

MEETING THE NEEDS OF OLDER MALE CAREGIVERS

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.

PhD Study Report, Findings and Recommendations

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PhD Title: 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.

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CONTENTS

1	Executive Summary.....	4
1.1	Research Methodology.....	4
1.2	Key Research Findings.....	4
1.3	Conclusion.....	5
1.4	Recommendations.....	5
2	Introduction.....	7
3	Policy Background.....	8
4	Aims and Objectives.....	10
4.1	Aim.....	10
4.2	Objectives.....	10
4.3	Definitions.....	10
5	Study Design and Methods.....	11
6	Ethics.....	11
7	Findings.....	12
8	Conclusions.....	20
9	Publications.....	22
10	Recommendations.....	23
11	References.....	24
12	Appendix 1.....	26
	Table 1: Data Collection Methods.....	11
	Table 2: Study Recommendations.....	23

1 EXECUTIVE SUMMARY

The aim of this study was to explore 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. Findings demonstrate that some older male caregivers can experience negative caregiver outcomes, which may not be alleviated by existing support services.

Currently, United Kingdom policy highlights the need to provide better support for caregivers through a range of support measures including respite, short breaks and self-directed support. Caregivers are entitled to a formal assessment of their support needs through a 'carers' assessment' undertaken by a health and social care practitioner. Traditionally, caregiving has been associated with females, however, an increasing number of males are assuming a caregiving role, with an estimated 59% of caregivers in the over 85 age group who are male. It has been reported that the support needs of male caregivers are neglected, and the impact of caregiver support for male caregivers is under-researched.¹

1.1 RESEARCH METHODOLOGY

This study involved four phases of research over a course of three years, as follows:

Phase 1: A survey designed to scope the extent of support for older male caregivers throughout the community/voluntary sector in Northern Ireland (N=39).

Phase 2: Semi-structured interviews with older male caregivers to explore their caregiving experience (N=24).

Phase 3: Nine focus groups with personnel from health and social care trusts and community/voluntary agencies to explore perceptions of the support services for older male caregivers (N=84).

Phase 4: A deliberative workshop with key stakeholders to synthesise research findings and make recommendations for the way forward (N=36).

This mixed methods study used SPSS (v24) to analyse quantitative data from phase 1, and thematic analysis² for qualitative data in phases 2, 3 and 4. There were also three papers published in peer-reviewed academic journals from the study.

1.2 KEY RESEARCH FINDINGS

- 1) *The approach of older male caregivers who care for a chronically ill spouse/partner can be influenced by views on traditional masculinity ideals such as strength and self-reliance. Study findings highlighted several differences in caregiving approach between male and female caregivers. A key theme identified in the data was the tendency for many older male caregivers to 'masculinise' caregiving.*

¹ Sharma et al. 2016; Dickinson et al. 2017

² Braun and Clarke 2006

- 2) *Although many older male caregivers derive satisfaction and meaning from their role, caregiving can also involve social isolation, loneliness and challenges to spousal intimacy. Study findings revealed a range of caregiving experiences, however loneliness and isolation amongst older male caregivers was commonly reported. Several study participants referred to changes to spousal intimacy (sexual or emotional) which posed challenges for them.*
- 3) *Support providers should be mindful of the gendered nature of caregiving and consider this when engaging and providing support to older male caregivers. Many male caregiver interview participants favoured an independent approach to their caregiving role. Most support providers recognised this, and also perceived difficulties in the provision of support for male caregivers, including engaging men and formal assessment of support needs.*

1.3 CONCLUSION

This study provides a novel understanding of the factors that underpin support for older male caregivers. The findings demonstrate that some older male caregivers can experience negative caregiver outcomes which may not be alleviated by existing support services. In engaging and providing support for older male caregivers, support providers should recognise the potential impact of social conditioning and gender constructions on older men's identification with traditional masculine ideals, and how this impacts on their caregiving role. Study findings highlighted a need to: improve the carers' assessment process through the recognition of gendered aspects of caregiving; engage men early in their caregiving journey; build long-term relationships with male caregivers in order to provide on-going support; enable more social opportunities through the provision of male-centred or activity-based social support (potentially through partnerships between statutory and community/voluntary sector); and to develop specialised support for men who are challenged by declining sexual intimacy.

