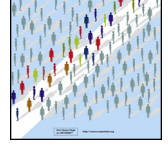




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Review article

Barriers and facilitators for male carers in accessing formal and informal support: A systematic review



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ABSTRACT

Unpaid, informal carers play a vital role in supporting people with long-term conditions. Being a carer can be challenging and carers may need support but they frequently fail to access it. Compared to research investigating the experiences of female carers, research with male carers is underdeveloped. The available evidence suggests male and female carers have many experiences in common but some research suggests that compared to females, male carers are even less likely to access services.

The aim of this systematic review was therefore to synthesise research investigating adult male carers' experiences of accessing formal and informal support focussing on the barriers and facilitators.

Nine health and social care electronic databases were searched (e.g. PubMed, PsychINFO, CINAHL Plus, Social Policy and Practice, Scopus). Seven studies (five qualitative and two quantitative) fitting the inclusion criteria were identified. All came from North America and most focussed on older carers caring for people with dementia. All seven studies described barriers to accessing support and three highlighted facilitators. Male carers felt committed to their role, seeing it as their responsibility but were often ambivalent about seeking help. Insufficient service information was frequently emphasised. Participants highlighted positive past experiences and professional or voluntary sector support in providing information and helping access services.

Research into male carers' experiences in accessing support remains underdeveloped. Research that distinguishes between, for example, the experiences of spouses and sons and with direct comparisons between male and female carers is needed. Whether gender specific services would benefit male carers remains undetermined.

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1. Introduction

Carers, or caregivers as they are also known, provide unpaid care often for family members with illness or disability. With increased life expectancy and growing numbers of people living with long-term conditions, numbers of carers worldwide are rising [1]. For example, in England and Wales between 2001 and 2011, carer numbers increased from 5.2 million to 5.8 million [2]. In the United Kingdom (UK) overall, this figure is projected to rise to approximately 9 million by 2037 [3].

Female carers outnumber male carers. In the UK, nearly three in five carers are female but male carers clearly still provide a huge amount of unpaid support. Furthermore the profile of carers changes with age. In the UK, for example, men aged over 85 years exceed female carers [2].

Whilst there are positive aspects to caring [4,5], there are also challenges. The negative impact of the caring role is often conceptualised as burden [6] and can include negative effects on carer mental health and quality of life [7–9]. Carers are also more likely to be socially isolated [10,11] and often have poorer physical health than non-carers [12].

Compared to the research into female carers' experiences, research into male carers' experiences is relatively underdeveloped [13,14] especially in relation to sons as carers [15,16]. However, although the available evidence suggests that male and female carers have many experiences in common, there are some differences perhaps related to gender roles [13]. Males are reported to adopt more independent attitudes and to take more task-orientated approaches to caring, when compared to female carers, who use more emotion-focussed strategies. Research also suggests female carers report higher levels of emotional distress, poorer physical health and burden than male carers [17–20].

Despite the challenges experienced by carers, international evidence shows carers frequently fail to access both informal support from families and friends and formal support provided by health and social care services and the voluntary sector [21,22]. A variety of barriers for carers in general when accessing support have been reported including lack of information, reluctance to use services because of a sense of duty and restrictions in service use due to cost or lack of availability [21,23].

Although the evidence is mixed [18] some research suggests that male carers are also less likely to access formal support services [24,25] and social support [26] than females. Reasons for gender differences are unclear but some research indicates male carers feel their needs are different to those of females, in part because they are less well recognised in the caring role by society and professionals [27]. Carers in general, but older male carers in particular, are often reluctant to identify themselves as carers [28], which may also reduce the likelihood of using services.

Taken together, this evidence suggests that a synthesis of research concerning the experiences of male carers in accessing support is needed. Improved understanding of why male carers may not be receiving the support they require, is very important.

Not only do male carers deserve help with their role but also, since greater carer distress and burden are related to earlier institutionalisation of those being cared for [29], supporting them is vital to avoid premature institutionalisation.

2. Aim

The aim of this systematic review was to identify and synthesise research investigating male carers' experiences of accessing formal and informal support focussing on perceptions of the barriers and facilitators.

3. Methods

The review followed the Centre of Reviews and Dissemination (CRD) guidance [30] and was reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines [31].

3.1. Electronic search strategy

The following electronic databases were searched: PubMed (1946 to July week 2 2015), Embase (1980 to July week 2 2015), PsychINFO (1967 to July week 2 2015), CINAHL Plus (1937 to July week 2 2015), the Allied and Complementary Medicine Database (AMED—1985 to July week 2 2015), Social Policy and Practice (SPP—1981 to July week 2 2015), Social Sciences Citation Index (SSCI—1970 to July week 2 2015), Scopus (1960 to July week 2 2015) and the Applied Social Sciences Index and Abstracts (ASSIA—1987 to July week 2 2015).

