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Supportive strategies for men who have a care role: an occupational perspective

Abstract

Background/Aim: Health and social care practitioners often work alongside care givers. The aim of this study is consider commonality in the experience of being a male caregiver from specific perspectives utilising secondary analysis of research related to fathers of an adult child who has intellectual disability, and a study related to older widowers.

Methods: Secondary analysis of findings arising from two qualitative studies of men who have experience of a care role from different perspectives was applied using a triangulation approach to illuminate, develop and enrich findings between studies.

Findings: Overarching themes across the two studies included ‘Aspects of a care role’ and ‘Supportive mechanisms’. The findings demonstrate that men from these specific groups are actively involved in care and there are varied aspects to a care role. Factors that support men include the provision of appropriate and timely information, time spent in leisure activities, support from family, friends and individualised services.

Conclusions: If service providers are aware of strategies that are useful to male carers, this may support the health and wellbeing of both carer and the person they support.

Key words

Men, Care role, Support strategies, Occupations

Background

Although women are still considered to be the main providers of care (Di Novi, Jacobs and Migheli, 2015; Walker, 2010) men can and do provide care within a range of roles that include partner or spouse, father, brother and son. It is increasingly likely that men will take on a care role due to factors such as increased longevity, reduced services associated with budgetary constraints, and social expectations (Grigorovich et al., 2016). Despite this, little attention has been given to the care role of men or the issues that may arise for men in a care-giver role (Eriksson and Sandberg, 2007; Sandberg and Eriksson, 2008) and there is a particular dearth of literature reporting on fathers who care for an adult child and older widowed men who provided care for their wives. For example, fathers of adults who have an intellectual disability are an under-represented group within the literature where there is predominantly a focus upon the role and needs of mothers (Yoong and Koritas 2012) despite the societal expectation that fathers will provide an enduring role in the support of their children. Similarly, most research regarding widowhood has focussed on the experience of older women rather than older men (Martin-Matthews, 2011) and there is limited research which explores the caring experiences of older widowers before the death of their wives (Collins, 2018). Research in the field of intellectual disability that does relate to fathers tends to be older, refers to fathers of children and employs a positivist perspective, all of which supports the call for studies that focus upon qualitative aspects of men in this particular care giving circumstance (Davys, Mitchell and Martin 2016). Correspondingly, research in the field of men caring for their wives tends to be older, related to dementia care and/or employs a quantitative approach (Baker, Robertson and Connelly, 2010, for example).

Differences between men and women within a care role

The literature suggests that men and women respond differently to the care role (Di Novi, Jacobs and Migheli, 2015; McDonnell and Ryan, 2014). Men are thought to be more comfortable with the practical tasks of caring yet are thought to have difficulty with the emotional and personal aspects of caring (Grigorovich et al., 2016; McDonnell and Ryan, 2014), however other studies demonstrate that men do take on personal care tasks (Campbell, 2010). A further difference noted is in relation to paid employment, women are more likely to give up paid employment to take on a care role full time in the presence of illness or disability within the family (Walker, 2010; Wright, Crettenden and Skinner, 2015). When men combine a care role and paid employment, they often comment upon difficulties such as conflict with colleagues, lower financial reward, reduced opportunities for promotion and problems in taking time off to meet carer demands (Watson, 2010; Carpenter and Towers, 2008).

Impact of care role upon men

A care role for men may present a negative impact upon health, finance, the opportunity to take part in valued activities such as work, social relationships, and leisure. This could result in feelings of frustration, guilt, sadness and grief (Grigorovich et al., 2016). For example, older men may experience loss of companionship and isolation due to their care role which is associated with reduced health (Milligan et al., 2016; Sanders, 2007; Eriksson and Sandberg, 2007). Men may also be aware of a social expectation to present themselves as strong and independent in order to demonstrate mastery and control (Sandberg and Eriksson, 2008; Eriksson and Sandberg, 2007). Some men may therefore only seek support at crisis point which could adversely affect their health and wellbeing. From a positive perspective, benefits from a male care role have been reported. For example, male carers are likely to receive increased service support compared to women (Bennett, 2009), and some gain a sense of purpose (Eriksson and Sandberg, 2007). There are also reports of learning

new skills, knowledge and the development of close relationships with family members (Grigorovich et al., 2016).

