### **INTRODUCTION**

Worldwide there will be 27.5 million new cases of cancer each year by 2040 (CRUK, 2018). Since the early 1990s, incidence rates for all cancers combined have increased by around 13% in the United Kingdom (UK), and there are currently more than 360,000 new cancer cases in the UK every year (CRUK, 2015). Due to improvements in diagnosis and treatment, people are living longer after cancer. This combination of increasing incidence rates and improved survival has increased the need for care.

However, due to the roll-back of the state (Hills, 1998) accelerated during a decade of austerity economics, formal care provision, such as local authority social care, has been diminished. Increasingly, 'informal' care provided by the families of those experiencing illness has replaced or supplemented formal provision, especially among those without financial resources to provide such care privately. Health and social care systems therefore increasingly depend on this significant contribution from these unpaid carers, especially in support of those diagnosed with cancer

### Context and consequences of caring

Caring for someone with cancer carries particular social and psychological consequences (Thomas and Morris, 2002) that may not be experienced in the same way by those caring for individuals due to other circumstances. For example, living with frailty or dementia typically involves a period of 'prolonged dwindling' (Murray et al, 2005) which may lead to a gradual transition into the caring role. By contrast, the carer of someone with cancer is usually thrust into the role and the disease can progress rapidly. Although positive aspects of the caring experience have been noted (Young and Snowden, 2017) there is now a growing evidence base that identifies the ways in which caring is often characterised by existential worries and distress (Olson, 2014; Seal et al, 2015). Carers supporting someone with a cancer diagnosis have been found to have greater anxiety and depression levels than general population controls (Burridge et al, 2009; Stenberg et al, 2010) and anxiety has been found to increase when caring for someone in the advanced stage of cancer (Trevino et al, 2018). Following treatment, carers, and particularly spousal carers, face challenges relating to treatment side effects, including wound care, changes in sexual function and living with

the fear that the cancer may return and become unmanageable (Butow et al, 2014; Girgis et al, 2013).

Yet, caring is a multifaceted concept (Thomas and Morris, 2002). The caring experience can differ according to compositional factors such as the socio-demographic characteristics of the carer, available support, the circumstances of the person cared for and contextual factors, including social and cultural influences and expectations within the caring relationship (Murray et al, 2010). It is important to recognise diversity within families, as the extent and process of family involvement can vary in different cultures (Pinquart and Sorensson, 2005). For that reason, factors which precede the caring experience can have an impact on the carer's response to their role and the emergence, or not, of a carer identity.

For example, scholars have debated how useful and inclusive the term 'carer' is, with Molyneaux et al, (2011) considering that the term actually fails those it claims to help. A significant issue is that some individuals do not self-identify with, or may dislike, the term preferring instead to be defined by the pre-existing relationship they are in, such as a spouse (Kutner, 2001). Indeed, Ussher et al, (2009) suggest that low participation in carer research may be related to use of the term 'carer' (or caregiver) with individuals not volunteering to take part as they do not relate to the term. Consequently, this may mean that particular groups of carers, such as older men, ethnic minority groups, and young carers, who are less likely to identify with the term, can be overlooked in carer research (Kutner, 2001; Milligan and Morbey, 2013; Carers UK, 2019).

# Changing patterns of care

Globally, the majority (70%) of unpaid care is carried out by women who are the spouse or family member, for example daughter, of the care receiver (Scofield et al, 1997; Miller et al, 1992; Suguira et al, 2004; Eriksson et al, 2013). These statistics have been interpreted through the lens of gender socialisation and in men's and women's participation in the labour market (Jenkins, 2017). In addition, the way responsibility to care is distributed in families can differ depending on the caring circumstances. For example, daughters are particularly likely to care for elderly parents (Grigoryeva, 2017). However, men also provide a substantial amount of care, with around 4 in 10 carers being men in the United States (44%) and Scotland (41%), and around half (49-51%) of all carers in Canada (Baker et al,

2010; The Scottish Government, 2015; NAC, 2015). Moreover, the gender profile of carers also changes with age and ethnic background. Analysis of the 2011 census for England and Wales revealed that in the population over 65, 15% of men were in a caring role, compared to 13% of women (Milligan and Morbey, 2016). In the USA, 54% of Asian and 41% of Hispanic carers of individuals over 50 are men (Sanders, 2008). Changes in the patterns of provision of informal care therefore challenge perceptions of caring as a role characteristically performed by women. However, increasing evidence on the *extent* of men's involvement in care has not transferred to the research literature (with some exceptions, for example, Willis et al, 2020 and Gilbert et al, 2014) around men's *experiences* of care or, where is it has, there are sometimes limitations.