Policy/decision makers, educators and support providers across the statutory and community/voluntary sector have a vital role to play in ensuring that all informal caregivers are effectively supported. It is especially important for support providers to be proactive in identifying and providing caregiver support to sub-groups of caregivers such as older males who may be reluctant to accept help with their caregiving role.

1.4 RECOMMENDATIONS

- **Policy:** Findings from this research suggest that male caregivers are less inclined to undertake a carers' assessment than their female counterparts. A review of the carers' assessment and follow-up process is therefore needed to ensure that the support needs of older male caregivers are formerly assessed.
- **Identification and engagement of older male caregivers:** Given the low engagement of older male caregivers identified in this research, it is suggested that under-pinning principles for supporting men as used in other men's support initiatives (such as Men's Shed or Man Alive Man Van) should inform the development of support for older male caregivers.

- **Partnerships:** Given many older male caregivers' preference for community-based support, further partnership between community-based and statutory healthcare agencies is recommended in order to improve options for caregiver support.
- **Gender:** Caregiving should be recognised as gendered. Support providers should be alert to potential differences in approach to caregiving and coping strategies between males and females, based on social conditioning and gender constructions.
- **Identification:** 'Early conversations' between male caregivers and support providers about support are recommended in order to raise awareness of the caregiver role and future support options.
- **Stereotypical assumptions:** Support providers should be alert to the potential for stereotypical assumptions underlying their engagement of male caregivers.
- **Collaboration with male caregivers:** Innovative support based on collaboration between support providers and male caregivers should be encouraged. This may enhance support for this population group.

2 INTRODUCTION

Global trends predict that the world's population aged over 60 years will have trebled from 605 million to 2 billion by 2050.³ These changing demographics will inevitably lead to increased pressure on social care services and budgets, and a greater reliance on informal/family caregivers.

Traditionally, caregiving has been associated with females, however, evidence suggests that more males are assuming a caregiving role than before.⁴ Male caregivers are especially prominent in older age groups, with an estimated 59% of caregivers in the over 85 age group who are male.⁵ Different approaches to caregiving between men and women have been recognised in previous literature⁶ and this has resulted in an awareness and increased focus on potentially different support needs which may be influenced by gender. Male caregivers are reported to derive satisfaction, meaning and reward from their caregiving role.⁷ However, other evidence has indicated that male caregivers have a poor awareness of, and a reluctance to use formal support,⁸ under-utilise training,⁹ and that they experience negative consequences in the financial, physical and mental health areas of their lives.¹⁰

Given that older men are more likely than women to nominate their partner as their main source of emotional support,¹¹ older male caregivers are potentially vulnerable when this emotional support decreases due to chronic illness. This study is therefore important because it shines a light on an emotional component of spousal relationships, particularly for men, which is often overlooked within literature relating to male caregivers.

Although men are becoming more visible as caregivers,¹² their support needs continue to be neglected, and the impact of caregiver support for male caregivers is under-researched.¹³ 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.

In the UK, 59% of caregivers in the over 85 age group are male.