The Embase search strategy was as follows: the MeSH (Medical Subject Heading) terms used are reported in italics and key words with truncation where appropriate: (*exp caregiver* OR care giver* OR care-giver* OR caregiver* OR carer* OR informal carer* OR informal caregiver* OR informal care giver* OR informal care-giver* OR family caregiver* OR family care giver* OR family care-giver* OR family carer*) AND (*perception* OR barrier* OR facilitat* OR enable* OR access* OR awareness*) AND (*men* OR spouses OR male* OR gender* OR sex) AND (*social support* OR community health services OR home care services OR day care OR home nursing OR health services OR self-help groups OR voluntary health agencies OR counseling OR counselling OR formal support OR social care OR community care services OR personal care OR telecare OR statutory service* OR voluntary service* OR respite OR day centre* OR peer support* OR befriender* OR support group* OR informal support OR famil* OR friend*).

Similar search strategies were developed according to the specific database and consisted of both MeSH terms and key words. Key words and combinations were the same throughout the database searching.

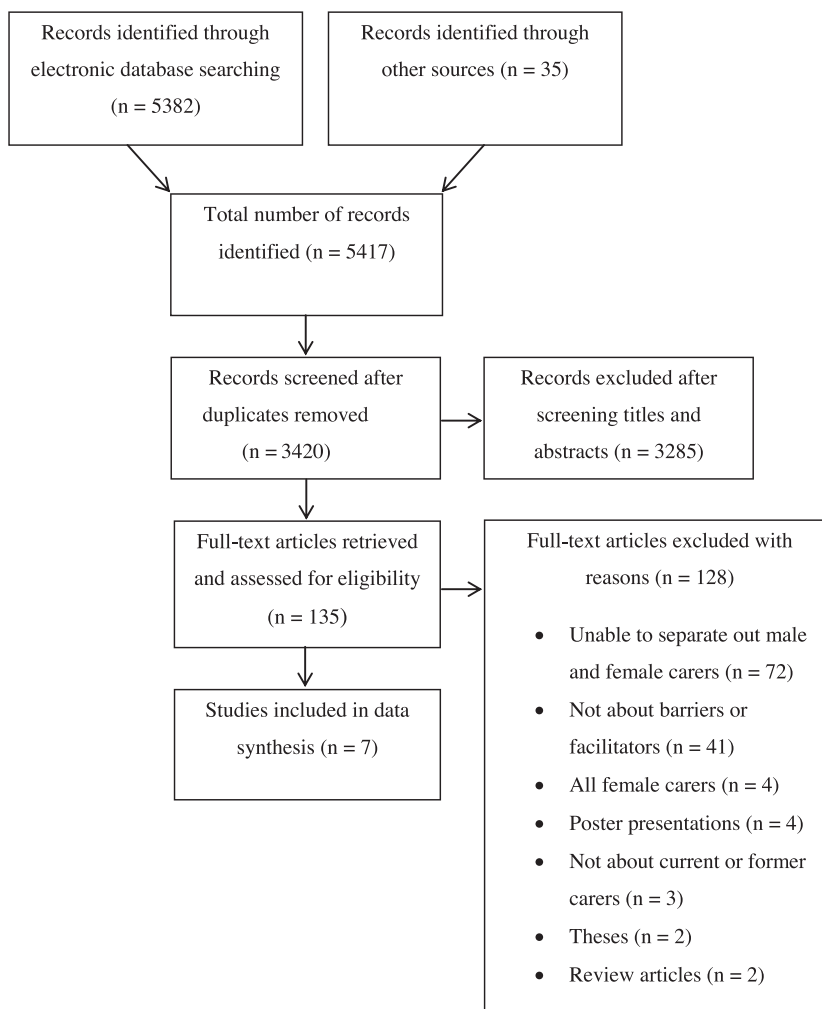


Fig. 1. PRISMA [31] flow diagram showing the process of including and excluding retrieved articles.

3.2. Other sources searched

Reference searching of relevant systematic reviews retrieved from electronic searches and included articles was undertaken. Experts in the field of research identified from the literature searches were also contacted to identify other potentially relevant unpublished articles.

3.3. Screening

Article screening was conducted in three stages: duplicate removal, title and abstract screening and full text screening. Screening was piloted to enhance consistency among reviewers in applying eligibility criteria.

