busy coping with their partner; this was often to their detriment. When Beatrice needed treatment for cancer or when Mavis had major heart surgery, arrangements for the partner's short-term care was coupled with the need to be practical in the long term. They talked about how they considered arrangements for what would happen to their spouse, should they die first; responsibility right up to the end. Mavis expressed concern for her own health but felt she had to stay strong for Peter.

When carers were no longer able to care, their health was cited in 72% of instances as the cause (Wollin & Sato, 2001). Carers adjusted as a response to the illness, re-evaluating previous values and making changes. Carers did this when they were faced with their own ill health. Similar to a 'pivotal moment', it gave them the impetus to make necessary adjustments. They talked about not worrying their (adult) children who they knew were busy with lives of their own. There was evidence of being resigned to accepting the situation – a 'no choice' sentiment (McWilliam *et al*, 1996) which Margaret spoke about in terms of her MS and several others reiterated the same sentiment.

Their experience of disturbed sleep and resulting day time fatigue was a big consideration for the majority of participants. Tiredness, lack of sleep and fatigue were experienced by carers particularly pre LTIC. Later, the demanding catheter resulted in their continuing to try and protect sleep, which they appreciated as a priority in order to be able to continue caring. Altered sleep and carers' health associated with this is documented in research (Brunier & McKeever, 1993) and specifically relating to MS, depression and sleep problems.

Protecting sleep eventually resulted in the majority moving to sleep in a room separate from their partner. They also recounted feeling exhausted physically as well as the mental strain of seeing their partner in this condition. Regarding the emotional stress, they experienced feeling less tolerant and less able to cope. In this study, the majority of carers were being treated for clinical depression and stress - psychological or physiological (Yehuda & McEwen, 2004).

### **6.10 Relationship change and dependency**

There were positive and negative experiences for carers both as an individual and for their relationship. They expressed sentiments that their partners were no longer the person they married which saddened them. In some cases, they considered their partner seemingly punished them if they went out leaving them, by ignoring them on their return.

The 'mutual' supporting aspect of the relationship was explored in Part II. There was evidence of interdependence and reciprocity between partners, suggesting that as HCPs we should be focusing support on both care giver and recipient. Kulig (1999) suggested that as couples age, their interdependence becomes more pronounced owing to shared life events such as having children, or if they worked together as was the case for Edward and Judith.

Carers experienced the increasing dependency and responsibility for their partner as their relationship shifted from being a partnership of equals to their new role and, for some, a parent/child relationship. They were aware of their partner's vulnerability and often they experienced the expectation from HCPs that they would take on doing more with the LTIC. This involved practical 'nursing' procedures related to the LTIC management such as irrigating the catheter. They were aware the DNs were busy and feeling slightly pressured, Judith had offered to take over the daily 'flushing' but this meant the DNs no longer visited, which she missed.

They were expected to order supplies and get equipment ready for the DNs visits for catheter changes and carried out the day-to-day practicalities of managing the catheter. The LTIC demanded frequent attention and vigilance, which had ramifications for their time.

To prevent urine infections, the importance of getting their partner to drink adequately was frequently mentioned because such a seemingly simple task was complicated as it was such a struggle to get their partner to comply. The intervention of the LTIC became more difficult to manage over time, often leaking as a result of infection and blockage. Their experiences of coping with a leaking LTIC was similar to pre-catheter incontinence, resulting in increased work (Gallagher & Pierce, 2002).

#### 6.10.1 Postive experiences of caring

Having a dependent partner impacted on carers' lives. For some, caring was a positive experience, of being able to do this for them as an expression of their marriage commitment and affection, but for others it was a burden. The study highlighted both negative and positive impact of assuming the role of caregiver for their spouse generally which is mirrored in literature [Chapter 2].

The carer's approach was in the context of 'doing the best I can'. Being acknowledged for this was important for those caring. Carers chose to focus on aspects of care that they considered a priority. Beatrice, for example was concerned about infection and she made the decision to use disinfectant extensively. There was insecurity in relation to providing the appropriate standard of care which was noticeable particularly with female carers, that it was their 'role' to care for their husbands and that others, such as paid carers if they had them, might not do as good as job. Beatrice liked to check up on the carers to make sure they were caring to her standard.

The marriage vow 'til death us do part' was poignant to this study with duty and marriage vows mentioned specifically by Jenny, Mary and LTIC user Margaret. Ultimately, caregivers wanted to care for their partner as they hoped they would for them if circumstances were different. They were sensitive to their partners' wishes and if they didn't mention marriage vows *per se*, what they showed was kindness. However, this was not without sacrificing something of themselves and they wrestled with the role as was evident in their frequent contradictions.

Van Manen (1990) wrote of the complexities and responsibility of caring experiences, and the way carers respond to their partner's needs suggests identifying another's vulnerability. The carers reaction, whether feeling morally bound was still an act of 'human responsiveness'. The 'worry' aspect was an intrinsic part of caring and became more of a concern over time. The increasing dependency on them as carers included becoming the 'voice' of their partner and their advocate. Carers all showed great resilience, often pragmatic in approach, some describing themselves in terms such as 'being feisty' in order to make sure their partner had the care they needed. There were examples of their becoming increasingly self-reliant with caring to ensure they had greater control over their situation in the case of Brian and Jenny.

#### 6.10.2 Feeling alone

In Part I, four out of the six LTIC users experienced difficulties with speech, dementia and cognitive impairment. For the carers, their partner's inability to communicate combined with cognitive decline/dementia was summed up by Mary's comment '*I live in a silent world*'. They felt very much by themselves. Being able to communicate with one's partner appeared to lessen the carer burden and feelings of isolation. Gordon and his wife Betty were able to support each other both emotionally and enjoyed a certain camaraderie. Interaction with others generally had declined since their partner's health had deteriorated and their social world became smaller. The three dyads were able to communicate and only Margaret showed mild cognitive changes.

### 6.10.3 Conflict within their relationship

Several carers had experienced the negative impact of caring on their life and identity (Charmaz, 1983). Changes meant that they no longer socialized as a couple and their world became smaller.

Pakenham's (2002) study as part of the development of a 'coping measure' for individuals who care for someone with MS, considered the adaptation process and coping as part of caring. The study recorded data of eighty-nine individuals who cared for someone with MS (fifty-seven per cent were male, mean age was 49.78 years and eighty-five per cent were married others were immediate family members). Data was gathered using a questionnaire asked about coping strategies with MS. The many challenges both physical and psychosocial were acknowledged though did not include catheters. Findings reported the benefits of support and reciprocity which resulted in greater adjustment. In contrast where carers were experiencing conflict and problems with behaviour, they were more likely to have higher levels of depression and stress. This aspect of 'conflict' from the care recipient and the resulting effect of their psychological well-being, was evident in Part I when care recipients did not want their partner to go out/leave them.

### 6.10.4 End of their physical relationship

The change to their relationship affected their physical and sexual relationship particularly if the LTIC was a urethral catheter. Hilary describes that at first their sex life continued because Mike had requested a supra pubic catheter but over time as his health deteriorated, this finished.

Carers talked about loss of togetherness and change in their relationship and any intimacy now related to personal care. Their new role involved dealing with the LTIC. Prior to this it had been coping with their partner's incontinence and helping after an incontinent episode, which was something they hadn't envisaged and felt unprepared for (Clare, 2003). For the male carers, Gordon's and Brian's

awkwardness with personal care was evident combined with being ill at ease talking about it. For Brian, this extended to not wishing their son to help his mum to empty the catheter bag in his absence. This happened on one occasion and Brian made sure it was not repeated.

Accompanying the loss of sex, there was loss of closeness and intimacy. Mavis interpreted this as loss of love. She blamed the loss of their physical relationship and any intimacy on the LTIC. The literature had suggested that with caregiver's involvement with personal care and care of a urethral LTIC, there was a change with their intimacy (Twigg, 2006), as this became their only intimate contact.

This PhD showed that caring for a spouse with a LTIC was not something that couples had anticipated or expected as part of their married life. It was noted in Kralic *et al* (2007) and RCN (2012) that the LTIC impacts on a couples' physical relationship. Chapple *et al*, (2014) had suggested that HCPs assume that if individuals would like advice or support in this area, they would ask for it, however research shows that they don't. This was mirrored in this PhD research and is something HCPs need to be aware of, so that they can raise the subject in the knowledge that people would prefer the opportunity to say they do not wish to talk about it, rather than not have it mentioned (Fowler *et al*, 2014).

## **6.11 Loss**

### **6.11.1 Personal loss**

Caregivers experienced a personal loss of self and a degree of independence. The 'loss' they explained was similar to bereavement, it was the loss of their former life and independence as an individual as well as loss of the partnership they had shared. Carers expressed mixed emotions, from feeling relief that it was not them with the LTIC, and guilt for considering it, but this was tempered with the sentiment that 'it is my life too'.

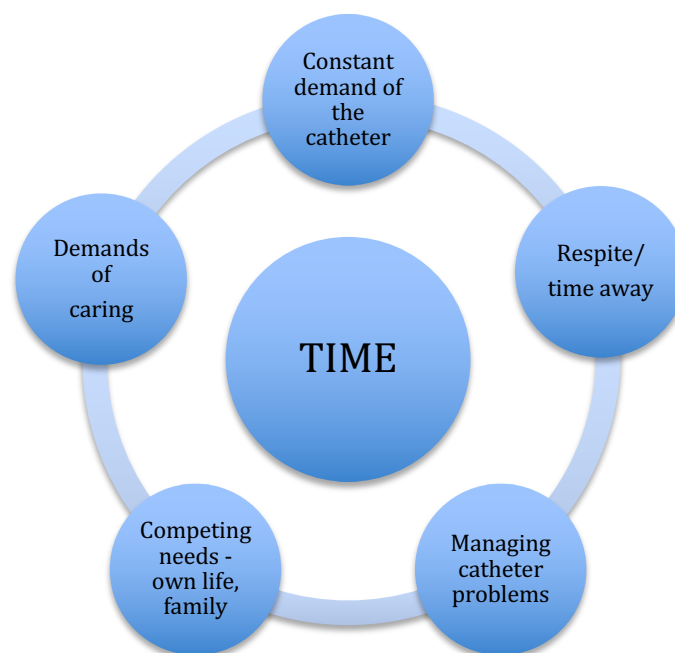


For LTIC users there was a degree of resentment and sometimes anger towards their situation. Margaret as a LTIC user, voiced her resentment of having to stay home when husband Brian went out and compared herself to her friends who enjoyed good health. Mike was no longer able to go out independently and knew he would never visit his brother in Australia again. Peter had been encouraged to give up his job as a volunteer at the hospice and now rarely went out.

### 6.11.2 Time short and their competing needs

Carers' experiences incorporated elements related to time and the interplay between other factors had a particular influence:

Figure 10 The influences on 'time'



Carers often found the constraint of keeping to routine impacted on their lives. In Part II, Mavis had to be around to let DNs in to the house each day because Peter was unable to get to the door. The DN visits were to flush Peter's LTIC, a task carers Judith and Jenny were doing in Part I to support DNs. Time in relation to catheter care necessitated a regular routine. LTIC users had previously had a similar routine including bag emptying, changing day to night bag and weekly bag changes. The LTIC also required a level of vigilance to check it was draining

and if the bag needed emptying. However, the impact of the catheter varied as Judith only emptied her husband's LTIC bag once a day whereas Beatrice was more stringent with her routine which was supported by the care agency's involvement.

There were competing demands on the carer's time, for themselves and their social needs (Beach, 1993) including a desire to support their children (Penning, 1998; Shyu, 2000). An example was Jenny's difficulties wanting to visit her pregnant daughter who was unwell but not being able to leave her husband by himself. There was evidence that the pressure of caring activities resulted in their needs being sidelined. Beatrice felt the pressure of time having to feed Clifford, who was slow eating lunch, before the agency carers arrived. In response to having to constantly 'clock watch', she chose to spend her weekly respite at home, alone, resting on the sofa with a cup of coffee. This was a time for balancing her needs (Shyu, 2000).

In addition to being governed by time, carers experienced an imbalance of either too much time or too little time. Carers Mavis and Brian in Part II, and Beatrice's experience in Part I, had resonance with 'temporal juggling' (Glasscoe & Smith, 2008, pp.261). As they spent the majority of time at home with their partner because they were unable to leave them, when not caring, they filled their time with solitary activities such as Solitaire for Joyce, or in Hilary's case, jobs around the home and housework. Joyce had plenty of time as she saw it: *'I mean, we're home all day, you've got plenty of time really haven't you...* but she was restricted to doing things at home she did not enjoy such as cooking.

