

An exploration of the impact of support
services in identifying and meeting the needs
of older male caregivers caring for a
chronically ill spouse/partner.

by

Anne Fee

MSc Social Research Skills, Ulster University, 2008

BSc (Hons), Psychology, Open University, 2002

Research conducted within the
Faculty of Life and Health Sciences
School of Nursing
Ulster University

Thesis submitted for the degree of

DOCTOR OF PHILOSOPHY

June 2020

I confirm that the word count for this thesis is less than 40,000 words

For my Mum

Mary Cummings

1931-2019

May the roads rise up to meet you,
May the wind be always at your back,
May the sun shine warm upon your face,
May the rains fall soft upon fields
And until we meet again
May God hold you in the palm of his hand.

TABLE OF CONTENTS

ACKNOWLEDGEMENTS.....	VIII
ABSTRACT	IX
ABBREVIATIONS	X
DECLARATION.....	XI
CHAPTER ONE: INTRODUCTION	1
1.1 Introduction.....	1
1.2 Researcher’s perspective	1
1.3 Study Context	3
1.4 Study rationale	4
1.5 Defining key concepts	7
1.6 Rising numbers of older male and spousal caregivers.....	8
1.7 Research aim.....	9
1.8 Thesis structure.....	10
Table 1: Structure of thesis.....	10
CHAPTER TWO: LITERATURE REVIEW AND THEORETICAL FRAMEWORK	13
2.1 Introduction.....	13
2.2 Literature review.....	13
2.3 Paper 1: Examining the support needs of older male spousal caregivers of people with a long-term condition: a systematic review of the literature.....	19

Paper 1: Examining the support needs of older male spousal caregivers of people with a long-term condition: a systematic review of the literature	20
2.4 Theoretical framework.....	54
2.5 Exploring gender differences in caregiving through coping strategies	58
2.6 Conclusion	61
CHAPTER THREE: METHODOLOGY.....	63
3.1 Introduction.....	63
3.2 Philosophical underpinning of the study	63
3.3 Overview of mixed methods research	65
Table 2: Six designs of mixed methods research	66
3.4 Rationale for using mixed methods in the current study	67
Table 3: Resolution of key issues.....	68
3.5 Data Collection and analysis	69
Table 4: Data collection across all phases.....	72
3.6 Sampling overview	73
3.7 Recruitment overview.....	74
3.8 Data analysis.....	75
3.9 Ethical considerations	77
Table 5: Ethical and governance approvals for all phases.....	77
3.10 Conclusion	79
CHAPTER FOUR: SCOPING SURVEY AND QUALITATIVE INTERVIEWS.....	81
4.1 Introduction.....	81
4.2 Background and local context	81

4.3	Methods	82
	Table 6: Summary of changes after pilot testing.....	85
4.4	Data collection and analysis	87
	Table 7: Survey respondent characteristics	88
4.5	Results	89
	Figure 3: Numbers of older male and female caregivers represented	91
	Figure 4: Most common type of support offered to all older caregivers	92
	Figure 5: Number of older caregivers (male and female) using services	93
	Figure 6: Number of male caregivers using services	94
4.6	Summary.....	96
4.7	Introduction.....	97
4.8	Methods	97
	Table 8: Participant eligibility criteria.....	98
	Table 9: Participant characteristics	99
4.9	Data collection	100
4.10	Data analysis.....	101
4.11	Rigour and trustworthiness	103
	Table 10: Examples of strategies to ensure validity (Creswell et al. 2018).....	104
4.12	Findings	105
	Paper 2: ‘When it faded in her.... it faded in me’: A qualitative study exploring the impact of caregiving on the experience of spousal intimacy for older male caregivers	106
4.13	Summary.....	136
4.14	Conclusion.....	136
 CHAPTER FIVE: FOCUS GROUP INTERVIEWS AND DELIBERATIVE WORKSHOP		138
5.1	Introduction.....	138
5.2	Context and rationale.....	138

5.3	Design and methods.....	140
	Table 11: Measures taken to minimise focus group risks	141
5.4	Data collection.....	141
	Table 12: Focus groups characteristics	144
	Table 13: Ethical issues associated with focus groups	146
5.5	Data analysis.....	147
5.6	Findings	148
	Paper 3: Exploring formal care providers’ perspectives of the support needs of older male spousal caregivers: a focus group study	149
5.7	Introduction.....	178
5.8	Background and rationale for using a deliberative approach	178
5.9	Design and methods.....	179
	Figure 7: Ladder of Inference, Argyris and Schon (1983)	180
	Table 14: Characteristics of Deliberative Workshop Participants.....	182
5.10	Data collection.....	183
5.11	Data analysis.....	184
5.12	Rigour	186
5.13	Findings	186
	Figure 8: Key priorities for increasing impact of support services for older male caregivers	193
5.14	Outcomes	194
	Table 15: How phase 4 met the aims of the deliberative process as outlined by Burchardt (2012).....	194
5.15	Summary of phase 4	195
5.16	Conclusion.....	195
	CHAPTER SIX: DISCUSSION.....	196

6.1	Introduction.....	196
6.2	Summary of key findings.....	198
	Figure 9: Merging of data to inform key findings.....	199
6.3	The impact of other sociodemographic factors on the caregiving experience	209
6.4	Learning from other areas of men’s help seeking	211
6.5	My PhD journey	214
6.6	Conclusion	217

CHAPTER SEVEN: CONCLUSIONS AND RECOMMENDATIONS..... 219

7.1	Introduction.....	219
7.2	Contribution to knowledge	219
7.3	Study strengths and limitations.....	220
7.4	Recommendations.....	222
7.5	Future research.....	225
7.6	Conclusion	226

REFERENCES..... 230

APPENDICES 253

Appendix 1 - Development of Codes from Male Caregiver Interviews	254
Appendix 2 - Mind-map Codes.....	255
Appendix 3 - Distress Protocol	256
Appendix 4 - Survey for Community-based Organisations.....	257

Appendix 5 - Survey Introduction Letter	263
Appendix 6 - MC Interviews: Promotional Flyer	264
Appendix 7 - Communication via Social Media.....	265
Appendix 8 – Press Release	266
Appendix 9 - MC Interviews: Participant Information Sheet	267
Appendix 10 - Interview Guide and Demographic Information.....	269
Appendix 11 - MC Interviews: Participant Consent Form	273
Appendix 12 - Field Notes	274
Appendix 13 - Initial Ideas Post-It Notes.....	276
Appendix 14 - Mind Map.....	277
Appendix 15 - Extract from Reflexive Journal.....	281
Appendix 16 - Promotional Flyer	282
Appendix 17- Focus Groups: Participant Information Sheet.....	283
Appendix 18 - Focus Groups: Participant Consent Form	285
Appendix 19 - Researcher Field Notes & Reflexive Journal – Focus Groups.....	286
Appendix 20 - Focus Group Topic Guide.....	287
Appendix 21- Exemplars of data, codes and themes: Focus Groups.....	288
Appendix 22 - Deliberative Workshop Social Media Information.....	294
Appendix 23 - Deliberative Workshop Participant Information Sheet (PIS)	295
Appendix 24 - Deliberative Workshop Participant Consent Form	297
Appendix 25 – Examples of themes, codes and data: Deliberative Workshop	298

Appendix 26 - Deliberative Workshop: participants in session one and two	299
Appendix 27 - Deliberative Workshop: Post-it notes and analysis	300
Appendix 28 - Deliberative Workshop: Priorities for support.....	301

ACKNOWLEDGEMENTS

I would like to extend gratitude to all study participants who contributed so much and gave their time generously. The male caregivers whom I interviewed, for their deeply moving and honest accounts of their caregiving experience; the formal support providers, and project steering group who gave their knowledge and time for the benefit of the study. My sincere thanks also go to the Public Health Agency NI (R&D Division) for funding of this project, without them this would not have been possible.

I am grateful to my supervisors Professor Sonja McIlfatrick and Professor Assumpta Ryan for their encouragement, guidance and expertise throughout the PhD process. Also, to my doctoral panel, Professor Eilis McCaughan and Dr. Paul Slater for their constructive criticism and support through the various stages of the study, and to Julie Cummins for her advice, technical expertise, and helping get me ‘over the line’.

My PhD colleagues were with me every step of the way, to celebrate the achievements and to commiserate when things didn’t go according to plan. Thank-you to Rosie Kelly, Alison Little, Beverley Turtle, Anita Rowe, Deirdre Harkin, Zillah Huddleston and Nikki Daniels. I am also grateful to Sheila and Jack Fee for their interest and involvement in the research, and agreement to use their photograph as the ‘face’ of the study.

Most thanks of all goes to my mum, my husband and my son. My mum for instilling in me a sense of hard work and determination, and belief in myself which enabled me to pursue this opportunity and to stick with it until the end; and to Adam for his love, moral support, domestic back-up, and cups of tea. Finally, thanks to Robert for his ideas, expertise, unwavering love, patience, friendship, encouragement and belief in me. I could not have done this without you.

ABSTRACT

Evidence increasingly shows that male caregivers have a different approach to caregiving than their female counterparts. Consequently, they may require a different form of support to enable them to sustain their caregiving role. Given that caregiving has traditionally been seen as a feminine activity, previous research has comprised predominantly female samples, and the impact of caregiver support for male caregivers is under-researched. The aim of this study was therefore to address this gap in the literature, by exploring the impact of support services in identifying and meeting the support needs of older male caregivers caring for a chronically ill spouse/partner at home.

A mixed methods approach was employed, which was informed by masculinity and coping theories, over four distinct phases. Quantitative data were collected through a survey (n=39), qualitative data were collected through individual interviews (n=24), focus groups (participants: n=84) and a deliberative workshop (participants: n=36).

Study findings related to three key areas. Firstly, it was recognised that the approach of older male spousal caregivers can be influenced by views on masculinity that are aligned to traditional hegemonic masculinity theories. Secondly, caregiving can involve social isolation, loneliness and challenges to spousal intimacy for older males. Thirdly, support providers should understand and be responsive to the gendered nature of caregiving and consider this when engaging and delivering support to older male caregivers. Findings demonstrated that older male caregivers experienced negative caregiver outcomes, which were not necessarily alleviated by existing support services.

The current study makes an original contribution to knowledge by advancing understanding about how existing caregiver support impacts on older male caregivers, in light of their particular approach to their caregiving role. Recommendations include improving awareness of this amongst formal support providers, and drawing on developments and ideas from other male-centred initiatives in men's healthcare and health promotion.

Key words: male caregivers; masculinity; support; intimacy; mixed methods

ABBREVIATIONS

Abbreviation	Meaning
ADL	Activities of daily living
AF	Anne Fee
AR	Assumpta Ryan
COPD	Chronic Obstructive Pulmonary Disorder
GPs	General Practitioner(s)
GRC	Gender Role Conflict
HSC or HSCT	Health and Social Care Trust
IADL	Instrumental activities of daily living
LTC	Long Term Condition
MEAAP	Mid and East Antrim Age Well Partnership
MND	Motor Neuron Disease
MS	Multiple Sclerosis
NA	Not Applicable
NFCSP	National Family Caregiver Support Program
NHS	National Health Service
NI	Northern Ireland
NSOC	National Study on Caregiving
OECD	Organisation for Economic Co-Operation Development
SDS	Self -Directed Support Scheme
SPSS	Software Package for Social Sciences
UK	United Kingdom
US	United States

DECLARATION

I confirm that the content of this thesis is all my own work and it has not been submitted, in part or whole, to any other university or institution.

I declare that with effect from the date on which the thesis is deposited in Ulster University Doctoral College, I permit:

1) The Librarian of Ulster University to allow the thesis to be copied in whole or in part without reference to me on the understanding that such authority applies to the provision of single copies made for study purposes of inclusion within the stock of another library.

2) This thesis be made available throughout the Ulster Institutional Repository or EthOS under the terms of the Ulster eThesis Deposit Agreement.

It is a condition of the use of this thesis that anyone who consults it must recognise that the copyright rests with the author and that no quotation from the thesis and no information derived from it may be published unless the source is properly acknowledged.

CHAPTER ONE: INTRODUCTION

1.1 Introduction

The aim of this PhD study was to explore the impact of support services in identifying and meeting the needs of older male caregivers caring for a chronically ill spouse/partner at home. Chapter one sets the scene by initially presenting information about the researcher's perspective. This provides insight to the researcher's background, and how the research idea evolved. The context for the study is outlined, followed by the study rationale, and an overview of key definitions to provide clarity around the population being studied. This is a publication-based thesis. As such, three papers have been submitted to and accepted for publication by three academic journals. The chapter ends with a summary of study aims and objectives, details of published papers, and an overview of the thesis structure.

1.2 Researcher's perspective

My interest in men as caregivers originated from my role working as 'Carers Co-Ordinator' within a Health and Social Care Trust (HSCT) in Northern Ireland. The role of Carers Co-Ordinator was developed with the aim of providing specific Trust based caregiver support, and enshrined in 'People First: Community Care for Northern Ireland' (Department for Health and Social Services 1990) policy. This role entailed implementing support services for family caregivers within the HSCT; providing carers' assessment training to health and social care professionals; working in partnership with community-based caregiver support organisations (such as Carers Northern Ireland); and working on regional initiatives such as implementation of the UK Carers Strategy. Each HSCT in Northern Ireland employed a Carers Co-Ordinator for this purpose. Through my direct work with caregivers within this role, I became increasingly aware that the support services offered by the HSCT were not meeting the needs of male caregivers. For example, when male caregivers attended a complementary therapy day although they appeared to enjoy the experience, they were reluctant to return, one reason given for this was that they felt outnumbered by females. Moreover, within the HSCT there were an estimated 3,804 older caregivers, and 46% of these caregivers were male (NISRA 2014). During my time as Carers Co-ordinator, although I met many family caregivers, approximately only 20-30 of these were older

males, many of whom were requesting support which was more suitable for men. There also appeared to be disparity between support services such as respite care being offered by the HSCT, and the needs of older male spousal caregivers. For example, some men suggested that the type of respite care being offered was not suitable as they did not want their wife being admitted to residential care for a week. It was clear that male caregivers had similar challenges to their female counterparts, yet my observations together with census data, and anecdotal evidence from colleagues suggested that they were generally hidden and only came forward for support when they felt they had no other option. Consequently, my opinion was that male caregivers (particularly within older age groups) remained on the periphery of support services - they were at best misunderstood and at worst marginalised. As this situation continued, and my awareness grew of the rising number of male caregivers, I undertook some further exploration about the experiences of older male caregivers. This took the form of in-depth discussions with social work colleagues within a community-based social work team. These discussions provided further support for my initial thoughts. Personally, I sought to gain a better understanding, and a way to address the issues as I perceived them, in order to improve practice. This resulted in the formulation of a research idea regarding exploring support needs of older male caregivers, and the feasibility of developing an intervention specifically targeted at this population. I applied and was awarded a doctoral fellowship from Research & Development within the Northern Ireland Public Health Agency, which enabled me to pursue this issue further through this PhD. Initially the study was focussed on the development of a support intervention specifically targeting older male caregivers through a mixed methods study design. However, in Phase 1 of the study, data from qualitative interviews undertaken with older male caregivers revealed that a specific support intervention was not what was needed. Rather, if existing services met the needs of male caregivers more effectively, this may enable older male caregivers to sustain their caregiving role and their own well-being. Thus, although the study changed slightly midway, the overall goal of highlighting how support for older male spousal caregivers could be improved was ultimately achieved.

1.3 Study Context

Evidence suggests that a greater number of males are assuming a caregiving role than before, (Baker, Robertson and Connelly 2010; Milligan and Morbey 2016; Comas-d'Argemir and Soronellas 2019). Male caregivers are especially prominent in older age groups, with an estimated 59% of caregivers in the over 85 age group who are male (Carers UK 2019). Different approaches to caregiving between men and women have been recognised in previous literature (Friedemann *et al.* 2014; Hong and Coogle 2016; Swinkles *et al.* 2019). This has resulted in an awareness and increased focus on potentially different support needs which may be influenced by gender. Whilst evidence exists to indicate that older male caregivers derive satisfaction, meaning and reward from their caregiving role (Sanders and Power 2009; Hellström *et al.* 2017; Comas-d'Argemir and Soronellas 2019), other evidence would contradict this. For example, according to Milligan and Morbey (2013), male caregivers were reluctant to identify with the caregiver label and had limited awareness of support services. Findings from other studies indicated that this sub group of caregivers were isolated and experienced a profound sense of loss, as well as negative consequences in the fitness, financial, physical and mental health areas of their lives (Haley *et al.* 2009; Milligan and Morbey 2013; 2016). It was also recognised that even though male caregivers were reported to experience high levels of stress, they tended to report low levels of burden (Baker *et al.* 2010; Akpinar *et al.* 2011; Robinson *et al.* 2014). This may have been caused by a reluctance to admit negative feelings (Baker *et al.* 2010; Akpinar *et al.* 2011), inability to process strong emotions (Sanders and Power 2009), or because acknowledging stress may be culturally unacceptable for men (Friedemann *et al.* 2014).

These findings, however, were in stark contrast to other evidence which indicated that female caregivers experienced more caregiving strain than male caregivers. For example, in an American quantitative study with caregivers of people with Multiple Sclerosis ($n=163$), which explored gender differences in caregiving approach, findings revealed that women reported higher perceived needs for social and emotional support, and higher levels of caregiver strain than male caregivers (Lee *et al.* 2015). Similar findings were noted in work undertaken in New Zealand, by Morgan and colleagues who, in their systematic review of gender and caregiving in the context of

old age ($n=19$), revealed that female caregivers experienced greater physical and mental strain than their male counterparts (Morgan *et al.* 2016). In light of these inconsistencies it is therefore important to explore the experiences of older male caregivers in order to better understand their support needs.

Research examining the support for older male caregivers is underdeveloped, especially when compared to female caregivers (Greenwood and Smyth 2015; Sharma *et al.* 2016). Limited existing evidence has indicated that male caregivers fail to access information (Greenwood and Smyth 2015); are hesitant to use formal support (Lin *et al.* 2012); and under-utilise support and training (Lopez-Anuarbe and Kohli 2019). Finally, a lack of engagement with male caregivers from formal support providers such as health and social care agencies has been noted in literature (Lopez-Anuarbe and Kohli 2019), as have cases of ‘gendered nuances’ underpinning assessment of support needs by health and social care providers (Milligan and Morbey 2013).

1.4 Study rationale

Policy in western societies has increasingly come to acknowledge the role of caregivers (Calvo-Perxas *et al.* 2018). Over recent decades the role of caregivers has been legitimised within the United States, with the introduction of the National Family Caregiver Support Program (NFCSP), which recognised family caregivers as requiring formal assistance with their role and paved the way for additional support. In the United Kingdom, government policy emphasised the rights of caregivers to have access to information, support, and to have a break from their caring (Department of Health, England 2010). It also acknowledged that caregivers often neglected their own health due to their caring role. Consequently, the Department of Health published the ‘Recognised, Valued and Supported’ national strategy in order to outline the way forward for government and community-based agencies in their support of caregivers (Department of Health, England 2010). This strategy laid the foundation for better recognition of informal caregivers, and for initiatives that supported caregivers to stay healthy and sustain their caring role for as long as necessary.

Within Northern Ireland, caregivers were first recognised by ‘People First: Community Care for Northern Ireland’ which recommended practical support for

informal caregivers (Department for Health and Social Services 1990). A review of this policy recommended that Health & Social Care Trusts should make support for caregivers a high priority and provided the foundation for the first Carers Strategy: ‘Valuing carers: proposals for a strategy for carers in Northern Ireland (Department of Health Social Services & Public Safety, 2002b). This was closely followed by the ‘Carers and Direct Payments Act 2002’, and the ‘Caring for Carers: Recognising, valuing and supporting the caring role, 2006’ (Department of Health Social Services & Public Safety 2006). Collectively these policy developments resulted in an obligation on Health and Social Care Trusts in Northern Ireland to ensure that all informal caregivers were offered a formal ‘carers’ assessment’. However, unlike the rest of the United Kingdom, there was no legally binding requirement for Trusts to provide this support (Department of Health NI 2017).

Given that caregiving has traditionally been viewed as a female activity (Office for National Statistics, 2013a), research about caregiving experiences comprised predominantly female samples. Consequently, male caregivers were under-represented in the literature, and their support needs are not well documented (McDonnell and Ryan 2014; Robinson *et al.* 2014; Fee *et al.* 2019). This is despite the evidence base that male caregivers are reported to experience significant stress, anxiety and depression (Accius 2017; Shu *et al.* 2017). Weinland (2009) highlighted a lack of information about the specific needs of male spousal caregivers and Sharma *et al.* (2016) concluded that the experiences of male caregivers are ‘relatively neglected’. Similar findings have been echoed by other qualitative researchers who highlighted lack of understanding about older men’s caregiving experience (Sanders and Power 2009).

Caregiving in later life is a role for which many people (regardless of gender) feel ill-equipped and unprepared. Older caregivers assume unfamiliar roles which are physically and emotionally demanding, at a time in their life when their own health may also be declining. Older male caregivers often take on non-traditional roles, such as household/domestic tasks, or providing care, against a backdrop of gendered role expectations and the navigation of a complex and unfamiliar healthcare system that men are reported to be ‘outside’ (Schwartz and McInnis-Dietrich 2015). Whilst spousal caregivers were reported to find meaning and adopt a positive attitude towards

caregiving (Eriksson and Sandberg 2008, Rykkje and Tranvag 2019), there is evidence to suggest otherwise. Several authors highlighted not only the likelihood of spousal caregivers experiencing declining mental and physical health, but also a greater number of chronic conditions (Haley *et al.* 2009; Oldenkamp *et al.* 2016). Vitaliano *et al.* (2011) asserted that spousal caregivers could be at greater risk of developing cognitive impairment such as dementia, due to factors including depression, isolation, diet and exercise. It was also reported that spousal caregivers who live with the care recipient experience greater negative caregiver outcomes than those to do not live together (Raccichini *et al.* 2009), and that older spousal caregivers were resistant to using family and community-based support resources (Friedemann *et al.* 2014). Particular challenges for male spousal caregivers have been identified in the literature. According to Ji *et al.* (2012) older husbands of cancer patients had an increased risk of coronary heart disease and stroke. Furthermore, a gradual decline in the spousal relationship can pose unique challenges for men who are caregivers. An American longitudinal study of gendered trajectories of support from close relationships in later life, revealed that men were more likely than women to nominate their partner as their main source of emotional support, with the likelihood increasing with age (Liao *et al.* 2018). This study is consistent with previous work (Gurung *et al.* 2003) and is important because it shines a light on an emotional component of spousal relationships in later life, particularly for men, which is often overlooked within caregiving literature.

Taken together these factors suggest that older male spousal caregivers may be particularly vulnerable to lack of support. Although men are becoming more visible as caregivers (Schwartz and McInnis-Dietrich 2015), male caregivers support needs continue to be neglected (Sanders and Power 2009; Sharma *et al.* 2016; Dickinson *et al.* 2017). Thus, a need for further research about the impact of support services in identifying and meeting the needs of older male spousal caregivers is important not only to clarify inconsistencies in current research, but also to address the lack of studies with all male samples (Dickinson *et al.* 2017).

1.5 Defining key concepts

Older male caregivers

For the purpose of this thesis, the term ‘older male caregivers’ refers to men over 65 years of age who look after a spouse or partner “*who need help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid*’ (NHS, England 2018). Older caregivers are defined as caregivers over 65 years of age as this is the definition of ‘older’ in western societies (World Health Organisation 2014).

Care activity

The broad term of caregiving also refers to practicalities of the care provided such as number of caregiving hours, and nature of support given. Previous literature categorised caregiving tasks as activities of daily living (ADL), such as personal care or feeding (Katz 1983). OECD (2005, p.17) states that activities of daily living include ‘*self-care activities that a person must perform every day, such as bathing, dressing, eating, getting in and out of bed, moving around, using the toilet*’. Instrumental activities of daily living (IADLs), include managing finances, food preparation, shopping, laundry or transport, (Lawton and Brody 1969). The number of caregiving hours involved, or the level and nature of caregiving tasks undertaken is generally dependant on the condition of the care recipient and extent of caregiving support provided by others.

Formal and informal care

Support provided to caregivers has been categorised as informal help from family and friends, and formal help from health and social care services or the voluntary sector (Greenwood and Smyth 2015). This thesis will use the term ‘formal support providers’ when referring to personnel from statutory (i.e. health and social care state funded agencies), or community-based agencies (non-government organisations such as Alzheimer’s Society or Marie Curie), who provide support (such as assessment, respite, or practical help) for informal caregivers.

1.6 Rising numbers of older male and spousal caregivers

Global trends predict that the world's population aged over 60 years will have trebled from 605 million to 2 billion by 2050 (World Health Organisation 2012). Similar trends are predicted for the United Kingdom, where the oldest ages are increasing the fastest. For example, it is estimated that people in the United Kingdom aged over 85 years will increase from 1.8 million to 3.3 million by 2033 (Department for Work and Pensions 2011; Office for National Statistics 2013). Likewise, Northern Ireland's population is ageing rapidly, with those in the age group of over 65 years growing by 25.2%, and over 85 years by 30%, in the last decade (Northern Ireland Statistics Research Agency 2018). These numbers are reflected in the number of older caregivers, with the UK Census (2011) reporting that in the past decade, the number of older caregivers increased by 35% whereas the rise in number of caregivers aged 25-64 years was just 4%. The fastest growing cohort of caregivers is those aged 85 years and over, whose numbers have risen by 128% in the past decade (Census 2011). This trend is set to continue with an estimated increase to over 1.8 million caregivers in England by 2030 (including approximately 200,000 aged 85+) (Carers UK 2019). It is important to note that the picture may be more complex given that many older caregivers in the United Kingdom and elsewhere don't easily identify themselves as caregivers (Carers Trust 2014).

Male caregivers

Evidence suggests that due to age related trends, and greater participation of females in the workforce, an increasing number of males are assuming a caregiving role. This is reflected in the literature (Baker, Robertson and Connelly, 2010; Milligan and Morbey 2016). Although numbers of female caregivers outnumber males (in people under 65 years), within the older age groups male caregivers outnumber females (Carers UK 2019). This finding is not just noted within the UK but internationally. In their study across 16 countries the Organisation for Economic Co-Operation and Development (OECD) found that there were more male caregivers within the over 75 age group than any other age (OECD 2011). An increasing number of male caregivers has also been observed in the United States with numbers rising from 28% in 1997 to 35% in 2018 (Family Caregiver Alliance 2019).

Spousal Caregivers

Although spousal caregiving comprises a large proportion of caregivers, very little is known about this caregiving subgroup. Stepler (2016) noted that, in the United States, older men were twice as likely to live with a spouse/partner than older women. This could be explained by a reported rise in life expectancy for men which has increased faster and by more than that of women, and also the finding that men are more likely to remarry after divorce and death than women (Stepler 2016). The increase in number of older male spousal caregivers in the United States is similar to the picture in the United Kingdom. In the UK an estimated one quarter of all older male caregivers are spousal, with the suggestion that male caregivers are more likely than female caregivers to provide care for a spouse (Office for National Statistics 2019). These factors combined with western governments focus on community care, point to a predominance of spousal caregiving in older age groups, with a rapidly increasing number of male spousal caregivers (Carers UK 2019; Milligan and Morbey 2016).

1.7 Research aim

Aim: To explore the impact of support services in identifying and meeting the needs of older male caregivers caring for a chronically ill spouse/partner at home.

Objectives:

1. To systematically review the evidence relating to the support needs of older male spousal caregivers.
2. To identify gaps in provision of support to older male caregivers by scoping current support provided by key community/voluntary groups/statutory services.
3. To explore the support needs of older male caregivers caring for a spouse/partner with a chronic long-term condition.
4. To explore the perspectives of health and social care professionals and community sector personnel about support services for older male caregivers.
5. To undertake a synthesis of key issues and make recommendations in relation to support services for older male caregivers through a deliberative workshop.

1.8 Thesis structure

This thesis details the development of an exploration of the impact of support services in identifying and meeting the needs of older male caregivers caring for a chronically ill spouse/partner. Initial chapters introduce the study and give an overview of relevant literature and design. The study methods and findings derived from the four phases are outlined in chapters four and five. Finally, these findings are discussed and overall conclusions and recommendations noted. As this is a publication-based thesis, there are also three papers submitted to and published within academic journals included. The following table (Table 1) contains details of each chapter and illustrates the association between these papers and the relevant chapter.

Table 1: Structure of thesis

<i>Chapter</i>	<i>Title</i>	<i>Contents</i>
Chapter One	Introduction	Chapter one gives an overview initially of the researcher's perspective, and information about the study context and rationale. This is followed by key demographic information about older male spousal caregivers, study aims and objectives, before a final section on the thesis structure is presented.
Chapter Two	Literature Review	Chapter two presents a critical appraisal of the literature and outlines the theoretical underpinning to the study. Specifically, an examination of previous literature relating to older male caregiver's support needs and highlighted gaps to be addressed by this study. This is followed by a critical consideration and rationale for two theoretical frameworks informing the study – masculinity and coping theories.
<i>Paper 1</i>	<i>Systematic Review of the literature</i>	<i>'Examining the support needs of older male spousal caregivers of people with a long-term condition: a systematic review of the literature'</i> .

		Published in International Journal of Older People Nursing. http://dx.doi.org/10.1111/opn.12318
Chapter Three	Design and Methodology	This chapter outlines the philosophical underpinning of the study, followed by a description of the mixed methods approach and application to the present study. A general overview of data collection, analysis, sampling and recruitment, rigour and ethical considerations are also presented.
Chapter Four	Scoping Review and Qualitative Interviews	A description of the methods and findings of preliminary phases of the study are contained in chapter four. This comprised an overview of the scoping exercise to determine the extent of support for older male caregivers from community-based agencies in Northern Ireland. This was followed by an outline of phase 2 qualitative interviews with older male spousal caregivers.
<i>Paper 2</i>	<i>Male Caregiver Interviews</i>	<i>'When it faded in her.... it faded in me': A qualitative study exploring the impact of caregiving on the experience of spousal intimacy for older male caregivers.</i> Published in Ageing and Society. https://doi.org/10.1017/S0144686X19000850
Chapter Five	Focus Groups and Deliberative Workshop	This chapter outlined the methods and findings from phases 3 and 4. Phase 3 comprised focus group interviews with formal support providers (n=9), in order to explore their perspective on support for older male caregivers. Phase 4 detailed the deliberative workshop, the aim of which was to reflect on study progress and findings to date; and to inform study conclusions and recommendations.

<i>Paper 3</i>	<i>Focus Groups</i>	<i>Exploring formal care providers' perspectives of the support needs of older male spousal caregivers: a focus group study.</i> Published in The British Journal of Social Work. https://doi.org/10.1093/bjsw/bcaa019
Chapter Six	Discussion	This chapter provides a summary of key findings and discusses them in relation to existing literature; and highlights a potential link between support for older male caregivers and the wider area of men's healthcare. An overview of the researchers PhD journey is also included.
Chapter Seven	Conclusions and Recommendations	In the final chapter, study strengths and limitations are detailed. Recommendations for practice, policy and future research are discussed, before a final conclusion is drawn.

CHAPTER TWO: LITERATURE REVIEW AND THEORETICAL FRAMEWORK

2.1 Introduction

The previous chapter contextualised male caregiving by providing an overview of current developments and issues in this area. The current chapter will examine existing background literature regarding gender, older male caregivers, spousal caregivers and the concept of support. While the current chapter provides information about the status of existing literature and a critique of this literature; additional detail about the literature search strategy, data analysis and findings is provided in Paper 1 '*Examining the support needs of older male spousal caregivers of people with a long-term condition: a systematic review of the literature*' (Section 2.3). The second part of this chapter will discuss the main theoretical frameworks which underpin the study, and the rationale for applying them. Together with Paper 1 this chapter will therefore highlight the relevance of key concepts from literature and theory in order to inform discussion throughout the thesis.

2.2 Literature review

Caregiving as a gendered concept

Despite some prior literature providing contradictory findings about gender differences in caregiving experience and use of support services (Miller and Cafasso 1992; Pinquart and Sorenson 2006; Akpınar, Küçükgüçlü and Yener 2011) the past two decades have seen a rise in recognition of the influence of gender in caregiving (Calasanti 2003; Gibbons *et al.* 2014; Hong and Coogle 2016; Swinkles *et al.* 2019; Rodriguez *et al.* 2019).

Calasanti (2003) was among the first to suggest gender-based differences between male and female spousal caregivers, concluding that caregivers fundamentally differed on the basis of gender, and on a set of gender based 'skills, resources, and expectations. She explained that older male spousal caregivers defined themselves as a 'man' (thus not identifying with being a nurturer), and that women defined themselves as being a 'woman' (therefore not identifying with being in charge). More recently, in a review of Calasanti's studies and other research in the area, Hong and Coogle (2016)

highlighted care-styles, suggesting that male caregivers were unwilling to relinquish their traditional dominant role within the household when they became caregivers which resulted in an authoritative/strong 'being in charge', managerial approach to their caregiving role. This contrasted with female caregivers who often chose not to relinquish their traditional female role, resulting in a nurturing approach to caregiving and any resulting stress/distress. These findings were consistent with other studies examining gender-based differences in experience and impact of caregiving (Pretorius *et al.* 2009; Ussher *et al.* 2013; Geiger *et al.* 2015; Rollero *et al.* 2016).

Older male caregivers use of support

The support *needs* of older male caregivers are explored in Paper 1 (section 2.3). Therefore, the current section will discuss literature examining older male caregivers' use of support from formal support providers. Although previous research found that in general older male caregivers were reluctant to use formal support, reasons for this remain unclear. Various causes for male caregivers' reluctance to access support have been explained, which have included: non-supportive interactions (such as previous bad experiences) (Neufeld and Kushner 2009); men being outside the care system (Schwartz *et al.* 2015); and guilt about asking for help (Sanders 2007). In the United Kingdom, Greenwood and Smyth (2015) undertook a systematic review about existing barriers and facilitators in male caregivers' use of support (n=7). Although findings showed ambivalence amongst male caregivers about their support use, authors also emphasised that male caregivers often experienced insufficient service information. In another study in the United Kingdom, Milligan and Morbey (2016) showed that male caregivers did use support services, however this was usually only when crisis had arisen.

Notably, there is a growing body of literature linking men's reluctance to use support services with their views on traditional masculinity. For example, in their qualitative study examining male caregiver's experience of caring for a dying partner (n=8), Judd *et al.* (2018) observed that help-seeking and accessing formal services was incompatible with the participants' sense of 'being a man'. Study findings revealed that participants drew on traditional male characteristics and acted out societal views on what it was to be a man, which resulted in a strong, stoic approach to caregiving and a reticence to accept additional help from support providers.

In their qualitative study about how older male caregivers' use of support impacted on their masculinity ($n=15$), Milligan and Morbey (2016) concluded that how older men performed caregiving impacted on how they performed masculinity. Authors noted that older male caregivers were more likely to refuse support than older female caregivers. They argued that, for older male caregivers, rather than ask for help to address caregiving challenges, they preferred to use skills learned through previous employment (such as being 'managerial').

These findings were consistent with a study by Robinson *et al.* (2014). In their scoping review about men caring for a person with dementia, authors highlighted the need for a framework to explain the link between older male caregivers' access to services and masculinities. Having said that, methodological issues were commonly reported in these studies such as small sample size (Milligan and Morbey 2016), or lack of clarity around study quality (Robinson *et al.* 2014) meaning that although these studies offered important insights to men's caregiving experiences and use of support, results should be treated with caution.

The experience of spousal caregivers

Although positive impacts of spousal caregiving have been noted (Eriksson and Sandberg 2008, Lloyd *et al.* 2016; Autio and Rissanen 2018), in comparison to literature on coping aspects of caregiving, literature highlighting positive aspects has been slow to develop. This may potentially be due to a lack of a coherent theory to frame our understanding of positive aspects of caregiving (Jagdev 2018). In their critical review of qualitative studies about positive impacts of caregiving within dementia Lloyd *et al.* (2016) found that spouses gained a sense of personal growth, accomplishment and feelings of closeness to the care recipient. However, this review only examined qualitative literature meaning that studies finding positive aspects of caregiving using other methodologies were excluded which may have limited findings. Similarly, in Norway, Rykkje and Tranvag (2019) examined the experience of older men caring for their wives with dementia ($n=5$), using qualitative interviews and hermeneutical interpretation. Findings revealed that husbands derived reward from their caregiving role and found their lives meaningful. However, as authors noted, the small sample size may suggest a bias towards resilient and resourceful husbands within

this context, thus it would be difficult to generalise these results to a broader population.

By contrast, other literature indicated that spousal male caregivers often experienced negative caregiving outcomes (Pretorius *et al.* 2009; O'Shaunessey, Lee and Lintern 2010; Haley *et al.* 2010; Fee *et al.* 2019). Older male spousal caregivers were reported to provide more assistance with tasks such as grocery shopping, housework and preparing meals than grown up children caregivers, and they did this with little support (Wagner 2006). Figures published in the 'Caregiving in the US' report (Reinhart *et al.* 2012), showed that 30% of male spousal caregivers assisted with toileting, even though 54% of male caregivers found it moderately to very difficult to assist with personal or intimate care needs. Additionally, Reinhart *et al.* (2012) suggested that 75% of male spousal caregivers were performing medical and nursing tasks for which they were unprepared and untrained. Compared with sons caring for an ageing parent, male caregivers for a spouse were more likely to be managing finances (76%), grocery shopping (98%), housework (92%), preparing meals (87%), and helping with transport (89 %). In Sweden, Pinquart and Sorenson (2011) undertook a meta-analysis of spouses, adult-children, and children-in-law as caregivers of older adults ($n=168$). Findings indicated that spousal caregivers reported lower levels of psychological well-being, more depression symptoms and more physical and financial burden than adult-children/children-in-law caregivers. Spousal caregivers experiencing more stressors could be partially explained by the fact that they co-resided with the care recipient. Study authors noted that sociodemographic factors, and spousal caregivers providing a greater number of caregiving tasks over a longer time frame also contributed to spousal caregiver stress.

Other evidence examined differences between husbands and wives, particularly in terms of secondary role strain. Secondary role strain relates to non-caregiving areas of life that are indirectly impacted by caregiving activities. Polenick and DePasquale (2017) examined secondary role strain with older spousal caregivers in their quantitative cross-sectional study ($n=367$) in the United States. Findings indicated that although wives reported more primary and secondary role related stressors than husbands, husbands were more susceptible to marital and family discord when their partner had multiple complex needs. The study found that overall, when comparable

levels of stress spread into other areas of life, husbands and wives were roughly equal in terms of caregiver burden and adverse health effects. However, study findings indicated ‘low levels’ of role strain, which may therefore not apply to spousal caregivers who were experiencing more intense role strain.

Defining the concept of caregiver support

There is a lack of conceptual clarity about social support, older people, and caregiving; leading to various interpretations about how support is measured and operationalised.

Within nursing literature caregiver support has been defined as:

‘The provision of general tangibles such as information, education, economic aid, goods and external services. They are prerequisites for facilitating the family carers’ competence or capacity in care. Moreover, it entails necessary qualities such as individualization, adaptability, lastingness, room for verbalizing emotions as well as an idea of reciprocal symmetrical exchange between involved parties.’
(Stolz *et al.* 2007).

More recently Soulsby and Bennett defined social support as ‘*a transactional process whereby our relationships provide a platform for the exchange of emotional and practical support*’ (Soulsby and Bennett, 2015, p. 110). Components of social support have been identified by Sherbourne and Stewart (1991) as emotional, affectionate, informational, tangible, and social interaction. Although literature has recognised a reluctance of older male caregivers to use psychological support (Baker *et al.* 2010; Milligan and Morbey 2013; Judd *et al.* 2018), there is some evidence that men will use psychological support if the support is suitable for their needs (Fogarty *et al.* 2015; Harris *et al.* 2015; Spindelov *et al.* 2017). Milligan and Morbey (2013) investigated support, and support needs of older male caregivers in their British study ($n=15$) employing narrative inquiry. Study findings revealed that older male caregivers were less likely than their female counterparts to ask for caregiving support, also that male caregivers were unlikely to be involved in support group activity that was ‘female dominated’. Greenwood and Smyth (2015) upheld some of these findings based on their systematic review of barriers and facilitators to male caregivers accessing support. Several others have also evidenced a reluctance of male caregivers to seek support due to difficulties in finding appropriate support or lack of awareness of

support services (Saunders 2007; Sandberg and Eriksson 2009a; Robinson *et al.* 2014; Rykkje and Tranvag 2019).

Caregivers (male and female) who are supported have better caregiving outcomes than those who are not (Singleton *et al.* 2002; Ablitt *et al.* 2009; Dam *et al.* 2016), and spousal caregivers are reported to benefit from periods of respite care (Salin *et al.* 2009). Caregivers with less social support, were also reported to perceive their caregiver role as more burdensome (Hwang *et al.* 2011). That being said, international evidence on the impact of caregiver support on outcomes such as well-being, quality of life, burden and depression show mixed results. Parker *et al.*'s (2010) meta-review of international evidence on caregiver support interventions found no evidence of improvements to caregiver stress, burden, psychological well-being or quality of life, as a result of support intervention. This may have been due to methodological issues within selected reviews such as the variable quality of reporting methods, results and outcomes; or even within the higher quality reviews it was noted that the quality of selected papers was poor. Findings in a subsequent meta-review (Thomas *et al.* 2017), indicated that although the quality of primary studies had improved slightly, still, there was little conclusive evidence about support interventions for caregivers. Authors highlighted that potential exists for specific sub-groups of caregivers, as they noted that '*no one size fits all*'. In this vein, in South Korea, a qualitative study with dementia caregiver dyads ($n=731$), Han *et al.* (2014) demonstrated that positive social interaction reduced psychological burden (such as depression or anxiety), while tangible support reduced non-psychological burden. These findings were supported by Piersol *et al.* (2017), who undertook a systematic review of effectiveness of interventions for caregivers of people with Alzheimer's Disease and related neurocognitive disorders. Study findings indicated that there was strong evidence that multicomponent psychoeducational interventions improved quality of life, confidence, and self-efficacy; and reduced caregiver burden. However, other similar studies have produced inconclusive findings. For example, Dam *et al.* (2016) undertook a systematic review of social support interventions with dementia caregivers in the Netherlands ($n=39$). Authors argued that due to various methodological issues (such as lack of any formal measurement of support) within selected studies, there was insufficient evidence to draw conclusions about which type of support worked best for particular social support outcomes. A quantitative study about changes in caregiver

burden between older male and female spousal caregivers was conducted by Swinkles *et al.* (2018) in the Netherlands ($n=279$ male, $n= 443$ female). This study recognised that different types of support interventions were required for male and female caregivers. Authors suggested that women may particularly benefit from interventions that help them to deal with the emotional impact of caregiving, whereas men may benefit from an intervention that addresses the stressors of care associated with caregiving intensity or increasingly complex care recipient needs.

Studies above have all been with mixed male and female samples - studies reporting the effectiveness of support interventions with older male spousal caregivers are rare. Thus, not only is there a gap in literature about support interventions for older male spousal caregivers, but studies that exist (using mixed gender samples), not only reveal inconclusive or mixed findings, but they failed to investigate the mechanisms by which support interventions influenced caregiver support outcomes, and evidence of poor methodological quality has been noted in several reviews.

2.3 Paper 1: Examining the support needs of older male spousal caregivers of people with a long-term condition: a systematic review of the literature.

The aim of this review was to identify and synthesise literature reporting on support needs of older male caregivers, who were providing care for a chronically ill spouse/partner at home. A systematic search of four electronic data bases resulted in eleven papers being included for review. Two core themes were identified: the need to maintain masculinity; the provision of social support. Findings suggested that dominant masculine norms may influence men's approach to caregiving, and also highlighted isolation and loneliness among this sub-group. Healthcare professionals should be aware of this gendered approach to caregiving in order to tailor effective sustainable support. This paper was published in 'International Journal for Older People Nursing':

Fee, A., Sonja McIlfatrick, S., & Ryan, A. (2020). Examining the support needs of older male spousal caregivers of people with a long-term condition: A systematic review of the literature. *International Journal of Older People Nursing*.2020;00:e12318. <http://dx.doi.org/10.1111/opn.12318>

**Paper 1: Examining the support needs of older male
spousal caregivers of people with a long-term
condition: a systematic review of the literature**

Examining the support needs of older male spousal caregivers of people with a long-term condition: a systematic review of the literature

Abstract

Aim: The aim of this review was to identify and synthesise literature reporting on support needs of older male caregivers, who are providing care for a chronically ill spouse/partner at home.

Background: Traditionally, informal caregiving has been perceived as a feminised activity. Consequently, caregiving research has been dominated by female samples, and male caregivers are grossly under-represented. Given the growing recognition of caregiving as a gendered concept, and the rise in number of male caregivers, particularly in later life, the need for better understanding of the needs of male caregivers is important in order to plan effective support for this population.

Design: A systematic literature review.

Methods: Four electronic databases and grey literature, were systematically searched.

Results: The systematic search resulted in 3,646 papers, eligibility criteria were applied to the full texts of 104 papers, and eleven papers met the inclusion criteria. Two core themes were identified: the need to maintain masculinity; the provision of social support.

Conclusion: Findings suggest that men may have a gendered approach to caregiving based on dominant masculine norms. This can be manifested in a reluctance to ask for or accept help, and a desire to retain control over caregiving. Findings also revealed isolation and loneliness experienced by older male caregivers, along with a preference for support to address this within a male specific context. It is suggested that healthcare professionals need to be informed about the male caregiver approach, and should also have an increased awareness of male caregivers support preferences and of their own gendered assumptions in order to deliver effective support to this population.

Implications for practice: Nurses have a key role in providing family support. Findings from this review suggest that nurses should be aware of the specific needs of

older male spousal caregivers if they are to provide effective care and support to this population group.

Key words: caregiver, masculinity, support, spousal, gerontological nursing

Summary Statement of Implications for Practice

What does this research add to existing knowledge in gerontology?

- The research advances understanding about support for older male spousal caregivers by identifying and synthesising literature reporting on support needs for this population who are grossly under-represented in caregiving and gerontology literature.
- Findings indicate that the provision of support from nurses and other healthcare providers which aligns with dominant masculinity norms may be appropriate for many older male caregivers.

What are the implications of this new knowledge for nursing care with older people?

- Earlier identification of support needs of older male caregivers may avoid crises, through appropriate signposting and tailored information using a collaborative approach.
- Given that caregiving is a gendered phenomenon, formal assessment of caregivers should include consideration of potential gender related influences on attitudes to support, such as male caregivers reported reluctance to seek help.

How could the findings be used to influence policy or practice or research or education?

- The review draws attention to issues such as ‘gendered assumptions’ about caregiver needs. Addressing this within nurse education may reduce reported stereotypical views of male caregivers from healthcare support providers.
- Findings of this review could inform policy or nurse education by aligning the concept of support for older male caregivers with the concept of support in the wider field of men’s help-seeking in healthcare.

Introduction

There is increasing evidence that older male caregivers have a different approach to their caregiving role from their female counterparts (Russell *et al.* 2008; Petoriosis *et al.* 2009; Hong & Coogle 2016) and consequently, may require different forms of support to sustain this role.

A global ageing population (WHO 2018) and increased prevalence of chronic long-term conditions (WHO 2018) has been noted in literature. Defined as ‘*conditions for which there is currently no cure, and which are managed with drugs and other treatment*’ (Department of Health, United Kingdom, 2012) these conditions can include dementia, cancer, heart disease, and Multiple Sclerosis (US National Library of Medicine). Evidence suggests that the needs of caregivers who are caring for older people with chronic conditions are poorly understood and remain largely under-recognised by community healthcare services (Ploeg *et al.* 2017). Moreover, long-term chronic conditions are reported to be a more significant predictor of caregiver burden than short term illness (Garlo *et al.* 2010).

Globally the number of informal/family caregivers is rising (van Groenou and De Boer, 2016). In the United States it is estimated that there are 65.7 million unpaid family caregivers. An increasing number of these caregivers are reported to be male, with numbers rising from 28% in 1997 to 35% in 2018 (Family Caregiver Alliance 2019). In Europe, the Organisation for Economic Co-Operation and Development (OECD) reported that there were more male caregivers within the over 75 age group than any other age (Colombo *et al.* 2011). This finding is also reflected in the United Kingdom with an estimated 6.5 million caregivers, 42% of whom are reported to be male, with the number rising to 59% within the over 85 age group (Carers UK, 2019).

The increase in numbers of older male caregivers is not surprising, since older men are more likely than older women to live with a spouse, (Poysti *et al.* 2012; Stepler, 2016). Evidence suggests that spousal caregivers provide a greater number of caregiving hours, and more intense caregiving tasks than grown up children caregivers (Litwin *et al.* 2014; Tremont and Davis, 2014). Older spousal caregivers have to adapt to the gradual decline of their marital relationship (O’Shaunessey, Lee and Lintern, 2010)

and older male spousal caregivers are reported to experience deterioration of their own health (Haley *et al.* 2010), increased loneliness (Pretorius *et al.*, 2009), and declining intimacy (Fee *et al.* 2019). Research about male caregivers remains under-developed (Sharma *et al.* 2016; Dickinson *et al.* 2017), with little understanding about the experience of caregiving husbands and their support needs.

Although some research suggests that support measures such as information, training and practical support are crucial for sustaining caregiving within the general caregiving population (Silva *et al.* 2013; McCabe *et al.* 2016; Fernandes *et al.* 2016), these studies have mainly been with female samples, and male caregivers are under-represented in the literature (Dickinson *et al.* 2017). However, it has been reported that male caregivers are less likely than female caregivers to report caregiver strain and burden, or have a limited perception of available support (Robinson *et al.* 2014; Greenwood and Smyth 2015). This raises the question about whether male caregivers' approach to support is influenced by gender, as suggested by previous research (Morgan *et al.* 2016; Swinkles *et al.* 2019). However, the focus of the current review is not on a comparison between male and female caregivers, in relation to negative outcomes. Rather, that the *approach* of male caregivers should be examined more conclusively. This subtle but important difference has implications for healthcare professionals in terms of how they assess need for support and deliver services to older male caregivers.

Research is beginning to recognise gender-related issues for caregivers, and particularly for older male caregivers (Robinson *et al.* 2014; Rollero, 2016). Evidence indicates that even though men and women may have similar caregiving experiences, they tend to have a different approach to caregiving, and a different way of accessing support (Morgan *et al.* 2016). It has been suggested that female caregivers have higher levels of stress, lower levels of well-being, and more depressive symptoms than male caregivers (Akpınar *et al.* 2011; Lee *et al.* 2015; Kim *et al.* 2016). An explanation for this could be that traditionally, caregiving has been dominated by females (Glauber *et al.* 2017), resulting in all female research samples; or that men who have traditional beliefs about masculinity are less likely to admit to feeling burdened in their caregiving role (Baker *et al.* 2010; Hong and Coogle, 2016). Moreover, questions have been raised about the appropriateness of measurement scales, including using the same tool

to measure depression/anxiety/stress in male and female caregivers (Sullivan *et al.* 2014; Yousaf *et al.* 2015). These authors maintain that certain tools can be more ‘female friendly’ leading to self-report bias, as female participants may be more comfortable articulating their stress/burden than male participants. This is supported by Seidler and colleagues who emphasise that tools such as ‘The Masculine Depression Scale’ (Magovcevic and Addis, 2008) would be more appropriate with males (Seidler *et al.* 2016). Seidler goes further to raise the issue of help-seeking behaviour with males and poses questions about how best to engage men in support, given their reticence to seek professional help for healthcare (Seidler *et al.* 2018). Findings from previous studies examining male caregivers’ use of support within caregiving have revealed some inconsistencies. It has been reported that male caregivers are reluctant to make use of formal support services, and when they do it is when a crisis has arisen (Milligan and Morbey, 2016). However, there is also some evidence to indicate that male caregivers frequently used formal support (Greenwood & Smyth, 2015). Thus, a need for further research about male caregivers’ use of support is important not only to clarify such inconsistencies, but also to address the lack of studies with all male samples (Dickinson *et al.* 2017).

Based on this emerging evidence it could be argued that there is a need to identify support requirements of older male caregivers as a precursor to meeting these needs. This is especially timely given the rising numbers of male caregivers, reported evidence of gendered care styles (Hong and Coogle, 2016); and the male approach to caregiving (Robinson *et al.* 2014). A recognition of support needs of older male spousal caregivers and a deeper understanding of how they could be addressed is also necessary in order to add to the limited knowledge base in the area, and to develop tailored, sustainable support for this population.

Aim

The aim was to identify and synthesise literature reporting on support needs of older male spousal caregivers. The specific research question was: ‘*What do we currently know about the support needs of older male caregivers who are caring for a chronically ill spouse/partner at home?*’. The following definitions were applied for the purpose of this review: ‘*support needs*’ refers to the need for emotional, instrumental, and informational resources needed to sustain caregiver well-being

within the caregiving role (Ostberg and Lennartsson, 2007); ‘male caregivers’ were defined as men who undertook a primary role, without remuneration, in the care of their chronically ill spouse/partner; ‘older’ was defined as caregivers aged over 65 years as this is the definition of ‘older’ in western societies (World Health Organisation, 2014).

Methods

A systematic review of the literature was undertaken in order to address the research question. Thematic synthesis was applied to findings (Thomas and Harden, 2008) due to its appropriateness for synthesising qualitative studies to provide deeper understanding of a research phenomenon from the perspective of participants. Search findings were listed in accordance with Preferred Reporting Items for Systematic Reviews and Meta-Analysis (Moher, 2010). The Enhancing Transparency of Reporting the Synthesis of Qualitative Research (ENTREQ) framework guided the reporting of review findings. The ENTREQ framework (Tone *et al.* 2012) aims to encourage transparency, through a checklist of 21 items to guide synthesis and reporting of qualitative research.

Search Strategy

The search strategy was pre-planned and primarily developed for Medline using medical subject headings (MeSH) terms, and text words. Searches that had been adapted for other databases were then conducted on 16th April 2019. The term caregiver included informal/family/unpaid caregivers. MeSH and keyword terms are outlined in Figure One. Electronic databases were systematically searched in April 2019, using the specified search terms. Choice of database was guided by study aims; relevance to caregiver support - such as medicine (Medline), nursing (CINAHL), psychology (PsycINFO) and more generally (Scopus/Google Scholar); and for their international perspective. The limits applied to searches were: written in English, involving participants over 65 years. Given the dearth of literature in this area, no date limits were applied. To enhance rigor, grey literature was searched iteratively, and included google.com, Google Scholar, OpenGrey, OpenDOAR), Systematic reviews register (PROSPERO) University Repositories, community-based organisations websites (including Alzheimer’s UK, Alzheimer’s Disease International); and relevant

government department websites from English speaking countries (including United Kingdom, United States and Australia).

MeSH & Keyword Terms:

- 1) Caregiver/
- 2) Caregiver* or care giver* or carer* or care-giver*
- 3) 1 or 2
- 4) ((carer* or caregiver* or care giver* or care-giver*) adj3 support*)
- 5) ((carer* or caregiver* or care giver* or care-giver*) adj3 need*)
- 6) ((carer* or caregiver* or care giver* or care-giver*) adj3 experience*)
- 7) ((carer* or caregiver* or care giver* or care-giver*) adj3 support* need*)
- 8) 4 or 5 or 6 or 7
- 9) 3 and 8
- 10) Child* or youth or young or son* or daughter* or offspring* or sibling*
- 11) 9 not 10
- 12) Male/
- 13) Male* or m?n or husband* or spous* or partner*
- 14) 12 or 13
- 15) 11 and 14
- 16) Limits to English

Figure 1: search terms

Article Screening

After removal of duplicates, articles were screened by title and abstract. Next, eligibility criteria (Table One), were applied to the full text by the review author (AF). Remaining articles were scrutinised and peer validated by the research team. Finally, reference lists of included papers were analysed for other relevant studies.

Table One: Eligibility Criteria

Inclusion Criteria	Exclusion Criteria
Studies which examine support needs of older male spousal caregivers, with an all male sample.	Studies which examine needs of female, male and female caregivers, or spousal dyads.
Caregivers (over 65 years old), who are the primary caregiver for a spouse/partner who has a chronic long term condition.	Caregivers within residential settings.
Living in the community.	Paid/formal care workers.
Focus of study is on male caregiver support needs; or caregiving experience with an emphasis on support needs.	Primary focus is on support needs of care recipient, or on other aspects of male caregivers (such as depression).
Informal/unpaid.	Parent/ sibling/adult children caregivers.

Methodological Quality Assessment

Even though some authors dispute the usefulness of methodological quality assessment for qualitative studies in systematic reviews (Lucas *et al.* 2007), Thomas & Harden would advocate for quality assessment. Therefore, studies in the current review were assessed using the Critical Appraisal Skills Programme Qualitative Checklist (CASP, 2018) (See Table Two). Two authors (AF, AR) assessed selected studies independently. Specifically, CASP comprises checklists of ten questions to enable a systematic consideration of the methodological approach of the study. Studies were not weighted on the basis of this assessment (Thomas and Harden 2008), and since all studies met the initial two screening two criteria (CASP, 2018), none were excluded.

Table Two: Critical Appraisal Skills Programme Qualitative Checklist (CASP, 2018)

Author and year	Q1 Statement of research aims?	Q2 Qualitative methodology appropriate?	Q3 Research design appropriate?	Q4 Recruitment strategy appropriate?	Q5 Data collection appropriate?	Q6 Consideration of relationship between researcher and participant?	Q7 Consideration of ethical issues	Q8 Data analysis rigour?	Q9 Statement of findings?
Harris 1993	Y*	Y	Y	Y	Y	CT*	N*	CT	Y
Coe & Neufeld 1999	Y	Y	Y	CT	Y	CT	Y	Y	Y
Lauderdale & Gallagher-Thompson 2002	Y	Y	CT	Y	CT	N	N	CT	Y
Russell 2004	Y	Y	Y	Y	Y	N	N	CT	Y
Russell 2007	N	Y	CT	Y	Y	N	CT	CT	CT
Brown <i>et al.</i> 2007	Y	Y	Y	Y	CT	CT	CT	Y	Y
Sanders & Power 2009	Y	Y	Y	Y	Y	CT	CT	Y	Y
Sandberg & Eriksson 2009	Y	Y	Y	Y	Y	N	Y	Y	Y
Pretorius <i>et al.</i> 2009	Y	Y	Y	CT	Y	N	CT	CT	Y
Milligan & Morbey 2016	Y	Y	Y	Y	Y	CT	Y	Y	Y
Hellström <i>et al.</i> 2017	Y	Y	Y	CT	Y	CT	Y	Y	Y

*Y = Yes N=No CT=Can't tell

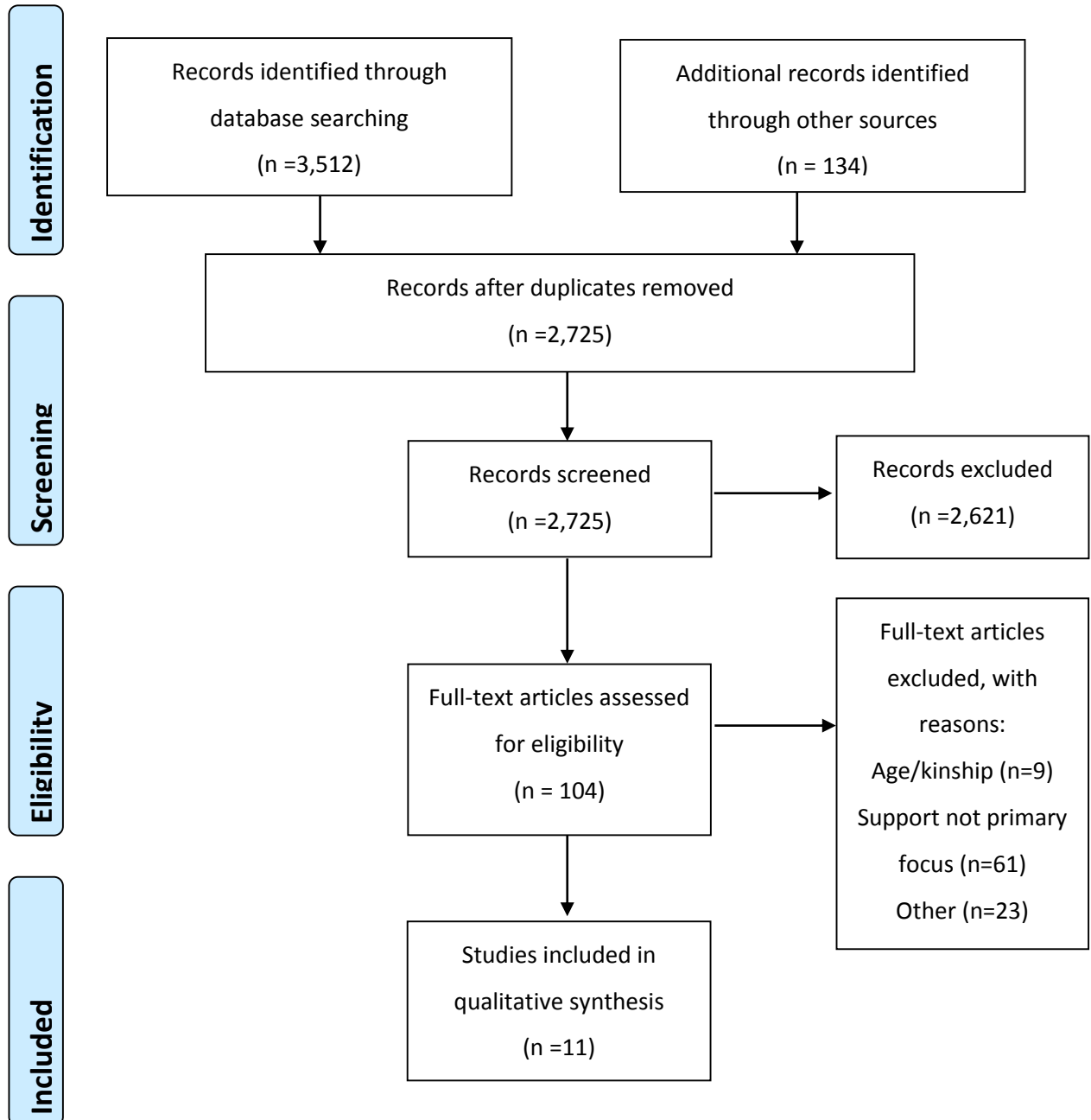
Data Synthesis and Analysis

Data were analysed using a thematic synthesis approach (Thomas and Harden, 2008). Data in the results/findings/conclusions section of selected papers were electronically extracted and entered into Nvivo 12 qualitative software for management and coding. Next, the first researcher (AF) inductively coded data line-by-line to identify key categories and concepts from the first study, based on the research question. Data from subsequent studies were added to the original, or new concepts and categories where required, in order to develop descriptive themes (based on findings in the primary studies). Codes and themes were discussed and checked for reliability through continuous peer review within the research team. A conceptual map was developed to visualise and compare themes, and to assist with ongoing interpretation of data. The final stage of analysis involved further interpretation and refinement of descriptive themes in order to generate more abstract analytical themes.

Findings

A total of 3,646 articles were identified and exported to Refworks Reference Management system. Duplicates were removed, and 2,725 articles were screened by title and abstract. Finally, eligibility criteria were applied to 104 articles, resulting in a final eleven articles for review (Figure Two). All eleven studies were assessed for methodological quality assessment. The methodological quality of studies varied. All eleven studies met the two screening criteria of 'Statement of Research Aims' and 'Qualitative Methodology Appropriate'. However, only four studies showed clear ethical approval, and six studies showed rigour in data analysis. Nine studies reported appropriate research design and ten studies presented a clear statement of findings.

Figure 2: PRISMA 2009 Flow Diagram



Study Characteristics

Characteristics of selected studies are summarised in Table Three. All eleven studies were qualitative, and were drawn from Scandinavia (2), United States of America (7), United Kingdom (1), and South Africa (1). Eight studies used semi-structured interviews with older male caregivers, one study used focus groups, one study used a psychoeducational support group, and one study used narrative correspondence from older male caregivers and interviews with service providers to collect data. A total of 504 male caregivers participated. All participants were married in heterosexual relationships. Although most were retired or had given up work to care, a range of previous employment was described including GP, taxi driver, accountant, farm labourer and teacher. It is acknowledged that some study participants were outside the age inclusion criterion (of over 65 years). However, we decided to include studies with a mean age of 65 or over, to ensure that we did not exclude studies where most of the participants met the criterion. Although all studies included care recipients living with dementia, nine studies listed this as the primary health condition, and some had additional health conditions (either physical or mental). Sample characteristics are detailed in Table Four.