Support strategies used by men who care

Strategies used by men to manage a care role are often referred to as pragmatic and ‘task focused’. For example, asking health care workers to look after their wives whilst their own needs are attended to, such as when visiting the doctor (Eriksson and Sandberg, 2007; Sandberg and Eriksson, 2008). A pragmatic approach to caring is also demonstrated by sons who used work related knowledge and technology, for example online banking (Grigorovich et al., 2016). This illustrates a problem solving approach amongst men (Sanders, 2007). The value of meeting other people in a similar situation to share knowledge and experience, has been cited amongst older men (Eriksson and Sandberg, 2007; Sandberg and Eriksson, 2008), by sons who care (Grigorovich et al., 2016) and older widowed men who were former carers (Collins, 2018). The value of friends and family who may be able to empathise with their situation is also noted (Neufeld, and Kushner, 2009).

A number of papers refer to the benefit of information, education and training. This could be service led, such as formal training sessions, however, the internet as a means of gaining access to information to support a carer role is also important (Grigorovich et al., 2016). The need for information to be provided at an early stage in the care process and the importance of services being appropriate to individual context are also key (Campbell, 2010; Sandberg and Eriksson, 2008).

Of particular relevance to health and social care practitioners is the literature that refers to men in a care role who use leisure as a coping strategy. Sons who care may consider their leisure pursuits as a form of relaxation and respite from their care role, and claim that not being able to engage in such activities has a negative impact upon health and wellbeing

(McDonnell and Ryan, 2014). Similarly the protection of leisure time is vital so that men can continue with valued interests which is viewed as a coping strategy (Grigorovich et al., 2016). The importance of participation in leisure is relevant within the profession of occupational therapy as balance between self-care, productivity and leisure is considered a core concept (Wagman, Hakansson and Bjorklund, 2018) and is considered important in the maintenance of physical and mental well-being, including family care giving situations (Nissmark and Fange, 2018).

Aim

The aim of this article is to present similarities in the experience of being a male caregiver from different role perspectives using secondary analysis of two studies, one related to fathers of an adult child who has intellectual disability (Davys, Mitchell and Martin, 2017) and the other on older widowers who have cared for their wives (Collins, 2018).

The aim of this article is to present secondary analysis of two specific groups of male carers, fathers of an adult child who has intellectual disability (Davys, Mitchell and Martin, 2017) and older widowers who have cared for their wives (Collins, 2018). The examination of these studies will consider if there is any commonality of experience between these two groups of male carers which may serve to inform service providers of their needs so as to enhance service provision.

Methods:

The overall methodological approach taken in each primary study was qualitative as appropriate in the exploration of individual experience and perceptions (Silverman, 2013). Davys, Mitchell and Martin (2017) took the stance of interpretative phenomenological analysis, whilst Collins (2018) used a framework of subtle realism. Ethical approval was

granted from the University of Salford and gatekeeper organisations for each study before any data was collected. Written informed consent for participation in the study and the reporting of anonymised data in academic journals for both studies was also gained. Data was collected between January 2016 and May 2016 for the fathers study, and between September 2013 and February 2014 for the widowers study.

Participants

Purposive sampling was utilised across both individual studies. Each study recruited 7 men who had experience of a care-giving role, had been or were still married, were White UK citizens living in the North West of England with an age range of 49-89. The mean age of the fathers was 62 years and the mean age of the widowers was 81 years. All men had children. Both authors utilised face to face semi-structured interviews to collect data. All interviews were audio recorded and transcribed using an interpretative phenomenological analysis framework for the fathers study and thematic analysis for the widowers.

Secondary analysis

Secondary analysis of data can be used to review existing data and support the presentation of new insights when a new question or perspective is applied (Corti, 2007). Additional positive aspects of secondary analysis are that it allows under-utilized findings to be reported without further intrusion upon participant's time (Jackson et al., 2013). The overall approach taken to secondary analysis of data within this paper is that of triangulation which is where commonality between data sets is explored in order to illuminate, develop and enrich the findings between studies (Morse, 1991). The first author reviewed the emergent themes and participant quotes from each study using a framework of analysis (Smith and Osbourn, 2008) to establish if there were any areas of commonality in findings between fathers of adults who have an intellectual disability and older widowers who cared for their

wives. Framework analysis can be used after data collection to present similarity of themes in studies that are linked yet separate, and therefore provide an overall analysis (Furber and McGowan (2011). Each author then returned to the interview transcripts to confirm the presence of these themes arising in each study as evidenced by participant quotes. Both authors then further reviewed the data from each study and commonly emerging overarching and subthemes were identified as presented in Table 1.