### 6.11.3 Loss and uncertainty about the future

*...if I was on my own, I would be out of here like a shot, because it's got a lot of rotten memories and I would like somewhere small, over at (name of small town is Gloucestershire) where I can see green fields and that's what I would probably do, if I don't go first!' (Beatrice)*

Uncertainty about the future and ever-increasing concern over being able to control what was happening are acknowledged as contributing to psychological distress (Irving, 2001). There was a great deal of uncertainty for the carers often because they were increasingly having problems with the LTIC but as previously mentioned, there was the uncertainty about their health and ability to continue to care. Their natural inclination was to avoid talking about it owing to the depressing nature of the subject (Quinn *et al*, 2008).

Carers' experiences were of loss and sadness related to their situation which at times had resonance with grief (Kubler-Ross, 1969), bereavement and loss. There were aspects of the five stages of grief in their accounts - from early denial and anger, a bargaining stage and finally depression as a response to the loss and acceptance that 'this is the way that it is'.

Similar to the Grief Cycle (Kubler-Ross, 1969) they moved between the 'stages' although not necessarily 'completing' a stage because of adverse events and changes owing to the influences and setbacks.

Recalling the early days of the LTIC when it was much more reliable gave the LTIC users and carers impetus to hope that things could be like this again. Hope is an important motivator and human need. I reflected that some of the situations they found themselves in were often lacking hope. The downbeat sentiment of loss expressed by Judith and Joyce was a reflection on how devoid of hope they felt at interview.

Ultimately carers felt responsibility and a commitment to their partner for life. Their reaction was to try not to dwell on the future, aware that inevitably one of them will be left when the other one dies. Cheung & Hocking (2004) identified caring as a time of anxiety and worry. This included concerns about what will happen to their partner if something happens to them and is also evidenced in other studies (Knight, Devereux, Godfry, 1997). As they were often the only carer, if they had a period of illness, as with Mavis and Beatrice, they made plans for their partner's care. Sentiment expressed as 'I hope they go first' identified

that spouses hoped they would outlive their partner (Wollin & Sato, 2001); the implication that their caring 'duty' had been fulfilled.

A way of coping with an uncertain future was to avoid thinking about it too much and to live each day as it came. This appeared a mutual decision although when there was a suggestion of discussion, as with Margaret's comments to Brian, they acknowledged the inevitability of their situation and that it was out of their control.

## **6.12 Summary**

The overall findings from Part 1 and II, in the context of IPA, suggest that carers considered the LTIC as a mixed blessing. Their experience adapting and adjusting to the LTIC was a complex process with multiple influences and factors that helped or hindered. It was a continually 'shifting' process (Paterson, 2001) as issues such as LTIC problems come to the fore. Some carers were in a perpetual state of adjusting in their caring role, particularly when LTIC blockage and infection were frequent. Over time, they became more adept at meeting the demands that caring for the LTIC imposed on their daily lives. The LTIC heralded a time of change and they had the opportunity, certainly in the early days, to return to some semblance of normal life. This change in their view of the LTIC presented the spousal caregivers with an incentive to be more accepting and optimistic of the LTIC.

The methodological approach illuminated the carers' experiences pre-catheter and the struggle to support their partner with challenging bladder symptoms including incontinence. Their poor early experience, lack of involvement or inclusion with decisions, had a negative impact initially on their ability to adapt and adjust. The LTIC brought with it specific caring issues but despite this, it was viewed as a positive intervention. Carers experiences of support from HCPs varied and respite/time out was always valued although its availability was not universal.

The LTIC affected their relationship and a contributory factor was their partner's increasing dependency on them in relation to both the LTIC and their general care needs. The LTIC demanded regular attention which conflicted with carers' own needs. For the majority of carers, the catheter coincided with the end of any physical intimacy – ultimately as a result of a deterioration in their partner's health related to the long-term condition which included bladder symptoms. It is acknowledged that the position of a urethral device may have been a contributor in some cases. Carers were anxious about the future, knowing their partner depended on them for all aspects of care and there was uncertainty about what would happen to their partner if they were not longer able to care.

## **Chapter 7**

### **Limitations and Implications for Practice**

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### **Limitations and Implications for Practice**

#### **7.1 Overview of the chapter**

This final chapter considers the limitations of the study and includes a critique of the methodology. The outcome of the study was to inform and improve practice and this chapter considers how this might be achieved. The chapter concludes with suggestions for future research.

#### **7.2 Introduction to the chapter**

The study explored an under-represented group within LTIC research, the informal spousal carers that often provided a vital role. The findings of this thesis make an original contribution to knowledge relating to carers' experience and the support they provide.

In our aging society, increasing numbers of people are living with multiple long-term conditions and it follows that some individuals will need a LTIC. This study demonstrated the problematic nature of LTICs documented in the literature. Similarities were noted from allied research related to carers managing technical health procedures, that preparation for managing, support and training needs to be on going. For practical reasons, care in people's home will need the support of their family, particularly from their spouse or partner. This reflects the economics of demand outweighing services available as individuals wish to stay in their own homes but need additional support.

#### **7.3 Contribution to knowledge**

The pre-PhD study was an opportunity to explore the experiences of LTIC users (Fowler *et al*, 2014) and informed this study but it left unanswered questions about what the LTIC was like for their spouse who became their carer. The study

aimed to redress this omission to help increase understanding of carers' experiences to inform practice.

Originally, I set out to record carers' experiences in isolation of their partner in Part I, having already considered the LTIC user (Fowler *et al*, 2014). However, the interview with Gordon and Betty suggested the dynamics of their relationship was an important factor (Rolland, 1994) for practical and psychological support and participants were choosing to have their partner with the LTIC present at the interview. This influenced the decision in Part II to explore the dyad studies. The re-analysis of three interviews from Fowler *et al* (2014) plus the additional interviews with their spouses in the PhD study, provided an opportunity to consider the full picture of caregiver and care recipient.

The LTIC had been a dramatic intervention for many of the LTIC recipients and what followed were both positive and negative experiences. This theme which eventually became a core theme across all the individual interviews was given the heading 'mixed blessing' to encompass how they viewed the LTIC experience.

The presence of their spouse's support was evident as a positive force. Part I, was a snap shot of carers' experiences. Further exploration in Part II included the added value of the catheter user's perspective, this time reviewed within the context of their spouses' experiences as part of the dyad case studies.

Overall, the majority of carers showed similarities and shared experiences with LTIC users (Fowler *et al*, 2014) but they perceived them differently or they impacted on them in a different way. The LTIC users' concerns about the LTIC leaking, blocking and pain, was also the carers' concern but the carer was also considering the consequences of needing to telephone the DN to attend, their disturbed sleep and dealing with a wet bed.

Carers attempted to adapt and adjust which involved taking one day at a time and problem-solving difficulties. As part of this they used strategies such as



'trade-off' and making modifications to their lifestyle. Coping with loss had similarities with grief - loss of their time and expected future life but wanting to do the best they could for their partner.

In Part II, spousal carers were aware that MS was not life limiting and they were looking at many years of caring. Becoming a carer redefined them as a couple and affected their ability to socialize, plus being at home so much could be isolating. Ultimately, they faced many of the burdens – and positives – of being a carer but the LTIC was 'one more thing' for them to deal with. The LTIC users experienced many of the same issues but were, in a sense, further on in their adjustment process. They were predominantly accepting, as a resigned acceptance, of their situation because their options were limited.

The study identified experiences of adjusting and the importance of involvement with care decisions and communication with the team involved for carers and the LTIC users. There was also evidence of relationship changes associated with increasing dependency and the carers' experiences of coping with the LTIC on a daily basis. As HCPs, we cannot afford to ignore the opinions of carers when making decisions about services and policies related to managing LTICs - because we need their assistance to support care.

The study confirmed findings in the literature relating to the LTIC users that carers were, like the LTIC users, unprepared for the catheter (Sweeney, Harrington & Button 2007). Previous research (Godfrey, 2008a) had suggested that LTIC users were unsure why they had a LTIC, however in this study, the issue was more to do with the manner of the decision for the LTIC, that caused distress. They all knew why they had the LTIC.

This thesis reaffirmed the demands of a LTIC, which Wilde (2014) suggested needed to be 'addressed on a daily basis' (pp.2). Although Wilde's (2014) study considered LTIC users, this could equally be applied to carers. LTIC users had the 'double stigma' normally discussed with dementia and aging (Moniz-Cook &

Manthorpe, 2009) but again, this could equally be associated with another two stigmatizing aspects - their long-term condition and a LTIC.

The long-term condition and aging were a big influence on the participants in this study as they were coping with multiple and complex influences on their situation and constantly having to adapt and adjust. Some carers managed the adjusting process with greater ease than others and were able to draw on and utilize strategies from their past. These were often self reliance, coping styles and carers described themselves as having a 'feisty' personality. This 'attribute' was used to speak up for their partner if challenging care decisions.

#### **7.4 The implications of theories and models on adjusting**

The study findings were considered in the context of Paterson's (2001) Shifting Perspective Model of Chronic Disease, which had resonance with LTIC users and their carers, as they assist their spouse. The 'fluid' model that constantly 'shifts' and acknowledges the ups and downs of dealing with a chronic disease - holds the same relevance when applied to the LTIC. The 'perspective' (pp.25) in this is the key aspect of this model, whether it is the individual's perspective with the condition or their carer. The outside influences, which Paterson (2001) refers to as the 'social context and life events' (pp.25), were evidenced in this study, such as the carer's health and the LTIC problems. The use of terms such as 'acceptance' or 'adjustment' are labels that we as HCPs tend to use when considering treatment, but Paterson's model (2001) acknowledges the onus should be on individual's needs within their experience, instead of viewing negatives such as limitations on what they are able to achieve. The approach suggested, is to consider the 'opportunities for transformation' (pp.21) and re consider their experiences in this light.

The continuum of Rolland's (1987) framework of chronic illness has been discussed [6.8], and later work by Rolland (1994) with reference to the Family Systems Illness Model (Rolland 1994, 1987), considers the family influence as a variable in coping and adapting. Many aspects of Rolland's model can be

identified within this PhD study (Rolland, 1994) relating to relationship changes, marriage vows and intimacy. The long-term condition is viewed as an 'uninvited guest' (pp.2) which had resonance with the LTIC literally coming between their physical relationship.

## **7.5 Considerations for improving practice**

Findings confirmed the importance of encouraging the involvement of both partners when a LTIC is considered. Partners did not routinely attend appointments prior to the LTIC. The study demonstrated the importance of communication and involvement with decisions as part of adjustment. This would require agreement from the LTIC user and therefore sensitive handling as LTIC users were often trying to maintain their independence and shield their partner from their long-term condition.

Review of HCP's assessment process of individuals with a LTIC includes partners but there are additional factors that this study explored that should be considered such as external influences of informal/family carers and their support and needs. The importance of a holistic assessment is noted in the literature (NICE, 2012, RCN, 2012) however reviewing assessment to include more detail relating to carer support would be a positive addition, acknowledging the complexity of caring for the device. Assessment may be supported with a tool such as the ICIQ-LTCqol as discussed [2.9.5] (Cotterill *et al*, 2015). This was developed for LTIC users and can be used for carers. To date this has only had sparse use.

For policy making, inclusion of carers' experiences would be a valuable addition. Individual's experiences are unique and although we can not assume everyone would want the same approach, the study highlights that improving communication in preparation pre-catheter and support early post catheter would be beneficial.

As part of the discussion with LTIC users and their partners, this study raised the important issue of talking about the potential impact on their relationship. What became apparent were the diverse needs of both the carer and the catheter user, and the intrusion of the LTIC into their relationship affected intimacy and sex.

Chronic illness affects intimacy within a relationship (Chamberlain Wilmoth, 2002) and the LTIC again, was a further influence on this. There was little evidence of HCPs talking to them about sex and a LTIC. A finding was that carers were not offended or upset to talk about it and sometimes anticipated that I would be talking about it as part of the interview.

The NICE pathway 'Long-term urinary catheters; prevention and control of healthcare-care associated infections in primary and community care' (2012) notes that patients and carers should have training and support for care of the device before leaving hospital, and ongoing support as long as the device is *insitu*. This study demonstrates that this is not always being followed through. There were positive interventions, however, often at a local level such as the Catheter Passport initiative [2.4.2].

In general, the sentiment of what they were saying about support, related to their knowing there was someone to help them if they needed it. This included information (Wilde, 2015a) to back up advice identified as important.

The study has a number of implications for practice - the information and support provided by HCPs could be focused on facilitating adapting and adjusting. As spousal carers, they had made extensive efforts to support their partner and this needs to be reflected in the approach to managing LTICs – providing the necessary information and support. Those carers who are active problem solvers, or who wish to have more involvement, the approach should be to support this without making it an expectation for everyone.

Support was valued but requirements were unique to individuals, which makes it more challenging to provide. Participants often chose to access a variety of

support to suit their individual needs when required. They tended to value the support based on the quality of their personal relationship and empathy with the provider, rather than their skills or resources. Carers lacked the initial support and skills training to deal with the LTIC and this is also mirrored in literature related to the 'wayfinding' experiences of family carers (McDonald *et al* (2017) coping with medical technologies. This highlights that current patient led support is falling short preparing carers who are not receiving on-going support.