Table Three: Summary of Reviewed Studies

Title & Journal	First Author & year of publication/ Country	Study design & method	Research Aims/Question	Data collection methods & analysis	Key Findings
<p>'The Misunderstood Caregiver? A qualitative Study about the Male Caregiver of Alzheimer's Disease Victims.'</p> <p><i>The Gerontologist</i></p>	<p>P. Harris 1993 United States</p>	<p>Qualitative Thematic</p>	<p>To obtain an in-depth understanding of what it is like for a man to take on the role of primary caregiver: his motivations, stresses, coping strategies, support networks, use of services, losses, accomplishments, satisfactions and needs.</p>	<p>Semi-structured interviews.</p>	<p>Identified themes of: commitment, social isolation, control, a structured routine combined with respite care, a problem solving approach, outside activities, sense of accomplishment, need for specialised services for men and limited expectations of help from children.</p> <p>Identified a need for gender-sensitive support that particularly addresses social isolation experienced by male caregivers.</p>
<p>'Male Caregivers Use of Formal Support.'</p>	<p>M. Coe 1999 United States</p>	<p>Qualitative Grounded Theory</p>	<p>To explore male caregivers perceptions of formal support.</p>	<p>Interactive interviews Constant comparison, coding, memoing and diagramming procedures.</p>	<p>Identified a process of four sequential stages of men making concessions for care: resisting, giving in, opening the door, making the match. Concluded that personal barriers deterred</p>

<i>Western Journal of Nursing Research</i>					some men from seeking help, and for those who did characteristics of the care providers acted as enabling and disabling factors in seeking and accepting help.
'Men Providing Care: What do they Need and How can we do it?'	S. Lauderdale 2002 United States	Qualitative	To recruit and implement psychoeducational groups for caregiving men designed to teach skills for managing distressful emotional reactions to caregiving situations.	Psychoeducational support group	Recommendations for clinical practice: 1) Promote support for men using gender-sensitive language. 2) For group support, providers should recruit men from a variety of formal and informal services. 3) Flexibility of time for group support is important for male caregivers.4) Content should include skills based approaches to managing distress as well as discussion of mutual experiences.
<i>Clinical Gerontologist</i>					
'Social Networks among elderly men caregivers.'	R. Russell 2004 United States	Qualitative Thematic	What are the ways in which social re-connection is established for elder men caregivers, what is the meaning they ascribed to current social networks, how do social networks affect their caregiving experience.	In-depth, semi-structured interviews.	Pre-retirement social networks were more important for men than previously thought (due to isolation); social networks for men caregivers are beneficial in lessening caregiver burden; and for many men, social networking with other men was of greatest benefit.
<i>The Journal of Men's Studies</i>					

'The Work of Elderly Male Caregivers - From Public Careers to an Unseen World'.	R. Russell 2007 USA	Qualitative. Thematic.	To explore how elderly male caregivers adapt to changes in social location, what resources they call upon, and what we can learn from this to inform future policy.	In-depth, semi-structured interviews.	Two themes were identified: 1) Success; 2) Struggle.
<i>Men & Masculinities</i>					
'Help-seeking by older husbands caring for wives with dementia.'	J. Brown 2007 United States	Qualitative. Grounded Theory.	To gain understanding of the help-seeking process of older husbands caring for wives with dementia.	Unstructured interviews.	Identified themes included: 'Doing the best I can' and 'continuing on' Help-seeking by older husband caregivers is complex and gender-specific.
<i>Journal of Advanced Nursing</i>					
'Roles, Responsibilities and Relationships among Older Husbands Caring for Wives with Progressive Dementia, and Other Chronic Conditions'.	S. Sanders 2009 United States	Qualitative Phenomenology.	'What are the changes in roles, responsibilities and relationships that husbands experience as they provide care for their chronically ill wives?'.	Semi-Structured interviews. Analysis: Content analysis, constant comparative method.	Two themes were identified: 1) Adaptation of old roles within the marital system to new roles associated with responsibilities of caregiving; 2) changes within the relationship between caregiver and care recipient, as a result of progression of memory loss and other chronic health conditions. Highlighted emotional aspect of male caregivers and suggested

Health & Social Work					that social workers were cognisant of this.
'From alert commander to passive spectator: older male carers experience of receiving formal support.'	J. Sandberg 2009 Sweden	Qualitative. Content analysis.	To describe older males experience of receiving formal support.	Three focus group discussions.	Three themes were identified: 1) using ad hoc solutions for maintaining a protective environment; 2) coping, but being left behind; 3) recapturing the caregiving role. Quantity and quality of support services must be considered for older male caregivers and a greater awareness with support providers that men should be involved as partners in care.
International Journal of Older People Nursing.					
'Sense of coherence among male caregivers in dementia. A South African Perspective'	C. Pretorius 2009 South Africa	Primarily Qualitative, with limited descriptive quantitative to facilitate analysis. Qualitative analysis – orientational, using Anotonovsky's	To explore the experiences of men caring for a spouse with dementia from a salutogenic perspective.	In depth semi-structured interviews.	Men reported various stressors and coping strategies. However, appeared to be effective and capable caregivers. Male's approach to caregiving differs from females – task orientated problem solving, effective use of resources and ability to find meaning and satisfaction are characteristic of the male approach.

			sense of coherence (2002) as a theoretical basis.		
'Care, Coping and Identity; Older Men's Experiences of Spousal Caregiving.'	C. Milligan 2016 United Kingdom	Qualitative. Narrative	To explore how older male caregivers in the UK cope with the experience of caregiving, the types of support they use, and how this impacts on their sense of self and identity as older men.	Narrative correspondence from male caregivers, and focus groups with support providers.	How older men construct and perform caregiving, and how the wider family and community respond to older men as caregivers, can impact on how they perform masculinity. This can increase loneliness and isolation.
<i>Journal of Aging Studies.</i>					
'Development of older men's caregiving roles for wives with dementia'.	I. Hellström 2017 Sweden	Qualitative. Constructivist.	To describe how older Swedish men approach the caregiver role of a wife with dementia over time.	Semi-structured interviews.	Three themes were identified: 1) me and it; 2) me despite it; 3) it and me. Themes illustrate how the men take on and normalise caregiving tasks, and internalise a language of caregiving activities.
<i>Scandinavian Journal of Caring Sciences</i>					

Table Four: Characteristics of Sample

Study	Number of participants	Duration of Caregiving	Spouse/partner chronic condition	Age Range
Harris (1993)	15 husbands	3-15 years (<i>M</i> =7.6)	Dementia	<i>M</i> =73
Coe & Neufeld (1999)	24 men (17 husbands)	2-11 years	Cognitive Impairment	33-87 (over 60: <i>n</i> =20)
Lauderdale & Gallagher-Thompson (2002)	6 men (5 husbands)	1-10 years (<i>M</i> =4)	Dementia	70-88 (<i>M</i> =78)
Russell (2004)	30 husbands	Unspecified	Dementia	68-90 years
Brown <i>et al.</i> (2007)	9 husbands	2-13 years (<i>M</i> = 6)	Dementia	70-85 years (<i>M</i> =79)
Russell (2007)	30 husbands	Unspecified	Dementia	68-90 years
Pretorius <i>et al.</i> (2009)	10 husbands	1-23 years (<i>M</i> = 6)	Dementia	61-88 years (<i>M</i> = 77)
Sandberg & Eriksson (2009)	11 husbands	2-15 years	Dementia	67-80 years
Sanders & Power (2009)	17 husbands	unspecified	Dementia and another chronic health condition	66-85 (<i>M</i> =77)
Milligan & Morbey (2016)	15 husbands	10 months – 30 years (<i>M</i> = 9.9)	Range of chronic health conditions (including	56-89 years (<i>M</i> = 69.5)

stroke, MS,
cancer)

Hellström et al. (2017)	7 husbands	Not Specified	Dementia	71-85 years
--------------------------------	------------	---------------	----------	-------------

Themes

Two themes were identified: ‘the need to maintain masculinity’; and ‘the provision of social support’.

Theme 1: The Need to Maintain Masculinity

This theme was identified in all studies, to a greater or lesser extent. It related to the concept of masculinity, how it influenced the approach to caregiving by many older male spousal caregivers, and how caregiving was ‘gendered’ in the eyes of families and institutions. Maintaining masculinity involved, for some, ‘re-framing’ their identity to maintain masculine traits and societal expectations. This was mainly achieved through the ‘professionalisation’ of caregiving tasks by applying skills from previous employment, such as management or technology (Russell, 2007; Milligan and Morbey, 2016; Hellström et al. 2017). Hellström et al. (2017) referred to using such strategies ‘to maintain a sense of a preserved orientation as a man’, including a ‘take charge’ attitude related to previous occupations.

In their study Sandberg and Eriksson (2009) explained that maintaining masculinity was ‘*The urge to be in control and manage the care without professional involvement*’. Others also referred to cognitive strategies to maintain control (Pretorius et al. 2009; Milligan and Morbey, 2016).

Maintaining masculinity through a protective approach towards their partners was evident in eight studies. This was exemplified through statements such as ‘*Being responsible for their wives’ wellbeing and protecting them from harm*’ (Sandberg and

Eriksson, 2009). However, authors noted that this sense of protection was often detrimental, as protectiveness '*combined with the desire to maintain their own independence, eventually became too demanding*', and that seeking external support was '*tantamount to failing in his role as husband and primary carer*' (Sandberg and Eriksson, 2009), or the inability to maintain a protective environment for their spouse, was also described as '*a devastating blow to the men's self-image*' (Sandberg and Eriksson 2009). Sandberg and Erikson further emphasised that '*what men regard as important in the formal support they receive, diverges sharply from what they are offered*' (Sandberg and Eriksson, 2009). In other words, participants viewed their spousal and caregiving expertise as crucial in their partner's ongoing care, and had the expectation that healthcare professionals would take this into account, however participants often felt excluded when care services 'took over' and did not consider the men's knowledge of their spouse. Thus, men tended not to accept the help that was offered. In a similar vein Milligan and Morbey (2016) concluded that the urge to take responsibility led to negative outcomes when participants had to ask for help, often resulting in help only being requested at crisis point. According to the care providers in their study, asking for help '*may be seen as indicative not only of an inability to cope, but as a perceived failure, as husbands, to provide for their wives*' (Milligan and Morbey, 2016). Findings in several other studies also indicated a reluctance to seek or accept help (Coe and Neufeld 1995; Russell 2004, 2007; Hellström *et al.* 2017).

There was also some evidence of a view of caregiving as 'gendered' from others such as families and healthcare professionals. Russell described reactions from friends and family to work that was considered 'men's work' such as building shelves or gardening, as opposed to the invisibility of care work, regarded by the relatives of some study participants as 'women's work' (Russell, 2007). Potential gender stereotypes with healthcare professionals were also evident in findings in Sandberg and Eriksson, where the perception of a support service manager was described as being '*highly influenced by stereotyped views of men's ability (or, rather lack thereof) to provide care*' (Sandberg and Eriksson, 2009).

Theme 2: The Provision of Social Support

Findings in this theme described the emotional and instrumental support needed by older male spousal caregivers.

Nine of the eleven studies highlighted aspects of the caregiving role that impacted negatively on caregivers emotional well-being. Studies commonly referred to men's sense of isolation and loneliness due to the '*declining ability to engage in social activities with other older men as a result of their caring role*' (Milligan and Morbey, 2016); or '*As they developed their skills as carers, they were almost entirely isolated in the role*' (Sandberg and Eriksson, 2009). This was further compounded by a profound sense of loss at the closeness and companionship that they had once shared with their partner, as described by Michael (Brown *et al.* 2007):

'I said, 'I can't get in there with you. I know you're in there somewhere and I can't bring you out here with me and I miss you so much'... She's been everything to me. She took care of everything. She's all I've got, the only woman, all I want. She's my companion... Alzheimer's took away my wife... 'cause she's not my wife anymore. I just miss her so'. (Brown et al. 2007)

This experience of loss, grief, and deep sadness were also emphasised by Sanders & Power (2009); Harris (1993); Sandberg and Eriksson (2009) and Hellström *et al.* (2017). Not only did Harris (1993) report that '*social isolation from family and friends*' was the second most common theme in their study, but Hellström *et al.* (2017) concluded that:

'a diminishment of social life that included social isolation, feelings of loneliness and a reduction of social and bodily contact were explicit in all the men's narratives' (Hellström et al. 2017)

Six studies reported that there was a pressing need amongst participants for more opportunities to have someone to talk to (Harris 1993; Russell 2004; Sanders and Power; Pretorius *et al.* 2009; Milligan and Morbey 2016, Hellström *et al.* 2017). Milligan and Morbey (2016) specified that for their participants:

'The narratives also revealed that many of the OMCs felt a real need and desire to have someone to talk to about the issues, but for this to be delivered through professional services (such as a mental health worker or counselling service) rather than friends or relatives' (Milligan and Morbey 2016)

When participants talked about the type of emotional support that would be beneficial they generally referred to a need for male specific support. This was highlighted by five studies (Harris 1993; Lauderdale and Gallagher-Thompson 2002; Russell 2004; Pretorius *et al.* 2009; Sandberg and Eriksson 2009), as described by a participant in the study by Harris (1993):

"I need to express my feelings with people who have experienced the same thing and understand. You just don't talk about those kind of things with women of our generation" (Harris 1993)

Instrumental support was reported to a lesser extent than emotional support. Five studies noted the importance of respite (Harris, 1993; Brown *et al.* 2007; Pretorius *et al.* 2009; Milligan and Morbey 2016; Hellström *et al.* 2017). For some study participants, respite provided through agency staff allowed important time away from the caregiving role, to pursue leisure/ social activities, personal appointments, or part-time employment. Other studies referred to more informal 'personal time', which was described as time watching television, or in the garden while the care recipient was in bed. This personal time away seemed to provide stress relief and was referred to by participants in Sanders and Power (2009) as '*the only factor that was going to ensure their survival as a caregiver*'.

Discussion

For this systematic review eleven papers were identified that discussed support for older male spousal caregivers.

Research has shown that caregivers (regardless of gender) who receive support experience better health outcomes, and physical/psychological wellbeing than those who do not (Ablitt *et al.* 2009; Dam *et al.* 2016). However, a lack of conceptual clarity about 'support' has previously existed within nursing research. This has been addressed by various authors (Stolz *et al.* 2007; Ostberg and Lennartsson, 2007). Langford *et al.* (1997) provided a more specific definition of social support in their conceptual analysis and concluded that defining attributes of social support were: emotional, instrumental, informational and appraisal.

Addressing the research question: *'What do we currently know about the support needs of older male caregivers who are caring for a chronically ill spouse/partner at home?'* the findings of this review highlight themes of: 'the need to maintain masculinity', and 'the provision of social support'. Maintaining masculinity included strategies whereby male caregivers sought to take responsibility or display a task oriented approach (Pretorius *et al.* 2009; Hellström *et al.* 2017). Re-framing masculinity involved approaching new caregiving tasks in a way that aligned with masculine ideals, or 'professionalisation' of caregiving tasks by applying skills from previous employment, (Russell, 2007; Milligan and Morbey, 2016; Hellström *et al.* 2017).

Connell's hegemonic masculinity theory (2005) characterises 'normal' masculine behaviour as independent, stoic, and self-reliant (Donaldson, 1993). These ideas become societal gender role expectations, and internalised gender norms, but complicity is often difficult for men. Gender norms can be restrictive to men when they are in a position of having to navigate through family, social and community life. Caregiving is an example of this and can pose a conflict for males as it is viewed by society as 'women's work' (Glauber, 2016), and performed in a *'feminised landscape of care, from which they often feel excluded'* (Milligan and Morbey, 2016). This conflict was described by O'Neil (1981b) as Gender Role Conflict (GRC). A unifying theme within GRC is 'fear of femininity', whereby men associated negative emotions with stereotypical female behaviour and values. This resulted in them distancing themselves from behaviour that is commonly associated with feminine traits. Tendencies to under-report caregiver stress, or limited perceptions of support (Fromme *et al.* 2005; Baker *et al.* 2010), have also been linked with GRC. An awareness of these factors amongst healthcare professionals may improve caregiver assessment or increase the likelihood of timely caregiver support interventions to avoid crisis.

A protective approach to caregiving of older male spousal caregivers was evident in findings. Selected studies reported that participants felt a sense of duty, as husbands, to provide care. Sandberg and Eriksson (2009), argued that the reluctance of older male spousal caregivers to use formal support was due to their difficulty in obtaining support which enabled them to continue to provide a protective environment. Often, they felt

that when care services became involved, they ‘took over’ and ignored the men’s spousal expertise. This often resulted in men feeling excluded from caregiving and from their spousal relationship (Sandberg and Eriksson, 2009). This is an important point as it sheds light on the consequences, in terms of support, for some older male caregivers when caregiving intersects with their masculine identity.

Studies depicted a range of emotions in relation to the caregiving role which included anger, frustration, sadness, grief and loss. Despite this, there was evidence of reticence to discuss such emotions. Milligan and Morbey (2016) pointed out that even though their narratives were ‘*strewn with references to stress, distress, self-doubt, worry, struggle*’ participants were reluctant to discuss these aspects of their role. Consistent with previous findings about male caregivers minimising emotion or under-reporting stress (Robinson *et al.* 2014.; Spindel *et al.* 2018), other authors described how interview participants made efforts to suppress strong emotions. This was particularly apparent in Sanders and Power (2009), when a participant described feeling sorry for himself as a ‘*brief moment of weakness*’. Also, Hellström *et al.* noted a tendency to block emotions as a coping strategy, and explained that interview participants were ‘*Keeping the discussion on a rational level was a way of keeping their emotions at bay*’ (Hellström *et al.* 2017).

‘Permission’ to discuss caregiving stress or the emotional impact of caregiving appeared to be important to study participants. One study noted how a participant only discussed his caregiving stress because he was taking part in a research project (Milligan and Morbey, 2016). Previous studies have highlighted a tendency for men to receive more emotional support from spouses than women, and for men to have ‘permission’ for an emotionally close relationship only with their spouse (Liao *et al.* 2018). Therefore, the declining spousal relationship was felt acutely by many study participants. Discussing emotion seemed to be more permissible if it took place in a certain setting. Several authors emphasised that although study participants experienced caregiver stress, they were more accepting of support to address this, if it was within a male-centred context such as men only discussions, activities or support groups (Harris 1993; Coe and Neufeld 1999; Lauderdale and Gallagher-Thompson 2002; Russell 2004; Milligan and Morbey 2016). Findings from the present review and other evidence indicates that men do seek and accept support in certain

circumstances (Fogarty *et al.*, 2015; Harris *et al.*, 2015). However, despite the growing interest in the development of man-centred support initiatives, there is still very limited understanding about what facilitates men's engagement with emotional support. Emerging research such as the scoping review about engaging men in psychological treatment, conducted by Seidler *et al.* (2018), have shed some light on the most effective strategies to engage men, by focussing on the 'how' of delivering support to men (as opposed to specific support measures). Authors suggested underlying prerequisites needed to engage and work with men, based on an acknowledgement of masculine socialisation leading to support which was goal-focused and action-orientated. They also highlighted current fundamental limitations in support service provision for men, including '*inadequate clinician training in gender socialisation*' (Mellanger and Lui, 2006), and '*clinicians bias toward or against masculinity*' (Owen, Wong and Rodolfa, 2009). Seidler *et al.* (2018) further identified four key themes: 'Building in Gender Socialisation; Clarifying Structure; Building Rapport and a Collaborative Relationship; and Tailoring Language. Themes not only acknowledged how gender role socialisation informed men's alignment to masculine norms, but also the importance of collaborative work with men, and an awareness of clinician's own gender role stereotypes, and biases regarding masculinity. Such gender role stereotypes and biases regarding masculinity have already been recognised in male caregiving literature (Sandberg and Eriksson 2009; Milligan and Morbey 2013).

In summary, this review has employed a novel thematic synthesis in reviewing the current literature about the support needs of older male spousal caregivers and has highlighted how masculinity may impact on support for this population. Consequently, there is a need to increase our understanding about the connection between men, caregiving and identity; and what this means for healthcare professionals. If 'support' is explored within the context of men's help seeking behaviour in healthcare (Seidler *et al.* 2018), this may help to inform a process of sustained engagement with older male caregivers, and the design and delivery of support for this population group.

Limitations

It could be suggested that the aims of reviewed studies were somewhat disparate, ranging from help-seeking processes, to formal support, or experiences of caregiving.

Nevertheless, all selected studies referred to significant support needs of older male caregivers, and therefore were included in the review. Studies included in the review related mainly to dementia, findings may have been different if studies had focussed on a range of chronic conditions. Given that the current review did not consider other influencing factors on older male caregiver support (such as sociodemographic factors, or stage in caregiving trajectory), this remains an area for future research.

Conclusion

This review can add to existing knowledge about support for older male caregivers. Healthcare professionals should be aware of how caregiving can impact on some men's masculinity, in what has traditionally been 'women's work', whilst maintaining their masculine identity. Findings revealed a gendered approach to caregiving where men endeavoured to maintain their masculine identity through adherence to masculine 'norms' such as a protective approach in their caregiving role, or a reluctance to seek/accept help or discuss emotions. Findings also revealed a need for social support to address isolation, loneliness and lack of companionship experienced by older male spousal caregivers, and for this to be delivered within a male specific context. If healthcare professionals are aware of the gendered approach of some male caregivers, then this can be taken into consideration when assessing male caregivers' needs for support. The identification of appropriate support for this population is important for future policy for several reasons. Firstly, greater emphasis on providing care in the community in western societies places additional responsibility on family caregivers. Secondly, an increasing population of people over the age of 85, suggests a continuing rise in the number of male caregivers, who are currently grossly under-represented in the caregiving literature.

Nursing Implications

- Nurses should be aware of the gendered approach to caregiving highlighted in this review. This knowledge is essential if nurses are to provide effective care and encourage the early uptake of support, potentially avoiding crisis, for this population group.

- As many men have demonstrated a protective approach to caregiving, it is important for nurses to acknowledge older male spousal caregiver's expertise in this area and plan the delivery of support collaboratively.
- Given that men often feel excluded from a '*feminised landscape of care*', nurses should be aware of isolation, and be equipped with information that could address this.

References

Ablitt, A., Jones, G., V, Muers, J. (2009) Living with dementia: a systematic review of relationship factors. *Aging & Mental Health* 13(4): 497–511. doi: 10.1080/13607860902774436

Addis, M. E. (2008) "Gender and depression in men". *Clinical Psychology: Science and Practice*. Wiley. 15 (3): 153–168. doi:10.1111/j.1468-2850.2008.00125.x

Akpınar, B., Küçükgülü, O., & Yener, G. (2011) Effects of gender on burden among caregivers of Alzheimer's patients. *Journal of Nursing Scholarship*, 43, 248–254.

Baker, K., Robertson, N., Connelly, D. (2010) Men caring for wives or partners with dementia: Masculinity, Strain & Gain *Ageing & Mental Health*, 14:3, 319-327 DOI: 10.1080/13607860903228788

Brown, J.W., Chen, S.-L., Mitchell, C. & Province, A. (2007) Help-seeking by older husbands caring for wives with dementia. *Journal of Advanced Nursing* 59(4), 352–360 doi: 10.1111/j.1365-2648.2007.04290.x

Carers UK (2015) *Caring into Later Life. The Growing Pressure on Older Carers.*

Critical Appraisal Skills Programme (2018) CASP (Qualitative) Checklist. [online] Available at: URL. Accessed: July 2019)

Coe, M., and Neufeld, A. (1999) 'Male caregivers Use of Formal Support', *Western Journal of Nursing Research*, 21(4), pp. 568–588.

Connell, R.W., Messerschmidt, J., W. (2005) Hegemonic Masculinity: Rethinking the concept. *Gender & Society*. Sage. 19 (6) 829-859. Doi: 10.1177/0891243205278639

Dam, A., E, de Vugt, M., E, Klinkenberg, I.P., Verhey, F.R., & van Boxtel, M.P., (2016) A systematic Review of social support interventions of caregivers of people with dementia. Are they doing what they promise? *Maturitas* 86 117-130

Department of Health UK (2012). Report. Long-term conditions compendium of Information: 3rd edition, accessed 26/6/19

Dickinson, C., Dow, J., Gibson, G., Hayes, L., Robalino, S., & Robinson, L. (2017) Psychosocial intervention for carers of people with dementia: What components are most effective and when? A systematic review of systematic reviews (Forthcoming/Available Online), *International Psychogeriatrics*.

Donaldson, M., (1993) "What is hegemonic masculinity?". *Theory and Society*. Springer. 22 (5): 643–657. doi:10.1007/BF00993540. JSTOR 657988

Ducharme, F. (1995) Longitudinal change in conjugal support and coping behaviours of elderly marital partners. *Journal of Family Nursing*. 1:281-302

Ellis, M., (2016). "Tough guys' less likely to be honest with doctor". *Medical News Today*.

Family Caregiver Alliance 2019. Caregiver statistics: Demographics. <https://www.caregiver.org/caregiver-statistics-demographics> (accessed on 26/06/19)

Fee, A., McIlpatrick SJ., Ryan, A., (2019) 'When it faded in her.... it faded in me': A qualitative study exploring the impact of caregiving on the experience of spousal intimacy for older male caregivers. *Ageing and Society*, pp. 1–22. doi: 10.1017/s0144686x19000850.

Fernandes, C., S., Angelo, M. (2016) Family caregivers: what do they need? An integrative review. *Rev Esc Enferm USP*. 2016;50(4):672-678. DOI: <http://dx.doi.org/10.1590/S0080-623420160000500019>

Fogarty, A. S., Proudfoot, J., Whittle, E. L., Player, M. J., Christensen, H., Hadzi-Pavlovic, D., & Wilhelm, K. (2015). Men's use of positive strategies for preventing and managing depression: A qualitative investigation. *Journal of Affective Disorders*, 188, 179–187. doi: 10.1016/j.jad.2015.08.070

Garlo, K., O'Leary, J.R., Van Ness, P.H., Fried, T.R., (2010) Burden in caregivers of older adults with advanced illness. *Journal American Geriatric Society*. 58:2315–2322. DOI: 10.1111/j.1532-5415.2010.03177.x

Glauber, R., (2017) Gender differences in spousal care across the later life course. *Research on Ageing*. Doi: 10.1177/0164027516644503

Greenwood, N., Smyth, R. (2015) Barriers and Facilitators for male carers in accessing formal and informal support. A systematic Review. *Maturitas* 82 162-169

Harris PB (1993) The Misunderstood Caregiver? A Qualitative Study of the Male Caregiver of Alzheimer's Disease Victims. *The Gerontologist* Vol. IS, No. 4, 551-556

Harris, M. G., Diminic, S., Reavley, N., Baxter, A., Pirkis, J., & Whiteford, H. A. (2015) Males' mental health disadvantage: An estimation of gender-specific changes in service utilisation for mental and substance use disorders in Australia. *Australian & New Zealand Journal of Psychiatry*, 49(9), 821–832. doi: <https://dx.doi.org/10.1177/0004867415577434>

Haley, WE., David, L., Roth, DL., Howard, G., Stafford, MM (2010) Caregiving Strain and Estimated Risk for Stroke and Coronary Heart Disease Among Spouse Caregivers. Differential by Race and Sex. *Stroke*. 2010; 41:331-336. Doi: 10.1161/STROKEAHA.109.568279

Hellström, I. et al. (2017) 'Development of older men's caregiving roles for wives with dementia', *Scandinavian Journal of Caring Sciences*. doi: 10.1111/scs.12419.

Hong, S.C., Coogle, C., L. (2016) Spousal Caregiving for Partners with Dementia: A Deductive Literature Review testing Calasanti's Gendered View of Care Work. *Journal of Applied Gerontology* Vol 35 (7) 759-787

Horowitz, K., (2016) "Psychologists Say Macho Behavior May Help Explain Men's Shorter Lifespans". *Mental Floss*.

Kim, MH., Dunkle, R.E., Lehning, A.J., Shen, H.W., Feld, S., Perone, A.K., (2016) Caregiver stressors and depressive symptoms among older husbands and wives in the United States. *Journal of Women & Ageing*. Doi: 10.1080/08952841.2016.1223962

Kramer, B. J. (2005). Men caregivers: An overview. In B. J. Kramer, & E. H. Thompson (Eds.), *Men as caregivers* (pp. 3–19). Amherst, NY: Prometheus.

Laditka S. A., Pappas-Rogich M., & Laditka J.N. (2001) Home and community –based services for well-educated older caregivers: gender differences and attitudes, barriers and use. *Home Health Care Services Quarterly* 19 (3), 1-17.

Laditka, S. B., Pappas-Rogich Dr P., H, M. and Laditka DA, J. N. (2008) Home and Community-Based Services for Well Educated Older Caregivers: Gender Differences in Attitudes, Barriers, and Use', *Home Health Care Services Quarterly*.1424. doi: 10.1300/J027v19n03_01.

Lauderdale, S., A., Gallagher-Thompson, D., (2003) Men Providing Care. *Clinical Gerontologist* 26: 1-2: 53-70 doi 10.1300/J018v26n01_06

Lee, E.J., DeDios, S., Fong, M.W.M. Simonette, C. & Lee G.K. (2015) Gender differences in coping among spousal caregivers of persons with multiple sclerosis. *Journal of Rehabilitation* 79 (4) 46-54

Liao, J. et al. (2018) 'Gendered trajectories of support from close relationships from middle to late life', *Ageing and Society*, 38(4), pp. 746–765. doi: 10.1017/S0144686X16001264.

Litwin, H., Stoeckel, K, J & Roll A., (2014) Relationship status and depressive symptoms among older co-resident caregivers. *Ageing & Mental Health* 18 (2) 225-231. Doi: 10.1080/13607863.2013.837148

McCabe, M., You, E., Tatangelo, G., (2016) Hearing their voices: A systematic Review of Family Caregivers Needs. *The Gerontologist*, Vol 56 No 5 e70-e88 doi: 10.1093/geront/gnw078

- McDonnell, E., Ryan A. (2011): Male Caregiving in Dementia: A review and commentary. *Dementia* 12:238.
- McDonnell, E., Ryan A. (2013): The experience of sons caring for a parent with dementia. *Dementia*. DOI 10.1177/1471301213485374
- Magovcevic, M., & Addis, M.E. (2008) The Masculine Depression Scale: development and psychometric evaluation. *Psychology of Men & Masculinity*, 9(3), 117 doi: 10. 1037
- Mellinger, T. N., & Liu, W. M. (2006). Men's issues in doctoral training: A survey of Counselling Psychology pro-grams. *Professional Psychology: Research and Practice*, 37, 196–204
- Milligan, C. & Morbey, H. (2016) 'Care, coping and identity: Older men's experiences of spousal care-giving', *Journal of Aging Studies*. doi: 10.1016/j.jaging.2016.05.002.
- Moher, D., Liberati, A., Tetzlaff J., Altman, D. & The PRISMA Group (2009) Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLOS Medicine* 6 (7), 1–6.
- Morgan, T. *et al.* (2016) 'Gender and family caregiving at the end-of-life in the context of old age: A systematic review', *Palliative Medicine*, 30(7), pp. 616–624. doi: 10.1177/0269216315625857.
- Oliffe J.L, Han C.S.E., (2014) Beyond Workers' Compensation: Men's Mental Health In and Out of Work. *American Journal of Men's Health*, Vol 8(1) 45 –53
- O'Neil, J. M. (1981b) Patterns of gender role conflict and strain: The fear of femininity in men's lives. *The Personal and Guidance Journal*, 1981, 60, 203-210. (b)
- O'Shaughnessy, M., Lee, K., & Lintern, T. (2010) Changes in the couple relationship in dementia care: Spouse carers' experiences. *Dementia*, 9, 237-258. doi:10.1177/1471301209354021
- Ostberg, V., & Lennartsson, C. (2007) Getting by with a little help: The importance of various types of social support for health problems. *Scandinavian Journal of Public Health*. 35: 197–204. DOI: 10.1080/14034940600813032
- Owen, J., Wong, Y. J., & Rodolfa, E. (2009) Empirical search for psychotherapists' gender competence in psychotherapy. *Psychotherapy: Theory, Research, Practice, Training*, 46(4), 448–458. <https://doi.org/10.1037/a0017958>
- Phillipson, L., Jones, S. C., & Magee, C. (2014) A review of the factors associated with the non-use of respite services by carers of people with dementia: Implications for policy and practice. *Health & Social Care in the Community*, 22, 1–12. doi:10.1111/hsc.12036

- Pinquart, M., & Sorenson, S., (2006) Gender differences in caregiver's stressors, social resources and health: an up-dated meta-analysis. *Journal of Gerontology* 61 (1) 2006 33-45
- Poysti, M.M., Laakkonen, M.L. Strandberg, T., Savikko, N., Sakari Tilvis, R., Eloniemi-Sulaova, U., Pitkila, KH (2012): Gender Differences in Dementia Spousal Caregiving. *International Journal of Alzheimer's Disease*. Article ID 162960,
- Pretorius, C., Walker, S. and Heyns, P. M. (2009) 'Sense of coherence amongst male caregivers in dementia: A South African perspective', *Dementia*. doi: 10.1177/1471301208099046.
- Robinson C.A., Bottorff J.L., Pesut B., Oliffe J.L., Thomlinson J., (2014) The Male Face of Caregiving: A Scoping Review of Men Caring for a Person with Dementia. *American Journal of Mens Health* Vol 8 (5) 409-426
- Rollero, C. (2016) The Experience of Men Caring for a Partner with Multiple Sclerosis. *Journal of Nursing Scholarship*, 2016; 48:5, 482–489. Doi: 10.1111/jnu.12231
- Roth, D.L., Perkins, M., Wadley, V.G., Temple, E.M., & Haley, W.E. (2009) Family caregiving and emotional strain: Associations with quality of life in a large national sample of middle-aged and older adults. *Quality of Life Research*, 18, 679–688.
- Russell R. (2004) Social Networks Among Elderly Men Caregivers. *The Journal of Men's Studies*, Vol. 13, No. 1, 121-142.
- Russell, R. (2007) 'The work of elderly men caregivers: From public careers to an unseen world', *Men and Masculinities*. doi: 10.1177/1097184X05277712.
- Sandberg H., & Eriksson J., (2009) From alert commander to passive spectator: older male carers' experience of receiving formal support. *International Journal of Older Peoples Nursing* 4, 33-40. Doi: 10.1111/j.1748-3743.2008. 00147.x
- Sanders, S., Power, J., (2009) Roles, Responsibilities, and Relationships among Older Husbands Caring for Wives with Progressive Dementia and Other Chronic Conditions. *Health & Social Work Volume* 34, (1) P 41-51
- Schwartz, A. J. (2013) Moderators of the impact of sociodemographic and economic factors on the well-being of caregiving men: Implications for social work practice and policy. (ProQuest Dissertation & Theses database), (3592893)
- Seidler, Z., E., Dawes, A., J., Rice, S.M., Oliffe, J., Dhillon, H., M. (2016) The role of masculinity in men's help-seeking for depression: A systematic review. *Clinical Psychology Review* 49 (2016) 106–118 doi: 10.1016/j.cpr.2016.09.002
- Seidler, Z., E., Rice, M., Oliffe, J., L., Fogarty, A., S., and M. Dhillon, H., M., (2018) Men in and Out of Treatment for Depression: Strategies for Improved Engagement. *Australian Psychologist* doi:10.1111/ap.12331

Sharma, N., Chakrabarti, S. and Grover, S. (2016) 'Gender differences in caregiving among family - caregivers of people with mental illnesses', *World Journal of Psychiatry*, 6(1), p. 7. doi: 10.5498/wjp.v6.i1.7.

Silva, A.L., Teixeira H.J., Teixeira M.J.C., Freitas S. (2013) The needs of informal caregivers of elderly people living at home: an integrative review. *Scandinavian Journal of Caring Sciences* 27; 792–803 doi: 10.1111/scs.12019

Stirling, C., Andrews, S., Croft, T., Vickers, J., Turner, P., & Robinson, A. (2010) Measuring dementia carers' unmet need for services—An exploratory mixed method study. *BMC Health Services Research*, 10, 122. doi:10.1186/1472-6963-10-122

Stepler, R. (2016) "Smaller Share of Women Ages 65 and Older are Living Alone: More are living with spouse or children." Washington, D.C.: Pew Research Center.

Stoltz, P., Willman, A., Ude'n, G., (2006) The meaning of support as narrated by family carers who care for a senior person at home. *Qualitative Health Research* 16 (5)

Stoltza, P., Andersson, E, P., Willmanc, A. (2007) Support in nursing—An evolutionary concept analysis. *International Journal of Nursing Studies* 44 1478–1489

Sugiura, K., Ito, M., Kutsumi, M., & Mikami, H. (2009) Gender differences in spousal caregiving in Japan. *Journal of Gerontology: Social Sciences*, 64B (1), 147–156, doi:10.1093/geronb/gbn005

Sullivan. L., Camic P.M., Brown, S.L., (2014): Masculinity, alexithymia, and fear of intimacy as predictors of UK men's attitudes towards seeking professional psychological help British Psychological Society.

Swinkels, J. *et al.* (2019) 'Explaining the Gender Gap in the Caregiving Burden of Partner Caregivers', *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*, 74(2), pp. 309–317. doi: 10.1093/geronb/gbx036.

Tong A., Flemming, K., McInnes, E., Olive S., Craig, J. (2012) Enhancing Transparency in reporting the synthesis of qualitative research: ETREQ. *BMC Medical Research Methodology* 12: 181

Tremont, G., & Davis, J. D. (2014) The Role of caregivers in the treatment of patients with dementia. In C. A. Noggle and R. S. Dean (Eds.), *The Neuropsychology of Cortial Dementias*. (pp. 393-422). New York, NY: Springer Publishing Company

US National Library of Medicine)

<https://medlineplus.gov/ency/patientinstructions/000602.htm>, accessed 26/6/19

van Groenou M., I., & De Boer A. (2016) Providing informal care in a changing society. *European Journal of Ageing*; 13:271–279. Doi: 10.1007/s10433-016-0370-7 PMID: 27610055

Weir, Kirsten (2017) "The men America left behind". *Monitor on Psychology*. American Psychological Association. 48 (2): 34.

Whittemore R., Knafl K., (2005) 'The integrative review: updated methodology', *Journal of Advanced Nursing*, 52(5), pp. 546–553. doi: 10.5001/omj.2009.40.

World Health Organisation (2002) The world health report 2002: reducing risks, promoting healthy life. Geneva, *World Health Organization, 2002*. Retrieved from https://www.who.int/nutrition/topics/2_background on 01/03/19

World Health Organization (2012). Active ageing: good health adds life to years. Policies and priority interventions for healthy ageing. Regional Office for Europe, Copenhagen, Denmark; 2012.

World Health Organisation (2018) Ageing and Health Fact sheet. Available at: <https://www.who.int/news-room/fact-sheets/detail/ageing-and-health>. Accessed 07/12/19

Yousaf, O., Popat, A. and Hunter, M. S. (2015) An investigation of masculinity attitudes, gender, and attitudes toward psychological help-seeking. *Psychology of Men and Masculinity*, 16 (2). 234 - 237. ISSN 1524-9220

2.4 Theoretical framework

According to Evans (2012), the use of an explicit theoretical framework in a mixed methods study can provide a logical, orderly, and efficient structure to integrate and summarise key aspects of separate study phases and link them to a coherent guide to understand and interpret the findings. Evans described theoretical frameworks as a map which provided navigation through complex human behaviours and practices, however cautioned against using a theoretical framework which has a poor ‘fit’ with the study. Such a framework could distort data or fail to properly investigate the phenomena under study (Sandelowski 2000b). In the current study theories perceived to be most appropriate to adequately frame the phenomena being studied were chosen based on the following considerations. Firstly, theories were selected that explained the ‘why’ of the research problem being examined; and after consideration about how robust the theories would be at predicting or influencing other similar populations (i.e. providing support for older men). Secondly, the researcher considered the extent to which the theories were consistent with her own perspective and experience of the phenomenon under study. Thirdly, the usefulness of the theories to guide future interventions/support for older male caregivers (Anderson *et al.* 2005) was explored. The following section gives an overview of the underpinning theoretical framework for the study by presenting first, key masculinity theories, and second coping theories. Theories of masculinity have relevance for the study due to the significance of evidence indicating that male caregivers strongly identify with masculine ideals based on masculinity (Robinson *et al.* 2014; Milligan and Morbey 2016). Additionally, evidence shows that caregiving psychological outcomes are related to coping strategies (Snyder *et al.* 2015). Given reports that older male caregivers use different coping strategies from their female counterparts (Hong and Coogle 2016), it was considered that coping theories were also appropriate for use in this study.

Overview of masculinity theories

Within caregiving literature, caring has traditionally been set within a ‘*feminised landscape of care*’ (Milligan and Morbey 2016). This is the social and cultural ‘norm’ within western society and is supported by systems and institutions. Therefore, caregiving men must navigate this role within a context of culturally defined roles, which historically has not included men as ‘natural’ caregivers. The concept of

masculinity has been linked to men's health and help-seeking behaviour by many theorists (Calasanti and King 2007; Robinson *et al.* 2014; Milligan and Morbey 2016).

Hegemonic Masculinity

Connell's seminal work in 1995, proposed multiple masculinities. Of these 'hegemonic masculinity' was posited as the dominant masculine ideal promoted within western society, at the expense of other non-hegemonic forms (Connell and Messerschmitt 2005). In Connell's theory, masculinity was characterised as strong, independent and competitive. It encouraged dominance and control over others, and the subordination of women was legitimised. Hegemonic masculinity underpins the socially constructed gender stereotype of expectations of men to not express emotions and remain strong and self-sufficient even in the face of stress or hardship (Pleck 1981; Rollero 2016).

Hegemonic masculinity is the idealised form of masculinity in western society. Men are socially supported to live up to these roles and expectations and are punished (through social ostracism) when they are unable to (Connell and Messerschmitt 2005). Ultimately this can be detrimental to men's health and wellbeing (O'Neil 2008a). As described in Paper 1 (section 2.3), O'Neil's (1981b) Gender Role Conflict (GRC) is a component of hegemonic masculinity. GRC is the term used to describe the conflict experienced by men that occurs when they contradict expected masculine norms by engaging in behaviour which has traditionally be seen as feminine (such as crying, seeking help or sharing emotions) (Levant 2011). Thus, a conflict may exist for men who are attempting to reconcile constructions of traditional masculinity with their caregiving role.

Baker *et al.* (2010) used the Gender Role Conflict Scale (O'Neil *et al.* 1986) to investigate older male caregiver's perceptions of strain and gain within their caregiving role. Study findings suggested that men who had traditional beliefs about masculinity were more likely to say that a) they're not feeling burdened, b) they feel uncertain about caring, c) they are more likely to articulate positive aspects of caring. Findings in Baker *et al.*'s study also supported the suggestion that because some male caregivers equate care as a feminine activity, they may struggle to construe themselves

within a caring role, which can result in a reluctance to access support services (Baker *et al.* 2010).

More recent literature has demonstrated how an identification with Connell's hegemonic masculinity can impact on men's experience of caregiving. This was evidenced in a qualitative study by Milligan and Morbey (2016). Authors explored older men's experiences of spousal caregiving in their UK study ($n=15$), and concluded that how men undertook their caregiving role and how society responded to them as caregivers (i.e. as independent and self-reliant) impacted on their masculine identity. A more recent investigation of cancer caregiving spousal experiences revealed that male caregivers viewed asking for help as incompatible with their masculine identity, and consequently were reluctant to seek assistance for themselves (Judd *et al.* 2018).

Although theories of Connell and O'Neil provide important insight into western norms of masculinity, the degree to which men adhere to this can depend on other contextual factors such as age, culture or sociodemographic background, and on the basis of this some authors have rejected Connell's theory. Connell's hegemonic masculinity theory has been criticized for being simplistic, therefore Connell and Messerschmit (2005) further developed the theory to incorporate costs, benefits and challenges of hegemonic masculinity. However, the theory was still criticised for being too rigid and not considering aspects of men's emotional lives, or vulnerabilities, particularly in a world where younger men are encouraged to be nurturing (Seidler *et al.* 2016). Other theorists have acknowledged the dichotomy of theorising men's power whilst also recognising and including men's vulnerability, especially within the caregiving literature.

More recently, Hanlon (2012) highlighted the importance of integrating power and dominance with emotional aspects of men's lives in order to provide a comprehensive understanding of the lived realities of men's lives. In his 'caring masculinities' theory (2008), Hanlon argued that masculinities could be categorised into three types, depending on how they related to caregiving and paid work. The first type of masculinity was 'conventional', whereby men's masculinity was defined through paid

work, and there was an expectation that females undertake care work. Secondly, 'sharing' men achieved a balance of paid work and caring role and viewed this as a way to maintain their sense of masculinity. The final category was 'carers', these men did not define masculinity through paid work, rather they had a strong commitment to caring, and viewed caring as 'nurturing'. Elliott (2016) further developed the concept of 'caring masculinities' from a feminist perspective, by developing a framework proposing a focus on relational and positive emotion rather than dominance or control (Elliott 2016). By examining the actual practice of caregiving men, caring masculinities integrates values of care into masculine identities. Given that participants in the current study (older male caregivers) are likely to have grown up during a time when gender roles were very defined, the impact of 'blurred' gender roles as a result of changing social gender norms should also be acknowledged within the theoretical framework. More recent theories appear to be highlighting a more 'fluid' social construction of masculinity which recognises the emotional side of men's lives. Given evidence suggesting that men who identify with traditional hegemonic masculinity 'norms' feel pressure to conform to these 'norms', a more fluid approach may result in less pressure to conform, and flexible approaches to caregiving. This would be an important consideration in the development of future caregiver support, especially in relation to younger male caregivers, or men who do not identify with traditional hegemonic masculinity ideology.

It could be argued that an emphasis on caregiver identity, as opposed to masculinity would be more appropriate as a framework for the current study, therefore Caregiver Identity Theory (Montgomery 2007) was given some consideration. In Caregiver Identity Theory (2007), Montgomery described caregiving as a systematic process of identity change from a pre-existing family relationship to one of a caregiver/care recipient relationship, resulting in caregiver burden. However, given that older male caregivers tend to not identify as caregivers (Milligan and Morbey 2016), preferring instead to identify as husbands, it was considered that the usefulness of Caregiver Identity Theory for the current study was limited.

Rationale for using masculinity theory in the current study

Theories of masculinity were thought to be a suitable framework for the current study for a number of reasons. Firstly, even though more recent theories of men and masculinity have been developed, the theme of hegemony continues to be a central and influential theme in such theories (for example Duncanson 2015). Connell's theory continues to be used in contemporary studies to explain how masculinity impacts on informal caregiving (Milligan and Morbey 2016; Judd *et al.* 2018; Barken and Simms-Gould 2018). Secondly, social constructionism advocates masculinity as a social construct which is maintained by social structures. This paradigm places men in a fluid, context dependant situation, where the ideals of masculinity (stoicism, independence) are related to their environment. Connell's hegemonic masculinity theory emphasised that gender was a social practice and described patterns of 'gender order' (or the 'norm') most frequent in western society, as constructions of masculinity differ around the world (cf. Bannon and Correia 2006; Ruspini *et al.* 2011). Finally, *older* male caregivers may have a tendency to align with traditional hegemonic masculinity values (Calasanti *et al.* 2013). Hegemonic masculinity is positioned as a proponent of traditional male ideals (such as strength, independence, stoicism), and rejection of feminine traits (such as expression of emotion or asking for help). Thus, traditional theories of masculinity provided a theoretical underpinning for the present study.

2.5 Exploring gender differences in caregiving through coping strategies

The concept of burden has long been associated with caregivers' experiences as a way to describe the physical, emotional and economic consequence of providing care (Gaugler *et al.* 2000). Evidence shows that caregiving psychological outcomes are related to coping strategies (Snyder *et al.* 2015). Whilst a lack of studies on caregiver coping strategies for male caregivers has been identified (Snyder *et al.* 2015; Spindelov *et al.* 2017), there are some indications that gender-based differences in caregiving coping exist. Therefore, it would be important to examine the impact of coping through an exploration of various coping strategies and their impact on caregiver outcomes.

It has been reported that a ‘task oriented’, or ‘problem-focused’ approach is employed by male caregivers, where there is a tendency to focus on finding solutions to problems. Lazarus and Folkman (1984) argued that problem-focused coping involved taking action to change the relationship between individuals and their environment. By contrast it is argued that female caregivers employ more of an ‘emotion focussed’ approach whereby they focus on reducing their level of emotional distress (Snyder *et al.* 2015). This style includes wishful thinking, ‘counting blessings’ or talking therapies to alleviate stress (Calasanti and King, 2007; Geiger *et al.* 2015; Snyder *et al.* 2015, Hong and Coogle 2016). Folkman and Moskowitz, (2004) explained that coping strategies were not essentially good or bad, rather that positive or negative consequences resulted depending on the stressor, and how it was evaluated by the individual.

Caregiving approaches were illustrated in a study by Milligan and Morbey (2016) who documented how older male caregivers relied on experiences from their previous working lives to apply problem-solving to their caregiving role. Authors illustrated how some participants had a ‘can do’ attitude as a result of training in the armed forces, or their scientific backgrounds. Other strategies included finding part time work, activity away from the home, or trying to maintain a weekly routine similar to life before illness. Authors concluded that how men coped with their caregiving role was not only significantly linked with their masculinity but could also pose challenges to their masculinity. Older male caregivers in that study addressed those challenges by re-affirming their masculinity through drawing on skills previously used in employment.

Stress process models

Studies such as Milligan and Morbey are theoretically rooted in stress process models (Lazarus and Folkman 1984; Pearlin and Lieberman 1981). These models have been widely used to explain how stressful events can result in maladaptive responses, and consequently lead to negative outcomes. Pearlin *et al.*’s model (1981) detailed the process whereby caregivers evaluated situations, in relation to background variables, and primary stressors such as challenges associated with care recipients’ illness (such as behaviour), or secondary stressors, such as how the caregiver viewed their role. As

part of this evaluation, caregiver resources (such as social and other forms of support) were also considered. When there was a perceived mismatch between a caregiving demand and available resources for meeting this demand, negative caregiving outcomes such as anxiety or depression could result. Thus, a key determinant of the stress process model was not the stressor itself (i.e. behaviour) but the caregiver's appraisal of its impact.

Pearlin's model was originally applied in a study examining coping strategies and relational aspects of care with older male caregivers ($n=363$) by Ducharme *et al.* (2007). In this Canadian study Ducharme and colleagues identified primary and secondary stressors for older caregiver husbands. Subjective stressors such as role overload, relational deprivation, quality of marital relationships and family conflict were all linked with psychological distress. Thus, Ducharme *et al.* concluded that subjective stressors were predictive of caregiver outcomes. A more recent study by Geiger *et al.* (2015) used secondary data from a study conducted in the United States with older male Alzheimer's caregivers ($n=138$), the aim of which was to explore the effect of coping strategies on caregiver burden through self-report questionnaires. Even though study findings revealed that male caregivers employed a task focused approach to their caregiving role, in relation to the effect of this approach on psychological outcome, further complexities were highlighted. Regarding outcomes such as caregiver anxiety and depression, task focused coping did not appear to alleviate these outcomes. Given that task focused coping depends on creating attainable goals (Folkman and Moskowitz 2000), it was possible that study participants failed to create achievable goals (therefore using task focused coping ineffectively), with no consequent alleviation of caregiver burden. Other evidence highlighted a lack of information and training for male caregivers, it is therefore possible that if male caregivers had adequate information and training, this may have been enough to enable them to create achievable goals and therefore task focused coping may have been more effective in reducing burden. Thus, Geiger *et al.* (2015) concluded that task focused coping could decrease caregiver burden but only if it was employed effectively and if male caregivers received support which maximised this type of coping (i.e. information and training). Stress process theories suggest that coping is enhanced, and stress reduced when the individual is in a position to re-appraise the situation either by

gaining new information or resources to deal with the ‘stressor’. Potential stressors could therefore be mediated by additional support/resources.

Many of the studies exploring older men’s coping strategies in their caregiving role have been within the context of Alzheimer’s Disease. However, Spendelow *et al.* (2017) examined older male caregivers coping strategies within the context of chronic medical conditions in the United Kingdom through a systematic review of the literature ($n=16$). Authors suggested that male caregivers utilised a range of coping strategies, broadly defined as either traditional or flexible. They maintained that within the ‘traditional’ approach, male caregivers identified with traditional hegemonic masculinity, within their caregiving role and were more prone to using traditional masculine traits such as focussing on practical tasks and avoiding emotion, therefore utilising a task focused approach. Spendelow emphasised that this approach may be linked to an attempt by men to ‘promote their worth’ among peers, or to gain additional confidence or competence in a role which is largely viewed as feminine. By contrast male caregivers who were defined in the study as ‘flexible’ tended to attempt to expand identity and behaviour beyond traditional masculine norms, thus challenging masculine traits. Examples of this included men taking on non-traditional roles such as providing personal care for their spouse or seeking help from others. Spendelow noted that the adoption of non-traditional behaviours was demonstrated in other domains of men’s lives and suggested that ‘flexibility in coping’ was important due to its link with psychological well-being. Spendelow concluded that a focus on positive masculinity (that is, supporting the approach to masculinity in an adaptive rather than a restrictive way), would enable male caregivers to utilise coping strategies that resulted in positive caregiver outcomes.

2.6 Conclusion

This chapter positioned the study within existing relevant literature and theoretical domains. It provided a basis for the development of the thesis argument by illustrating previous research evidence that outlined how caregiving could be perceived as a gendered concept, influenced by social and cultural norms. How these impact on older male caregivers with regard to their caregiving approach and existing support structures and processes is key in this study. Underpinned by the broad overview

presented in this chapter, a more focused examination of support needs of older male caregivers was provided in Paper 1 (section 2.3): *Examining the support needs of older male spousal caregivers of people with a long-term condition: a systematic review of the literature*'.

The next chapter will present an account of the study methodology. This will show how the philosophical underpinnings influenced decisions about study design and methodology, along with an in-depth explanation of the mixed methods study design.

CHAPTER THREE: METHODOLOGY

3.1 Introduction

The previous chapter described literature relevant to the subject area together with an overview of the theoretical framework which underpinned the study. The aim of this chapter is to present key elements of the research design and methodology. The first section describes the philosophical assumptions which guided the study, and the researcher's ontological, epistemological and methodological approach. The focus of the second section is on mixed methods research, including rationale for this approach and application to the study. In the third section a summary of sampling and recruitment is presented, followed by data collection, analysis, rigour, and finally, ethical considerations. Further detail regarding specific data collection and analysis methods are included in the chapters relating to each phase (chapters four and five).

3.2 Philosophical underpinning of the study

Creswell and Creswell (2018) advised that researchers should make explicit the philosophical ideas they espouse as part of the research plan. This is important in order to explain their choice of research approach (i.e. qualitative, quantitative or mixed methods). Therefore, the following section will explain the rationale for choosing a mixed methods research approach. The researcher's ontological, epistemological and methodological positions will demonstrate how these positions have informed research design and methodology and addressed the aims of the study.

A research paradigm has been defined by Guba as 'a basic set of beliefs that guides action' (Guba 1990: 17). This basic set of beliefs about the world is chosen by a researcher and informs research development and design. Thus, philosophical paradigms provide structure for the research by informing methodologies and giving insight to a research problem. Traditionally, researchers have aligned with either qualitative or quantitative design and methodology. Qualitative researchers, who typically have an inductive approach generally fall within the 'constructivist' approach, whereas deductively driven quantitative researchers generally align with 'post-positivism'. It was previously suggested that each distinct method offered a unique insight into a research problem and could not be mixed with any other method

(Johnston and Onwuegbuzie 2004). However, mixed methods research where qualitative and quantitative methods are mixed in order to investigate a research problem has gained popularity in recent years (i.e. Plano Clark and Creswell 2008; Creswell and Plano Clarke 2011), even though the lack of corresponding philosophical paradigm has proved problematic. This has been addressed in literature with the identification of pragmatism as a suitable underpinning paradigm for the mixed methods design (Morgan 2007; Teddlie and Tashakkori 2009; Johnson and Gray 2010; Creswell and Plano Clark 2011).

Pragmatism is adopted when researchers are concerned with moving '*towards solving practical problems in the real world*' (Feilzer 2010, p.8). Researchers often choose a pragmatic stance in order to address research questions that do not fit within either a singular qualitative or quantitative approach. Pragmatism has increasingly gained support over the past decade (Johnson and Onwuegbuzie 2004; Morgan 2007; Feilzer 2010), although it has also drawn criticism. For example, Foss and Ellefsen (2002) highlighted the complexity of combining qualitative and quantitative approaches since they came from different epistemological perspectives. The current study adopted a pragmatic approach with a mixed methods design. Within this design quantitative data relating to the use of support services by older male caregivers was collected through the distribution of a survey to community-based organisations. This provided important baseline contextual information about the frequency and nature of support services accessed. Subsequently, qualitative data was collected through interviews with older male caregivers and focus groups with support providers. This qualitative data provided explanations and further insight into the impact of support services in identifying and meeting the needs of older male caregivers caring for a chronically ill spouse/partner at home. Therefore, the qualitative data provided the predominant conceptual contribution to the phenomenon under investigation.

The focus on gender and how it related to men's experience of their caregiving role within this study influenced the decision to use a framework of masculinities in order to better understand how older men might reconcile constructions of masculinity with their caregiving role. Furthermore, given that gender relates to socially constructed performances that are underpinned by accepted male/female norms or behaviours (Connell and Messerschmitt 2005), a social constructionist perspective was applied to

the study. Not only does social constructionism advocate masculinity as context dependant and dynamic, but this view also holds that masculinity is reinforced and reproduced by social processes and institutions (Bottorff *et al.* 2015). Given that caregiving has been traditionally positioned within gendered cultural practices and associated with mainly feminine behaviour, an examination of how masculinity intersects with private and social processes within a caregiving context through social constructionism is appropriate. Creswell and Creswell (2018) suggested that the goal of research which has been informed by a social constructivist view was to rely as much as possible on the views and experiences of the research participants. Humans make sense of the world based on their historic perspectives. Thus, in the current study, the researcher sought to investigate the phenomenon within its own context (in the field) and gathered information personally. Also, the researcher's interpretation was shaped by her own experiences and background. This was influenced by the researcher's belief that identity is socially constructed and is reinforced by societal processes and systems, set within an evolving culture and context. The researcher's epistemological position aligns with interpretivism. Due to her previous experiences of managing support services for family caregivers (section 1.2), and a growing recognition that current support services weren't meeting the needs of older male caregivers, the researcher sought to gain a deeper understanding of this issue. Thus, an interpretive approach accommodated the researcher's desire to develop explanations about this issue from the perspective of participants lived experiences.

3.3 Overview of mixed methods research

The current study employed a mixed methods research design. Creswell and Plano Clarke (2007) asserted that a mixed methods design was one that provided a better understanding of research problems than either approach used in isolation. Essentially mixed methods research involves the collection and analysis of both quantitative and qualitative data, integrating data in a certain way to deepen understanding about the topic under investigation, or identifying new areas for research (Creswell and Plano Clarke 2011). According to Teddlie and Tashakkori (2009), the combination of surveys and interviews in a study provides a more complete picture that can result in enhanced theory development and/or practice. This allows the researcher to view the research phenomenon from different perspectives and has also been reported to be an

effective method for triangulation of data (Tashakkori and Teddlie 2003). Six main types of mixed methods design are detailed in Table 2 to illustrate key differences in approach (Creswell and Plano Clarke 2011).

Table 2: Six designs of mixed methods research

DESIGN NAME	PRIORITY	SEQUENCING	INTEGRATION
SEQUENTIAL EXPLANATORY DESIGN	Typically, quantitative but can be either.	Two phase design with quantitative data being collected first.	Interpretation stage.
SEQUENTIAL EXPLORATORY DESIGN	Typically, qualitative but can be either.	Two phase design with qualitative data being collected first.	Interpretation stage.
SEQUENTIAL TRANSFORMATIVE DESIGN	Can be either.	Theoretical perspective of researcher determines order of data collection.	Interpretation stage.
CONCURRENT TRIANGULATION DESIGN	Can be either.	Data collected concurrently on one phase.	Either analysis or interpretation stage.
CONCURRENT NESTED (EMBEDDED) DESIGN	Priority is given to the approach that guides project. Other approach is nested within.	Data collected concurrently.	Typically, the analysis stage.
CONCURRENT TRANSFORMATIVE DESIGN	Can be either, depending on the theoretical perspective of the study.	Data collected concurrently.	Either analysis or interpretation stage.

According to Creswell and Plano Clark (2011) the aims of each design differ, based on how and when data is collected and how it is integrated. For example, the concurrent nested design involves collecting and analysing quantitative or qualitative data along with a secondary data set. Alternatively, the concurrent triangulation design involves collecting two types of data concurrently and analysing separately. A third mixed

methods design, exploratory sequential, involves initially collecting qualitative data followed by the collection and analysis of quantitative data. This method is most suitable for the development of new tools such as surveys, classifications, or variables. The design chosen for the current study was explanatory sequential. Creswell and Plano Clark (2011) assert that in this design, quantitative data collection and analysis is followed by qualitative data and analysis, and that the data collection phases are linked together by using the quantitative data to inform the qualitative data, questions and sampling (Creswell and Plano Clark 2011). In the current study this was demonstrated through initially collecting quantitative data using a survey, the results of which informed the development of subsequent qualitative phases.

3.4 Rationale for using mixed methods in the current study

As described in the last section, a key strength of using mixed methods research is to combine the strengths of both quantitative and qualitative data. Furthermore, combining data from a 'variety of sources that do not share the same weakness' (Craig *et al.* 2008), can add strength to the study. According to Creswell and Plano Clarke a further strength of this approach is that it can add credibility to findings by integrating the methods, as well as providing the study with structure (quantitative data) and process (qualitative data) (Creswell and Plano Clarke 2011). Although studies using only quantitative methodology can add important understanding of a phenomenon, they can lack insight to findings. For example, Ducharme and colleagues provided descriptive findings to deepen understanding of the caregiving experience of older husbands, however a lack of elaboration may have limited the study findings and avenues for further research (Ducharme *et al.* 2006). Given that the aim of the current study was to explore the impact of support services in identifying and meeting the needs of older male spousal caregivers, it was considered important to firstly gauge the extent and scope of support services in Northern Ireland, in order to establish a baseline of support resources offered. Subsequent data collection involved an exploration of the ways in which support needs were identified and met, from the perspective of older male spousal caregivers and from statutory and community-based support service providers.

Mixed methods research involves resolving certain issues by making decisions in three main areas: 1) Which data collection approach takes priority in the study - quantitative or qualitative? 2) How is the data collection and analysis sequenced? 3) At what point is the data integrated/mixed? In the current study, these decisions were determined by factors such as the research questions and overall purpose of the study along with consideration of relevant methodological discussions in the literature (Tashakkori and Teddlie 1998; Creswell *et al.* 2003). Table 3 depicts how these issues were resolved.

Table 3: Resolution of key issues

Issue to be resolved	Resolution
Priority (the weight or attention each approach received throughout the data collection and analysis) (Morgan <i>et al.</i> 1998)	Typically, within explanatory sequential mixed methods, the quantitative aspect is given priority. However, depending on the research goal, scope of qualitative and quantitative research questions, and design of each phase priority may be given to the qualitative data (Morgan <i>et al.</i> 1998). In the present study, priority was given to the qualitative data because this provided rich in-depth insight to the experiences and motivations of older male caregivers and their use of support services, and the perspectives of support providers and stakeholders on the effectiveness of support in meeting these needs. Also, although the quantitative data collection was robust, it resulted in only descriptive statistics.
Sequencing (whether the qualitative and quantitative data and analysis occur in sequence or concurrently) (Morgan <i>et al.</i> 1998)	The aim of the first phase of the current study was to establish a baseline of the scope of support provided by the community/voluntary sector in Northern Ireland. This was achieved through a survey to collect quantitative data. On the basis of these results qualitative phases were sequenced in order to inform subsequent phases. Findings from the qualitative phases provided understanding about caregiving experience and motivation for engaging with support, thus helping to explain results from the initial phase.
Integration (stage where the integration of the quantitative and qualitative methods occurs) (Tashakkori and Teddlie 1998)	In the current study the quantitative and qualitative data was connected at intermediate stages of the study by the preliminary findings of the initial phases informing the development of subsequent phases (Hanson <i>et al.</i> 2005). For example, the development of some of the interview questions for the qualitative phases were based on the results from the initial quantitative phase (survey data). Ultimately, integration of results from the quantitative and qualitative data occurred through interpretation of results from the entire study.

Rationale for using explanatory sequential mixed methods

The six mixed methods designs detailed in section 3.3 (Table 2) were considered at the research design stage of the current study. The exploratory sequential method could not be selected as the purpose of this design is to explore unknown variables with the aim of developing an instrument. Likewise, since the aim of the embedded design was to improve experiments this was also not suitable. The three concurrent designs described (concurrent triangulation, concurrent nested and concurrent transformative) were also rejected as in these methods data was collected concurrently and not sequentially. The aim of the current study was to explore the impact of support services in identifying and meeting the needs of older male caregivers caring for a chronically ill spouse/partner at home. The explanatory sequential design was considered to be most appropriate to meet this aim since data from a range of perspectives was required, and was gathered sequentially, with initial phases informing subsequent phases.

The sequential explanatory design in the current study comprised distinct phases (Table 4) - the collection of quantitative followed by the collection of qualitative data. During the first study phase a survey was used to collect quantitative data. Although the data provided precise numerical results, it did not provide depth or richness of data. Thus, the quantitative data was a driver for subsequent phases comprising interviews with older male caregivers, focus groups with support providers and a deliberative workshop with key stakeholders.

3.5 Data Collection and analysis

Specific details on data collection tools and methods will be outlined in chapters four (section 4.4 and section 4.9) and chapter five (section 5.4 and section 5.10). The current section will explain the rationale for choice of tools and methods.

Rationale for choice of data collection methods and selection of tools

Each study phase involved a separate data collection (Table 4, p. 71). In phase 1, a survey was designed to collect information about caregiver support services provided by community-based agencies across Northern Ireland. A survey was chosen over other methods of data collection for a number of reasons. Primarily, it has been suggested that surveys were a simple and effective method of gathering data in order

to explore concepts or to describe populations (Taylor *et al.* 2015). In addition, given the structured nature of questions, respondents may have difficulty in deviating from the point, therefore they are reliable in terms of consistency.

However, surveys also have disadvantages. As Parahoo (2014) pointed out, there is no opportunity for the respondent to clarify any questions or information, which may result in misinterpretation of questions. Furthermore, the researcher cannot be sure about the quality of the responses, as it may be completed in a superficial way, with some questions not being answered, or by the respondent conferring with someone else (especially if the respondent has literacy difficulties). Finally, low response rates are a well-known problem with surveys. This may be due to 'question fatigue', especially common amongst health and social care personnel, who are asked to take part in research on a regular basis. However, there are certain strategies which can be employed to improve response rate, such as making contact with the respondent to let them know that they will be receiving the survey or ensuring that the survey is short and easy to respond to. The popularity of using surveys as a data collection method suggests that the benefits outweigh the costs, and some of the disadvantages can be overcome through planning, piloting and survey design (Parahoo 2014, p. 294).

In phase 2, interviews were used to gather data from older male caregivers about their caregiving experience. Semi-structured face-to-face interviews were selected over other types of research methods for this phase for the following reasons: 1) semi-structured interviews allow for an in-depth exploration of a chosen subject, with the minimum prompts from an interview guide (Bowling 2009); 2) due to the sensitivity of the subject nature, it was thought that face-to-face interviews would enable interview participants to speak frankly about their caregiving experience in a confidential and supportive environment. Corbin and Morse (2003) highlighted the key features of semi-structured interviews as their usefulness for researching areas that were complex or sensitive; flexibility that allowed researchers to pursue emergent themes; and that they allowed researchers to explore the perceptions of individuals, and all the possible ways that respondents experience the phenomena being studied.

In phase 3 focus groups were used to gather data about the perspectives of formal support providers regarding support for older male caregivers. Several reasons influenced the decision to use focus groups as a data collection method for this phase of the study. Firstly, analysis of data generated from the male caregiver interviews about their experience of receiving external support resulted in preliminary findings. It was evident from findings that external support providers needed to be engaged in discussion about their experience of delivering support services to older male caregivers, in order to shed light on some of the points raised by interview participants. Secondly, the aim of the focus groups was to generate deeper understanding of motivations, behaviour, opinions and other factors that influenced the delivery of support from formal support providers to older male caregivers.