Source: UK Census 2011

³ World Health Organisation 2012

⁴ Milligan and Morbey 2016; Comas-d'Argemir and Soronellas 2019

⁵ UK Census 2011

⁶ Swinkles et al. 2019

⁷ Hellström et al. 2017; Comas-d'Argemir and Soronellas 2019

⁸ Lin et al. 2012

⁹ Lopez-Anuarbe and Kohli 2019

¹⁰ Milligan and Morbey 2013;2016

¹¹ Liao et al. 2018

¹² Schwartz and McInnis-Dietrich 2015

¹³ Sharma et al. 2016; Dickinson et al. 2017

3 POLICY BACKGROUND

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 United Kingdom (UK).¹⁴ UK government policy has increasingly emphasised the rights of caregivers to have access to information and support, and to have a break from their caring role, enshrined in the 'Recognised, Valued and Supported' national strategy (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 in 'People First: Community Care for Northern Ireland' which recommended practical support for informal caregivers (Department for Health and Social Services, 1990). This was followed by other policy and legislative developments including: 'Valuing carers: proposals for a strategy for carers in Northern Ireland' (Department of Health Social Services & Public Safety, 2002b); 'Carers and Direct Payments (NI) Act 2002'; and the 'Caring for Carers: Recognising, valuing and supporting the caring role, 2006'. These developments resulted in an obligation on Health and Social Care (HSC) Trusts in Northern Ireland to work to identify caregivers, and to ensure that all informal caregivers were offered a 'carers' assessment'.

In 2011, 'Transforming Your Care' (TYC) highlighted the need to change the provision and delivery of health and social care in Northern Ireland, through a greater emphasis on the individual at the centre of care, and care in the community. Specifically, TYC called for a policy review of carers' assessments; recognition of caregivers' roles as partners in providing care; and improved practical help for caregivers (including respite and the provision of short breaks). Although the implementation of recommendations contained in TYC were laid out in locally based population plans developed by each HSC Trust, subsequent research has questioned the implementation and effectiveness of some specific aspects of this policy¹⁵ in relation to caregivers. TYC did however, lay the foundations for more recent policy developments.

The rights of caregivers in Northern Ireland should be put on a legal footing in line with the rest of the UK, and a strategy to bring them into the heart of transformation of adult care and support should be adopted (The Expert Advisory Panel).

Source: Power to People Report: Department of Health NI, 2017

Current Policy Context

'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 and have personalised budgets or breaks from caring.

¹⁴ Valuing Carers 2015 – the rising value of carers' support [2015] University of Sheffield, University of Leeds and CIRCLE

¹⁵ Supporting Older Carers'. Commissioner for Older People Northern Ireland. COPNI 2014

In Northern Ireland a completed carers' assessment does not carry the same legal weight as in the rest of the UK, which automatically places caregivers in Northern Ireland at a disadvantage in terms of having their support needs assessed and met. In 'Power to People – Proposals to reboot adult care and support in N.I.'¹⁶, the Expert Advisory Panel proposed that the rights of caregivers in Northern Ireland are put on a legal footing in line with the rest of the UK, adopting a strategy to bring them into the heart of transformation of adult care and support. This would be especially important for older male caregivers given the reported adverse caregiving outcomes for this population group.¹⁷



¹⁶ Department of Health NI (2017)

¹⁷ Milligan and Morbey (2013)

4 AIMS AND OBJECTIVES

4.1 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”.

4.2 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.

4.3 DEFINITIONS

- Male caregivers referred to in this report are in the age category of 65 years or over. They are the primary caregiver for a spouse or partner who has a diagnosed chronic long term health condition. The care they give is unpaid.¹⁸
- The term ‘support providers’ will be used 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 Carers NI), who provide support (such as assessment, information, respite, or practical help) for informal caregivers.

¹⁸ NHS, England 2018

5 STUDY DESIGN AND METHODS

In this mixed methods study quantitative and qualitative data were collected over four distinct phases, as outlined in Table 1: Data Collection Methods.

Table 1: Data Collection Methods

Phase	Data Collection	Number of Participants
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. Quantitative data were analysed using SPSS (V24) to generate descriptive statistics.	N=39
Phase 2	Caregiver Support Needs: Study objective 3 was to explore the support needs of older male caregivers caring for a spouse/partner with a chronic long-term condition. Therefore, during this phase data were gathered by conducting one-to-one interviews with older male caregivers. Data were analysed using thematic analysis.	N=24
Phase 3	Service Provider Focus Groups: Phase 3 explored perspectives of health and social care professionals and community/voluntary sector personnel about support services for older male caregivers, through focus group interviews. Nine focus groups were conducted, and data were analysed using thematic analysis. ¹⁹	N=84
Phase 4	Deliberative Workshop: Consistent with study objective 5, phase 4 consisted of a deliberative workshop for key stakeholders from across the statutory and community/voluntary sectors (Appendix 1), to facilitate reflection and discussion of the study's findings. The workshop was guided by the 'Ladder of Inference Model' ²⁰ , and the resulting data were analysed using thematic analysis.	N=36

6 ETHICS

Ethical and governance approval for all study phases was granted from Ulster University School of Nursing Research Ethics Committee, participating HSC Trusts, and OREC (NI), NHS, Health Research Authority (17/WM/0119).