Participants reported the impact on socializing and change to their relationship which included their identity as a couple being viewed differently and difficulty making new friends. Activities they previously enjoyed were curtailed or compromised because they could no longer participate or felt like taking part. The value of 'time out' was acknowledged as helpful and encouraging interaction with others when things were better. When they had support, they were able to plan for future, such as Mavis and her trip to support her daughter.

To support carers, discussion should take place early on about respite (Ashworth & Baker, 2000). The type of respite might be outside of the conventional view of what this is. Rather, it is about the value of making 'time' for themselves during the day. There was also the case for taking 'real breaks' away (de al Cuesta-Benjumea, 2010). DNs are in a position to encourage this different slant on 'time out' and respite.

### Designing a resource

An outcome of this thesis could be to produce a leaflet for HCPs such as DNs, with information on the findings with suggestions they may wish to raise with carers. This could incorporate the importance of early carer inclusion, practical skills helpful when dealing with the LTIC and the importance of 'time-out', acknowledging the 'mixed blessing' aspect of caring for a LTIC.

Carers are isolated and need to feel listened to as well as have time to talk. The importance of being included in discussions, active listening and having their views taken in to account (Wells *et al*, 2011; Quinn *et al*, 2008) was highlighted.

If their partner was unable to communicate, this was even more important as they were making decisions on their behalf. Rolland (1994) suggests that if communication is difficult within a couple relationship, then encouraging them to 'consider the consequences' (pp.3) can be a way forward to negotiate a solution.

When carers were involved with procedures such as catheter irrigations (Jenny and Judith), these were time consuming but conversely, Mavis found the intrusion of the DNs into her home to complete the same task equally intrusive. The compromise might have been somewhere between such as a shared intervention or carers might have been happy to continue if they felt there was support available at other times.

The carers in this study were happy to support their spouses, but they were equally aware that there was an expectation that they would, rather than a collaborative approach. The relentlessness of caring and constant need to adapt to changes imposed on them, not only by the LTIC, but more likely by their partner's health, often affected their health. Respite was a reprieve but not everyone had official respite support.

The tension within the dyad appeared exacerbated by tiredness and fatigue, feeling they had no time for themselves. Carers sometimes felt punished by their partner's behaviour if they went out, leaving them at home. The changes in the LTIC user's personality as part of their illness or as their way of trying to maintain control, was another difficulty they had to contend with (Martinez-Martin & De la Cuesta-Benjumea, 2013; Tanji *et al*, 2007).

There were examples of valued support from families and from external agencies for couples such as Mike and Hilary. However, other carers and their partners had poor experiences, such as when waiting for help when the catheter blocked at night and uncertainty about unfamiliar DNs at a time when they felt vulnerable. It was this uncertainty that prompted Brian to become 'self-sufficient' with catheter changes.

Carers and the LTIC users were isolated from others in the same situation. The LTIC was at times a 'tether' which kept them closer to home. For some, going away from home, meant the additional anxiety of coping with the LTIC if something went wrong. Research acknowledges incontinence as a stigmatized condition and by association catheters share this, and how isolating this can be (Godfrey 2008a). As HCPs we need to acknowledge that there is no forum for LTIC carers. The MS website ([mssociety.org.uk](http://mssociety.org.uk)) offers support and advice generally to carers but continence management advice is only briefly covered.

The so-called 'honeymoon period' with the LTIC raised expectations. Individuals may benefit from advice in preparation for subsequent stages which may be more challenging. Building trust with support in the early days offers the potential to assist with adjusting.

The catheter was a solution in difficult circumstances but was never going to 'solve' all the problems for LTIC users and carers, but with no current alternative, they made the best of it (Prinjha *et al*, 2016). The importance of having a realistic approach was identified in the study from some individuals. The LTIC is noted in the literature as being the 'final alternative' (Fowler *et al*, 2014) owing to the documented high risk of complications (Kunin 1997; RCN, 2012). If HCPs were negative – or positive – this clouded people's view of the LTIC. Mike's understanding that his catheter was the 'last resort' appeared to make him more accepting of it. Brian's approach was to do as he always did and consult an 'expert', who reaffirmed it was the appropriate decision. In both these cases, this influenced their acceptance.

Many of the participants in this study demonstrated vulnerability because of their circumstances. Several carers experienced isolation because their caregiving responsibilities reduced interaction with others. In some cases, adult children's distress at seeing a parent with a LTC meant they reduced their contact.

For LTIC users, they too shared a vulnerability, not always able to talk about their early embarrassment with incontinence and after the LTIC they became very dependent on their spouse. Margaret's situation with Brian carrying out her catheterization and flouting hygiene issues was a prominent example of her vulnerability.

The evidence from studies with LTIC users, documents adjustment can be a turbulent journey taking up to twelve months (Wilde, 2002). This suggests that support during the early adjustment should be to the fore during this time. Although this study did not specifically focus on that early time period, there was no evidence of HCPs proactively preparing for the possibility of the spouses needing to become more involved. For the future, a consideration might be for HCPs, particularly the DNs who are most likely to come in to contact with the carers (and LTIC user), to talk to the couple about future support.

## **7.6 Limitations of the study**

This is the first study considering the family carer managing LTICs in the community and should be viewed in this context. This is an exploratory study which has inherent limitations. IPA has small samples and there were no other studies for comparison. The participants were recruited through a small number of DN bases which could have resulted in an unintentional selection bias as the DNs were approaching only LTIC users they were seeing at the time. They would have been coming into contact with the carers as part of routine LTIC changes but also those who were having catheter problems. Another consideration, more in term of influences as opposed to limitations, was that carers who experienced problems associated with their spouse's catheter may have been more willing to take part if looking for solutions, thus giving a biased view of the extent of LTIC problems. The limited geographical area might also mean that experiences of HCP support were particular to the region.

The re-analysis of the interviews with the LTIC users, needs to be considered as a limitation because of the variation in study design between the two studies



(Fowler *et al*, 2014). However, these variances were slight with similarity of approach and semi-structured interviews, and the focus was aligned with this PhD study as it had been influential in informing the study. There were advantages of re-analysis, providing a longitudinal aspect to the study. Couples Margaret and Brian, plus Mavis and Peter, were both present at one interview, which had enabled their interaction and comments to be explored.

I considered whether the telephone conversation the following day with interviewees might have been used more effectively, however no new revelations transpired, other than carers reiterating their views from the previous day.

### Carer diary

The original study design included the option of a three-day diary for carers to complete after the visit. The inclusion of the diary was in acknowledgement that the interview was a single meeting and to provide them with an opportunity to record anything else that came to mind after the event. If the interview had to be curtailed for some reason, such as their needing to attend to their caring duties, they had the opportunity to add further information in the diary if they wished.

In reality, the diary did not work. Carers were reticent about completing it, considering we had talked about their experiences. It was a further reflection on how 'time poor' they were.

## **7.7 Reflecting on the methodology**

A relatively 'new' methodological approach (Smith, 1996; Smith, Flowers & Osborn, 1997), IPA is increasingly used outside of its psychology beginnings (Smith, 2010). The studies frequently explore psychological issues, subjective experiences and the meaning of these experiences (Smith, 2010). Smith (2004) suggests that IPA is useful when the research focus is multi-dimensional and relatively 'novel' (Spiers & Smith, 2012). The novel aspect of this research has

been mentioned, that it relates to a medical device as opposed to a health condition.

In line with guidance, aiming for 'methodological clarity' (Clark *et al*, 2015, pp.280) and transparency in the research process, I incorporated guidance relating to IPA (Smith, Flowers & Larkin, 2009) as documented in Chapter 3. At the start of the study, developing ideas and approach, I critiqued the methodology (Smith, 2010). I had previous experience of using a GT approach and it was beneficial to have a working comparison. IPA, with its meaning focused approach, concerned with the individual's personal accounts and their 'sense-making' (Smith & Osborne, 2003) of their experience, worked well with the epistemological position of this nursing-based study.

IPA has had its critics and the approach has been scrutinized not least by Jonathan Smith who was instrumental in its development (2010; Smith & Osborne, 2007). Any early reservations I had about it were answered (Hefferon & Gil-Rodriguez, 2011; Pringle *et al*, 2011; Reid, Flowers & Larkin, 2005). Smith, (2010) offered his own critique of the approach by reviewing articles that used the methodology and he opened my eyes to possible negatives I had not considered at the time. IPA had been used in similar studies as 'carers experiences' were third in the corpus of work of the thirty papers he critiqued – the first being seventy-nine papers on patient illness and the second, forty-five related to psychological distress. Although Smith (2010) states that IPA is not limited to specific topics, it was reassuring to consider similar questions had been answered in associated areas. The positive that IPA affords 'more room for creativity' (Willig, 2001) made it particularly suitable because of the more unusual focus of this study.

In view of its interpretive nature, it is suggested that it can be more daunting for novice researchers. However, Smith, Jarman & Osborn (1999) provided detailed guidance on the process of analysis and support to ensure quality in IPA (Smith, Flowers & Larkin, 2009).

The limitations identified (Willig, 2008) included the 'role of language'. The language participants use is paramount to communicating their experience however Willig (2008) makes the point that 'language constructs, rather than describes reality' (pp.66), so it has more to do with how they recount the experience and their view of it rather than the experience itself. Because we are potentially considering and acknowledging an individual's experience, Willig (2008) suggests that it is the words that become the experience in essence – and we can not ever really know what someone else is experiencing.

The starting position for IPA is the assumption that the data from the interview will tell us how that individual feels and thinks (Harre, 1998). Whatever the enquiry, it is how they perceive the world that becomes their experience.

In Chapter 3, I discussed the choice of IPA to answer the research question, following consideration of alternative approaches (pp.57 - 61). Reflecting on the benefits of the methodological approach, there were limitations which are important to critically discuss. I have previously mentioned that I envisaged the caregivers might not always be able to distinguish their experiences with the LTIC from those of caring for their partner *per se*; the arrival of the LTIC often coinciding with their partner's deteriorating health due to their long-term condition.

Throughout this thesis, I have acknowledged there was often a blurring of the carers' experiences of their partner's long-term condition and experiences of the LTIC. This presents difficulties if drawing conclusions about spousal carers' experiences in relation to the LTIC only. Carers were keen to talk about their experiences of the catheter and were reflective and thoughtful in their answers. The fundamental approach of IPA was to record what they said and how they make sense of their experiences. Despite my efforts during data collection, the long-term condition and the catheter were often seen by carers as interlinked; they either could not, or did not distinguish between the two. Certain experiences related to the LTIC were easier to recall such as the early days when it had been more prominent in their life, or when it was particularly challenging

to manage, for instance if it blocked. The discussion refers back to the research question and highlights that it is possible that some of the experiences carers had could be reflective of other factors in their home life and relationships and could be experienced by other carers in relation to similar medical technologies and other long-term conditions.

The discussion clarifies that IPA advocates presenting the complexity and detail of participants' lived experiences, as a result, it was not methodologically appropriate to separate out the LTIC from the long-term condition in the analysis. The fact that sometimes carers did not separate the two, was in a sense a finding of the study.

IPA acknowledges the researcher in this process of analysis and the influence of their 'bias' – highlighting the importance of being reflexive and the hermeneutic aspect of IPA. The data, and the researcher, should be subjected to the same scrutiny, to identify pre-conceptions and assumptions because without this, we cannot truly engage in the experiences of others.

A criticism of IPA is that participants need to be able to articulate their experiences, suggesting that the approach benefits those participants who are able to do this (Smith, Flowers & Larkin, 2009). There was evidence of this in the study, as Mike struggled at times to articulate what he wanted to say. The situation was exacerbated by his being a shy man and MS affecting his speech which was slurred. Hilary, his partner, was also ill at ease talking about her feelings, although I felt this was her consciously holding back on divulging too much. The interviews with these two were more difficult to analyse which affirms the above criticism of IPA. However, their interviews were informative because of the hesitations and repetitions.

### **7.8 Reflecting on the method**

The selection of participants was in part dependent to who was currently on the caseload of the DN team. In that sense there was an element of convenience

sampling. I appreciate that those taking part had to be willing to do so. The DNs knew me and I was very aware that despite being busy they gave up their time to help. They had background knowledge of the family that wasn't always noted in their records. The recruiting aspect of the study was very positive for this reason.

In Part I, consideration of the partner's long-term condition could have been considered when selecting participants. This was addressed in Part II with further purposeful selection and the focus on MS.

Some participants such as Mavis in Part II, were very motivated to tell their story, as was Jenny in Part I, because they felt discontented with the way they (and their partner) had been treated. Their need to narrate their experiences could have produced variances in the data within a small study such as this. Conversely their experiences were not lone experiences and there were elements of satisfaction with HCPs that were a counter point to this.