The aim of phase 4 was to facilitate reflection and discussion of the study's findings and contribute to the development of strategic recommendations relating to support services for older male caregivers through a deliberative workshop with key stakeholders. The reasons for using this approach were two-fold. Primarily, a desire to include a stakeholder group who could deliberate on study findings to improve 'quality and breadth' of information from the study that would inform study recommendations (Bennett *et al.* 2004). Secondly, bringing diverse groups together (caregiver support providers from the statutory and community sectors; funders; policy makers; academics; older male caregivers) may provide opportunities to challenge, adding credibility to study findings.

Data collected across all phases is summarised in Table 4.

Table 4: Data collection across all phases

Phase 1	Scoping Exercise: In accordance with the second study objective of identifying gaps in provision of support for older male caregivers this phase comprised a scoping exercise with a range of key stakeholder organisations using a survey.
Phase 2	Caregiver Support Needs: Study objective three was to explore the support needs of older male caregivers caring for someone with a chronic long-term condition. Therefore, during this phase data were gathered by conducting one-to-one interviews with 24 older male caregivers.
Phase 3	Service Provider Focus Groups: Phase 3 explored the elements of, and barriers to, support services for older male caregivers by undertaking focus group interviews with personnel from HSC and community-based support agencies, consistent with study objective four.
Phase 4	Deliberative Workshop: Study objective five was to synthesise key issues and make recommendations in relation to support services for older male caregivers through a deliberative workshop. Therefore, phase 4 consisted of a deliberative workshop to facilitate reflection and discussion of the study's findings in order to meet this objective.

Achieving data integration

A phased approach to the study allowed data collection and analysis to occur sequentially, and data integration took place mainly during the methods level of research (Creswell *et al.* 2011). Specifically, data was integrated through 'building' - that is, procedures from one stage in the process are used to build latter stages (Fetters *et al.* 2013). An example of this in the current study was when results from the quantitative phase (survey), shed light on older male caregivers use of community-based services, and was therefore included in the interview schedule for the interviews with older male caregivers. At latter stages, 'merging' also occurred when data from all phases were brought together for comparison. This is further described in Chapter 6 (section 6.2). A visual representation of data integration is presented in Figure 1.

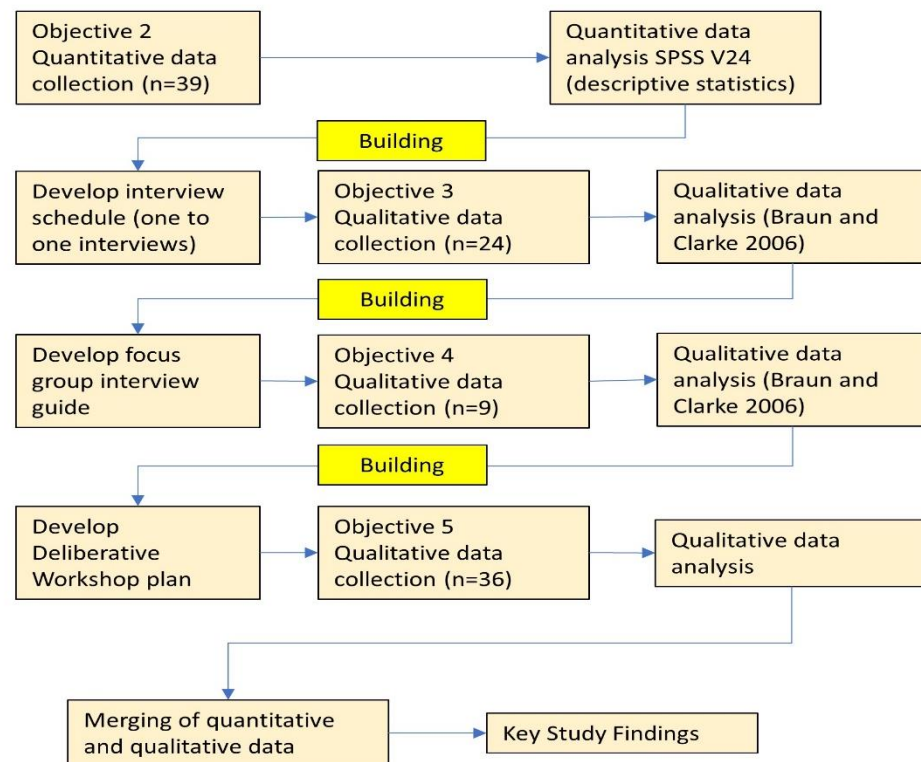


Figure 1: Visual representation of mixed methods design and stages of integration.

3.6 Sampling overview

Specific detail on the sampling approach for the survey and male caregiver interviews will be outlined in chapter four (section 4.3 and 4.8), and for focus groups and deliberative workshop in chapter five (section 5.4 and 5.9) respectively. The following section provides a broad overview and rationale for the sampling process and offers some practical examples of how this was applied in the study. For the initial quantitative phase (survey), the total population of community-based agencies offering support to caregivers were targeted.

For the subsequent qualitative phases of this study the sampling process was informed by: 1) eligibility criteria; 2) sample size (through consideration of theoretical and practical concerns); and 3) sampling strategy.

- 1) **Eligibility Criteria:** A set of inclusion and exclusion criteria must be specified in order to target a certain population group (Luborsky and Rubinstein 1995). Thus, for the qualitative study phases ‘older male spousal caregivers’ was a key criterion in eligibility criteria.
- 2) **Sample Size:** For phase 1 (quantitative data), the total population of community-based agencies offering support to caregivers were targeted. For phases two and three (qualitative) an approximation of size was agreed for each phase (with upper and lower limits). This size was flexible enough to enable the required resource allocation, to monitor data collection as it progressed, and to alter the size if necessary (on theoretical or practical grounds) (Silverman 2010).
- 3) **Sampling Strategy:** A purposive sample was chosen for all study phases. In phase 2, interviews continued until data saturation was reached; in phase 3 a mix of community-based and statutory organisations were included; and in phase 4 the sample identified key stakeholders. The reason for this was to ensure that either older male caregivers, or key stakeholders of older male caregivers were included in data collection as they had a unique understanding or perspective on the phenomenon being studied (Mason 2002).

3.7 Recruitment overview

As mentioned in section 1.2, the researcher’s previous career as Carers Co-Ordinator entailed managing services for family caregivers within in a Health and Social Care Trust. This role involved working relationships with health and social care practitioners, personnel with community-based agencies (such as Alzheimer’s Society and Chest Heart & Stroke), informal caregivers, and regional colleagues. These established relationships were a starting point for distribution of the survey (phase 1), recruitment for male caregiver interviews (phase 2), focus groups with formal support providers (phase 3) and the Deliberative Workshop (phase 4). Further detail about recruitment strategies is provided in chapters four and five (see sections 4.8 and 5.9). The study was also promoted through press releases, social media, and relevant newsletters, which resulted in study participants coming forward to express interest. A project steering group was convened for the duration of the study. The aim of this group was firstly to ensure Patient and Public Representation (PPI) in the study, and secondly to ensure ownership by individuals and agencies that extended beyond

academics (Pizzo *et al.* 2015). The group comprised representatives from HSC Trusts, community-based agencies, academics and a male caregiver.

3.8 Data analysis

Detailed data analysis procedures are provided in chapters four and five (see sections 4.4, 4.10 and 5.5, 5.10) and describe analysis techniques for each study phase. Computer assisted data management and analysis was employed throughout the study. For quantitative analysis this involved the use of Windows SPSS V24 qualitative data management software to generate descriptive statistics. For qualitative data, transcriptions were uploaded to QSR NVivo 11 and 12 qualitative software for data storage, management and code development.

Narrative analysis was initially considered for analysis of semi-structured interview transcripts. Narrative inquiry has been described as the study of stories and storytelling (Sarvimaki 2015), and it has previously been used as a way to provide deeper understanding and insight into the everyday lives of caregivers (Wiles 2003, Tretteteig *et al.* 2017). Previous authors have applied it due to its relevance for examining event sequences (such as hesitations or utterances during interviews). However, the main focus of interviews in the current study was to identify common themes across all participants in order to establish gaps in support services and common caregiving experiences. Therefore, narrative analysis was excluded as a method and thematic analysis was chosen. Due to its flexibility and prior application to healthcare and caregiver studies thematic analysis was used throughout the study to generate codes and themes inductively (Braun and Clarke 2006).

To ensure rigour other analytic techniques were employed, such as the use of 'Post-It' notes (Appendix 1) and mind maps (Appendix 2) to assist with the visualisation and interpretation of data. Qualitative analysis was underpinned by theories of masculinity and coping strategies, and adopted a social constructivist stance. Initial coding across all phases was conducted by the study author (AF). Emerging codes and themes were discussed with academic supervisors and the project steering group, and new codes/themes were identified through an iterative process. An overview of study design is presented in Figure 2.

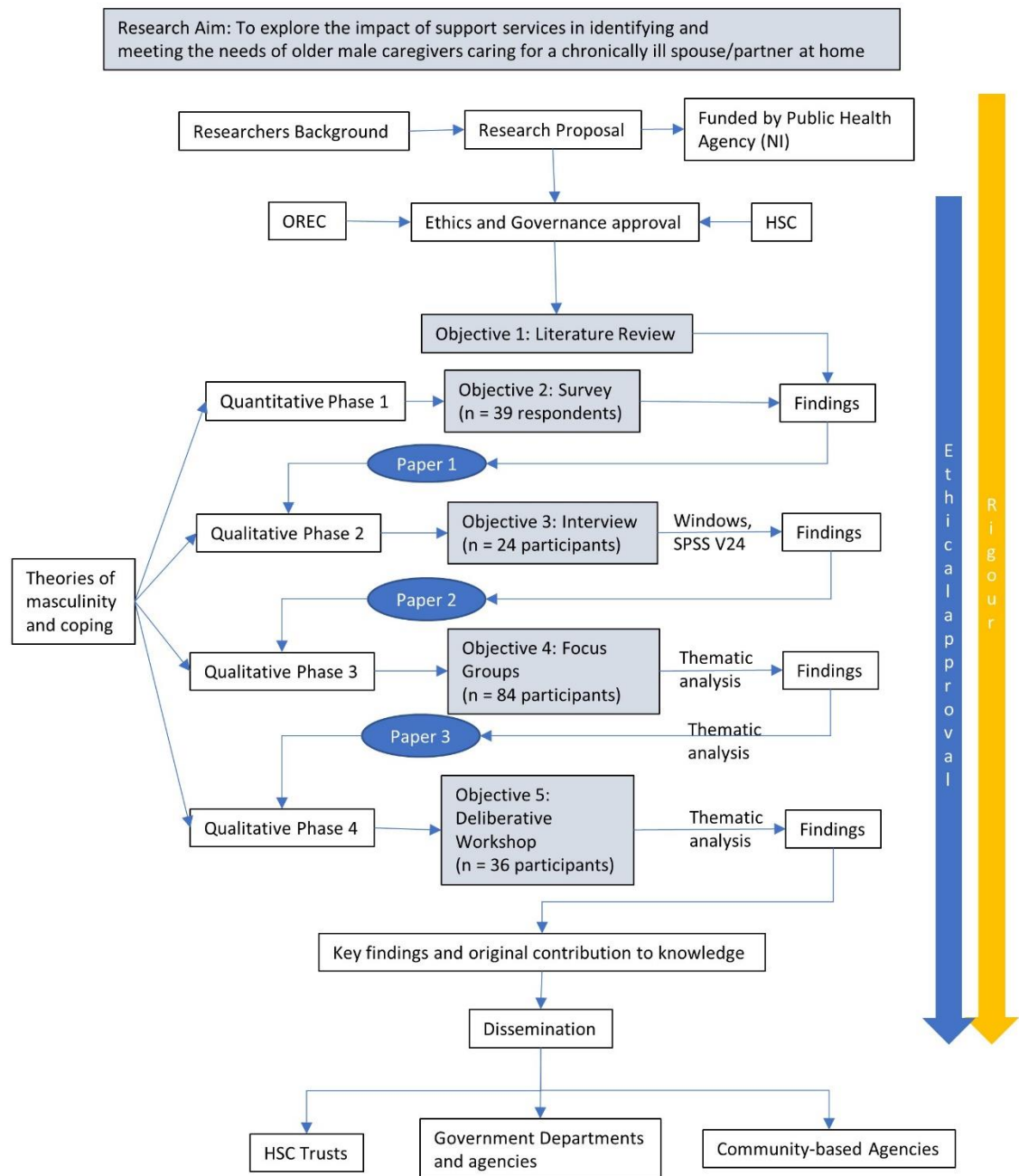


Figure 2: Study design

3.9 Ethical considerations

Ethical and governance approvals

Ethical approval for all study phases was sought and granted. Details of ethical and governance approval for each phase is contained in Table 5.

Table 5: Ethical and governance approvals for all phases

Phase	Ethical Approval	Date	HSC Governance Approval Number
Phase 1 Survey of community-based agencies in Northern Ireland	Ulster University School of Nursing, Research Ethics Committee (17/0021)	14/03/17	NA
Phase 2 Interviews with older male caregivers	Ulster University School of Nursing, Research Ethics Committee (17/0021)	24/03/17	NT 17-0558-04. 27/06/17
	OREC (NI), NHS, Health Research Authority (17/WM/0119)	26/04/017	
Phase 3 Focus Groups with statutory and community-based personnel	Ulster University School of Nursing, Research Ethics Committee (17/0021)	5/10/18	NT 18-0638-10. 13/11/18 WT 18/27 01/11/18 SET.18.30. 31/01/19
Phase 4 Deliberative Workshop	Ulster University School of Nursing, Research Ethics Committee (17/0021)	5/10/18	NT 18-0638-10. 13/11/18 WT 18/27 01/11/18 SET.18.30. 31/01/19

How ethical considerations were applied to study phases

Informed consent

According to Corbin and Morse (2003) a researcher's skill, experience and personal attributes have the potential to diffuse any upsetting or embarrassing interviews. This was echoed by Parahoo (2014) who stressed the importance of interviewer behaviour. Specifically, it is vital that before interviews take place, potential participants need as much study information as possible, and enough time should be given for participants to decide whether to take part. In the current study (phases 2 - 4) this involved two stages. During the first stage, information sheets containing details such as study background, confidentiality, data storage, and contact details of research team and complaints procedures were supplied to potential participants. Stage two involved supplying consent forms to be signed prior to data collection. The researcher reiterated key aspects of the study before the consent forms were signed. Completed forms were kept in a locked filing cabinet in a locked office that only the researcher could access.

Researcher safety

In line with the University lone worker policy, the researcher adhered to measures to ensure her safety during interviews and focus groups. This included telling a family member where the data collection was taking place and an estimated start and end time; keeping a fully charged mobile phone at all times; and maintaining awareness of possible risks.

Confidentiality

In line with the Data Protection Act 1998, and the General Data Protection Regulation 2018, the privacy and confidentiality of all study participants was protected. Examples included only collecting required personal data; informing all participants about how data would be used and stored; ensuring all audio recordings and documentation was stored on an encrypted computer, in locked University premises that only the research team could access; and the use of pseudonyms to replace participant's real names.

Participant welfare

Participants sometimes feel pressure to become involved in research either because they know the health professional involved, or they have been (or are currently) in receipt of services. Interviews can also potentially violate privacy if the participant discloses information that they did not mean to. The interviewer is responsible for ensuring that this is not the case. Measures put in place to mitigate these risks in the current study included a recruitment strategy that included social media and press so as to not entirely depend on health professionals recruiting participants; participant information given at several points throughout the recruitment and interview process (when the study was advertised, when initial contact was made with the researcher, and again immediately before the interview commenced). The researcher took time to answer any questions or provide clarification to all interview participants when necessary.

In recognition that interviews with older male caregivers in phase 2 had potential to raise sensitive issues for the participants a 'Distress Protocol' (Appendix 3) was implemented and adhered to. Also, in recognition that the researcher undertaking the interviews was female and participants were male, time was spent during the interview in establishing and maintaining rapport. Rapport was established in a number of ways such as making contact before the interview, arriving on time, and engaging in general conversation before the interview. During the interview rapport was maintained by observing body language and non-verbal responses, such as facial expressions.

3.10 Conclusion

The focus of this chapter was on the study design and methodology. The chapter began by presenting a justification of philosophical assumptions which guided the study, and the researcher's ontological, epistemological and methodological approach. The second section in the chapter outlined a rationale for employing explanatory sequential mixed methods approach including details about priority sequencing and integration of data over the four study phases. The final section of the chapter comprised an overview of data collection and analysis methods; sampling and recruitment; and ethical considerations and approval. This section was intended to provide general background context and rationale for specific decisions, with more specific details

about data collection and analysis; sampling and recruitment for each study phase presented in chapters four and five. The next chapter, chapter four, provides details of phases 1 and 2 of the study.

CHAPTER FOUR: SCOPING SURVEY AND QUALITATIVE INTERVIEWS

4.1 Introduction

This chapter is divided into two sections. The first section details the initial study phase - a Scoping Survey. A summary of background and context frames the status of support services offered by community-based agencies in Northern Ireland and will set the scene for the initial phase. This will be followed by methods, data collection and analysis, before findings of the first phase are presented. The second section presents an overview of the second study phase - semi-structured interviews with older male caregivers. In this section there is a description of methodology and findings from this phase as well as an outline of rigour and trustworthiness measures informing the phase. A more detailed account of the first theme in findings from phase 2 are detailed in paper 2: *'When it faded in her, it faded in me': A qualitative study exploring the impact of spousal intimacy for older male caregivers.* Finally, a conclusion for this phase is drawn before a summary of the chapter is given.

Phase 1 – Scoping Survey

4.2 Background and local context

This section provides context to the status of community-based agencies in Northern Ireland. This is followed by details about the development, distribution and results of a survey which aimed to scope the extent and level of support for older male caregivers from community-based agencies, in order to provide a regional benchmark for these services within Northern Ireland.

Support offered by community-based agencies

Also known as non-governmental organisations or third sector organisations (Wilson, Lavis and Guta 2012), community-based agencies are non-statutory, non-profit organisations (including charities) that work at local level. The importance of community-based agencies has been previously recognised as a mechanism for providing an advocacy role within health and social care (Blas *et al.* 2008; Carey and

Braunack-Meyer 2009), and increasingly for their involvement in research to inform policy and practice (Sanders *et al.* 2004). There were a number of reasons for involving these agencies in the current study. First, the researcher had previous experience of working with community-based agencies, and recognised the contribution that they made to caregiver support (often with caregivers who were not known to statutory services), thus to not include them in a scoping exercise about the range of support offered to caregivers would be a significant omission. Second, Chillaig *et al.* (2002) noted that because community-based agencies were situated within local communities, they were best placed to understand the needs of constituents. Finally, Milligan and Conradson (2006) suggested that due to the constitutional and funding independence of community-based agencies, they were likely to act in the best interests of the public rather than the government.

Community-based agencies offer a range of support services to people who live with long term conditions and their caregivers. Agencies are funded by local Health Trusts, National Lottery, government or charitable donations. Some groups may be national (United Kingdom based), regional (Northern Ireland based, with small local branches) or local (only existing in one area). The range of support offered through these groups can include social events/peer support; counselling; stress management; information provision about illness progression; short breaks; benefits, welfare and legal advice.

4.3 Methods

Survey design

As mentioned in section 3.5, in the current study a survey was thought to be the most appropriate method of deriving quantitative data to establish a baseline of the status of caregiver support in Northern Ireland. In line with a mixed methods approach, this data could be used to inform the collection of subsequent qualitative data.

The aim of the survey was to explore the type and level of support offered by community-based agencies to older caregivers (male and female) with a specific focus on older male caregivers. The objectives were to:

1. Document the nature and range of support services provided for older caregivers;

2. Document the nature of support services that were provided specifically for male caregivers;
3. Identify barriers in providing support for older male caregivers.

The researcher sought to identify pre-existing surveys which could be adapted for use in the current study, however, no other established questionnaires or instruments in this topic area could be identified. Therefore, a survey was developed by the researcher based on the study aims and literature review (in liaison with an Ulster University Life and Health Sciences librarian). Survey design was guided by Krosnick and Presser (2010), who suggested that survey development should be based upon the best practice in experience and methodological research. Other more detailed elements of guidance from Krosnick and Presser were integrated into the survey design. For example, the researcher acknowledged that in terms of asking respondents to specify the numbers of male caregivers using a particular service, recall error may be minimised by asking respondents to recall numbers over the previous month rather than the previous year.

The survey comprised fourteen questions (ten quantitative and four qualitative) in three distinct sections (Appendix 4). The first section invited participants to give background and contact details about their organisation; the second section related to services offered to all caregivers; and the third section related specifically to male caregivers. Variables in the quantitative questions were developed in partnership with Health & Social Care Trust Carers Co-Ordinators. As described in the introductory chapter (Section 1.2) Carers Co-ordinators work closely with community-based caregiver support agencies and have expertise in the range of support services offered. Quantitative questions therefore included various types of support that may be offered to caregivers, for example written information, befriending, training and stress management. Original versions of the survey invited respondents to answer questions relating to services used by female caregivers, followed by questions about services used by male caregivers. However, feedback from the pilot stage indicated that community-based agencies may not be able to provide detail on the use of their services based on gender (given that some agencies had no male members), therefore this question (Question 5) was changed to ask which support services were provided in general. Then, to facilitate the agencies who could provide gender specific detail,

further questions were added (questions 6-8) that focussed on types of support services used by male caregivers.

Qualitative questions were included in the questionnaire in order to provide context, and to give respondents the opportunity to include their own perceptions of support needs of older male caregivers. The content of qualitative questions was informed by relevant literature about male caregiver support (Milligan and Morbey 2013; Greenwood and Smyth 2015). Based on this, the following questions were included in the questionnaire: 1) *'Are you aware of any particular difficulties experienced by men caring for their spouse/partner with a long-term chronic condition. If so, what?'*; 2) *'Please use the space below to add anything else you would like us to know about providing support to older male caregivers'*; 3) *'Would you like to know more about the unique needs of male caregivers by being kept updated about the progress of this research?'* 4) *'Would you like to add anything else?'*

It is also noteworthy that the survey was developed with consideration of the range of agencies/individuals who would be responding. For example, an individual volunteer living in a local community setting, and offering support to family caregivers through a support group (i.e. 'xxxx Church Carers Group') would receive the same questionnaire as a national organisation with paid staff, and more resources (i.e. Alzheimer's Society). Pilot testing ensured that the survey was equally suitable for both types of group.

Pilot testing the survey

After initial development, the survey was pilot tested to ensure rigour and relevance. The aim of the pilot stage was to ensure that recipients could interpret the questions as intended; that the survey took the time stated in the cover letter to complete; and that suggested answers in the 'tic box' format covered all options available.

The pilot comprised two stages. The first stage involved piloting with HSCT Carers Co-Ordinators, project steering group, and key academics. During this stage, the draft survey and cover letter were emailed to the HSCT Carers Co-Ordinators for feedback. An additional two academics (not part of the project steering group), both with

expertise in statistics and survey design also provided feedback on design and content. To ensure rigour, the second stage of the pilot involved liaison with an Alzheimer's group in another location that would not be used in the main survey. Four individuals who ran groups that included caregivers completed the survey, three by email and one by phone. This was thought to be a suitable approach, as the Alzheimer's Society in Donegal could give relevant feedback about the content and process of the survey, however, they would not be part of the main sample (as they are based in Donegal, Ireland).

A summary of the changes that were made as a result of the pilot is contained in the following table.

Table 6: Summary of changes after pilot testing

<i>FIRST PILOT FEEDBACK CHANGES</i>	
CARERS CO-ORDINATORS	Estimated time for completion of the survey was changed. Requests for specific detail about female caregivers and male caregivers were changed to facilitate agencies who had no male members. Question number reduced from 15 questions to 12.
STEERING GROUP	Additional information was added about confidentiality and data management. Additional information about availability of data and survey results was added to cover letter.
ACADEMICS	Changes made to questions to encourage respondents to give answer in 'rank' order. Changes made to wording of some questions – i.e. 'how many' changed to 'how many in past month'. Flow of questions was confusing, and repetitive, therefore four questions were condensed into two.
<i>SECOND PILOT FEEDBACK CHANGES</i>	
ALZHEIMER'S SOCIETY OF IRELAND	Additional question added to the survey regarding geographical area covered. Option for support by email was added to survey.

Feedback from the pilot study indicated that it took respondents between eight and thirty minutes to complete the survey. Changes were therefore made to make questions more concise. One of the main changes made during the initial pilot was to add a rank order, however, this posed problems for respondents during the second pilot phase, because they reported that they found the question either difficult to understand or difficult to rank (because they did not have access to relevant information). The decision to keep the question about rank order was made, because it was thought that the level of different types of support, as well as the frequency of support would be valuable in subsequent analyses. However, the question wording was changed, to attempt to lessen any confusion.

Sample and recruitment

The survey was distributed to all community/voluntary based agencies in Northern Ireland who offered support to adults with long term conditions and their caregivers, and to groups who provided support to caregivers only.

The sample was identified in liaison with the regional Trust Carers Co-Ordinators. Given Carers Co-Ordinators' familiarity with existing caregiver support services, it was considered that this group would be best placed to advise on the contact details in order to populate the database of organisations who would receive the survey. After the pilot stage, Carers Co-ordinators were asked (via email) for information relating to support services for caregivers, specifically any handbooks, directories or lists of groups within the community/voluntary sector who provided support for caregivers (within adult services). Carers Co-Ordinators returned information including caregivers' directories, information booklets and contact details of caregiver support organisations which represented all Trusts across Northern Ireland.

The aim of the study was to explore the impact of support services in identifying and meeting the needs of older male caregivers caring for a spouse with a chronic long-term condition. When the information was received, the researcher scrutinised each carer booklet or list of support groups and excluded the contacts that were not relevant (groups supporting caregivers of children; learning disability groups; Autism Spectrum Disorder groups). The above groups were excluded as a) they related to

caregivers who looked after children, and b) they did not meet the definition of chronic long term condition, as outlined in the survey: '*A condition that has developed over time, and that cannot, at present, be cured but can be controlled by medication and other therapies (examples: Dementia, Parkinson's Disease, MS, Motor Neurone Disease, Cancer, COPD, Stroke, Depression, Brain Injury).*'

In addition to the information supplied by Carers Co-Ordinators, the researcher also searched the internet for information about caregiver support through large voluntary organisations, delivered at a local level – specifically: MS Society, Parkinson's UK, Alzheimer's Society, Chest Heart & Stroke as some of this information was missing from the information supplied by Carers Co-ordinators. An Excel spreadsheet was populated with the group's name, contact details, and information about when the survey was distributed and returned.

4.4 Data collection and analysis

Data collection

Sixty-two surveys were distributed to community-based agencies in Northern Ireland who were known to offer caregiver support on 4th July 2017, along with a letter containing further study information (Appendix 5). The sample included small independent caregiver support groups as well as larger umbrella groups with a number of local branches. After initial contact had been made with the group by telephone, the survey was either emailed or posted. On 26th July and 10th September reminders were emailed to groups who had not responded. Thirty-nine completed surveys were returned yielding a response rate of 63%. Respondents were invited to return the survey by email ($n=28$), by post ($n=10$), or with the researcher over the telephone ($n=1$). Types of groups who responded ranged from large UK organisations (i.e. Parkinson's UK), to Northern Ireland regional groups (i.e. Age NI), to small locally based independent groups (i.e. Church Carers Support Group). A summary of respondent characteristics is included in Table 7.

Table 7: Survey respondent characteristics

Ident- ifier	Type of Group	Area Covered	Ident- ifier	Type of Group	Area Covered
1	<i>Dementia</i>	<i>Local</i>	21	<i>Cardiac Support</i>	<i>Regional</i>
2	<i>Carer Support</i>	<i>Local</i>	22	<i>Cardiac Support</i>	<i>Regional</i>
3	<i>Carer Support</i>	<i>Local</i>	23	<i>Stroke</i>	<i>Local</i>
4	<i>Carer Support</i>	<i>Local</i>	24	<i>Respiratory Support</i>	<i>Regional</i>
5	<i>Cancer Support</i>	<i>Regional</i>	25	<i>Respiratory Support</i>	<i>Regional</i>
6	<i>Carer Support</i>	<i>Local</i>	26	<i>Stroke</i>	<i>Regional</i>
7	<i>Carer Support</i>	<i>Local</i>	27	<i>Stroke</i>	<i>Regional</i>
8	<i>Huntington's Disease</i>	<i>Regional</i>	28	<i>Mental Health</i>	<i>Regional</i>
9	<i>Parkinson's Disease</i>	<i>National</i>	29	<i>Carer Support</i>	<i>Local</i>
10	<i>Dementia</i>	<i>Regional</i>	30	<i>Stroke</i>	<i>Regional</i>
11	<i>Carer Support</i>	<i>Local</i>	31	<i>MS</i>	<i>Regional</i>
12	<i>Arthritis</i>	<i>Regional</i>	32	<i>Mental Health</i>	<i>Regional</i>
13	<i>Brain Injury</i>	<i>Regional</i>	33	<i>Dementia</i>	<i>National</i>
14	<i>Older Age</i>	<i>Regional</i>	34	<i>Dementia</i>	<i>National</i>
15	<i>Parkinson's Disease</i>	<i>Local</i>	35	<i>Dementia</i>	<i>National</i>
16	<i>Carer Support</i>	<i>Local</i>	36	<i>Dementia</i>	<i>National</i>
17	<i>Cancer Support</i>	<i>Regional</i>	37	<i>Dementia</i>	<i>National</i>
18	<i>Disability Support</i>	<i>National</i>	38	<i>Dementia</i>	<i>National</i>
19	<i>MND</i>	<i>Regional</i>	39	<i>Dementia</i>	<i>National</i>
20	<i>Carer Support</i>	<i>Local</i>			

Data analysis

Quantitative Data: Quantitative data were cleansed, coded, and entered into Windows SPSS quantitative data management software (version 24). Missing data were identified and replaced with the code '99' in the SPSS dataset. This analysis generated only basic descriptive statistics due to the small sample size.

Qualitative Data: A thematic approach was used to analyse qualitative data. Data were coded, and main themes were identified. Data generated by the two qualitative questions resulted in two overarching themes.

Validity and reliability

Fowler (2014) described survey validity as the relationship between the variable being measured and the respondent's answer, that is, the degree to which the survey measured what it claimed to measure. Reliability is the extent to which respondents in similar situations provided similar answers to questions (Fowler 2014).

Measures taken to enhance validity and reliability in the current study included piloting the survey and having it reviewed by an external academic (a qualitative researcher), who checked for face and content validity. Also, the literature was searched to identify similar surveys, in order to inform the development of the current survey, however, as previously noted, no similar surveys could be identified.

4.5 Results

Results are reported in relation to first, the provision of support resources; and second the uptake of support resources.

Quantitative data

Regarding the number of older male caregivers using community-based agencies, Figure 3 illustrates that in the past month, community-based agencies showed that their membership comprised 18% male caregivers. It is therefore noteworthy that the sample of caregivers within respondent organisations was overwhelmingly female. In terms of support offered to all older caregivers, the survey asked, '*Which types of information and support do you provide for caregivers?*'. Respondents indicated services by ticking boxes from a range of options. Support services comprised a range of practical and emotional support measures and were categorised as: written information (including: leaflets, website, newsletter), and other forms of support (including: befriending, respite, counselling and training).

Figure 4 illustrates the extent of types of support offered to all caregivers by community-based agencies. Results showed that the most common type of support offered by agencies was ‘Peer/Social’ at 23.5%, this was closely followed by ‘Online/Phone Advice’ (21.3%), written materials (19.1%), and therapeutic support (16.4%). The least commonly offered type of support was training (1%), followed by short breaks (respite care) (2%).

In relation to *utilization* of these services by caregivers, Question 5 on the survey invited respondents to indicate how many older caregivers had used particular services (i.e. website, counselling, training) in the past month. Results for this question are illustrated in Figure 5. The most frequently used service in the past month was ‘Peer/Social’ with 27.4% of caregivers using this service. The least frequently used was ‘Training’ with only 2.5% of older caregivers having used this in the past month. Therefore, the most frequently offered and most frequently used service by the older caregivers who responded to the study (mainly female) was Peer/Social support (which included befriending, support groups, peer support).

Figure 6 shows information for survey question number 8, which asked ‘*Which type of supports are most utilised by male caregivers?*’. Results showed the number of male caregivers who used particular services in the past month. The most popular category was Peer/Social with 23.70% of male caregivers using this in the past month, followed by therapeutic support (19.2%), and then online support (17%). ‘Short breaks’ (respite care) were the least used, with only 1.48% of male caregivers availing of this in the past month. Only one organisation said that they offered support specifically to male caregivers.

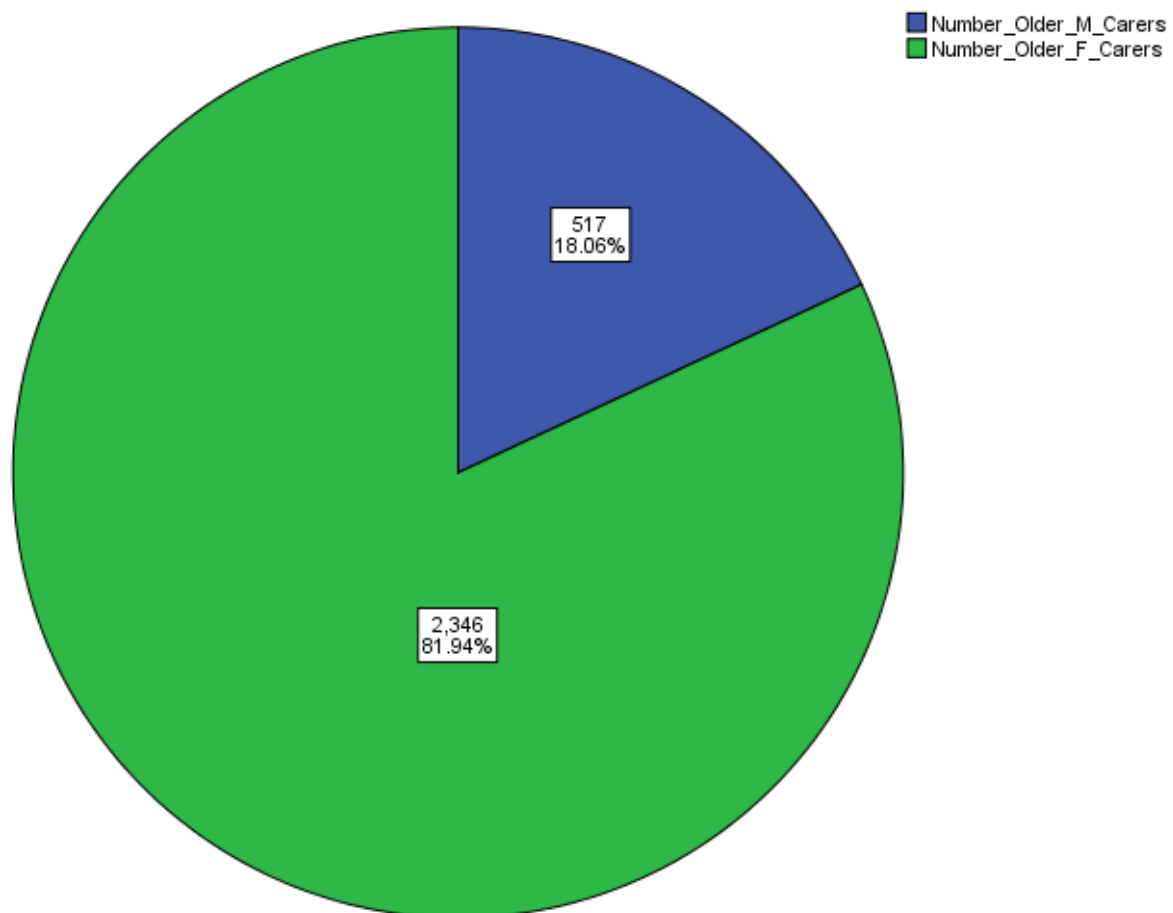


Figure 3: Numbers of older male and female caregivers represented

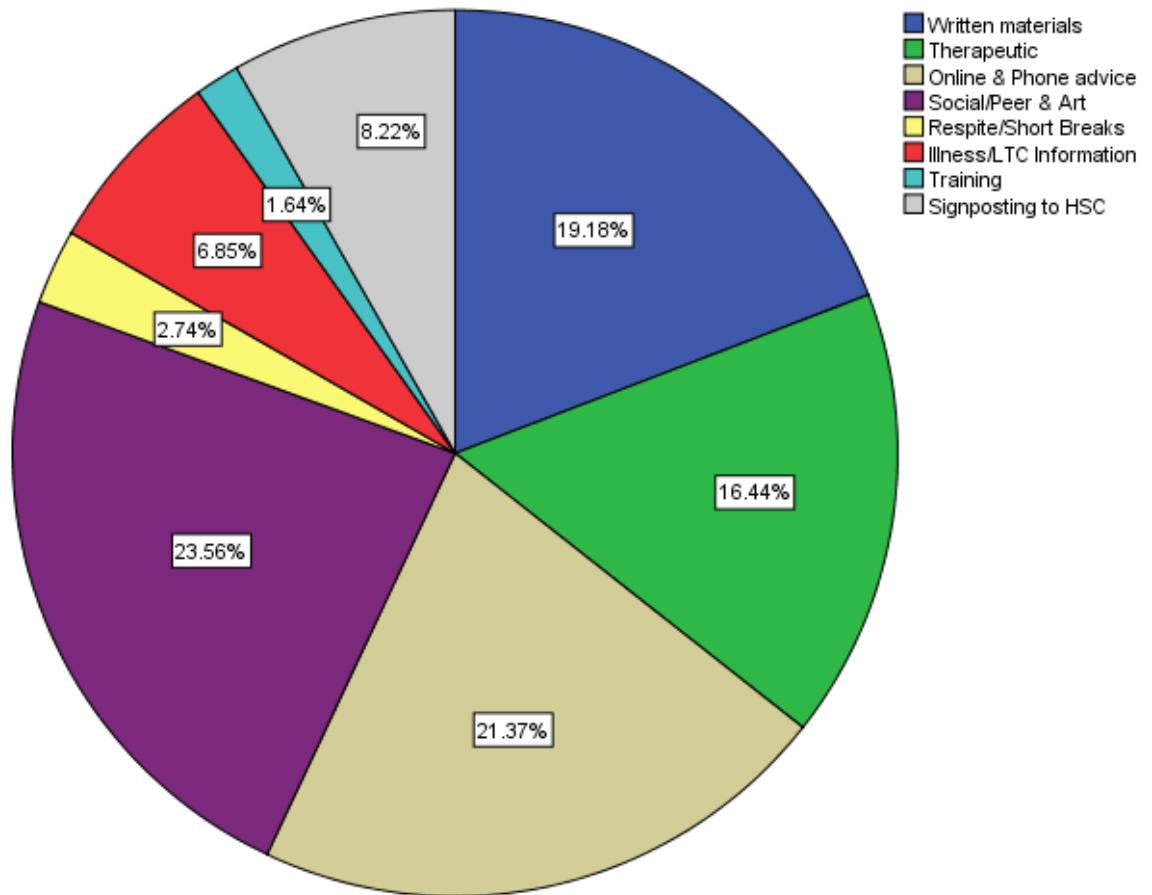


Figure 4: Most common type of support offered to all older caregivers

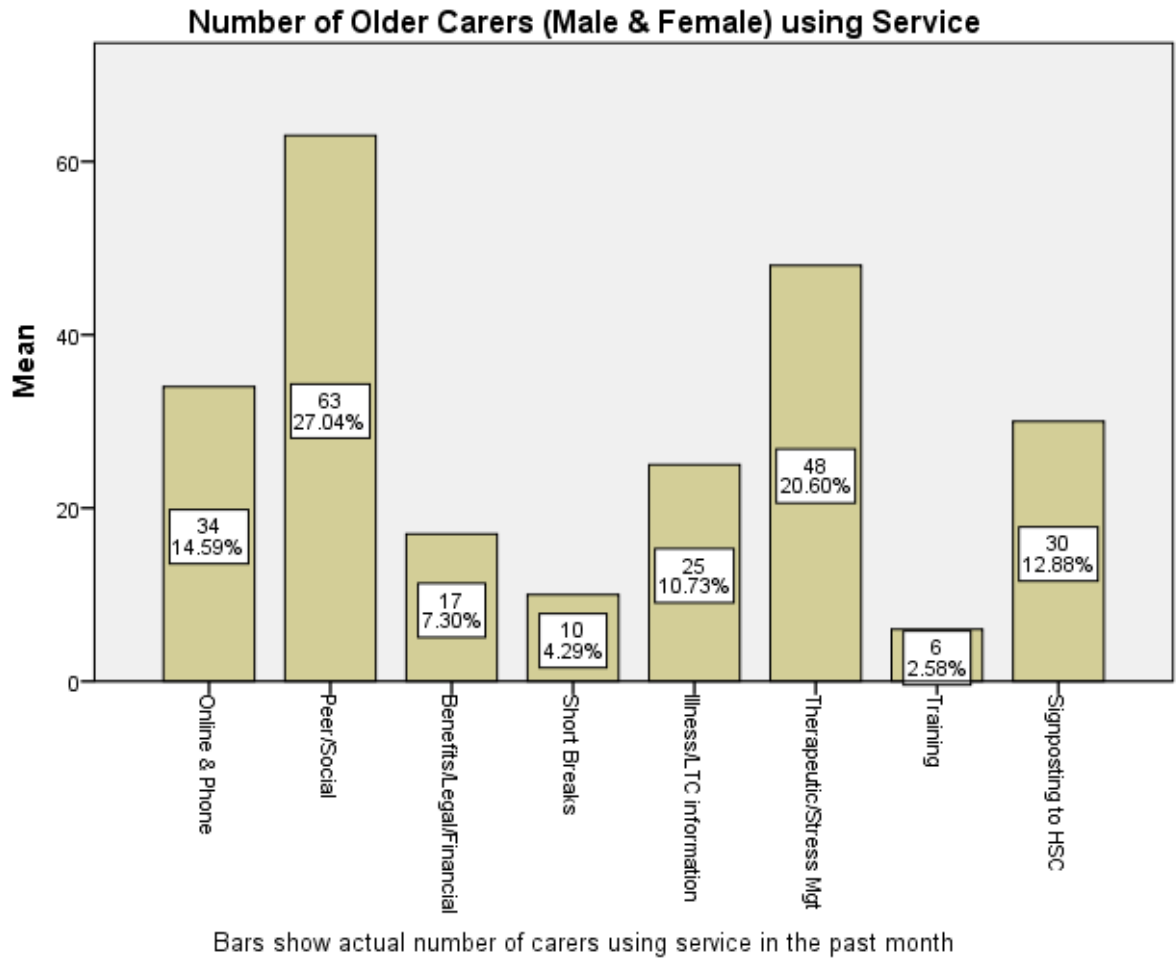


Figure 5: Number of older caregivers (male and female) using services

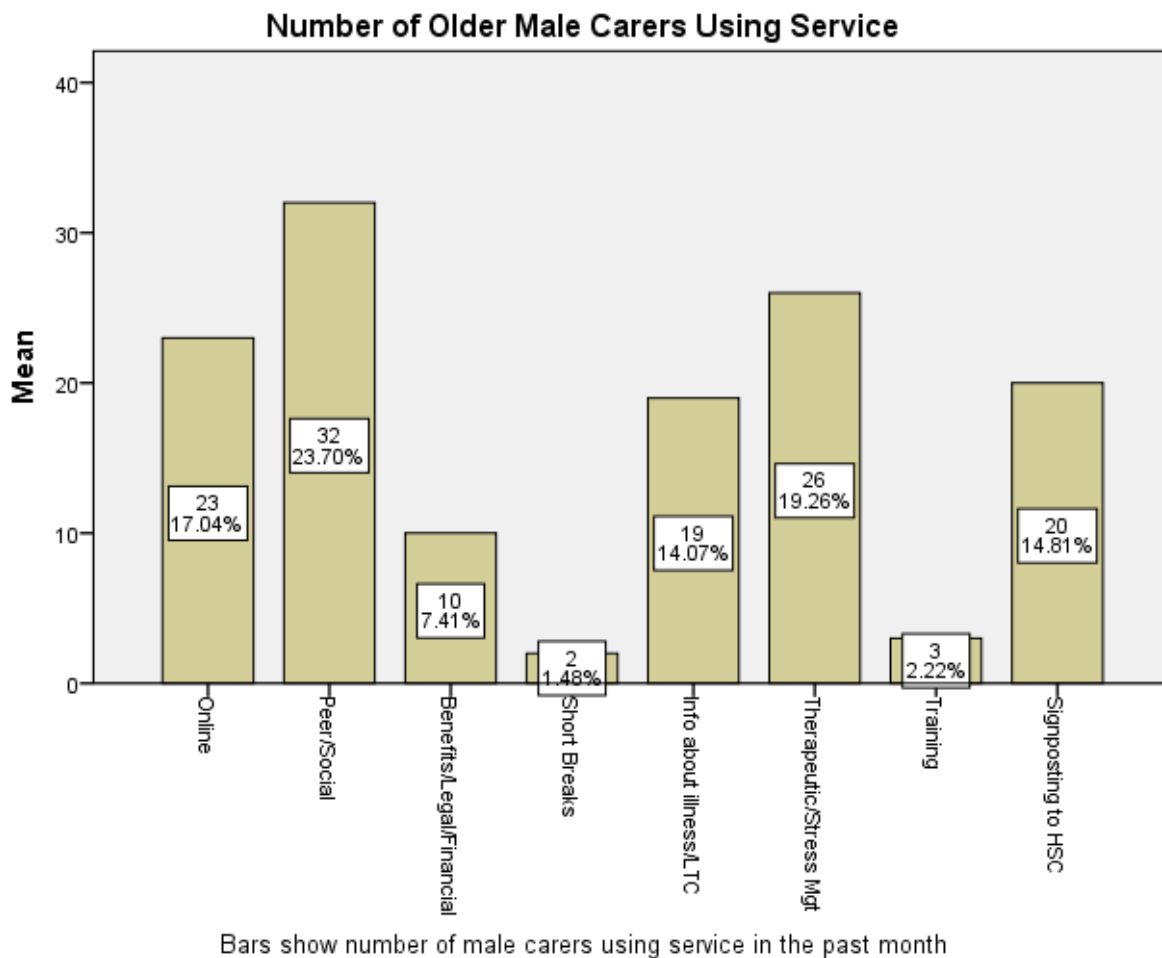


Figure 6: Number of male caregivers using services

Overall, quantitative results indicated that there were fewer male caregivers using peer and social support, than in the mainly female group. Also, there were more male caregivers using online, signposting and illness information support than those in the mainly female category. Finally, male caregivers used less short breaks (respite care) than the mainly female category.

Qualitative Data

Two questions in the survey invited respondents' views of the particular difficulties experienced by men caring for a spouse with a chronic long-term condition, and also anything else about support provided for male caregivers. Qualitative data were subject to thematic analysis. Direct quotes used to illustrate examples of findings were attributed to the type of organisation (i.e. local, regional or national) in order to preserve anonymity of survey respondents. The key themes that were identified from

data were: 1) communication with older male caregivers; 2) isolation of older male caregivers.

Theme One: Communication with older male caregivers

Ten community-based agencies reported that, in their view older male caregivers *'are normally harder to engage'*. Others reported that older male caregivers were reluctant to ask for help, or less aware of support services, which on occasion may have resulted in crisis.

'They tend not to talk about their personal struggle, change of role, lack of friendship... try to cope without assistance'. (Regional agency)

'Male carers can initially be reluctant to accept support. Many often report feelings of guilt in wanting the support-this can often lead to crisis situation as they may not be able to communicate their problems until situation is unmanageable'. (Regional agency)

Although some respondents commented that in their view, men generally were slow to come forward for help, another agency suggested that they were more likely to ask for help around the more practical issues.

'They may source help to cope with practical issues but are reluctant to express any emotional difficulties and at times appear 'detached'. (Regional agency)

However other agencies noted that the environment for supporting men was an important factor in providing support, suggesting that men would prefer to be with other men for support.

'In our experience men want to talk to other men, and although we have had a couple of men coming along to our group, they didn't stay, as there were too many women!' (Local agency)

'I have been asked in the past by a male carer (when I had invited him to my monthly carer support group) are there any other men attending? When I had told him yes, he seemed happier to attend. He wanted male company and perhaps wouldn't have felt as at ease if it was all women attending'. (National agency)

Theme Two: Isolation of male caregivers

Several respondents suggested that their view of male caregivers was that they were isolated. This may have been because men tended to have less extensive social networks than women, or that their ability to maintain friendships was lessened as a result of their caregiving role, which could potentially have compounded their isolation.

'Feeling of isolation. Difficulty keeping on top of everything in terms of caring role, maintaining house and family and work if still employed. Can also be financial difficulties. Men sometimes do not have the same support networks as women so it can be difficult. Older carers may also have their own health problems to manage' (Regional agency)

Other agencies suggested that a further compounding factor in older male caregivers' isolation was the lack of respite care, as described by two service managers:

'Yes - lack of respite facilities to allow male carers to be able to attend groups and activities which would be of interest to them. One male carer even reports difficulty in accessing respite to allow him to attend church.' (Regional agency)

'Difficulty getting out of the house. Some men cannot leave partner alone, so getting someone to sit with their partner can be difficult and then they feel guilty leaving their partner.' (Regional agency)

4.6 Summary

Sixty-two surveys were distributed to community-based agencies throughout Northern Ireland. Thirty-nine completed surveys were returned. After analysis, results indicated that the most common type of support service *offered* by community-based organisations for caregiver support (for male and female caregivers) was Social/Peer support. The most frequently *used* support service by male caregivers was peer/social support (which included befriending, support groups, peer support). Similarly, the most frequently offered and most frequently used support service by older caregivers (mainly female) was Social/Peer support. The support service that was least frequently offered by community-based agencies to older caregivers was training, and the support services which were least frequently taken up by male caregivers was short breaks,

closely followed by training. Key themes emerging from qualitative data were isolation, and difficulties in communicating with older male caregivers.

Findings from phase 1 illustrated a low uptake of community-based support services from male caregivers in Northern Ireland. Some evidence also indicated that when male caregivers did access support they were more likely to use online, signposting and illness information support; and less likely to use social/peer support than those in the mainly female caregiver group. Qualitative evidence showed that many community-based agencies are aware of specific difficulties of male caregivers in their role, however only one agency offered specific male caregiver support.

Phase 2 - Male Caregiver Interviews

4.7 Introduction

The previous section detailed the extent of support services provided by community-based agencies in Northern Ireland to older male caregivers. Phase 1 results highlighted low membership of male caregivers in community-based agencies, and low uptake of support from these agencies by male caregivers. These results informed the development of the current phase: Phase 2 – one-to-one interviews with older male caregivers. The aim of the interviews was to gain a better understanding of older male spousal caregivers' experience of providing care for their wives/partners who were living with a chronic long-term condition. This section provides an overview of the recruitment, data collection and findings of the individual interviews conducted with a sample of older male spousal caregivers.

4.8 Methods

Eligibility Criteria

The eligibility criteria for participants in the one-to-one interviews is highlighted in Table 8.

Table 8: Participant eligibility criteria

Males over the age of 65
Primary caregiver for a chronically ill spouse/partner
Living in the community (in Northern Ireland)
Given written informed consent

Sample and recruitment

A purposive sample of interview participants (Silverman 2004) was chosen for the study. The reasons being that a sample of a population with similar characteristics and situations was needed (older male caregivers caring for a spouse); and also that an appropriate sample was recruited in order to address the research question.

Relevant organisations within the statutory, and community/voluntary sector were contacted and encouraged to distribute a promotional flyer about the study to informal male caregivers who met the criteria (Appendix 6). Information was also circulated through social media (Appendix 7) and local press (Appendix 8), and interested individuals contacted the researcher to express an interest. If, after an initial phone-call potential participants were still interested, they were sent a participant information sheet in order to ensure that their decision to participate was fully informed (Appendix 9). The age range of the all-male sample was 61 – 83 years; further details of participants' characteristics are provided in Table 9. Although participant eligibility criteria stated that the age range was males over 65 years of age, one participant was included who was aged 61. It is noted that this was not as a result of recruitment issues, rather that the age of the participant was only discovered during the interview process. Four potential participants were excluded from the study after initial contact had been made. One because they resided outside the study site and three because they stopped communicating with the researcher, after initially expressing interest. Pseudonyms were used to protect anonymity.

Table 9: Participant characteristics

Participant	Length of time caring	Age of Caregiver	Age of partner	Length of relationship (years)
Clive	9 years	72	69	46
Simon	13 years	75	75	52
Sean	2 years	82	81	59
Dessie	8 years	73	75	49
Jack	4 years	68	66	39
Joseph	9 years	68	59	32
Robert	4 years	69	70	41
Gerry	14 years	61	54	27
Mark	7 years	65	61	40
Mike	4 years	76	76	51
Ian	22 years	70	65	42
Gary	6 years	66	66	33
Harry	8 years	81	78	60
Dan	6 years	66	68	38
Paul	3 years	81	78	54
Tim	4 years	79	77	56
Noel	2 years	72	60	16
Patrick	15 years	73	70	37
Bobby	5 years	68	63	41
Aidan	6 years	70	69	48
Andy	5 years	72	69	39
Berty	2 years	68	64	44
Colin	7 years	66	68	47
Alan	4 years	83	83	58

4.9 Data collection

An interview guide (Bryman 2015) (Appendix 10) was developed in line with the study objectives, findings from quantitative phase, relevant theory, and a review of the literature. The interview guide included questions and prompts which aimed to provide further insight to some of the findings from the quantitative phase (such as low membership of community-based agencies). As explained in section 2.4 (Theoretical Framework) theories of masculinity and coping were considered appropriate to use in order to explore male caregiving which is performed in a 'feminised landscape of care' (Milligan and Morbey 2016). Even though these theories informed the interview guide, it was also recognised that they may contain inherent bias which could potentially impact on findings. This was addressed by firstly, piloting the interview guide; and secondly, ensuring that the interview guide was flexible and included prompts to allow for other information

In order to maximise validity, the guide was developed in liaison with the project steering group. There was agreement between the research team and the steering group about the main topics to be covered in the interviews however, additional prompts and probes ensured that the researcher and interviewee could explore sensitive or important issues in more depth. The interview guide was piloted with two older male caregivers which resulted in two modifications to the original guide. These modifications included changing the order of some questions and including additional prompts.

Interviews were conducted between November 2017 and January 2018 and lasted between 45-90 minutes. Interviews were digitally recorded (with written informed consent), and took place either in the caregiver's own home, a community venue or a local day centre. Caregivers were interviewed alone. Consent to be interviewed was obtained during the initial telephone conversation, and informed written consent was obtained before the interview commenced (Appendix 11). Demographic information was also collected.

Ethical approval was obtained to interview between 15-25 participants. Mason (2010) advised that fifteen minimum and fifty maximum participants would suffice for sample size in most qualitative studies. However, it has also been speculated that the length of

interview, topic being studied, and depth of analysis were also influencing factors on sample size and when data saturation occurred (O'Reilly and Parker 2013d). For the current study, data saturation was reached after 24 interviews when no new themes or information emerged (Green and Thorogood 2009). The aim of the interviews was to gain a better understanding of older male caregivers' experience of providing care for their wives/partners who were living with a chronic long-term condition. The interview guide provided a broad framework in which to explore caregiving experience, including support needs, utilisation of support services, information, and coping mechanisms. Field notes (Appendix 12) were completed by the researcher after each interview to record the interview experience and any data which would not have been apparent from the interview transcript - for example, body language and emotions.

4.10 Data analysis

Inductive thematic analysis was adopted for this phase for the following reasons: 1) It is widely used in healthcare and caregiver studies; 2) Thematic analysis is a flexible approach to analysing qualitative data, which can be used in its own right or as a process which is performed within a different analytic tradition (Braun and Clarke 2006). The process of analysing began during data collection, as the researcher was noticing recurring themes during the semi-structured interviews. Notes were made about these observations in the field notes. To further develop the analytic framework, the six steps outlined in Braun and Clarke (2006) were followed in the process of analysis:

Step 1:

Familiarisation with the data. Interviews were transcribed verbatim and transcripts were checked against the original digital recording. The researcher also used this exercise to make notes on the transcripts about non-verbal occurrences, including emotional responses (for example laughter, crying, despondency). The researcher actively read and re-read each transcript, to appreciate the scope of the content, and to begin the process of identifying recurrent themes, patterns and relationships. No codes were generated at this stage; however informal notes were taken.

Step 2:

Initial ideas were generated based on the researcher's interpretation of the most interesting data elements such as beliefs, motivations, barriers, facilitators, and values. These initial ideas were manually recorded on transcripts and written on post-it notes (Appendix 13). The post-it notes were attached to the wall and sorted into broadly similar groupings.

The second part of this phase involved using QSR NVivo (11) qualitative data management software, to code the data in a similar way to the previous stage. The coding process in NVivo was systematically applied to the data set, with the aim of identifying repeated patterns with relevance to the study aims, theoretical context, and other key literature. Codes included: 'Identification with 'caregiver''; 'getting on with it'; 'loneliness'; 'emotional support'; 'marriage vows'. A second researcher (AR) checked the codes against data to enhance rigour and credibility (Quinn-Patton 2002). Steps in analysis were discussed amongst researchers at regular meetings.

Step 3:

The list of codes was sorted into potential themes, and the coded data extracts were collated within identified themes using NVivo. The use of a mind map provided a way to illustrate connections and patterns between codes, and themes, and enabled the researcher to continually develop and refine ideas. The development of themes was informed by Braun and Clarke (2006): *'A theme captures something important about the data in relation to the research question and represents some level of patterned level of response or meaning within the data set.'*

Step 4:

During this phase, analysis continued at two levels. Firstly, codes were further checked and refined, re-named, re-defined, merged, and some were discarded. Themes were further refined to ensure that codes/data within them were coherent, and adequately reflected the meaning intended (this was done by examining all collated data for each sub-theme); and also, that there were clear distinctions between the themes, with no ambiguity. This resulted in four iterations of the mind map (Appendix 14). At the second level of this step, the themes were considered in relation to the entire data set,

and whether the picture captured the entire intended meaning – in relation to the study aim and the theoretical context. Within this phase of consideration, additional data from the dataset which had previously been missed was coded or re-coded, to ensure that the overall story from the data had been told.

Step 5:

During this step, the collated data extracts for each theme were examined and analysed and combined with other key literature, the epistemological approach, theoretical context and study aim. It was intended that the resulting overarching themes would be the final stage in the development of a conceptual hierarchy and be a concept that reflected the essence of the codes. Refinement of the main themes continued until it was clear that each of the four themes were distinct, logical, covered the scope of codes belonging to them, and in total they covered the breadth and depth of the meanings and patterns across the dataset.

Step 6:

Final analysis and write up of report. The aim of this step was to provide a logical, concise and interesting account of the data (including extracts), which described data and provided an argument in relation to the research question.

4.11 Rigour and trustworthiness

As described in more detail in Paper 2 (section 4.12) the trustworthiness of the present study was established by ensuring the following (Lincoln & Guba 1985):

Credibility: This was assured through the involvement of the project steering group, who assisted with development of the interview guide, and also the coding process by way of reviewing and discussing evolving themes.

Transferability: This included maintaining field notes, detail on sample size, interview guide, inclusion criteria, interview procedure.

Dependability and confirmability: This included an audit trail comprising: researcher reflexive journal (Appendix 15) and defined analytical techniques for thematic analysis (coding mind maps).

Validity: Creswell (2018 p.199) emphasised that qualitative validity involved inclusion of procedures throughout data collection to ensure that findings were accurate, whereas qualitative reliability was to do with a consistent approach to data collection across research teams and projects (Gibbs 2007). It was further suggested by Creswell (2018) that researchers used several strategies to ensure validity. Steps taken to ensure validity in the current phase are outlined in Table 10.

Table 10: Examples of strategies to ensure validity (Creswell et al. 2018)

Validity Procedure	Example
Peer Debriefing	Throughout the analysis of transcripts process peers were involved in asking questions about analysis and viewing data from an objective perspective. This ensured that interpretation of data went beyond the researcher and enhanced accuracy of the researchers account.
‘Thick’ description	Findings included additional details such as field notes, different perspectives or interview setting. This potentially enhanced understanding, and added richness to the reader’s experience.
Researcher Bias (reflexivity)	This involved the researcher’s self-reflection, by way of a reflexive journal (Appendix 15). In this journal the researcher recorded personal reflections of how their experience and values may have influenced the study (Lincoln and Guba 1985).

4.12 Findings

Findings revealed four overarching themes: 1) Declining Intimacy; 2) Caregiving and Masculinity; 3) Emotional Impact of Caregiving; 4) Service-Related Barriers and Enablers to Caregiving. Findings from theme one are presented in the following paper (Paper 2) ‘*When it faded in her, it faded in me*’: A qualitative study exploring the impact of spousal intimacy for older male caregivers’. This paper was published in *Ageing & Society*:

Fee, A., Sonja McIlfatrick, S., & Ryan, A. (2019). ‘When it faded in her... it faded in me’: A qualitative study exploring the impact of care-giving on the experience of spousal intimacy for older male care-givers. *Ageing and Society*, 1-22.

Doi:10.1017/S0144686X19000850

<https://doi.org/10.1017/S0144686X19000850>

Paper 2: ‘When it faded in her.... it faded in me’: A qualitative study exploring the impact of caregiving on the experience of spousal intimacy for older male caregivers



ARTICLE

‘When it faded in her ... it faded in me’: a qualitative study exploring the impact of care-giving on the experience of spousal intimacy for older male care-givers

Anne Fee^{1*} , Sonja McIlfatrick¹ and Assumpta Ryan¹

¹School of Nursing and Institute of Nursing and Health Research, Ulster University, Newtownabbey, UK

*Corresponding author. Email: fee-a1@ulster.ac.uk

(Accepted 7 June 2019)

Abstract

Older male care-givers play an increasingly important role in informal care-giving, yet they have received little attention in the literature. The aim of this study was to explore the impact of care-giving on the experience of spousal intimacy for older male care-givers. Twenty-four older male care-givers, drawn from a region of the United Kingdom, participated in one-to-one interviews about their care-giving role. Thematic analysis was used to analyse data, and the study was underpinned by theories of masculinity. Three main themes were identified: (a) ‘Impact of care-giving on the experience of *sexual* intimacy’; (b) ‘Impact of care-giving on the experience of *emotional* intimacy’; and (c) ‘Not up for discussion’. When sexual intimacy declined, some older male care-givers prioritised emotional intimacy; some struggled with the decline; and some were reluctant to discuss the issue. Additionally, some care-givers reported that they had not received support from external support providers for declining sexual or emotional intimacy. Intimacy has been highlighted as important for care-givers given its link with care-giver wellbeing and quality of life. Results of this study suggest that sexual and emotional intimacy was an issue for older male care-givers, and that this issue should be considered by external support providers as part of a holistic assessment of need in order to tailor effective support.

Keywords: care-givers; male; intimacy; masculinity; gender; support

Introduction

The importance of sexual and emotional intimacy on the quality of marital/long-term relationships is becoming increasingly recognised (Heiman *et al.* 2011; Davies *et al.*, 2012). Studies with heterosexual older couples have demonstrated that ongoing intimacy can improve quality of life, and physical and mental wellbeing (Droes *et al.*, 2006; Hayes and Boylstein, 2009; Davies *et al.*, 2012). It has

© Cambridge University Press 2019. This is an Open Access article, distributed under the terms of the Creative Commons Attribution licence (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted re-use, distribution, and reproduction in any medium, provided the original work is properly cited.

also been found that for spousal care-givers (male and female), satisfaction with intimacy significantly contributes to care-giver wellbeing (Nogueira *et al.*, 2015; Brotman *et al.*, 2016). According to Svetlik *et al.* (2005), declining intimacy can result in negative perceptions about the quality of the relationship and consequently higher care-giver burden. Thus, identifying factors which may contribute to decline in intimacy could potentially increase our knowledge about the experience of care-givers and inform future care-giver support.

Within the literature it has been noted that the onset of chronic illness can result in various losses which can impact aspects of the relationship. This includes reduction in shared activities (O'Shaughnessy *et al.*, 2010), companionship, communication and sexual intimacy (Davies *et al.*, 2010; Harris *et al.*, 2011). Consequently, the care-giving partner may experience a decline in the perceived relationship quality, through decreased mutuality, support, marital intimacy and satisfaction (Baikie, 2002).

Sexual and emotional intimacy

Sexual Intimacy has been defined as 'the behaviour directly associated with sexual relations and being sexually aroused' (Sinnott and Shifren, 2001). In a recent integrative review of literature, Holdsworth and McCabe (2018) explored the impact of dementia on relationships, intimacy and sexuality in later life, from the perspective of the care-giver, the person with dementia and the couple. In the review, the authors examined 13 international papers over a 20-year period. Findings not only suggested a lack of research in this area, but also highlighted various methodological issues such as stage and type of illness, age of participant and small sample size. Notably, the authors concluded that for most couples, sexual activity had stopped or declined. For some couples, this had been replaced with other forms of physical expression such as holding hands and hugging. Some spousal care-givers reported that they did not recognise their partner as their spouse anymore, or they were no longer in love with them (Davies *et al.*, 2010). Similarly, in their qualitative study comparing dementia care-giver dyads (N = 74) with an older dyads control group (N = 21), Nogueira *et al.* (2016) reported decreased sexual satisfaction. They found that the care-giving role impacted on spousal intimacy as it involved caring for a spouse with a progressive chronic condition (dementia), which involved various behavioural symptoms and memory impairment. This resulted in feelings of loss and emotional burden, and consequently a lack of sexual intimacy. These findings are consistent with other literature which demonstrated that not only does sexual intimacy often decline in care-giving dyads, but it was often replaced with greater emotional intimacy (Davies *et al.*, 2010; Harris *et al.*, 2011; Boylstein and Hayes, 2012; Galinsky and Waite, 2014; Merrick *et al.*, 2016).

According to Sternberg (1997), emotional intimacy is defined as 'the emotional component of a relationship, including feelings of closeness, warmth, connectedness, and bondedness in loving relationships'. Harris *et al.* (2011) undertook a phenomenological study (N = 10) examining how dementia impacted on couple intimacy from a care-giver perspective. Findings revealed that prior to diagnoses, the quality of the marital relationship was important for the impact of the condition on the relationship; and, for all couples, declining emotional intimacy was due to ambiguity of intimacy, or overwhelming stress of the care-giving role.