¹⁹ Braun and Clarke (2006)

²⁰ Argyris and Schon (1983), the 'Ladder of Inference'

7 FINDINGS

1. Identification with traditional masculinity has previously been described in caregiving literature as men's conformity to masculine ideals such as strength, stoicism and self-reliance. Findings in this study suggest that these traditional ideals subtly underscore many males' approach to their caregiving role. Often when males become caregivers this involves taking on household tasks that they previously may not have undertaken. Even though some men in the study explained that they had always helped out in the home, for others these were new tasks. Several men described how they approached household tasks by drawing on existing skills or experience (sometimes learned in previous employment). Participants described how they 'de-cluttered' by removing ornaments and small furniture items to make cleaning more manageable; only bought clothes that didn't need ironed; or undertook housing adaptations to prolong their partner's independence. Others took a managerial approach, whereby they independently managed all aspects of the caregiving role themselves (even when adult children offered help). This 'task-focused' approach appeared to enable men to 'masculinise' their caregiving role – in other words, finding and providing solutions for caregiving tasks affirmed their role as provider and protector, to their partner and to wider society.

A desire to be seen as strong and independent were demonstrated in other aspects of how men approached their caregiving role. For example, several male caregiver interview participants described how they did not ask for help, preferring to rely on their own expertise of their partner's illness. One described how he would forgo respite in favour of being always available in case his partner had a panic attack:

'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'. (Male Caregiver Interview Participant 8)

Furthermore, support providers observed that some older male caregivers were reluctant to verbalise the more stressful aspects of their role, for fear of appearing weak:

'You can tell he was presenting with the nerves in his voice. You could see the stress and see the tears well up, but he wouldn't speak about the emotions. It has got to the stage now – that was about two or three weeks ago – where he's not refusing help, but he's not accepting the help'. (Focus Group Participant, Statutory Agency 5)

KEY FINDING ONE

The approach of older male caregivers who care for a chronically ill spouse/partner can be influenced by views on traditional masculinity ideals such as strength, stoicism and self-reliance.

These quotes suggest that although male caregiver interview participants generally viewed an independent approach to caregiving as positive, support providers observed that this could limit men's wellbeing. For example, some support providers perceived reluctance from male caregivers to engage with support services, and suggested that this could result in a crisis or a breakdown in caregiving arrangements.

'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.'

(Focus Group Participant, Statutory Agency 1).

'What I have seen in the last year is that sometimes people walk in without an appointment, and all of them have been male. It has always been crisis-driven. They'll stick with it and stick with it and not pick up the phone.'

(Focus Group Participant, Statutory Agency 3).

Findings also suggested that some caregiving tasks could be perceived as potentially threatening men's masculine identity. An example of this was in the provision of personal care, which some viewed as a 'non-traditional' activity for men. Although several participants explained that this was a chance to show their love for their wives and preserve their dignity, others were embarrassed at being associated with an activity that was traditionally seen by society as feminine. As explained by one participant:

'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. I'm at the stage, I just take it as it comes. Every couple of days, a new pad. I have to go and buy 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.'

(Male Caregiver Interview Participant 21)

2. During interviews, male caregivers spoke about the emotional aspects of their caregiving role. Although most expressed commitment and love for their partner, some also experienced a profound sense of loss, isolation and loneliness which was often compounded by lack of communication with their partner. Many male caregivers experienced isolation through becoming increasingly housebound. Some explained that this was due to their partner's progressing illness (particularly mobility issues); friends 'dropping away'; or fewer opportunities to socialise or maintain sporting or other social activities. Interview 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 his experience:

KEY FINDING TWO

Although many older male caregivers derive satisfaction and meaning from their role, caregiving can also involve social isolation, loneliness and challenges to spousal intimacy.