More consistency with who was present at interview would have made analysis more straightforward for comparison. The study demonstrated the limited time carers had and the practicalities of a one-off interview. However, it was also an opportunity to talk to a 'hard to reach' group whose voice is missing from research. An 'obstacle' for the interviews taking place with just the carer was the availability of a private space in the house, away from their spouse. This resulted in several interviewee comments that they were happy to have their partner present – and in some cases they opted to have them present as they saw themselves as a partnership.

I did not purposefully select in relation to details about their relationship other than they were married and as it happened, they had all been married for some time. There is evidence in related studies that the length of time a couple are married, or in a long-term relationship, influences well-being - with less strain as a spousal caregiver noted, the longer the marriage (Berry & Murphy, 1995).

## **7.9 Reflecting on Part II, considering the use of case study**

A consideration in Part II related to 'generalizability' (Clarke *et al*, 2015, pp.280). If exploring the uniqueness of participants' experiences of a phenomenon, there is risk of losing the individual story by focusing on similarities across cases. With so few 'cases', the concern is that this could result in generalizations. This issue is addressed within IPA in this study, through purposeful selection for a homogenous group and the ideographic aspect of the methodology that acknowledges the individual. The idea was that each dyad might present underlying similar 'sentiments' related to their experiences, as well as shared experiences across cases. It was this aspect that could potentially help inform practice. Whilst each individual within the dyad presents unique aspects of the phenomenon in question, the case study analysis explored the message from the case relevant to the research question overall.

## **7.10 Carers' knowledge and experiences being acknowledged**

Care of LTICs is an aspect of caring that has the potential for improvement in light of what carers were identifying. Anecdotally I am aware that their support is recognized by the DN service but there needs to be recognition of their role officially and this needs to be rigorously evidenced.

Part of effective communication involves being listened to. The carers desire for this to happen was evidenced in part by their agreeing to be interviewed, and it was an opportunity to have their questions answered. Many of the carers acknowledged their experience of caring for the LTIC daily, they had become proficient in how to manage it and had valuable experience that could help others in similar circumstances.

## **7.11 Future direction for research**

The study identified the lack of information and evidence about LTICs from the perspective of spousal carers and findings showed what a vital role they play. The approach of current policy includes provision of integrated services in the

community to support care in the home. However, the focus of care is primarily on the individual with the LTIC in the first instance. Encouraging person centered care and fitting services around individual's needs (DoH, 2006) means including their carers. This study has shown that carers are very involved with LTIC management similar to managing other medical technologies at home (McDonald *et al*, 2017). To develop services to support informal carers in the community, a further, more specific enquiry with LTIC carers would be helpful to explore in greater detail, the kind of support they would find helpful at points of transition with caring.

### **7.12 Reflecting on my PhD journey**

The experience of this PhD has had a far-reaching effect beyond this study. Reflecting on my personal journey, I can appreciate how much it has enhanced my clinical practice generally and my knowledge of the research process.

During the study I also found myself on a parallel journey, when my father was ill and needed a LTIC. The experience of having several roles - nurse, daughter and researcher, was an interesting one whilst doing this study. I was not sure at the time how much this would impact on the study and although I was a daughter not a partner, it provided an interesting insight into my 'carer' perspective. My 'nursing' role and my 'researcher' role was sometimes at odds with my position as a daughter supporting her dad, who in turn was struggling to cope himself. Communication was hindered by my dad's increasing dementia. I could identify and empathize with many aspects of trying to accommodate the device in to our lives, that the carers and LTIC users experienced.

The use of a reflective diary was invaluable during the study, as an opportunity to 'step back' and consider what was taking place. It has been helpful in enabling me to acknowledge my bias at the start of the study. It was also my companion when interpreting the data. Being aware that my experiences could influence the study was a concern throughout but the diary helped to challenge my approach.

My lasting impression from the interviews was how open and willing the carers were to share their experiences. This was a cathartic experience for some and undertaken for altruistic reasons by others, in the hope that it would help carers in similar circumstances and lead to changes in practice. They talked about the challenges relating to the LTIC but they also talked about caring when committed to a relationship. Some shared their sorrow about aspects of their lives whereas others found caring fulfilling and something they wanted to do for their spouse, taking in pride in what they did. The majority were somewhere in between.

### **7.13 Conclusion**

The implications of this study for practice suggests the benefits of including and involving carers with the catheter user when decision making and managing LTICs in the community. This would involve practical and psychological support over time to help them adapt and adjust to the device as a couple. This study suggests similarities with supporting 'couples coping' (Rolland, 1994), acknowledging the benefit of this approach in managing long-term conditions.

The findings suggest that many of the spousal carers' experiences of life with a LTIC were similar to those identified in previous studies with LTIC users - as a time of transition and adjusting. Managing the catheter for their partner involved taking full responsibility for it in many cases. They experienced similar difficulties related to the challenges the device imposes on LTIC users in the early days of their self managing the device. There were similarities with studies that considered spousal carers' experiences of similar technologies. The lack of evidence about carers' experiences means that carers' needs have not been recognized, which has hindered appropriate support.

For the carers in this study, like many carers generally, it highlighted the isolating nature of 'caring' especially when the one you care for can not support, or communicate with you, which left many of them feeling trapped by their circumstances. A reflection of our time, is the Government announcement of the creation of a Ministry of Loneliness (17.01.18). This study highlights the number



of carers who were receiving treatment for depression. Even if carers appear to be managing, they would still value being offered support. The study highlighted the importance of being involved with decisions and having the opportunity to talk about their partner's care.

Gaps in services such as continence services, have been identified (Wagg *et al*, 2014). Self-management and cost effective care that is based at home is highlighted as the way forward. HCPs need to recognize the important role of spousal carers in the context of LTICs and services may need to offer flexible support in the future, working in collaboration with carers.

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## **Appendices**

## Appendix 1

### Literature Search Strategy

An extensive and comprehensive literature review of nursing and allied health journals (UK and international) and online data bases was carried out using British Nursing Index (BNI), Cumulative Index of Nursing and Allied Health Literature (CINAHL), MEDLINE, AMED, PsycINFO. A combination of free text phrase and word searching was used with thesaurus search terms in each database in turn, to ensure retrieval of relevant references. The review included the Cochrane library for evidence informing healthcare policy, guidance and decision-making with a focus on indwelling and long-term use of catheters (Niel-Weise *et al*, 2012).

The systematic review to identify articles employed search terms '*urinary catheter*' (to distinguish it from a cardiac catheter), *long-term catheterisation*, *indwelling*, *urinary catheter*, *supra public catheter*, *urethral catheter* and this was combined with '*spousal carer*' and connotation of the term – examples included: '*informal carer*' and '*family carer*,' or combined with the alternative '*caregiver*', '*partner*' and '*spouse*'. The frequency of terms was helpful to justify the terminology adopted in this study.

It was slightly disconcerting to discover the absence of research in this area despite systematically working through each data base and using every conceivable term. In addition, I considered allied areas to review – such as '*incontinence*' and combined this with '*informal carer*' and the terms used previously. Searching '*incontinence*' resulted in vast numbers of references but the focus was narrowed considerably when combined with '*carer*' or '*caregiver*' and, again, the alternative terms tried previously. This information provided background to the study as pre-catheter problems of incontinence (Gallagher & Pearce, 2002; Cassells & Watt, 2003). Further exploration of allied research followed, in combination with Boolean terms of '*or*' and '*and*' – with: '*Quality of life*' (QoL), '*support*', '*burden*', '*adjusting*', '*adapting*' and '*adjustment*'.

I also reviewed literature in relation to specific diseases or injury where a LTIC would most likely be used such as spinal cord injury, neurological conditions such as Parkinson's disease, Multiple Sclerosis, stroke and dementia. In addition, I carried out searches of specific authors, admittedly not a robust method for revealing literature, but it was reassuring to note the same articles were presented, as it is a relatively small field of research and many authors collaborate and produce regular contributions.



## Appendix 2

### Detailed Stages of IPA Analysis

<i>Detailed Stages of Analysis</i>	
<b>1. Reading/re-reading</b>	<p>Each interview was completed as an individual piece, considering the idiographic components. I listened to the recording, making notes about observations to begin the process of becoming familiar with the content. I did this as soon as I could following the interview.</p> <p>When I finished transcribing the interview, I checked the transcript against the recording. This was followed by reading and re-reading the transcript (Smith, Flowers and Larkin, 2009). By this time, I was becoming very familiar with the text. I considered if there was anything at this early stage that I might wish to 'bracket' – that is, any of my experiences that might impact on what I was reading, using the research diary during this process.</p>
<b>2. Initial noting</b>	<p>Whilst reading, notes were made in the margin; developing an 'interpretive commentary' (Reid <i>et al</i>, 2005). This included descriptive, linguistic and conceptual comments as part of the early analysis, noting anything that might be of interest. There are considered no 'rules' as to what to include. I included changes in speech or pauses, all the time increasing familiarity and 'closeness' with the text.</p>
<b>3. Developing [emergent] Themes</b>	<p>This is where the iterative process of starting to identify and develop themes began. I was particularly mindful of the individual's actual words throughout the process as it was my intention to capture the carer's 'voice'. I aimed to maintain the connection between their words and my interpretation and remain consistent (Smith &amp; Eatough, 2006). Being 'new' to IPA I was aware of keeping carer's words 'visible' as far as possible in the heading of the emergent themes.</p>
<b>4. Reviewing Themes and searching for connections</b>	<p>I had a long list of themes as they appeared chronologically in the interview. At this stage, the approach was to be interrogative and critical, to clustering themes, if appropriate, making connections and consider how they fit together. I also looked for 'oppositional relationships' (Smith, Flowers &amp; Larkin, 2009) such as the positives and negatives of the LTIC. This stage was part of moving</p>

	<p>towards over-arching themes or 'super-ordinate' themes, referred to as abstraction. Some themes came up more than once and this was noted.</p> <p>This stage involved constant back checking, questioning of the data and making use of the hermeneutic circle.</p>
<b>5. Moving to the next 'case'</b>	<p>Once the analysis of the individual interview had gone through this process, the analysis moved to the next 'case'. Each interview followed the same thorough process.</p>
<b>6. Looking for patterns across cases</b>	<p>The next stage involved looking for connections or patterns across all the cases with the focus on meaning not just on frequency. The name of the theme needed to encapsulate the meaning. To start with I used quotes as far as possible but as the analysis continued and there was further reconfiguring, some of the superordinate themes changed and were re-named, or they became sub-ordinate themes. The final result was a master table of themes.</p>

## **Appendix 3**

### **Ethical approval documents - approval letters**

**Southmead Research Ethics Committee**

c/o Clinical Governance Directorate  
Beaufort House  
Southmead Hospital  
Westbury-on-Trym  
Bristol  
BS10 5NB

Telephone: 0117 959 5207  
Facsimile: 0117 323 2832

17 August 2009

Mrs Sarah Fowler



Dear Mrs Fowler

<b>Study Title:</b>	<b>Investigating the experiences of informal caregivers, caring for a long-term indwelling urinary catheter</b>
<b>REC reference number:</b>	<b>09/H0102/44</b>
<b>Protocol number:</b>	<b>1</b>

Thank you for your letter of 15 August 2009, responding to the Committee's request for further information on the above research and submitting revised documentation.

I have considered the further information on behalf of the Committee.

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

**Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

**Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for

research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Interview details - Visit schedule	1	12 June 2009
Student's Summary CV		11 June 2009
Sample Diary/Patient Card	1	
Interview Schedules/Topic Guides	1	18 June 2009
Compensation Arrangements		01 August 2008
Letter from Sponsor		29 June 2009
Summary/Synopsis	1	01 April 2009
Protocol	1	11 May 2009
Investigator CV		10 June 2009
REC application		30 June 2009
Participant Information Sheet: - Carer	2	05 August 2009
Participant Information Sheet: - Health Professional	2	05 August 2009
Permission to be Contacted form	1	20 July 2009
Response to Request for Further Information		15 August 2009

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review.

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nres.npsa.nhs.uk](mailto:referencegroup@nres.npsa.nhs.uk).

**09/H0102/44**

**Please quote this number on all correspondence**

Yours sincerely

**Dr [REDACTED]  
Chair**

Email: [REDACTED]@nbt.nhs.uk

<i>Enclosures:</i>	"After ethical review – guidance for researchers"
<i>Copy to:</i>	<i>Prof [REDACTED], University of West of England Dr [REDACTED], University of West of England R&amp;D office for NHS Bristol</i>

**South West 4 REC**  
(formerly Southmead REC)  
Beaufort House  
Southmead Hospital  
Westbury-on-Trym  
Bristol  
BS10 5NB

Tel: 0117 323 5211  
Fax: 0117 323 2832

18 October 2010

Mrs Sarah Fowler



Dear Mrs Fowler

**Study title:** Investigating the experiences of informal caregivers, caring for a long-term indwelling urinary catheter  
**REC reference:** 09/H0102/44  
**Amendment number:** 1  
**Amendment date:** 18 October 2010

Thank you for your letter of 18 October 2010, notifying the Committee of the above amendment.