Older male care-givers

The present study sought to contribute to knowledge and to existing literature by exploring spousal intimacy from the perspective of older male care-givers. Whilst previous studies have explored the impact of chronic conditions such as dementia on spousal intimacy/sexuality (Davies *et al.*, 2010, 2012; Harris *et al.*, 2011; Merrick *et al.*, 2016; Youell and Callaghan, 2016; Roelofs *et al.*, 2017), none of them has taken account of the older male care-givers' perspective.

Traditionally the domain of females, the number of informal male family care-givers is rising (Pöysti *et al.*, 2012). It is estimated that approximately 42 per cent of informal care-givers in the United Kingdom (UK) are male, with this number rising to 59 per cent for care-givers aged over 85 years (Carers UK, 2015). There is a growing interest in their particular approach to care-giving (Hong and Coogle, 2014), however, there is a dearth of literature about this population.

Previous studies that have examined gender as a factor in spousal care-giving have tended to focus on the female care-giver perspective (O'Shaughnessy *et al.*, 2010; Youell and Callaghan, 2016), or on comparisons between care-giving husbands and wives (Boylstein and Hayes, 2012; Davies *et al.*, 2012; Nogueira *et al.*, 2016). It has previously been argued that for male care-givers the loss of spousal sexual intimacy is linked with a decline in masculinity (Clarke *et al.*, 2003). Hayes and Boylstein (2009) examined this in their qualitative study of spousal care-givers in the United States of America (13 males and 15 females). Study authors argued that women perceived their caring role as more 'motherly' than spousal, whereas men expressed a greater desire for sexual intimacy, and appeared to continue to identify with 'husband' in spite of their care-giving role. This raises questions about the link between sexual intimacy and self-identity. In their systematic review of the impact of dementia on marriage, Evans and Lee noted that male spousal care-givers appeared to be reluctant to continue with sexual relations if they were unsure about consent, thus identifying strongly with the role of 'guardian' (Evans and Lee, 2014). Similarly, this protective approach to care-giving was noted in a study by Milligan and Morbey (2016). Given that previous studies suggest that not only are there gender differences in the experiences of marital intimacy in later life (Simonelli *et al.*, 2008; Hayes and Boylstein, 2009; Davies *et al.*, 2012; Evans and Lee, 2014), but for older male spousal care-givers, it can be reasonably assumed that sexual intimacy and identification with traditional masculine traits may be connected, as indicated in analysis of the data from the present study.

Older male care-givers are reported to be at risk of social isolation and lack of support (Milligan and Morbey, 2016). Arguably, older male care-givers are also at risk of isolation and lack of support regarding their experience of spousal intimacy, particularly in light of myths and ageist stereotypes which portray older adults as asexual. Dominguez and Barbagallo (2016) reported that societal prejudices and misconceptions about sexuality in older age can inhibit individuals from discussing their sexual needs with health-care staff, for fear of raising something inappropriate (Griffiths, 1988). According to Dominguez and Barbagallo (2016), there is a lack of support for sexuality in older age, and a failure to incorporate sexuality as a need in holistic assessment, or indeed to provide specialised gender-specific training about sexuality to health and social care professionals (Davies *et al.*, 2012).

Theoretical framework

It has been theorised that Connell's (1995) hegemonic masculinity theory provides an understanding of how masculine ideology can influence men's approach to care-giving (Milligan and Morbey, 2016). Connell provided the basis for O'Neil's gender role conflict theory (O'Neil, 1981), which suggests that men's wellbeing is limited by adherence to masculine ideology such as 'fear of femininity', or fear of displaying traits which could be seen as feminine. Figure 1 is an illustration of how Connell's (1995) theory has shaped O'Neil's gender role conflict theory, which underpins this study and a number of previous similar studies. This was considered to be a suitable framework, given previous reports that men view care-giving as a 'feminised activity', which is at odds with traditional masculine traits (Baker *et al.*, 2010). The framework aids interpretation of the current data by providing a theoretical underpinning of Connell's hegemonic masculinity theory, and through this, illuminates how care-giving may contribute to a diminishment of traditional masculine identity.

In summary, it is known that older male care-givers tend to be isolated, have a poor awareness of external support services, and that care-giving impacts on the physical, mental and financial areas of male care-giver's lives (Milligan and Morbey, 2016). However, there is a dearth of literature about how the care-giving role impacts on the area of intimacy for older male care-givers. This is an important area given the significance of intimacy for quality of life and care-giver wellbeing (Davies *et al.*, 2012; Nogueira *et al.*, 2015), and also the reported acceleration to residential placement for the care recipient when intimacy declines (Davies *et al.*, 2010).

The current study contributes to the literature in two ways. First, it provides valuable insight into the experience of spousal intimacy for older male care-givers, by analysing qualitative data generated through interviews with older male care-givers (all heterosexual, in long-term committed relationships). Second, it considers the influence of masculinity in the approach of male care-givers to spousal intimacy, and the implications of this for the future development of support for male care-givers.

Methodology

The aim of this study was to gain an understanding of the impact of care-giving on the experience of spousal intimacy for older male care-givers. The design employed was qualitative, using semi-structured interviews and thematic analysis (Braun and Clarke, 2006). Considering the sensitive nature of the topic, a qualitative approach using one-to-one interviews was considered the most suitable for the collection of data.

Sample

A purposive sample of interview participants (Silverman, 2004) was chosen for the study. Participants were recruited from organisations within statutory and community/voluntary sectors in a region of the UK. The inclusion criteria were: male care-giver; over 60 years old; primary care-giver for a chronically ill spouse/partner; living in the community; and ability to give informed consent. Chronic illnesses of the

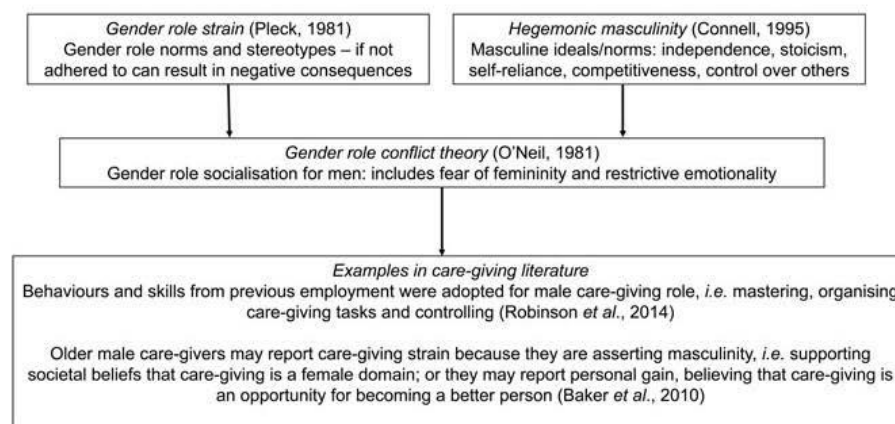


Figure 1. Theoretical framework.

care recipients were dementia (N = 16), stroke (N = 4), Parkinson's disease (N = 2), multiple sclerosis (N = 1) and severe epilepsy (N = 1). Details of participants' characteristics are in Table 1.

Ethical considerations

Due to the sensitive nature of the subject area, a number of ethical considerations were noted. Primarily, it was recognised that interviews could raise potentially distressing or embarrassing issues. This was addressed by the implementation of a 'distress protocol' which detailed suggestions such as taking a break from the interview or ensuring the participant had sufficient information about support organisations if needed. Also, in light of the fact that the researcher was female, and all participants were male, it was acknowledged that time spent building rapport was important, and that when sensitive or personal issues (such as sexual intimacy) were discussed, maintaining rapport was crucial. Rapport was established by the researcher arriving on time, making general conversation upon arrival, on occasions self-disclosure ('I grew up around here', 'I also have a labrador') and looking at family photographs. Maintaining this rapport involved employing empathy and listening skills throughout the interview, maintaining a friendly and open disposition, and acknowledging feelings where appropriate. The researcher was satisfied that for most participants, rapport was present by body language, facial expressions, a feeling of flow and connection, and by the responses given and the way they were given.

The study was granted ethical approval from OREC (UK), Ulster University Filter Committee, and Northern Health and Social Care Trust (REC reference 17/WM/0019).

Data collection

Twenty-four semi-structured interviews were undertaken with older male care-givers (on their own) at home or in a local venue. The interview schedule

Table 1. Participant characteristics

Identifier	Length of time caring (years)	Age of care-giver	Length of relationship (years)	Age of partner
Clive	9	72	46	69
Simon	13	75	52	75
Sean	2	82	59	81
Dessie	8	73	49	75
Jack	4	68	39	66
Joseph	9	68	32	59
Robert	4	69	41	70
Gerry	14	61	27	54
Mark	7	65	40	61
Mike	4	76	51	76
Ian	22	70	42	65
Gary	6	66	33	66
Harry	8	81	60	78
Dan	6	66	38	68
Paul	3	81	54	78
Tim	4	79	56	77
Noel	2	72	16	60
Patrick	15	73	37	70
Bobby	5	68	41	63
Aidan	6	70	48	69
Andy	5	72	39	69
Berty	2	68	44	64
Colin	7	66	47	68
Alan	4	83	58	83

was developed in liaison with the inter-disciplinary project steering group (comprising statutory and voluntary-sector personnel, a male care-giver and academics). The schedule was informed by study objectives and relevant theory, and aimed to elicit information about experience of care-giving, including information about the impact of care-giving on spousal intimacy. The schedule covered aspects such as how the care-giving role had affected sexual intimacy or emotional intimacy within the relationship, and experiences of formal and informal support. The intention was to use the term 'intimacy' in its broadest sense during interviews. In this way, if participants felt comfortable enough to discuss sexual intimacy, then they could. However, if they did not appear to be comfortable, then they would not feel obliged to refer to sexual intimacy. In general, if participants talked openly

about other intimate aspects of care, then the researcher would have gently encouraged discussion about sexual intimacy, at the appropriate time. However, introducing sexual intimacy was a risk which had to be carefully managed.

The semi-structured nature of the interviews ensured that whilst there was a focus, questions were open enough to allow for exploration of issues. The interview schedule was piloted with two older male care-givers which resulted in two modifications to the original schedule. The first modification was to collect demographic information during or at the end of the interview as opposed to the beginning, and the second was to change the order of two questions and add further prompts in order to improve the flow of questions. A £20 supermarket voucher was given to all interview participants, and funding was made available to arrange alternative care for the duration of the interview, if needed. Interviews were conducted by the first author (AF), a middle-aged female, with previous experience of working with male care-givers in a Health Trust in the UK, and who had recently undertaken specialised in-depth interview training. Interviews lasted between 45 and 90 minutes and were digitally recorded (with written consent).

Data analysis

Cross-sectional thematic analysis was used to analyse data (Braun and Clarke, 2006). Thematic analysis is a flexible approach to analysing qualitative data, which can be used in its own right or as a process which is performed within a different analytic tradition (Braun and Clarke, 2006). This approach involved six key phases: (a) familiarisation with the data, (b) generating initial codes, (c) searching for themes, (d) reviewing themes, (e) defining and naming themes, and (f) producing the report.

Interviews were transcribed verbatim, and the first author (AF) checked all transcripts against audio recordings to ensure accuracy. After reading and re-reading transcripts for familiarisation, an initial coding framework was developed as a result of line-by-line coding and importing data into NVivo 11 qualitative data management software by the first author (AF). The coding framework was underpinned by the research aim, relevant theory and key literature, with codes/sub-themes being developed based on relevance to these, as opposed to frequency of words or concepts. Two authors agreed on the final coding framework (AF and AR). Codes and themes were regularly discussed within the research team and project steering group. These discussions involved the use of mind maps (Buzan and Buzan, 1994) to illustrate relationships between codes and themes, thus allowing three overarching themes to be developed and refined (*see Table 2*).

Rigour

The trustworthiness of the present study was established by ensuring credibility, transferability, and dependability and confirmability (Lincoln and Guba, 1985).

Credibility

Initial emerging themes were peer reviewed and any differences of opinion were discussed until consensus was reached. Key themes were then developed, refined

Table 2. Description of overarching themes, sub-themes and codes

Theme 1: The impact of care-giving on the experience of sexual intimacy	
Sub-theme: • Decline or loss of sexual intimacy	Sub-theme: • Impact of the loss/decline of sexual intimacy on the relationship
Codes: Impact of illness on physical contact Reasons for loss of sexual contact	Codes: Dealing with loss of sexual contact – positive Dealing with loss of sexual contact – negative Resignation
Theme 2: The impact of care-giving on the experience of emotional intimacy	
Sub-theme: • Prioritising emotional intimacy	Sub-theme: • Loss of emotional intimacy
Codes: Impact of increased emotional intimacy Gratitude	Codes: Decreasing conversation Impact of loss of closeness
Theme 3: Not up for discussion	
Sub-theme: • A taboo subject?	Sub-theme: • Getting on with it
Codes: Impact of illness on marriage A taboo subject?	Codes: Coping strategy Household tasks take priority

and named. Codes were checked against data to enhance credibility (Quinn-Patton, 2002). The multi-disciplinary project steering group was involved throughout, with the development of the interview schedule, and also the coding process by way of reviewing and discussing evolving themes in order to assist with interpretation of the data.

Transferability

Transferability was assured through the provision of descriptive data including field notes, detail on sample size, interview schedule, inclusion criteria, and interview procedure.

Dependability and confirmability

Dependability and confirmability were assured through an audit trail comprising: researcher reflexive journal, team meeting notes, steering group minutes and defined analytical techniques for thematic analysis (coding mind maps).

Findings

Analysis of data from a larger study which explored support needs for older male care-givers revealed that sexuality and intimacy was an important element in men's experience of providing care. As a sub-study of this larger study, the current study explored the impact of care-giving on the experience of spousal intimacy with older male care-givers. Analysis revealed two main aspects of the impact of care-giving on intimacy: impact on *sexual* intimacy and impact on *emotional* intimacy. Data from participants who did not discuss the issue were also categorised, which resulted in the third overarching theme: 'Not up for discussion'. Pseudonyms were used for direct quotes.

Theme 1: The impact of care-giving on the experience of sexual intimacy

Sub-theme 1: Decline of sexual intimacy – 'Even if I could have I wouldn't have'

Decline of sexual intimacy was reported by all participants. One reason given for declining sexual intimacy appeared to be inhibited desire. Some participants described symptoms which related to their partner's illness such as urinating and defecating, and they were unable to relate to their partner in a sexual way:

I suppose the intimate thing would be it changes your relationship ... When you have to evacuate somebody's bowel because they are so constipated for so long, that changes how you relate to them, and in that sense a relationship probably becomes more distant as a way of coping. (Gary)

You're lying there beside them, trying to hold them in a seizure and you know rightly at the same time they're urinating themselves and possibly defecating, right, you don't think of it any more as a sexual thing. That goes out the window, you know what I mean? (Gerry)

Other reasons given for decline in sexual intimacy could not be as easily associated with the care-giving role as those outlined above, however, they do seem to be unique to *older* care-givers. For instance, a number of men had attributed decline in sexual intimacy to older age or to a previous health condition associated with older age, such as prostate or bladder cancer. These quotes illustrate the impact that a previous treatment for cancer had on sexual activity:

I took prostate cancer. That was about 12 years ago ... That meant that sex or intercourse didn't happen because when you have 40 shots of radio ... The cancer, thankfully, is gone, but it does have that effect ... I'm 75 years old. After 60, you start to wane off anyway. (Simon)

Awk no, sure we are old now ... No, that sort of thing has gone away from us. Then with my bladder cancer, that didn't do anything like that any good. (Sean)

A further obstacle to sexual activity reported by the participants was communication difficulties in the advanced stages of illness. Lack of communication seems to have created a degree of ambiguity to sexual intimacy. One participant explained

10 A Fee *et al.*

that although sexual activity would have satisfied him, due to lack of communication from his wife he was unsure about whether it would have satisfied her and so 'it wouldn't have been fair', for the past ten years they 'have been close, just kissing and cuddling'. Thus, it appeared that the type and stage of illness of the care recipient may have influenced participants' experience of intimacy. Another participant described his wife's reaction when he kissed her goodnight:

If [wife] is tucked in bed and I'm going to bed I always give her a kiss goodnight, on her forehead, and if I try to kiss her on the lips she will bite me, because anything coming around there is food. (Dessie)

Sub-theme 2: Impact of declining sexual intimacy on the relationship – 'You lose the sexual contact in your life ... That is difficult to deal with'

Perceptions of the impact of declining sexual intimacy on the relationship differed between participants. Although some men attributed this decline to their own age or health, others viewed it as a natural progression of their partner's illness and rationalised it as such. Also, some men focused on increased emotional intimacy, which they saw as important in maintaining closeness and connection:

We both realise we're getting on in life ... You know we actually talk more now ... we've more time for each other. (Gerry)

We always cuddle, it's the last thing we do before going to sleep is have a kiss and cuddle. We can have a cuddle any time of the day. (Jack)

Some participants portrayed resignation or a sense of acceptance. For Gerry, a 'fear of God' provided a coping mechanism and would suggest that his strong religious belief also influenced his perspectives on intimacy:

It's not something that bothers me personally, that we don't have a regular sex life ... I'm not going to go outside of my house looking for it, you know and I think that maybe comes a wee bit from my knowledge of God and the fear of God. (Gerry)

On the other hand, some men experienced declining sexual intimacy as a struggle. Even though participants were at different stages of the care-giving trajectory, they had all been in long-term committed relationships, and reported that before their partner's illness they were satisfied with their relationship and committed to their partner:

Intimacy has disappeared. Just physically can't respond. We always made a point of a kiss and a big cuddle at least once a day but intimacy has disappeared, it's non-existent. (Robert)

For a small number of men, their marriage vows or religious beliefs seemed to conflict with ideas they were considering for dealing with the decline of sexual intimacy:

You lose the sexual contact in your life. There's no way you're messing about with it, but I miss it ... That is difficult to deal with. It puts up the evil challenge of ... I stood at the front of my church, and I made some promises, and when that hits you, it starts to challenge you as much as, well, do I, or don't I, [wife] doesn't know me, she's like a baby, and you get into that quagmire of thinking, and some people would admire me for sticking to my guns ... I'm a frustrated old bugger. (Dessie)

A participant described how other people had said to him, 'if you still have those urges sort them out', however, he said that there was 'no temptation'. He went on, however, to describe how he had considered other options. This was the first time he had discussed this deeply personal area with anyone (the researcher), and when asked if he had thought about discussing it with anyone else he said he 'wouldn't know where to go':

I'd love to see what the professionals said that I should do. Should I adopt the moral issues, *i.e.* my wedding vows, or is there, in their eyes, because of the condition that my wife is in, is there somebody saying, it's okay. But, that's a curiosity I've got, but there's no temptation. (Dessie)

Theme 2: The impact of care-giving on the experience of emotional intimacy

Sub-theme 1: Prioritising emotional intimacy – 'It just probably tests the glue that holds you together'

Participants had different experiences of the impact of care-giving on *emotional* intimacy. Some had prioritised emotional intimacy over sexual intimacy as a way of sustaining their partnership and gaining reward and satisfaction from their care-giving role. For example, these participants described small ways of continuing to share everyday experiences and were grateful for this:

We still get on well yet. I'll go over beside her and she'll sit and hold your hand there in the chair ... Somebody said to me, 'would it have been better if [wife] had have had a heart attack and died?' I said, 'no, it wouldn't, [wife]'s still there'. I suppose everybody looks at it differently. (Tim)

We get stronger, it gets stronger, we do everything together, everywhere we go [wife] wants your hand. (Mike)

Every Saturday, I'd take her into town and have lunch. Sometimes, you get no reaction to it, but sometimes it's 'That's nice' or 'That's lovely' ... I get satisfaction from that. (Simon)

Sub-theme 2: Loss of emotional intimacy – 'We've always done everything together and now we don't do anything really'

The following participants reported a decline in emotional intimacy and felt a profound sense of loss. Given that these are spousal care-givers who live with their partner, lack of conversation as the illness progressed led to a lack of emotional intimacy which seemed to compound their sense of loneliness:

12 A Fee *et al.*

[Wife] doesn't talk. This is one of the first things, you know, when it really began to, sort of, bite. One of the first things that [wife] lost was the ability to talk. (Bobby)

I mean another aspect of it is my loneliness, [wife] just loves watching the TV and then falling asleep ... I might as well be alone in the house, there's no communication. (Robert)

We've no family and we've always done everything together and now we don't do anything really. (Joseph)

I felt very lonely. I think that was the real suicidal part of it, just sitting here ... it was like mourning somebody and still living with them and that's very true. (Colin)

A small number of participants who spoke about lack of intimacy were considering placement in long-term residential care, one had recently moved his wife into a residential facility and another one was considering permanent placement as, with sadness, he felt he had come to the end of his role as care-giver:

The future, well, the future I know is she's going to be in a home, I know that, it took a long time coming to her. (Clive)

Theme 3: Not up for discussion

Sub-theme 1: A taboo subject? – 'I don't think I need to elaborate'

Findings in Theme 3 suggest that some men did not wish to discuss 'intimacy', either because they did not view it as a priority in the relationship or because they did not feel comfortable discussing it.

The question 'How has your partner's illness affected your relationship/marriage?' was a preliminary question, to signal that the discussion was moving to a more personal level. Subsequent questions depended on participant's responses to previous questions that may have been of a sensitive nature (such as personal care) and the response to the question above. If there was still evidence of good rapport, the researcher then asked, 'And has your partner's illness affected your intimacy at all? A small number of men sought clarification at this point (*e.g.* 'Do you mean sex-wise?'). Others seemed comfortable, and proceeded to refer to or discuss sexual intimacy (either briefly or at length). On the other hand, if the researcher felt that the rapport was not sufficient, or there was some discomfort around previous discussion regarding personal care, the researcher did not ask about intimacy, and these participants responded to the original question of 'How has your partner's illness affected your relationship/marriage?' These participants described issues which perhaps were more important to them, such as memory loss or lack of opportunity for joint activity:

I have to understand that there are a lot of things she might not remember. We still talk a wee bit, but she doesn't talk really much now. (Andy)

The only way it has affected it is we can't go out the same now. (Dan)

Well we used to like going away on holidays and we used to run to England a lot. Well that's all stopped now because you just can't do it. (Mark)

Additionally, a small number of men acknowledged sexual intimacy in the relationship but referred to it in an historical context, and did not wish to give further detail, for example:

Not really, I mean we're of an age where it's very platonic, we share everything and, the intimacy – we still would be shy, I mean whenever we were getting ready at night for bed [wife] used the bathroom or another bedroom, things like that but, you know, we're good. (Mike)

Sub-theme 2: Getting on with it – 'You adapt, you overcome, you get on with it'

Data included in this sub-theme indicated that some participants adopted a very practical approach to their care-giving role, and did not portray sexual or emotional intimacy as being an important element in their marriage. Their 'getting on with it' strategy appeared to indicate that their priority within their care-giving role was to manage practical tasks, and they seemed focused and organised:

The clothes are sitting out and I have to wash them and hang them up. I try to get them all dried. I have to be one step ahead all the time. I have to make a list of all the shopping. I'm afraid of being at home and caught cold. As I say, I do all the cooking. All the cooking. It's all mine. (Andy)

I just deal with it in the present. We just get on ... I devised, you know, got the care package going with Bluebird, direct payments, all of this, and I had to arrange my own. I think I got so involved in the caring part of it that I really didn't think about anything else, you know. It was just, basically, it was something that had to be done, and make sure that it operated properly. (Bobby)

To tell you the truth, cleaning is basically my hobby now, washing, cleaning, cooking ... I've removed a lot of stuff, ornaments and stuff, I've decluttered because what it means is less things to dust, less things to lift really. (Dan)

You have it to do so you just get on and do it. Nobody else is going to do it for you. (Mark)

Discussion

In this study, semi-structured qualitative interviews were conducted with 24 older male spousal care-givers, with the aim of exploring the impact of care-giving on their experience of intimacy. Study findings revealed that all participants experienced a decline of sexual intimacy with their long-term partner/spouse. However, these changes were not always found to be associated with their partner's illness. For a small number of participants this was due to their own age/health status, or to the importance given to intimacy by them. Some participants appeared to accept that change in intimacy was a result of ageing or illness progression, and

many of these participants reported expressions of emotional intimacy. Others, however, felt frustrated or increasingly lonely as their spousal intimacy decreased, and a number of participants did not discuss the issue.

The impact of care-giving on the experiences of intimacy for care-givers has been largely unexplored in care-giving literature, and even less so for older male care-givers in committed heterosexual relationships. Previous evidence has indicated that within care-giving spousal relationships, sexual intimacy often declines because the care-giver becomes the 'parent', and they cease to see themselves as spouse (Nogueira *et al.*, 2013), thus rendering the role of care-giver and spouse as incompatible (Kaplan, 2001), or that lost sexual intimacy is the result of the burden of care (Simonelli *et al.*, 2008; Nogueira *et al.*, 2016).

Even though there is little understanding about the impact of care-giving on older male care-givers, international literature about sexuality in later life is steadily increasing. Recent studies have found that men in later life continue to place importance on sexual activity and tend to remain sexually active (Fileborn *et al.*, 2017). However, they may see it as context-dependent (Fileborn *et al.*, 2017), where 'intimacy' is central to their sexual experience (Sandberg *et al.*, 2013). Similarly, Palacios-Ceña *et al.* (2012) suggested that marriage or having a long-term partner provides the context for most sexual activity among heterosexual couples in later life. Also, Waite *et al.* (2017) note that ill-health (for older men) is not necessarily detrimental to sexual activity, and where couples think that it is important, sexual activity of some kind may still continue.

In the current study, various reasons were reported for changes in sexual intimacy, and participants spoke about the impact of this on themselves and their relationships. Three participants attributed the decline in sexual intimacy to 'old age'. Given that the sample were all 'older' (*i.e.* over 60 years old), there is an increased likelihood that health conditions associated with advancing years may have impacted on intimacy. For instance, two of the participants explained that previous treatment for prostate and bladder cancer was the reason for their decline in sexual intimacy. Further analysis of the data also revealed that of the participants who appeared to be more accepting of decline in intimacy ($N = 4$), three were towards the older end of the age spectrum (75–83). The six participants who seemed to struggle with decline in intimacy tended to be towards the younger end (66–73). These findings may indicate a difference between care-givers at the older and the younger end of the age spectrum in the sample, in their approach to spousal intimacy. Although it is not possible to draw a conclusion from such a small sample, this finding is consistent with other research (*see* Fileborn *et al.*, 2017). Furthermore, it also raises questions about the influence of other factors, such as age, age-related health conditions, stage in the care-giving trajectory, type of illness of the care recipient, or external factors such as religion or culture, on the experience of intimacy for older male care-givers.

Some participants described an acceptance of declining sexual intimacy. They portrayed a transition from previous sexual activity to greater emotional intimacy focusing on good experiences within the relationship, such as going out to lunch, holding hands or talking more. These participants appeared to want to maintain emotional intimacy as a source of support and reassurance, to increase

their level of satisfaction with the relationship, and to decrease feelings of frustration and isolation.

Maintaining emotional intimacy in this way could be interpreted as what some participants perceive as a natural part of a long marriage/long-term relationship. This expectation, however, would only be possible if the quality of the pre-morbid relationship was suitable (Molyneaux *et al.*, 2011). Participants in the current study frequently spoke about their sense of commitment and reciprocity, explaining that 'she would do it for me'. Findings such as these may be explained with Rusbult's (1983) model of investment (*i.e.* commitment and relationship satisfaction) within the social exchange theory, whereby individuals stay within a relationship if rewards outweigh costs. On balance, a long marriage/long-term committed relationship will involve many costs and rewards – not necessarily experienced within the same time-frame, and possibly perceived differently by spouses/partners and outsiders. This is illustrated in the data by participants who describe small rewards/satisfactions within their care-giving role, such as their partner thanking them for what they do or holding their hand. Furthermore, participants used phrases such as 'in sickness and in health', 'till death do us part', and referred to commitment and marriage vows – this could explain why participants sometimes overlooked personal sacrifice in favour of investing in the marriage/relationship, which for them is the reward. This perhaps demonstrates that although care-giving within a long-term committed relationship could be seen as a 'cost/sacrifice' to outsiders, some participants experienced it as a reward, as a way of repaying their spouse/partner, which provided balance in the relationship and validation for their role. Arguably, this sense of investment in a relationship through cost and reward could apply to both male and female spousal care-givers. However, validation and experiencing reward for their care-giving role may be especially important for male care-givers, who have been reported to view care-giving as a 'feminised' activity and at odds with traditional masculine traits (Baker *et al.*, 2010).

Just as some participants reported an increase in emotional intimacy when sexual intimacy declined, others portrayed resignation or struggled with changes in sexual intimacy. These participants reported gradual decline in all forms of intimacy as their partners' illness progressed, and they struggled with the challenges of adjusting to a changing role. Describing feelings of grief, anger, frustration, guilt and worry, several men found that they were unable to come to terms with the deteriorating situation. Participants reported feeling stressed and isolated, and did not know how much longer they could sustain their caring role. For some in this group, long-term placement in residential care was a realistic option being considered. It has previously been recognised that declining emotional intimacy, as perceived by the care-giver, has accelerated admission to long-term residential care. For example, Davies *et al.* (2010) undertook a study with 14 dementia and nine mild memory impairment (MMI) care-givers, using focus groups and content analysis to investigate the impact of dementia and MMI on sexuality in spousal relationships. Study findings revealed that due to care-giving stressors, care-givers experienced uncertainty about the future of the relationship and the majority had considered placement in residential care. Authors also recognised the importance of support for intimacy from external providers, suggesting couples counselling or new relationship rituals to compensate for the emotional and cognitive

decline of the affected partner. This, they suggest, may lessen care-giver burden and delay admission into residential care.

Although the present study examined spousal care-giving intimacy with a sample of older male care-givers, it is acknowledged that older males and females can have similar experiences of spousal care-giving. However, previous research has speculated that although males and females may have similar care-giving experiences, their approach and coping strategies may be different – based on gender (Chen, 2014; Hong and Coogle, 2014). Analysis of data in the present study has resulted in questions around whether the male care-giving approach is influenced by gender and, if it is, how this impacts on subsequent support. For example, findings in Theme 3 of the present study related to participants who did not discuss intimacy. This may indicate discomfort around discussing such a personal area, perhaps with a female researcher (Thorpe *et al.*, 2017). Alternatively, it may indicate an approach where intimacy is viewed as low priority within the context of the care-giving role. Even though this could also apply to female care-givers, the difference is that older men are likely to have had jobs/careers, where they felt valued and visible (Russell, 2007). The transition to care-giving, traditionally the domain of females, may result in male care-givers feeling that their masculinity is challenged by providing unpaid, ‘unskilled’ care (Baker *et al.*, 2010; Hrženjak, 2013). Therefore, it is possible that they may have constructed their care-giving in a way that was less challenging by ‘professionalisation’ of care tasks, and aligning their role to one of management and problem solving. Examples of this in the current data include participants who found solutions to household difficulties such as replacing carpets with wooden floors (to avoid Hoovering), employing someone to clean or de-cluttering. Within this approach, some male care-givers may view task completion and problem solving as a high priority and intimacy as a low priority. In their UK study with 15 older male care-givers, Milligan and Morbey (2016) employed narrative analysis to examine how older male care-givers coped with care-giving and how it impacted on their sense of identity. Findings highlighted male care-givers’ tendency to use their past experience (through work or education) in their approach to care-giving, therefore re-affirming their masculinity by continuing in their pre-care-giving role of provider/protector. Authors also noted that societal views of male care-givers can sometimes have a diminishing effect on masculinity, as some care-givers in the narratives explained that they were ridiculed by peers for learning how to cook or sew as it was seen to be ‘unmanly’. Consequently, male care-givers in the study experienced increased isolation as a result of their care-giving role.

A sense of ‘diminishing’ masculinity as a result of the care-giving role is also demonstrated in the current data. Some of the participants stated that they used medication to help them cope with care-giving. Colin was prescribed antidepressants as he was experiencing suicidal feelings. When he mentioned the use of antidepressants as a coping strategy to a friend, he was ridiculed. His friend seemingly had interpreted his actions as a sign of weakness, as he commented that ‘a big strong man like you’ should not need antidepressants. This type of scenario could compromise Colin’s masculine identity, not only through having to ask for help, but also due to the consequences of admitting to taking antidepressants (*i.e.* peer pressure to be a ‘strong man’).

As previously noted, Connell's (1995) hegemonic masculinity theory has traditionally been used to explain men's approach to care-giving, and within the current study it is a useful framework to interpret data and to explain how the care-giving role can potentially lead to poor care-giving outcomes for older male care-givers (Figure 1). Connell characterises 'normal' masculine behaviour as independent, stoic and self-reliant (Mahalik *et al.*, 2003). Adhering to these ideals can be difficult for men who are navigating family or care-giving situations, and these 'gender norms' can be restrictive for men, particularly in situations where they may need support. Thus, men's need for help and support in their care-giving role can conflict with their masculine identity (O'Neil, 1981). This conflict was described by O'Neil (1981) as gender role conflict. A particular element of gender role conflict is men's tendency to distance themselves from feminine traits or values, sometimes leading to limited choices resulting in poor outcomes for male care-givers, such as increased isolation (Robinson *et al.*, 2014; Greenwood and Smyth, 2015).

This is further illustrated in the current data by the reluctance shown by some study participants to identify themselves as a 'care-giver', or portraying a 'getting on with it' attitude whereby they coped with everything themselves and only sought help when a crisis arose (as these are seen as feminine traits). Reports of intrusion on privacy, dissatisfaction with previous services and a belief that they could cope without additional help resulted in low uptake of support for many participants.

In relation to the question of the influence of gender on care-giving, posed previously, there appears to be a growing recognition of gendered coping strategies (Pretorius *et al.*, 2009; Hong and Coogle, 2014). Calasanti (2006) suggests 'gender different care styles' to explain how men's approach to care-giving is rooted in masculinity, therefore influencing their coping strategies (Hong and Coogle, 2014). However, findings on the impact of gender on care-giving outcomes with other studies are largely inconclusive (Miller and Cafasso, 1992; Pinquart and Sörensen, 2006; Akpınar *et al.*, 2011).

Either way, the emergence of men-centred support programmes targeting physical and mental health, such as 'Man Alive Man Van' (UK) and 'Men's Shed' (Australia and UK/Ireland), are relevant in the debate about gender-based support. These initiatives may reinforce the suggestion that, in terms of support needs, males and females may have different support needs, with males tending to prefer and engage with support which aligns with and does not threaten traditional masculinity ideology.

In the current, and previous studies (Dourado *et al.*, 2010), no data relating to support from external support providers for changing or declining intimacy was found. This could be due to a number of factors, including male care-givers' reluctance to discuss this personal matter or to seek/accept help in their care-giving role, or lack of recognition from health-care support providers about sexuality needs in later life. Recent evidence indicates that health-care practitioners believe that sexuality support is beyond their remit and think that they have inadequate knowledge/training in this area. There is also evidence to suggest that female health-care staff have less-permissible attitudes in their evaluation of sexual appropriateness than their male counterparts (Haesler *et al.*, 2016). Brotman *et al.* (2016) go further to point out that the age and gender of health-care professionals affected their comfort levels in this area, and that although staff understood the importance of

discussing sexuality, they often felt ‘awkward’ about raising such a personal issue or assumed that it was not a priority for the care-giver. Findings such as these would be particularly important to consider in planning future support for male care-givers. Given the importance of sexual and emotional intimacy for quality of life in ageing and care-giving (Davies *et al.*, 2012; Roelofs *et al.*, 2017), and the reluctance of some male care-givers and health-care practitioners to discuss the issue, there is undoubtedly a need for specialised or gender-specific training in this area for support personnel (Davies *et al.*, 2012).

It is recognised that complex gender dynamics are involved with a female researcher interviewing male participants, and in analysing resulting data. A discussion of this research would not be complete without further consideration of how this was managed and the steps taken to minimise any impact on data. The issue of ‘intimacy’ had potential to cause discomfort or embarrassment to this cohort of older male care-givers. Even though some previous research has suggested that female researchers may enable male interview participants to ‘open up’ (Manderson *et al.*, 2007), it is also recognised that a male researcher could have elicited a different response. Arguably, though, so too could a researcher who was a different age or from a different ethnic background. Although the potential for the gendered social context to impact on the data produced could not be totally eliminated, it was managed through regular researcher team meetings, and detailed reflexivity and field notes kept by the researcher who conducted the interviews (AF).

Given the sensitivity of the subject area, maintaining rapport was crucial (Dickson-Swift *et al.*, 2007). Establishment and maintenance of rapport varied, and with the small number of participants where rapport was not evident, the issue of sexual intimacy was not pursued.

Findings from the current study would suggest that the role of care-giver impacts on spousal intimacy for older male care-givers in a committed heterosexual relationship. Similar to other studies, data analysis revealed that participants were experiencing declining sexual intimacy after the onset of their partner’s chronic illness (Holdsworth and McCabe, 2018); uncertainty around their future care-giving role due to a sense of burden or physical/emotional stress (Harris *et al.*, 2011); and, for some, consideration of institutional placement (Davies *et al.*, 2010).

This study adds to what is known about intimacy in spousal heterosexual relationships when one partner has a chronic illness and both are older. To our knowledge, no other studies have examined spousal intimacy from an older male care-giver’s perspective. Also, little is known about the influence of masculinity on older male care-giver’s experience of spousal intimacy, therefore, our findings contribute important new data to this emerging body of research.

Study limitations

As with all research, it is important to acknowledge study limitations and to consider how they may have impacted on findings. First, during the interviews, owing to the sensitive subject nature, ‘intimacy’ was introduced gradually by the researcher. Depending on initial reactions to this, some participants received further prompts, and some not. It could be argued that this is a limitation as there was a differentiation in questions and prompts between participants. It is also

noted that as the researcher was female, this may have affected the dynamic of the interviews. Second, although dementia was the chronic condition experienced by the majority of care recipients in the study (N = 16), other chronic conditions were also included in the study. These were stroke, epilepsy, multiple sclerosis, and Parkinson's disease. Consequently, care recipients had a broad range of illness symptoms, which will have impacted on the care-giver experience. Finally, as the sample was recruited mainly through support agencies, it is assumed that they had all received external support, and this may have set them apart from other care-givers who were not receiving any support at all.

Conclusion

Study findings suggested that whilst all participants experienced a decline of sexual intimacy, some had placed increased importance on emotional intimacy. Others, however, reported frustration and sadness at the decline of both sexual and emotional intimacy, and consequently questioned how much longer they could continue in their care-giving role. A further group of participants did not discuss the area of sexual/emotional intimacy, which may indicate a reluctance to discuss this deeply personal issue, or that it was no longer an area of concern and that other more practical aspects of care-giving were given higher priority. Given the importance of sexual and emotional intimacy for quality of life in ageing and care-giving (Davies *et al.*, 2012; Roelofs *et al.*, 2017), it is noteworthy that the findings did not reveal any evidence of discussions with external support providers around intimacy. It could be suggested that not only are male care-givers unlikely to ask for support around spousal intimacy, due to their 'independent' approach to care-giving (Hong and Coogle, 2014), but that external support providers are hesitant to offer support in this area (Brotman *et al.*, 2016; Haesler *et al.*, 2016). Finally, findings from the current study indicated that future support for spousal male care-givers should consider a tailored approach which includes recognition of gender as a factor in coping, and acknowledges that support for older male care-givers should align with dominant masculine norms.

Acknowledgements. The authors wish to acknowledge the male care-givers who gave up their time to be interviewed for this study.

Financial support. This work was supported by the HSC Research & Development Division, Northern Ireland Public Health Agency, UK. The financial sponsors played no role in the design, execution, analysis and interpretation of data, or writing of the study.

Conflict of interest. The authors declare no conflicts of interest.

Ethical standards. The study was granted ethical approval from OREC (UK), Ulster University Filter Committee, and Northern Health and Social Care Trust (REC reference 17/WM/0019).

References

- Akpınar B, Küçükgüçlü O and Yener G (2011) Effects of gender on burden among caregivers of Alzheimer's patients. *Journal of Nursing Scholarship* 43, 248–254.
- Baikie E (2002) The impact of dementia on marital relationships. *Sexual and Relationship Therapy* 17, 289–299.
- Baker KL, Robertson N and Connelly D (2010) Men caring for wives or partners with dementia: masculinity, strain and gain. *Ageing & Mental Health* 14, 319–327.

20 A Fee *et al.*

- Boylstein C and Hayes J (2012) Reconstructing marital closeness while caring for a spouse with Alzheimer's. *Journal of Family Issues* **33**, 584–612.
- Braun V and Clarke V (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* **3**, 77–101.
- Brotman S, Drummand J, Silverman M, Sussman T, Orzeck P, Barylek L, Wallack I and Billette V (2016) Talking about sexuality and intimacy with women spousal caregivers: perspectives of service providers. *Health & Social Work* **41**, 263–269.
- Buzan T and Buzan B (1994) *The Mind Map Book: How to Use Radiant Thinking to Maximize Your Brain's Untapped Potential*. New York, NY: Dutton.
- Calasanti T (2006) Gender and old age: lessons from spousal care work. In Calasanti T and Slevin K (eds), *Age Matters, Re-aligning Feminist Thinking*. New York, NY: Routledge, pp. 269–294.
- Carers UK (2015) *State of Caring 2015*. Available at <http://www.carersuk.org/stateofcaring>.
- Chen Y (2014) Differences in outcomes of caregiver support services for male and female carers. *Sage Open* **4**, July–September, doi:10.1177/2158244014548169.
- Clarke JA, Inui TS, Silliman RA, Bokhour BG, Krasnow SH and Robinson RA (2003) Patients perceptions of quality of life after treatment for early prostate cancer. *Journal of Clinical Oncology* **21**, 3777–3784.
- Connell RW (1995) *Masculinities*. Berkeley, CA: California University Press.
- Davies HD, Newkirk LA, Pitts CB, Coughlin A, Sridhar SB, McKenzie Zeiss L and Zeiss AM (2010) The impact of dementia and mild memory impairment (MMI) on intimacy and sexuality on spousal relationships. *International Psychogeriatrics* **22**, 618–628.
- Davies H, Sridhar S, Newkirk L, Beaudreau S and O'Hara R (2012) Gender differences in sexual behaviours of AD patients and their relationship to spousal caregiver well-being. *Ageing and Mental Health* **16**, 89–101.
- Dickson-Swift V, James EL, Kippen S and Liamputtong P (2007) Doing sensitive research: what challenges do qualitative researchers face? *Qualitative Research* **7**, 327–353.
- Dominguez LJ and Barbagallo M (2016) Ageing and sexuality. *European Geriatric Medicine* **7**, 512–518.
- Dourado M, Finamore C, Barroso M, Santos R and Laks J (2010) Sexual satisfaction in dementia. Perspectives of patients and spouses. *Sexuality and Disability* **28**, 195–203.
- Droes RM, Boelens-van der Knoop BCC, Bos J, Meihuizen L, Ettema TP, Gerristen GL and Scholzel-Dorenbos CJM (2006) Quality of life in dementia perspective. An explorative study of variations in opinions among people with dementia and their professional caregivers, and the literature. *Dementia* **5**, 534–558.
- Evans D and Lee E (2014) Impact of dementia on marriage: a qualitative systematic review. *Dementia* **13**, 330–349.
- Fileborn B, Hinchliff S, Lyons A, Heywood W, Minichiello V, Brown G, Malta S, Barrett C and Crameri C (2017) The importance of sex, and the meaning of sex and sexual pleasure for men aged 60 and over. *Archives of Sexual Behaviour* **46**, 2079–2110.
- Galinsky AM and Waite LJ (2014) Sexual activity and psychological health as mediators of the relationship between physical health and marital quality. *Journals of Gerontology: Psychological Sciences and Social Sciences* **69B**, 482–492.
- Greenwood N and Smyth R (2015) Barriers and facilitators for male carers in accessing formal and informal support. *A systematic review*. *Maturitas* **82**, 162–169.
- Griffiths E (1988) No sex please, we're over 60. *Nursing Times* **84**, 34–35.
- Haesler E, Bauer M and Fetherstonhaugh D (2016) Sexuality, sexual health and older people, a systematic review of research on the knowledge and attitudes of health professionals. *Nurse Education Today* **40**, 57–71.
- Harris SM, Adams MS, Zubatsky M and White M (2011) A caregiver perspective of how Alzheimer's disease and related disorders affect couple intimacy. *Ageing & Mental Health* **15**, 950–960.
- Hayes J and Boylstein C (2009) Living and loving with dementia, negotiating spousal and caregiving identity through narrative. *Journal of Ageing Studies* **23**, 48–59.
- Heiman J, Long Smith S, Fisher W, Sand M and Rosen R (2011) Sexual satisfaction and relationship happiness in midlife in older couples in five countries. *Archives of Sexual Behaviour* **40**, 741–753.
- Holdsworth K and McCabe M (2018) The impact of dementia on relationships, intimacy and sexuality in later life couples: an integrative qualitative analysis of existing literature. *Clinical Gerontologist* **41**, 3–19.

- Hong SC and Coogle CL (2014) Spousal caregiving for partners with dementia: a deductive literature review testing Calasanti's gendered view of care work. *Journal of Applied Gerontology* 35, 759–787.
- Hrženjak M (2013) Negotiating masculinity in informal paid care work. *International Review of Sociology* 23, 346–362.
- Kaplan L (2001) A couplehood typology for spouses of institutionalised persons with Alzheimer's disease: perceptions of 'we'-'I'. *Family Relations* 50, 87–98.
- Lincoln YS and Guba EG (1985) *Naturalistic Inquiry*. Newbury Park, CA: Sage.
- Mahalik JR, Locke BD, Ludlow LH, Diemer MA, Scott RP, Gottfried M and Freitas G (2003) Development of the conformity to masculine norms inventory. *Psychology of Men and Masculinity* 4, 3–25.
- Manderson L, Bennett E and Andajani-Sutjahjo S (2007) The social dynamics of the interview: age, class & gender. *Qualitative Health Research* 16, 1317–1334.
- Merrick K, Camic P and O'Shaughnessy M (2016) Couples constructing their experiences of dementia: a relational perspective. *Dementia* 15, 34–50.
- Miller B and Cafasso L (1992) Gender differences in caregiving: fact or artefact? *Gerontologist* 32, 498–507.
- Milligan C and Morbey H (2016) Care, coping & identity: older men's experiences of caregiving. *Journal of Ageing Studies* 38, 105–114.
- Molyneaux VJ, Butchard S, Simpson J and Murry C (2011) The co-construction of couple hood in dementia. *Dementia* 11, 483–502.
- Nogueira MML, Brazil D, Sousa MFB, Santos RL and Dourado MCN (2013) Sexual satisfaction in dementia. *Revista de Psiquiatria Clínica* 40, 77–80.
- Nogueira MML, Neto JPS, Sousa MFB, Santos RL, Rosa RDL, Belfort T, Torres B and Dourado MCN (2015) Spouse-caregivers' quality of life in Alzheimer's disease. *International Psychogeriatrics* 27, 837–845.
- Nogueira MML, Neto JPS, Sousa MFB, Santos RL, Rosa RDL, Lacerda IB, Baptista MAT and Dourado MCN (2016) Perception of change in sexual activity in people with Alzheimer's disease: view of people with dementia and their spouse caregivers. *International Psychogeriatrics* 29, 185–193.
- O'Neil JM (1981) Patterns of gender role conflict and strain: sexism and fear of femininity in men's lives. *Personnel and Guidance Journal* 60, 203–210.
- O'Shaughnessy M, Lee K and Lintern T (2010) Changes in the couple relationship in dementia care. *Dementia* 9, 327–258.
- Palacios-Ceña D, Carrasco-Garrido P, Hernández-Barrera V, Alonso-Blanco CP, Jiménez-García R and Fernández-de-las-Peñas C (2012) Sexual behaviors among older adults in Spain: results from a population-based national sexual health survey. *Journal of Sexual Medicine* 9, 121–129.
- Pinquart M and Sörensen S (2006) Gender differences in caregiver stressors, social resources, and health: an updated meta-analysis. *Journals of Gerontology: Psychological Sciences and Social Sciences* 61B, 33–45.
- Pleck JH (1981) *The Myth of Masculinity*. Cambridge, MA: MIT Press.
- Pöysti MM, Laakkonen ML, Strandberg T, Savikko N, Tilvis RS, Eloniemi-Sulkava U and Pitkälä KH (2012) Gender differences in dementia spousal caregiving. *International Journal of Alzheimer's Disease* 2012, 162960.
- Pretorius C, Walker S and Malan Heyns P (2009) Sense of coherence amongst male caregivers in dementia. *A South African perspective*. *Dementia* 8, 70–94.
- Quinn-Patton M (2002) Two decades of developments in qualitative inquiry. A personal experiential perspective. *Qualitative Social Work* 1, 261–283.
- Robinson CA, Bottorff JL, Pesut B, Oliffe JL and Thomlinson J (2014) The male face of caregiving: a scoping review of men caring for a person with dementia. *American Journal of Men's Health* 8, 409–426.
- Roelofs TX, Luijkx KG and Embregts PJ (2017) Love, intimacy, and sexuality in residential dementia care: a spousal perspective. *Dementia* 18, 936–950.
- Rusbult CE (1983) A longitudinal test of the investment model: the development (and deterioration) of satisfaction and commitment in heterosexual involvements. *Journal of Personality and Social Psychology* 45, 101–117.
- Russell R (2007) The work of elderly men caregivers: from public careers to an unseen world. *Men and Masculinities* 9, 298–314.
- Sandberg L (2013) Just feeling a naked body close to you: men, sexuality and intimacy in later life. *Sexualities* 16, 261–282.
- Silverman D (2004) *Qualitative Research: Theory, Method and Practice*. London: Sage.

- Simonelli C, Tripodi F, Rossi R, Fabrisi A, Lembo D, Cosmi V and Pierleoni L** (2008) The influence of caregiver burden on sexual intimacy and marital satisfaction in couples with an Alzheimer's spouse. *International Journal of Clinical Practice* **62**, 47–52.
- Sinnott J and Shifren K** (2001) Gender and ageing: gender differences and gender roles. In Birren J and Schai K (eds), *Handbook of the Psychology of Ageing*. San Diego, CA: Academic Press, pp. 454–476.
- Sternberg RJ** (1997) Construct validation of a triangular love scale. *European Journal of Social Psychology* **27**, 313–335.
- Svetlik RND, Dooley WK, Weiner MF, Williamson GM and Walters AS** (2005) Declines in satisfaction with physical intimacy predict caregiver perceptions of overall relationship: a study of elderly caregiving spousal dyads. *Sexuality and Disability* **23**, 65–79.
- Thorpe R, Hawkes G, Dune T, Fileborn B, Pitts M and Minichiello V** (2017) Hidden boundaries and shared meanings: the roles of researcher characteristics and cultural norms in shaping understandings of sexuality in the unstructured interview setting. *International Journal of Social Research Methodology* **21**, 205–217.
- Waite IJ, Iveniuk J, Laumann EO and McClintock M** (2017) Sexuality in older couples: individual and dyadic characteristics. *Archives of Sexual Behaviour* **46**, 605–618.
- Youell J and Callaghan J** (2016) 'I don't know if you want to know this': carers' understanding of intimacy in long-term relationships when one partner has dementia. *Ageing & Society* **35**, 946–967.

Cite this article: Fee A, McIlpatrick S, Ryan A (2019). 'When it faded in her ... it faded in me': a qualitative study exploring the impact of care-giving on the experience of spousal intimacy for older male care-givers. *Ageing & Society* 1–22. <https://doi.org/10.1017/S0144686X19000850>

Theme Two: Caregiving and Masculinity

Caregiving as a gendered concept was highlighted in this theme. Some data suggested that men's approach to caregiving was influenced by traditional masculine norms, such as independence, stoicism and protectiveness. One such example of this was around help-seeking behaviour. Even though several men asked for and received help from family and formal support services, there were many more who were reluctant to ask for help, preferring to manage the situation on their own. One participant described how *'I knew I needed help, but I never wanted help, to be quite honest with you'*. Others emphasised that they would accept help, if it was offered, but that they would never ask for it.

'I've coined a phrase, carers don't ask, carers accept. I won't ask you for help but if you offer me, I'll accept it'. (Joseph)

Another participant described how he was unaware of services that existed and the implications of this for support:

'I think maybe someone might have contacted me and said, 'would you like literature on this?' or 'would you like someone to talk to?' I think that's the way it was really, I don't recall being asked and I certainly didn't go and say is there anything I can have on this because I didn't know. If you don't know to ask, what do you ask for, how do you know what to ask for?' (Noel)

Other participants offered an alternative perspective about what influenced their help seeking. Some explained that they were concerned about their spouses' reaction if they had accepted other women in to the house to help out:

'I said 'XXXX, I'm going to have to get someone'... I call it nurses because if I said women, that's just an ordinary woman, I call it nurses because then it's accepted'. (Clive)

'She maybe wouldn't like women in the house. I don't think she would'. (Harry)

Also within this theme, personal care was highlighted as a significant element of the caregiving role, and for some participants, they were managing aspects of personal

care that they would previously never have been exposed to. Buying continence pads posed problems:

'Sometimes, it's asking people in those centres, and sometimes I'm too embarrassed to ask. Like pads, for instance. I don't know if men would ask about that'. (Dessie)

'There are things I have to get for my wife, of a personal nature. Undergarments. It's difficult going into shops, for me to lift a packet of those and go to the counter and pay... I have to go and lift pads. There's one of those automatic ones, you do it yourself. Nobody will see that. So, I just take a chance on what size they are and what way they fit. I don't know.' (Mark)

Mark also commented that with other aspects of personal care, it was staff within the day centre attended by his wife that provided information about how to manage:

'I can go to some of them and say, 'Look, I have to get things' and they say, 'This is what you do'. They're right down to earth. I can do that. I'd be kind of lost without that centre and the help they give me'. (Mark)

Other participants described difficulties around how to dress their partners, as recalled by Clive:

'The one thing I find hardest is what to put on her and my wife has got wardrobes galore of clothes. I'd be in shorts and a short-sleeved shirt, that's what I wear, even when I'm at the garage, cold doesn't bother me, and I found that that's what I was putting on my wife, not shorts but short-sleeved stuff and I remember I said this is not right, I don't feel the cold, but she does. So, I said does this go with this, do I put this on, would this look daft? That's what I find, that's the hardest thing for me what to put on her'. (Clive)

Dealing with underwear was another area which presented challenges for Noel and Dan:

'Putting on a bra or taking off her bra, just can't do it..., I mean she needs a woman's touch there'. (Noel)

'The one article I found the hardest to work out is the bra. I've worked it out now, label to the right, that's the way I remember, and she's put it on inside out, upside down, I've seen her put it on, that's why I had to do

it then, I've got to learn how to do this, taken many a bra off but putting them on is a different thing'. (Dan)

Another area highlighted within this theme was that of household tasks. Although some participants explained that they had no problem with cooking and cleaning, as they had always helped with this, others were challenged by taking on what was a new role for them.

'I didn't know about washing clothes. You put the woollens in and the cottons in and if you put them all on coloureds, you'll maybe find that your vest that was white has turned pink! So, I had to learn a wee bit about that. About cooking food, the difficulties with that'. (Gerry)

'I don't mean this in a detrimental kind of way to women, but to actually cook and washing and things like that, it would be one of the jobs that they do anyway. So, it wouldn't be something different, they would actually just be having an extra job caring for a person put on top of it. I think for a man it's a complete change, there's lots of things that become different'. (Clive)

Some men also described how they changed household systems to better suit their approach. They appeared to take a managerial approach to finding solutions for household tasks, and some explained this within the context of being a man. For example, Gerry commented:

'I say, 'A man's got to do what a man's got to do'. The clothes are sitting out and I have to wash them.I have to be one step ahead all the time. With cooking, I have to think what to make next'. (Gerry)

Several reported that they had de-cluttered (by removing all ornaments), changed from carpets to wooden flooring, or only bought clothes that didn't need ironed in order to make some household tasks such as dusting, hoovering and ironing more manageable. A sense of protectiveness came thorough strongly in some men's account of their caregiving role. Data suggested that men felt a duty to act as a protector in the face of their partner's illness. Alan and Jack described their experience.

'I don't really think anything could have helped because I wouldn't have wanted anybody to sit in with me to give an hour's ... because I wanted

to be there to ... I knew how to get her out of a panic attack, I could bring her out of it'. (Alan)

'I don't leave her behind for that sort of thing. If something happened, I'd be afraid if I was out and she got up to touch something, or maybe got electrocuted or hurt and wouldn't know where to turn or how to use the phone. (Jack)

This sense of protection seemed to be reinforced by a feeling of 'she would do it for me'.

'I always remember, when you get married, 'In sickness and in health, for richer, for poorer'. As well as that, if the shoe was on the other foot, I know she'd do it for me. She'd do everything for me. I just know that. So, I'm going to do it for her. (Harry)

'I tried to think, if it was the other way about, I know she'd do it for me, so I'll do it for her. I'm quite happy to do that. (Aidan)

Theme Three: Emotional impact of caregiving

The third overarching theme dealt with a range of emotional experiences which impacted on caregiving. Most participants made some reference to loneliness or isolation in relation to their caregiving role. A number of factors influenced feelings of loneliness. Several men described feelings of loneliness due to their partners deteriorating health which had resulted in the gradual loss of important aspects of their relationship - such as conversation.

'I mean another aspect of it is my loneliness, (XXXX) just loves watching the TV and then falling asleep and if there's an interesting programme or whatever but most times I would just sit with her and I might as well be alone in the house, there's no communication and it's a bit of loneliness on my part as well and that gets me frustrated because I've umpteen jobs to do about the house and I feel my need is to be with her and to help her'. (Aidan)

'I felt very lonely. I think that was the real suicidal part of it, just sitting here...., it was like mourning somebody and still living with them and that's very true'. (Colin)

Feelings of isolation were also commonly reported. Participants attributed their isolation to decreasing opportunities for socialisation due to aspects of their partner's illness. One participant described that symptoms of his partner's dementia included a personality change which made her aggressive and insulting towards visitors. He explained that friends had 'dropped away' as they were uncertain how to deal with this. He emphasised that he did not blame his partner or friends for this but felt incredibly isolated and hopeless about the situation. Other men acknowledged isolation without elaborating on reasons for this,

'Close friends.....people who we had physically helped through the years and done a lot for through the years. One of them, we'd be lucky to get a phone call a year. The other one, we get no phone calls. The neighbours, you can't expect them to keep running in and out because it's long term we're talking.' (Clive)

'You feel alone, very alone and regardless of my social contacts and my sport that I was involved with, I can't do it because I'm frightened of leaving her by herself'. (Jack)

'Well, the main social life is with my brother-in-law and also my sister-in-law, we'd have dinner on a Saturday night down at her house or they would come to us. They're coming less and less to my house because it's getting to be more work to get the house and prepare for them and things like that and then we would eat out on occasion'. (Noel)

'The care circle consists of me, and then occasional participants like my sister who is very helpful when she can be, but she has her own family and so on, and XXXX across the street'. (Simon)

There was however, some evidence of men seeking and benefitting from individual solutions to their need for emotional support. Alan described an emotional outlet which provided support:

'I've recently discovered an auntie, she's getting on a bit now and I was talking to her about it and we ended up having quite a long conversation. She's really good, so I could unburden. You're not really looking for answers when you talk to people, you just want to talk.' (Alan)

For Dessie, attendance at a carer support group based in the day centre that his wife attended provided emotional support, practical information and a social outlet:

'Once a month all the other carers, we meet, just for a chat, sometimes we can put people in from Social Services to update us on what's up, what's down, or what we're losing, or what we're getting, and what other services are becoming available, or being cut. You meet people who have dealt with a problem in one way, but it's much handier than the way I dealt with it, or vice versa, and we all feed off each other. I regard that meeting as the highlight of my month, because it's a wee bit of a social occasion, and its tea and biscuits, or something like that, just for kindness. But the rapport between everybody is fantastic. It's really good.' (Dessie)

Alan also described how attendance at an Alzheimer's support group had provided information and a social outlet:

'This carers' course was very good. For one, it did explain things that I didn't know and for two, it gave me the chance to talk to other carers who were under similar circumstances' (Alan)

Theme Four: Service related barriers and enablers to caregiving.

Theme four described barriers and enablers to support from formal services (such as support from statutory health and social care providers). Many participants referred to respite as being an important aspect of their coping strategy. Residential respite was usually offered, whereby their spouse/partner was admitted to a residential facility for a specific time period. However, due to previous bad experiences, some participants were very reluctant to use it again, preferring to use a 'sitting service' where an external agency came to their home and provided care, to enable the caregiver to have time away. This too was problematic. Many men explained that they would have liked time at the weekends for sporting events. Participants gave examples of sports such as target shooting, golf, sailing and football which not only provided a break from caregiving but also opportunities for socialising and exercise. However, this was often difficult to arrange, resulting in disappointment for the participants.

'XXXX went into respite care and I decided to decorate the place. It was only a week. The respite was a disaster. It didn't suit XXXX at all. There was no chance of her ever going into a home again after that'. (Alan)

'The social worker said, 'what is it you miss'?, and I said, 'golf on a Sunday' and she said I'll try and get you golf on a Sunday'. But, no, she got me the four days, the four afternoon sits. But, no, we didn't quite make it to the Sundays and the golf. But, you see, I need five hours respite probably at the minimum to be able to get down and have a game of golf and back and on a Sunday which is not good. No, I mean I knew that wasn't going to happen, but it was a goal.' (Robert)

'She put out into the brokerage to try and get people to come in on a Saturday so that I could get out ... I used to target shoot, so that I could go to that. The big problem is the brokerage, it's alright they will get somebody to sit with XXXX, but for a long period of time and if XXXX has to go for toilet needs, a whole lot of them won't do it.' (Clive)

Other service related barriers to support were reported such as equipment and continence products.

'The equipment – the bed, the hoist – were absolutely essential. They worked very well for me eventually. You get trained for the hoist. You can't use the hoist unless you're trained. I was using it six weeks before I was trained. Bureaucracy was disgraceful'. (Alan)

'There was one girl, I told her about the problem I had with pads. I wanted the pull-up pads, but they didn't keep them. I said, 'I'm sorry, but that's what she had because I'm going to put them on'. The two district nurses came, and they pulled them up. I said, 'How do they do that?' The girl tried to demonstrate, and I couldn't even do it right. So, after an argument, I won the case and we got them. I think I had to go to a politician to get some'. (Harry)

By contrast there were also examples of supportive experiences and interactions, including the provision of respite.

'The social worker got us two day sits. We have that and two days in Wilson House. I mightn't do anything. Sometimes, I just walk round the house, but I have a couple of hours, rather than 24. It just lifted me. I was able to carry on. The support you get from Social Services and support workers, district nurses has to be good – which I had'. (Robert)

Other supportive experiences were described, sometimes with social workers, but occasionally it was from unexpected quarters such as staff working in Day Centres. Male caregivers appreciated support from people who they had built a relationship with, and who were skilled and/or knowledgeable about their particular needs.

'XXXX Centre, the staff are very good. Honestly, I couldn't say enough about the great things they do. I just have to go in and say, 'I'm having a wee bit of difficulty with this or that'. (Dessie)

'But, the social worker calls and that's mainly for me, for my benefit, if that's the right word, and she gave me a list of homes to look at, specific homes for specific needs, and it's just good to have someone to talk to, to be honest with you, to have an intelligent conversation with because I don't have an intelligent conversation with my wife'. (Clive)

'So it was really until the Dementia Home Support Team got involved, that was a year ago, September-time a year ago, and they helped me get some sitting services and that because I was having trouble where I was taking XXXX out, say, shopping, she'd get there and then decide she didn't want to be there and wanted to go home and while you can drag a screaming kid round a supermarket, you can't do the same with a grown woman. So, that helped greatly, I have to say they were fantastic in the help and the support and the psychological support as well because they actually sat in themselves to let me go to some of the courses that the Alzheimer's Society were running in regard to carers. Because I couldn't get to any of the carer's groups, again because we'd no family, it's just me and XXXX'. (Robert)

4.13 Summary

The aim of this phase was to explore older males' caregiving experience through qualitative interviews. Findings revealed four overarching themes: Declining Intimacy; Caregiving and Masculinity; Emotional Impact of Caregiving; and Service-Related Barriers and Enablers to Caregiving. A reluctance to ask for help with their caregiving role, loneliness/isolation, and impact of caregiving on intimacy were commonly reported by participants. Male caregivers also referred to issues around provision of support from formal agencies, such as availability of appropriate respite, or issues with equipment or continence products. These findings point to a need for better understanding from formal support providers of the influence of gender on caregiving in order to provide more tailored support to older male spousal caregivers.

4.14 Conclusion

This chapter reported findings of the quantitative study phase, a scoping exercise; and also the first qualitative study phase - interviews with older male caregivers. Phase 1

findings revealed that membership of community-based agencies was mainly female, and very few services were offered that were specifically targeted at males; although there was some evidence of uptake of generic services by male caregivers. Analysis of data from phase 2 resulted in four main themes that described the experiences of older male caregivers. These themes were: 1) Declining Intimacy; 2) Caregiving and Masculinity; 3) Emotional Impact of Caregiving; 4) Service-Related Barriers and Enablers to Caregiving. The first theme 'Declining Intimacy' was analysed as a subset of data and contained in the paper: *'When it faded in her.... it faded in me': A qualitative study exploring the impact of caregiving on the experience of spousal intimacy for older male caregivers'*. Taken together these findings provide quantitative and qualitative findings that begin to describe support services for older male caregivers, and form the basis for the development of the next phases - phase 3 and phase 4. The next chapter will provide further detail about these study phases, exploring the phenomenon further through focus groups with statutory support providers (phase 3), and a deliberative workshop with key stakeholders (phase 4).

CHAPTER FIVE: FOCUS GROUP INTERVIEWS AND DELIBERATIVE WORKSHOP

5.1 Introduction

The previous chapter reported findings of the first two study phases: phase 1 - quantitative scoping exercise; and phase 2 - qualitative interviews with older male spousal caregivers. Findings indicated a lack of support for older male caregivers from community-based agencies and a lack of provision and uptake of other support from the statutory sector. The current chapter details the next two phases - phase 3, focus groups with formal support providers; and phase 4, a deliberative workshop with key stakeholders. Phase 3 provides an overview and rationale for undertaking focus groups with formal support providers. A detailed account of phase 3 is included in Paper 3 (section 5.6). In phase 4 details of background, data collection, analysis and findings of a deliberative workshop with key stakeholders are presented, before the conclusion is drawn.

