



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.

Short Report

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Funded By: HSC R&D Division, Public Health Agency

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Evidence Brief

Why did we start?

Traditionally, caregiving has been associated with females, however, evidence suggests that more males are assuming a caregiving role than before. Male spousal caregivers are especially prominent in older age groups. Different approaches to caregiving between men and women have been previously recognised, and this has resulted in an awareness and increased focus on potentially different support needs which may be influenced by gender. A need therefore exists to examine whether current carer psychological support services (such as carer support groups or counselling); or practical services (such as respite or domiciliary care) serve the support needs of older male caregivers.

What did we do?

A mixed methods study comprising four phases. 1) Distribution of a survey to support agencies throughout the community/voluntary sector (N=39) to identify gaps in provision of support for older male caregivers. Quantitative data was analysed using SPSS for descriptive statistics. 2) Interviews with older male caregivers (N=24) to explore their support needs. Qualitative data was analysed using thematic analysis. 3) Nine Focus groups with key support providers from statutory and voluntary agencies (N=84 participants) to explore their experience of providing support to older male caregivers. Qualitative data was analysed using thematic analysis. 4) Deliberative workshop with key stakeholders (N=36) to consider findings and agree recommendations for the way forward.

What answer did we get?

The approach of older male spousal caregivers can be influenced by traditional views on masculinity (such as a managerial and independent approach). Although many older male caregivers derive satisfaction and meaning from their role, caregiving can also involve social isolation, loneliness and challenges to spousal intimacy. Existing support services provided by statutory and community-based agencies can vary in their effectiveness.

What should be done now?

Support providers should be aware of the gendered nature of caregiving and consider this when engaging and delivering support to older male caregivers. 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. Principles underpinning initiatives in the wider field of men's healthcare and health promotion could be applied when developing support for older male caregivers.

Background

Global trends predict that the world's population aged over 60 years will have trebled from 605 million to two billion by 2050 (World Health Organisation 2012). 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 (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 (Swinkles et al. 2019) 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 (Comas-d'Argemir and Soronellas 2019). However, other evidence has indicated that male caregivers have a poor awareness of, and a reluctance to use formal support (Lin *et al.* 2012), under-utilise training, (Lopez-Anuarbe and Kohli 2019) and that they experience negative consequences in the financial, physical and mental health areas of their lives (Milligan and Morbey 2013;2016). Although men are becoming more visible as caregivers, (Schwartz and McInnis-Dietrich 2015) their support needs continue to be neglected, and the impact of caregiver support for male caregivers is under-researched (Sharma et al. 2016; Dickenson et al. 2017)

Given that older men are more likely than women to nominate their partner as their main source of emotional support, 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.

Support services are defined as practical caregiver support including respite (such as day care for the care recipient), help with medication or personal care, or the provision of information and advice; along with psychological caregiver support including talking therapies, managing stress training, or befriending. These services may be delivered by health and social care (HSC) practitioners (such as nurses or social workers) employed by statutory agencies such as the local health trust, or staff employed by community-based agencies or charities (such as Alzheimer's Society or Marie Curie). Statutory and community-based agencies are referred to throughout this report as support service providers.

Aims and objectives

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.

Methods

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

Table 1: Data Collection Methods

Phase	Data Collection
Phase 1	Scoping Exercise: A scoping exercise with a range of community-based support service providers using a survey (N=39). Agencies included Carers Trust, Alzheimer’s Society, and Chest, Heart and Stroke (NI). Quantitative data were analysed using SPSS (V24) to generate descriptive statistics.
Phase 2	Caregiver Interviews: Qualitative data were gathered by conducting one-to-one interviews with older male caregivers (N=24). Data were analysed using thematic analysis (Braun and Clarke 2006).
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 (N=84). Nine focus groups were conducted, and data were analysed using thematic analysis.
Phase 4	Deliberative Workshop: Phase 4 consisted of a deliberative workshop for key stakeholders from across the statutory and community/voluntary sectors, to facilitate reflection and discussion of the study’s findings (N=36). Data were analysed using thematic analysis.

Ethics

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

Personal and Public Involvement (PPI)

Personal and public involvement (PPI) has been essential in the development and operation of our research. PPI was demonstrated through the involvement of a male carer, representatives of a HSC Trust, and the voluntary sector, specifically in the following areas:

1. Development of research idea and ongoing validation of research phases.
2. Assisting with design and composition of materials such as Participant Information Sheet, and piloting interview guides.
3. Input to ethics and governance approval.
3. Input to theme generation within the qualitative analysis stages.
4. Assistance with recruitment of participants through making contacts within their own organisations, and attendance at focus groups.
5. Input to the final stages (Deliberative Workshop) and contributing to reflections on research findings and to recommendations on the way forward.

Findings

Findings suggest that some older male caregivers experienced negative caregiver outcomes which were not alleviated by existing support services. In this study, some men's conformity with traditional masculine ideals such as strength and stoicism appeared to lead to an independent and protective approach to caregiving, which resulted in an underutilisation of support services. There was evidence of a managerial approach to caregiving, whereby male caregivers 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. Although older male caregivers generally viewed an independent approach to caregiving as positive, health and social care practitioners observed that this could limit men's wellbeing.