The Committee does not consider this to be a “substantial amendment” as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

**Documents received**

The documents received were as follows:

Document	Version	Date	
Notification of a Minor Amendment	1	18 October 2010	
Covering Letter		18 October 2010	

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**09/H0102/44:**

**Please quote this number on all**

**correspondence**

Yours sincerely

Mr [REDACTED]

*Committee Co-ordinator*

E-mail: [REDACTED]

*Copy to:*

*Dr* [REDACTED]



## **Appendix 4**

### **Carer Information Sheet Health Professional Information Sheet**

## CARER INFORMATION SHEET

**Title:** Investigating the experiences of caregivers, caring for a relative with a long term indwelling urinary catheter

### **Invitation**

You are being invited to take part in a research study. Before you decide it is important for you to understand why this study is being carried out and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask us if there is anything that is not clear or if you would like more information.

### **What is the purpose of the study?**

A large number of people suffer from bladder problems. Many rely on long-term catheters for controlling their symptoms. Although we know something about what life is like for the person who has the urinary catheter, we do not have much information about the family members who are often involved in the care of the person with the catheter on a daily basis.

The aim of the research is to help inform the nurses and doctors about how they can support relatives who care for someone with a catheter, by asking carers how it affects their lives and what could be done to make the situation easier. Collecting information about their experiences will help to determine the impact caring for a catheter has on the daily life of carers. This will provide useful information when developing community services in the future.

### **Why have I been chosen for this study?**

You have been chosen because you are involved in caring for a relative who uses a long-term catheter.

**Do I have to take part?**

No. It is up to you to decide whether or not to take part. If you do not wish to participate in this study please destroy this sheet and we will not contact you again.

**What will happen to me if I decide to take part?**

If you do decide to take part, the research will involve a one-off interview, which can take place at home or your preferred location. The interview will last for a maximum of sixty minutes.

After the interview you will be asked whether you are willing to record your experiences of caring for a relative with a catheter in a diary to be kept for a three-day period. You are free to choose whether you want to complete a diary or not. You may wish to only take part in the interview.

**What are the possible benefits of taking part in this study?**

You will receive no direct benefit from taking part in this study. However, the information you give will provide nurses, and doctors a better understanding of the needs of those who look after people with urinary catheters. It is hoped that this will help in the development of information leaflets and improved support for relatives in the future.

**Will my taking part in this study be kept confidential?**

Yes. All the information collected during this study will be kept strictly confidential as required by the Data Protection Act (1998).

**What will happen to the results of the research?**

The final results of the study will be published in a scientific journal for nurses and will be presented at a conference for health professionals in this field.

**Who is organizing and supporting the research?**

This research has been supported by University of West of England and is part of a PhD qualification.

**Who has reviewed the study?**

The ethical aspects of the study have been reviewed by Southmead Research Ethics Committee, Bristol and University Faculty Ethics Committee plus the

research proposal has been reviewed by the Faculty Graduate Studies Committee and Supervisory team, University of West of England.

**What is if I wish to make a complaint?**

If you feel that something has gone wrong with the process of being involved in the study, please contact Professor [REDACTED] and let him know of your concerns by writing to him at this address: Professor [REDACTED] of Health and Life Sciences, University of the West of England, Glenside Campus, Blackberry Hill, Stapleton, Bristol, BS16 1DD.

**If you are interested in taking part in the research, please tell the district nurse or complete the attached form giving permission for the researcher to contact you.**

If using the form, please return it in the stamped addressed envelope provided.

**Thank you**

**Research Team Contact Details:**

**Chief Investigator:**

Dr [REDACTED]  
C/o School of Health and Social Care  
UWE, Glenside Campus  
Blackberry Hill, Bristol, BS16 1DD  
[REDACTED]

**Researcher:**

Sarah Fowler, research student  
email: [REDACTED]  
mobile – [REDACTED]

## HEALTH PROFESSIONAL INFORMATION SHEET

**Title:** Investigating the experiences of caregivers, caring for a relative with a long term indwelling urinary catheter

### **What is the purpose of the study?**

Many people with bladder problems rely on long term indwelling catheters for controlling their symptoms. Although we know something about what life is like for the person with the urinary catheter, we do not have much information about the family members who are often involved in the care of the person with the catheter on a daily basis.

The aim of the research is to help inform health professionals about how they can best support relatives who care for someone with an indwelling catheter by asking carers how it affects their lives and what could be done to make the situation easier. This will provide useful information when developing community services in the future.

### **We would be grateful if you can help recruit spousal/partner carers of patients with a long-term catheter.**

The research student will contact the district nursing team to arrange a brief appointment to provide information on the study and ask whether you would be willing to approach carers who may be interested in taking part. Potential participants can either tell the district nurse they are willing to take part or complete a reply slip (attached) and return it, in the stamped addressed envelope, direct to the researcher.

A carer is defined as someone who is involved with some aspect of the catheter care. This study is aimed at carers who live with the long-term catheter user such as a spouse or partner. Both the carer and catheter user need to be over eighteen years of age and care will be taken that all data collected will be anonymised.

### **What will the commitment be if the carer takes part?**

The researcher will arrange to visit the carer at home or their preferred location—for a one-off interview, which will last for a maximum of sixty minutes. As an option, after the interview the carer will be asked whether they are willing to record their experiences of caring for a catheter in a diary, for a three-day period. They are free to choose whether they wish to complete the diary or not.

### **What will happen to the results of the research?**

The final results of the study will be published in a scientific journal for nurses and will be presented at a national conference for health professionals in this field.

### **Who is organizing and supporting the research?**

This research has been supported by University of West of England, Bristol and forms part of a PhD qualification.

### **Who has reviewed the study?**

The ethical aspects of the study have been reviewed by Southmead Research Ethics Committee, Bristol and the University Faculty Ethics Committee plus the research proposal has been reviewed by the Faculty Graduate Studies Committee and Supervisory team, University of West of England

*Thank you very much for your help*

### **Research team contact details:**

#### **Chief Investigator:**

Dr [REDACTED]  
c/o School of Health and Social Care  
University of West of England  
Glenside Campus  
Blackberry Hill, Bristol  
BS16 1DD  
[REDACTED]

#### **Researcher:**

Sarah Fowler, Research Student  
email: [REDACTED]  
mobile: [REDACTED]

## **Appendix 5. Pen Portraits Part I**

Gordon, Jenny, Joyce, Judith, Mary and Beatrice

### **A pen portrait of Gordon**

Gordon aged 80 is the primary carer for his wife, Betty who was the same age. They live in the same house they purchased just after they were married, forty-four years ago and have three grown up children.

When Betty was seriously ill with a spinal abscess and in intensive care, Gordon thought he was going to lose her. Nine years later, this episode remained very vivid in his mind and had been life changing for both of them. After many months in hospital, she came home with a LTIC and a colostomy, unable to walk and limited ability to stand owing to spinal nerve damage.

Gordon who was made redundant when the cardboard mill where he worked closed, assumed responsibility for all of Betty's care. Although the focus of the interview was his experiences, Betty's presence and contributions demonstrated their interdependency. He played down what he did for her, particularly aspects of personal care, which he felt uneasy talking about. Betty in contrast talked very openly and frankly about how much he helped her, and how difficult she found the catheter which frequently leaked. They supported each other, psychologically and physically with help from the DNs, neighbours and friends.

## **A Pen Portrait of Jenny**

Jenny is 58 years old and cares for her husband Phil, aged 59, who has secondary progressive Multiple Sclerosis (MS). They live in a three bedroom, semi-detached house with what Jenny describes as 'disabled aids everywhere'. They have two grown up children – their son left home eighteen months ago as he said he couldn't cope with his father's MS; they rarely see him. Their daughter has Spina Bifida and is married, is pregnant with her first child. Jenny would like to be able to spend more time supporting her with the baby when the time comes but knows this will be difficult because of caring for Phil.

Phil is totally dependent on others for all his care needs. As his bladder became affected by MS and was failing to empty completely, initially he was using intermittent self catheterisation (ISC). However, increasing problems with urinary tract infections and his physical deterioration meant he was less able to manage ISC. Jenny worked shifts at the time and was unable to help him. Five years ago, the decision was made to change to a supra pubic LTIC. Jenny is not aware of having any information about a supra pubic, catheter but her understanding was that a LTIC would be less problematic.

Phil contracted MRSA whilst in hospital for the initial ISC insertion and after an extended inpatient hospital stay, Jenny made a formal complaint against the hospital for negligence as she was unhappy with the care he was receiving. The LTIC has continued to be problematic and Jenny takes an interest in everything catheter related, researching via the internet regarding its management.

Jenny's life is caring and she sees herself as the person others turn to for help. She cared for her mother who had kidney failure and died aged 52 when Jenny was 26 years old. Her father used to bring Jenny's mother round to her house every day for 6 months before she died so Jenny could care for her while her father went to work and she was home with her children. Jenny retired from work to care for Phil. She has support from a care agency who get Phil up each morning and put him to bed. They empty the catheter bag and change the day to night bag and vice versa.

Jenny has four hours respite a week when a carer comes to sit with Phil. She uses this time to do the ironing and jobs around the house. She loves the garden and spends any spare time there, saying it is her place of 'peace and tranquility'.



## **A Pen portrait of Joyce**

Joyce, sixty-seven, cares for her husband Jim, sixty-eight years old, who has Parkinson's disease (PD). He has a supra pubic catheter to manage daytime incontinence and nocturia which is Parkinson's related. Prior to the catheter thirteen months ago, they both had disturbed sleep with Jim getting up eight to ten times each night to urinate. She thought the catheter would be 'better for him' not to have to keep going to the toilet but also considered it was to give her a night's sleep.

Jim and Joyce moved to a smaller house and garden because they thought would be easier to manage - Jim was diagnosed with PD soon after they moved. The three bedroom, semi-detached house which they bought new eleven years ago, is on an estate in a suburb of the city. Joyce feels isolated where they live as most of the neighbours are out at work in the day and they only exchange pleasantries.

They have three grown up, married sons - their middle son and his wife visit three times a week. Her daughter in law works as a care worker supporting people with dementia. She brings a cooked meal once a fortnight.

Owing to his PD, Jim has difficulty communicating, which Joyce says can be 'a bit awkward'. Jim is unable to walk but can stand if supported for short periods and he uses a wheelchair. Although Jim is average weight, he is taller than Joan who is of slight build and owing to his physical limitations, she has to use all her physical strength to help him move. Many of the adaptations to make the house more accessible fail to meet their needs. The ramp to the house has a step up before the doorway, making it difficult to assist Jim in and out of the house so they rarely go out unless to the GPs as it can take Joyce up to twenty minutes to maneuver him into the car.

Joyce sees the catheter as a good thing because it enables her to have a better night's sleep. She is home all day with her husband and the daily routine involves cooking meals, - 'I've never liked cooking much' and housework - the house was immaculate. In the evening she reads and plays solitaire on the laptop in the kitchen/diner after he has gone to bed.

## **A Pen portrait of Judith**

Judith is 76 years old and lives with her husband Edward who is 90. They have been married for 52 years and Judith is the primary carer with support from a home care agency. Judith and Edward live in a large, three storey Georgian town house in an affluent part of the city. They have four grown up children – two married daughters who live away, one son lives just outside the city with his family, and their youngest, single, son lives nearby. Judith says that the decision to move was postponed over the years and now it is a case of having to stay where they are as moving would be too difficult in view of Edward's current health.

Edward has had an indwelling urethral catheter for the past nine months. He had been experiencing increasing difficulties not being able to urinate and dribbling incontinence due to an enlarged (benign) prostate. His worsening urinary symptoms impacted on both their lives as needed to get up at least four times a night and as he needed assistance, they both had disturbed sleep. Edward became virtually housebound because of his bladder symptoms which latterly included a urinary tract infection and this, combined with tiredness due to disturbed nights was the precursor for their GP suggesting catheterization as the most appropriate option.

Edward is tall and morbidly obese. He is unable to stand or weight bear which means he always needs hoisting and uses a wheelchair all the time. Co-morbidities include type II diabetes, renal disease and osteoarthritis. His progressive decline in general health contributes to increasing care requirements.

Agency carers visit to get him up in the morning and attend to his personal care and caring for the catheter. They do the weekly bag change and morning disconnection of the night bag and emptying. They return in the evening to put Edward to bed - including emptying his catheter, however Judith attaches the day bag to the night bag. They only pay for carers in the week so the weekends Judith puts Edward to bed, gets him up, with the support of her youngest son who lives locally.