In a review of the nursing and health literature that aimed to identify sampling and analysis issues in male carer studies for someone with dementia, Houde (2002) reported small convenience samples, lack of analysis by family relationship and an overreliance on cross-sectional designs. A wider and related issue is attitudes towards men. Farrell et al, (2014) discuss the notion of the male 'empathy gap', proposing that male distress is often overlooked since men are positioned in society to offer, rather than to receive, protection. Accordingly, researchers who are interested in emotionally complex topics may not always prioritise the male experience. This has led some scholars to refer to men as 'the forgotten carers' (Arber & Gilbert, 1989).

It is acknowledged that there is a degree of circularity to this argument. Men do not always identify with the role, and some may actively reject carer discourses, deeming them to be feminine (Elliot, 2016). Thus, rather than researchers 'forgetting' about men, it may be that the complex way in which men define their masculinity in relation to care affects their willingness to engage with research on carers. In any case, it seems likely that omitting men from research on caring is a significant omission, as evidence suggests that gender and the experience of caring are inextricably intertwined, in complex ways (Ussher and Sandoval, 2008; Cancian and Oliker 2000).

## Experiences of caring

In cross-sectional studies, gender is cited as an important influence on the carer experience but it is not always analysed beyond its association with outcomes such as 'burden' and quality of life (Kim et al, 2015; Shrank et al, 2016). Qualitative research has indicated that while male and female carers have many experiences in common, there are some notable differences. Ussher et al (2013), for example, used semi-structured interviews to explore gender differences in carers of people living with cancer in Australia. They reported that women positioned themselves as an 'all-encompassing carer' believing they had to perform a number of caring tasks, whereas, in contrast, men primarily positioned their caring role as a competency task to be mastered. Research has also highlighted that men may find it difficult to adapt to the role of carer due to socially constructed gender expectations that position caring as a feminine practice. This may lead men to experience 'role incongruence' (Allen, 1994), as they perceive their caring role as a challenge to their identity (Seymour-Smith and Wetherell, 2006).

As well as these important questions of gendered caring identities, gender-based differences have also been considered in the context of the physical and mental health effects of caring. Several studies have identified, for example, that female carers report higher rates of depression and anxiety, and lower life satisfaction and quality of life ratings compared with male carers (Pertz et al, 2011; Hagedoorn et al, 2000). In Pertz et al's (2011) examination of gender differences in levels of distress among carers of someone diagnosed with cancer, however, female participants far outnumbered male (245 women, 119 men), introducing possible bias that was not considered in the paper.

Several theoretical explanations have been offered to account for why women may experience more distress. In summary, scholars have tended to accept the idea that women's role in families makes them more nurturing, relationship-focused and reactive to stressors (Dorres et al, 2010). Caring is socially constructed as a central part of women's gender role, and so can result in 'compulsive' caring and 'over-responsibility', linked to distress (Forssen et al, 2005 pg 660). Research reports, however, that men also experience anxiety when taking on the emotional care of their partner (Ussher and Perz, 2010; Ussher and Sandoval, 2008) as well as exhaustion, depression and disturbed sleep (Milne and Hatzidimitriadou, 2003) and finds they may conceptualise caring as a challenge to their

identity (Seymour-Smith and Wetherell, 2006). Consequently, men's role in families and the expectation that they will demonstrate emotional strength (Calasanti and King, 2007) may make them less likely to *report* distress (as opposed to actually feeling less distress) than women. Not all scholars agree that caring behaviours follow gendered norms. Nevertheless, it is evident that caring has a significant – and potentially *different* health and psychosocial impact – on men and women, with consequences for the design and implementation of tailored supportive interventions.

Crucially, though, if Arber and Gilbert's assertion (in their 1989 article) that men are the 'forgotten carers', and underrepresented in research, remains true, then it is important to establish if understandings of the caring experience are skewed towards women's perspectives, before questions of appropriate intervention development are asked. This paper examines the gender balance of participants in studies of people caring for someone living with cancer.

### **METHODS**

We conducted a systematic review that asked the following question:

 What are the proportions of men and women in studies exploring the experiences of family carers of someone living with cancer?