Although, many older male caregivers derived satisfaction and meaning from their role, and an independent approach was advocated, data also indicated a range of other emotions associated with caregiving including profound loneliness, frustration, loss, suicidal feelings, and social isolation. For some, their partners progressing illness led to communication difficulties which increased their loneliness; and others experienced isolation through becoming increasingly housebound. Some explained that this was due friends 'dropping away'; or fewer opportunities to socialise or maintain sporting or other social activities.

Some data suggested that older male caregivers experienced changes to spousal intimacy (sexual or emotional). Data from interviews with older male caregivers suggested that they felt committed to their partner and expressed a desire to abide by their marriage vows. Although these interview 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 which were no longer being met. It was clear from these participants that there was little specialised support from health and social care practitioners to help them to navigate this.

Although support service providers (including health and social care practitioners and community-based agencies such as Alzheimer's Society) were skilled and resourceful in their support of all caregivers (regardless of gender) there were also notable challenges. For health and social care practitioners employed by HSC trusts, these included difficulty in accessing practical support services and funding for carer support. Others 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 HSC practitioners. Moreover, it was also reported that a difference in approach to caregiving between males and females existed, which impacted their respective support needs. For example, it was acknowledged by HSC practitioners that male caregivers tended to be independent, and sometimes were reluctant to accept offers of support (such as a break away from their caregiving role), suggesting that this could result in a crisis or a breakdown in caregiving arrangements. Additionally, some other HSC practitioners and community-based

agency personnel perceived male caregivers as 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 reported 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. Study participants across statutory and community-based agencies tended to agree that some existing support initiatives such as carer support groups did not work well with older males, suggesting that this was because men were more interested in practical support than talking, or that carer support groups were attended by women only.

It was also recognised that a greater focus on aspects of support such as language, timing, and relationships was key to effective engagement with men. Specifically, the importance of using language that was more in keeping with the spousal relationship (i.e. 'husband' as opposed to 'carer'); having *'early conversations'* about support and giving information in order to avoid crisis situations. Thus, it was suggested that proactively identifying and 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.

Formal assessment of support needs by support service providers was highlighted as an issue. Some HSC practitioners 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. There was general agreement that the title of 'carers assessment' often led to confusion as many caregivers did not understand the purpose of such an assessment. One HSC practitioner 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?'*

Some differences were noted between statutory provision of carer support (such as HSC trusts) and community-based provision (such as Alzheimer's Society or Marie Curie). 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 service 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. Furthermore, there was some evidence to suggest that older male caregivers were more likely to access community-based support (such as welfare or legal advice) before accessing statutory services (such as respite care).

Even though support service providers in the current study acknowledged that all caregiver support was tailored to individual need (irrespective of gender), it was agreed that due to limited identification, assessment and engagement with male caregivers opportunities to offer support were often limited. Furthermore, male caregivers' preference for male-centred or activity-based social support as opposed to talking therapies or support groups also meant that support could not be provided as such male-centered/activity-based caregiver support did not currently exist. Findings suggest that support which is more effective at meeting the

particular needs of older male caregivers should be developed. For example, initiatives in the wider area of men's healthcare and health promotion (such as Men's Shed) have demonstrated the efficacy of gender sensitive support. As such, principles underpinning these initiatives could be applied when developing support for older male caregivers.

Conclusion

This study comprised four distinct phases: a scoping exercise to establish the level of support from community-based agencies for older male caregivers; qualitative interviews with older male caregivers to explore their caregiving experience; focus group interviews with support service provider staff (such as statutory HSC trust and community-based agencies including Alzheimer's Society); and a deliberative workshop.

The findings demonstrate that some older male caregivers can experience negative caregiver outcomes which may not be alleviated by existing caregiver support services. In engaging and providing support for older male caregivers, support service providers should recognise the potential impact of social conditioning and gender constructions on older men's identification with traditional masculine ideals, and how this may impact on their caregiving role. For example, there is a need to engage men early in the caregiving trajectory; and for support service providers to build long-term relationships with male caregivers in order to embed information and support. Furthermore, given the low uptake of carers' assessments by older male caregivers, there is a need to focus on encouraging older male caregivers to avail of the carers' assessment. This would enhance the recognition of their particular support needs, including any specialised support needed such as the navigation of declining spousal intimacy.

Study findings also 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 to address loneliness and social isolation.

Future caregiving support initiatives should consider caregiving as a gendered concept. As such policy and decision makers should learn from and use principles for supporting men in other areas of men's health promotion (such as Men's shed) to underpin the development of support for male caregivers. This may address issues such as low levels of identification, engagement and assessment of older male caregivers identified in this study.

Practice and Policy Implications

Practice:

Engagement: Low levels of engagement of older male caregivers identified in this study needs to be addressed. Under-pinning principles for supporting men 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.

Education of support providers: 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.

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 provider, and encourage older male caregivers to engage with services at an earlier point, in order to avoid crisis.

Policy:

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 - 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.

Sustainable partnerships: Given older male caregivers' preference for community-based support highlighted by this and other research, 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.

Pathway to Impact

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.

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