Edward occasionally goes in to a nursing home for respite care and Judith goes away. He doesn't like her going away though she knows that when she returns she will have to 'pick up the bits' as his condition deteriorates when she is away.

## **A Pen Portrait of Mary**

Mary, 63 years old, cares for her 66-year-old husband, Paul who has Parkinson's Disease (PD). Paul requires total care as he is immobile, unable to move his head, has dysphagia (difficulty swallowing), dysphasia (difficulty with speech) and cognitive decline. He is doubly incontinent and has had a urethral catheter for sixteen months.

When he was last in hospital, to give her a break and also to re assess his needs as his health had deteriorated, he fell out of bed, pulling his catheter out. He developed a pressure sore which became infected with MRSA. Mary was so dissatisfied with his care, that she discharged him from hospital against the hospital's advice.

They live in the same three bed room, semi-detached house for all their 41-year married life. They have three grown up children – a married son and daughter who live nearby and their youngest, unmarried son moved abroad last year. The married son and his wife have a young family. Mary cared for her mum, who died four years ago after a long illness and her dad has since died. She doesn't want to be a burden to her children.

Mary devotes her life to caring for her Paul. She considers his PD was triggered by stress which followed her collapse while on holiday a few years ago. She was rushed to intensive care with a ruptured ulcer and had major surgery. Paul nursed her back to health but then became ill himself with PD.

Mary has support from neighbours and friends but their world has become smaller as they are able to do less and less because of his deteriorating health: *'my life's dead! It's the way I chose it, it's the way I chose it...'*

## **A Pen portrait of Beatrice**

Beatrice is 80 years old and cares for her husband Clifford, also aged 80, who had a stroke. He had a urethral catheter a year ago when incontinence became more problematic to manage. He also has renal disease. Clifford is immobile and has to be hoisted with a full body sling and he needs assistance with daily living activities such as feeding. Since his stroke, dementia noticeably impacts on his ability to hold a conversation. Beatrice and Clifford have two sons – one lives locally which pre-empted their move to the area and their other son and his family live abroad.

Their home is a modest three bedroom house in an out of town development. This is a big change from their previous five bedroom, detached house by the coast which Clifford had built, complete with large outdoor pool. Their antique furniture and large paintings appear out of place in the small rooms of their current home. Due to Clifford's health, Beatrice has found it difficult to make friends and socialize, her time taken up with caring. She misses her old home and feels isolated where they live now.

Carers from an agency support Beatrice with Clifford's care. They come to the house three times each day - to get Clifford up in the morning, return after lunch and their last visit is around 6 pm when they put Clifford to bed. They support with all personal care and empty the catheter bag however Beatrice changes the weekly catheter bag and attaches the night bag/day bag. The catheter is changed by the DN every six weeks and is prone to leaking.

The agency carers vary from day to day and currently Beatrice is challenging the decision to reduce the number of carers each visit from two to one. Her own health is currently good although she had a recent cancer scare. Rheumatoid arthritis in her hands can affect her ability to manage the catheter. Beatrice is present when the carers attend her husband and there are aspects of care that she does - such as putting cream on his bottom to protect skin, before the incontinence pad is put on.

Clifford goes to a day centre once a week as part of respite for Beatrice. During this time she describes enjoying relaxing on the sofa with a book and a cup of coffee. It is a time without having to constantly watch the clock ready for the next visit from the carers.

## Appendix 6

### Interview Guide/Prompts

#### Background

- Can you describe your home?
- Can you tell me how long have you been married/together?
- Can you tell me about the catheter - why they had one?
- What were things like before?

#### Level of involvement with catheter care

- Can you tell me about care and the catheter?

#### If the carer changes the catheter -

- Can you tell me more about this?

#### About the decision-making

- Can you tell me about the decision when they first had the catheter?

#### Psychological/emotional aspect of caring

- How do you feel about the catheter?
- Can you tell me about when you first had to deal with the catheter?

#### Support with caring for the catheter

- What support/involvement do you have caring for your (husband/wife)?
- What advice would have been helpful in the early days?

#### Relationships/Socialising

- Has the catheter affected your relationship? Can you tell me more about this?
- Can you tell me about daily life /going out - has it been affected?
- Has your partner having a catheter affected your family/friends in any way?

#### Night time -

- Can you tell me about night-time and the catheter?

#### General -

- Overall, how much does the catheter interfere with your everyday life?
- Do you have time for yourself? Can you tell me more about this...?

## **Appendix 7**

### **Example of entry in reflective diary**

#### Reflective diary

I am in the process of applying for ethics and talked to department informally about use of video with carers. They dissuaded me as said it would make it more challenging to gain ethical approval.

The reason for the contemplating this was visiting a man at home in my role as continence advisor, in the early days of my PhD. He had been discharged home from hospital following a stroke and he had a LTIC. I met him and his wife at their house and she was trying to manage the LTIC.

Their house was immaculate, and he was sat in an enormous chair supported by pillows, immobile and had lost his speech. The house, their marital home for 50 years, had cream carpet, not a speck of dust and yet in to this environment was incontinence which was managed by a catheter. My knowledge that can catheters leak and how impractical the house was for her manage his continence (he was doubly incontinent) made me think of what a stressful situation this was. I was at the house to complete a questionnaire on his behalf to validate a tool to measure QoL. On leaving the house, she talked to me in the hall to the front door, in hushed tones, about how difficult she found caring and the catheter was not easy for her to manage.

The video or even a photograph would have contextualized the situation in this visual age, but it would have been very intrusive - and posed the question - what would the video add to a carer's interview? probably not a lot... It made me question how voyeuristic I would feel. It would have aided 'observation' and anyone who was looking at the analysis but carers might have declined being videoed. The decision in the end was to ask people to describe their home as first question at the beginning of the interview. Their description combined with my observations goes some way to painting a picture of or illustrate the environment and the circumstances

## Appendix 8

**Example of a theme across cases.** This example is from Part I relating to the LTIC decision

<b>Jenny and Phil (LTIC user)</b>	<i>'no, I think it was just decided by the hospital'</i> pp.2 but his bladder not emptying
<b>Beatrice and Clifford (LTIC user)</b>	<i>'...in the beginning, um I have to say in my impression of the district nurse was 'oh we don't want to do that...'</i> pp.3 visit to GP and then DNs called to say would come and fit – she was relieved.
<b>Judith and Edward (LTIC user)</b>	GP made the decision - <i>'in the end the doctor said'</i> pp.1– she was exhausted and he constantly needed the toilet
<b>Mary and Paul (LTIC user)</b>	Hospital doctor said <i>'he needs a catheter really'</i> pp.2 because of wet beds (she sleeps with him).
<b>Joyce and Jim (LTIC user)</b>	Hospital Consultant suggested – to give Joyce a nights sleep. His Parkinson's deteriorating – <i>'...thought it would be better for him because he wouldn't have to keep, you know, keep going to the toilet and me taking him to the toilet all the time'</i> pp.5
<b>Gordon and Betty (LTIC user)</b>	She was in hospital – very poorly and had LTIC which was never removed <i>'She had it right from the start'</i> pp.5

## Appendix 9

### Example of exploratory comments

Dyad interview with Mavis (09) (caring for Peter)

Descriptive comments – normal text

*Linguistic comments – italic*

Conceptual comments - underlined

Emergent Themes	Original Transcript	Exploratory comments
<p><b>Loss of togetherness</b> <b>Sleeping apart</b></p> <p><b>Excluded from areas of the house</b> – due to disability</p>	<p><b>S</b> First of all, can I ask you to describe the house, your home?</p> <p><b>09</b> <b>I live</b> in what’s called a chalet bungalow, that means that the main bedroom where <b>Peter sleeps...and I sleep, some of the time, is downstairs</b>, the bathroom’s down stairs,</p> <p><b>and all the living areas that he accesses is downstairs.</b></p> <p><b>Upstairs we’ve got two other rooms and another loo.</b></p>	<p><i>‘I live’ as opposed to ‘we’</i> live in a chalet bungalow – sleep downstairs.</p> <p>They sleep separately – she has moved (some of the time) <u>feeling awkward saying that she doesn’t sleep with him all the time – reference marital and relevance - she later talks about in the interview and their loss of physical relationship/intimacy</u></p> <p>Peter cannot access rooms upstairs – <u>when 09 sleeps away from him, she sleeps in a part of the house that he cannot get to</u></p>
<p><b>Environment Excluded from area downstairs</b></p> <p><b>Changes to the environment</b> <b>Financial implications of</b></p>	<p><b>S</b> And you’ve made quite a few things changed it looks like?</p> <p><b>09</b> We’ve had, yes, we’ve had, yes, <b>the local authority has been in and widened the doors</b>, so all the doors are now widened, wide enough to get a wheelchair in and out, <b>especially the front door, the local authority ramped, put a ramp in to the front door</b> and</p> <p>um...<b>we ourselves, um some years ago, had the bath taken out and a wet room made...so its...the house is mostly</b></p>	<p>Had assessment by local authority for financial support to make alterations to the house – to make house more accessible – ramps, widening door etc.</p> <p>Self-financed alterations to structure of the house – wet room</p> <p>Still limited access to one passage in the house – can’t get wheelchair down</p>



<p><b>changes/ability to get support</b></p>	<p><b>accessible for Peter, except there is one part where the passage is quite narrow, but its wide enough, it can't be widened, it's impossible to widen it, it does take a wheelchair. It doesn't take the electric wheelchair which is 18 inches wide, is a little too wide</b> but it does go down there but scrapes a bit</p>	<p>Scrapes to wall – <u>damage caused by wheelchair – tidy house, evidence of recent decoration – financial implications/time/trying to keep home nice</u></p>
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## Appendix 10

**Part I** Super-ordinate themes and sub-ordinate themes in relation to objectives

<b>Part I Super-ordinate Themes</b>	<b>Objective: Understanding carer experiences</b>	<b>Objective: How the LTIC impact on carer's daily life and their experiences of support</b>	
Theme 1  <b>The phenomenology of the environment</b>	1b Adaptions but still difficulties	1c Relocating and loneliness	1a Decision to downsize
Theme 2  <b>The LTIC as a 'mixed blessing'</b>	2a Lead up to the LTIC and decision  2c Managing LTIC problems <i>- doing the best they can</i>	2b Positives about the LTIC  2c Managing LTIC problems <i>- doing the best they can</i>	
Theme 3  <b>The caring experience - dependency and their competing needs</b>	3a Making decisions for both <i>- catheter changes</i>  3c Competing needs <i>- time</i> <i>- respite</i>  3d What will be will be	3a Making decisions for both <i>- being fussy and feisty</i>  3c Competing needs <i>- adjusting</i> <i>- impact on carer's health</i>	3b Impact of their changing relationship <i>- sense of loss</i> <i>- duty and marriage</i> <i>- physical relationship</i> <i>- living in silent world</i>
Theme 4  <b>Experience of support</b>	4a & 4b Positive and negative experience	4a & 4b Positive and negative support  4c impact on the family	

## Appendix 11

<b>Part II</b> Dyad super-ordinate themes/sub-ordinate themes in relation to objectives
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Super-ordinate Themes	Objective: - Understanding experiences	Objective: Impact on their daily life and experiences of support	Further Objective Part II: LTIC in context of their relationship	Dyad interview
Before the LTIC and making the decision	1b <i>'He just said, I decided'</i> 1a The embarrassment of 'water problems'			Hilary & Mike
<b>THE LTIC DECISION</b>	1b <i>'They didn't tell him it was for the rest of his life'</i> 1a <i>'I didn't decide, it's a bone of contention'</i>			Mavis & Peter
<i>'It's a godsend – and it has it's problems'</i>	1a The LTIC decision 1b <i>'I mind all the water infections'</i>			Brian & Margaret
Adjusting	2a Adjusting - over time	2b The LTIC always on your mind	2c Concern for the future	Hilary & Mike
<b>ADJUSTING</b> and trade-off	2a Positives about the LTIC 2b <i>'I've had to fight for everything'</i>		3b Intimate relationship 3e Maintaining their life-style	Mavis & Peter
Adjusting to the LTIC  Adjusting/Control		3a Regret loss and adjustment 3d Looking out for yourself 3c About not being embarrassed 2a Involvement with the LTIC 2b LTC - the practical solution 2c Self-reliance and maintaining control		Brian & Margaret
Adjusting/Support		3a Support from DN's 3b <i>'We've got a good family'</i> 3c <i>'I'm having....to do everything for him'</i>		Hilary & Mike
<b>IMPACT ON RELATIONSHIP</b>			4a Physical relationship 4b <i>'You've got to take the good with the bad'</i>	Hilary & Mike
Impact on their relationship		3a Mavis health 3e Support	3b Loss of physical intimacy	

			3c A part of the house that is 'out of bounds' 3d loss	Mavis & Peter
Relationship/the Future			4a <i>'We were looking forward to having a great life'</i>	Mavis & Peter
Relationship/future <i>'So I tell him - do not die!'</i>			4a Uncertain future	Brian & Margaret

## Appendix 12

**Article:** Fowler, S., Godfrey, H., Fader, M., Timoney, A.G., Long, A. (2014). Living with a long-term indwelling urinary catheter: Catheter users' experience. *Journal of Wound, Ostomy and Continence Nursing*, 41: pp.597-603

### **Living with a Long-term, Indwelling Urinary Catheter - Catheter Users' Experience**

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## **ABSTRACT**

**Purpose:** The purpose of this study was to explore the experiences of long-term catheter users drawn from a heterogeneous population.