PRISMA (Preferred Reporting Items for Systematic reviews and Meta-Analysis) guidelines (Moher et al, 2009) were used to enhance rigour in the review process and transparency in reporting. PRISMA is an evidence-based minimum set of items for reporting in systematic reviews. The review was registered on PROSPERO (registration: CRD42018103767).

# Search strategy

A systematic search of the following electronic databases was undertaken: CINAHL, PsycINFO, AMED, and MEDLINE. The search included studies published in English from January 1995 to August 2018. This time period was chosen as caring as a research topic began to develop in the mid-1990s, coinciding with policy initiatives and the rise in community care (Heaton, 1999). Although other systematic reviews were excluded from the review, the reference lists of any relevant ones were hand searched. A broad search

strategy was used to capture all forms of caring for someone with cancer using the following search terms:

- 1. Carer OR caregiver OR family care\* OR spousal care\*
- 2. Cancer OR neoplasm OR oncology

### Inclusion and exclusion criteria

Inclusion criteria were as follows: (1) adult carers of a family member / spouse / partner over 18 years old who has received a cancer diagnosis; (2) any type of cancer; (3) written in English; (4) primary research published between January 1995 and August 2018; (5) main focus on the impact or experience of caring.

Exclusion criteria were: (1) carers of children and non-family members (i.e., friends, neighbours); (2) mixed samples, including carer and patient samples; (3) caring for a patient with advanced cancer / end of life / palliative research; (4) bereaved carers; (5) not primary research (grey literature, protocols, discussion papers, systematic reviews); (6) research not directly focused on the impact or experience of caring, such as psychometric testing and intervention effectiveness.

No exclusions were made on time from diagnosis, although we decided to exclude end of life and paediatric care due to the distinct experiences of these carers. It is also known that paediatric palliative care samples are predominantly female (Macdonald et al, 2010).

# Data extraction

Figure 1 shows the process used to identify articles in the review. To reduce bias, four reviewers were involved in a five-step data extraction process. Reviewers were chosen due to their previous experience of conducting systematic reviews and subject knowledge.

# *Insert figure 1 here (PRISMA flow)*

First, reviewer 1 (AS) identified articles (n=4,159) through online searching of the four databases. All articles were exported to EndNote, X9 (Clarivate Analytics) and combined with the 8 articles identified through hand searching. Duplicates were removed in EndNote. Second, article titles were screened by reviewer 1 to identify those meeting the inclusion

criteria. Third, abstracts from retained articles were reviewed by AS; if they met the inclusion criteria the full text was accessed and assessed for eligibility by JY. Fourth, reviewers 1 (AS) and 2 (JY) independently reviewed the full text of the remaining articles (n=399) to assess eligibility. Reasons for exclusion at this stage were recorded, with any disagreements resolved through discussion. To enhance rigour, before proceeding to data extraction, reviewers 3 and 4 (RK, LB) reviewed a random selection (30%) of excluded articles to verify that they had been appropriately excluded. After discussion it was agreed by all reviewers that three articles had been incorrectly excluded. Finally, once agreement on eligibility had been reached, relevant information from each article was extracted into a table (Table 1) that noted: study setting, design and relevant sample information, including the number of males and females included in the study. Quality assessment was not applied to the included studies, as the aim of the review was to enumerate the gender split of participants rather than to make any judgements or exclusions based on study quality.

### **RESULTS**

### Study characteristics

Table 1 presents a summary of the 82 articles included in this review. The majority of these studies were conducted in the USA (39% n=32) and Australia (17% n=14) but studies from sixteen different countries are represented in the review. The year range of the articles was 1997-2018 but most (55% n=45) studies were conducted between 2010 and 2018. Most had a quantitative design (70%, n=57), using surveys to measure variables such as quality of life, burden, depression, relationship quality and sleep quality. Overall, there was a general focus on the problematic consequences of caring. Qualitative studies (n=22) primarily focused on the needs and experiences of carers at a particular time point, such as, following treatment. There were three mixed methods studies.

Cancer types experienced by the person cared for varied, but breast and colorectal cancer were most common. Time from diagnosis ranged from 6 weeks (Mosher et al, 2015) to 7 years post diagnosis (Balfe et al, 2016). This was not always stated, however, and some studies reported the stage, such as 'receiving treatment' or 'post-treatment'. The mean age of the carers (in the 62 studies where a mean age was recorded) was 53.9 years.