'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'.
(Male Caregiver Interview Participant 16)

Others commented that although they had a desire to talk to friends about their caregiving role, they were aware that this may have implications about how they were viewed, due to societal pressure on men to be strong and in control. One described his friend's reaction when he confided that he was taking antidepressants to help him cope with his caregiver role:

'This fella that knows me pretty well. A lot of months ago he says to me, "XXXX, how are you keeping yourself?" and I says, "XXXX, I'm dead on" but I wasn't telling him really the honest truth, "see only for them antidepressants, I couldn't cope". He looked at me and he says, "XXXX, a big strong-looking guy like you needing antidepressants?". I didn't make any comment because you don't know unless you're living with it'. (Male Caregiver Interview Participant 16)

Findings also highlighted a desire for more peer support and opportunities that would enable participants to maintain their social or sporting connections. Some data also indicated a preference for male-centred or activity-based social support as opposed to talking therapies or support groups.

'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!' (Survey Respondent, Community-based Agency 27)

Several male caregiver interview participants explained how sexual or emotional intimacy had changed within their relationship. They felt committed to their partner and expressed a desire to abide by their marriage vows. Although these participants generally accepted that declining sexual or emotional intimacy may be part of chronic illness progression, they were also challenged as they had needs around spousal intimacy (physical or emotional) which were no longer being met.

'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.' (Male Caregiver Interview Participant 5)

'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.' (Male Caregiver Interview Participant 21)

It was clear from these participants that there was little specialised support from support providers to enable them to navigate these particular challenges. Study data also indicated a perception amongst some support providers that the topic of declining sexual or spousal intimacy was either beyond their remit, or that they lacked training or adequate knowledge in this area.

'Is there training available for staff to talk to male carers about intimacy issues? Sometimes it's the elephant in the room. Because this is really important'. (Deliberative Workshop Participant, Statutory Agency 2)

3. Although it was clear that support providers were skilled and resourceful in their support of caregivers, there were also notable challenges. For statutory support providers, these included difficulty in accessing practical support services and funding. Some explained that eligibility criteria for support meant that 'It has to be breaking point, and somebody is going to walk out the door' in order to be eligible for support such as a 'sitting service'. Potentially this meant that some support needs could not be met and resulted in frustration for many support providers. As one focus group participant explained:

KEY FINDING THREE

Support providers should be mindful of the gendered nature of caregiving and consider this when engaging and providing support to older male caregivers.

'There's an expectation that we can provide a lot more than we actually can. I think men have a tendency to want a sitting service – rather than someone being in the home while they're there, they'd prefer to welcome someone into the home when they're not there. That's what we struggle to offer as much, because the budget doesn't allow it. The threshold to get the sitting service needs to be fairly high. If we gave everybody who wanted the sitting service the sitting service, we wouldn't have a budget at the end of the day'. (Focus Group Participant, Statutory Agency 1)

Another participant explained how this situation impacted on male caregivers:

'Most of the carers I have prefer sits and some time out. Most of them will ask for sits as opposed to somebody coming in to do hands-on care. That's the majority of my male carers'. (Focus Group Participant, Statutory Agency 1)

However, another participant gave examples of how their creative approach had potential to lessen the impact of this:

'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'. (Focus Group participant, Statutory Agency 1)

Community-based agencies appeared to have flexibility to respond to support needs as they were not subject to the same constraints as statutory agencies. Although all support providers emphasised that support was tailored to individual need, community based agencies described examples of their approach, which appeared to be particularly flexible and responsive: As explained by one focus group participant:

'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.' (Focus Group Participant, Community-based Agency 1)

Engaging men

Participants generally acknowledged that male caregivers were harder to engage than their female counterparts, as explained by one focus group participant: 'we need to reach out to men in a different way'. Some support providers explained that female caregivers may engage at an earlier stage of their caregiving journey 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 and traditional roles, so they wouldn't have been as freely engaged or involved with health professionals, whereas women would traditionally have done that as children were growing up, so they're comfortable by the time they get to later life with engaging with professional people. Men of that age group are maybe less so and it's a new thing for them. It's a big ask.' (Focus Group Participant Statutory Agency 2)