Phase 3 – Focus Groups

5.2 Context and rationale

Caregiver support

The aim of this study was to explore the impact of support services in identifying and meeting the needs of older male caregivers caring for a chronically ill spouse/partner at home. The term ‘support’ refers to the provision of services to meet the emotional, instrumental, and informational needs of older male spousal caregivers in order to sustain their caregiving role. The importance of support for older male spousal caregivers was previously discussed in Chapter Two (Literature Review). Additionally, the findings of phase 2 (older male caregiver interviews), revealed that masculinity impacted on male caregiver’s approach to their caring role; the emotional impacts of caregiving included loneliness and isolation; and that support from formal providers (such as social workers) could be either a barrier or enabler to sustaining the caregiving role. Given these findings, it was clear that formal support providers needed

to be engaged in discussion about their experience of delivering support services to older male caregivers in order to shed light on some of the points raised during caregiver interviews. The views of health and social care professionals about the impact of caregiver support have been previously reported in the literature (Ekstedt *et al.* 2014; Aldaz *et al.* 2016; Beiber *et al.* 2019). However, this was in relation to male *and* female caregivers, and the studies were conducted in illness specific settings (i.e. cancer care). Therefore, a gap in knowledge exists about the impact of support services for older male caregivers, across chronic conditions, from the perspective of formal support providers.

'Formal Support Providers'

Previous literature on caregiver support has categorised support as 'formal' or 'informal'. Formal caregiver support tends to be from formalised services such as statutory health and social care providers, or funded community-based agencies. Support can take the form of practical support including respite care, written information, or domiciliary support (such as assistance with meals or medication); or therapeutic support (including counselling, befriending or social activities). For this study, the term 'formal support providers' refers to personnel from statutory (i.e. health and social care government funded agencies,) or community-based agencies (for example Alzheimer's Society or Marie Curie) who provide support (such as assessment, respite, or practical help) for informal caregivers.

Statutory support

Caregiver support provided by statutory agencies, such as HSCT is generally based on assessed need. The nature and level of support is dependent on the outcome of assessments known as 'carers' assessment' and is undertaken by statutory health and social care practitioners (such as social workers or community nurses). That being said, if the practitioner is aware that the caregiving situation is at breaking point or crisis, support will be provided irrespective of whether or not a carers' assessment has been completed based on the practitioner's professional judgement.

Community-based support

Community-based agencies are independently funded (i.e. National Lottery, charitable donations, or Service Level Agreement with the HSCT). These agencies may be small locally run groups, or branches of a larger organisation (such as Alzheimer's Society or Marie Curie). Due to their independence they have the potential to have greater flexibility without the policy and legal constraints that affect statutory providers. However, they still must adhere to relevant legal requirements when working with vulnerable people, for example they are duty bound to undertake a criminal record check on staff/volunteers.

Aim: In line with study objective 4, the aim of the focus group interviews was to explore the perspectives of health and social care professionals and community-based agency personnel about support services for older male spousal caregivers.

5.3 Design and methods

Focus groups were chosen above other types of data collection for this study phase for several reasons. Firstly, it was thought that focus groups, as opposed to any other method of data collection (such as interviews), were the most effective way to further investigate support for older male caregivers, given the aim of focus groups to gain an understanding of a phenomenon through the eyes of key stakeholders (Krueger and Casey 2015). Secondly, according to Kitzinger (1995) a particular strength of focus groups is that they allow for group interactions involving exploration and clarification of views and attitudes, which was thought to be important in gathering perceptions of whole teams including a range of staff/volunteers together for this phase. Finally, the aim of the focus groups was to generate deeper understanding to motivations, behaviour, opinions and other factors that influenced the delivery of support from formal support providers to older male caregivers. As such, it was thought that the interactions and 'safe' environment of focus groups could provide opportunities to gather important qualitative data from many participants at once (Krueger and Casey 2000). There are, however limitations and risks with using focus groups as a data collection method. These risks and the way in which they were minimised in the current study are highlighted in Table 11.

Table 11: Measures taken to minimise focus group risks

Risk	Risk Reduction Measures
Participant recruitment.	Close collaboration with team leaders within the Health and Social Care Trust; and managers within the community-based agencies, and guidance from the Project Steering Group ensured that any recruitment problems were addressed at an early stage.
Participants not contributing to the discussion.	The moderator established a rapport with the group and encouraged participants to introduce themselves at the beginning of the session. This contributed towards participants ‘hearing their own voice’ at an early stage in the session.
One (or several) participants dominating the discussion.	All group participants were encouraged to talk, by the moderator’s use of eye contact and body language, or by directing questions towards a particular section of the group.
Not getting ‘rich’ data.	The moderator used probes such as ‘ <i>what do you mean?</i> ’, ‘ <i>tell me more about that</i> ’. These probes used early in the discussion signified the importance of precision of responses.

5.4 Data collection

Sample

Purposeful sampling was used (Silverman 2004), however, as this is not random sampling, researcher bias may have been an issue. This was addressed by asking locality managers within HSC Trusts to inform suitable teams about the study (who met inclusion criteria). Regarding the community-based agencies, discussion with the project steering group (which included community representatives) guided the recruitment strategy.

Recruitment

Inclusion criteria were: *Community based teams comprising health/social care personnel within mental health for older people or older people’s services, within a statutory Health Trust or voluntary sector organisation.*

A promotional flyer (Appendix 16) and cover letter were developed by the researcher. Within HSC Trusts local collaborators or locality managers identified by the researcher or the relevant Trust research office, circulated this study information to teams who met the inclusion criteria. Teams expressed an interest by directly contacting the researcher who then forwarded study information, including a participant information sheet (Appendix 17) and consent form, (Appendix 18). Recruitment for community-based agencies involved the researcher contacting agencies (as agreed with the Project Steering Group) with study information (as described above). Similar to the HSC Trusts, community-based agencies who were interested in the study contacted the researcher to receive further information. When groups agreed to participate, the researcher arranged a suitable date and time for the focus group. The manager was then emailed confirmation of the arrangements and asked to distribute the participant information sheet and participant consent form to all participants. To further ensure attendance the researcher again emailed the manager a number of days before the focus group (Morgan 1988), both to remind the team of the focus group and to finalise numbers for hospitality and refreshments. All participants signed a consent form prior to the commencement of the focus group, and all sessions were digitally recorded (with informed written consent).

The initial intention of the researcher was to target all five HSC Trusts in Northern Ireland for focus groups (one focus group per Trust), to ensure geographical representation. Therefore, all Trusts were initially contacted and approached for ethical approval. However, this process proved more straightforward with some Trusts than others, with only three of the five Trusts granting ethical approval within the specified time frame. Given the time constraints on the study, after a certain point, the decision was taken to undertake focus groups with three HSC Trusts as opposed to five. It is important to note that the three Trusts who gave ethical approval within the specified time frame covered both rural and urban areas of Northern Ireland, with an adequate geographical spread throughout the province.

Krueger and Casey (2015, p. 23) suggested that after three to four focus groups, the researcher should determine whether saturation has been reached. In the current study,

after four focus groups with community-based agencies ($n=33$), the research team determined that data saturation had been reached with community-based agencies as no new information was being discussed (Mason 2010). After the fifth focus group with HSC Trusts ($n=51$) it was deemed that data saturation had been reached with HSC Trusts, therefore no additional focus groups were undertaken.

Composition of focus groups

The goal of a focus group discussion is to create a safe, permissible environment, where people do not feel judged, rather they are able to express how they really think and feel about an issue (Krueger and Casey 2015 p. 4-5). The skill of the moderator is paramount in ensuring this environment is created and maintained, and the size and composition of the group also influences the group dynamic. As described in Paper 3, (section 5.6) the present study involved focus groups with government funded statutory providers of support to older male caregivers, based within HSC Trusts; and also with community-based independently funded providers of support. The reason for facilitating the groups separately was to do with implicit perceptions of power differential between these groups, as experienced by the researcher in previous practice.

Unlike other focus groups which often comprise a group of strangers with similar characteristics, the focus groups in the current study consisted of participants in 'pre-existing groups' – that is they were known to one another. Krueger and Casey (2000) cautioned against the use of enlisting pre-existing groups as focus group participants, as these groups often had pre-existing dynamics. Krueger, from a realist perspective, maintained that this could influence discussion through the existence of implicit and explicit hierarchies within the group, leading to potential inhibition of negative contributions or disclosures. In contrast, Kitzinger's (1994) constructivist perspective was that pre-existing groups offered a 'naturalistic', exchange of views, within a specific setting. Focus group participants ($n=84$), comprised a broad range of healthcare and community sector personnel, including social workers, nurses, managers, psychiatrists and community support workers, as detailed in Table 12. The researcher kept detailed field notes about each focus group which included non-verbal

data, context, prior communication, number and composition of the group, group interactions, and overall flow and energy of the session (Appendix 19).

Table 12: Focus groups characteristics

Group ID and date	Number of participants	Composition of group (professions represented and gender)	Locality
Group 1 17/10/18	11	Regional Service Manager (1), locality service co-ordinator (4), community support (6) 3 Male, 8 Female	Urban
Group 2 05/11/18	8	Service Manager (1), Community Support (5) Volunteers (2) All Female	Rural
Group 3 12/11/18	10	Service Manager (1), volunteers (4), community support (5) 2 Male, 8 Female	Urban
Group 4 14/11/18	11	Team leader (1), Psychiatry (2) Community Psychiatric Nurse (2), social work (6) 4 Male, 7 Female	Urban
Group 5 21/11/18	5	Service Manager (1), Community Support (4) 1 Male, 4 Female	Rural
Group 6 10/01/19	9	Social work (6), community support (1), student social workers (2). All female	Urban
Group 7 21/01/19	5	Team Leader (1), Social Work (3), Community Support (1) All female	Rural
Group 8 20/01/19	11	Team Leader (1), Clinical Psychology (2), Assistant Psychologist (1), Occupational Therapy (1), Community Psychiatric Nurse (2), Social Worker (2), Community Support (2). 10 Female, 1 Male	Rural/Urban
Group 9 01/02/10	14	Nursing (3), Occupational Therapy (3), Social Work (4), Psychology (2), Psychiatrist (1), Ward Manager (1) 9 Female, 5 Male	Rural

Setting

The focus groups interviews were generally held in participants' place of work. For the HSC Trust teams, all focus groups were undertaken within their office (with the agreement of the team leader). With the community-based agencies, two focus groups were held in their offices, and two were facilitated in a neutral venue organised by the researcher (one hotel and one community venue). The groups were facilitated during working hours, at lunchtime and lunch was provided for all participants.

Pilot study

Piloting focus groups is useful for improving quality of data, question flow, effectiveness of the moderator and structure (Breen 2006). Although Breen also suggested that at least three pilot groups should be undertaken, resource constraints meant that for this study only one could be conducted (with a community-based agency). The aim of this pilot study was for the researcher to anticipate answers to questions; to identify areas that needed additional probes; to check participants' understanding of questions and to gauge general time frames for questions. After the pilot, the interview guide was changed to improve the flow (by changing the question sequence) and also with the inclusion of a number of additional prompts.

Interview guide

The focus group interview guide (Breen 2006) (Appendix 20) was developed in accordance with the study aims, and relevant literature. Specifically, Krueger and Casey (2015, p.7) suggest that focus group questions should be a series of predetermined, sequenced, open-ended and logical questions. Questions were planned that were clear, short, concise, open ended and one directional. Questions followed the sequence of: Opening, Introduction, Transition, Key, Ending (Krueger and Casey 2015). Focus groups were moderated by the researcher (AF), who had previously undertaken training in moderation of focus groups at Ulster University. The moderator also had prior experience of working within statutory and community-based agencies, and a background of facilitating focus groups within Northern HSC Trust.

Each focus group commenced with the moderator explaining the background to the study; the format of the focus group session; an explanation about her own background

and role within the group; the use of digital recorders; and some focus group conventions such as confidentiality, the amount of time to be taken; and that all contributions were important (Bryman 2015). The moderator then distributed consent forms which all participants signed. Next, participants were invited to introduce themselves and explain their role within the team. The moderator then began with general questions to encourage involvement – such as ‘*Give me a general indication of the number of older male caregivers on your caseload?*’ During the focus group interviews probes were used to explore issues in more depth. The final question was an ‘ending question’ which could have been ‘*have we missed anything*’ or ‘*is there anything else to be said on this?*’. Even though the questions had been carefully formulated and sequenced, the aim of the moderator was to moderate the discussion in a way that was natural and spontaneous, in an attempt to elicit participant’s perspectives without feeling pressure or judgement (Krueger and Casey 2015).

Governance approval and ethical considerations

As described in section 3.9 (Ethical Considerations) HSC governance approval for this phase was granted. Breen (2007) raises some important ethical issues for consideration when running focus groups. Some of these are detailed in Table 13, along with a description of how the issues were addressed by the researcher.

Table 13: Ethical issues associated with focus groups

Issue	Resolution
Ensuring that participants are at ease and able to speak within the group.	When the focus group commenced, participants were each invited to introduce themselves, which gave them an opportunity to speak at an early stage. The aim of the moderator was to set the scene and achieve a balance of a relatively relaxed and permissive atmosphere, whilst ensuring that the atmosphere wasn’t too rigid and formal.
Assuring confidentiality	Prior to the focus group, participants received information about confidentiality and data protection. This was reiterated by the moderator at

the beginning of the session, with participants being assured that pseudonyms would be used to protect identity in any resulting reports.

Confusion with timing or sequencing of questions. Questions were asked in a conversational manner. The moderator anticipated the flow of discussion, and asked questions in a logical manner according to the flow. Answers were summarised regularly to check participants' understanding.

Apprehension about timing of the session. The moderator ensured that the session began and finished on time. *'We have about 15 minutes left'* articulated by the moderator, signified that the session was nearing the end.

5.5 Data analysis

A description of analytic procedures for focus group data follows in paper 3 *'Exploring formal care providers' perspectives of the support needs of older male spousal caregivers: a focus group study'* (section 5.6). Rather than replicate text from paper 3, the following section is intended to provide further rationale and additional information about the data analysis process used.

Krueger and Casey suggest that in focus groups, data collection and analysis are concurrent (Krueger 1998). They point out that data collection can be improved if the analysis continues between focus groups, in this way the researcher can identify questions that are not producing useful information and rectify this at the next group. Data analysis began during the focus groups, as the researcher was alert to changes in the group's energy and enthusiasm (by monitoring numbers of people speaking and body language); individuals becoming emotional (either verbally or by body language); and individuals changing their minds. If in doubt the researcher sought clarification or explored these situations further with questions or prompts. Non-verbal communications (observational data) such as gestures and intonation, and external stimuli, were recorded in researcher's field notes during the focus group to supplement the transcriptions and aid analysis.

Qualitative thematic analysis was chosen over quantitative content analysis as the aim of this phase was to explore contextual interpretative accounts of focus group participants' experiences, as opposed to identifying recurrent instances of data (Silverman 2014). That being said, as Wilkinson (2011) noted there is often crossover between quantitative content analysis and qualitative thematic analysis, in that both methods treat what people say as a 'window' into their perceptions (Silverman 2014). The aim of the qualitative thematic analysis was to understand participant's meanings, and to illustrate this by way of data extracts. Further details of data analysis are contained in Paper 3 (section 5.6), and an illustration of how codes and themes were mapped is contained in Appendix 21.

According to Lincoln and Guba (1985), findings can be enhanced through the inclusion of credibility measures. In the present study, credibility of focus groups findings was assured through measures such as triangulation of data and peer debriefing. For peer debriefing, data was reviewed by peers who questioned the development of codes and themes and offered an objective view of interpretation.

5.6 Findings

The findings of the focus group interviews are presented in the following paper (Paper 3), entitled '*Exploring formal care providers' perspectives of the support needs of older male spousal caregivers: a focus group study*'. This paper was published in the British Journal of Social Work:

Fee, A., Sonja McIlfatrick, S., & Ryan, A. (2020). Exploring Formal Care Providers' Perspectives of the Support Needs of Older Male Spousal Care-givers: A Focus Group Study. *The British Journal of Social Work*, bcaa019.

<https://doi.org/10.1093/bjsw/bcaa019>

**Paper 3: Exploring formal care providers' perspectives of
the support needs of older male spousal caregivers: a focus
group study**

*Exploring formal care providers' perspectives of the support needs of
older male spousal caregivers: a focus group study*

^{1*}Anne Fee, ²Sonja McIlfatrick, and ³Assumpta Ryan

¹Institute of Nursing and Health Research, Ulster University, Shore Road,
Newtownabbey BT37 0QB

² Institute of Nursing and Health Research, Ulster University, Shore Road,
Newtownabbey BT37 0QB

³ Institute of Nursing and Health Research, Ulster University, Magee Campus,
Londonderry, BT48 7JL

*Correspondence to be sent to: Anne Fee, Ulster University, Shore Road,
Newtownabbey BT37 0QB. ORCID ID: <https://orcid.org/0000-0002-5685-8079>. Email:
a.fee@ulster.ac.uk

Funding and Acknowledgements:

Authors wish to acknowledge funding for this study from HSC R&D Division, Public Health Agency (NI) EAT/5216/15.

*Exploring formal care providers' perspectives of the support needs of
older male spousal caregivers: a focus group study*

Abstract

Formal support comprises services provided by health, social care and community-based agencies, including charities. Evidence indicates poor uptake of formal support by older male caregivers who often fail to accept help until a crisis point is reached. Given the growing recognition of caregiving as gendered, there is a need for enhanced understanding of how support providers can assess and address the needs of this caregiving sub-group. The aim of the study was to explore formal care providers' perspectives of support for older male spousal caregivers through focus group interviews. The study was conducted in a region in the United Kingdom with four community-based agencies (participants: n=33), and five statutory healthcare providers (participants: n=51). Thematic data analysis resulted in the identification of three themes: Service Priorities; Engaging Men; Assessment of Need. Findings revealed that service flexibility was key to providing support; difficulties in engaging men in support and a low take-up of carers' assessments were potential barriers to support. Social Workers should have an in-depth understanding of how caregiving is gendered and how this may influence the support needs of older male spousal caregivers. Enhanced carers' assessment training, which highlights collaboration in planning and delivery of tailored support, may result in support which enables older male caregivers to sustain their caregiving role.

Key words: caregiver, gender, male, masculinity, spousal, support

Introduction

A global ageing population and rise in the number of long-term chronic conditions are resulting in an increased necessity for informal caregivers (van Groenou and De Boer, 2016; OECD, 2018). Whilst informal caregiving has traditionally been the domain of females, evidence indicates an increase in the numbers of male caregivers (Poysti *et al.* 2012). In the United Kingdom, older male caregivers are more likely than older female caregivers to provide care for a spouse. According to the Office for National Statistics (ONS) this may be because females typically provide care for a range of family members, however when a female needs care, often her spouse/partner is the only person who can provide it (ONS, 2019).

As well as experiencing satisfaction and reward from caregiving, older male spousal caregivers can be subject to declining physical and psychological well-being, declining intimacy, and profound social isolation (Milligan and Morbey, 2013; Fee *et al.* 2019). Older male caregivers are also more likely to live with a spouse than older females (Stepler, 2016), and there is evidence to suggest that spousal caregivers are at greater risk of depression, coronary heart disease and stroke than non-spousal (Haley *et al.* 2009; Ji *et al.* 2012).

Caregivers (regardless of gender) who receive support experience better health outcomes and physical/psychological well-being than those who do not (Dam *et al.* 2016). Given this evidence, and the likelihood that older caregivers will also have their own health concerns, it is vital that they receive effective support, not only to sustain their own well-being, but also to maintain the informal caregiving system, thus reducing state costs (Kaschowitz and Brandt, 2017; Verbakel *et al.* 2017). Despite these negative caregiver outcomes, a poor take-up of formal support services (such as respite or practical help) has been reported in the general caregiving population (Singh

et al. 2014). A study by Lindahl *et al.* (2009) in Sweden found that when healthcare professionals entered the home, power and status issues could potentially arise, due to 'home' being the place where family values predominated. This made the establishment of a 'professional friendship' (based on collaboration between professionals and caregivers), which Lindahl suggested was a core component of effective support, difficult. This suggestion has been supported more recently by others who have noted that establishing and maintaining trusting relationships between caregivers and healthcare personnel could be challenging (Büscher *et al.* 2011; Singh *et al.* 2014).

In recent years, gender differences in the take-up of caregiver support have been highlighted in the literature (Milligan and Morbey, 2016). Given that older male caregivers may not identify with the caregiver label and are reported to have an independent and stoic approach to caregiving (Milligan and Morbey, 2013; Robinson *et al.* 2014), they may be particularly vulnerable to lack of support. Although previous research found that in general older male caregivers were reluctant to use formal support, reasons for this remain unclear. Various causes for male caregivers' reluctance to access support have been highlighted, including: non-supportive interactions (such as previous bad experiences of support) (Neufeld and Kushner, 2009); men being outside the care system (Schwartz *et al.* 2015); and guilt about asking for help (Sanders, 2007).

Although some literature has highlighted health and social care professionals' perspectives of providing caregiver support in illness specific settings, such as cancer care or dementia (Aldaz *et al.* 2016; Bieber *et al.* 2019), research about health and social care professionals' perspectives of support needs that are common to caregivers

collectively (such as respite, training or practical help) is sparse, but necessary from a public policy perspective.

Within the United Kingdom, there are separate arrangements for the delivery of public health and social care services. Devolved administrations for England, Scotland, Wales and Northern Ireland, resulted in a health and social care provision which was unique to these jurisdictions. The current study was conducted in Northern Ireland, where health and social care services are integrated, and are delivered by teams of health and social care professionals (including social workers and nurses) within state funded Health and Social Care Trusts (HSCTs). In addition, some social care services (such as befriending, and respite) are provided by paid staff, such as community support workers, based in non-government agencies, also known as ‘community-based agencies’ (CBAs). Although both HSCTs and CBAs provide support to caregivers, there are some notable differences in how they provide these services. This includes HSCTs adherence to the application of regional eligibility criteria which aims to provide fair access to support services for services users. In contrast, CBAs are not obliged to apply these criteria.

As there is a dearth of research in this area, there is a need to consider the perspectives of formal care providers in determining the support needs of older male spousal caregivers. This is important given reported barriers for male caregivers in accessing formal support (Greenwood and Smyth, 2015), the ‘male approach’ to caregiving (Robinson *et al.* 2014), and the suggestion that male caregivers are more likely than female caregivers to provide care for a spouse (ONS, 2019). Insight into the relationship between formal care providers and older male caregivers, and the identification of factors that hinder or enable engagement and the provision of support may help to inform future support for this population group.

This study was part of a larger project which aimed to examine support needs of older male caregivers in Northern Ireland. Although the current study explored perspectives of formal care providers, a different phase of the larger project explored the use of support services from the perspectives of older male caregivers using qualitative interviews. A project steering group comprising representatives from HSCTs and CBAs; academics and a male caregiver were involved in the current study and the larger project.

For the purpose of this study, the term ‘formal care provider’ will be used as a collective term to incorporate health and social care staff who work across both statutory and community/voluntary sectors. Older caregivers are defined as caregivers over 65 years of age as this is the definition of ‘older’ in western societies (World Health Organisation 2014).

Study aim: To explore the perspectives of formal care providers about support services for older male spousal caregivers.

Design and Method

Design

A qualitative exploratory approach, using Thematic Analysis was employed (Braun and Clarke 2006). This comprised focus groups ($n=9$) with formal care providers across Northern Ireland.

Sample

Participants ($n=84$), included a range of health and social care (HSC) professionals (including social workers, nurses and mental health professionals), employed by state funded Health and Social Care Trusts (HSCTs). Community-based agency (CBA) personnel included community support staff (including community support workers, and managers) who were paid employees of a non-government agency (including Alzheimer's Society and Marie Curie), in Northern Ireland. Kitzinger (1995) suggests that the ideal size for a focus group should be 4-8 participants, however Krueger and Casey (2015) maintain that group size can be as large as 12. The current study had a minimum of 5 and a maximum of 14 participants.

Recruitment

Inclusion criteria were: Health/social care professionals within mental health for older people or older people's services (over 65), within a Health and Social Care Trust or a community-based agency.

Recruitment of participants was undertaken in liaison with local collaborators within selected agencies. Study information was circulated, and focus groups were arranged at a mutually agreed venue and time (during staff working hours) for relevant teams. All participants signed a consent form prior to the commencement of the focus group, and all sessions were digitally audio recorded (with informed consent).

Data Collection

According to Kitzinger (1995), focus groups are useful for exploring not only peoples' experiences, but also what, how and why they think certain things. In the present study focus groups were moderated by the researcher (AF), who had previous experience of working within a healthcare setting, and who was trained in facilitating focus groups.

The focus group schedule was developed in accordance with the study's aims and findings from the relevant research literature, and was piloted with one CBA. After the pilot, the schedule was altered to improve the flow by changing the question sequence and adding further prompts. Krueger and Casey (2015, p.7) suggest that focus group questions should be predetermined, sequenced, open-ended and logical. Questions in the current study began with general questions to encourage involvement – such as '*Can you give me a general indication of the number of older male caregivers on your caseload?*'. Thereafter, questions aimed to encourage open discussion about participants' experience of identifying, assessing and supporting older male caregivers. Probes were used frequently by the moderator to explore practical examples in more depth.

After four focus groups with CBAs, and five with HSCTs the researcher determined that data saturation had been reached, as no new information was being discussed (Krueger and Casey, 2015). In addition to the focus group schedule the researcher (AF) maintained in-depth field notes to record information such as context, prior communication, number and composition of the group, interactions, and overall flow and energy of the session.

Data Analysis

An inductive thematic analysis was employed to systematically organise, condense, categorise and refine data (Braun and Clarke, 2006). This approach involved six key phases: 1) familiarisation with the data, 2) generating initial codes, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes, 6) producing the report. Following the initial focus groups, data collection and analysis were undertaken simultaneously to inform later stages of data collection. Focus groups were professionally transcribed verbatim. The researcher (AF), read and re-read transcripts

for accuracy and familiarity. Next, a coding framework was developed by the researcher (AF), which included 24 initial codes (including coping strategy, carers' assessments, crisis, service flexibility). Underlying meanings of the categories were discussed with the project steering group, and the other authors (SMcI, AR), to identify overarching themes. Data were imported into QSR NVivo 12 qualitative software, for management and refinement.

Rigour

Strategies for ensuring rigor (Lincoln and Guba 1985) in the current study included: 1) The rich mix of participants (including social workers, nurses, community support workers and mental health professionals) ensured credibility. 2) Detailed descriptions of the data collection and analysis procedures, along with the use of Nvivo software to organise and interrogate data demonstrated confirmability and transferability. 3) Credibility was enhanced through peer debriefing - reviewing, refining and validating initial emerging themes. Also the project steering group was involved with the development of the focus group interview guide. 4) Researcher bias was addressed through the use of a reflexive journal, and peer debriefing.

Ethical Approval

Ethical approval for the study was granted by Ulster University Filter Committee, and governance approval was obtained from the following Health and Social Care Trusts: Northern HSC Trust (Ref: NT18-0638-10), South Eastern HSC Trust (Ref: SET 18-30), Western HSC Trust (Ref: WT 18/27).

Findings

Nine focus group interviews with personnel from HSCTs, and CBAs (participants: n=84) were undertaken. Data analysis resulted in the identification of three themes: Service Priorities; Engaging Men; Assessment of Need.

Theme 1: Service Priorities: *'Doing something that's actually going to be beneficial'*

Findings in this theme revealed several key differences in approach between HSCTs and CBAs to the delivery of support for older male caregivers. One factor that seemed to influence support prioritisation was eligibility criteria that was applied by health and social care professionals within HSCTs during assessment. Social workers explained that application of this criteria meant that only caregivers who were at 'breaking point', or those in 'critical' need received support. However, this often resulted in prioritisation whereby *'physical needs override emotional needs'*. One social worker described her difficulty in obtaining caregiver respite:

'The Trust doesn't really view it as a critical need or essential, whereas we view it as essential on our cases, but we know how difficult it is. So, we aren't even really offering it to people because we know we can't get it. It has to be proved that this person can't be left on their own... It has to be breaking point, and somebody is going to walk out the door... And even at that.... You might not even get it'. (HSCT4, Social Worker)

By contrast, CBAs who were not constrained by the same eligibility criteria, appeared able to provide support at an earlier stage, thereby potentially delaying the need for more intensive support. This was illustrated by one CBA participant who explained that their organisation did not close cases, which enabled them to respond to need more proactively.

'It's about us being, I suppose, proactive, and reactive, but we change with their needs. The beauty about going forward now is, we keep a case open now, where before we used to close it' (CBA3, Service Manager)

HSC professionals did have the option of referring older male caregivers to CBAs for support, and there was evidence to suggest that some did, however this was inconsistent across services. Reasons for the inconsistency in referrals were not discussed in depth, however, one participant explained that there was a wide variation of the services provided by CBAs and this may have been caused by geographical factors.

'I think the service provision from the voluntary sector community-based services is quite variable. For example, in the XXXXX area, the Alzheimer's Society provides services where the carer can go, and they go into one group while the person with dementia goes into another group that runs simultaneously. It doesn't create difficulties. In the XXXXX area, we don't have that. They have a brilliant thing in XXXX and it's a wee bit too far for our client group'. (HSCT 1, Social Work Team Leader)

Differences in the *flexibility* of services offered by formal care providers were also noted. For example, participants from HSCTs appeared to be limited to 'in house'

support measures (residential respite or packages of care) which, despite the efforts of HSC professionals to be creative, still did not allow them to match services to male caregivers' individual requirements. One social worker explained that a male caregiver on her caseload had been offered a care package (agency staff assisting with personal care and medication) but had declined this as he preferred to undertake these tasks himself. He had subsequently requested a sitting service to enable him to go out once a week, but this had been refused as he had already declined a care package. The social worker described how she could '*see the deterioration in his health*', because of this situation. This type of scenario often led to frustration among social workers, as they acknowledged the lack of choice and control with current support options, with one social worker commenting '*It would be more person centred doing something that's actually going to be beneficial.*' (HSCT 3, Social Worker)

On the other hand, CBAs appeared to have greater flexibility, in that they seemed to have more scope to meet individual needs, because either they offered a range of services from their own agency, or they referred to another agency. A noteworthy perspective from one CBA participant was that inflexible services offered by HSCTs had the effect of '*disempowering*' caregivers due to a feeling of services being '*imposed*' on them and a loss of control. It was observed that flexibility and a focus on tailoring individual support, could result in appropriate and sustainable support. As exemplified by a support worker from a CBA:

'A service user that we would have had..... he cared for his wife totally himself. She was bad at that stage. He said, I don't have children. He wants to learn a bit of skype, so he could skype with the family. Prescriptions, order prescriptions on-line and check his bills. All those

things that took the pressure off, and order groceries, because trying to get groceries was impossible. So, we organised for somebody to come into the house then to teach him IT skills.’ (CBAI, Service Manager)

The importance of companionship (for example a befriending scheme), was also emphasised, and that matching older male caregivers with someone similar was crucial to making this support effective. A community support worker gave an example of this:

‘We had one gentleman who used to play rugby, and he was matched with a gentleman who just loved rugby, and their friendship was just, it was great.... and they would have walked down to XXXX Stadium, and just chatted about it, come back. He would have been exhausted from his walk, but he slept on the sofa, and the volunteer gave about twenty minutes to the wife. It was probably one of the most simplistic but most effective matches in our service’. (CBAI, Community Support Worker)

Although some HSCT participants recognised caregiving as a gendered phenomenon, and the implications of this for support, findings from the current data did not indicate that this was being addressed from within the organisation. A HSCT social worker explained the current situation:

‘Social services are generally very female dominated at this level, at Band 6 and 7. I wonder if there were more male domiciliary carers in agencies and more male social workers – there is a heavy dominant female perspective there – would it be easier for those male carers relax and take up services as they are available?’ (HSCT3 Social Worker)

Theme 2: Engaging Men: ‘we need to reach out to men in a different way’

Participants generally acknowledged that male caregivers were harder to engage than their female counterparts, and there was evidence of staff skills as several described that ‘we need to reach out to men in a different way’, or that support staff had to ‘do a bit of prying’. Some social workers explained that female caregivers may engage at an earlier stage of their caregiving trajectory than males, due to the tendency for females to be more familiar with the healthcare system than males.

‘Sometimes, with male carers, you really have to do some work with them to encourage them to accept or even try a package of care. It will reduce the burden on them. I don’t know whether it stems back to the fact that we’re working with older male carers and that generation had traditional roles, so they wouldn’t have been as freely engaged or involved with health professionals.’ (HSCT3, Social Worker)

Many participants attributed difficulties in engagement and subsequent support to ‘masculine traits’. Specifically, an apparent reluctance of male caregivers to verbalise their stress, or to talk about any difficulty associated with their caregiving role.

‘Men don’t talk about these things. They don’t talk about feelings, or maybe they don’t know how to bring the conversation up. Maybe women are able to bring it more easily.... Women are, they’re quite open about how they feel and the difficulties of caring as well as the rewards of it’.
(HSCT5, Social Worker)

It was reported that men’s reluctance to engage, or to discuss caregiving difficulties often resulted in situations reaching crisis point. This was frustrating for HSC

professionals as they observed that earlier intervention could potentially have prevented crisis. One mental health practitioner described a situation where not only had a crisis taken place that resulted in distress for caregiver, but also for the care recipient:

'He was quite a frail old man himself and his wife had problems with depression, which had progressed into dementia. By the time it was referred to us in the team and we went out, it was just a mess. She hadn't had her medication, she was quite dishevelled, but he felt he had to cope with that. He downplayed it and said he could manage, but he really wasn't managing. It took a couple of visits to get him to actually admit.... I think he did feel embarrassed that he couldn't cope'. (HSCT1, Mental Health Practitioner)

Several participants explained that time spent on building trusting relationships could encourage engagement with male caregivers. Whilst building relationships with all caregivers is important in providing support, it was commonly suggested that it took more time to build relationships with male caregivers.

'I can find sometimes going out that it takes longer to build up a relationship with a male carer than a female carer. A female carer will chat to you a lot sooner and will ring you up about things I find that a lot of male carers lost out by not ringing you back about things. So, it just takes that bit longer for a male carer for whatever reason it is than a female carer.' (CBA1, Service Manager)

However, as one mental health practitioner described, no matter how hard they tried to establish or maintain a relationship, sometimes this was not enough to prevent caregiver breakdown.

'You knew going in that they weren't giving you the full experience of stress..... You would try to get as many openings as you could, but they wouldn't necessarily let you in or acknowledge that emotion. You knew that if you went back into that house in three months' time, they could be at breaking point.... They reached the point where they were in tears. I remember seeing someone shaking with stress. It was completely beyond what he could cope with'. (HSCT1, Mental Health Practitioner)

Theme 3: Assessment of Need: 'A carers' assessment wouldn't tend to be a priority'.

Given that caregiver support was based on assessed need, all formal care providers had a protocol for such assessments. CBAs had their own assessment processes, while HSCTs implemented formal carers' assessments. Findings revealed that some HSC professionals did not routinely offer carers' assessments to caregivers. One CBA community support worker suggested that older male caregivers were unaware of services offered by the HSCT:

'They don't know the carers' assessment exists, or they don't know that respite exists, or how you might access it if they were'. (CBA3, Community Support Worker)

However, a HSC social worker emphasised that whilst carers' assessments were offered to both male and female caregivers, the take-up was mainly from female caregivers. Even though this imbalance may reflect the numbers of male and female

caregivers who were known to formal support providers it was also noted that male caregivers took less time to complete the carers' assessment than their female counterparts, as explained by this social worker:

'I have mostly women who accepted it. One or two men. I even find that I would spend a shorter period of time with the men than the women. Maybe half an hour or 45 minutes. You can be going for an hour and a half with ladies, maybe longer'. (HSCT3, Social Worker)

More generally, evidence indicated a lack of confidence from HSC professionals in the system of carers' assessments and their overall effectiveness. Arguably this could have impacted on the uptake of carers' assessments by male caregivers.

'A carers' assessment is never a priority. I mean, it should be, but realistically, a carers' assessment wouldn't tend to be a priority.' (HSCT2, Social Worker)

Despite this, some evidence showed that when male caregivers had a carers' assessment it could have resulted in a request for specific support. One example of this was that male caregivers tended to need time away at the weekends to take part in sporting events, and often requested a 'sitting service' (agency staff who provide care while the primary caregiver has time away) in order to meet this need. However, 'sitting services' were more difficult to secure at weekends, due to unavailability of agency staff and cost, which meant that often the request for a sitting service at the weekend could not be met.

'I know some males now, for them to get a break from the caring role, it would mean them maybe going out for a few hours, maybe going golfing, maybe going

with friends for a longer period of time. Sometimes that's difficult to get and have somebody sitting in for respite or for day care, so generally they don't go because they're maybe away for a more prolonged time. Again, that's a generalisation but that could be a reason too, why people are having difficulties'. (HSCT4, Service Manager)

It was generally agreed that household tasks such as cooking and cleaning could potentially pose challenges. Participants explained that this may be more of a problem for men within this age group (over 65). This was because their spouse/partner may have traditionally undertaken these tasks within the home. Several mentioned services such as 'home helps' (i.e. agency staff who provide help with household tasks such as cleaning and ironing), and disappointment from male caregivers when they realised that this service no longer existed. Even though many male caregivers were resourceful in overcoming household challenges - such as using U Tube to learn how to use the washing machine - formal care providers often had to address this specific need with male caregivers, more so than females.

'So, the practicalities of running a home, in a sense, sometimes men need a wee bit more help, because it was always something that the woman always did. So, the cooking, and the cleaning, and fixing the curtains, and doing those things. ... So, some of that, I hear more of that than the other way around' (CBA4, Regional Service Manager).

Discussion

This study explored of the perspectives of formal care providers about support services for older male spousal caregivers through focus group interviews. Data analysis resulted in the identification of three themes: Service Priorities; Engaging Men; Assessment of Need.

Study findings highlighted some key differences between the approach of HSCTs and CBAs. As mentioned in the Introduction, HSCTs adhere to regional eligibility criteria which aims to provide fair access to support services for service users. This is because HSCT operate within a legislative and policy framework (Carer's and Direct Payments Act (Northern Ireland) 2002; 'Caring for Carers' Strategy NI, 2006). Aforementioned eligibility criteria determine how services are provided by the HSCT, however the application of this criteria can pose challenges. The example of one social worker who maintained that *'physical needs override emotional needs'* may have implied a restrictive approach. This appeared to oblige HSC professionals to primarily focus on addressing the physical needs, due to caregivers having to be in *'critical'* need in order to meet eligibility criteria for respite. This not only resulted in frustration amongst some HSC professionals that these constraints limited their ability to offer effective support, but also that caregivers who did not meet the *'critical'* criteria were placed on a long waiting list for support services. By contrast, CBAs, although also experiencing constraints around lack of resources, appeared to show greater flexibility in addressing both the physical and emotional needs of older male caregivers. Some data suggested that this was achieved through collaboration with caregivers to identify individual needs which led to tailored support, along with availability of appropriate resources,

such as matching male caregivers with male befrienders to attend a rugby match, or delivering bespoke IT training.

The importance of close collaboration in tailoring support has also been noted by other authors. In their qualitative study of older male caregivers' experiences of formal support by Sandberg and Eriksson (2009), authors concluded that healthcare services were trying to '*induce them to withdraw from the caring role*'. This conflicted with male caregivers who expected to maintain their marital relationship, and preferred to be actively involved in the care process with care services. Expectations of a collaborative approach to care were more likely to be met when healthcare professionals regarded caregivers as equal partners and a '*professional friendship*' was established (Lindahl *et al.* 2009). This was supported by Stephan *et al.* (2015) which showed that successful collaboration between healthcare providers and dementia caregivers ($n=30$) was due to well-trained empathic healthcare staff.

It could be argued that such collaboration is equally important for female caregivers as male caregivers. However, given older male caregivers' reported isolation, limited perception of caregiver support, and reluctance to report caregiver strain (Milligan and Morbey, 2013; Robinson *et al.* 2014), they may be particularly vulnerable to lack of support, therefore formal care providers should be aware of this potential gap in service provision.

Study data revealed some men's reluctance to talk about, or a tendency to 'downplay' caregiving stress, meant that situations tended to escalate, and sometimes resulted in crisis. Although some healthcare professionals attributed this reluctance to gender (specifically masculinity), others categorised these men within a certain 'generation'. Previous literature has suggested that the 'silent generation' (those born between 1925-

1945) were conservative and independent, often showing a reluctance to seek help (Strauss and Howe, 1991). However, other caregiving literature has found that *gender* is an important indicator of caregiver coping styles (Snyder *et al.* 2015; Hong and Coogle 2016;), with male caregivers often drawing on dominant masculine ‘norms’ in their caregiving approach (Baker *et al.* 2010; Robinson *et al.* 2014). Connell’s Hegemonic Masculinity theory has previously been used to explain male caregivers’ reluctance to seek or accept help with their caregiving role (Connell and Messerschmidt 2005; Robinson *et al.* 2014). Connell posited ‘hegemonic’ masculinity as the dominant masculine ideal within western society. In her theory, hegemonic masculinity was characterised as strong, independent and competitive, and men who identified with hegemonic masculinity distanced themselves from female traits such as expressing emotions or showing vulnerability. Although hegemonic masculinity provides important insight into cultural norms of masculinity, according to Hanlon (2012) it is incompatible with aspects of men’s emotional lives, such as the need to express emotion or intimacy. Furthermore, Hanlon (2012) outlined costs to hegemonic masculinity when men are unable to meet masculine ideals. These ‘costs’ were also evident in the current data, with one social worker who described a male caregiver in tears, and ‘*shaking with stress*’, which she attributed to challenges within his caregiving role. Elliott’s practice based model - caring masculinities - proposed a focus on relational and positive emotion rather than dominance or control (Elliott, 2016). By examining the actual practice of caregiving men, caring masculinities integrated values of care into masculine identities, therefore, this model may be useful in informing future practice of providing support that aligns with masculinity.

Within the arena of men’s mental health, authors have highlighted specific approaches to engaging men, and the delivery of support measures targeted at men (Seidler *et al.*

2016; Pirkis *et al.*, 2018). For example, in their Australian study of ‘active ingredients’ in men’s mental health promotion, Pirkis *et al.* (2018), emphasised the importance of recognising the gendered expectations and societal pressures on men.

In the present study, along with personal barriers to support, there was evidence of systemic barriers. Health and Social Care Trusts in Northern Ireland have a statutory obligation to offer all caregivers a formal carers’ assessment (DHSSPS NI, 2005). Assessment can be undertaken by any healthcare/social care professional. Individual assessment of need is at the heart of social work practice, and social workers are uniquely positioned for establishing relationships and facilitating comprehensive assessment (Milne *et al.* 2014). Current findings revealed that although CBA personnel reported that carers’ assessments were not routinely offered to caregivers, HSC professionals reported the opposite – that they were. However, some social workers also explained that the take-up was low, and that carers’ assessments were not a priority. This finding is consistent with previous work by Seddon and Robinson (2015), who examined carers’ assessment from the perspectives of social care practitioners in the United Kingdom ($n=383$). The longitudinal study which spanned twenty years, revealed that practitioners were ambivalent about carers’ assessments, often resulting in failure to formally identify caregiver support needs. Reasons for this ambivalence included a lack of acceptable support measures to meet caregiver needs, causing practitioners to be cautious about raising expectations through assessment; and high caseloads meaning that assessments were not completed in a timely manner, if at all. Separate assessments for the caregiver and care recipient also caused confusion both for practitioners and families. Authors concluded that practitioner ambivalence and confusion resulted in variations in the carers’ assessment process and a reactive response to caregiver support need. Seddon and Robinson (2015) emphasised that

post-qualifying carers' assessment training is required for health and social care practitioners. Additionally, a shift in priority for caregiver support needs is required at a commissioning and policy level to address the lack of innovative support measures which results in the reported ambivalence of social care practitioners.

It could be suggested that a limitation of this study was the facilitation of separate focus groups for HSC professionals, and CBA personnel. If focus groups had comprised a mix of these agencies, this may have allowed for more in-depth debate between organisations on key issues. As it was, views were given on issues (such as carers' assessment), which differed, and there was no opportunity to challenge or debate differences in opinion. Mixing the groups would also have allowed each organisation to gain a deeper understanding of the other. Nevertheless, there was also strength in undertaking focus groups with separate organisations. For example, each group already had a shared language, organisational culture, and understanding of their role. This facilitated straight-forward engagement of the group, and potentially less time spent on establishing intragroup rapport.

Conclusion

Although not an objective, findings of this study shed some light on key differences between statutory and community-based agencies, in the provision of support for older male spousal caregivers. Given the shifting policy environment with a greater emphasis on choice and control it would be important for social workers and other formal care providers to have an in-depth understanding of the support needs of older male spousal caregivers.

The current study highlighted challenges faced by HSCTs in providing effective support to older male caregivers despite evidence of staff skills in this area. CBAs

appeared to have greater flexibility of service provision, and examples of innovative caregiver support provided by some CBAs were highlighted. Although HSCTs operate within a different legislative framework, there may still be scope to improve effectiveness of support through greater engagement and collaboration with male caregivers, and a deeper understanding of their approach to their caregiving role. Secondly, most study participants acknowledged gender related influences on engagement with older male spousal caregivers and subsequent take-up of caregiver support. Current data indicated that many older male spousal caregivers preferred to maintain an element of choice and control over their caregiving role, resulting in a preference for support that facilitated this. Third, the implementation of carers' assessment was recognised as potentially ineffective in accessing the support needs of older male caregivers. Therefore, although some HSC professionals recognise caregiving as a gendered phenomenon, there is a lack of gender specific training for staff, and of gender specific assessment and caregiver support. Effective assessment leading to collaboration in planning and delivery of support, and increased awareness of gender differences in caregiving may result in support which aligns with masculinity and enables male caregivers to sustain their caregiving role.

Further research, drawing on the wider areas of men's help-seeking within healthcare could inform health and social care practitioner training, and could also explore male-centred support which could be more effective for male caregivers. A deeper understanding of personal and systemic barriers that influence the take-up of support for older male spousal caregivers is important to plan for future support, given the rising numbers and limited research about this population group.

References

Aldaz, B. E., Treharne, G. J., Knight, R. G., Connor, T. S., Perez, D. (2016) Oncology Health Professionals perspectives on the psychosocial support needs of cancer patients during oncology treatment. *Journal of Health Psychology*. DOI: 10.1177/1359105315626999.

Beiber, A., Nguyen, N., Meyer, G., Stephan, A. (2018) Influences on the access to and use of formal community care by people with dementia and their informal caregivers: a scoping review. *BMC Health Services Research*. DOI:10.1186/s12913-018-3825-z.

Braun, V., and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*. 3(2): 77:101.

Büscher, A., Astedt-Kurki, P., Paavilainen, E., Schnepp, W. (2011) Negotiations about helpfulness-the relationship between formal and informal care in home care arrangements. *Scandinavian Journal of Caring Sciences* 25:706:15.

Connell, R.W., Messerschmidt, J.W. (2005) Hegemonic Masculinity: Rethinking the concept. *Gender & Society*. Sage. 19 (6) 829-859. DOI: 10.1177/0891243205278639.

Dam, A. E., de Vugt, M. E., Klinkenberg, I.P., Verhey, F.R., and van Boxtel, M.P. (2016) A systematic Review of social support interventions of caregivers of people with dementia. Are they doing what they promise? *Maturitas* 86 117:130.

Department of Health Social Services and Public Safety (2005): CARERS AND DIRECT PAYMENTS ACT (NORTHERN IRELAND) 2002 CARERS' ASSESSMENT & INFORMATION GUIDANCE. <http://www.legislation.gov.uk/ni/2002/6/contents> (Accessed 01/07/19).

Department of Health Social Services and Public Safety 2006: Caring for Carers, <https://www.healthni.gov.uk/publications/caring-carers> . (Accessed 01/07/19).

Elliott, K. (2016) Caring Masculinities: Theorizing an Emerging Concept. *Men & Masculinities*. DOI: 10.1177/1097184X15576203.

Fee, A. McIlfatrick, S., Ryan, A. (2019) 'When it faded in her.... it faded in me': A qualitative study exploring the impact of caregiving on the experience of spousal intimacy for older male caregivers. *Ageing and Society*, DOI: 10.1017/S0144686X19000850 .

Grande, G. E., Austin, L., Ewing, G., O'Leary, N., and Roberts, C. (2017) Assessing the impact of a Carer Support Needs Assessment Tool (CSNAT) intervention in palliative home care: A stepped wedge cluster trial. *BMJ Supportive and Palliative Care*, DOI:10.1136/bmjspcare-2014-000829.

Greenwood, N., and Smyth, R. (2015) Barriers and Facilitators for male carers in accessing formal and informal support. A systematic Review. *Maturitas* 82: 162:169.

Hanlon, N. (2012) *Masculinities, Care and Equality: Identity and Nurture in Men's Lives*. Basingstoke, UK: Palgrave Macmillan.

Haley, W.E., David, L., Roth, D.L., Howard, G., Stafford, M.M. (2009) Caregiving Strain and Estimated Risk for Stroke and Coronary Heart Disease Among Spouse Caregivers. Differential by Race and Sex. *Stroke*. 41:331:336.

Hong, S., C. and Coogle, C., L. (2016) Spousal Caregiving for Partners with Dementia: A Deductive Literature Review Testing Calasantis Gendered View of Care Work', *Journal of Applied Gerontology*, 35(7) 759–787. DOI 10.1177/0733464814542246.

Ji., J, Zoller, B., Sundquist, K., Sundquist, J. (2012) Increased Risks of Coronary Heart Disease and Stroke Among Spousal Caregivers of Cancer Patients. *Circulation*. 125:1742:1747.

Kaschowitz, J., and Brandt, M. (2017) Health effects of informal caregiving across Europe: A longitudinal approach. *Social Science and Medicine* 173 72:80. DOI:10.1016/j.socscimed.2016.11.036.

Kitzinger, J. (1995) Qualitative research. Introducing focus groups. *British Medical Journal*, 311: 299:302.

Krueger, R. A. and Casey M.A. (2015) *Focus Groups, A Practical Guide for Applied Research*. SAGE Publications CA.

Lin, I.F., Holly, R.F., and Hsueh-Sheng, W. (2012) Negative and positive caregiving experiences: a closer look at the intersection of gender and relationships. *Family Relations*. 61: 343:358.

Lincoln, Y., S., and Guba, E., G. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications.

Lindahl, B., Lidén, E., Lindblad, B. (2009) A meta-synthesis describing the relationships between patients, informal caregivers and health professionals in home-care settings. *Journal of Clinical Nursing* 20: 454:63.

Milligan, C. and Morbey, H. (2013) *Older men who care: understanding their support and support needs*. Lancaster University. Lancaster University Centre for Ageing Research.

Milligan, C. and Morbey, H. (2016) Care, coping and identity: Older men's experiences of spousal care-giving. *Journal of Aging Studies*. DOI: 10.1016/j.jaging.2016.05.002.

OECD (2018), Care Needed: Improving the Lives of People with Dementia, OECD Health Policy Studies, OECD Publishing, Paris, <https://doi.org/10.1787/9789264085107-en>. (Accessed 01/07/19).

Office for National Statistics (2019) Living longer: caring in later working life. Available at: <https://www.ons.gov.uk/releases/livinglongercaringinlaterworkinglife> (Accessed 25/06/19).

Pirkis, J., Schlichthorst, M., King, K., Lockley, A., Keogh, L., Reifels, L., Spittal, M.J., and Phelps, A. (2018): Looking for the ‘active ingredients’ in a men’s mental health promotion intervention, *Advances in Mental Health*, DOI: 10.1080/18387357.2018.1526095.

Poysti, M., M., Laakkonen, M., L., Strandberg, T., Savikko, N., Sakari Tilvis, R., Eloniemi-Sulaova, U., Pitkila, K., H. (2012) Gender Differences in Dementia Spousal Caregiving. *International Journal of Alzheimer’s Disease*. DOI: 10.1155/2012/162960.

Robinson, C.A., Bottorff, J.L., Pesut, B., Oliffe, J.L., Thomlinson, J. (2014) The Male Face of Caregiving: A Scoping Review of Men Caring for a Person with Dementia. *American Journal of Mens Health* 8(5) 409:426.

Sandberg, J. and Eriksson, H. (2009) From alert commander to passive spectator: older male carers’ experience of receiving formal support. *International Journal of Older People Nursing* DOI:10.1111/j.1748-3743.2008.00147.x.

Sanders, S. (2007) Experiences of Rural Male Caregivers of Older Adults with Their Informal Support Networks, *Journal of Gerontological Social Work*. DOI: 10.1300/J083v49n04_06.

Seddon, D., and Robinson, C. (2015) Carer assessment: continuing tensions and dilemmas for social care practice. *Health & Social Care in the Community*. DOI: 10.1111/hsc.12115.

Seidler, Z., E., Dawes, A., J., Rice, S.M., Oliffe, J., Dhillon, H., M. (2016) The role of masculinity in men's help-seeking for depression: A systematic review. *Clinical Psychology Review* DOI: 10.1016/j.cpr.2016.09.002.

Singh, P., Hussain, R., Khan, A., Irwin, L., Foskey, R. (2014) Dementia care: intersecting informal family care and formal care systems. *Journal of Aging Research*. DOI: 10.1155/2014/486521.

Snyder, C. M., Fauth, E., Wanzek, J., Piercy, K. W., Norton, M. C., Corcoran, C., Tschanz, J. T. (2015). Dementia caregivers’ coping strategies and their relationship to health and well-being: The Cache County Study. *Aging & Mental Health*, 19(5), 390–399.

Stephan, A., Möhler, R., Renom-Guiteras, A., Meyer, G. (2015) Successful collaboration in dementia care from the perspectives of healthcare professionals and informal carers in Germany: results from a focus group study. *BMC Health Services*

Research DOI 10.1186/s12913-015-0875-3.

Stepler, R. (2016) Smaller Share of Women Ages 65 and Older are Living Alone: More are living with spouse or children. Washington, D.C.: Pew Research Center.
Strauss, W. and Howe, N. (1991). *Generations: The History of America's Future, 1584–2069*. New York: William Morrow.

van Groenou M., I., and De Boer A. (2016) Providing informal care in a changing society. *European Journal of Ageing*. Doi: 10.1007/s10433-016-0370-7 PMID: 27610055.

Verbakel, E., Tamlagsrønning, S., Winstone, L., Fjær, E.L., Eikemo, T.A. (2017) Informal care in Europe: findings from the European Social Survey (2014) special module on the social determinants of health. *European Journal of Public Health*. DOI:10.1093/eurpub/ckw229 PMID: 28355645.

World Health Organization (2014). Health statistics and health information systems. from <http://www.who.int/healthinfo/survey/ageingdefnolder/en/>. (Accessed 21/12/19).

Zodikoff, B., D. (2007). Gender differences in the community service use attitudes of older spousal caregiver-care recipient couples. *Home Health Care Services Quarterly*. DOI: 10.1300/J027v26n02_01.

Phase 4 – Deliberative Workshop

5.7 Introduction

The previous section presented an overview of phase 3 in the study – focus group interviews, along with the paper ‘*Exploring formal care providers’ perspectives of the support needs of older male spousal caregivers: a focus group study*’ which detailed data analysis and findings of this phase. The current section will progress the thesis by describing the final phase of the study, Phase 4 - Deliberative Workshop. The background and rationale for using a deliberative process for the final study phase are explained first. This is followed by a description of the design and methods of the particular deliberative process employed. Next, data collection and analysis are outlined along with the rationale for using these particular methods. Findings from data analysis and ethical aspects are outlined before a final conclusion is drawn. In line with study objective five, the aim of the deliberative workshop was to: *Contribute to the development of strategic recommendations relating to support services for older male spousal caregivers.*

5.8 Background and rationale for using a deliberative approach

‘Deliberative methods are those activities and processes where participants thoughtfully and thoroughly weigh arguments, discuss options and collaboratively make decisions about particular and urgent questions in communities or organisations’ (Fisher et al. 2003).

Dyzek (2010) asserted that deliberative research was rooted in political philosophy and aimed to develop more defined processes of democracy which assisted communication between informed individuals. Deliberative inquiry is a process involving the combination of a component of deliberation with a component of enquiry (Wouters and DeFraine 2019). It is a collaborative approach involving different stakeholders, and which integrates investigation with different viewpoints through negotiation and deliberation in order to reach a decision or determine action (Kanuka 2010; Savin-Baden and Major 2013).

In her examination of deliberative research as a research technique, Burchardt (2012) argued that the deliberative process involved three main aims.

1. Firstly, to reach peoples' '*informed and considered judgements and underlying values in relation to the subject in hand*'. This she suggests should be arrived at through public reasoning.
2. Secondly, this process should be based on the researcher supplying information (which can be questioned) about the issue being considered.
3. Lastly, the expectation that participant's views have the potential to be changed by the research.

A deliberative method was chosen for phase 4 primarily because it enabled exchange of arguments amongst informed stakeholders from a range of backgrounds, resulting in a quality and breadth of information on which decisions could be made (Bennett *et al.* 2004). Furthermore, according to Frame and O' Connor (2011) deliberative research can foster or strengthen relationships between stakeholder groups and government and build trust between groups. Given that future collaboration between the various stakeholders involved in caregiver support in Northern Ireland is desired, the deliberative process may therefore play a part in facilitating this. According to Abdullah and Rahman (2017), deliberative processes provide a bridge between citizens and policy makers that improves mutual understanding and facilitates collective work. Finally, decisions about future support that are made by key stakeholders (such as male caregivers and support providers) will potentially have greater legitimacy and be better informed (Cohen 2003; Bekkers and Edwards 2007). Therefore, it could be argued that recommendations resulting from study findings for policy or practice, may be strengthened by employing a deliberative process.

5.9 Design and methods

Design

A qualitative approach was adopted, using Thematic Analysis (Braun and Clarke 2006). This comprised a workshop with stakeholders drawn from the statutory, community, and academic sectors. In order to meet the systematic aspect of deliberative research, a model developed by Argyris and Schon (1983), the 'Ladder of Inference' was used to guide the deliberative process (Figure 7). This model proposed

three steps designed to progress conversations from observable data through to action. The first of these steps ‘What?’ commences after the presentation of research findings (data). ‘What?’ relates to meanings of the data for participants, what ‘resonated’ with them. The second step ‘So what?’ encourages participants to discuss assumptions based on their meanings from the first step and to reach agreed conclusions. The final step ‘What Now?’ facilitates the group to discuss common beliefs, collective history, culture and experiences in light of conclusions agreed so far and encourages overall agreement on a way forward in the form of prioritised actions. How this model was applied to this phase is further discussed in Section 10.

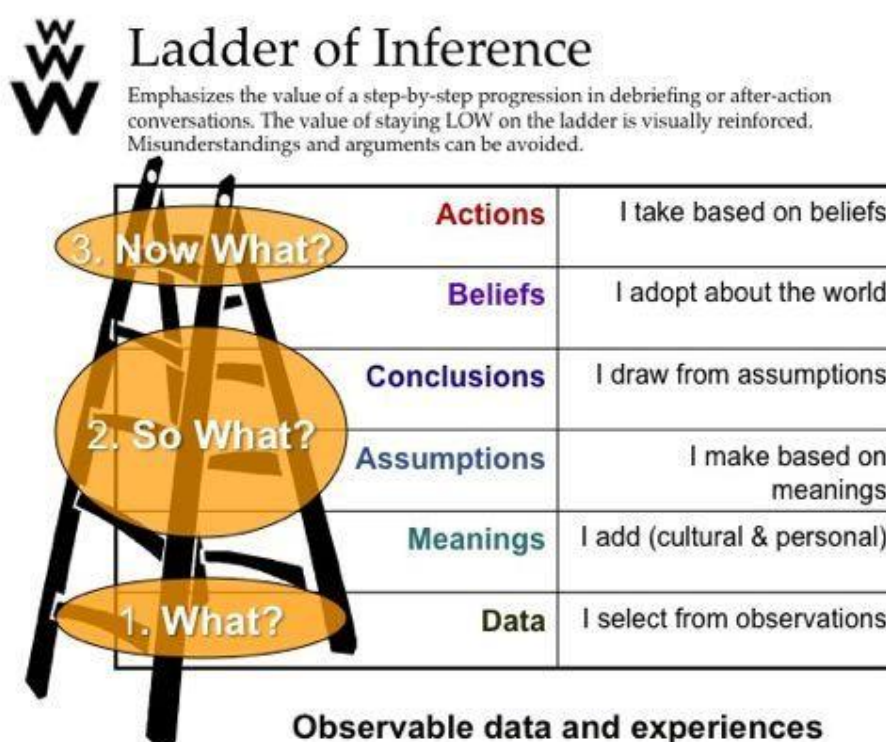


Figure 7: Ladder of Inference, Argyris and Schon (1983)

Sample

A purposive sample of thirty key stakeholders were invited to take part. Burchardt (2012) stated that numbers for deliberative research depended on the research question and how the participants were sampled. Participants comprised a broad range of stakeholders with an interest in older male caregivers. This included health and social care professionals (social workers, service managers and clinicians); community

sector personnel including community support workers and managers; academics; and a male caregiver. Also attending were policy and decision makers at a senior level from Department of Health (NI), Public Health Agency (NI), a member of a Health Trust Executive Board, and a Director from a community-based agency. There was also a broad geographical spread of representation from across Northern Ireland, including representation from all healthcare Trusts. However, even though the diversity of this group reflected a range of stakeholders, it was notable that some key individuals were unable to attend including representative from men's groups (such as Men's Shed), and organisations that advocate on behalf of patients/caregivers (such as Patient and Client Council, NI). One older male caregiver attended the event, however, three were invited with the intention of having a male caregiver with each discussion group. Several agencies sent more than one person, so the final number of participants at the deliberative workshop was thirty-six.

Recruitment

Inclusion criteria were: Health/social care professionals, community/voluntary sector personnel, male caregivers, academics, policy makers and funders with an interest in older male caregivers in Northern Ireland.

Recruitment of participants was undertaken in partnership with one of the largest health and social care Trusts in Northern Ireland. The reason for selecting this Trust over others was that the researcher had previously been employed by this Trust and so already had knowledge and a working relationship with the organisation. Whilst it was recognised that a limitation of this approach was that it may have impacted on attendance (i.e. more participants attending from this Trust than the other Trusts), it was also considered that the advantages of this outweighed the disadvantages. For example, by the Trust being actively involved in the organisation of the event this may have encouraged shared ownership (Lipmanowicz and McCandless 2013, p. 103), and the potential to implement recommendations arising from the workshop within this organisation. Also, in order to ensure participation from all Trusts in Northern Ireland, the researcher worked closely with the regional Carer Co-Ordinators in identifying potential participants and promoting the event. Table 14 details Deliberative Workshop participants' characteristics.

Table 14: Characteristics of Deliberative Workshop Participants

Background	Number	Gender
Representatives from Practice		
Social Work	4	4 F
Psychiatry	1	1 M
Community Support	7	7 F
Community Psychiatric Nursing	2	2 F
Allied Health Professional	2	1 M, 1 F
Psychology	3	2 F, 1 M
Trust based carer representatives (including Carer Co-Ordinators)	5	5 F
Community Based Agency, Manager or Director	2	2 F
HSC Trust Executive Director	1	1 M
Representatives from Government Agencies		
Public Health Agency	1	1 M
Department of Health	2	2 F
Health & Social Care Board	2	2 F
Other Representatives		
Male caregivers	1	1 M
University academics	3	3 F
Facilitators	2	2 F

Study information was circulated to participants who met inclusion criteria via email by local collaborators or managers within the target organisations, or the researcher; and was also promoted through social media (Appendix 22). Participants who expressed an interest were sent a participant information sheet (Appendix 23), and extra participant information sheets were made available at the event. All participants signed a consent form (Appendix 24) prior to the commencement of the workshop.

5.10 Data collection

The workshop was held in a relatively central location (which was easily accessed by main motorways), on 8th May 2019, from 9.30 am-1pm. An external facilitator assisted with the design and facilitation of the workshop. Several factors influenced this decision. According to Burchardt (2012) the facilitation of a deliberative workshop is crucial, therefore careful consideration was given to who would undertake this role. Moreover, a balance must be maintained between careful consideration and articulation of the topic (including differences of opinion) by all participants, whilst ensuring no one opinion dominates, and agreeing a common position (Burchardt 2012). Whilst members of the research team had experience in undertaking research and other types of facilitation, it was agreed that someone external to the project with necessary expertise and skills of a deliberative process would work in partnership with the researcher. The researcher and external facilitator worked together to design the workshop structure and content. Both were involved in the delivery of the workshop, with the researcher presenting the study findings and background information and providing answers to questions and clarification where needed; and the external facilitator facilitating group discussions. In order to take a systematic approach, Argyris and Schon's Ladder of Inference (1983) was applied over a four-stage process (Brearley *et al.* 2014).

On arrival participants were allocated to a colour coded group. Groups had been pre-determined in liaison with the HSC Trust to ensure that each group comprised a mixture of statutory, community and other participants, and a range of seniority/experience. Participants were seated around tables (with eight - ten participants) in their colour coded discussion groups for the first two sessions (Appendix 26). This provided opportunities for discussion based on '*encounters with contrasting points of view*' (Burchardt 2012). In accordance with the 'Ladder of Inference' the first session of the workshop involved a presentation of the background and study findings, by the researcher, followed by small group discussions entitled 'What'. During this first session participants discussed what had resonated with them about the research findings, and the meanings they had attached, before feeding back to the larger group. Session two progressed to small group discussions titled 'So What?'. In this session participants discussed the importance of the research findings,

emerging patterns, and if/how their interpretation of the findings may be influenced by assumptions based on their own experience or values. During this session participants were also tasked to move towards conclusions that may form the basis of recommendations to improve support services for older male caregivers. Sessions one and two resulted in a set of agreed main points about the research findings and how they resonated with participants' own experiences, interpretations or perceptions of older male spousal caregivers. These discussions were recorded (with permission), using digital recorders which were placed on each table and operated by a designated participant.