#### Insert table 1 here

# *Informal carer samples*

Across the 82 articles included in this review, the samples had 5,096 male participants (35.5%) and 9,256 female participants (64.5%). No papers had a balanced ratio of male to female participants. Twenty-three papers (28%) had less than 25% of participants who were men and 11 papers (13%) had less than 25% of participants who were women. The majority of participants were partners/spouses, followed by the adult child of the person with cancer receiving care. In the main, in the articles in this review, the number of male participants in cancer carer studies has increased over time, from under 100 in 1995 to 900 in 2015. From 2015-2018, however, the overall number decreased to under 300 (Figure 2). The next section explores the sample characteristics in further detail, separated into qualitative, quantitative and mixed method research.

# Figure 2 here

#### Qualitative research

Across the 22 qualitative studies, the samples included 316 females (54.3%) and 266 males (45.7%). Interviews were primarily used to collect data. One study (Teschendorf et al, 2007) used a focus group, and two studies used qualitative analysis derived from openended survey questions (Lindholm et al, 2007; Montford et al, 2016).

In 20 (91%) of the qualitative studies, the majority of participants were the spouse or partner of the care receiver. In the four studies (Lindholm et al, 2007; Han et al, 2016; Kejkornkaew et al, 2016; Raveis et al, 2005) that referred to 'sons' or 'daughters', there were 64 daughters and 5 sons. This figure was skewed, however, by the study by Raveis et al, (2005) who focused on only recruiting a large sample (n=50) of daughters.

Four studies contained a 100% male sample of spousal carers (Lopez et al, 2012; Hilton et al, 2000; Fitch and Allard 2007; Montford et al, 2016) and one study (Oldham et al, 2006) a 100% female sample. In the studies with all male samples, the focus was on exploring men's experiences of caring for a partner or spouse with breast or gynaecological

cancer. Oldham et al (2016) explored female experiences of caring for someone with testicular cancer.

### Quantitative research

Across the 57 quantitative studies, the samples included 8,728 females (65.3%) and 4,641 males (34.7%). All studies used a questionnaire design to meet their study aims. Questionnaires were predominantly used to examine the correlation between different variables. For example, if particular demographic and clinical characteristics were associated with outcomes such as sleep quality, guilt, adjustment, marital satisfaction, strain, depression, fatigue and quality of life. A number of studies used questionnaires to describe particular states, such as physical and mental health, or attributes, such as self-efficacy and caring motivations. Finally, other areas of research included exploring unmet needs and post-traumatic growth.

In 45 (79%) studies the majority of participants were the partner or spouse of the care receiver. Where only the relationship was reported it was harder to determine the number of men and women within particular relationships, as some papers stated the most common relationship, such as 'spouse' and some just stated 'other' or 'adult child', rather than recording 'son' or 'daughter'.

Two studies (Segin et al, 2006; Cairo Notari et al, 2017) had a 100% male sample and 2 studies (Vines et al, 2013; Fletcher et al, 2008) had a 100% female sample. These studies focused on a particular cancer type, such as breast or prostate cancer and the carers were mainly the spouse or partner of the care receiver. The researchers in these studies did not state if they intentionally wanted single sex participant samples. A possible explanation is that they happened to only recruit participants in heterosexual patient / carer relationships.

### Mixed methods

Across the three mixed methods studies, the samples had 212 females (52.9%) and 189 males (47.1%). The majority of participants were spousal carers, but daughters, mothers and sisters were also included (Beaver et al, 2007). All three studies synthesised questionnaire findings with data from semi-structured interviews to meet their study aims.

Two studies (Soothill et al, 2001; Beaver et al, 2006) explored the needs of carers. Hawkins et al (2009) examined changes in sexuality and intimacy amongst spousal carers.

### DISCUSSION

This systematic review has quantified for the first time the composition of men and women in carer research samples within the context of a cancer diagnosis. Overall, for every man included in carer research of this type, there are two women; 35.5% of study participants were men, 64.5% were women. Qualitative and mixed method studies were more balanced, with more equal proportions of men (45.7%) and women (54.3%) and there were some studies that focused solely on the male experience. Quantitative studies were more unbalanced; 34.7% were men, 65.3% women. These findings have important implications relating to the terminology and sampling approach used in research examining the experiences of carers of people living with cancer.