**Subjects and Settings:** The sample comprised 27 community-dwelling long-term catheter users. Participants included 14 females (4 urethral, 10 suprapubic catheter users) and 13 male users (6 urethral, 7 suprapubic) between 22 and 96 years of age. Interviews were conducted in participants' homes except 1, which took place in a urology outpatient department based on the participant's preference.

**Methods:** A qualitative research design using an interpretive description approach was used for data collection and analysis. All interviews were electronically recorded and transcribed verbatim. Interpretive description involved familiarization with the data, thematic analysis, and the development of an interpretive account.

**Results:** The impact of the catheter and daily living adjustments that catheter users made are captured within 8 themes: (1) making adjustments; (2) managing away from home; (3) night time adjustment; (4) catheter problems; (5) social interaction; (6) support from others; (7) unpredictability; and (8) intimacy and body image.

**Conclusions:** Catheter users' experiences of living with a catheter are shaped by a variety of interrelated factors. Some participants were determined to overcome catheter-related problems and develop self-reliance whilst others adopted a more resigned approach to living with a catheter. Having a catheter enabled some participants to experience greater freedom whilst others led more restricted lives as a consequence of catheterization.

**Key words:** adults, indwelling urinary catheter, adults, qualitative research, self-management, suprapubic catheter, urethral catheterization.

## **Introduction**

Long-term indwelling catheters (LTCs) are sometimes used when all other options have been tried or are deemed unsuitable for managing urinary retention and intractable incontinence (1,2,3). Prolonged urinary catheterization in primary and community care settings is most prevalent in older people (4). However, the population of community dwelling long-term catheter users includes younger people with spinal cord injuries and other neurological disorders such as multiple sclerosis.

While many long term users value the indwelling catheter's ability to prevent urinary leakage (5,6) and improve independence (7), the research literature emphasizes catheters as a 'final alternative' (6) for bladder management and advocate its avoidance where possible due to the high risk of complications (8,4,9).

Few studies have explored the personal experiences of LTC users and most focus on older people (10-12). A study of long-term catheter users aged over 65 years revealed that older people adapt to living with a catheter as a consequence of either being 'at ease' or 'uneasy' with the catheter (10) while other studies report that catheter users appear to adjust following a period of transition (11,12). Studies also suggest that many people are inadequately prepared for life with an indwelling catheter (6) and some people were unsure why this method of management had been selected (10).

Early negative experience of the catheter influences acceptance, with positive adjustment requiring comprehensive preparation and support from healthcare professionals (11, 6, 4). However, there is a lack of contemporary knowledge about the experiences of the current catheter population and their priorities concerning both catheter care and the devices and products for long-term use. The aim of this study was to develop an interpretive description of the experiences and priorities of long-term catheter users drawn from a heterogeneous population.

## **Methods**

This qualitative study explored the experiences of adults living with a long-term catheter; it employed an interpretive description approach for data collection and analysis (13,14). This grounded approach aims to articulate themes emerging in relation to clinical phenomena and answer questions of clinical relevance (14).

Twenty-seven catheter users were recruited using purposive sampling strategies. The profile of the sample reflected the heterogeneous population of long-term catheter users and included males and females ranging in age from 22 and 96 years (Table 1). The sample included both urethral and suprapubic catheter users. Participants had varying duration of catheter usage and a range of self-reported reasons for long-term catheterization (Table 2). Inclusion criteria included adults using an indwelling catheter (suprapubic or urethral) for more 3 months as a long-term bladder management strategy.

In-depth interviews were designed to capture the experiences of long-term catheter users. Semi-structured face-to-face interviews took place between January 2007 and April 2008. Open-ended questions were used to elicit patients' views and perceptions of life with an indwelling catheter. Each interview began with a brief overview of the purpose of the study, followed by an open-ended question 'What is life like with your catheter?' (11). Study procedures were reviewed and ethical approval was granted by the Research Ethics Committee (reference number 06/Q2002/23); permissions were obtained from 2 community trusts and 1 hospital-based trust.

### Data Analysis

Interviews were electronically recorded and transcribed verbatim. In keeping with the interpretive description approach, data collection and analysis was an iterative process (14). This approach to interpretive description enables the researcher to become familiar with the data, synthesize meanings, theorize relationships and make interpretations to generate findings (15). During



analysis, codes were constantly compared and refined according to new data and thematic patterns which characterized the experience of long-term catheterization were developed (14). An iterative process of developing, comparing and refining generated a number of themes and sub-themes (Table 3). Interviews with catheter users continued until data saturation was reached and no new themes or insights were obtained (15).

### Rigor

Rigor or trustworthiness in qualitative research is established when the reader can follow the steps taken by the researcher and is aware of the influences and actions of the researcher (16). Using examples to illustrate findings supports the authenticity of the data analysis. The credibility of the findings was also enhanced by an experienced researcher who independently confirmed the analysis and interpretation of two interview transcripts.

### **Results**

The purposive sample of twenty-seven long term catheter users (14 women and 13 men) were all white British citizens. All were aged between 22 to 96 years and had used an indwelling catheter for a varying period (6 months to 40 years). The reasons for long-term catheterization varied; 13 participants had neurological diseases or disorders including multiple sclerosis, cerebrovascular accident, encephalitis, arachnoiditis and spinal cord injury. Two had cerebral palsy and 1 had spina bifida. Bladder obstruction was the reason for catheterization in 5 participants, including one with an enlarged prostate (his dementia precluded him from surgery), 3 experienced retention following surgery, and 1 following removal of a bladder tumor. The remaining 6 participants reported intractable incontinence, 2 post prostatectomy, 2 post extensive gynecological surgery, and 2 participants who were uncertain of the cause (Table 2). The participants reflect the heterogeneous group of catheter users (22).

A number of themes and sub themes were identified; they demonstrated the social impact of long-term indwelling catheterization and daily living

adjustments as a result of the physiological impact and the emotional adjustment (Table 3). Major themes were: making adjustments, managing away from home, night time adjustment, catheter problems, social interaction, unpredictability, support from others, and intimacy and body image.

### *Making Adjustments*

Adjusting and accepting the catheter were influenced by the reason for catheterisation and whether the individual had been involved in the decision to have a catheter, how long they had used it and whether they were currently experiencing difficulties. As one participant noted, “...for the first few years, you’ve got to learn how to deal with it. But now I’m so used to it, it’s a matter of life now”. The term ‘acceptance’ was more likely to be used if they had had the catheter for some time. Several participants talked about resigning themselves to it. One stated, “I’ve made a life with the catheter... I know I’ve got to accept it; I’ve got no way out.”

Older participants were more likely to resign themselves to changes as they aged with the device. They appeared to adopt a pragmatic approach to aspects of living with the catheter and were more likely to adhere to a routine and appeared more comfortable with familiar destinations.

Those who were able to adopt a problem solving-approach towards the catheter difficulties, often with the support of a family member, appeared to find adjustment easier. Participants desired information on catheter management to help understand the catheter.

The 6 participants with spinal cord injury (SCI) were a younger cohort within the study sample and comprised 3 women (aged 22- 60 years) and 3 men (aged 42- 57 years). They appeared more self-reliant and had knowledge of the catheter reflected in evidence of a problem-solving approach to catheter management. They were also provided with education and support at a spinal injury center that

included practical advice such as placing the catheter bag in a bucket to prevent leaking at night and ways to manage bag emptying when away from home.

Negative statements about long-term indwelling catheterization were linked to resentment of having to use the device, especially if the catheter was problematic. Sentiments expressed were sometimes accompanied by awareness that catheterization was the only option left, which created concerns. For example, one woman experienced intractable incontinence following several unsuccessful gynecological surgical procedures; she noted, *“So there are pros and cons, the cons being that one resents having to use artificial means to go to the loo you know, but that’s my lot.”* People recounted difficulty adjusting emotionally and described a sense of loss of a life they had before; one respondent stated, *“I would give anything to be without a catheter, but I know I never will ...You just have to accept it.”*

Participants who had previously experienced incontinence frequently described the benefits of catheterization as reducing anxiety about incontinence. The stigma of incontinence prompted one man to comment that the catheter was *“ideal”*, despite experiencing frequent catheter blockage requiring changes every 4 weeks. Another interviewee with a catheter valve expressed a high level of satisfaction, *“The only thing I don’t do now which I used to do is swimming... but otherwise I live a pretty normal life. I think I’ve been very lucky.”*

The extra time required to carry out daily tasks was frequently reported. This included making sure the catheter bag was consistently emptied prior to leaving the house and taking catheter supplies. Time demands also impacted respondents’ ability to act spontaneously; one participant stated, *“...it’s a performance and time consuming...there’s so much paraphernalia and luggage you know...’ if anybody says come and have coffee or something, can you manage 10 am? I say well if I get up at 6 I probably can!”* Negative comments were related to

the catheter bag, and participants described how they tried to conceal its presence.

Adaptations to existing clothing were rarely used; people were more likely to make judicious choices of clothing to help disguise the bag's presence such as trousers with a wider leg. One respondent shared, *"You have to sort of work it out. I mean you can't wear tights, I have to wear stockings to cover the bag up you know. I like to keep it covered. I think skirts are a better idea with a catheter..."*.

### *Managing Away From Home*

Travel was often dependent on either being accompanied by a family carer. Participants often stated a preference for returning to destinations previously visited. As people got older or their health deteriorated, the desire to travel abroad or go to unfamiliar places diminished or ceased altogether. Others expressed a determination not to permit the catheter to restrict their activities; this attitude was mainly expressed by younger respondents. As one respondent who travelled with a paid care provider stated, *"Well, it's not going to stop me going [abroad] but...partly because I'm so used to the incontinence problem..."*

A weekly visit to familiar destinations such as the supermarket and coffee shop were frequently cited as the only time when older participants went out other than to attend a physician or hospital appointment. Participants noted that supermarket toilets are preferred because they tend to be more prevalent than public, accessible toilets and are often cleaner. and with disabled facilities were preferential. In the absence of toilets, particularly for those in a wheelchair, containers were used in cars and curb side drains were used to empty the urine collect bag. Women only rarely used this strategy; they were more likely to restrict fluid intake. Emptying the catheter bag away from home was generally avoided if possible but having support related to levels of independence, providing the ability to manage bag emptying away from home. One respondent commented, *"You've just got to remember where the toilets are ...if you've not got*

*anything to drain into – try and find somewhere private to drain if you haven't got the car."*

For ambulatory men, the need to access their leg bag meant using the individual toilet cubicle, in public accessible toilets. One male respondent stated, "*...I'd never use the urinal because I have to pull my trousers down, so I've always got to go into a WC...(individual toilet cubicle)*'

### *Nighttime Adjustment*

Participants talked about interrupted sleep due to concerns or problems with catheter drainage. For some, the positioning of the drainage bag affected sleep; however comorbid conditions were perceived as more likely to affect sleeping position, such as needing to sit up to aid breathing. In contrast, others reported an improved sleep pattern as they no longer had to get up at night to urinate. Participants expressed awareness that position in bed could affect catheter drainage, and people frequently monitored drainage in an attempt to understand the cause of the fluctuations. One gentleman had a routine to deal with such an eventuality, "*I wake up, I think 'God my bladder feels a bit distended' and there's nothing in the bag so I get out and sit on the edge of the bed ...and gently just squeeze the tube so I can feel the urine running through."*

Participants with an indwelling catheter and spinal cord injury stated they had received instruction on the importance of drinking large volumes to prevent catheter blockage from medical staff at a spinal cord injury facility and adopted a good fluid intake regime when discharged. Most placed the overnight drainage bag in a bucket rather than use a stand because of a past experience with a leaking or ruptured bag.

Decreased mobility created concern about having to empty a heavy bag and 1 female respondent opted to empty the bag in to a bucket during the night. She

stated, “...it’s awkward for me to walk and hold the bag, it’s heavy...if I drop it, it would be extremely painful and I could stagger and slip.”