Trustworthiness

Rigor is enhanced in this presentation of these findings as both initial studies adopted a similar research approach. In addition, the overarching themes and subthemes were present in both data sets which supports credibility, and confirmability was enhanced by commonality in participant quotes across themes (Finlay, 2006). Each individual study utilized a reflexive diary and peer review of all themes and evidence which further supports credibility and trustworthiness.

Findings

From careful reading of the findings across the two studies, a number of common themes were found which may offer a valuable contribution to health and social care professionals who support men in a care role. Overall the themes presented demonstrate that men do provide an active care role that they perceive both negative and positive impact upon their lives, and a number of supportive mechanisms are reported which may be of value to service providers as they seek to deliver relevant and effective services (refer to table 1).

Aspects of a care role

Active care role

As identified in the literature, women provide more personal and domestic care tasks than men, however it was clear from analysis of transcripts across both studies that men do carry out personal care tasks. Within the fathers' study, where a wife was present and able, it was generally she who took on the majority of the personal care tasks yet fathers did provide support with intimate care that included toileting, bathing and cutting up food. In the case of a widowed father where there was no wife to provide care, he took responsibility for personal care:

“...I have to cut up his food, he certainly couldn't cook or anything like that...he wouldn't dream of washing himself. I really have to make him have a shower or brush his teeth...” (Alan, father)

Similarly within the widowers' study, many of the participants talked about the personal care tasks they helped their wives with before they died:

“She (wife) was doubly incontinent so she was having to be constantly changed, singly I handled all the necessary pads and whatever...” (Frank, widower)

Negative impact of a care role

Negative psychological wellbeing was an adverse impact comprising of worry and a sense of loss. For fathers with a care role, loss referred to hopes, anticipated dreams and wishes for their child that were no longer likely to come to fruition, worry was centred on the health and wellbeing of the adult child and for the future:

“...he's very vulnerable...you have to link arms when you go out in the street with him because he doesn't really see three dimensionally...he doesn't even see curbs and steps or anything like that”. (Alan, father)

The care role was also linked to restrictions in social contact and networks. Some fathers avoided general social contact as other people may not “understand” their situation whilst others made comment that people who were not in a similar situation would not want to hear about their concerns or relate to their situation. Others raised concern that people would make negative judgements which led to social restriction and isolation:

“... (We) aren't out socialising every night.... Yes so we know we have those restrictions...it's those practical things like ...making sure there has got to be somebody home when she has returned, when she is at college...” (Stephen, father)

Some widowers talked about the negative impact of their caring role on their wellbeing, as Robert explained:

“I was run down before-hand because the last fortnight she was home, we'd get to bed and it wouldn't be above ten minutes before she'd say she wanted the toilet, and we were up and down like that all night”

Adaptation to a care role

Being a carer was associated with the development of alternative activities and interests, and there was evidence within both studies that men are able to adapt within and beyond the care role. For the fathers, initial reactions were of shock, grief, bereavement and distress, yet ultimately this gave way to adaptation described as acceptance or rearranging life to accommodate the needs of the person cared for:

“...I definitely feel there was a period of bereavement...but I don't think we spent years wallowing ...we just tried to work out what's possible and start rearranging our lives around it really”. (Barry, father)

For some of the older widowers adaptation to a care role helped them to adapt to later transitions, as Frank explained:

“Of course with her being incapacitated...I had to then look after the house, look after the food everything. So that made me in a position where I was kind of self-sufficient. ...So I've a kind of easier transition in that way”

Positive impact of a care role

Despite the negative impacts that a care role can generate, there was evidence of benefits, for example new hobbies or interests, learning new skills, gaining knowledge and information. The development of positive personal attributes such as patience and compassion were also mentioned as was being able to support others in a similar situation:

“I am very much trying to raise the profile...of carers...I have been involved in a lot of development panels...I was involved in NHS Direct in their evaluation...” (Keith, father)