In session three, the group were together as a whole (as opposed to separate tables). During this session, titled 'Now What?' the facilitator sought to elicit information about actions and practical steps for a way forward based on the deliberations and conclusions arising from the previous sessions. Participants first worked in pairs, to agree ideas for addressing the highlighted issues around providing support for older male caregivers and recorded their top three ideas on large sticky notes. Next the group shared all ideas collectively, and the facilitator placed the sticky notes on the wall (Appendix 27), grouping similar ideas together, along with a theme name that reflected the content of the grouping. This process ensured continued participation by everyone in discussion and refinement of key ideas and utilised a consensus methodology for final agreement of a broad range of ideas, and overarching themes. Finally, participants were invited to indicate their top three preferences (by marking the sticky notes) in order of importance of what, in their view, could influence the improvement of support services for older male caregivers. This resulted in action points which were prioritised according to preferences of participants.

5.11 Data analysis

Initially qualitative content analysis (Graneheim and Lundman 2004) was considered for data analysis, due to its focus on categorising manifest and latent data but given that it is largely based on communication theory and quantifying the data (Graneheim and Lundman 2004), it was excluded as a suitable method. Thematic analysis is similar to qualitative content analysis and the two are often used interchangeably (Sandelowski and Leeman 2012). Even though both approaches allow for qualitative

analysis of data, thematic analysis emphasises more the contextualised and nuanced account of the data (Loffe and Yardley 2004; Braun and Clarke 2006).

Sessions one and two

As detailed above, in Section 5.10 (Data collection), during session one, participants discussed 'what' issues resonated with them from study findings. In session two participants answered the question 'So What' during which they discussed the importance of the findings and assumptions they had that may have influenced their perceptions. Each table discussion during sessions one and two was digitally recorded and transcribed. Inductive thematic analysis was employed to systematically organise, condense, categorise and refine data (Braun and Clarke 2006). This approach involved six key phases: 1) familiarisation with the data, 2) generating initial codes, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes, 6) producing the report. For session one data were imported to QSR NVivo 12 qualitative data management software, for categorisation and refinement. The coding process in NVivo was systematically applied to the data set, with the aim of identifying repeated patterns with relevance to the aim of phase 4. This was repeated as a separate process for session two.

Given that discussions during sessions one and two tended to follow similar threads codes resulting from analysis of these sessions were similar. For example, the codes of 'flexibility of services' and 'identification of male caregiver' were identified in data sets for both sessions. Therefore, in order to avoid duplication, the two datasets and resulting codes were merged. Examples of raw data, and codes, as discussed by participants are presented in Appendix 25. Codes were then sorted into potential sub-themes, and the coded data extracts were collated within identified sub-themes using NVivo. Two overarching themes were drawn from the codes: components of effective support; and perceived obstacles in support provision.

Session three

As described in Section 5.10 (Data collection), session three involved the entire group coming together to consider conclusions drawn from sessions one and two. As session three was based on verbal group agreement on support priorities, it did not involve

interpretation or analysis by the researcher. Rather, raw data taken directly off sticky notes was used to create a table of findings which were prioritised according to participant's preferences (Appendix 28).

5.12 Rigour

In line with Lincoln and Guba (1985) credibility was enhanced in this study through the rich mix of participants (including health and social care professionals, a male caregiver, academics, community support workers, funders and policy makers). Moreover, participants ranged in age, background and level of seniority, which contributed various perspectives to the phenomena under study.

Credibility of data analysis was assured by using QSR Nvivo 12 to manage data and to ensure that no relevant data was excluded, or irrelevant data included. This was reflected in the categories and themes developed through analysis and presented in the findings section. Other measures taken during data collection and analysis included keeping records of personal reflections; audio recordings and transcripts; continuous revisiting of the data in order to generate initial codes and ensuring that resulting codes and themes reflected raw data; the use of sticky notes, charts and mind maps to enable theme development. Furthermore, both study supervisors attended the deliberative workshop which ensured peer debriefing and enhanced credibility. Transferability was assured by providing details of procedures such as sampling technique, and inclusion criteria.

5.13 Findings

Sessions one and two

Two overarching themes were identified from thematic analysis of the data from sessions one and two. The themes were: 1) components of effective support; 2) perceived obstacles in support provision.

Theme One: Components of effective support: ‘Early Conversations’

The first theme described aspects of support for male caregivers that participants thought either had worked or would work, considering what the study findings had revealed thus far.

Some participants explained that building relationships was a key aspect of engaging men and ensuring support was matched to need. Participants reflected that often individual staff had the ability to ‘*build the relationship and encourage uptake of service*’. A range of different perspectives were noted in this theme: some thought that the relationships formed between male caregivers and support workers was crucial and that therefore if support workers were able to undertake carers’ assessments this would improve uptake levels. Others reported that the relationship with social workers was vital, as social workers had important skills in providing emotional support, which, if delivered at the right time, could potentially alleviate the need for more intensive support such as a care package:

‘In social work and social services, the priority certainly seems to be in care packages, and I think a lot of people don’t need care packages..... I think social workers are very good at providing emotional support, but it’s getting the time to take on cases that don’t necessarily need a care package and I think that that would alleviate a lot of problems... it seems to have been in the past number of years a reluctance to take on referrals for cases that needed emotional support.... I think social workers are good at that, they can do that well, other people can too, but I think that’s something that we’ve missed’. (Social Worker, HSCT)

In terms of effective support that had worked in the past with older male caregivers, several participants highlighted examples from their area of work. Some participants emphasised the importance of timing, and said that if men were reluctant to identify themselves as caregivers, the onus was on the healthcare professional:

‘This is where it needs to start earlier, it’s about identification, that’s the first point in this for me, it’s the one thing that stood out, with all of it, not just that the male carer needs to identify themselves as a carer but that professionals need to see them as a carer too, and that’s half the battle,... whether the person that they’re looking after is about to come out of hospital, that man should be identified as a carer there and then, so that’s where it should start, and even though nobody likes to be called a carer...but I think there is something to be said for actually having that

conversation, that 'you will be providing care for your wife going forward', and that he's starting to hear that himself'. (Community Support Worker, community sector)

'I think as a community and voluntary sector member that we are in at that early stage, they know exactly what's happening, not when something critical happens'. (Community Support Worker, community sector)

'It's about those early conversations that say this is how life is changing for you and that this is the role you find yourself in, regardless of whether or not they identify with it. And having those very very, non-formal, not going in heavy footed, conversations with men in particular'. (Social Worker, HSCT)

'And saying, you know you're doing a great job...you're doing really really well, that wee bit of encouragement too, because sometimes men just get a wee bit down in the heart, men like that more than women... because they do feel that they're failing in a whole lot of different ways, especially even as regards the housework, and the washing and things like that'. (Social Worker, HSCT)

Other, more practical innovative ideas were described. A social worker made reference to the Trusts' 'Self Directed Support' scheme (SDS) whereby caregivers had the option to decide the type of support most suitable for them though a managed budget, or a direct payment.

'For example we had a male carer who was assessed as needing 10 hours a week so under SDS he went fishing. He went fishing because that's what he's always done. So a member of the family agreed to go and sit and let him do that, and it works, it's been working for years. So it does keep the family together..... we have loads of examples of that'. (Social Worker, HSCT)

A participant observed that on the basis of data presented from previous study phases, there seemed to be a lack of awareness amongst older male caregivers about support services, and therefore she questioned whether older male caregivers knew about Self Direct Support (SDS). Although some other participants said that as far as they knew, older male caregivers would have been aware of SDS, there seemed to be a broader consensus that this was only the males who had been identified as caregivers, and male caregivers who were not identified as such remained unaware of support services.

Reference was also made to successful partnership approaches such as HSC Trust and Mid and East Antrim Age Well Partnership (MEAAP):

'We are working alongside MEAAP and have introduced a project whereby we're going in to the GPs once a month and MEAAP, and basically working with the GPs directly, with the community navigator which is someone who signposts the service user to the community and voluntary sector, and it's been hugely beneficial, it's been a massive success, we've eleven GPs fully engaged, it's getting greater and the successful and we are going in at source I suppose and trying to implement a new preventative strategy'. (Service Manager HSCT)

These innovative ideas would be difficult to implement if support services were not flexible. Several participants suggested that older male caregivers needed support with household tasks such as cooking or cleaning. Others gave examples such as isolation of many male caregivers resulting in a lack of awareness of support. Many participants agreed that these issues could be addressed if services were more proactive and responsive to individual need, as described by one social worker.

'I find the lack of support for male carers around domestic tasks, no support or helping the men to learn how to cook or whatever. Just thinking about two clients on our team, the wife broke her arm, and she had to go in to an assessment bed. He literally couldn't make a cup of tea, or look after himself at home, so he had to go in to respite because there was no family support. We waited so long for the care package, if he'd had a care package it might have been different but. There's no services for maybe short term intervention work, like teaching male clients how to make food or, daily household tasks like cleaning'. (Community Support Manager, community sector)

There was some recognition amongst participants that more flexible support services may allow for implementation of ideas and delivery of support that recognised the difference in support needs between male and female caregivers. As one service manager within a statutory organisation said about male caregivers:

'They don't want to sit round and drink tea and talk. Group support needs to be very focussed'. (Service Manager HSCT)

Theme Two - Perceived obstacles in support provision: 'What if I fail the carers' assessment?'

Many participants reported that men and women approached their caregiving role in different ways and that this posed challenges for how men accessed support. Participants stated that men had '*Different help seeking behaviour to women, and that's why services aren't suitable*'; or that '*Women know what they need for support, men don't tend to know*'. Men reaching crisis before seeking help was a point that was picked up by participants and was attributed to either the stigma associated with being a male caregiver, a lack of awareness of available support resources, or a lack of contact point within a support service. One participant's observation of male caregivers was that '*They're afraid to say how much they are suffering because of the repercussions*'. Other participants agreed that older male caregivers found it easier to engage with voluntary sector agencies than statutory agencies:

'I do find that males are more willing to engage with voluntary and community organisations than they are with our statutory agencies.... I don't know its maybe the fear of the formal organisations... and in the community they're much more willing to engage with that'. (Social Worker, HSCT)

Likewise, there was acknowledgement that the role of the GP was important in encouraging caregivers to take up support services, however this process seemed to be ineffective, as explained by one participant:

'Our' State of Caring' survey last year showed that older carers particularly...Less than 2% of older carers were told by their GP about support that was available to them as carers, and that's just from our survey, but it was with over 600 carers in Northern Ireland'. (Manager, community sector)

The use of language and terminology were also highlighted as a potential obstacle in the provision of support. This was exemplified by several participants who mentioned that the title of 'carers' assessment', often led to confusion as caregivers did not understand the purpose of such an assessment. One social worker described her experience of some male caregivers on her caseload who had the perception of a carers' assessment as a tool to assess their ability to provide care. She explained that men's thinking on this was along the lines of: '*I'm the man of the house and I can cope*

..what if I fail the carers' assessment.?. Also, community-based agencies explained that they seldom used the term 'carer', since many older male caregivers did not like this term, preferring instead to be called 'husband/partner'. They emphasised that statutory organisations seemed to be *'bogged down with formal processes that make the use of this language necessary... carer support, carers' assessment...'*, and they saw this as a barrier to engagement with older male caregivers.

A mismatch between services offered and needs of older male caregivers was also identified in the data. One participant commented that there was: *'A gap between what they value and what we are providing'*. Some participants described how components of support (such as respite or help with domestic tasks) were not available to them, as they were not in 'critical' need. One social worker explained that care packages (where agency staff provided support with personal care, assisting with meals and medication) seemed to be replacing important social support:

'When people are referred though to us it's for a care package, and we go out, we assess their need, we deem if they're entitled to it, and it's very much about the bureaucracy side of it, where we become care managers in relation to managing their care package, and the social support has kind of 'gone amiss'. (Social Worker, HSCT)

Another participant offered an explanation as to why care packages were offered: *'the onus has been on care packages because it keeps people out of acute beds'*.

Session Three

In this session, the question of: *'What could be done to increase the impact of support services in identifying and meeting the needs of older male caregivers caring for an ill spouse/partner?'* was posed to participants. Based on deliberations during sessions one and two, participants identified and agreed key priorities as a basis for recommendations to increase the impact of support services for this population.

As previously mentioned in Section 5.11 (Data analysis) session three did not involve in-depth analysis of data, rather a reporting of participant's preferences about ideas to improve support services for older male caregivers. The process of participants discussing, formulating, agreeing and prioritising ideas (discussed in previous

sections) resulted in four key priorities of: Training and Awareness Raising; Person Centred Support; Carer's Assessment; Working Together. These four priorities are further detailed in Figure 8, which lists priorities by agreement (i.e. number one priority had the most participant agreement). Listed under each priority are participant's practical ideas for implementation along with the number of other participants who agreed with this idea (in parenthesis). For example, the first priority is 'Training and Awareness Raising', beneath this is 'Training for professionals on needs of male caregivers (11)'. This means that 11 participants supported the idea of training professionals on the needs of male caregivers.

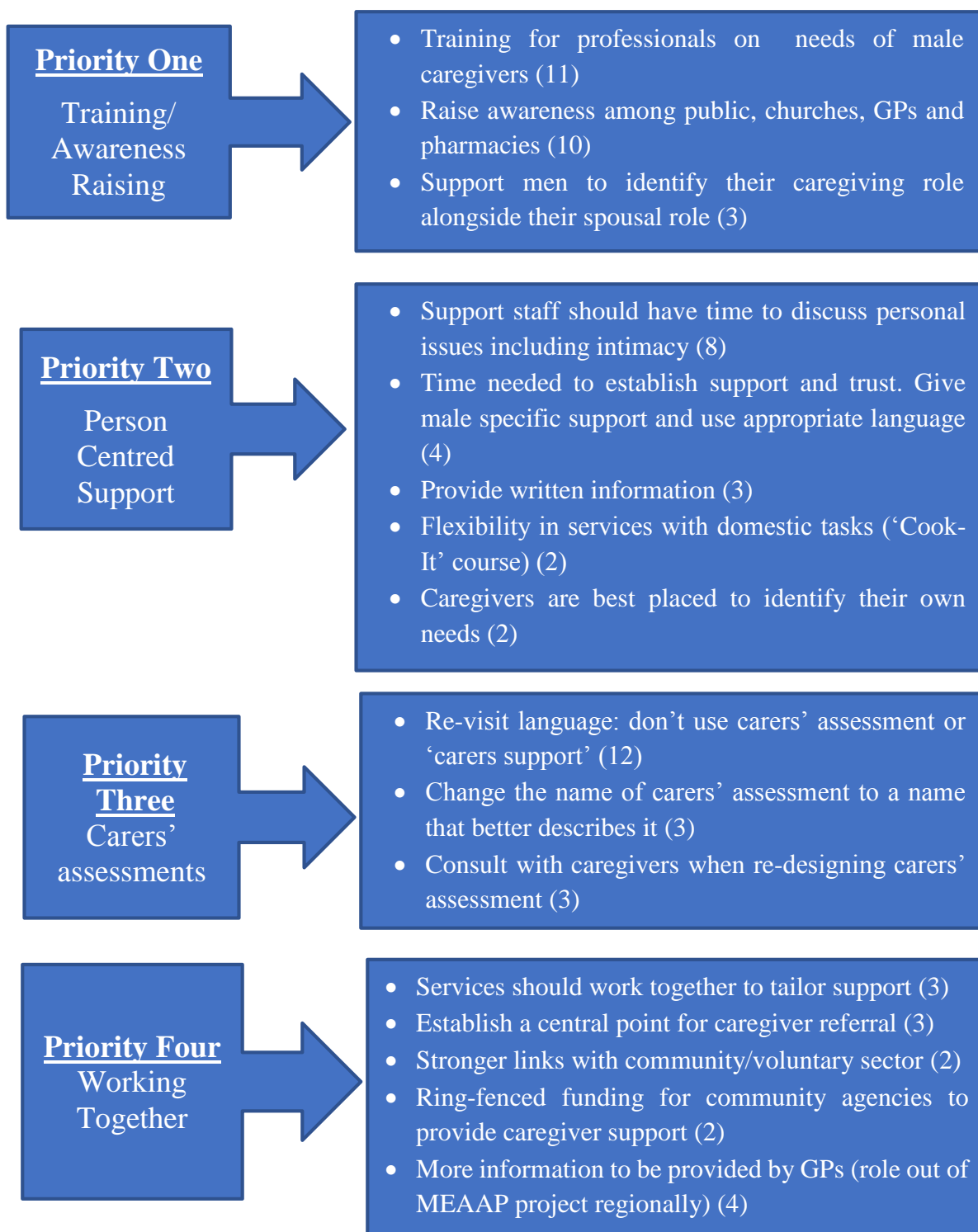


Figure 8: Key priorities for increasing impact of support services for older male caregivers

5.14 Outcomes

A summary of how this phase met the aims of the deliberative process as developed by Burchardt (2012) is outlined in Table 14.

Table 15: How phase 4 met the aims of the deliberative process as outlined by Burchardt (2012)

Aim	How Aim Was Met
<p>‘Firstly, the aim of the research is to reach people’s informed and considered judgements and underlying values in relation to the subject in hand, through a process of public reasoning. Public reasoning implies, as a minimum, encounters with contrasting points of view and a requirement to justify opinions through arguments which make sense to others (Rawls, 1997).’</p>	<p>‘Public reasoning’ was assured through the organisation of discussion groups comprising a mixture of individuals from statutory, community and other individuals all with different expertise and level of seniority.</p>
<p>‘Secondly, the process involves researchers providing information (sometimes written, but often through experts available for questioning) to participants about the subject under discussion.’</p>	<p>Participant information sheets containing study information were provided to all participants. Further, the research team were present for the entirety of the workshop and available for questioning.</p>
<p>‘Thirdly, and related to the preceding points, there is an expectation that the beliefs and values of participants may be transformed by involvement in the research.’</p>	<p>Whether the beliefs and values of participants were ‘transformed’ is inconclusive. However, there was evidence of ideas being shared and ideas challenged amongst participants.</p>

Burchardt’s (2012) aim of ‘*encounters with contrasting points of view*’ was met through the range of participants attending the workshop. Not only were there

representatives from across the statutory and community sectors, but a notable range of experience and seniority was also represented. This allowed participants to engage with individuals who they would not normally encounter. For example, social workers engaged with policy makers; a male carer engaged with funders; and academics engaged with community-based staff. Discussions were in-depth, with several modes of engagement facilitated (pairs, small groups and whole group).

The aim of phase 4 to: *‘Contribute to the development of strategic recommendations relating to support services for older male spousal caregivers’* was achieved through a systematic deliberative process and resulted in the establishment of four priorities for a way forward for support services for this population.

5.15 Summary of phase 4

The previous section detailed the final phase of the study: Phase 4 - Deliberative Workshop. In the first part background and rationale for using a deliberative process was presented. This was followed by a description of the design and methods of the particular deliberative process employed. In the third and fourth parts, data collection and analyses were outlined along with the rationale for using these methods. Findings and outcomes of the deliberative workshop were then presented, before concluding.

5.16 Conclusion

This chapter discussed phase 3 and phase 4 of the study. Phase 3 explored the perceptions of formal support providers about support for older male spousal caregivers through the use of focus group interviews. An overview of analysis was presented, with further detail about analysis and findings contained in Paper 3 entitled: *‘Exploring formal care providers’ perspectives of the support needs of older male spousal caregivers: a focus group study.’* This was followed by the final phase of the study, which comprised a deliberative workshop with key stakeholders. Phase 4 was a culmination of study findings which provided the basis for in-depth discussion by key stakeholders. The outcome of phase 4 was a set of four key priorities which can be used to inform recommendations aimed at improving formal support services for older male caregivers. The next chapter (Chapter Six) will provide detailed discussion about findings from all study phases in light of other relevant research.

CHAPTER SIX: DISCUSSION

6.1 Introduction

This chapter will discuss key findings from the study in relation to existing literature. A dearth of literature has been identified regarding the support needs of older males who are caring for a chronically ill spouse at home. Given the rise in numbers of older male caregivers, and increasing recognition of caregiving as a gendered phenomenon, it is important that we determine the types of support that will enable older male caregivers to sustain their caregiving role for as long as possible. Although key aspects of study findings are embedded in the papers included in this thesis, this chapter will develop the argument further by discussing these key aspects in more detail. The chapter will begin with an overview of key findings, before discussing each one in turn. This is followed by insight into the researchers PhD journey, with examples of strategies used to address challenges when undertaking the study, and to help illustrate development as a researcher throughout the process. Finally, a conclusion is drawn.

The study aim was: To explore the impact of support services in identifying and meeting the needs of older male caregivers caring for a chronically ill spouse/partner at home. This aim was achieved through the following objectives:

1. To systematically review the evidence relating to the support needs of older male spousal caregivers.
2. To identify gaps in provision of support to older male caregivers by scoping current support provided by key community/voluntary groups/statutory services.
3. To explore the support needs of older male caregivers caring for a spouse/partner with a chronic long-term condition.
4. To explore the perspectives of health and social care professionals and voluntary sector personnel about support services for older male caregivers.

5. To undertake a synthesis of key issues and make recommendations in relation to support services for older male caregivers through a deliberative workshop.

In exploring the impact of support services in identifying and meeting the needs of older male caregivers caring for a chronically ill spouse/partner, there could have been a tendency to emphasise negative aspects of caregiving. For example, interview participants were asked to elaborate on support needs particularly around perceived lack of support, and this tended to generate data about caregiving challenges. In the interest of balance, participants were also invited to describe rewards of the caregiver role. Similarly, focus group participants were invited to describe barriers to caregiver support. Although findings of focus groups included data about perceived barriers, findings also highlighted facilitators of support. Nevertheless, this could suggest a potential perceived researcher-bias, associated with the stance taken in exploring support needs (in the absence of available support) and challenges or barriers (in the absence of facilitators). This may have been due to the influence of other literature (as outlined in section 2.2), or anecdotal evidence from the researcher's background.

Key study findings have been presented in three main areas (described below), followed by an explanation of how all study data was integrated to inform findings (Figure 9).

6.2 Summary of key findings

Key Finding One:

The approach of older male caregivers who care for a chronically ill spouse can be influenced by views on masculinity that are aligned to traditional hegemonic theories.

- Previous findings indicating that older male caregivers have a masculinity informed approach to caregiving have been upheld in this study. Literature and study data suggest that the approach of many older male caregivers aligns with masculine ideals (such as a managerial and independent approach) which can result in a task-focused coping strategy.

Key Finding Two:

Although many older male spousal caregivers derive satisfaction and meaning from their role, caregiving can also involve social isolation, loneliness and challenges to spousal intimacy.

- Study findings suggested that older male spousal caregivers were increasingly lonely and socially isolated. Declining spousal intimacy was also highlighted as a challenge for older male caregivers, and there was little evidence of support to address these issues.

Key Finding Three:

Support providers should understand and be responsive to the gendered nature of caregiving and consider this when engaging and delivering support to older male caregivers.

- Study findings revealed barriers to support for older male caregivers which included ineffective engagement of male caregivers, and some support services were perceived to be inflexible. Relationships with formal support providers were highlighted as key in delivering sustainable effective support.

As described in section 3.5 in the current study data was integrated mainly at the methods level of research (Fetters *et al.*2013). Furthermore, when data from

quantitative and qualitative phases had been analysed, it was merged in order to inform final key study findings. This is illustrated in Figure 9.

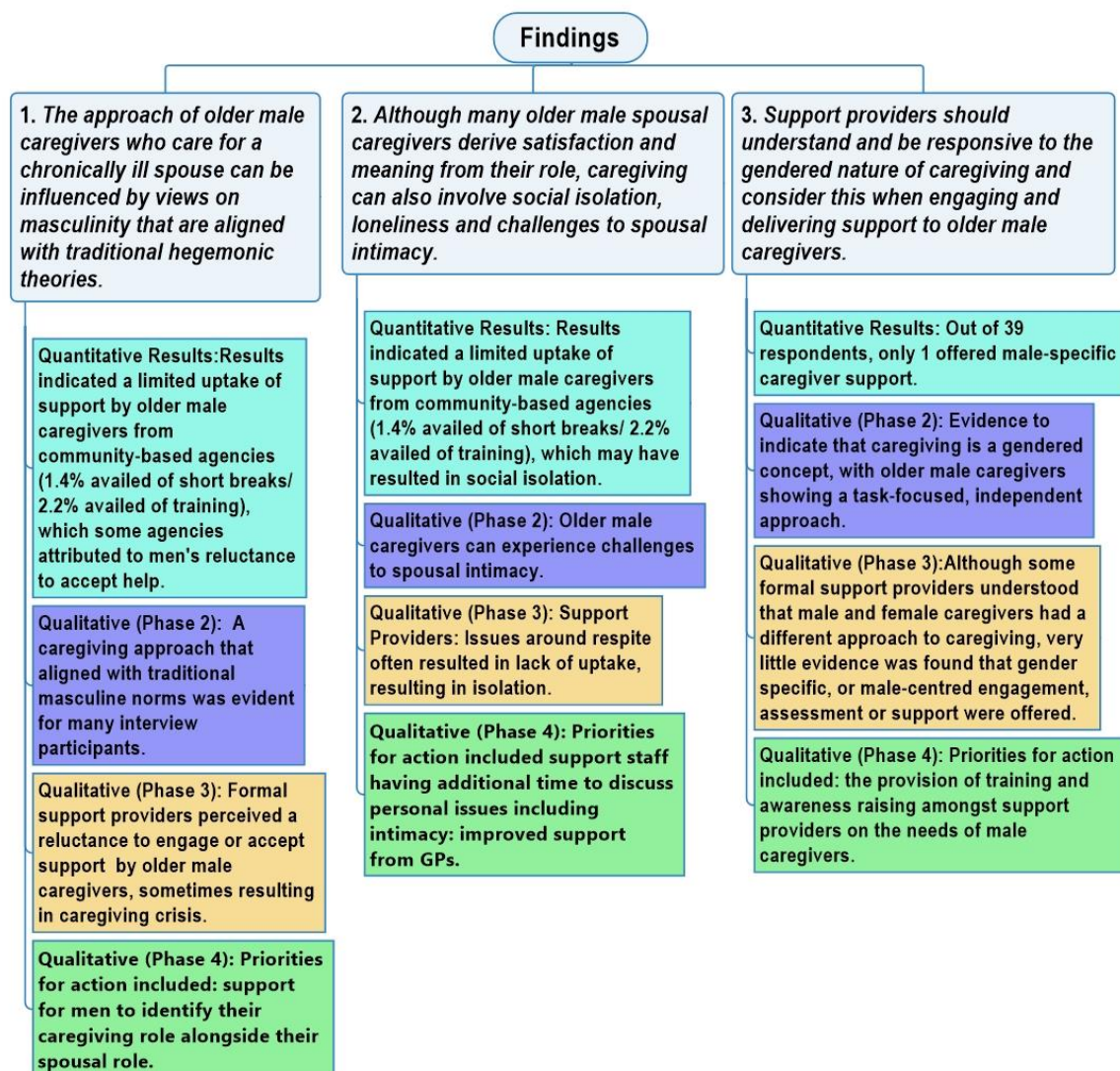


Figure 9: Merging of data to inform key findings.

6.2.1 The approach of older male caregivers who care for a chronically ill spouse can be influenced by views on masculinity that are aligned to traditional hegemonic theories.

Traditionally caregiving has been positioned within the female domain, with western societal expectations and prevailing gender norms continuing to reinforce this (Hrzenjak 2013). However, literature increasingly recognises caregiving as a gendered phenomenon, and that men's approach to caregiving is rooted in socially informed gender repertoires (Baker, Robertson and Connelly 2010; Robinson *et al.* 2014; Milligan and Morbey 2016). Nevertheless, women still make up the majority of caregivers in what has been described as a '*feminised landscape of care*' (Greenwood and Smith 2015), and some male caregivers struggle with their caregiving role as they equate care as a feminine activity (Baker *et al.* 2010). In their Canadian scoping review of male caregivers within dementia ($n=30$), Robinson *et al.* (2014) reported that dominant ideas of masculinity (including independence, stoicism, restricted emotionality and duty) underpinned men's approach to caregiving. Authors noted that even though male caregivers were experiencing high levels of stress, they often reported low levels of caregiver burden, and attributed this to '*holding traditional masculine values*'. More recent findings within the UK have reflected this, suggesting an association between caregiving and masculinity which resulted in increased loneliness and social isolation (Milligan and Morbey 2016). This raises the question about how men reconcile 'doing care' and 'doing gender' (Hanlon 2012), especially given their increasing numbers (particularly in older age groups), and reported negative caregiving outcomes. In the current study, findings illustrated how older male caregiver's views on masculinity influenced their caregiving through an independent and protective approach. For example, Joseph described how although he would accept help if it was offered, he would never have asked for it. Also, several participants explained that they were reluctant to leave their wives either on their own (Jack), or with anyone else (Alan), for fear that something bad may happen. Alan described how he was the only person who could help his wife if she was having a panic attack, therefore he would not accept anyone else sitting with his wife to give him a break. Consistent with these findings, during focus group interviews some healthcare

practitioners reported that in their experience older male caregivers did not seek help, which a mental health practitioner perceived as embarrassment at not being able to cope.

Although these findings were interpreted as adherence to traditional masculine norms, a small amount of data suggested otherwise. Some male caregivers reported that their wives were not open to other women coming in to their home to offer support. Consequently, offers of support were rejected by male caregivers and in the absence of available male support staff, no support could be provided. This provides an alternative insight into male caregiver's motivations to not accepting help. It could also be argued that an independent approach to caregiving may be more to do with age than gender. It has previously been suggested that in older age groups, gender stereotypes are less pronounced than in younger age groups (O'Neil 2008a), or that older people are 'ungendered' (Spector-Mersel 2006). However, this has been disputed more recently by Hrzenjak (2013) who asserted that, in relation to what constituted 'male' and 'female' work, gender stereotypes were especially persistent in older generations.

Findings in the present study echoed previous research which suggested that older male caregivers who identified strongly with masculine 'norms', and who experienced pressure in conforming to these norms, felt that their identity was threatened by their caregiving role (Akpinar *et al.* 2011; Spindelov *et al.* 2017; Judd *et al.* 2018). In order to mitigate this threat, some older male caregivers 'reframed' masculinity. In the present study this strategy was also evident. Gerry adopted a managerial approach to his caregiving role, viewing it as his job as a 'man' to complete his washing and cooking tasks to the best of his ability. Others gave examples of removing ornaments from the house, in order to reduce cleaning, or only buying clothes that didn't need ironed. Similarly, in their scoping review of dementia male caregivers ($n=30$), Robinson *et al.* (2014) reported that older male caregivers constructed their caregiving role in a way that affirmed their masculine identity. Examples of this included identifying and mastering tasks in a way which aligned with their previous occupation (such as using technology for on-line shopping). This gave them a sense of control and self-worth in the face of undertaking new tasks, which others may have viewed as feminine. These findings resonated with subsequent work by Spindelov *et al.* (2017).

In their systematic review about coping and adjustment with male caregivers ($n=16$), authors argued that in order to legitimise caregiving tasks which were traditionally viewed as female, men tended to re-frame these tasks by merging them with previous occupational tasks in order to masculinise them. As explained in section 2.4, this coping strategy entailed taking a task-focussed approach whereby solutions for problems were found in order to alleviate caregiver stress.

More recently, in the United Kingdom, Judd *et al.* (2018) revealed that help seeking for male caregivers was ‘incompatible’ with aspects of their caregiving role and their identity. Authors of Judd’s qualitative study about male caregivers providing care for a dying partner ($n=8$), revealed that men experienced a sense of guilt when they ‘turned away’ from their partners’ pain towards their own, which resulted in a reluctance to ask for help. This in turn, influenced their sense of ‘being a man’ and living up to commonly held male traits of being strong, protective and in control which was incompatible with their attitude towards help-seeking.

6.2.2 Although many older male spousal caregivers derive satisfaction and meaning from their role, caregiving can also involve social isolation, loneliness and challenges to spousal intimacy.

Many older male caregivers in the current study spoke about the emotional aspects of their caregiving role. Consequently, a key finding from the qualitative interviews was the emotional impact of caregiving. Participants described feelings of profound loneliness, frustration, loss, hopelessness, suicidal feelings and social isolation. As described in Paper 2 (section 4.12), interview participants described loneliness, sometimes through tears, as they detailed their caregiving journey and the losses encountered during this time. For some this was due to decreasing opportunities for social activities; and for others it was as a result of their partner’s progressing illness. Several participants emphasised the need to address this loneliness by having someone to talk to. One participant explained that he wasn’t looking for answers, he just wanted to talk; another described the local carers support group meeting as ‘*the highlight of my month*’. This is not surprising given evidence suggesting that male caregivers

experienced more emotional burden than male non-caregivers (Schwartz *et al.* 2015). Likewise, findings from other qualitative literature highlighted loneliness among male caregivers. In their scoping review of male dementia caregivers ($n=30$) Robinson *et al.* (2014) suggested that male caregivers often experienced loneliness because men had smaller social networks than women, therefore they had less access to social opportunities (Sun *et al.* 2008). Other studies demonstrated that loneliness was not unique to older male caregivers, as shown by Greenwood *et al.* (2019) who concluded that loneliness was predominant amongst older housebound caregivers (male and female). However, the necessity to address loneliness in the older male spousal caregiver population is important given the suggestion that older males rely more on emotional support from their spouse than older women (Liao *et al.* 2018), and also that older males tend to only have a close emotional bond with one person in their lives, most often their spouse (Ducharme *et al.* 2006). Thus, when the spousal relationship declines due to chronic illness older male caregivers can often experience loneliness.

Many study participants revealed a picture of changing sexual or emotional intimacy within their relationship. Spousal intimacy with a sample of older male caregivers has not been explored in literature previously. It was not an original aim of this study, but arose during interviews about support needs of this population. In the present study, interviews with older male caregivers and health and social care providers revealed a lack of support for older male caregivers who were experiencing changes in spousal intimacy. Previous literature has highlighted a reluctance by formal support providers to offer support for sexuality as they believed it to be beyond their remit or knowledge. Paper 2 (section 4.12) also described how age and gender may influence healthcare professionals' comfort levels when addressing issues of sexuality with clients (Brotman *et al.* 2016). This is significant given evidence of the importance of sexual and emotional intimacy for quality of life in ageing and caregiving (Davies *et al.* 2012; Roelofs, Luijkx and Embregts 2017), and of the importance of sex in the lives of many older men (Fileborne *et al.* 2017). Existing evidence about spousal intimacy for older couples has involved mixed samples and revealed that often spousal intimacy declines when one partner has a chronic illness (Davies *et al.* 2012). As described in Paper 2 (Section 4.12), a number of participants spoke openly about this issue during the interviews, with some explaining that they struggled with changing intimacy. Other

participants were reluctant to discuss spousal intimacy, possibly because they viewed spousal intimacy as a low priority, or not relevant for the current interview. Alternatively, their reluctance may have indicated discomfort of discussing such personal issues with a female researcher.

It is important to consider how a female researcher may have shaped discussions about spousal intimacy given that interview participants were male. Complex gender dynamics in interviews about sensitive or potentially embarrassing topics have been noted in previous literature (Fileborne *et al.* 2017). However, gender differences between the researcher and the research participant can be either helpful or unhelpful, and findings from previous literature about this are inconsistent. Some authors have argued that male interviewees are more open with male interviewers (Williams and Heikes 1993), although this is contradicted by Manderson (2007) who asserted that female interviewers may enable male interview participants to ‘open up’. This could potentially be explained by female researchers showing dominant feminine norms (including nurturance and compassion) which may encourage some men to engage in traditionally feminized traits such as expressing emotions (Schwalbe and Wolkomir 2003). Others have suggested that, in a display of masculinity, male interview participants may attempt to gain control over the interview where the interviewer is female (Schwalbe and Wolkomir 2001; Sallee and Harris 2011). In contrast, findings from more recent work by Jachyra, Atkinson, and Gibson (2014) indicated that men who internalised masculine norms such as stigma around male intimacies (based on homophobia) may be reluctant to participate in an interview about sexual intimacy with a male researcher.

In terms of any gender-based bias that may have influenced data collection or interpretation, the maintenance of a reflexive journal during the study allowed the researcher to adopt a reflexive stance as far as possible. Although researcher bias cannot be eliminated, the use of multiple strategies can go some way towards mitigating bias. Given the importance of mitigating researcher bias in the creation of knowledge (Berger 2013), a more detailed account of strategies used to minimise bias will be provided in section 6.5 - My PhD journey.

6.2.3 Formal support providers should understand and be responsive to the gendered nature of caregiving and consider this when engaging and delivering support to older male caregivers.

Findings in the current study identified a perception from many formal support providers that older male caregivers did not want to engage or were reluctant to discuss emotional aspects of caregiving. A community-based support provider commented that older male caregivers...*'are reluctant to express any emotional difficulties and at times appear 'detached'*. A focus group participant described how *'men don't talk about these things. They don't talk about feelings'*. That being said, others recognised that the environment was important because, in their experience, men preferred to talk to other men. Two community-based agencies reported that males who attended their (all female) support group did not want to return after the first visit, as there were *'too many women!'*

Some focus group participants had the perception that older male caregivers were harder to engage and build a relationship with than older female caregivers. Several participants were of the view that a different approach was needed with older male caregivers, with one social worker suggesting that *'we need to reach out to men in a different way'*. Deliberative workshop participants suggested that difficulty engaging older male caregivers could be addressed by timing and more appropriate use of language (particularly regarding carers' assessment). Social workers emphasised the importance of having *'early conversations'* at the beginning of the caregiving trajectory in order to increase awareness about their caregiving role, and how life may change as a result. Previous literature has also recognised the importance of early engagement. Stephan *et al.* (2015) suggested that better strategies were urgently needed to improve facilitation of initial engagement between caregivers and healthcare professionals. Authors stressed that a healthcare system that embraced a proactive approach would encourage collaboration about support provided and ultimately improve caregiver outcomes. Engaging men in support (such as giving information) at an early stage may help to build confidence of older male caregivers and prepare them for new roles, and also to identify more easily as a caregiver as well as a spouse. Similar to findings of the current study, Lopez *et al.* (2019) suggested that timing of caregiver engagement was important. Authors stressed that because the caregiver role

evolved with the needs of the care recipient it was vital to offer support early in the caregiving trajectory before the caregiver became 'overwhelmed'.

The importance of relationship building for the facilitation of timely and effective caregiver support was articulated by formal support providers in focus groups and the deliberative workshop. The establishment of an ongoing relationship between the caregiver and a skilled practitioner was important in helping to identify support needs and access appropriate support. Whether this relationship was primarily with staff from a statutory or community-based agency was debated by study participants, and some held the view that older male caregivers were more inclined to access support from community-based agencies, or through GPs than statutory health and social care organisations. This assertion was supported to some extent by several participants in the qualitative interviews who gave examples of support from individuals other than social workers or designated key workers (such as day-care staff, or Alzheimer's Society). In their commentary about the needs of male caregivers and care organisations in the United States, Schwartz and McInnis-Dittrich (2015) described how older male caregivers were '*outside the service system*'. They asserted that it was important to distinguish between formal and informal support, and suggested that men may be more open to informal than formal support. Authors emphasised that although 'care services' (or formal support providers) were not designed to reach out to male caregivers, health and social care practitioners now had a unique opportunity to engage them, due to their increasing visibility. Schwartz and McInnis-Dittrich (2015) further explained that understanding men's perceptions and experiences of utilising support services was vital if men were to be facilitated to access support.

There was a general consensus among participants in the deliberative workshop that community-based agencies appeared to be more flexible and responsive to male caregiver needs. Community-based agencies also appeared to tailor their 'generic' service to take cognisance of differences between male and female caregivers. For example, one agency described how they found a befriender for an older male caregiver who could accompany him to rugby matches on a regular basis. It has been noted elsewhere in literature that older male caregivers have a preference for community-based support (Bottorff *et al.* 2015; Jewkes and Morrell 2015; Sharma *et*

al. 2016). In their Australian study about help-seeking and efficacy to find respite services for dementia caregivers ($n=84$), Phillipson *et al.* (2019) reported a preference for community-based respite services. Arguably the reason for this could be the reported formality under which statutory services operated, as evidenced in the current study, with some participants commenting that these formalities (such as the use of formal language) were a barrier to engagement with male caregivers. Undoubtedly, it could be argued that such formalities were necessary due to legal and policy obligations. But this inevitably raises questions as to whether the perceived formality becomes a barrier to addressing need.

It has been suggested that a pre-requisite for the delivery of support to older male caregivers was a recognition of some support providers' own gender role stereotype biases regarding masculinity and caregiving (Sandberg and Eriksson 2009b; Milligan and Morbey 2013). Milligan and Morbey (2013) examined support needs and support provision to older male caregivers in the UK. They interviewed older male caregivers to explore their support experiences ($n=15$), and formal support providers ($n=9$) to determine whether there were gender-based differences in support services offered. In relation to the latter, findings demonstrated '*gendered nuances subtly underpin care provider's experiences of older carers and their assessment of needs*'. There was some evidence of this in the current study. Comments from support provider personnel such as: '*Men don't talk about these things. They don't talk about feelings*' potentially indicated a perspective influenced by gender stereotypes which could impact on the provision of support services. This was at odds with interview participants who articulated the emotional impact of their caregiving role by describing loneliness, isolation and frustration. Notably, several older male caregivers spoke about their experiences of changing spousal sexual and emotional intimacy (as described in Paper 2), and how they needed support in this area, but were unaware of any available support for this sensitive issue.

Potentially this issue could be addressed with a comprehensive and holistic assessment of caregiver needs. As discussed in Paper 3 (section 5.6), the carers' assessment tool currently exists to assess caregiver support needs. HSCT have a statutory obligation to offer caregivers an assessment of their support needs (which can include

information, or respite care). According to the Department of Health (2019), *‘a Carers’ Assessment is carried out to determine the support needs of the person in commencing or sustaining their caring role; or in addressing the risks to the sustainability of that caring role; or the risks to the carers’ own health and wellbeing.’*

The carers’ assessment process was developed as a result of legislation which aimed to introduce parity of esteem for caregivers and service users. As informal caregiving becomes more prevalent, the necessity for service providers to assess and meet caregivers’ support needs becomes more pressing. Increasingly, policy advocates that support should be as much about helping caregivers lead a fulfilled life (including a social life), as combatting burden and stress (Larkin and Milne 2013). ‘Health and Wellbeing 2026, Delivering Together’ (DHSSPS, NI 2016) recognised the necessity of improving current caregiver support by encouraging greater uptake of carers’ assessments to ensure that caregivers could access up to date information, have personalised budgets and breaks from caring. However, it does not go far enough in drawing attention to caregiving sub-groups who may have specific needs over and above generic caregiver support. It is a legal requirement throughout the UK for carers’ assessments to be offered to caregivers. However, as mentioned in the introductory chapter (Section 1.4), in Northern Ireland a completed assessment does not carry the same legal weight as in the rest of the UK. In ‘Power to the People – Proposals to reboot adult care in N.I.’, the Expert Advisory Panel proposed that the rights of caregivers in Northern Ireland are put on a legal footing and that a strategy to bring them into the heart of transformation of adult care and support is adopted. This should go some way to increasing service delivery for caregivers in Northern Ireland.

Given that carers’ assessments have been the operationalized form of assessing caregivers needs, underpinned by legislation and policy, it is surprising that the translation of this into practice has been fraught with problems (Seddon and Robinson 2015; Brooks and Glendenning 2017). Data in the current study and previous literature highlighted a lack of uptake of carers’ assessments, and ambivalence from professionals regarding the assessment process (Scourfield 2005; Seddon and Robinson 2015). Within Northern Ireland, there was an overall decline in the number of carers’ assessments offered during 2019, and more than half of the caregivers who

were offered an assessment by healthcare professionals declined the offer (Department of Health, 2019).

Questions therefore remain as to why the implementation of carers' assessment is not effective in adequately assessing caregiver support needs; and why current caregiver policy and legislation is not being translated into practice. It could be argued that a lack of uptake of carers' assessments might be attributable to a misinterpretation of the assessment as an assessment of carer competence and abilities rather than an assessment of the support they require. Alternatively, it could be due to ambivalence amongst health and social care practitioners about the carers' assessment process (Seddon and Robinson 2015) (as further detailed in Paper 2, section 4.12).

6.3 The impact of other sociodemographic factors on the caregiving experience

All caregivers experience a degree of burden. This burden has been associated with caregiver and care-recipient relationship, caregiver characteristics, and caregiver support (Lopez-Anuarbe and Kohli 2019). Since factors such as age, ethnicity, education and income have been shown to influence caregiving experience (Chappell *et al.* 2015) it is important to question to what extent gender or other sociocultural factors could lead to the findings of the present study.

Similar to the dearth of literature on older male caregivers there is a dearth of literature to draw from when answering the above question, because caregiver characteristics are frequently not included in caregiving literature. For example, Arbel, Bingham and Dawson (2019) undertook a scoping review on literature about the sex and gender differences between dementia spousal caregivers ($n=61$). Study findings revealed that many of the selected studies did not include important sociodemographic sample characteristics, and also that sampling techniques of many studies could have influenced findings. Nevertheless, some prior studies have shown that variables such as age can be an important factor on caregiver experience, albeit with mixed results. Turner *et al.* (2016) suggested that the oldest carers (80+) demonstrated significant resilience and adapted to their caregiving role better than their younger counterparts. By contrast, in their narrative review of the experiences of the 'oldest carers' (aged

over 75) Greenwood *et al.* (2016) demonstrated mixed results from studies. Quantitative studies in their review illustrated the challenges of caring leading to caregiver burden, whereas the qualitative studies tended to focus more on the rewards of caring, and some studies indicated that for older caregivers caregiving may be less challenging than for younger caregivers. However, in subsequent research by Greenwood *et al.* (2019) findings highlighted challenges faced by older caregivers including, coping with their own declining physical and emotional health and loneliness. In another study of care networks of caregivers in the Netherlands, Bijnsdorp *et al.* (2019) concluded that *all* older caregivers required support due, not to the care recipient's illness, but rather due to their own age or fragility.

Other sociodemographic factors which may have influenced findings of the present study include education and class/income. In a qualitative investigation of caregiver's use of home-based support services in Norway ($n=430$), findings revealed that caregiver characteristics of higher age and higher education level influenced use of these services, with older and more well educated caregivers using services more frequently (Moholt *et al.* 2018). Authors concluded that caregivers who were better educated may be more aware of their rights about services and more capable of accessing them. However, Potter (2018) disputed these claims, suggesting that education was not associated with use of formal services. Findings from Potter's quantitative study in the United States, showed that it was factors including care-recipient health and function as well as where caregivers lived that mainly influenced use of support services.

The current study involved study participants who were in heterosexual relationships. It should be acknowledged that caregivers with same the sex spouse/partner may have a different experience related to their sexual orientation within their caregiving role. For example, previous literature has suggested that older gay and lesbian caregivers may face stigma and discrimination, within a caregiving context (Barrett and Cramer 2015; Brotman *et al.* 2007). More recently Alba *et al.* (2020) emphasised that within spousal caregiving, negative impacts may be greater when stigma and marginalisation target both LGBTI partners. In addition, Alba *et al.* (2020) stressed that these negative impacts may go beyond health and social care, and may include issues such as same

sex caregiving partners not having access to family leave benefits or power of attorney privileges.

The previous text showed mixed evidence about the extent that other sociocultural factors influenced caregiver experiences and the use of support by older male caregivers. Some studies demonstrated that age was the most important factor in use of support services (Greenwood *et al.* 2019; Bijnsdorp *et al.* 2019), while other studies noted that educational background (Moholt *et al.* 2018) determined use of support services. No information about education or income was collected as part of the current study therefore no conclusion could be drawn about its impact on participant caregiving experience. Findings in the current study illustrate how the caregiving approach of older male caregivers can be influenced by views on masculinity aligning with traditional hegemonic theories, thereby impacting on their use of support services.

6.4 Learning from other areas of men's help seeking

Within the past decade there has been a growing recognition that gender socialisation of men may have resulted in men developing fewer emotional skills, difficulty in identifying and articulating feelings, recognising and articulating symptoms of depression, and inhibition of help seeking behaviour through masculine norms (Kingerlee *et al.* 2014; Seidler *et al.* 2016). This recognition has underpinned the development of initiatives within men's mental healthcare and health promotion to address these issues through the delivery of gender specific initiatives that target men. These initiatives have tended to be based on a strength-based approach to men's health (Oliffe *et al.* 2014, Seidler *et al.* 2018). Rather than focus on the deficits of masculinity, there has been an increasing trend to apply men's problem solving and protective aspects of their masculinity to their own health.

In their systematic review of the role of masculinity in men's help-seeking for depression, Seidler *et al.* (2016) found that men's conformity to traditional masculine ideals such as restricted emotionality, stoicism, and duty stemmed from dominant male socialisation in western society. Seidler further noted the 'invisibility' of the gendered nature of men's mental health in literature. Their systematic review of the literature

reinforced previous findings that adherence to masculine norms both increased likelihood of distress and decreased the likelihood of asking for help. They disagreed with the popular assumption that men don't engage with psychological support, rather they found that men would engage if it was '*accessible, appropriate and engaging*'.

Seidler *et al.* 2016 suggested that the healthcare help-seeking process for males goes beyond the activity of seeking help. It incorporated experiences of consultation and treatment processes which may include medication or therapy; and discussions about the problem. This is consistent with findings from a subsequent scoping review by Seidler *et al.* (2018) of engaging men in psychological treatment. Authors emphasised the importance of clinicians acknowledging male socialisation processes and how adherence to masculine ideas may affect engagement in the implementation of 'male-appropriate' psychological treatment. Even if men want to seek help, often they are reluctant to for fear of ridicule by other men (Dolan, Staples, Summer and Hundt 2005; Whitley *et al.* 2007). This was evident in data from the current study (Paper 2), when 'Colin' took antidepressants to cope with caregiving he was ostracised by his peer group. Conformity to masculine ideals (such as men being seen as 'strong' and not needing help) is at odds with the help seeking process, thus impacting the engagement of men who identify with masculine ideology.

An example of an approach to psychological support for men that demonstrates findings by Seidler *et al.* (2016;2018) is Men's Shed, which originated in Australia, and is now common throughout the UK and Ireland. This initiative aimed to decrease social isolation and improve older men's mental well-being through men-centred social interaction. In their scoping review of Men's Shed and other gendered interventions, Milligan *et al.* (2013) showed some limited evidence that these gendered initiatives improved the mental health and well-being of older men, but no evidence was found of improvements to physical health. A more recent study by Hlambelo (2015), in which Men's Sheds were again evaluated showed improvements in both physical and mental wellbeing for older men. In her study health improvements were attributed not only to the provision of meaningful male specific activities (which appealed to men's sense of self-worth similar to former employment), but also to a male-centred environment where they felt valued, supported and respected by other

men. This perceived social support modulated stress response and resulted in better health outcomes (Hlambelo 2015). Men's Shed is a good example of a male-centred community-based project.

As part of their scoping review of men's mental health interventions ($n=25$), Seaton *et al.* (2017) evaluated the integration of gender specific influences in the content and delivery of men's mental health promotion programmes. They concluded that the defining features of previous male centred programmes were the integration of a 'gender sensitive focus' (i.e. taking account of masculine ideals). Seaton noted that the definition of 'gender-sensitive' in this context were programmes: *'that recognize the specific needs and realities of men based on the social construction of gender roles'* (World Health Organisation 2007, p.4). Components of programmes that were successful included: use of language - i.e. 'Mental fitness' as opposed to 'social isolation' or 'depression'; and gender sensitive branding (i.e. partnering with a men's organisation as opposed to a mental health organisation). Whilst Seaton and colleagues recognised that these studies may be limited by small sample sizes, they did report important changes within samples of socially isolated men. This was attributed to all male support and reciprocity, activity-based programme designs that were not perceived as 'therapy', and the use of sport to normalise improvements in well-being. This has been demonstrated in subsequent studies. For example, in Canada, Bottorff *et al.* (2018) explored gender related factors that motivated men's smoking cessation ($n=56$). Study findings revealed that characteristics such as fighting for self-control and competing underpinned men's motivation to stop smoking. Furthermore, men in this study preferred encouragement from other men over 'experts' telling them what to do. Thus, findings from previous research have emphasised that *how* support is offered to men is as important as the type of support. Authors have suggested that gender sensitive strategies can extend beyond health and fitness to the wider area of men's health promotion (Bottorff *et al.* 2018). Importantly, Robinson *et al.* (2014) emphasised the benefits of fully linking *'men's caregiver research to gender relations and men's health issues as a means to articulate strategies to sustain the health and well-being of men caregivers'*.

In light of evidence of improvements in men's mental health through the provision of gender sensitive support described above, the extent to which caregiver support for older male caregivers could be improved through the application of gender sensitive support needs to be considered. For example, data in the current study highlighted a need for emotional support. Given men's preference for support in a male centred environment, questions exist as to whether more opportunities for peer support, such as more male support staff or male befrienders, would impact on caregiver outcomes. Also, evidence in the current study indicated that older male caregivers had a poor awareness of information and support services, and yet a preference for community-based support. Therefore, it would be important to consider whether the provision of support could be improved if there was increased community-based support for older male caregivers, and closer working arrangements between statutory and community-based agencies offering support to this population.

Furthermore, given many older men's alignment with masculine norms such as competitiveness and mastery, perhaps a more effective approach to encouraging men to access information and training would be one which promotes training as 'honing skills', or becoming 'the best', as opposed to 'needing support'. In a similar vein, given evidence indicating a 'task-focused' approach by male caregivers, in situations where support providers are aware that male caregivers are experiencing stress, it could be suggested that a focus on creating attainable goals to alleviate stress may be more appealing to men than talking therapies, or stress management initiatives. Finally, further exploration is merited to ascertain whether increasing awareness of support providers gendered assumptions and approach to engaging men would influence their approach or impact on their biases.

6.5 My PhD journey

In the introductory chapter I described how my previous work with older male caregivers highlighted a potential gap in service provision in meeting their support needs. This thesis would not be complete without a reflection of how the study of this has impacted on me personally, the main challenges experienced and how I have developed as a researcher throughout the process. Given that this study explored gender, a key challenge for me was how I, as a female, approached a male dominated

subject area. Recent research has highlighted the complexities and the gendered implications of women studying men. For example, Lefkowich (2019) asserted that female interviewers could unintentionally have an expectation of men to be in control of their emotions, or be able to communicate assertively. Consequently, when participants did not comply with these social norms, aspects of their experiences or nuanced expressions of their gender may be missed.

Early in the research process, and as a result of reading a wide variety of empirical work, I became aware of the importance of reflexivity, in order to acknowledge how gender (and other factors) could influence data collection, interpretation and ultimately study findings. Throughout the course of the study I kept a reflexive journal. This journal was an opportunity for me to record issues such as cognitions and emotions, gendered assumptions or potential role conflict. I further realised that the knowledge generated through this study would not be independent of me. Rather, the qualitative stages of the research I was embarking on were a co-construction between myself and the study participants. Acknowledging this, I had to bring awareness of my 'positioning' to the study which included my characteristics (such as age and gender), background, culture, education, personal beliefs and biases. I had to take responsibility for my own position, and the effect that my position would have on the research participants and setting; the questions being asked; and the collection and analysis of data. Moreover, I was aware that my world view could impact on the way that I filtered the information and made meaning from the data, thus shaping the study findings (Kacem and Chaitin 2006).

Consequently, throughout the course of the study I continually self-monitored - a process of internal dialogue and critical self-reflection, with the aim of becoming more attuned to my own reactions to participants and data. In this way, my awareness of my own inherent bias grew throughout the study. An example of this was during the interviews with older male caregivers, specifically the discussions around sexual intimacy. When the first participant spontaneously began to recount the decline in his spousal sexual intimacy, I was uncomfortable, and even though I stayed with the discussion it posed a considerable challenge for me. After the interview, a process of self-reflection through peer review and reflexive journal writing enabled me to address

the issues around my own sensitivities that had possibly been triggered during the interview. Consequently, when sexual intimacy was discussed during subsequent interviews, although there was still a certain level of discomfort on my part, I felt more prepared and better able to facilitate the discussion.

Berger (2015) described how, during the course of a study, a researcher can move from a position of ‘outsider’ to ‘insider’, with the latter being the researcher who shares similar experiences to the research participant. During the course of this study I moved to being a caregiver for my mum who was living with dementia. Although I initially perceived my own status as a caregiver as affording me unique insight into the world of my study participants, I was unprepared for the ‘blurred boundaries’ that this created (Drake 2010). For example, when I shared my caregiving experiences with a participant, I became aware that the interview dynamics had changed, and I became the ‘interviewee’ while he asked me questions about my mum’s illness (as his wife also had dementia). I was also aware that sharing my experience had the potential to create a situation whereby participants did not specify certain details as they assumed that these details would be obvious to me (such as being aware of the side effects of drugs commonly prescribed for Alzheimer’s disease).

Throughout the course of this study I have been striving to balance feelings of being overwhelmed and stressed by the amount of data being generated, with gratitude to the participants who gave so freely of their time and experience for the benefit of the study. Some of the stress was the result of my desire to get interpretation of the data ‘right’ and produce interesting findings so that participants would not feel that their time was wasted. I continually had to question this approach, and discussions with supervisors and colleagues helped this questioning process greatly. ‘Staying true to the data’ became a mantra, and as such I endeavoured to keep men’s words to the fore with the use of many quotations, throughout the findings.

Finally, I recognise that no research is free of the experiences or personality of the researcher. As such, I was continually aware of how I interpreted data and filtered information based on my own assumptions and biases. Throughout this PhD journey I have learned to question, and discovered that within qualitative research it’s not just

the participants' words that need to be analysed - equally significant were my own responses (verbal and non-verbal), as well as many contextual factors. Consequently, the continual process of critical self-reflection, and how I have changed as a result have turned out to be a more important outcome of the study than I could have ever anticipated when I began this journey.

6.6 Conclusion

Initially the focus of this study was to investigate the feasibility of developing a caregiver support programme targeted specifically at older male caregivers. However, analysis of data from the first study phase (male caregiver interviews) showed that male caregivers did not want a male caregiver programme to be developed, rather, they suggested that if existing services worked more effectively, they would feel better supported. On the basis of this the aim of the study changed to explore the impact of existing support services in meeting the needs of this population. Subsequent study phases therefore explored the views of formal support providers and other key stakeholders in order to ensure views were considered from all perspectives.

Overall study findings revealed that the approach of older male caregivers who care for a chronically ill spouse/partner can be influenced by views on masculinity that are aligned to traditional hegemonic theories; although many older male spousal caregivers derive satisfaction and meaning from their role, caregiving can also involve social isolation, loneliness and challenges to spousal intimacy; and support providers should understand and be responsive to the gendered nature of caregiving and consider this when engaging and delivering support to older male caregivers.

Considering the implications of these study findings for future support for older male caregivers, the current study draws on developments in other areas of men's mental health and health promotion. The aim of this is to advance understanding of how to provide support to men that aligns with masculine ideology and gendered expectations. Potentially this could provide a basis for improving support services to older male caregivers. The following chapter (Chapter Seven) will describe how this study contributes to knowledge, and outlines a number of study strengths and limitations. Recommendations for policy, education and practice will be discussed before a detailed study conclusion is presented.

CHAPTER SEVEN: CONCLUSIONS AND RECOMMENDATIONS

7.1 Introduction

The previous chapter presented an in-depth discussion about study findings in light of existing literature. This chapter will begin by presenting the contribution to knowledge, and also describe a number of study strengths and limitations. The chapter will discuss how study findings have the potential to influence future policy, practice and education. A number of ideas for future research will then be discussed. Finally, a conclusion is drawn which will summarise study design, findings, and how the new knowledge resulting from this study may influence decision makers and practitioners in providing effective and sustainable support of older male spousal caregivers.

7.2 Contribution to knowledge

This study is important as it contributes new knowledge to an under-researched area and addresses a significant gap in the literature. To the best of the researcher's knowledge, this is the first study to explore the impact of existing support services in identifying and meeting the needs of older male caregivers, who are caring for a spouse/partner at home. The study exposed a dearth of literature about the needs of older male spousal caregivers, and whilst this is slowly improving due to the rising number of male caregivers, empirical literature about how best to support this sub-group of caregivers is still scarce.

As part of the mixed methods approach, this study is the first to collect quantitative data about the status of support from community-based agencies offered to male caregivers in Northern Ireland. As such it has established a baseline about the amount and type of existing support, which has highlighted a gap in male specific support for caregivers from these agencies.

An increased awareness amongst formal support providers that male caregivers need support, and a better understanding of how this support should be delivered is crucial if older male caregivers are to continue to provide care for as long as possible, thus

enabling more people to be cared for in the community and minimising costs to the State. Findings from this study highlighted perspectives from some formal support providers that may hinder engagement of older male caregivers and subsequent provision of support. The current process of engagement, assessment and continued support for older male spousal caregivers is flawed, and although issues with caregiver support have been previously noted in literature, for older male caregivers it is particularly important that these issues are addressed given reported negative caregiving outcomes for this population group. Specifically, study findings revealed an emotional impact on older male spousal caregivers not previously noted in literature. Findings highlighted challenges with declining spousal intimacy for some male caregivers, and a lack of awareness from some formal support providers that this was an issue.

This study advances understanding about how principles from male-centred psychological support initiatives within the wider field of men's healthcare could contribute to support for older male caregivers. Previous research has shown improvements in men's psychological well-being and through participation in gender sensitized programmes. It could be argued that elements of these initiatives (such as use of language, or peer support from other males) could be translated into caregiver support that may improve outcomes for older male caregivers.

7.3 Study strengths and limitations

Strengths

The mixed methods study design ensured a richness of data through the collection of both quantitative and qualitative data. In the current study the quantitative component established the status of support for older male caregivers in Northern Ireland, and the qualitative component shed light on older men's experiences of caregiver support, and perceptions of support provision for older male caregivers from formal support providers. As such, the reported limited generalisability of a qualitative approach, and limited depth of understanding of a quantitative approach were addressed by using mixed methods in the current study (Green *et al.* 2015).

Given the research area, this approach was thought to be the most suitable as it entailed data collection and interpretation in clear, distinct stages which also allowed for triangulation of data to enhance transparency. The qualitative component was dominant which was also a strength of the current study by providing a deeper understanding of a range of support experiences of older male caregivers. This was coupled with an array of perspectives and process information from support providers (including practitioners, policy makers and funders) which illuminated some barriers and facilitators to support for older male caregivers.

It was also considered that a mixed methods design would allow for more effective dissemination and implementation of findings. Green *et al.* (2015) asserted that mixed methods design greatly improved ‘buy in’ from key stakeholders through the involvement of patients, practitioners and policy makers from the community in which the research is to be disseminated in the research process. This was achieved in the current study.

Limitations

Whilst there was important new knowledge generated about the experience of and provision of support for older male caregivers in this study, it is also worth considering some limitations and their potential impact on study findings. Several specific study limitations were described in the three included papers (sections 2.3, 4.12, 5.6), however a description of more general study limitations follows. Firstly, it is acknowledged that this study was not confined to caregivers of one specific illness or at one particular stage of the caregiving trajectory. Given that caregiver experience can also be influenced by care-recipient abilities (depending on the nature of the illness), and stage of the illness (for example early stages or advanced dementia), it is recognised that this may have impacted on study findings.

Secondly, as highlighted earlier (Chapter 6, section 6.2), the potential for researcher-bias exists. For example, in the context of the focus of the study on support needs as opposed to support available, and also in the context of the focus on challenges and barriers experienced by older male caregivers without due regard to the identification

of facilitators. While the researcher endeavoured to minimise bias, the potential for its existence must be recognised.

Thirdly, although the quantitative phase of the study provided important numerical data to add context, a direct comparison between the services used by males only and the services used by females only may have been easier if the survey questions had been configured differently. For example, survey questions about the use of support services first asked about 'older caregivers' (that is, male and female), and second asked about service use by 'older male caregivers'. However, as explained in section 4.3 the draft survey was pilot tested, and the wording and sequence of questions in the final survey was based on feedback from the pilot stage.

Fourthly, given that all interview participants in phase 2 were in heterosexual relationships, a perceived sample bias should be acknowledged.

Fifthly, phase 3 involved a deliberative workshop. Contributions to this workshop may have been strengthened by the inclusion of more male caregivers, and also more participants from community-based agencies who had direct experience of delivering men-centred initiatives (such as Men's Shed). Given the participation by key policy makers at the workshop, this may have been a missed opportunity for these policy makers to hear directly from male caregivers and experienced practitioners in men-centred support.

Finally, it could be argued that a female researcher undertaking research with an all-male sample influenced findings due to dynamics during the interviews, or gendered assumptions/researcher bias during interpretation of data. However, this was addressed by using a range of measures discussed in section 6.5 (My PhD Journey).

7.4 Recommendations

The following section discusses some important recommendations for the areas of policy, practice and education.

Policy:

Carers strategy: The ‘Health and Wellbeing, 2026, Delivering Together’ (Department of Health (NI) 2016) states that by 2026 within the population of NI there will be more people who are over 65 than under 16. Furthermore, between 2014 and 2039 the number of people aged 85 and over will have increased by 157%. These changing demographics will inevitably lead to increased pressure on social care services and budgets and an increased reliance on informal/family caregivers. Family/informal caregivers are a hugely significant policy consideration, given their input to the lives of those they care for, and the associated reduction in State costs, estimated to be £132 billion per year in the UK (Buckner and Yeandle 2015). Their willingness and ability to undertake this unpaid work needs to be continually recognised and should therefore place them at the centre of future health and social care policy.

While strategies and policies referred to above recognise the importance of providing support to caregivers, gaps and inconsistencies exist at the delivery level. For example, no strategy documents to date have recognised the impact of gender on caregiving despite the growing body of evidence showing that males and females have a different approach to caregiving. Evidence from this study and elsewhere shows that older male caregivers support needs are poorly assessed under the current system, and that, due to changing demographics, support services to this population need to be considered carefully as part of the carers’ assessment process.

Carers’ assessment: A lack of uptake of carers’ assessment by older male caregivers should be acknowledged by policy makers. An urgent review of the carers’ assessment and follow-up process is required in order to address the issues raised by this and other research (Seddon and Robinson 2015). A comprehensive person-centred gender sensitive review of caregiver support needs, prompted by support providers, which reviews caregiver support on a regular basis throughout the caregiving trajectory should replace the current carers’ assessment.

Identification and engagement: The lack of identification and engagement of older male caregivers should be recognised by policy and decision makers, and steps should be taken to address this. Policy and decision makers should be cognisant of

developments in the wider field of psychological support for men, particularly the examples of men centred initiatives such as Men's Shed (as discussed in Section 6.4). Existing evidence in this area shows that men-centred programmes are effective at reducing stress and improving caregiving outcomes (Nurmi *et al.* 2016; Botorff *et al.* 2018).