As outlined in study Finding 1, some men's adherence to traditional masculine ideals of strength and independence potentially resulted in greater difficulty in engagement. Many support providers recognised this, as explained by participants across different focus groups:

'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.' (Focus Group Participant Statutory Agency 5)

'Males are more likely to engage with voluntary organisations as opposed to statutory organisations. Although they don't want to sit round and drink tea and talk. Group support needs to be very focussed.' (Focus Group Participant, Statutory Agency 4)

'They may source help to cope with practical issues but are reluctant to express any emotional difficulties and at times appear 'detached.' (Survey Respondent, Community-based Agency 15)

In spite of this, it was recognised that a greater focus on aspects of support such as language, timing, and relationships was key to effective engagement. Specifically, the importance of using language that was more in keeping with the spousal relationship (as opposed to 'carer'); having 'early conversations' about support and giving information in order to avoid crisis situations:

'Language we use? Day to day voluntary organisations don't use the term carers at all. Statutories seem to... They don't want to be called a carer but formal processes make the use of this language necessary... carer support, carers assessment... We need bespoke programmes.' (Deliberative Workshop Participant, Community-based Agency 6)

Other deliberative workshop participants agreed that the title of 'carers' assessment', often led to confusion as caregivers did not understand the purpose of such an assessment. One participant 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'?

Assessment of need:

There was a general perception that male caregivers were more reluctant than female caregivers to accept the offer of a carers' assessment, and some focus group participants were of the view that male caregivers were unaware of support or carers' assessments:

'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' (Focus Group Participant, Community-based Agency 3)

However, some focus group participants emphasised that whilst carers' assessments were offered to all caregivers, the take-up was mainly from female caregivers. It was also noted that male caregivers took less time to complete the carers' assessment than their female counterparts, as explained by this participant:

'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.' (Focus Group Participant, Statutory Agency 3)

All support providers agreed that caregivers should have their support needs properly assessed, and even though most HSC practitioners explained that they offered carers' assessments to all caregivers there was one who's view was that due to other service pressures, carers' assessments generally weren't a priority.

'A carers' assessment is never a priority. I mean, it should be, but realistically, a carers' assessment wouldn't tend to be a priority.' (Focus Group Participant, Statutory Agency 2)

Finally, a range of views were offered about men's reluctance to engage with services or express emotions. Although these views included professional judgements based on experience over many years, in a small number of cases they bordered on stereotypical assumptions, which subtly underpinned some support providers' perceptions of male caregivers.

8 CONCLUSIONS

- The findings demonstrate that some older male caregivers can experience negative caregiver outcomes which may not be alleviated by existing support services. In engaging and providing support for older male caregivers, support providers should recognise the potential impact of social conditioning and gender constructions on older men's identification with traditional masculine ideals, and how this impacts on their caregiving role.
- Differences between male and female caregivers may necessitate a different approach to support that makes allowances for the gendered nature of caregiving. In particular, some men's conformity with traditional masculine ideals such as strength and stoicism appears to influence their approach to caregiving. This can result in a reluctance to ask for help, which formal support providers should be alert to. The findings also indicate a lack of specialised support for men who are challenged by declining sexual intimacy. A focus on encouraging older male caregivers to avail of the carers' assessment would enhance the recognition of their particular support needs.
- Study findings highlighted male caregivers' desire for more peer support and social opportunities; and a preference for male-centred or activity-based social support as opposed to talking therapies or support groups. There is a need to engage men early in the caregiving trajectory; and for support providers to build long-term relationships with male caregivers in order to offer information and support.