In the widowers study George used his experience to improve dementia care and to support others in a similar situation:

“I know my way around the social care system better than anybody (laughs) I can find my way around it so we got the best for (her). So that is where I put my energy now”

Supportive mechanisms

Support from family and friends

In the widowers study, the men valued emotional and instrumental support from family and friends. Similarly, fathers referred to the value of support from family and sometimes friends:

“I think it was all the support of our friends that accepted (son) and our parents and then the professional input that (wife) sought that I latched on to”. (James, father)

Supportive friends were on hand to give respite care also for the widowers, as Frank explained:

“...so very fortunately she'd got some good friends who would come in and sit with her and let me go and play a little bit of golf, you know a couple of times of week, which you know that sort of thing made a big difference to me...”

Appropriate support from services, knowledge and information

All fathers made both negative and positive comments about services, from individual employees to the overall systems. When asked what helps; fathers stated that services need to be proactive, consistent, timely, flexible, able to meet individual needs, and that staff need to be well trained and communicative:

“... (son) has to fit into the hours rather than the hours have to be what (son) needs...we don't get reported back...or copies in ...Nobody tells us...we're just totally uninformed” (James, father)

One of the older widowers, William, talked about being an advocate for his wife and his frustration with accessing services:

“I’ve been (her) mouthpiece...you know, been playing hell...things I’ve done...we couldn’t get the money off the council, well we could but it got bogged down, you know what it’s like councils are...”

Men within the fathers study referred to the value of information that allowed them to access relevant support, services and practical skills or knowledge. Similarly Arthur, a widower, described how he found organisations to be informative:

“...but when you’ve been to a few of these talks you suddenly begin to realise what it’s all about, you know, the Alzheimer’s society, oh yes you talk to a load of people.”

Meaningful occupations, hobbies and interests

In both studies, men who attended organisations, interest groups or had hobbies, said these were supportive. Engagement with meaningful activities appeared to act as an ameliorating factor in managing the negative impact of caring. Fathers used involvement in voluntary roles and leisure pursuits as “time away” from their situation to support their health and wellbeing:

“...there’s several days a month where I get out and do other stuff (non-care role related)...We all need space at some point on our own...” (Barry, father)

Support from other men in a similar situation

Support from men in a similar situation was apparent for the widowers, who valued socialising with other men particularly during leisure activities. Robert talked about joining his local Veteran’s club and the male camaraderie he enjoys there, similarly in the fathers study, Keith spoke about wanting contact with other men in a similar situation who would understand:

“Yes, I would (like to opportunity to interact with other fathers in the same situation)...You can’t say to somebody who had got normal children, my lad did this

at snooker or he managed to do this, but somebody who has experienced the same things, they'd say that's great".

Some of the fathers however stated that they were uncomfortable discussing feelings with other men and would not want to attend groups that concerned feelings, were unstructured or not relevant to their situation. They considered the discussion of feelings in a group setting to be the domain of women:

“...being female, you all talk more than we do and you expose deeper down bits than we (men) do...I would hardly go to my best friend and open up to him” (Alan, father)

This respondent further explained that to be emotionally open in a public setting was not congruent with the expectations of a male role in society. This may reflect the age group of the participants (50 and over) but overall the findings suggest that services need to be aware of and provide services that specifically address the needs of male carers.

Discussion

Health and social care professionals are expected to work in partnership with service users and their carers (Health and Care Professions Council 2016) therefore it is important that they are aware of the needs and strategies that support male carers (Sandberg and Eriksson, 2008). When families and carers are not supported, this may have a negative impact upon the health and wellbeing of both the person cared for and their carer (Nissmark and Fange, 2018). This article presents a secondary analysis of themes arising from two studies with men who have experienced a care role. The first study explored the roles, needs and concerns of fathers of adults who have an intellectual disability. The second study explored the personal communities of older widowers who had cared for their wives. The findings add to the limited literature reporting on the experiences of male carers and have a number of implications for supporting men in a care role.