Practice:

Sustainable partnerships: Given older male caregivers preference for community-based support highlighted by this and other research (Nurmi *et al.* 2016), closer partnership between community-based and statutory healthcare agencies is required in order to deliver person-centred, creative and sustainable solutions to the support needs of older male caregivers.

Caregiving and gender: Caregiving as a gendered concept should be recognised by formal support providers. In practice this means understanding the differences in approach to caregiving and coping strategies between males and females, and appreciating the social conditioning and gender constructions which may impact on older males' caregiving experience. Specifically, support providers should not assume that a perceived reluctance to engage with services means that male caregivers do not need help, rather that more suitable support should be investigated and implemented.

Early identification: The importance of having 'early conversations' with older male caregivers should be emphasised with formal support providers. This may result in older male caregivers identifying as caregivers as well as husbands, strengthen the relationship between the caregiver and support provider, and encourage older male caregivers to engage with services at an earlier point, in order to avoid crisis.

Education:

Gendered assumptions: Findings from this study have drawn attention to 'gendered assumptions' about older male caregivers and their approach to their caregiving role. It is important that this is highlighted within ongoing training and education for nurses, social workers, and community support staff. Addressing this issue may reduce

stereotypical views and ‘gendered nuances’ reported in this study and elsewhere (Milligan and Morbey 2013).

A collaborative approach: Findings from this study have revealed that if older male spousal caregivers are to accept support, they tend to prefer a collaborative approach to providing care. That is, they don’t want formal support providers to ‘take over’ rather they need to retain some control over caregiving and need to be involved in the decision-making process. Although this could apply to all caregivers regardless of gender, it is particularly important for older males given their reported reluctance to accept support. Formal support providers should be aware that often the way in which support is provided is as important as the type of support for older male spousal caregivers.

7.5 Future research

Building on findings from this study, there is a need for future research to investigate how sociodemographic factors could influence the approach of older male spousal caregivers. The limited existing evidence base on this shows mixed results, as discussed in Section 6.4. Given suggestions that hegemonic masculinity is fluid and context dependant (Connell and Messerschmitt 2005), we cannot assume that even if masculinity *is* performed through the approach of older male caregivers, it will look the same across a diverse population, or indeed that a gender sensitive support approach will have a similar impact across a range of educational or income backgrounds. How the suggested ‘gender sensitized’ support initiatives could be adapted to take account of all sociodemographic variables warrants further investigation. Given that current support services are mainly female dominated, and some existing evidence indicates ‘gendered nuances’ in the approach of formal support providers (Milligan and Morbey 2013), there is a need for research with formal support providers about how stereotypical assumptions may influence support for older male caregivers. Moreover, future research about whether or not the gender of health and social care professionals could impact on caregiver outcomes is warranted.

Given that the current study explored service provision from ‘formal’ care providers (i.e. support staff from statutory and community-based agencies); for pragmatic reasons, the experience of ‘informal’ caregivers were not considered. However, it is acknowledged that the voices of other family members, who may have assisted the men in their caregiving role, were missing from the current study. Future research could investigate the potential wider role of family members who provide ‘informal’ support for older male caregivers.

Evidence in the current study indicated that many male caregivers were committed to their role, and other evidence has found that this population can derive meaning and satisfaction from the role. However, within the current study it was not clear how the positive aspects of caregiving mitigated the stressful aspects of the role. Therefore, future studies could explore the positive aspects in greater depth, focusing on whether it is possible to align positive aspects of male caregiving with caregiver support.

7.6 Conclusion

A growing number of older male caregivers and increased awareness of caregiving as gendered has highlighted the need to better understand the suitability of existing caregiver support services across an increasingly diverse range of caregivers.

Research shows that male and female caregivers take a different approach to their caregiving role. The limited evidence base on the experiences and support needs of older male caregivers indicates that this population group tend to take a stoic and self-reliant approach to their role. This approach, coupled with older male caregivers’ reported reluctance to ask for or accept help until a crisis point can result in increased caregiver stress, negative outcomes for the care recipient, and potentially a breakdown in caregiving arrangements.

Given that caregiving has historically been viewed as a female activity, previous research has comprised predominantly female samples. Consequently, existing

caregiving literature mainly relates to women's experiences of caregiving and the support they need to enable them to sustain that role. Thus, men's experiences of caregiving are under-researched and their support needs are poorly understood. The present study aimed to address this gap, by exploring the impact of current caregiving support services in identifying and meeting the needs of older male spousal caregivers. Study findings related to 3 key areas. Firstly, it was recognised that the approach of older male caregivers who care for a chronically ill spouse can be influenced by views on masculinity that are aligned to traditional hegemonic masculinity theories. Secondly, although many older male spousal caregivers derive satisfaction and meaning from their role, caregiving can also involve social isolation, loneliness and challenges to spousal intimacy. Thirdly, support providers should understand and be responsive to the gendered nature of caregiving and consider this when engaging and delivering support to older male caregivers.

These findings demonstrate that older male caregivers experience negative caregiver outcomes, that are not necessarily alleviated by existing support services. It could be argued that this also applies to female caregivers, however, these findings are especially pertinent for males given evidence that men are more likely than women to rely on their spouse for emotional support, so when this support decreases due to chronic illness, men can be particularly vulnerable to a lack of emotional support, leading to loneliness and social isolation.

Consistent with masculinities theories that underpin this study, formal support providers should be cognisant of the impact of social conditioning and gender constructions on older men's identification with traditional masculine norms, especially when assessing need and providing support to this population. Furthermore, coping theories which also underpinned this study can potentially give insight into how older men apply their task-focussed approach to their caregiving role, and how this may impact support needs. For example, the quantitative phase of this study demonstrated a low uptake of training for older male caregivers. Given that task focused coping depends on creating attainable goals, it could be argued that if male caregivers had adequate information and training, this may have been enough to enable

them to create achievable goals and therefore task focused coping may have been more effective in reducing burden.

As study findings show, older male caregivers are willing to talk about caregiver burden and, can be engaged in psychological support if it is suitable. Older male caregiver's preference for support which aligns with traditional masculine norms is also reinforced by findings in other areas of men's health promotion and help seeking, as described in Section 6.4. Drawing on recent developments in support for men in the wider area of men's healthcare and mental health initiatives, it has been shown that gender aware support initiatives within a male centred environment (i.e. Mens Sheds) improve the health and well-being of older men (Milligan *et al.* 2013; Hlambelo 2015). These gender sensitized initiatives build on the positive aspects of masculinity, rather than focussing on deficits of masculinity.

Given the developments described above, this study advances understanding about how principles unpinning these initiatives could contribute to support for older male caregivers. Findings in the current study indicate that effective caregiving support for older males includes an awareness by formal support providers that there are gender-based differences in caregiving, and that many older male caregivers tend to prefer and engage with caregiving support which aligns with and does not threaten traditional masculinity ideology.

A prerequisite to the delivery of effective and sustainable support to older male caregivers is undoubtedly a commitment from government to place informal caregivers at the centre of support services reform (as outlined in 'Health and Wellbeing 2026, Delivering Together' (DHSSPS, NI 2016)). Although government policy has recognised the vital role played by caregivers and the associated savings to the State, it could be argued that insufficient resources have been allocated at the implementation level to provide adequate and flexible caregiver support. In a Northern Ireland context, enforcing caregivers' legislation that applies throughout the UK to Northern Ireland may help to improve the carer's assessment process, and would inevitably highlight caregiver's rights to effective support.

Finally, in section 1.2 I described how I was inspired to address the issues for older male caregivers that I had become aware of as part of my Carers Co-Ordinators role within HSCT. I believe that through the exploration of the issues from various perspectives afforded by this study, there is now a better understanding of the research phenomenon and a basis of recommendation from which to go forward to improve practice and support services for older male caregivers.

REFERENCES

- Abdullah, N. N. and Abdul Rahman, M. F. (2017) 'The Use of Deliberative Democracy in Public Policy Making Process', *SSRN Electronic Journal*, (March). doi: 10.2139/ssrn.2769105.
- Ablitt, A., Jones, G., V, Muers, J. (2009) Living with dementia: a systematic review of relationship factors. *Aging & Mental Health* 13(4): 497–511. doi: 10.1080/13607860902774436.
- Accius, J. Breaking Stereotypes: Spotlight on Male Family Caregivers. 2017. Available online: <https://www.aarp.org/content/dam/aarp/ppi/2017-01/Breaking-Stereotypes-Spotlight-on-Male-Family-Caregivers.pdf> (accessed on 23/10/19).
- Age UK: Centre for Policy on Ageing on behalf of Age UK (2014) Review: Changing family structures and their impact on the care of older people.
- Akpınar, B., Küçükgüçlü, Ö. and Yener, G. (2011) 'Effects of Gender on Burden Among Caregivers of Alzheimer's Patients', *Journal of Nursing Scholarship*, 43(3), pp. 248–254. doi: 10.1111/j.1547-5069.2011.01402.x.
- Alba, B, Lyons, A, Waling, A, et al. Health, well-being, and social support in older Australian lesbian and gay care-givers. *Health Soc Care Community*. 2020; 28: 204– 215. <https://doi.org/10.1111/hsc.12854>
- Aldaz, B. E. *et al.* (2017) 'Oncology healthcare professionals' perspectives on the psychosocial support needs of cancer patients during oncology treatment'. doi: 10.1177/1359105315626999.
- Anderson, E. and McCormack, M. (2018) 'Inclusive Masculinity Theory: overview, reflection and refinement', *Journal of Gender Studies*. Routledge, 27(5), pp. 547–561. doi: 10.1080/09589236.2016.1245605.
- Anderson, R. M., Funnell, M. M. and Hernandez, C. A. (2005) 'Choosing and using theories in diabetes education research', *Diabetes Educator*, 31(4), pp. 513–520. doi: 10.1177/0145721705278947.
- Appleton, D. *et al.* (2018) 'Our disease: a qualitative meta-synthesis of the experiences of spousal/partner caregivers of people with multiple sclerosis', *Scandinavian Journal of Caring Sciences*, 32(4), pp. 1262–1278. doi: 10.1111/scs.12601.
- Arbel, I., Bingham, K. S. and Dawson, D. R. (2019) 'A Scoping Review of Literature on Sex and Gender Differences Among Dementia Spousal Caregivers', *The Gerontologist*. doi: 10.1093/geront/gny177.

Argyris, C. and Schon D. (1983) *Reasoning, Learning, and Action*, Jossey-Bass, San Francisco.

Autio, T. and Rissanen, S. (2018) 'Positive emotions in caring for a spouse: a literature review', *Scandinavian Journal of Caring Sciences*, 32(1), pp. 45–55. doi: 10.1111/scs.12452.

Baker, K., L., Robertson, N., and Connelly, D. (2010) Men caring for wives or partners with dementia: Masculinity, strain and gain. *Aging & Mental Health*, 14, 319-327.

Bannon, I., and Correia, M. (eds.) (2006). *The other half of gender: Men's issues in development*. Washington, DC: World Bank.

Barken, R. and Sims-Gould, J. (2018) 'Home Support Workers and Older Men: The Implications of Masculinity for Later Life Care', *Men and Masculinities*, pp. 1–18. doi: 10.1177/1097184X18804308.

Barrett, C., and Cramer, P. (2015). *An extra degree of difficulty: An evidence based resource exploring the experiences and needs of older LGBTI carers and the carers of older LGBTI people*. Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne

Beiber, A., Nguyen, N., Meyer, G., Stephan, A. (2018) Influences on the access to and use of formal community care by people with dementia and their informal caregivers: a scoping review. *BMC Health Services Research*. doi:10.1186/s12913-018-3825-z.

Bennett, W. L. *et al.* (2004) 'Managing the public sphere: Journalistic construction of the great globalization debate', *Journal of Communication*, 54(3), pp. 437–455. doi: 10.1093/joc/54.3.437.

Bekkers, V., and Edwards, A. (2007) Legitimacy and democracy: a conceptual framework for assessing governance practices. In: Bekkers V, Dijkstra G, Edwards A, Fenger M (eds) *Governance and the democratic deficit: Assessing the democratic legitimacy of governance practices*. Ashgate, Aldershot, pp 35–60.

Berger, R. (2015) Now I see it, now I don't: Researcher's position and reflexivity in qualitative research, *Qualitative Research*. Vol. 15(2) 219–234 doi: 10.1177/1468794112468475.

Bergman, M.M. (2008) *Advances in Mixed Methods Research: Theories and Applications*, Sage, London.

Bergman M.M. (2009) *Mixed Methods Research*, Sage, London.

Bernard, R. H. (2012). *Social research methods: Qualitative and quantitative approaches* (2nd ed.). Thousand Oaks, CA: Sage.

Beyea, S. C., and Nicoll, L. H. (2000) Learn more using focus groups. *AORN Journal*, 71, 897–900.

Bijnsdorp, F. M. *et al.* (2019) ‘Who provides care in the last year of life? A description of care networks of community-dwelling older adults in the Netherlands’, *BMC Palliative Care*. 18(1), pp. 1–11. doi: 10.1186/s12904-019-0425-6.

Blas, E., Gilson, L., Kelly, M.P., Labonté, R., Lapitan, J., Muntaner, C.,... Vaghri, Z. (2008). Addressing social determinants of health inequities: What can the state and civil society do? *The Lancet*, 372(11), 1684-1689.

Bottorff, J. L. *et al.* (2015) ‘An Updated Review of Interventions that Include Promotion of Physical Activity for Adult Men’, *Sports Medicine*. Springer International Publishing, 45(6), pp. 775–800. doi: 10.1007/s40279-014-0286-3.

Bottorff, J. L. *et al.* (2018) ‘Smoke-Free Men: Competing and Connecting to Quit’, *American Journal of Health Promotion*, 32(1), pp. 135–142. doi: 10.1177/0890117116671257.

Bowling, A., 2002. *Research Methods in Health: Investigating Health and Health Services*, 4th ed. Open University Press, Buckingham.

Boylstein, C., and Hayes, J. (2012) Reconstructing marital closeness while caring for a spouse with Alzheimer’s. *Journal of Family Issues* 33 (5) 584–612.

Braun, V., and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3 (2). 77:101.

Brearley, S.G., Blake, S., Milligan, C., Seamark, D., Thomas, C., Turner, M., Wang, X. and Payne S. (2014) ‘Deliberative panels: developing recommendations for supporting stakeholder and user involvement. *Palliative Medicine* 28(6),641-642.

Breen, R. L. (2006) ‘A practical guide to focus-group research’, *Journal of Geography in Higher Education*, 30(3), pp. 463–475. doi: 10.1080/03098260600927575.

Brooks, J., Mitchell, W. and Glendinning, C. (2017) Personalisation, personal budgets and family carers: whose assessment? Whose budget? *Journal of Social Work* 17 (2), 147-166. doi: 10.1177/1468017316638554.

Brotman, S., Ryan, B., Collins, S., Chamberland, L., Cormier, R., Julien D., ... Richard, B. (2007). Coming out to care: Caregivers of gay and lesbian seniors in Canada. *The Gerontologist*, 47, 490–503.

Brotman, S., Drummand, J., Silverman, M., Sussman, T., Orzeck, P., Barylek, L., Wallack, I., Billette, V. (2016) Talking about sexuality and intimacy with women spousal caregivers: Perspectives of Service Providers. *Health & Social Work* 41, 263-269.

- Bryman, A. (2015) *Social Research methods*. 5th ed oxford: Oxford University Press.
- Buckner, L. and Yeandle, S. (2015) *Valuing carers 2015: the rising value of carers' support*. London: Carers UK. Available at: https://www.sheffield.ac.uk/polopoly_fs/1.546409!/file/Valuing-Carers-2015.pdf (accessed 15/01/20)
- Burchardt, T. (2012) 'Deliberative research as a tool to make value judgements', *Qualitative Research*, 14(3), pp. 353–370. doi: 10.1177/1468794112469624.
- Büscher, A., Astedt-Kurki, P., Paavilainen, E., Schnepf, W. (2011) Negotiations about helpfulness-the relationship between formal and informal care in home care arrangements. *Scandinavian Journal of Caring Sciences*. 2011; 25:706:15.
- Carers UK: State of Caring 2019, Carers UK. <http://www.carersuk.org/stateofcaring> (accessed 01/09/19).
- Calasanti, T. and King, N. (2007) 'Taking "women's work" "like a man": Husbands' experiences of care work', *Gerontologist*, 47(4), pp. 516–527. doi: 10.1093/geront/47.4.516.
- Care Alliance Ireland (2013a) *Family Caring in Ireland*, May 2013. Retrieved from www.carealliance.ie/userfiles/file/Report%202013%20Web%20SP.pdf (accessed 17/06/19)
- Calasanti, T. (2003). Gender differences in informal care work for persons with Alzheimer's disease. Final project report to the Alzheimer's and Related Diseases Research Award Fund (Available from the Virginia Center on Aging, School of Allied Health Professions, Virginia Commonwealth University, P.O. Box 980229, Richmond, VA 23298-0229).
- Calvo´-Perxas L, Vilalta-Franch J, Litwin H, Turro´-Garriga O, Mira P, Garre-Olmo J (2018) What seems to matter in public policy and the health of informal caregivers? A cross-sectional study in 12 European countries. *PLoS ONE* 13(3): e0194232. <https://doi.org/10.1371/journal.pone.0194232> (accessed 14/11/19).
- Carers Trust (2014) *Husband, Partner, Dad, Son, Carer? A Survey of the Experiences and Needs of Male Carers*.
- Carey, G. E. and Braunack-Mayer, A. J. (2009) 'Exploring the effects of government funding on community-based organizations: "Top-down" or "bottom-up" approaches to health promotion?', *Global Health Promotion*, 16(3), pp. 45–52. doi: 10.1177/1757975909339765.
- Chappell, N. L., Dujela, C. and Smith, A. (2015) 'Caregiver Well-Being: Intersections of Relationship and Gender', *Research on Aging*, 37(6), pp. 623–645. doi: 10.1177/0164027514549258.

Chillag, K. *et al.* (2002) 'Factors affecting the delivery of HIV/AIDS prevention programs by community-based organizations', *AIDS Education and Prevention*, 14(3 SUPPL.), pp. 27–37. doi: 10.1521/aeap.14.4.27.23886.

Cohen J (2003) Deliberation and democratic legitimacy. In: Matravers D, Pike J (eds) *Debates in contemporary political philosophy. An anthology*. Routledge in association with the Open University, London, pp 342–360.

Comas-d'Argemir, D. and Soronellas, M. (2019) 'Men as Carers in Long-Term Caring: Doing Gender and Doing Kinship', *Journal of Family Issues*, 40(3), pp. 315–339. doi: 10.1177/0192513X18813185.

Connell R.W., Messerschmidt, JW, (2005) Hegemonic Masculinity: Rethinking the concept. *Gender & Society*. Sage. 19 (6) 829-859. doi: 10.1177/0891243205278639.

Corbin, J. and Morse, J. M. (2003) 'Qualitative Inquiry The Unstructured Interactive Interview ' *Qualitative Inquiry*, 9(3), pp. 335–354. doi: 10.1177/1077800403251757.

Craig, P. *et al.* (2008) 'Developing and evaluating complex interventions: new guidance', *BMJ (Clinical research ed.)*, 337(September), p. a1655. doi: 10.1136/bmj.a1655.

Creswell J.W., & Plano Clarke V.L., Gutman, M.I., and Hanson, W.E (2003) Advanced Mixed Methods Research Designs. In Tashakkori, A and Teddlie, C (Eds) *Handbook of mixed methods in social and behavioural research* (pp. 209-240). Thousand Oaks: Sage Publications.

Creswell, J. W., & V. L. Plano Clark. (2007). *Designing and conducting mixed methods research*. Thousand Oaks, CA: Sage Publications.

Creswell, J.W. and Plano Clark, V.L. (2011). Choosing A Mixed Methods design. In: Creswell, J.W. ed. *Designing and Conducting Mixed Methods Research*. 2nd ed. London: SAGE, 53-107.

Creswell, J.W. and Creswell J.D., (2018) *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*, by John Creswell and J. David Creswell. Thousand Oaks, CA: Sage Publications.

Cutcliffe, J. (2003) 'Reconsidering Reflexivity: Introducing the Case for Intellectual Entrepreneurship', *Qualitative Health Research* 13(1): 136–48.

Dam, A., E., de Vugt, M., E., Klinkenberg, I.P., Verhey, F.R., & van Boxtel, M.P., (2016) A systematic Review of social support interventions of caregivers of people with dementia. Are they doing what they promise? *Maturitas* 86 117:130.

Davies, H., Sridhar, S., Newkirk, L., Beaudreau, S., and O'Hara, R (2012) Gender differences in sexual behaviours of AD patients and their relationship to spousal caregiver well-being. *Ageing and Mental Health* 16 (1) 89-101.

Davis, M. M. *et al.* (2012) “‘Did I do as best as the system would let me?’ Healthcare professional views on hospital to home care transitions.’, *Journal of general internal medicine*, 27(12), pp. 1649–1656. doi: 10.1007/s11606-012-2169-3.

Department for Work and Pensions (2011). Number of Future Centenarians by Age Group

Department of Health (England) (2010): Recognised, Valued and Supported, next steps for the carers strategy.

Department of Health (England) (2010): Recognised, Valued and Supported, next steps for the carers strategy.

Department of Health Social Services and Public Safety (NI) (2002b). Valuing Carers: Proposals for a Strategy for Carers in Northern Ireland. Belfast.

Department of Health Social Services and Public Safety (NI). Transforming Your Care (2011).

Department of Health NI. (2016) Health and Wellbeing 2026: Delivering Together. Belfast. Retrieved from: <https://www.healthni.gov.uk/sites/default/files/publications/health/health-and-wellbeing-2026-deliveringtogether.pdf> (accessed 20/01/20).

Department of Health and Social Services and Public Safety (NI) (2017). Power to the People report. P. 17.

Department of Health NI (2019). Quarterly Carers’ Statistics for Northern Ireland (July-September 2019). Community Information. Available at Branch <https://www.health-ni.gov.uk/topics/dhssps-statistics-and-research-socialservices/social-care-statistics> (accessed 31/12/19).

DHSS (1990). People First: Community Care for Northern Ireland in the 1990s. Belfast: Department of Health and Social Services (Northern Ireland).

DHSSPS (2006). Caring for Carers: Recognising, Valuing and Supporting the Caring Role. Belfast: Department of Health, Social Services and Public Safety (Northern Ireland).

Dickinson, C., Dow, J., Gibson, G., Hayes, L., Robalino, S., and Robinson, L. (2017) Psychosocial intervention for carers of people with dementia: What components are most effective and when? A systematic review of systematic reviews. *International Psychogeriatrics*. 26, 1-13.

Dolan, A., Staples, V., Summer, S., and Hundt, G. L. (2005). “You ain’t going to say . . . I’ve got a problem down there”: Workplace-based prostate health promotion with men. *Health Education Research*, 20, 730-738.

Drake P (2010) Grasping at methodological understanding: a cautionary tale from insider research. *International Journal of Research and Method in Education* 33(1): 85–99.

Dryzek, J. (2010) *Foundations and Frontiers of Deliberative Governance*. Oxford: OUP.

Ducharme, F. (1995) Longitudinal change in conjugal support and coping behaviours of elderly marital partners. *Journal of Family Nursing*. 1:281-302.

Ducharme, F., Le'vesque, L., Lachance, L., Zarit, S., Ve'zina, J., Gangbe, M., and Caron, C. D. (2006). Older husbands as caregivers of their wives: A descriptive study of the context and relational aspects of care. *International Journal of Nursing Studies*, 43, 567–579.

Ducharme, F. *et al.* (2007) 'Changes in health outcomes among older husband caregivers: A one-year longitudinal study', *International Journal of Aging and Human Development*, 65(1), pp. 73–96. doi: 10.2190/9754-21RH-5148-8025.

Duncanson, C. (2015) 'Hegemonic Masculinity and the Possibility of Change in Gender Relations', *Men and Masculinities*, 18(2), pp. 231–248. doi: 10.1177/1097184X15584912.

Ekstedt, M. *et al.* (2014) 'Health Care Professionals' Perspectives of the Experiences of Family Caregivers During In-Patient Cancer Care', *Journal of Family Nursing*, 20(4), pp. 462–486. doi: 10.1177/1074840714556179.

Elliott, K. (2016) 'Caring Masculinities', *Men and Masculinities*, 19(3), pp. 240–259. doi: 10.1177/1097184x15576203.

Eriksson, H. and Sandberg, J. (2008) Transitions in men's caring identities: experiences from home-based care to nursing home placement. *International Journal of Older People Nursing* 3, 131–137.

Evans, B. C., Coon, D. W. and Ume, E. (2012) 'Use of Theoretical Frameworks as a Pragmatic Guide for Mixed', *Journal of Mixed Methods Research*, 5(4), pp. 276–292. doi: 10.1177/1558689811412972.

Family Caregiver Alliance 2019. Caregiver statistics: Demographics. <https://www.caregiver.org/caregiver-statistics-demographics> (accessed on 26/06/19).

Farrimond, H. (2012). Beyond the caveman: Rethinking masculinity in relation to men's help-seeking. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 16, 208-225. doi: <http://dx.doi.org/10.1177/1363459311403943>.

Fee, A., McIlpatrick, S. and Ryan, A. (2019) "'When it faded in her ... it faded in me": a qualitative study exploring the impact of care-giving on the experience of spousal intimacy for older male care-givers', *Ageing and Society*, pp. 1–22. doi: 10.1017/s0144686x19000850.

- Feilzer, M. Y. (2010) 'Doing mixed methods research pragmatically: Implications for the rediscovery of pragmatism as a research paradigm', *Journal of Mixed Methods Research*, 4(1), pp. 6–16. doi: 10.1177/1558689809349691.
- Fileborn, B., Hinchliff, S., Lyons, A. et al. (6 more authors) (2017) The Importance of Sex and the Meaning of Sex and Sexual Pleasure for Men Aged 60 and Older Who Engage in Heterosexual Relationships: Findings from a Qualitative Interview Study. *Archives of Sexual Behavior*. doi:10.1007/s10508-016-0918-9.
- Fischer, F. (2003) Reframing public policy: Discursive politics and deliberative practices. Oxford University Press, Oxford.
- Fogarty, A. S., Proudfoot, J., Whittle, E. L., Player, M. J., Christensen, H., Hadzi-Pavlovic, D., and Wilhelm, K. (2015). Men's use of positive strategies for preventing and managing depression: A qualitative investigation. *Journal of Affective Disorders*, 188, 179–187. doi: 10.1016/j.jad.2015.08.070.
- Folkman, S. and Moskowitz, J. T. (2000) 'Positive affect and the other side of coping', *American Psychologist*, 55(6), pp. 647–654. doi: 10.1037/0003-066X.55.6.647.
- Folkman, S., Moskowitz, J.T.(2004) Coping: Pitfalls and promise. *Annual Review of Psychology*. 55:745–774.
- Foss, C. and Ellefsen, B. (2002) 'The value of combining qualitative and quantitative approaches in nursing research by means of method triangulation', *Journal of Advanced Nursing*, 40(2), pp. 242–248. doi: 10.1046/j.1365-2648.2002.02366.x.
- Fowler, F. J. (2014). Survey research methods (5th ed.). Los Angeles, CA: Sage.
- Friedemann, M. and Buckwalter, K.C.(2014) Family Caregiver Role and Burden Related to Gender and Family Relationships. *Journal of Family Nursing*. 20, 313–336.
- Gaugler, J. E., Davey, A., Pearlin, L. I., Zarit, S. H., (2000) Modelling caregiver adaptation over time: The longitudinal impact of behavior problems. *Psychology and Aging*, 15:437-450.
- Geiger, J. R. et al. (2015) 'Burden among male Alzheimer's caregivers: Effects of distinct coping strategies', *American Journal of Alzheimer's Disease and other Dementias*, 30(3), pp. 238–246. doi: 10.1177/1533317514552666.
- Gibbs G.R., (2007) Analysing qualitative data. In U. Flick (Ed.), *The Sage qualitative research kit*. Thousand Oaks, CA: Sage.
- Gibbons, C. et al. (2014) 'The Psychological and Health Consequences of Caring for a Spouse With Dementia: A Critical Comparison of Husbands and Wives', *Journal of Women and Aging*, 26(1), pp. 3–21. doi: 10.1080/08952841.2014.854571.

Gibson, M., and Denner, B. J. (2000). Men's health report 2000: The MAN model. Pathways to men's health. Daylesford, Victoria, Australia: Centre for Advancement of Men's Health.

Glauber, R. (2017) 'Gender Differences in Spousal Care Across the Later Life Course', *Research on Aging*, 39(8), pp. 934–959. doi: 10.1177/0164027516644503.

Graneheim, U. H. and Lundman, B. (2004) 'Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness', *Nurse Education Today*, 24(2), pp. 105–112. doi: 10.1016/j.nedt.2003.10.001.

Greene, J.C. and Hall, J.N. (2010) Dialectics and pragmatism: being of consequence. In Tashakkori, A., Teddlie, C. (Eds): SAGE Handbook of Mixed Methods in Social and Behavioural Research, 2nd edition, Sage, Thousand Oaks, CA.

Green, J. and Thorogood, N (2009 [2004]). Qualitative methods for health research (2nd ed.). Thousand Oaks, CA: Sage.

Green, C., Duan, N., Gibbons, R., Hoagwood, K., Palinkas, L., and Wisdom, J. (2015). Approaches to mixed methods dissemination and implementation research: Methods, strengths, caveats, and opportunities. *Administration and Policy in Mental Health and Mental Health Services Research*, 42, 508–523. doi:10.1007/s10488-014-0552-6.

Greenwood, N. and Smith, R. (2015) 'Barriers and facilitators for male carers in accessing formal and informal support: A systematic review', *Maturitas*. doi: 10.1016/j.maturitas.2015.07.013.

Greenwood, N. *et al.* (2016) 'The oldest carers : A narrative review and synthesis of the experiences of carers aged over 75 years'. *Maturitas* 94, pp. 161–172.

Greenwood, N. *et al.* (2019) 'A qualitative study of older informal carers ' experiences and perceptions of their caring role'. *Maturitas*, pp. 1–7. doi: 10.1016/j.maturitas.2019.03.006.

Guba E.G. (1990) *The Paradigm Dialogue*. Newbury Park, California, London. Sage.

Gurung, R. A. R., Taylor, S. E. and Seeman, T. E. (2003) 'Accounting for changes in social support among married older adults: Insights from the MacArthur Studies of Successful Aging', *Psychology and Aging*, 18(3), pp. 487–496. doi: 10.1037/0882-7974.18.3.487.

Haley, W. E. *et al.* (2010) 'Caregiving strain and estimated risk for stroke and coronary heart disease among spouse caregivers: Differential effects by race and sex', *Stroke*, 41(2), pp. 331–336. doi: 10.1161/STROKEAHA.109.568279.

Han, J. W. *et al.* (2014) 'Effects of social supports on burden in caregivers of people with dementia', *International Psychogeriatrics*. Cambridge University Press, 26(10), pp. 1639–1648. doi: 10.1017/S1041610214001331.

Hanlon, N. (2012) *Masculinities, Care and Equality: Identity and Nurture in Men's Lives*. Basingstoke, UK: Palgrave Macmillan.

Hanson, W. E., J. W. Creswell, V. L. Plano Clark, K. P. Petska, and J. D. Creswell. 2005. Mixed methods research designs in counseling psychology. *Journal of Counseling Psychology* 52 (2): 224–35.

Harris, M. G., Diminic, S., Reavley, N., Baxter, A., Pirkis, J., & Whiteford, H. A. (2015) Males' mental health disadvantage: An estimation of gender-specific changes in service utilisation for mental and substance use disorders in Australia. *Australian & New Zealand Journal of Psychiatry*, 49(9), 821–832. doi: <https://dx.doi.org/10.1177/0004867415577434>.

Hellström, I. *et al.* (2017) 'Development of older men's caregiving roles for wives with dementia', *Scandinavian Journal of Caring Sciences*, 31(4), pp. 957–964. doi: 10.1111/scs.12419.

Hlambelo, L. (2015) 'Impact of men's sheds on the health and wellbeing of the men involved: A biopsychosocial study', *PhD thesis, Western Sydney University*, p. 338. Available at: <https://researchdirect.westernsydney.edu.au/islandora/object/uws%3A36955/datastream/PDF/download/citation.pdf>.

Hong, S. C. and Coogle, C. L. (2016) 'Spousal Caregiving for Partners with Dementia: A Deductive Literature Review Testing Calasantis Gendered View of Care Work', *Journal of Applied Gerontology*, 35(7), pp. 759–787. doi: 10.1177/0733464814542246.

Hrženjak, M. (2013) 'Negotiating masculinity in informal paid care work', *International Review of Sociology*, 23(2), pp. 346–362. doi: 10.1080/03906701.2013.804296.

Hwang, B., Fleischmann, K. E., Howie-Esquivel, J., Stotts, N. A., & Dracup, K. (2011). Caregiving for patients with heart failure: Impact on patients' families. *American Journal of Critical Care*, 20(6), 431-442. doi:10.4037/ajcc20114.

Jachyra, P., Atkinson, M., and Gibson, B. E. (2014). Gender performativity during interviews with adolescent boys. *Qualitative Research in Sport, Exercise and Health*, 6, 568–582.

Jewkes, R. *et al.* (2015) 'Hegemonic masculinity: combining theory and practice in gender interventions', *Culture, Health and Sexuality*. Routledge, 17, pp. 96–111. doi: 10.1080/13691058.2015.1085094.

Ji, J. *et al.* (2012) 'Increased risks of coronary heart disease and stroke among spousal caregivers of cancer patients', *Circulation*, 125(14), pp. 1742–1747. doi: 10.1161/CIRCULATIONAHA.111.057018.

Johnson, B. and Gray, R. (2010) A history of philosophical and theoretical issues for mixed methods research. in Tashakkori, A., Teddlie, C. (Eds): SAGE Handbook of Mixed Methods in Social and Behavioural Research, 2nd edition, Sage, Thousand Oaks, CA.

Johnson, R. B. and Onwuegbuzie, A. J. (2004) 'Mixed Methods Research: A Research Paradigm Whose Time Has Come', *Educational Researcher*, 33(7), pp. 14–26. doi: 10.3102/0013189X033007014.

Judd, R., Guy, H. and Howard, R. A. (2018) 'Caring for a Dying Partner: The Male Experience', *Journal of Palliative Care*, 34(1), pp. 5–11. doi: 10.1177/0825859718774679.

Kacen, L. and Chaitin, J. (2006) The times are a changing: understanding qualitative research in ambiguous, conflictual and changing contexts. *Qualitative Report* 11: 209–228.

Kanuka, H., Rourke, L. and Laflamme, E. (2007) 'The influence of instructional methods on the quality of online discussion', *British Journal of Educational Technology*, 38(2), pp. 260–271. doi: 10.1111/j.1467-8535.2006.00620.x.

Katz, S. (1983). Assessing self-maintenance: Activities of daily living, mobility, and instrumental activities of daily living. *Journal of the American Geriatrics Society*, 31, 721-727.

Kerpershoek, L., Woods, B., Wolfs, C., Verhey, F., Bieber, A., Stephan, A., ... Bieber, A. (2018). Do caregiver profiles predict the use of dementia care services? *Aging & Mental Health*, 1-8. <https://doi.org/10.1080/13607863.2018.1544215>.

Kingerlee, R., Precious, D., Sullivan, L., and Barry, J. (2014). Engaging with the emotional lives of men. *Psychology*, 27(6), 418–421.

Kingry, M. J., Tiedje, L. B. and Friedman, L. L. (1990). Focus groups: a research technique for nursing. *Nursing Research*, 39, 124–125.

Kitzinger J. (1994) The methodology of focus groups: the importance of interaction between research participants. *Sociology of Health and Illness* 16, 103–121.

Kitzinger, J. (1995). Qualitative research. Introducing focus groups. *BMJ*, 311, 299–302.

Krosnick J. A., Presser S., 2010: Handbook of Survey Research, Emerald Group Publishing Ltd.

Krueger, R. A., and Casey, M. A. (2000). Focus groups: A practical guide for applied researchers (3rd ed.). Thousand Oaks, CA: Sage.

Krueger R.A., Casey M.A., (2015). Focus Groups, A Practical Guide for Applied Research. SAGE publications CA.

- Lachance, L. *et al.* (2006) 'Older husbands as caregivers of their wives : A descriptive study of the context and relational aspects of care', 43, pp. 567–579. doi: 10.1016/j.ijnurstu.2005.07.007.
- Larkin, M., and Milne, A. (2013). Carers and Empowerment in the Uk: A Critical Reflection. *Social Policy and Society*, 13(1), 25-38.
- Lawton, M.P., and Brody, E.M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. *The Gerontologist*, 9 (3), 179-186. doi:10.1093/geront/9.3_Part_1.179
- Lazarus, R. and Folkman, S. (1984) *Stress, Appraisal, and Coping*. New York: Springer Publishing Co.
- Lee, E.J., DeDios, S., Fong, M.W.M. Simonette, C. and Lee G.K. (2015) Gender differences in coping among spousal caregivers of persons with multiple sclerosis. *Journal of Rehabilitation* 79 (4) 46-54.
- Lefkowich, M. (2019) When Women Study Men: Gendered Implications for Qualitative Research. *International Journal of Qualitative Methods* 18: 1–9. doi: 10.1177/1609406919872388.
- Leung, L. (2019) 'The Challenges Male Carers Face in Hong Kong : Implications for Practice and Policy The Challenges Male Carers Face in Hong Kong : Implications for Practice and Policy', *Australian Social Work*. Taylor & Francis, pp. 1–13. doi: 10.1080/0312407X.2019.1660388.
- Levant, R. F. (2011). Research in the psychology of men and masculinity using the gender role strain paradigm as a framework. *American Psychologist*, 66(8), 765-776. doi.org/10.1037/a0025034.
- Liao, J. *et al.* (2018) 'Gendered trajectories of support from close relationships from middle to late life', *Ageing and Society*, 38(4), pp. 746–765. doi: 10.1017/S0144686X16001264.
- Lin, F., Holly R.F., and Hsueh-Sheng, W. (2012) Negative and Positive caregiving experiences: a closer look at the intersection of gender and relationships. *Family Relations* 61 (2) pp 343 – 358.
- Lindahl, B. Lidén., Lindblad, B. (2011) A meta-synthesis describing the relationships between patients, informal caregivers and health professionals in home-care settings. *Journal of Clinical Nursing* 20 454:63.
- Lipmanowicz, H., and McCandless, K., (2013) *The surprising power of liberating structures*. Liberating Structures Press p 197-202.
- Lincoln, Y., S., and Guba, E., G. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage.

- Lloyd, J., Patterson, T., and Muers, J. (2016). The positive aspects of caregiving in dementia: A critical review of the qualitative literature. *Dementia*, 15(6), 1534-1561.
- Loffe, H., Yardley, L. (2004) Content and thematic analysis. In: Marks DF, Yardley L (eds). *Research Methods for Clinical and Health Psychology*(1st edn). London: Sage Publications, 56–69
- Lopez–Anuarbe, M. and Kohli, P. (2019) ‘Understanding Male Caregivers’ Emotional, Financial, and Physical Burden in the United States’, *Healthcare*, 7(2), p. 72. doi: 10.3390/healthcare7020072.
- Lunaigh, C. O. and Lawlor, B. A.(2008) Loneliness and the health of older people. *International Journal of Geriatric Psychiatry*, 23(12) 1213-21.
- Luborsky, M.R. and Rubinstein, R.L. (1995). Sampling in qualitative research: Rationale, Issues and Methods. *Research on Aging*, 17, 89-113.
- Magovcevic, M., and Addis, M.E. (2008) The Masculine Depression Scale: development and psychometric evaluation. *Psychology of Men & Masculinity*, 9(3), 117 doi: 10. 1037.
- Manderson, L., Bennett, E., Andajani-Sutjahjo, S. (2007) The Social Dynamics of the Interview: Age, Class & Gender. *Qualitative Health Research*. doi: 10. 1177/1049732306294512.
- Mason, J. (2002). *Qualitative researching*, 2nd Edition. London: Sage.
- Mason, M. (2010) ‘Sample size and saturation in PhD studies using qualitative interviews’, *Forum Qualitative Sozialforschung*, 11(3). doi: 10.17169/fqs-11.3.1428.
- McCabe, M., You, E. and Tatangelo, G. (2016a) ‘Hearing Their Voice: A Systematic Review of Dementia Family Caregivers’ Needs’, *Gerontologist*, 56(5), pp. e70–e88. doi: 10.1093/geront/gnw078.
- McCabe, M., You, E. and Tatangelo, G. (2016b) ‘Hearing Their Voice: A Systematic Review of Dementia Family Caregivers’ Needs’, *Gerontologist*, 56(5), pp. e70–e88. doi: 10.1093/geront/gnw078.
- McDonnell, E. and Ryan, A. A. (2014) ‘The experience of sons caring for a parent with dementia’, *Dementia*, 13(6), pp. 788–802. doi: 10.1177/1471301213485374.
- Miller, B., and Cafasso, L. (1992). Gender differences in caregiving: Fact or artifact? *The Gerontologist*, 32, 498-507.
- Milligan, C., Conradson, D. (2006) *Contemporary landscapes of welfare: the 'voluntary turn'? Landscapes of voluntarism: New spaces of health, welfare and governance*. Edited by: Milligan C, Conradson D. Bristol, UK: The Policy Press, 1-14.
- Milligan, C. and Morbey, H. (2013) ‘Older men who care : understanding their support and support needs’, (December), pp. 1–37.

Milligan, C. and Morbey, H. (2016) 'Care, coping and identity: Older men's experiences of spousal care-giving', *Journal of Aging Studies*. doi: 10.1016/j.jaging.2016.05.002.

Moholt, J. M. *et al.* (2018) 'Factors affecting the use of home-based services and out-of-home respite care services: A survey of family caregivers for older persons with dementia in Northern Norway', *Dementia*. doi: 10.1177/1471301218804981.

Montgomery, R. J. V. (Ed.) (2002). A new look at community based respite programs: Utilization, satisfaction, and development. New York: Haworth Press.

Montgomery, R. J. V., *et al.* (2007) Family caregiving. In J. A. Blackburn & C. N. Dulmus (Eds.), *Handbook of gerontology: evidencebased approaches to theory, practice, and policy*, (pp. 426–454). Hoboken, NJ: Wiley.

Morgan, D.L. (1988). Focus groups as qualitative research (Sage University Paper Series on Qualitative Research Methods, Vol. 16). Beverly Hills: Sage Publications.

Morgan, D. (1998). Practical strategies for combining qualitative and quantitative methods: Applications to health research. *Qualitative Health Research* 8:362–76.

Morgan, D. L. (2007). Paradigms lost and pragmatism regained. *Journal of Mixed Methods Research*, 1, 48-76.

Morgan, T. *et al.* (2016) 'Gender and family caregiving at the end-of-life in the context of old age: A systematic review', *Palliative Medicine*, 30(7), pp. 616–624. doi: 10.1177/0269216315625857.

National Alliance for Caregiving (NAC) & American Association of Retired Persons (AARP) Caregiving in the US 2015: A focused look at those caring for someone age 50 or older, executive summary. Bethesda, MD and Washington, DC: NAC & AARP; 2009. Funded by The MetLife Foundation. Retrieved from <http://www.caregiving.org/pdf/research/FINALRegularExSum50plus.pdf>. accessed 26/06/19

NHS England 2018: Definition of carer: <https://www.england.nhs.uk/commissioning/comm-carers/carers/> (accessed 16/10/19)

Nogueira, M.,M.,L., Neto, J.,P.,S., Sousa, M.,F.,B., Santos, R.,L., Rosa, R.,D.,L., Lacerda, I.B., Baptista, M.,A.,T., Dourado, M.,C.,N. (2016) Perception of Change in Sexual Activity in people with Alzheimer's Disease: View of people with dementia and their spouse caregivers. *International Psychogeriatrics* 2016.

Northern Ireland Statistics and Research Agency (NISRA) (2014) *Northern Ireland Census 2011: Key Statistics Summary Report*. NISRA, Belfast.

Northern Ireland Statistics and Research Agency (2017). 2016-based population projections for Northern Ireland.

Northern Ireland Statistics and Research Agency (2018). Estimates of the population aged 85 and over Northern Ireland, 2017 (and revised 2001 to 2016).

Nurmi, M. A., Mackenzie, C., Roger, K., Reynolds, K., and Urquhart, J. (2016). Older men's perceptions of the need for and access to male-focused community programs such as Men's Sheds. *Ageing & Society*. doi:10.1017/S0144686X16001331.

O'Neil, J., Helms, B. J. and Gable, R. K. (1986) 'Gender-role conflict scale : College men ' s fear of femininity Gender-Role Conflict Scale : College Men's Fear of Femininity. *Sex Roles* 14 5-6. doi: 10.1007/BF00287583.

O'Neil, J. M. (2008) 'Summarizing 25 Years of Research on Men's Gender Role Conflict Using the Gender Role Conflict Scale: New Research Paradigms and Clinical Implications', *The Counseling Psychologist*, 36(3), pp. 358–445. doi: 10.1177/0011000008317057.

O'Reilly, M. and Parker, N. (2013) "'Unsatisfactory Saturation": A critical exploration of the notion of saturated sample sizes in qualitative research', *Qualitative Research*, 13(2), pp. 190–197. doi: 10.1177/1468794112446106.

O'Shaughnessy, M., Lee, K. and Lintern, T. (2010) 'Changes in the couple relationship in dementia care: Spouse carers' experiences', *Dementia*, 9(2), pp. 237–258. doi: 10.1177/1471301209354021.

Office of National Statistics (2013a). 2011 census - unpaid care snapshot. available at: <http://www.ons.gov.uk/ons/guide-method/census/2011/carers%20week/index.html> (accessed 18/6/10).

Office of National Statistics (2013) Population Estimates for UK, England and Wales, Scotland and Northern Ireland. <http://www.ons.gov.uk/ons/rel/pop-estimate/populationestimates-for-uk--england-and-wales-scotland-and-northernireland/2009/index.html> (accessed 18/06/19).

Office for National Statistics (2019) Living longer: caring in later working life. Available at: <https://www.ons.gov.uk/releases/livinglongercaringinlaterworkinglife> (Accessed 25/06/19).

Oldenkamp, M. *et al.* (2016) 'Subjective burden among spousal and adult-child informal caregivers of older adults: results from a longitudinal cohort study', *BMC Geriatrics*. *BMC Geriatrics*, 16(1), pp. 1–11. doi: 10.1186/s12877-016-0387-y.

Oliffe, J. L. and Han, C. S. E. (2014) 'Beyond Workers' Compensation: Men's Mental Health In and Out of Work', *American Journal of Men's Health*, 8(1), pp. 45–53. doi: 10.1177/1557988313490786.

Organisation for Economic Organisation and Development (OECD) (2005). *Long Term Care for Older People*. OECD, Paris.

Organisation for Economic Co-Operation and Development (2011): 'The impact of caring on family carers', in OECD (ed) *Help Wanted? Providing and paying for long-term care*. Paris: OECD.

Parahoo, K., (2014) *Nursing Research, Principles, Process and Issues*. Third Edition.

Parker, G., Arksey, H. and Harden, M. (2010) *Meta-review of International Evidence on Interventions to Support Carers*. Available at: <http://eprints.whiterose.ac.uk/73552/>.

Pearlin, L. I., Lieberman, M. A., Menaghan, E. G., & Mullan, J. T. (1981). The stress process. *Journal of Health and Social Behavior*, 22, 337–356. doi:10.2307/2136676.

Phillipson, L. *et al.* (2019) 'Knowledge, help-seeking and efficacy to find respite services: An exploratory study in help-seeking carers of people with dementia in the context of aged care reforms 11 Medical and Health Sciences 1117 Public Health and Health Services', *BMC Geriatrics*. *BMC Geriatrics*, 19(1), pp. 1–9. doi: 10.1186/s12877-018-1009-7.

Piersol, C. V., Canton, K., Connor, S. E., Giller, I., Lipman, S., and Sager, S. (2017). Effectiveness of interventions for caregivers of people with Alzheimer's disease and related major neurocognitive disorders: A systematic review. *American Journal of Occupational Therapy*, 71, 7105180020. <https://doi.org/10.5014/ajot.2017.027581>.

Pinquart, M. and Sörensen, S. (2003) 'Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis', *Psychology and Aging*, 18(2), pp. 250–267. doi: 10.1037/0882-7974.18.2.250.

Pinquart, M. and Sörensen, S. (2006) 'Helping caregivers of persons with dementia: which interventions work and how large are their effects?', *International Psychogeriatrics*, 18(4), pp. 577–595. doi: 10.1017/s1041610206003462.

Pinquart, M.; Sorensen, S. (2011) Spouses, Adult Children, and Children-in-Law as Caregivers of Older Adults: A Meta-Analytic Comparison. *Psychology and Aging* (26), 1–14.

Pizzo, E., Doyle, C., Matthews, R. and Barlow, J. (2015), Patient and public involvement: how much do we spend and what are the benefits?. *Health Expectations* 18: 1918-1926. doi:[10.1111/hex.12204](https://doi.org/10.1111/hex.12204).

Plano Clark, V.L. and Creswell, J.W. (2008) *The Mixed Methods Reader*, Sage, Thousand Oaks, CA.

Pleck, J. 1981. *The myth of masculinity*. Cambridge, MA: MIT Press.

Pleck J.H., (1995): The gender role strain paradigm. An update. In RF Lavant & WS Pollack (eds). *A new psychology of men*. P11 -32. New York. Basic Books.

Polenick, C. A. and DePasquale, N. (2017) ‘Predictors of Secondary Role Strains Among Spousal Caregivers of Older Adults With Functional Disability’, *The Gerontologist*, 00(00), pp. 1–13. doi: 10.1093/geront/gnx204.

Potter, A. J. (2018) ‘Factors Associated With Caregivers’ Use of Support Services and Caregivers’ Nonuse of Services Sought’, *Journal of Aging and Social Policy*. Routledge, 30(2), pp. 155–172. doi: 10.1080/08959420.2017.1414539.

Pöysti, M. M. *et al.* (2012) ‘Gender Differences in Dementia Spousal Caregiving’, *International Journal of Alzheimer’s Disease*. doi: 10.1155/2012/162960.

Pretorius, C., Walker, S. and Heyns, P. M. (2009) ‘Sense of coherence amongst male caregivers in dementia: A South African perspective’. *Dementia*. doi: 10.1177/1471301208099046.

Quinn-Patton M., (2002) Two Decades of Developments in Qualitative Inquiry. A Personal Experiential Perspective. *Qualitative Social Work I*, 261-283.

Raccichini, A. *et al.* (2009) ‘The caregiver’s burden of Alzheimer patients: Differences between live-in and non-live-in’, *American Journal of Alzheimer’s Disease and other Dementias*, 24(5), pp. 377–383. doi: 10.1177/1533317509340025.

Raggi, A. *et al.* (2015) ‘The burden of distress and related coping processes in family caregivers of patients with Alzheimer’s disease living in the community’, *Journal of the Neurological Sciences*. Elsevier B.V., 358(1–2), pp. 77–81. doi: 10.1016/j.jns.2015.08.024.

Rawls, J. (1997) “The idea of public reason revisited”, *University of Chicago Law Review*, 64 (3): 765-807.

Reinhard, S., Levin, C and S. Samis, *Home Alone: Family Caregiving Providing Complex Chronic Care* (Washington, DC: AARP Public Policy Institute, 2012), <http://www.aarp.org/home-family/caregiving/info-10-2012/home-alone-family-caregivers-providing-complex-chronic-care.html>.(accessed 20/4/18).

Reissman CK (2008): *Narrative Methods for the human sciences*. Los Angeles. Sage Publications 2008.

Robinson, C. A. *et al.* (2014) ‘The Male Face of Caregiving: A Scoping Review of Men Caring for a Person With Dementia’, *American Journal of Men’s Health*, 8(5), pp. 409–426. doi: 10.1177/1557988313519671.

Robinson, N. (1999) ‘The use of focus group methodology - With selected examples from sexual health research’, *Journal of Advanced Nursing*, 29(4), pp. 905–913. doi: 10.1046/j.1365-2648.1999.00966.x.

- Rodríguez-Madrid, M. N. *et al.* (2019) 'Gender differences in social support received by informal caregivers: A personal network analysis approach', *International Journal of Environmental Research and Public Health*, 16(1), pp. 1–15. doi: 10.3390/ijerph16010091.
- Roelofs, T.X., Luijkx, K.G. and Embregts, P.J. (2017) Love, intimacy, and sexuality in residential dementia care: a spousal perspective. *Dementia* 18, 936–950.
- Rollero, C. (2016) 'The Experience of Men Caring for a Partner With Multiple Sclerosis', *Journal of Nursing Scholarship*, 48(5), pp. 482–489. doi: 10.1111/jnu.12231.
- Ruspini, E., Hearn, J., Pease, B. and Pringle, K. (eds.) (2011). Men and masculinities around the world. Transforming men's practices. New York: Palgrave Macmillan.
- Rykkje, L. and Tranvåg, O. (2019) 'Caring for One's Wife With Dementia—at Home: Older Husbands' Experiences With Managing Challenges of Everyday Life', *SAGE Open*, 9(1). doi: 10.1177/2158244019834453.
- Salin, S., Kaunonen, M., and Astedt-Kurki, P. (2009). Informal carers of older family members: How they manage and what support they receive from respite care. *Journal of Clinical Nursing*, 18, 492-501. doi:10.1111/j.1365-2702.2008.02550.x
- Sallee, M. W., & Harris, F III. (2011). Gender performance in qualitative studies of masculinities. *Qualitative Research*, 11, 409–429.
- Sandberg, J. and Eriksson, H. (2009a) 'From alert commander to passive spectator: older male carers' experience of receiving formal support', *International Journal of Older People Nursing*. doi: 10.1111/j.1748-3743.2008.00147.x.
- Sandberg, J. and Eriksson, H. (2009b) 'From alert commander to passive spectator: older male carers' experience of receiving formal support', *International Journal of Older People Nursing*, 4(1), pp. 33–40. doi: 10.1111/j.1748-3743.2008.00147.x.
- Sandelowski, M. (2000) 'Combining Qualitative and Quantitative Sampling, Data Collection, and Analysis Techniques in Mixed-Method Studies', *Research in Nursing & Health*, 23(3), pp. 246–255. doi: 10.1002/1098-240x(200006)23:3<246::aid-nur9>3.3.co;2-8.
- Sandelowski, M. and Leeman, J. (2012) 'Writing usable qualitative health research findings', *Qualitative Health Research*, 22(10), pp. 1404–1413. doi: 10.1177/1049732312450368.
- Sanders D, Labonte R, Baum F, Chopra M (2004) Making research matter: a civil society perspective on health research. World Health Organisation. 82: 757-763.
- Sanders, S. and Power, J. (2009) 'Roles, Responsibilities, and Relationships among Older Husbands Caring for Wives with Progressive Dementia and Other Chronic Conditions', *Health and Social Work*.34(1):41–51.

- Sarvimiki, A. (2015): Health Ageing, Narrative Method, and research ethics. *Scandinavian Journal of Public Health*, 43, 57-60.
- Savin-Baden, M., and Major, C.,H. (2013) *Qualitative research: The essential guide to theory and practice*. Routledge, London.
- Schulz, R. *et al.* (2017) 'Changing Structures and Processes to Support Family Caregivers of Seriously Ill Patients', *Journal of Palliative Medicine*, 21, p. jpm.2017.0437. doi: 10.1089/jpm.2017.0437.
- Schwalbe, M.,L.,and Wolkomer, M. (2001) Interviewing men. In: Gubrium JF, Holstein JA, editors. *Handbook of interview research: Context and method*. Thousand Oaks, CA: SAGE; pp. 203–220.
- Schwalbe, M. L., and Wolkomir, M. (2003). Interviewing men. In J. Holstein & J. Gubrium (Eds.), *Inside interviewing: New lenses, new concerns*. Thousand Oaks, CA: SAGE.
- Schwartz, A. J. and McInnis-Dittrich, K. (2015) 'Meeting the Needs of Male Caregivers by Increasing Access to Accountable Care Organizations', *Journal of Gerontological Social Work*, 58(7–8), pp. 655–670. doi: 10.1080/01634372.2015.1067852.
- Scourfield, P. (2005). Understanding Why Carers' Assessments Do Not Always Take Place. *Practice: Social Work in Action*, 17(1), 15-28.
- Seaton, C. L. *et al.* (2017) 'Men's Mental Health Promotion Interventions: A Scoping Review', *American Journal of Men's Health*, 11(6), pp. 1823–1837. doi: 10.1177/1557988317728353.
- Seddon, D., Robinson, C. (2015) Carer assessment: continuing tensions and dilemmas for social care practice. *Health & Social Care in the Community*. 23(1), 14:22 doi: 10.1111/hsc.12115.
- Seidler, Z. E. *et al.* (2016) 'The role of masculinity in men's help-seeking for depression: A systematic review', *Clinical Psychology Review*. Elsevier Ltd, 49, pp. 106–118. doi: 10.1016/j.cpr.2016.09.002.
- Seidler, Z. E., Rice, S. M., Ogradniczuk, J. S., Oliffe, J. L., and Dhillon, H. M. (2018). Engaging men in psychological treatment: A scoping review. *American Journal of Men's Health*, 12, 1882–1900. [http://dx .doi.org/10.1177/1557988318792157](http://dx.doi.org/10.1177/1557988318792157).
- Seidler, Z.E., Rice, S., River, J., *et al.* (2018) Men's mental health: a case for a masculinities model. *Journal of Men's Studies* 26: 92–104.
- Sharma, N., Chakrabarti, S. and Grover, S. (2016) 'Gender differences in caregiving among family - caregivers of people with mental illnesses', *World Journal of Psychiatry*, 6(1), p. 7. doi: 10.5498/wjp.v6.i1.7.

Sherbourne, C.D., and Stewart, A.L. (1991). The MOS-SSS social support survey. *Social Science & Medicine*, 32(6), 705-714.

Shu, C. C. *et al.* (2017) 'Health status, health behaviours and anxiety symptoms of older male caregivers: Findings from the Concord Health and Ageing in Men Project', *Australasian Journal on Ageing*, 36(2), pp. 151–157. doi: 10.1111/ajag.12376.

Singh, P., Hussain, R., Khan, A., Irwin, L., Foskey, R. (2014) Dementia care: intersecting informal family care and formal care systems. *Journal of Aging Research*. 2014:1–9

Singleton, N., Maung, N.A., Cowie, I., Sparks, J., Bumpstead, R., Meltzer, H., (2002) Mental Health of Carers Office for National Statistics. London <http://tinyurl.com/knxukhc>.

Silverman, D. (2004) *Qualitative Research: Theory, Method and Practice*. London: Sage Publications.

Silverman, D. (2010). *Doing qualitative research*, 3rd Edition. London: Sage.

Silverman, D (2014) *Interpreting Qualitative Data*. London. Sage Publications.

Sim, J. (1998) 'Collecting and analysing qualitative data: Issues raised by the focus group', *Journal of Advanced Nursing*, 28(2), pp. 345–352. doi: 10.1046/j.1365-2648.1998.00692.x.

Singh, P. *et al.* (2014) 'Dementia Care: Intersecting Informal Family Care and Formal Care Systems', *Journal of Aging Research*, 2014, pp. 1–9. doi: 10.1155/2014/486521.

Snyder, C. M., Fauth, E., Wanzek, J., Piercy, K. W., Norton, M. C., Corcoran, C., ...Tschanz, J. T. (2014). Dementia caregivers' coping strategies and their relationship to health and well-being: The Cache County Study. *Aging & Mental Health*, 19(5), 390–399.

Soulsby, L. K., and Bennett, K. M. (2015). How relationships help us to age well. *The Psychologist*. 28(2), 110-113.

Spector-Mersel, G. (2006). Never-aging stories: Western hegemonic masculinity scripts. *Journal of Gender Studies*, 15(1), 67–82.

Spendelov, J. S., Adam, L. A. and Fairhurst, B. R. (2017) 'Coping and Adjustment in Informal Male Carers: A Systematic Review of Qualitative Studies', *Psychology of Men and Masculinities* 18(2), pp. 134–143.

Stephan, A. *et al.* (2015) 'Successful collaboration in dementia care from the perspectives of healthcare professionals and informal carers in Germany: Results from a focus group study', *BMC Health Services Research*. ???, 15(1), pp. 1–13. doi: 10.1186/s12913-015-0875-3.

Stepler, R. (2016) "Smaller Share of Women Ages 65 and Older are Living Alone: More are living with spouse or children." Washington, D.C.: Pew Research Center.

Stoltz, P., Willman, A., Ude'n, G., (2006) The meaning of support as narrated by family carers who care for a senior person at home. *Qualitative Health Research* 16 (5).

Sullivan. L., Camic P.M., Brown, S.L., (2014): Masculinity, alexithymia, and fear of intimacy as predictors of UK men's attitudes towards seeking professional psychological help. *British Psychological Society*.

Sun, F., Roff, L. L., Klemmack, D., & Burgio, L. D. (2008). The influences of gender and religiousness on Alzheimer disease caregivers' use of informal support and formal services. *Journal of Aging and Health*, 20, 937-953. doi:10.1177/0898264308324652.

Swinkles, J, Broese van Groenou, MI, de Boer, A., van Tilburg, TG, (2018) Male and Female Partner-Caregivers' Burden: Does It Get Worse Over Time? *The Gerontologist*, 1-9 doi:10.1093/geront/gny132.

Swinkels, J. *et al.* (2019) 'Explaining the Gender Gap in the Caregiving Burden of Partner Caregivers', *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*, 74(2), pp. 309-317. doi: 10.1093/geronb/gbx036.

Tashakkori, A., and C. Teddlie. (1998). *Mixed methodology: Combining qualitative and quantitative approaches*. Applied Social Research Methods Series, vol. 46. Thousand Oaks, CA: Sage.

Tashakkori A., & Teddlie C., (Eds) (2003) *Handbook of mixed methods in social and behavioural research*. Thousand Oaks: Sage Publications.

Taylor, B.J., Campbell, K. & McGlade, A., (2015). *Understanding and Using Research in Social Work* K. Wharton, ed., Thousand Oaks CA: Sage Publications Inc.

Teddlie, C. and Tashakkori, A. (2003) 'Major issues and controversies in the use of mixed methods in the social and behavioural sciences in Tashakkori', A., Teddlie C. (Eds): *Handbook of Mixed Methods in Social and Behavioural Research*, Sage, Thousand Oaks, CA.

Teddlie, C. and Tashakkori, A. (2006) 'A general typology of research designs featuring mixed methods'. *Research in the Schools*, Vol. 13, No. 1, pp.12-28.

Teddlie, C. and Tashakkori, A. (2009) *Foundations of Mixed Methods Research: Integrating Quantitative and Qualitative Approaches in the Social and Behavioural Sciences*, Sage, Thousand Oaks, CA.

Thomas S., Dalton J., Harden M., Eastwood A., Parker G. (2017) Updated Meta-Review of evidence on support for carers. *Health Serv Deliv Res* 2017: 5 (12).

- Tretteteig, S., Vatne, S. and Rokstad, A. M. M. (2017) 'Meaning in family caregiving for people with dementia: A narrative study about relationships, values, and motivation, and how day care influences these factors', *Journal of Multidisciplinary Healthcare*, 10, pp. 445–455. doi: 10.2147/JMDH.S151507.
- Turner, M. *et al.* (2016) 'Caring for a dying spouse at the end of life: "It's one of the things you volunteer for when you get married": A qualitative study of the oldest carers' experiences', *Age and Ageing*, 45(3), pp. 421–426. doi: 10.1093/ageing/afw047.
- Ussher, J. M. *et al.* (2013) 'The gendered construction and experience of difficulties and rewards in cancer care', *Qualitative Health Research*, 23(7), pp. 900–915. doi: 10.1177/1049732313484197.
- Vitaliano, P. P. *et al.* (2011) 'Does caring for a spouse with dementia promote cognitive decline? A hypothesis and proposed mechanisms', *Journal of the American Geriatrics Society*, 59(5), pp. 900–908. doi: 10.1111/j.1532-5415.2011.03368.x
- Wagner, C. Bigatti S and Storniolo, A (2006) "Quality of Life of Husbands of Women with Breast Cancer," *Psycho-Oncology*, Vol. 15: 109–120.
- Weinland, J. A. (2009) 'African American Male Caregivers', *American journal of men's health*, pp. 16–24.
- Whitley, E. M., Jarrett, N. C., Young, A. M. W., Adeyemi, S. A., and Perez, L. M. (2007). Building effective programs to improve men's health. *American Journal of Men's Health*, 1, 294-306.
- Wiles, J. (2003): Daily Geographies of caregivers, mobility routine scale. *Social Science and Medicine* 57 1307 – 1325.
- Wilkinson, S. (2011) Focus Group Research. In D Silverman (ed). *Qualitative Research*. third edition. London. Sage pp 168-84.
- Williams, A. M., Wang, L. and Kitchen, P. (2016) 'Impacts of care-giving and sources of support: A comparison of end-of-life and non-end-of-life caregivers in Canada', *Health and Social Care in the Community*, 24(2), pp. 214–224. doi: 10.1111/hsc.12205.
- Williams, C.L., Heikes, E.J. (1993) The importance of researcher's gender in the in-depth interview: Evidence from two case studies of male nurses. *Gender & Society*.7:280–291
- Wilson, M. G., Lavis, J. N. and Guta, A. (2012) 'Community-based organizations in the health sector: A scoping review', *Health Research Policy and Systems*, 10, pp. 1–9. doi: 10.1186/1478-4505-10-36.

World Health Organisation (2002) The world health report 2002: reducing risks, promoting healthy life. Geneva, *World Health Organization, 2002*. Retrieved from https://www.who.int/nutrition/topics/2_background on 01/03/19.

World Health Organization. (2007). Engaging men and boys in changing gender-based inequity in health: Evidence from programme interventions. Geneva.

World Health Organisation (2012) World Health Statistics 2012 Indicator compendium.
http://www.who.int/gho/publications/world_health_statistics/WHS2012_IndicatorCompendium.pdf. on 18/06/19.

World Health Organization (2014). Health statistics and health information systems. from <http://www.who.int/healthinfo/survey/ageingdefnolder/en/>. (accessed 18/6/19).