- Even though study findings revealed a reluctance by some male caregivers to accept help with their caregiving role, and a perception from some support providers that male caregivers avoided engagement, this does not mean that male caregivers do not need help. Rather, that support which is more effective at meeting their particular needs should be developed. For example, initiatives in the wider area of men's healthcare and health promotion have demonstrated the efficacy of gender sensitive support. As such, principles underpinning these initiatives could be applied when developing support for older male caregivers. Examples of this include Men's Shed ²¹ or Man Alive Man Van.²² Findings in the current study indicate that many older male caregivers tend to prefer 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). Government policy has recognised the vital role played by caregivers and the associated savings to the State. It could be argued however, that insufficient resources have been allocated at the implementation level to provide adequate and flexible caregiver support, spanning all caregiver sub-groups including older male caregivers. 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 may have a different approach to caregiving.
- In Northern Ireland, enforcing caregivers' legislation that applies throughout the UK may help to improve the uptake of carers' assessment, highlight caregiver's rights to effective support, and improve formal support provider's capacity to deliver such support.

²¹ <http://northernirelandmenssheds.org/>

²² <https://cancerfocusni.org/cancer-prevention/mens-health/>

9 PUBLICATIONS

These study findings have been published as papers in three peer-reviewed academic journals, as follows:

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>

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>

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>



10 RECOMMENDATIONS

On the basis of study findings, a list of recommendations is contained in Table 2: Study Recommendations.

Table 2: Study Recommendations

AREA	RECOMMENDATIONS
Policy	<ul style="list-style-type: none"> • Carers' assessment: Although a low up-take of carers assessments has previously been recognised in the UK, this research has indicated that many older male caregivers are especially reluctant to take up the offer of a carers' assessment, often resulting in a lack for formal assessment of their support needs. A review of the carers' assessment and follow-up process is necessary to address the issues raised by this and other research. • Engagement: Low levels of engagement of older male caregivers identified in this study needs to be addressed. Under-pinning principles for supporting men as used in other men's support initiatives (such as Men's Shed or Man Alive Man Van) should inform the development of support for older male caregivers.
Practice	<ul style="list-style-type: none"> • Sustainable partnerships: Given older male caregivers' preference for community-based support highlighted by this and other research (Nurmi et al. 2016), further partnership between community-based and statutory healthcare agencies is required. This may ensure the delivery of person-centred, creative and sustainable solutions to the support needs of older male caregivers. • Caregiving and gender: Caregiving as a gendered concept should underpin the development of future caregiving support. In practice this means being mindful of potential 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. • Identification of male caregivers: The importance of having 'early conversations' regarding support with older male caregivers should be emphasised. This may result in older male caregivers identifying as caregivers as well as husbands, strengthen the relationship between the caregiver and support agencies, and encourage older male caregivers to engage with services at an earlier point, in order to avoid crisis.
Education	<ul style="list-style-type: none"> • Stereotypical assumptions: Some study data indicated subtle stereotypical assumptions about 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.²³ • A collaborative approach: Older male caregivers tend to prefer a collaborative approach to providing care. Although this could apply to all caregivers regardless of gender, it is particularly important for older males given their reported reluctance to accept support. Educators should promote innovative support with a partnership approach between support provider and caregiver, which may enhance support for older male caregivers.

²³ Milligan and Morbey 2013

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12 APPENDIX 1

Organisations who contributed to study findings through representation at focus groups, deliberative workshop and/or completion of survey:

Statutory Organisations	
Northern HSC Trust	NI Ambulance Service
South Eastern HSC Trust	Integrated Care Partnership
Southern HSC Trust	Department of Health (N.I.)
Western HSC Trust	Public Health Agency (R&D Division)
Belfast HSC Trust	

Community-based agencies/Charities	
Dementia N.I.	British Red Cross
Mid-East Antrim Age Well Partnership	Bethany Church Carers Group
Age NI	Confederation of Community Groups Newry
Carers NI	Ballymena and District Carers Group
Alzheimer's Society	Mindwise
Marie Curie (NI)	The Stroke Association
Northern Ireland Chest Heart and Stroke	Extracare
Brainwaves N.I.	CAUSE N.I.
Parkinson's UK	Carers Trust
Arthritis N.I.	Cancer Focus N.I.
Action Mental Health Men's Shed	Mid-Ulster Dementia Support Group
Huntington's Disease Association N.I.	Lisburn & District Carers Group
Motor Neurone Disease Association (N.I.)	MS Society