# Carer terminology

Carer terminology is neutral – in theory – yet, perhaps, *gender-biased* in practice. In the context of this review, the term 'carer' or 'caregiver' is used to refer to a *person* who provides support and assistance to someone who has a cancer diagnosis. Therefore, the term itself does not signify gender or the relationship to the person receiving care. Our review has identified that the term is predominantly used in cancer research to encapsulate the *female* carer (partner/daughter) experience, yet, this is rarely highlighted in studies. This potentially downplays possible differences in carer's experiences which might inhibit understanding of the supportive care needs of men and women who care.

## Carer sampling

Sampling in carer research may be *gender-blind*. For example, within the wider context of health research, Phillips and Hamberg (2016) discuss the idea of researchers being 'gender blind' after finding that only 6% of randomised control trials from high impact medical journals discussed sex/gender in the analysis and interpretation of results. This, they argued, had serious implications for the understanding of the relationship between gender and health outcomes. Within the carer literature, the term carer is (theoretically) gender neutral, so researchers may not consider gender to be an important factor in

sampling strategies or relevant to their study's aims. Understandably, as caring is the focus of the study, recruitment strategies tend to focus on identifying 'carers' irrespective of their gender. Authors use inclusion criteria based on factors such as relationship to the care receiver (e.g. spouse), proximity to the care receiver (e.g. living in the same household) or hours of care provided. Alternatively, in some studies researchers asked the person receiving care to nominate who they felt supports them the most (Larbert et al, 2017). However, this prioritises role over the compositional characteristics of the individual, such as gender, ethnicity, socio-economic status, that existed *before* they became a carer. With the exception of studies specifically focused on gender this may be detrimental as it potentially skews understanding of the caring experience.

# Understanding the imbalance

To begin to disentangle issues such as gender bias and gender blindness it is important to consider why there are a disproportionate number of females in cancer carer samples. Two explanations may be likely. First, studies included in this review, like many other studies, relied on convenience sampling (Pruchno et al, 2008). That is, participants were selected due to their accessibility and proximity to the researcher. The advantage of convenience sampling is that it is cost-effective and practical (Fredman et al, 2004). However, a limitation is that it can lead to underrepresentation in the sample. For instance, Pruchno et al (2008) and Fredman et al (2004), when comparing characteristics of carers recruited through random sampling to convenience sampling, found that participants recruited through convenience sampling were younger, more likely to be female, and to have a better education and higher levels of carer burden. This is likely because convenience sampling is shaped by self-selecting bias (Eitkan et al, 2016). Participants tend to be more motivated and better connected to their communities, so have better knowledge of services and recruitment opportunities (Brodaty et al, (2014). If sampling and recruitment strategies can affect study findings, it becomes even more important to balance the gender composition of the sample where possible.

Second, there may be differences in men's and women's willingness to take part in research. Scholars have reflected upon sampling issues in qualitative research, including difficulties in recruiting men (Brown, 2001). For example, Cornwell (1984) interviewed family members about health and illness and reported that she did not have any problems

recruiting women but that men were more reluctant, with several refusing to take part. Similar challenges are discussed by Oliffe and Mroz (2005) and Schwalbe and Wolkomir (2001). Possible explanations for these challenges include the researcher/participant gender dynamic and what has been termed by Schalbe and Wolkomir (2001) as the 'threat potential' of the interview.

The gender of the interviewer has been raised as an important factor in willingness to take part in research. For instance, when the interview topic is deemed to be sensitive, female gender has been framed as a beneficial resource, as it can encourage participation and openness (Lohan, 2000). Chapple and Ziebland (2002) explored how prostate cancer affected men's sense of masculinity and asked their participants (*n*=52) if they would like to be interviewed by a man or a woman; all but one asked for a woman. Yet, in contrast, it has also been proposed that when researching 'sensitive' topics such as sexuality, violence or mental illness, same-sex interviews may be preferred by male participants, as they may offer a sense of shared masculine identity and rapport (Broom et al, 2009; Smith and Braunack-Mayer, 2014). Accordingly, it seems that before the research has even started, gender may affect recruitment.

Brown (2001) acknowledges, furthermore, that in tandem with the gender of the researcher, the interview topic can affect participation. Brown (2001) and others (Oliffe and Mroz, 2005; Pini, 2005; Walby, 2010) have discussed men's reluctance to talk about their health within research. Emotions play a significant role in the discussion of health (and illness) as these conditions can evoke feelings of, for example, fear, shame, sadness and guilt (Bowman, 2001). Consequently, Affleck et al, (2012), discussing qualitative interviews and different theories of emotional inexpression, believe it is likely that the level of emotional discussion required within a long interview on a topic, such as illness, may be uncomfortable and perhaps daunting for some men. For that reason, some men may be reluctant to talk about their caring experiences in a research interview and do not volunteer to take part.