The men in both studies demonstrated active engagement with their care role as either fathers or husbands. This included personal care, which differs to some previous studies that have found men to be less comfortable with personal care tasks (Grigorovich et al., 2016; McDonnell and Ryan, 2014) yet supports the findings of Campbell (2010). Being a carer presented challenges for both fathers and widowers. This secondary analysis indicates that the men experience worry, reduced participation in valued activities, and a lack of social contact which can negatively impact their health and wellbeing. These findings further support previous studies regarding the negative impact of caregiving (Sandberg and Eriksson, 2008; Eriksson and Sandberg, 2007). Despite this, men demonstrated adaptation and reported positive aspects of care giving such as the development of alternative occupations, learning new skills and the development of personal attributes. This builds on previous research which suggests that some men gain a sense of meaning and purpose from their care role (Eriksson and Sandberg, 2007).

The supportive mechanisms apparent in both studies include family, friends, engagement in meaningful occupations, leisure interests, acquisition of relevant information, and good service provision. It is also interesting to note the value of support from men in a similar situation. Findings across both studies present the concept that some men enjoyed the opportunity of mixing with other men (without women being present) and the opportunity to share with men in a similar position. This concept is present within existing research (Eriksson and Sandberg, 2007; Sandberg and Eriksson, 2008; Collins, 2018). However, some men across the studies expressed an unwillingness to discuss emotional or personal issues with other men. Diversity should be recognised by service providers so that individual needs can be met.

The use of leisure interests and valued roles as a strategy to manage stress and enhance wellbeing supports findings from previous research (Grigorovich et al., 2016;

McDonnell and Ryan, 2014). This concept is prevalent in the field of occupational science where maintenance of meaningful and purposeful roles and activities is aligned with positive mental and physical wellbeing (Fossey and Newton Scanian, 2014). Perceptions of service provision across the studies were mixed. Positive reports referred to services being useful and informative, whilst negative reports referred to a lack of funding and services not being appropriate to individual need. Such mixed perspectives of service providers by service users is expressed elsewhere (Carpenter and Towers, 2008; Ly and Goldberg, 2014).

As it is likely that demand upon male carers will continue due to social expectation, increased life expectancy and reduced formal care provision (Grigorovich et al., 2016) it is imperative that service providers deliver timely and relevant services to support male carers. With consideration to the findings from this secondary analysis and previous research (Davys, Mitchell and Martin, 2017), services need to ensure that male carers are supported by strategies such as time away from the care role so that they can continue to use leisure interests to support their health and wellbeing, provide relevant and appropriate information such as condition management or relevant legislation and policy. Male carers should also be given the opportunity to meet with others in a similar situation if they wish to do so. It is also advisable that they are involved in service planning and review so as to ensure that services are relevant and fit for purpose (Towers, 2009).

Limitations

It is acknowledged that these secondary analysis findings derive from two small qualitative studies and that the population of each study was different however participants across the studies shared the characteristics of being men with experience of a care role and therefore provided the opportunity to consider aspects of a male care role from different perspectives. Although a different methodological perspective was taken for each study, both were

grounded in the qualitative tradition and used a form of thematic analysis. It is also acknowledged that participant and public involvement in the research design and methodology of the original studies would have enhanced the quality of these studies (National Institute of Health research, 2019).

Future research

It may be beneficial for future research to consider the needs and concerns of younger men who have a support role and those from other specific groups, for example men who care for older parents or siblings. Additionally, it would be of value to research women in similar care giving situations, and to compare and contrast the findings between the different groups.

Conclusions and implications for practice:

This secondary analysis demonstrates that men do take an active part in care roles and that there are positive and negatives aspects to such a role which supports and develops findings from previous studies. Importantly the findings illustrate the positive attributes and opportunities that may arise from men having a care role, and the value of meaningful and purposeful activities as a strategy for maintaining health and wellbeing. It is important that service providers acknowledge the needs and support strategies that are useful to male carers. These include the provision of timely and relevant information alongside practical and individualized support to maintain relationships, the opportunity to engage in leisure pursuits and seek support from others in a similar situation if they so wish. If male carers are not adequately supported, this could have a detrimental impact upon their health and well-being, as well as the person they care for, and result in an increased cost to wider society.

Declaration of interest:

The authors report no conflict of interest.

Key points:

- Men are actively involved in care roles
- There may be positive and negative aspects to a care role for men.
- Support strategies may include friends, family and men in a similar situation.
- Men perceive time to pursue hobbies and interests as supportive to a care role.
- Knowledge, information and appropriate support from services are also valued.
- Support should be tailored to meet individual need.

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