A number of participants talked about feeling guilty contacting the ‘out of hours’ nurses and felt it more stressful if the nurse was new to them or not familiar with their catheter. The pain of blockage and poor past experience of non-routine catheter changes contributed to the distress associated with these experiences. In contrast a few of those interviewed recounted always having a catheter change at night due to blockage and were more familiar with the ‘out of hours’ nurses than the day team.

All but one participant had experienced 1 or more episodes of leakage primarily from defective bags, leading to damage to bedding, carpets, or furnishings. They reported routinely using mattress protectors and bath towels as a way to protect these. These items were preferred because they were readily available and washable, offered security and comfort, and were considered absorbent if needed. They were a visibly ‘normal’ household object and not an incontinence sheet.

### *Catheter Problems*

A range of catheter problems were reported such as catheter associated urinary tract infection (CAUTI) and their effects could be profound. As one participant noted, “... your whole life obviously changes ... I’ve lost my appetite and I’ve lost my enthusiasm to go out...” Nevertheless, only half of participants mentioned the impact of CAUTIs independently, before the prompt question. Changes in urine, including odor, associated with catheter associated with CAUTIs were mentioned by interviewees who recognized this sign as a possible precursor to infection. Several participants referred to some of their catheter problems, such as infection, as time-limited episodes that occurred in the past and they put them behind them.

Respondents linked indwelling catheters to physical discomfort, especially for those more recently catheterized. Women particularly, found the urethral catheter uncomfortable because they felt they were sat on it for much of the day. This was cited as one of the reasons to change to a suprapubic catheter.

Suprapubic catheter users reported 'soreness' at the suprapubic site, and some experienced urethral leakage which they found distressing. In some cases, urethral leakage necessitated wearing a pad. Participants reported experiencing pain when the catheter blocked. Participants described the leakage particularly from the supra pubic site as if it were a wound.

The catheter bag and fixation straps or devices required a period of adjustment. Participants also noted these straps or devices could cause irritation or skin damage. One respondent stated, "*I do wear long pants and that's so the catheter [bag] isn't on my leg it's on the pants.*" Participants preferred securing straps rather than the sleeve to support the bag due to dexterity and mobility limitations placing it in position, sometimes only using 1 strap or nothing at all, particularly while they were at home. Several participants opted to tuck the catheter bag in the top of their sock or up into the elasticated ankle of leisure trousers. There was generally poor awareness of potential damage to the bladder neck through having an unsecured bag, and catheter securement devices were rarely used.

### *Social Interaction*

People who reported difficulty adjusting to a long-term indwelling urinary catheter frequently described themselves as socially isolated and were more likely to have poor support systems and multiple comorbid conditions. One woman, living by herself, described having a catheter as the most distressing aspect of her daily life, "*Well for one thing...I don't sort of...like going places, because, to be honest with you I feel unclean...*"

In contrast, an indwelling urinary catheter offered some participants freedom from embarrassing incontinence episodes and increased their ability to socialize. Family events, such as a meal out, were viewed as particularly important and frequently used as a measure of quality of life. Those who had previously experienced incontinence described an initial positive period of '*greater freedom*' when they first had a catheter inserted. The majority of those interviewed had support, often from family, to realize this regained sense of freedom.

### *Support from Others*

Physical and psychological support, particularly from spouses, was important to all participants. For those with no immediate family living nearby, the district nurse played a pivotal role helping users manage and adjust to life with their catheter. Loss of that support such as the death of a spouse had a profound effect on life with a catheter. One respondent noted, "*... the last few years I think – since my husband died..., it's sort of been worse...because he was so good... I just feel that I can't sort of go places.....*"

Confiding in others about having an indwelling catheter was often limited to immediate family. Participants reported that when close friends were told, they were supportive and frequently used humor as a strategy to relieve potential embarrassment.

### *Unpredictability*

The unpredictability of drainage made it difficult for participants to plan ahead, particularly when away from home. One participant noted, "*...I'm sat in a meeting and I'm perfectly fine and the next minute I am bursting and have to open the valve before I get to the loo, otherwise I'd bypass [leak around the catheter].*"

Monitoring behavior involved patting the bag surreptitiously through clothing, all but 1 of those interviewed adopted this behavior at some point.



Unaccountable fluctuations in catheter drainage gave rise to anxieties about the bag overflowing and the need to empty it, particularly if in unfamiliar surroundings. One respondent observed, *“We have a coffee morning at church, and they say, ‘oh that left leg is swollen’ and I could crawl under the table because I realize that it’s because my bag is filling up...”*

For some participants the need to monitor the drainage bag impacted their ability to socialize with confidence. Participants talked of being prepared *‘just in case’* and felt more confident if they had a car to get home or were near home. Support from others helped to ease anxieties and helped with practicalities of management.

### *Intimacy and Body Image*

A small number of male participants spoke about the impact of the catheter on physical relationships and intimacy: *“It’s a huge driving force in mankind. Far greater than a lot of people like to admit...”* When prompted, most participants were of the opinion that issues related to intimacy and body image should be discussed more openly, ideally prior to initial catheterisation or soon afterwards depending on the circumstances. One participant noted that *“... you are getting to know somebody then the truth can come out in time and it could be, you know, hopefully dealt with.”* Younger women stated the catheter made them feel differently about their body image and constituted a visual reminder of incontinence.

## **Discussion**

Findings from this study reveal much about catheter users’ experiences living with a long-term indwelling catheter and the difficulties they encounter. Eight themes were identified to encapsulate these experiences including making adjustments, managing away from home, night time adjustment, catheter problems, social interaction, unpredictability, support from others, and intimacy and body image.

Recognizing the difficulties but being resigned to having an indwelling catheter, echoed findings in other studies that reported that although there were negative aspects to having a LTC, participants were philosophical about the device and acknowledged its value (11,10). The majority of participants reported as many positive as negatives comments about having a catheter. Participants revealed differences in their personal experiences of adjusting to long-term catheterization. This study highlights the importance of practical and psychological support from family, particularly from spouses. It also endorsed findings from previous studies, which identified the importance of support from healthcare professionals who helped catheter users adapt to and manage the catheter (11, 6,10). Those participants who found it more difficult to cope, or were having difficulty adjusting psychologically to life with a catheter, indicated these difficulties affected their social confidence.

The varied experiences of LTC users were complex and many of the themes to emerge were interlinked. The physical requirements of catheterization necessitated careful logistical planning and loss of spontaneity, which impacted on daily life. Participants' priorities centered around attempts to maintain normalcy in daily life and avoid the stigma associated with being different (17). The complexity of adjustment was influenced by external situations such as loss of support, for example, the death of a spouse. Study findings suggest that adjustment was not a linear progression towards acceptance; instead, it is better described as fluctuating depending on circumstances. This observation had resonance with what Godfrey (11) identified as 'a wavering acceptance' of the catheter and Sweeney (6) described as a 'continuum of adjustment'.

The process of adjustment was also influenced by how much control participants considered they had over the catheter, manifested as predictability of the drainage and whether they could determine how the catheter would behave.

Participants revealed their efforts to counteract the catheter's unpredictability of drainage and this involved frequent monitoring of the catheter bag; they described frequently patting the bag to avoid filling to the point it became visible underneath clothing. This was defined as significant because it reflected a part of the body that had previously functioned 'silently' (18,19) but now demanded attention and became the object of healthcare interventions (20).

Catheter-related complications, such as CAUTIs, catheter blockage or bypassing exerted dramatic effects on participants' lives. However, these complications were perceived as transient problems, which participants often optimistically compartmentalized. Persons with LTCs frequently became adept at recognizing and managing CAUTIs with experience and the passing of years. In contrast, unpredictability of drainage, bag emptying, and the visibility of the bag were ongoing issues, irrespective of the length of time with the catheter.

Catheter users in this study employed a variety of strategies to manage daily life including not drinking when out, with the intended result of not needing to empty the bag so frequently, if at all. Alternately, they described returning to their car to empty the bag in to a bottle or via a curb side drain.

Participants appeared more accepting of the catheter if they were involved in the decision to have a catheter inserted if urinary incontinence previously affected their daily life. With the exception of those with catheters following a spinal cord injury, participants recounted being aware that their bladder was not functioning normally prior to the initial catheterization. Several participants used the term 'last resort' when describing the decision to have a LTC. This phrase has been highlighted in previous studies and has historically been used by healthcare providers when describing indications for a long-term catheter (4). For participants in this study, describing catheterization as a last resort created concern and raised anxiety about what would happen, particularly if they were having difficulties with the indwelling catheter.

The impact of the catheter on physical relationships and intimacy was highlighted by participants; other studies have also identified these issues as important for catheter users (6, 11). Kralik and colleagues (12) noted that having a catheter initially also affected physical closeness with extended family such as grandchildren. The present study highlighted the importance of discussing intimacy and physical relationships prior to people having an indwelling catheter inserted or as soon as possible afterward.

The majority of interviewees with a spinal cord injury tended to be younger and a previously healthy and active cohort who underwent catheterization unexpectedly and suddenly as a consequence of their injury. Following a period of adjustment, this group predominantly displayed high levels of determination to overcome problems and develop self-reliance routines. In contrast, participants who experienced a gradual decline through ill-health, loss of family members or friends and an increasingly narrowing social sphere, adopted a more resigned approach to daily life. Such differences relating to declining health have previously been reported (21).

Among respondents with spinal cord injuries, knowledge of the catheter, and a 'developed embodied knowledge of self-management' was generally more apparent than with other participants (22,23). Greater knowledge about managing an indwelling catheter was assisted by the care and teaching they received prior to discharge from a spinal cord injury center. In contrast, the majority of participants reported limited knowledge of catheter management and even less awareness of the variety of products available. Such practice is contrary to the evidence recommending support and information (10,11) and limits the ability for self-management (24). Persons with LTCs would benefit ongoing education and support from healthcare professionals, especially as circumstances change and people age.

The theme of night time management has not previously been identified. Participants independently adopted similar strategies when adjusting to sleeping with a catheter. The frequent use of a bath towel to protect the bed was reported in addition to experience of damage to bedding and the bed from leakage. The study highlighted the need for information to be made available regarding nighttime management with explanation of the effect of posture on drainage, with potential to cause problems for some people, and strategies to manage catheter blockage. This information was particularly pertinent for the small group identified in this study as consistently having the catheter changed at night due to blockage. Specialist support and information were provided by persons who were cared for at the spinal cord injury center.

### **Study Limitations**

Many of those interviewed had rarely, if ever, talked about their experiences, particularly with a stranger and this might have affected how much they chose to divulge. It is possible that participants were less open about their care experiences as they were aware that the interviewer was a research nurse.

### **Conclusion**

Participants reported various experiences of adjusting to long-term catheterization and their adjustment appeared to be fluctuating rather than a linear progression towards acceptance. The process of adjustment was influenced by how much control participants considered they had over the catheter, and the support they had from spouses, family and healthcare professionals. Catheter users not only developed various strategies to manage daily living but also at nighttime to accommodate sleeping with a catheter. Study findings indicate that catheter users would value education and practical information about managing their catheters both day and night. Results also suggest that discussion about intimacy and physical relationships should occur prior to having a catheter or as soon as possible thereafter. This study identified

the need for support to be ongoing with the inclusion of both practical and psychological support to help negate of the impact of the catheter.

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**Table 1. Participants**

<b>Sex</b>	<b>Age range (years)</b>	<b>Urethral Catheter</b>	<b>Supra Pubic Catheter</b>
Female	22 - 86	4	10
Male	42 - 96	6	7

**Table 2. Reasons for catheterization**

<b>Reason</b>	<b>Number of participants</b>
Neurological disease	7
Neurological damage	6
Birth anomaly	3
Bladder outlet obstruction	5
Intractable incontinence	6



**Table 3. Themes**

Major Theme	Subthemes
Making adjustments	<ul style="list-style-type: none"><li>- Resignation over time</li><li>- Allowing extra time</li><li>- Normalization</li><li>- Clothing and concealment</li><li>- Managing expectation</li></ul>
Managing away from home	<ul style="list-style-type: none"><li>- Travel/leaving the house</li><li>- Draining the bag</li><li>- Restricting drinking</li></ul>
Unpredictability	<ul style="list-style-type: none"><li>- Bag monitoring</li><li>- Anxiety over catheter performance and reliability</li></ul>
Night time adjustment	<ul style="list-style-type: none"><li>- Effect on sleeping/position in bed</li><li>- Managing the bag</li><li>- Protecting the bed</li><li>- Out of hours service</li></ul>
Catheter problems	<ul style="list-style-type: none"><li>- Soreness, discomfort and pain</li><li>- Leakage, infection, blockage</li><li>- Securing the bag</li></ul>
Social interaction	<ul style="list-style-type: none"><li>- Isolation</li><li>- Greater freedom</li></ul>
Support from others	<ul style="list-style-type: none"><li>- Spousal support</li></ul>
Intimacy and body image	<ul style="list-style-type: none"><li>- Physical relationships</li><li>- Body image</li></ul>