We acknowledge that men are not a homogenous group. Men do take part in research and are comfortable talking about sensitive or difficult issues within a research interview. Indeed, there was an overall higher proportion of male participants (45.7%) in the qualitative studies than in the quantitative (34.7%) studies, suggesting that researchers are

committed to recognising and researching the male carer experience. Moreover, our study indicates that male participants are willing to share these experiences, when asked. It has also been suggested that researchers may wish to consider other research methods, such as photo-voice and visual storytelling, to encourage more men to participate in research (Affleck et al, 2012).

## *Implications for future research*

Taking this into consideration, the research community should reflect upon these sampling issues and move towards ensuring research samples represent the extent to which men and women are involved in informal caring. The evidence suggests that in some countries there are relatively balanced (41-51%) numbers of males and females providing care and that carer profiles vary by age and ethnicity. Yet this has not translated into carer research samples. There would thus be great merit in trying to understand the barriers to men's participation in research. We recommend that researchers consult men when designing carer studies, not only to discuss their study's proposed aims and data collection methods but also to consider how to increase men's participation in research. Masculinity intersects with factors such as age, socioeconomic status and ethnicity, and researchers should endeavour to consult as broadly as possible to capture the perspectives of men who are not always heard.

It has been proposed that support for carers could be tailored to their gender (Ussher et al, 2009). This is underpinned by a belief that men and women who care have different support needs and should be supported differently. It has been suggested, for example, that men are more task-oriented and focused on problem-solving in their approach to care and that women are more emotion-focused (Pretorius, 2009; Navaie-Waliser et al, 2002). This may affect preferences for support; Milligan and Morbey (2016) consider that male carers may be less likely than women to access supportive services as they feel their needs are different.

Nevertheless, help-seeking is complex. In the context of living with cancer it was reported that men do engage in help-seeking activities but were most uncomfortable asking for help to manage their distress. More research is required that directly compares male

and female experiences, perceptions and support preferences (Greenwood and Smith, 2015). This would provide a rationale for balanced research samples in order to understand the carer experience equally from the perspectives of men and women. It was not the intention of this review to reinforce difference; its aim was to encourage parity. Caring is emotionally and practically demanding. In order to support those who care, and reduce the likelihood of negative experiences among carers, it is vital that the contribution both male and female carers offer is recognised in research.

## Strengths and Limitations

Our study is significant as it is the first time that the gender composition of international research samples of people caring for someone living with cancer has been reported. However, it has limitations. First, despite our efforts to conduct a broad search it may have failed to identify all articles in the field. There is selection bias as we did not include studies published in languages other than English, unpublished studies, 'grey literature' and dissertations.

Second, we did not include studies that focused on end of life or paediatric care, due to the distinct experiences these carers face. Nor did we include carers who were unrelated to the person receiving care by blood or marriage. The term carer can include a wide range of relationships including friends, neighbours and work colleagues. We recognise that expanding the inclusion criteria to include studies in end of life and paediatric care and a broader definition of carer may have changed the findings reported. Future research, replicating the approach used in this study, should be conducted to assess the composition of carer samples using a wider definition of the term carer and broader focus of study. Finally, we acknowledge that our findings are unique to the cancer context. There are differences in caring for someone with cancer in comparison to, for example, frailty. Therefore, the range of tasks the carer is engaged in and time spent caring will impact on the availability of carers for research studies.

# **CONCLUSION**

Men are underrepresented in carer samples. We therefore know less about their experiences and this has implications for the conceptualisation of care within the context of cancer. Accordingly, our findings are a catalyst for researchers to question their assumptions surrounding the carer role. This is necessary because sampling in carer research may be gender-blind. Researchers may not consider gender to be an important factor in sampling strategies. Yet, there is evidence to the contrary. Gender and the caring experience are inextricably linked. For that reason, when designing research to understand the impact of caring, researchers should ensure that male carers are provided with the opportunity to take part. This is important for developing a more comprehensive understanding of the caring experience to inform and develop supportive interventions.

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Conflict of interest statement

The Author(s) declare that there is no conflict of interest.

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