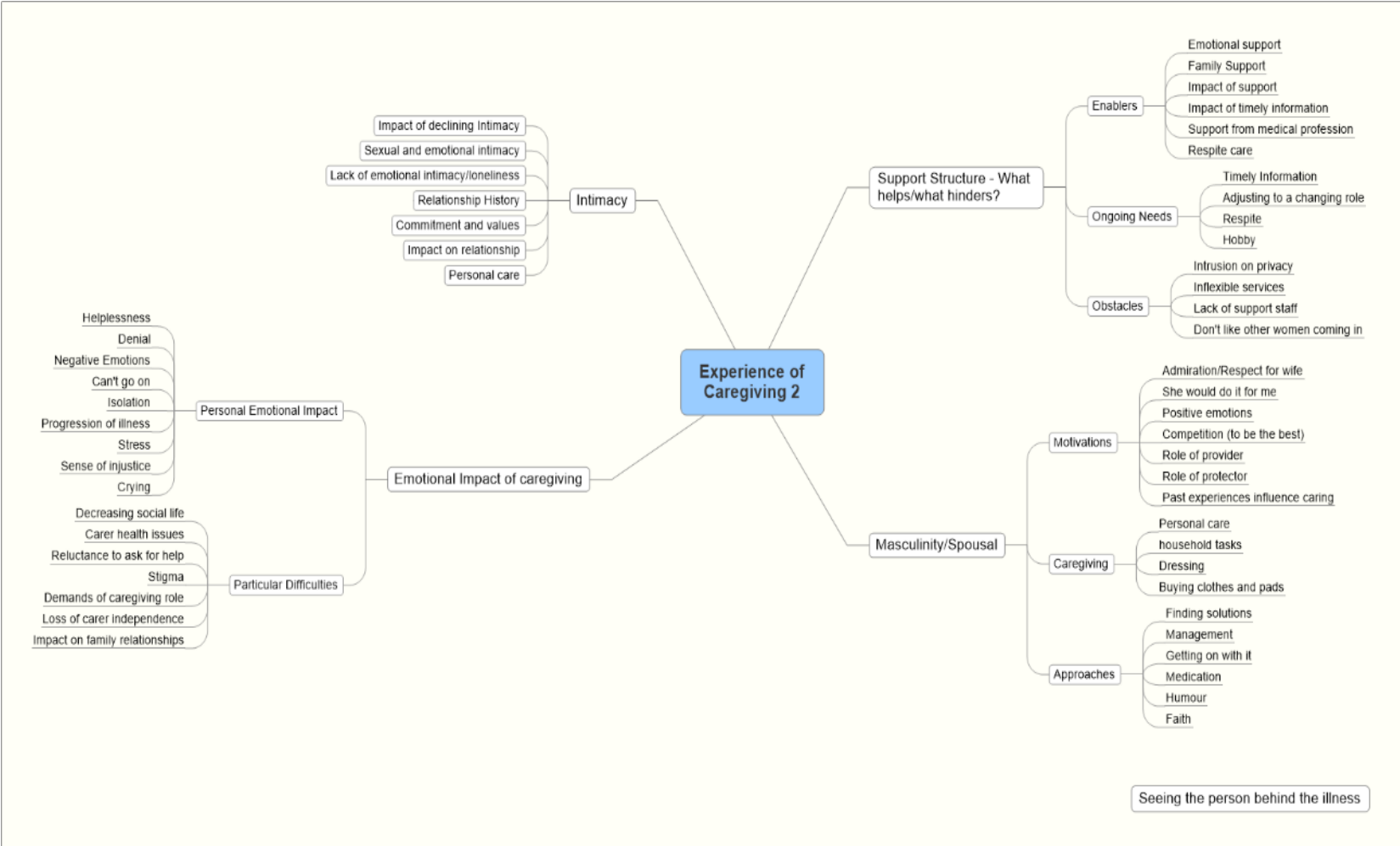
Wouters, R, De Fraine, B, Simons M (2019) What is at Stake in Deliberative Inquiry? A Review about a Deliberative Practice. *Systematic Practice in Action Research* 32:1-93 <https://doi.org/10.1007/s11213-018-9457>.

Youell, J., Callaghan, J. E. M. and Buchanan, K. (2016) “I don’t know if you want to know this”: carers’ understandings of intimacy in long-term relationships when one partner has dementia’, *Ageing and Society*, 36(5), pp. 946–967. doi: 10.1017/s0144686x15000045.

Yousaf, O., Papat, A. and Hunter, M. S. (2015) An investigation of masculinity attitudes, gender, and attitudes toward psychological help-seeking. *Psychology of Men and Masculinity*, 16 (2). 234 - 237. ISSN 1524-9220.

APPENDICES

Appendix 2 - Mind-map Codes



Appendix 3 - Distress Protocol

Distress Protocol

Study Title: ***'The development and piloting of a supportive intervention to meet the needs of older male carers looking after a spouse/partner with a long term condition: a feasibility study'***.

During the interview process the interview participant will be monitored by the researcher for signs of stress or emotional distress, such as agitation, crying, quietness, anger, or physical/emotional discomfort.

If this occurs, the researcher will:

- Offer support/assistance;
- Ask the participant if they need a break, or to terminate the interview;
- Ask the participant if they would like to move on to a different question/topic.

If necessary, a short break will be convened, and the interview will continue when the participant is composed and happy to continue. The researcher will continue to monitor the participant's composure closely.

Alternatively, if the participant does not want to continue, the interview can be terminated, and the researcher will offer support for the remainder of the time. Extra time can be provided if necessary and appropriate.

The researcher will offer information about external support agencies, and if necessary will seek permission for a follow up phone call in the day/s after the interview takes place. The participant will also be encouraged to contact a friend/relative or a support organisation (detailed below) for support.

If necessary, the Chief Investigator will be informed

Carer Support Organisations:

Good Day, Good Carer, Telephone: 028 3026 1022

Carers Northern Ireland: 028 9043 9843

Appendix 4 - Survey for Community-based Organisations



PROVISION OF SUPPORT FROM THE COMMUNITY/VOLUNTARY SECTOR IN NORTHERN IRELAND FOR OLDER MALE CARERS

STUDY

Scoping the range and extent of support for family (informal) carers, from the community/voluntary sector, with particular reference to older male carers.

Anne Fee

Faculty of Life & Health Sciences, Ulster University,
Room 12J03, Shore Road, Belfast, BT370QB

Aim of Survey

The aim of this survey is to gather information about the provision of support from community and voluntary organisations to older male carers who are looking after a spouse/partner with a long term chronic condition/illness.

Definitions:

Carer: A person who, without payment, provides regular and substantial help to a spouse /partner who may not be able to manage without this help because of frailty, illness or disability.

Long Term Chronic Condition/Illness: A condition that has developed over time, and that cannot, at present, be cured, but can be controlled by medication and other therapies (examples: Dementia, Parkinson's Disease, MS, Motor Neurone Disease, Cancer, COPD, Stroke, Depression, Brain Injury etc.)

Section 1: About Your Organisation

1. Organisation Contact Details	
Organisation Name:	
Key Contact:	
Address & Phone Number:	
Email & Website address:	

2. Please state organisation's main aim:

Section 2: About Your Services/Support

3. Does your organisation provide? (Please tick all that apply)	
Support for adults living with chronic long term conditions	
Support for carers	
Other (Please specify):	

4. If your organisation supports adults living with long term chronic conditions only, please describe if/ how you support their carers (<i>Please tick appropriate box</i>)	
We don't come in to contact with their carers (<i>please go directly to question 9</i>)	
We signpost carers to an appropriate support organisation if necessary (<i>please go directly to question 9</i>)	
We provide some support for carers (<i>please continue with questions</i>)	

5. Which types of information & support do you provide for carers? (<i>Please rank top 3-5 answers in order of use (i.e. number of carers who use it) with the most used service being '1', the next most used service being '2', etc. to a maximum of 5 if necessary.</i>)	
Written Information:	
Leaflets/Booklets	
Books	
Website	
Newsletter	
Articles in local papers/other newsletters	
Carer support information is included in the information that we provide to the person with the illness/condition.	
Other Types of Support:	
Access to a trained counsellor	
One to one informal support	
Telephone help line	
On-Line Forum	
Email based support	
Befriending Scheme	
Peer Support	
Social Outings	
Annual Events (Christmas Dinner etc.)	
Welfare/Benefits/Legal Advice	
Respite/Short Breaks	
Information about the progression of the illness/condition	
Carer Training (Moving & Handling etc.)	
Stress management, relaxation sessions etc.	
Art based activity	
Signposting to Health and Social Care Staff	
Complementary Therapy	
Other (Please specify):	

Section 3 – About Specific Support for Male Carers

6. Do you provide support which is specific to male carers?	
Yes (<i>Please continue with questions</i>):	
No (<i>Please elaborate</i>):	
Sometimes (<i>Please elaborate</i>):	

7. Approximately how many older (over 65) male carers would be in your membership (<i>Please tick appropriate box</i>)	
0	
0 - 10	
11 - 20	
21 - 30	
More than 30	
Don't Know	

8. Which types of information/support are most utilized by <u>male carers</u>? (<i>Please rank answers in order of use (1-5), with the most used service being '1', the next most used service being '2' etc.</i>), and include approximately how many male carers have used this service in the past month.		
	Service provided?	For how many?
Website Use		
Telephone advice/guidance		
Social events		
Peer Support/support groups		
Respite services/Short Breaks		
Befriending		
Counselling		
Written information/leaflets		
Carer Training (moving & handling, first aid etc.)		
Stress management/relaxation etc. sessions		
Physical activity (walking group, sports etc.)		
Art based activity		
On-Line Forum		
Benefits/Welfare /Legal Advice		
Signposting to health & social care staff		

Information about the progression of the illness/condition		
Don't know		
Other (please specify):		

9 When completing this survey, did your answers relate to (<i>Please tick appropriate box</i>):	
Support based in one area (i.e. town, village etc.)	
Support covering a council area	
Support covering one Trust area	
Support covering more than one Trust	
Northern Ireland wide	
Other (please specify):	

10. Are you aware of any particular difficulties experienced by men caring for their spouse/partner with a long term chronic condition. If so, what?

11. Are you aware of any particular barriers to male carers accessing help or support?

12. Would you like to know more about the unique needs of male carers by being kept updated about the progress of this research?

13. Would you like to add anything else?

Thank you for taking the time to complete the survey!

Email: fee-a1@email.ulster.ac.uk

Anne Fee (Researcher), Faculty of Health & Life Sciences,
Room 12J03, University of Ulster, Shore Road, Jordanstown

BT37 0QB

Appendix 5 - Survey Introduction Letter



7th July 2017

Dear XXXX,

Ulster University is currently surveying the community and voluntary sector in Northern Ireland in order to scope the provision of information and support for older male carers who are looking after a spouse/partner who has a chronic long-term illness/condition.

Research suggests that informal (family) male carers may not have the same support needs as their female counterparts and may not ask for help with their caring role until a crisis arises. Therefore, we are undertaking a study to explore the information and support needs of older male carers, and the current provision of support from the community and voluntary sector in Northern Ireland.

This unique study, which is funded by NI Public Health Agency (R & D Division), is the first of its kind in Northern Ireland and it is anticipated that the study will result in new information that can contribute to the development of carer support, which historically has been under-researched and underdeveloped in relation to male carers. We are contacting your organisation as you currently support adults who live with a chronic long-term condition and/or their carers.

I attach a survey aimed at gathering baseline information about services for carers, particularly male carers. I would be really grateful if you, or someone else in your organisation, could complete the survey, and return to me by email. All organisations who complete the survey will automatically receive a copy of the study findings which may be useful for ongoing development of your organisation. All survey responses will be treated confidentially, with only the researcher having access to them.

Data collected through the survey process will be collated and analysed in order provide a regional benchmark for carer support from the community and voluntary sector, and to identify gaps in service provision and key emerging trends. Only anonymised data will feature in any future reports.

If you need further clarification or have any questions about the survey or the study, please feel free to give me a ring on 07907579875. I would be grateful if you could return the survey to me by **24th July 2017**.

Many thanks for your assistance,

Yours sincerely,

Anne Fee

Anne Fee (Researcher)

Appendix 6 - MC Interviews: Promotional Flyer

92,000 men in Northern Ireland care for a family member.

Are you one of them?



Ulster University are undertaking a unique new study into men who look after their wife or partner who has a chronic long-term illness.

We are seeking participants (over the age of 65) for a one off interview about their experiences of looking after their wife/partner.

Interviews will be undertaken in local day centre or participants own home. Expenses can be provided to arrange alternative care if necessary. A £20 voucher for Tesco/Asda will be offered to all interview participants.

Please contact Anne Fee on 02890 368 386, or email fee-a1@email.ulster.ac.uk for further details.

Appendix 7 - Communication via Social Media

Recruitment on social media for interview participants

The screenshot shows a Facebook page for 'BCRC Community Navigator for Older People'. The page header includes the name, a search bar, and navigation links like 'Home', 'Find Friends', and 'Create'. The profile picture shows a group of people. The main content is a post from 5 October 2017, titled 'Research on Male Carers being carried out by the University of Ulster. Contact Anne Fee via the details below for more info. Alternative care and £20 voucher available to participants. A fantastic opportunity to have your voice heard if you are a Male who cares for someone!!'. The post features a graphic with the text 'Over 92,000 men in Northern Ireland care for a family member who has a disability, illness or frailty. Are you one of them?' and an image of a group of people, one in red. Below the graphic, it states 'Ulster University are undertaking a unique new study about men who look after their wife/partner who has a chronic long term illness. We are seeking male participants for a one off interview about their experiences of looking after their wife/partner.' It also provides contact information for Anne Fee and mentions that interviews will be undertaken in local day centres or participants' own homes, with expenses provided and a £20 supermarket voucher offered. The post has 5 likes, 1 comment, and 12 shares. The right sidebar shows the page's rating (5.0), community information (350 likes, 373 followers), about section (028 276 65068), page transparency, and related pages like 'Age Concern Causeway', 'Loughgiel Community...', and 'The Salvation Army La...'. The bottom of the page shows interaction buttons for 'Like', 'Comment', and 'Share'.

Appendix 8 – Press Release

Men urged to offer experience of caring

MALE family carers have been encouraged to offer their experience of caring towards research being conducted thanks to funding from the Public Health Agency.

The unique three-year research project is currently being conducted by Ulster University about the experiences of male family carers.

In Northern Ireland there are approximately 214,000 informal 'family' carers, and it is estimated that 42 per cent of these carers are male.

This number is set to rise due to the ageing population, living with more long term chronic conditions, and the trend to provide more care at home.

Even though female carers can experience

similar caregiver stress to males, research suggests that females have a greater capacity to access support, and have more supportive networks than their male counterparts.

Recent research has shown that males often adopt a different approach to caring than females, but little is known about how to address their unique support needs.

Clare-Anne Magee, Carers Northern Ireland said: "We know that male carers exist but there are huge gaps in our collective knowl-

edge as to where they are, what specific issues they face when caring and what particular interventions they need to support them in their caring role.

"All carers struggle with broadly the same issues (for example, access to short breaks/respice, financial difficulties as a result of caring, carer's mental health and wellbeing or balancing care and work) but historically, we know that men are less likely to seek support with some of these issues in comparison to their female counterparts.

"In order to identify and support male carers, we need to start the conversation, engage with them, and professionals working with them, to research their needs and develop

strategies and interventions to support them in their caring roles.

"The research team is keen to hear from any male carers who would be willing to be interviewed about their experience of caring, particularly men who are at home caring for their spouse/partner who has a long term disability/illness or frailty, for example Parkinson's Disease, Alzheimer's, Stroke etc.

"Interviews can be carried out at home or in a mutually agreeable location, and alternative care can be provided for their spouse/partner during the interview process if required."

For further information and to register interest contact Anne Fee at Feea1@ulster.ac.uk

Appendix 9 - MC Interviews: Participant Information Sheet



Participant Information Sheet

Dear Participant,

We would like to tell you about a study that is being undertaken by Ulster University, as part of a doctoral study, about the experiences of men who are looking after their wife/partner who has a serious long-term illness.

In Northern Ireland there are approximately 214,000 informal carers (family members looking after a relative who is unable to look after themselves due to illness, frailty or disability). Even though family carers were traditionally thought of as female, the number of men caring for someone at home is rising and the estimated number of male carers is now 43%. Even though caring for your wife/partner is rewarding, occasionally it can be tiring or stressful and there have been a number of initiatives developed by the Health Service that aim to help family carers deal with this stress. However, we know that these initiatives tend to be more appealing to female carers, and we believe that male carers experience their 'caring role' differently from females.

The aim of this study is therefore to gather information about how husbands/partners manage their 'caring role' and what, if any, additional help male carers may need in order to help them to continue for as long as necessary.

Why have you been approached?

You have been given information about this study as you are a male who is looking after his wife/partner who has a serious long-term illness and we believe that your experience and expertise could make a valuable contribution to this research initiative.

What is involved if you decide to participate?

The study involves gathering as much information as possible on men's experiences of looking after their wives/partners who have a long-term illness. In particular, the study seeks to uncover any difficulties involved with caring for your wife/partner, or any ways that additional initiatives can be developed that help with the more difficult aspects of providing care.

The researcher intends to gather this information through face to face interviews with participants which will last about an hour. Interviews will be undertaken either in your own home or in a local day centre. If you wish to be interviewed in your own home, arrangements can be made to provide alternative care for your wife/partner in another room whilst the interview is in progress. We will also give you a supermarket voucher (value of £20) in order to acknowledge your expertise and time contribution. The discussion will be audio recorded (with your permission), in order to ensure that all information is captured. Before the interview the researcher will gather some demographic information (i.e. name, age and health condition of yourself and your spouse/partner and information about care provided and support received).

What happens to the information?

All information provided as part of the study will be managed in accordance with the Data Protection Act. However, if during the course of the interview, we find out that you or someone else is at risk of harm we are obliged to act on this information and share it with a health or social care professional. Information from all the recorded discussions will be transcribed and will be carefully analysed in order to draw conclusions about what matters to male carers and guide the remainder of the study. Your name or personal details will **not** be used when the information is being transcribed or in any subsequent report, and after transcription the recordings will be destroyed.

Findings and conclusions from the interview process will be circulated to each person who takes part. In addition, participants will also be kept informed if the interview data is used at later stages of the study.

Who is funding this study?

The study is being funded by the Health Social Care, Research & Development Division, Public Health Agency. If during any part of the process you wish to raise a complaint, this can be done by referring to 'Research Study Volunteer Complaints Procedure', available through the Ulster University Research Office (028 90 366518.)

What should I do now?

Participation in this study is entirely voluntary and if you wish to take part, please contact me on 028 90 368386 in order to arrange a suitable date, time and place for your interview.

If you are still unsure if you want to take part in the study or have further questions about any aspect of the study then please contact me on 028 90 368386. If you do not wish to participate, that's fine, simply disregard this information.

Many thanks,

Anne Fee,
Doctoral Student

Professor Sonja McIlpatrick,
Principal Investigator

Appendix 10 - Interview Guide and Demographic Information

Study Title:

Development and piloting of a supportive intervention to meet the needs of older male carers looking after a spouse/partner with a long-term condition: a feasibility study.

Interview Procedure:

The researcher will have pre-arranged the time, date and location for the interview. When arriving at the venue, the researcher will introduce herself and ensure that the participant is comfortable and content to go through the interview process. The researcher will outline the time for the interview (one – two hours), and check that the participant has this amount of time to be interviewed.

The researcher will outline the background and purpose of the study and give general guidance around main elements of the interview (including the interview being tape recorded). The researcher will check if the participant is still happy to continue, and if so, will be invited to sign the consent form.

Upon consent being gained, the interview will commence. The researcher will start the digital recorder and begin with the general demographic questions. When the demographic questions have been completed (approx. 10 minutes), the researcher will check that the participant is still comfortable and if so, will continue with main interview questions.

At the end of the interview the participant will be asked if they have anything else to add and will be asked if they have any further questions. Information about next steps in the study will be given. The researcher will check that they are not uncomfortable or distressed, and the recording device will be switched off.

Demographic Information

Caregiver

Name of Caregiver:

Age:

Relationship to care recipient:

Outline of any significant health condition:

Spouse/partner

Name of spouse/partner:

Age:

Nature, and stage of Long-term Illness (s):

Approximate Date of Diagnosis:

Care Provided

Approximately how much care per week is provided (in hours)?

0 – 10

10 – 20

20 – 30

30 – 40

40 – 50

50+

What other forms of **regular** support do you receive to help with your spouse/partner?

Statutory:

Day Centre

Meals service /preparation

residential (respite)

Personal care/help with dressing

Medication Management

GP/Pharmacist/HSC practitioners (please specify)

Other:

Non- Statutory:

Help from friends/family/neighbours/church

Befriending Scheme

Driving service (volunteers)

Carer support group

Information days/courses

Telephone helpline

Other:

Do you receive any 'one off' short breaks, away from your caring role?

If so, please describe.

Interview Guide

Question	Prompts
Section One – Your needs and experiences of support	
1) Tell me about how it's been for you since your wife/partner became ill.	<ul style="list-style-type: none"> How do you view your role – husband/caregiver?
2) What is your experience of help provided by Social Services or other organisations such as charities/voluntary groups?	<ul style="list-style-type: none"> What was your experience of organisations (such as local Social Services or voluntary groups such as Alzheimer's society)? Based on your experience, how could navigation through the 'system' been made easier?
3) Do you get any help from other sources?	<ul style="list-style-type: none"> Were you offered help from friends, family, neighbours, church? If so, when? Why did you either accept or not accept help?
Section Two– your experiences and needs around practical issues	
4) Can you think of practical issues that have been challenging for you whilst looking after your wife/partner?	<ul style="list-style-type: none"> Cared for person: medication, incontinence, sleeplessness, behaviour, dietary concerns Other: shopping, cooking, cleaning etc. How do you feel about changes in your relationship – emotional and/or physical aspects?
5) What would you have needed to be put in place to cope with these issues?	

Section Three—Your experiences of and need for Information	
<p>6) In relation to your caring role, what have your experiences been of getting information (for example about the progression of the illness, medication, benefits or other financial advice etc.)</p> <p>7) What additional information might you have needed that may have been beneficial to you?</p>	<ul style="list-style-type: none"> • How easy or difficult has it been to get information? • Where is/was your main source of information?
Section Four – Development of further support	
<p>8) Based on your experience of looking after your wife, what else could be done by others to help men who are looking after their wives/partners at home?</p>	<ul style="list-style-type: none"> • What in particular has helped you cope with particular problems you've encountered? • If the health service decided to provide more help for family carers: how/ when would be the right time to offer help? What do you think might be a barrier, or what would encourage you to take up this help?
Section Five – Satisfaction of providing care	
<p>9) What would you say are the main satisfactions of providing care for your wife/partner?</p>	<ul style="list-style-type: none"> • Are there new things that you have learned, or become expert at?

Appendix 11 - MC Interviews: Participant Consent Form

Participant Consent Form

Title of Study:

'The development and piloting of a supportive intervention to meet the needs of older male carers looking after a spouse/partner with a long-term condition: a feasibility study'.

I confirm that I have been given, read and understood the information for this study. I have been able to contact the research team with any queries.

I understand that my participation is entirely voluntary and I am free to withdraw at any time without giving a reason and without my rights, or those of my family being affected in any way.

I understand that the researchers will hold all the information and data that has been collected securely and in confidence. All efforts have been made to ensure that I cannot be identified as a participant in this study. I give permission for the researchers to hold relevant personal data, on the understanding that it will be held securely and will not be made available to anyone other than the research team.

I agree to participate in the above study and to have my one-to-one interview tape recorded.

Your name:

Date:

Signature:

Home Address:

Telephone number:

Researcher name:

Date:

Signature:

Appendix 12 - Field Notes

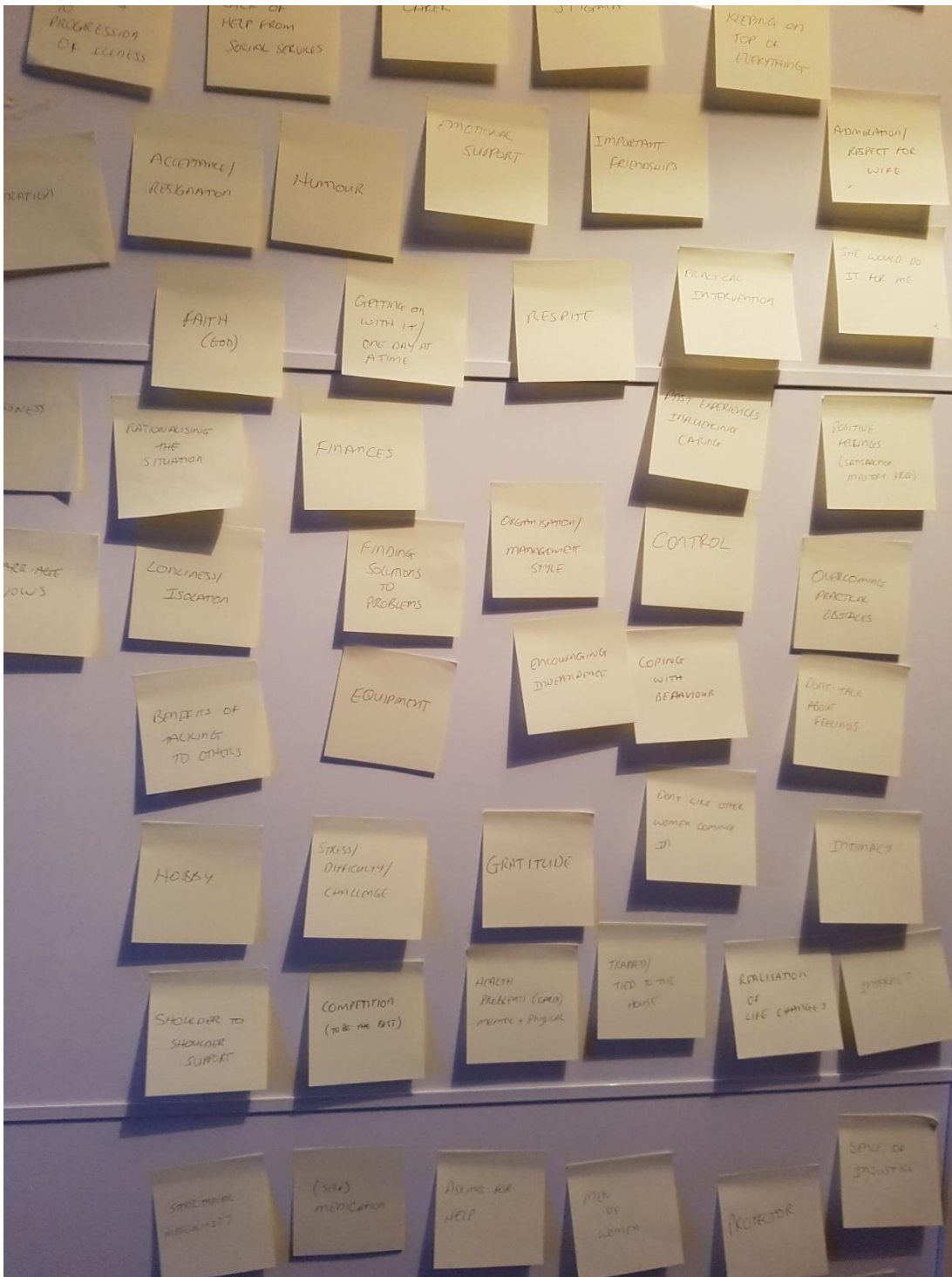
I met XXX on the morning of xx/xx/x while his wife was attending the local day centre. I went to his house which was in an area that I was familiar with. He had chosen to have the interview at home as he didn't have too much time, and thought it would save time if I came to him. XXX was aged 79, and had been married to XXX for 51 years. Around 6 years ago XXX had been diagnosed with Alzheimer's Disease, and she had deteriorated quite rapidly especially over the past two years. She now had limited mobility, no speech and limited memory. XXX had both worked in manual jobs, and had two grown up children who both lived abroad (so limited family support).

When I arrived at the house, I was welcomed in and shown into the living room, where I sat on the sofa, opposite to XXX who was in an armchair. I told him that I had grown up not far away, and that helped to establish some common ground between us. When arranging the interview on the phone XXX had been nervous about the confidentiality of the interviews, so I spent some time initially with him reassuring him about the process, how data would be stored, when it would be destroyed, and the use of pseudonyms in any reporting. XXX said that he was happy to continue, and the interview began. About 20 minutes in xxx was talking about his hobby of painting and went to fetch some art work he had done in another room, and brought them in to me to show me. This was quite a disruption to the interview and I struggled to re-establish the process, but I was also aware that talking about his art was important for maintaining rapport. In the living room, where the interview was taking place there were many photos of his wife and them both as a couple. During the interview XXX showed me photographs of his wife quite often, or an activity they used to do. I think the point he was making was how full their lives used to be, and how much he now missed, although he was keen to show me more recent photos and how well XXX looked, to demonstrate how well he was looking after her. I thought his keenness to show his ability to be a good caregiver was interesting. XXX was also keen to tell me how he had cared for his mother-in-law in the final months of her life (with Alzheimer's Disease), almost as though he wanted to let me know he was 'qualified' for this role. In general, I got the impression that XXX wanted to let me know that had risen to the challenges of his caregiving role. Although he did not say he was lonely, he

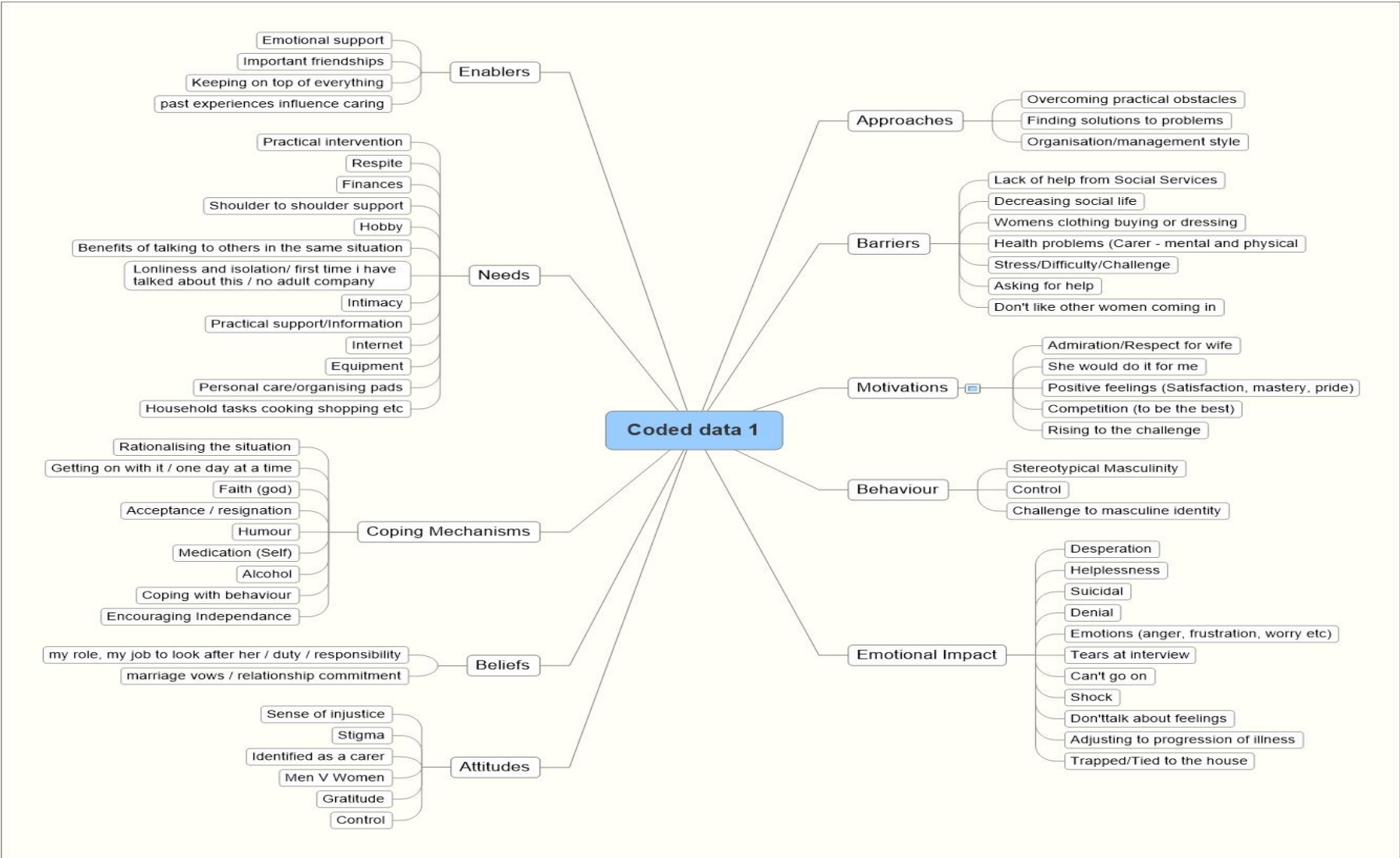
emphasised the enjoyment he got from an art class he used to attend as it gave him the opportunity to socialise, and now that it had finished he really missed it.

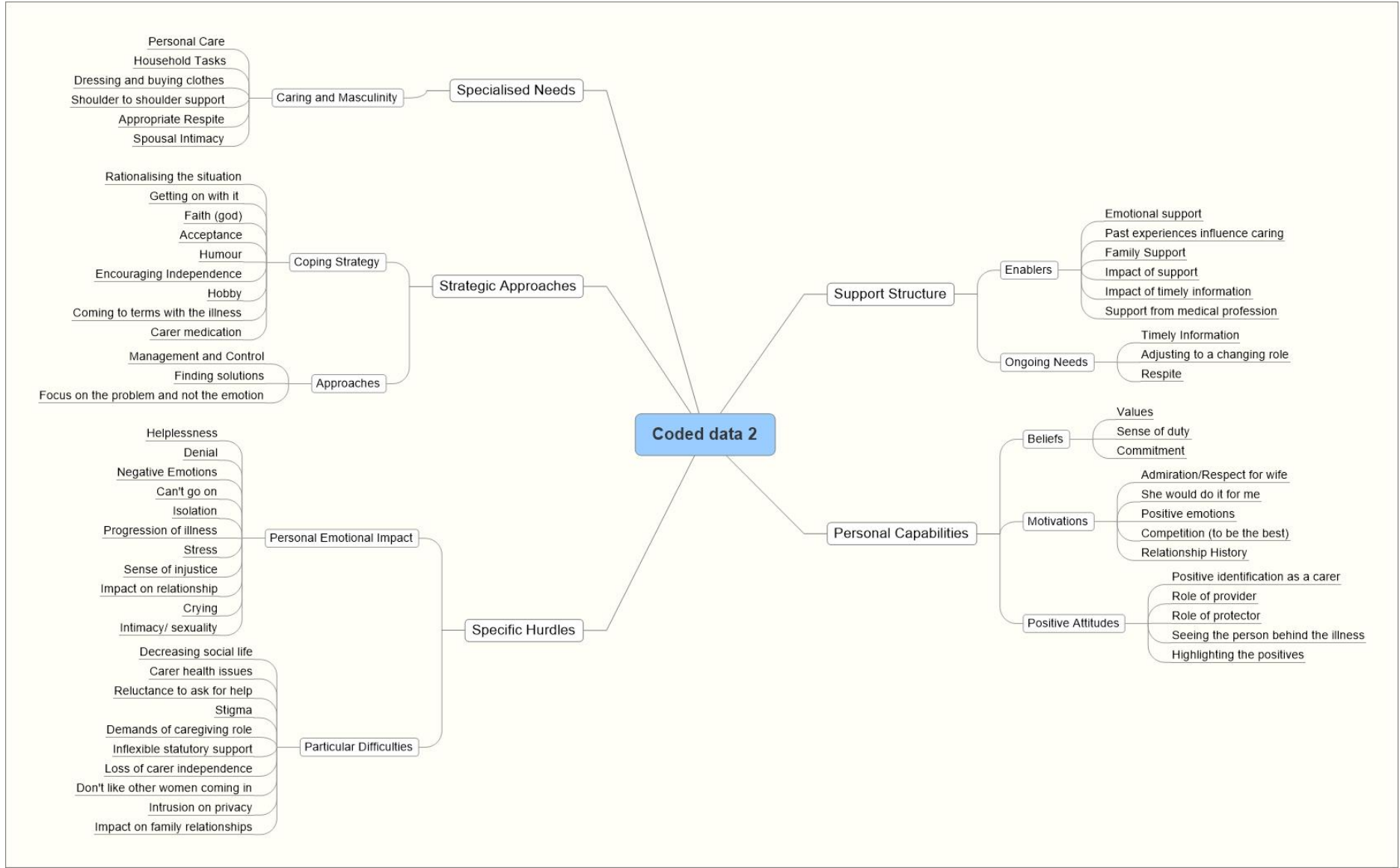
After an hour or so XXX let me know that he needed to get ready to collect his wife, and the interview concluded. After giving him information about what would happen to the interview data, I thanked him and left.

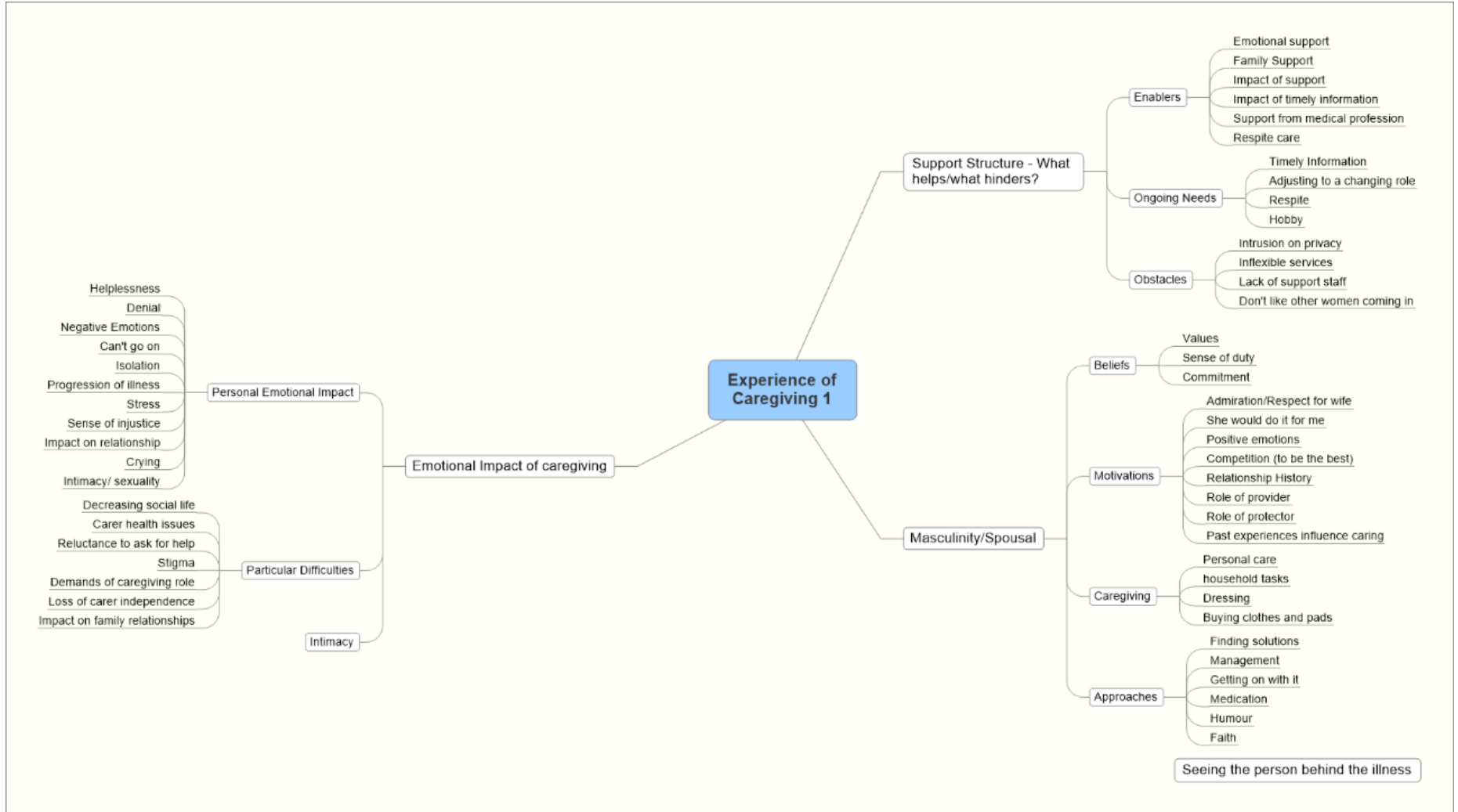
Appendix 13 - Initial Ideas Post-It Notes

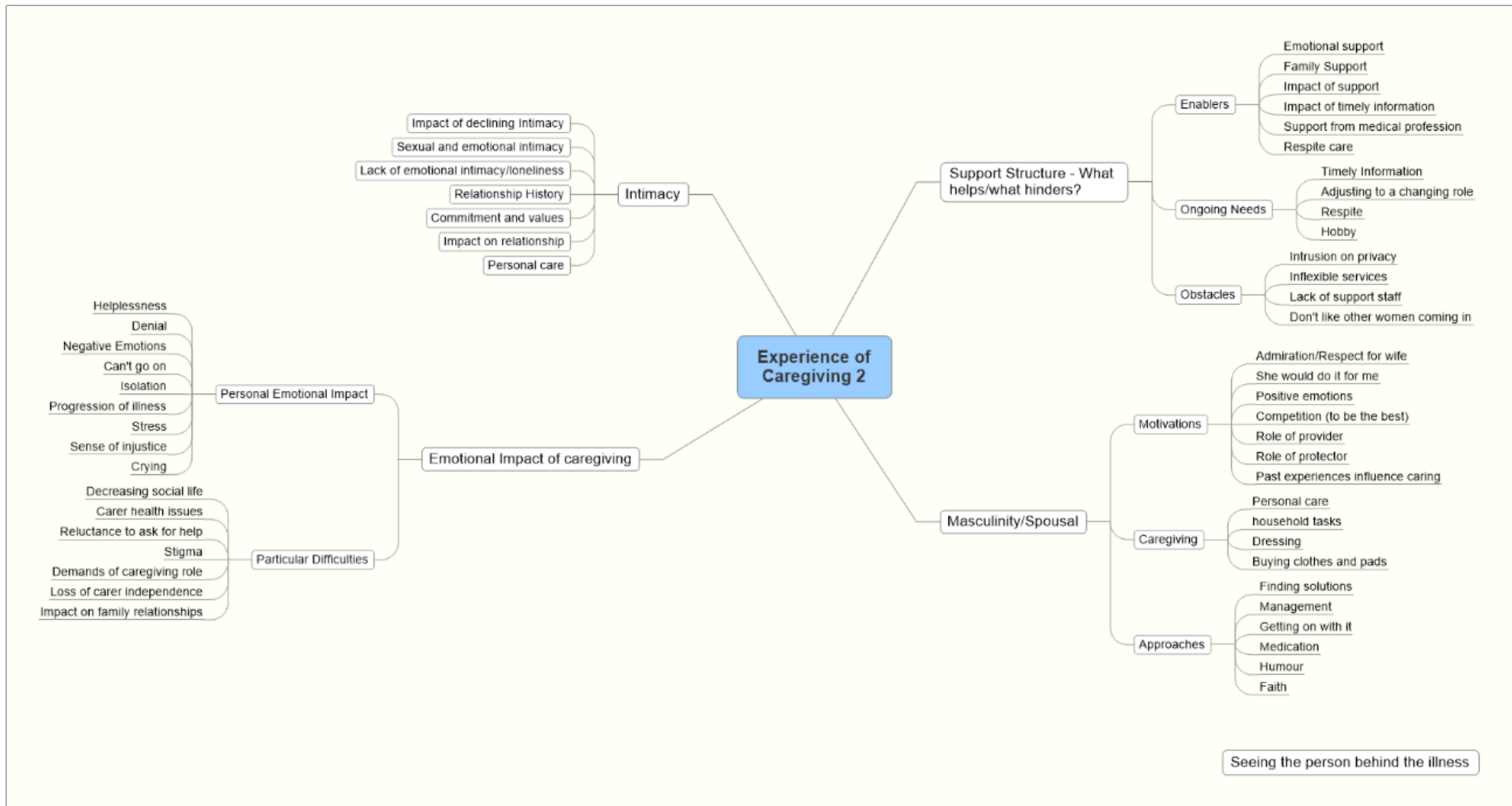


Appendix 14 - Mind Map









Seeing the person behind the illness

Appendix 15 - Extract from Reflexive Journal

Reflexive Journal

Removed in line with data protection guidelines

Appendix 16 - Promotional Flyer




 Ulster
University

Do you work for a service that provides support for informal family carers?

Focus group for agencies who provide support for family carers, to discuss their experience of supporting older male carers.

Date: 00/00/2018

Time: 12.30pm- 1.30pm

Venue: TBC

Ulster University are undertaking a study about older men who look after their chronically ill spouse/partner. We are interested in talking to agencies who provide support for older male carers, in order to discuss current support provision, and explore ideas for future support.

If you have any further queries, please contact:
 Anne Fee (PhD Researcher) or Fee-a1@ulster.ac.uk
 Professor Sonja McIlfatrick (Chief Investigator)
sj.mcilfatrick@ulster.ac.uk

Appendix 17- Focus Groups: Participant Information Sheet

Participant Information Sheet

We would like to tell you about a study that is being undertaken by Ulster University, for a PhD, about the experiences of men who are looking after their wife/partner who has a serious long-term illness. The title of the study is: *'An exploration of the impact of support services in identifying and meeting the needs of older male carers caring for a chronically ill spouse/partner'*.

In Northern Ireland there are approximately 214,000 informal carers (family members looking after a relative who is unable to look after themselves due to illness, frailty or disability). Even though family carers were traditionally thought of as female, the number of men caring for someone at home is rising and the estimated number of male carers is now 43%. Even though caring for your wife/partner is rewarding, occasionally it can be tiring or stressful and there have been a number of initiatives developed by the Health Service that aim to help family carers deal with this stress. However, we know that these initiatives tend to be more appealing to female carers, and we believe that male carers experience their caring role differently from females.

The aim of this study is therefore to gather information about how husbands/partners manage their 'caring role', particularly in relation to any current support or support needs. Also, what, if any, additional help male carers may need in order to help them to continue with their caring role for as long as necessary. The findings from the study will be used to influence future healthcare decisions.

Why have you been approached?

You have been given information about this study as you are healthcare/social care, or community sector personnel who provides support services for carers and we believe that your experience and expertise could make a valuable contribution to this research initiative.

What is involved if you decide to participate?

In a previous phase of this study the researcher undertook interviews with 24 older male carers. The data from these interviews has now been analysed.

This current phase of the study involves the researcher meeting with personnel from the health/social care sector in order to discuss findings from the interviews, and to explore the experiences of health/social care personnel in providing support for older male carers.

The researcher intends to gather this information through focus group interviews with participants which will last around one hour. Focus Groups will be facilitated on HSC Trust premises and lunch will be provided for all participants. The discussion will be audio recorded (with your permission), in order to ensure that all information is captured.

What happens to the information that you give?

All information provided as part of the study will be managed in accordance with the Data Protection Act. However, If during the course of the interview, we find out that you or someone else is at risk of harm we will have to act on this information and share it with a health or social care professional. Information from all the taped discussions will be transcribed and will be carefully analysed in order to draw conclusions about what matters to male carers and guide the remainder of the study. Your name or personal details will **not** be used when the information is being

transcribed or in any subsequent report, and after transcription the digital recordings will be destroyed.

Findings and conclusions from the interview process will be circulated to each person who takes part. In addition, participants will also be kept informed if the interview data is used at later stages of the study.

Who is funding this study?

The study is being funded by the Public Health Agency Research and Development Office. If during any part of the process you wish to raise a complaint, this can be done by referring 'Research Study Volunteer Complaints Procedure', available through the Ulster University Research Office (028 90 366518.)

What should you do now?

Participation in this study is entirely voluntary and if you wish to take part, please complete the Participant Consent Form overleaf and return in the stamped addressed envelope by.....

If you are still unsure if you want to take part in the study or have further questions about any aspect of the study then please contact me.

For further information, please contact:

<p>Professor Sonja McIlfratrick School of Nursing, Ulster University, Shore Road, Newtownabbey, BT370QB</p> <p>Ph: 028 90368386 Email: sj.mcilfratrick@ulster.ac.uk</p>	<p>Mrs Anne Fee, Researcher, School of Nursing, Ulster University, Shore Road, Newtownabbey BT370QB</p> <p>Ph: 028 90368386 Email: Fee-a1@ulster.ac.uk</p>
---	---

If you wish to raise a complaint about the study, or to speak to someone other than the research team please contact:

<p>Mr Nick Curry, Ph: 028 90366692, Email: n.curry@ulster.ac.uk Research & Innovation, Ulster University, Shore Road, Newtownabbey, BT370QB <i>Mr Nick Curry is an informed individual and not a member of the research team.</i></p>

Appendix 18 - Focus Groups: Participant Consent Form

Participant Consent Form

Title of Study:

An exploration of the impact of support services in identifying and meeting the needs of older male carers caring for a chronically ill spouse/partner.

I confirm that I have been given, read and understood the information for this study. I have been able to contact the research team with any queries.	Yes/No
I understand that my participation is entirely voluntary, and I am free to withdraw at any time without giving a reason.	Yes/No
I understand that the researchers will hold all the information and data that has been collected securely and in confidence. All efforts have been made to ensure that I cannot be identified as a participant in this study. I give permission for the researchers to hold relevant personal data, on the understanding that it will be held securely and will not be made available to anyone other than the research team.	Yes/No
I agree to participate in the above study and to have my contribution audio recorded.	Yes/No

Your name:

Date:

Signature:

Organisation:

Researcher name:

Date:

Signature:

Appendix 19 - Researcher Field Notes & Reflexive Journal – Focus Groups

xxxxxxxxxx, 10 January 2019

Removed in line with data protection guidelines

Appendix 20 - Focus Group Topic Guide

Phase 3

Support Service Focus Groups

Topic Guide

Focus Groups Aim: To explore the perspectives of health and social care professionals and voluntary sector personnel about support services for older male carers.

Introduction and general experiences	Prompts
1) Give me a general indication of the number of older male caregivers on your caseload. 2) What is the experience of providing information and general support for older male caregivers?	Why? How?
Section 1: Flexibility	
How are older male caregivers identified? How are their support needs assessed? What, in their view, are the constraints around offering support?	Continence Service Short Breaks/Respite Sitting Services District Nursing Domiciliary Care Services Carers' assessment
Section 2: Emotional support	
Male carers place importance on having someone to talk to... What are your views/experience of providing emotional support? How could your service provide opportunities for emotional support?	Key worker/Social worker Short Breaks/Respite Friends and Family Social Events/signposting Spousal Intimacy
Section 3: Support that aligns with masculine traits	
Traditional carer supports are more accessible for female carers.... What type of support do you think your service could provide for male caregivers? where do you think the barriers are? Anything else?	Are there difference between male and female carers? Awareness of the caregiving approach of male carers.

Appendix 21- Exemplars of data, codes and themes: Focus Groups

Narrative Exemplars	Initial Code	Nvivo node	Themes
<p><i>There are problems with sourcing overnight sits. I can only think of one caseload at the minute with overnight sits going in. They're very rare. Usually, we would be saying that if it gets to that point in time where someone needs 24-hour care, we tend to push towards residential care. It would be lovely to be able to give people more than we can.</i></p> <p><i>We have nobody who provides overnight sits. We will be creative. If somebody didn't want their loved one to go into respite for a short break, we will request that the money we would have spent on a short break be translated into those hours and get sits that way. It's virtually impossible to get someone to do an overnight sit, unless it's done through direct payments and personal assistance.</i></p> <p><i>And the support they need, for example, a service user that we would have had, and Catherine you would have had, he cared for his wife totally himself. She was bad at that stage. He said, I don't have children. He wants to learn how to skype, so he could skype with the family. Prescriptions, order prescriptions on-line and check his bills. All those things that took the pressure off, and order groceries, because trying to get groceries was impossible. So, we organised for somebody to come into the house then to teach him IT skills.</i></p>	<p>Services based on need</p> <p>Overcoming barriers</p> <p>Tailoring support to individual needs</p>	<p>Meeting actual need</p> <p>Person centred support</p> <p>Person entered support</p>	<p><i>Service Flexibility</i></p>

<p><i>What doesn't make sense is the cost of a week's respite and nursing care or in residential care. We can get that no problem. Everybody gets offered that. People don't necessarily want it, but those people that don't want it shouldn't really be getting anything else. I suppose we do sitting services as a weekly thing, that you get two hours a week, which is typically what it would be if we got it, but for people who don't want a week's respite maybe we should be able to look at a block of a sitting service, a one off, because you can understand from a funding point of view granting a weekly service, potentially long term, but a short term, it's something we've never actually thought of.</i></p> <p><i>The Trust doesn't really view it as a critical need or essential, whereas we view it as essential on our cases, but we know how difficult it is. So, we aren't even really offering it to people because we know we can't get it. It has to be proved that this person can't be left on their own... It has to be breaking point, and somebody is going to walk out the door... And even at that.... You might not even get it.</i></p> <p><i>Social services are generally very female dominated at this level, at Band 6 and 7. I wonder if there were more male domiciliary carers in agencies and more male social workers – there is a heavy dominant female perspective there – would it be easier for those male carers relax and take up services as they are available.</i></p>	<p>Incompatibility between support needs and services provided</p> <p>Disparity between critical and essential support need</p> <p>Composition of support staff impacting on gender-based support</p>	<p>Inflexibility</p> <p>Eligibility Criteria</p> <p>Caregiving as gendered</p>	
<p><i>Sometimes, with male carers, you really have to do some work with them to encourage them to accept or even try a package of care. It will reduce the burden on them. I don't know whether it stems back to the fact that we're working with older male carers and that generation had</i></p>	<p>Encouraging men to accept support</p>	<p>Building relationships</p>	

<p><i>traditional roles, so they wouldn't have been as freely engaged or involved with health professionals.</i></p> <p><i>Men don't talk about these things. They don't talk about feelings, or maybe they don't know how to bring the conversation up. Maybe women are able to bring it more easily.... Women are, they're quite open about how they feel and the difficulties of caring as well as the rewards of it.</i></p> <p><i>I can find sometimes going out that it takes longer to build up a relationship with a male carer than a female carer. A female carer will chat to you a lot sooner and will ring you up about things I find that a lot of male carers lost out by not ringing you back about things. So, it just takes that bit longer for a male carer for whatever reason it is than a female carer.</i></p> <p><i>He was quite a frail old man himself and his wife had problems with depression, which had progressed into dementia. By the time it was referred to us in the team and we went out, it was just a mess. She hadn't had her medication, she was quite dishevelled, but he felt he had to cope with that. He downplayed it and said he could manage, but he really wasn't managing. It took a couple of visits to get him to actually admit.... I think he did feel embarrassed that he couldn't cope.</i></p> <p><i>I suppose that's why men's sheds and stuff are so important, because men who are fifty plus, I suppose, are the least likely to engage in any sort of services. So, I suppose, as Adrian was saying, they do want to talk about tractors and stuff, but, I suppose, that's their way of coping.</i></p>	<p>Differences between male and female caregivers</p> <p>Differences between male and female caregivers</p> <p>Mens embarrassment at not coping with caring</p> <p>Male-centred support</p>	<p>Perceived masculine traits</p> <p>Building relationships</p> <p>Independent approach</p> <p>Perceived masculine traits</p>	<p>Engaging Men</p>
---	---	---	----------------------------

<p><i>So, that space, as such, to even to be able to express what they're feeling in their own way, and often that is through practical things like gardening, or building, and that's fine. So, maybe just a space to be able to do that.</i></p> <p><i>I find too that you will find male carers will have lesser social interests than female carers, and whenever the caring role takes over they actually give up far easier in their social interests, and it comes to the stage that they don't know how to go out any more, and they don't know to join groups so they won't go and re-join.</i></p> <p><i>Some of them don't identify themselves as carers. As a label, they don't maybe know what really what it entails, or what actually it entails.</i></p> <p><i>I: And again, is that for men and women, are you thinking?</i></p> <p><i>F: Well, I'm thinking mostly of the men.</i></p> <p><i>I: Why do you think that is?</i></p> <p><i>F: It's chalk and cheese. Just women have a natural, I don't know, natural role, having to provide care for people, or even just socially, or whatever.</i></p>	<p>Caregiving resulting in decreasing social networks</p> <p>Male caregivers' reluctance to identify as caregivers</p>	<p>Isolation</p> <p>Barriers to engagement</p>	
<p><i>I know a few people who, when I've asked them had they had a carer's assessment, they've said, no, but I'm not sure whether they understand what the actual person meant. I think that, in itself, is telling, because if a carer assessment was done, or did actually have an outcome, they would know that it was a carer's assessment, and they would recognise it was a carer's assessment. But if it was another form that they filled</i></p>	<p>Lack of understanding /awareness of carers assessment</p>	<p>Caregivers lack of awareness</p>	

<p><i>in, that nothing really happened afterwards, they don't even remember doing it.</i></p> <p><i>A carers' assessment is never a priority. I mean, it should be, but realistically, a carers' assessment wouldn't tend to be a priority.</i></p> <p><i>They don't know the carers' assessment exists, or they don't know that respite exists, or how you might access it if they were.</i></p> <p><i>I have mostly women who accepted it. One or two men. I even find that I would spend a shorter period of time with the men than the women. Maybe half an hour or 45 minutes. You can be going for an hour and a half with ladies, maybe longer. They're just more open about how they're feeling and how much stress it is on them. I think it's practical help for me. They're not really willing to talk about how it's affecting them.</i></p> <p><i>All the services we provide are all on the basis of the carer's assessment and I do explain to people that, in the future, if you do want a short break, it is on the basis of this assessment. If they can't see something tangible in the near future, they don't. Yet, the experiences with the females, when you do have that away from the home setting – I would usually do them away from the home setting and that's very therapeutic. A lot of women will report how helpful it is to have the opportunity to sit and be able to talk openly about how we feel and the</i></p>	<p>Staff lack of confidence in carers' assessment</p> <p>Lack of awareness</p> <p>Disparity in uptake of carers' assessments between males and females</p> <p>Disparity in uptake of carers' assessments between males and females</p> <p>Male caregivers' reluctance to accept carers' assessment</p>	<p>Barriers to carers' assessments</p> <p>Caregivers lack of awareness</p> <p>Barriers to assessment of need</p> <p>Barriers to assessment of need</p>	<p>Assessment of Need</p>
--	--	--	----------------------------------

<p><i>challenges. It is so challenging. It's something that our male carers, when you reflect on it, are really missing out on.</i></p> <p><i>the caseload I had before I was team leader would have had a number of male carers. I found that maybe they were a bit more reluctant to accept the carer's assessment than females would have been. They weren't as comfortable with sitting and talking about how being a carer impacted on them.</i></p> <p><i>'I know some males now, for them to get a break from the caring role, it would mean them maybe going out for a few hours, maybe going golfing, maybe going with friends for a longer period of time. Sometimes that's difficult to get and have somebody sitting in for respite or for day care, so generally they don't go because they're maybe away for a more prolonged time. Again, that's a generalisation but that could be a reason too, why people are having difficulties'</i></p>	<p>Lack of resources for meeting assessed needs.</p> <p>Assessment of need based on traditional gender-based roles</p>	<p>Barrier to assessment of need</p> <p>Barrier to meeting assessed need</p>	
--	--	--	--

Appendix 22 - Deliberative Workshop Social Media Information

 **Men's Health Ireland** @MensHealthIRL · May 4

You are invited to a workshop to discuss support for older male carers and to develop recommendations for future support ...



Ulster University

Support Services for Informal Family Carers

Deliberative Workshop to discuss support for older male carers and develop recommendations for future support

Date: 8th May 2019
Time: 9.30am – 1.00pm
Venue: Dunsilly Hotel, Antrim

Ulster University is undertaking a study about older men who look after their chronically ill spouse/partner. We are interested in meeting with agencies who provide support for carers, in order to discuss current support provision, and develop recommendations for future support of older male carers.

If you have any further queries, please contact:
 Anne Fee (PhD Researcher) | Fee-a1@ulster.ac.uk
 Prof Sonja McIlfratrick (Chief Investigator) | sj.mcilfratrick@ulster.ac.uk

🗨️ 4 🍷 3 ✉️

Appendix 23 - Deliberative Workshop Participant Information Sheet (PIS)

Participant Information Sheet

We would like to tell you about a study that is being undertaken by Ulster University, for a PhD, about the experiences of men who are looking after their wife/partner who has a serious long-term illness. The title of this study is: *'An exploration of the impact of support services in identifying and meeting the needs of older male carers caring for a chronically ill spouse/partner'*.

In Northern Ireland there are approximately 214,000 informal carers (family members looking after a relative who is unable to look after themselves due to illness, frailty or disability). Even though family carers were traditionally thought of as female, the number of men caring for someone at home is rising and the estimated number of male carers is now 43%. Even though caring for a spouse is rewarding, occasionally it can be tiring or stressful and there have been a number of initiatives developed by the Health Service that aim to help family carers deal with this stress. However, we know that these initiatives tend to be more appealing to female carers, and we believe that male carers experience their caring role differently from females.

The aim of this study is therefore to gather information about how husbands/partners manage their 'caring role', particularly in relation to any current support or support needs. Also, what, if any, additional help male carers may need in order to help them to continue with their caring role for as long as necessary. The findings from the study will be used to influence future healthcare decisions.

Why have you been approached?

You have been given information about this study as you are key healthcare/social care, or community sector personnel who provides or manages support services for carers and we believe that your experience and expertise could make a valuable contribution to this research initiative.

What is involved if you decide to participate?

In previous phases of this study the researcher undertook interviews with 24 older male carers and followed these with focus groups with health/social care personnel. The data from these interviews/focus groups has now been analysed. This current phase of the study involves the facilitation of a deliberative workshop for personnel and decision makers from the health/social care and voluntary/community sectors, in order to consider findings from the interviews, and to develop recommendations on the way forward for the support of older male carers. Discussions will be audio recorded (with your permission), in order to ensure that all information is captured.

What happens to the information that you give?

All information provided as part of the study will be managed in accordance with the Data Protection Act. However, if during the course of the interview, we find out that you or someone else is at risk of harm we will have to act on this information and share it with a

health or social care professional. Information from all the taped discussions will be transcribed and will be carefully analysed in order to draw conclusions about what matters to male carers and guide the remainder of the study. Your name or personal details will **not** be used when the information is being transcribed or in any subsequent report, and after transcription the digital recordings will be destroyed. Findings and conclusions from this process will be circulated to each person who takes part. In addition, participants will also be kept informed if data is used at later stages of the study.

Who is funding this study?

The study is being funded by the Public Health Agency Research and Development Office. If during any part of the process you wish to raise a complaint, this can be done by referring 'Research Study Volunteer Complaints Procedure', available through the Ulster University Research Office (028 90 366518.)

What should you do now?

If you wish to attend the deliberative workshop, please ring XXXXXXXXX, or email: XXXXXXXXX to book a place. Lunch will be provided after the workshop. If you have further questions about any aspect of the study then please contact me.

For further information, please contact:

<p>Professor Sonja McIlfratrick School of Nursing, Ulster University, Shore Road, Newtownabbey, BT370QB</p> <p>Ph: 028 90368386 Email: sj.mcilfratrick@ulster.ac.uk</p>	<p>Mrs Anne Fee, Researcher, School of Nursing, Ulster University, Shore Road, Newtownabbey BT370QB</p> <p>Ph: 028 90368386 Email: Fee-a1@ulster.ac.uk</p>
---	--

If you wish to raise a complaint about the study, or to speak to someone other than the research team please contact:

<p>Mr Nick Curry, Ph: 028 90366692, Email: n.curry@ulster.ac.uk Research & Innovation, Ulster University, Shore Road, Newtownabbey, BT370QB <i>Mr Nick Curry is an informed individual and not a member of the research team.</i></p>

Appendix 24 - Deliberative Workshop Participant Consent Form

Participant Consent Form

Deliberative Workshop - Supporting Older Male Carers

xxxxxxxxxx, Antrim 8th May 2019

Title of Study: *An exploration of the impact of support services in identifying and meeting the needs of older male carers caring for a chronically ill spouse/partner.*

I confirm that I have been given, read and understood the information for this study. I have been able to contact the research team with any queries.	Yes/No
I understand that my participation is entirely voluntary, and I am free to withdraw at any time without giving a reason.	Yes/No
I understand that the researchers will hold all the information and data that has been collected securely and in confidence. All efforts have been made to ensure that I cannot be identified as a participant in this study. I give permission for the researchers to hold relevant personal data, on the understanding that it will be held securely and will not be made available to anyone other than the research team.	Yes/No
I agree to participate in the above study and to have my contribution audio recorded.	Yes/No

Your name:

Date:

Signature:

Organisation:

Telephone number:

Researcher name:

Date:

Signature:

Appendix 25 – Examples of themes, codes and data: Deliberative Workshop

<i>Theme 1: Components of effective support</i>		
Codes	Male-centred Support	Flexibility of Services
Examples of raw data: session 1	<i>'that wee bit of encouragement too, because sometimes men just get a wee bit down in the heart.... because they do feel that they're failing in a whole lot of different ways, especially even as regards the housework, and the washing and things like that'</i>	<i>'We had a male carer who was assessed as needing 10 hours a week. So under SDS he went fishing. He went fishing because that's what he's always done'.</i>
Examples of raw data: session 2	<i>'They don't want to sit round and drink tea and talk. Group support needs to be very focussed.'</i>	<i>'The caring journey changes constantly, so services need to reflect that'.</i>
<i>Theme 2: Perceived obstacles in support provision</i>		
Codes	Men's approach to seeking help	Confusing Language
Examples of raw data: session 1	<i>(men have)... 'different help-seeking behaviour to women and that's why services aren't suitable'</i>	<i>'I'm the man of the house and I can cope... What if I fail the Carers' assessment'.</i>
Examples of raw data: session 2	<i>'They're afraid to say how much they are suffering because of the repercussions'.</i>	<i>(Statutory organisations seem to be) 'bogged down with formal processes that make the use of this language necessary..'</i>

Appendix 26 - Deliberative Workshop: participants in session one and two



Appendix 27 - Deliberative Workshop: Post-it notes and analysis



Appendix 28 - Deliberative Workshop: Priorities for support