First, all article duplicates were removed. Next the two authors independently screened titles and abstracts. Any discrepancies were resolved by discussion. Copies of articles appearing to meet the inclusion criteria based on the title and abstract checking were obtained for full text review. Occasionally it was impossible to determine article relevance on the basis of the title and abstract, therefore full text copies were screened.

Finally, full manuscripts of any relevant titles and abstracts were obtained and independently scrutinised by the authors. Multiple publications from the same study population identified during full-text review were screened for data duplication. Reasons for

exclusion were tracked. Again discrepancies were resolved by discussion.

At this stage of the screening process, one author scanned reference lists of the included studies and relevant reviews for potentially relevant references not identified from the database searches. Eligibility or otherwise, was confirmed by a second reviewer.

3.4. Study selection criteria

There were no date restrictions. Research studies were included if they were published in English in peer reviewed journals, used qualitative, quantitative or mixed method and were primary research. To be included they also needed to:

- Investigate the experiences of adult male carers of people in living in the community.
- Investigate formal or informal support.
- Report barriers and/or facilitators to accessing services.

Articles were excluded if they were reviews, commentary articles or letters and it was impossible to distinguish between findings for males and females. They were also excluded if they investigated:

- Carers under 18 years old.

Table 1
Study methods and aims.

Author (year); country	Study type, design & sampling	Study aims	Support explored	Data analysis
Brown, Chen, Mitchell & Province (2007); [37] USA	Qualitative Cross-sectional Convenience	Gain understanding of help seeking process of older husbands caring for wives with dementia	Informal: friendships Formal: e.g. cleaning services, home health aides, day care centres & medical support	Thematic, informed by grounded theory
Coe & Neufeld (1999); [38] Canada	Qualitative Longitudinal Convenience	Explore male carers' perceptions of formal support	Formal: support services generally	Grounded theory techniques
Harris (1993); [39] USA	Qualitative Cross-sectional Non-random purposeful	Gain insight into world of male carers	Formal & informal: peer support	Thematic
Laditka, Pappas-Rogich & Laditka (2001); [40] USA	Quantitative Cross-sectional Convenience	Examine gender differences in carers' use, interest in & barriers & attitudes towards services	Formal: e.g. home health care, hospice care, adult day care, personal counsellors, meals-on-wheels, support groups	Chi-squared; Fisher's Exact for gender comparisons
Neufeld & Kushner (2009); [41] Canada	Qualitative Longitudinal/ethnographic Convenience	Explore carers' perceptions of non-supportive & supportive interactions with family, friends & professionals	Formal: support services generally	Thematic with matrices & typologies
Sanders (2007); [42] USA	Qualitative Longitudinal Convenience	Examine male carers' experience of informal support networks	Informal: family & friends	Thematic
Zodikoff (2007); [43] USA	Quantitative Cross-sectional Convenience	Examine gender differences in attitudes towards community services	Formal: e.g. personal care, cleaners, support groups, information, emergency response system, medical transport, day care, health care workers (e.g. nurses)	Descriptive statistics; T-tests; chi-squared <i>p</i> value set at < 0.10.

- Carers of people not living in the community (e.g. residential care).

3.5. Articles coming close to inclusion but excluded

Four articles came close to inclusion in the review but were excluded. One [32] was excluded because gender differences were not reported. Two [33,34] were excluded because neither barriers nor facilitators were described. Thompson et al. [35] was excluded because of the paucity of relevant findings provided.

3.6. Quality assessment

The quality of included studies was assessed independently by the two authors using the QualSyst quality appraisal tool [36]. This was selected because it permits scoring for both qualitative and quantitative studies. Disagreements in ratings were rare but where they occurred, they were discussed and consensus achieved. Studies were not excluded based on quality scores but the assessment process enhanced study interrogation.

3.7. Data extraction and management

Data were extracted using standardised data extraction forms. The extracted data were entered into tables.

4. Findings

4.1. Study characteristics

In total, 5417 records were identified, with 3420 titles and abstracts screened after duplicate removal. Of these, 135 full-text articles were retrieved and assessed for eligibility, with seven studies fitting the inclusion criteria and subsequently included in the data synthesis. Details of the process of including and excluding articles are available in Fig. 1.

All came from North America, with five from the USA [37,39,40,42,43] and two from Canada [38,41]. Five were qualitative [37,38,39,41,42] and two were quantitative [40,43]. Four were cross-sectional [37,39,40,43] and three longitudinal [38,41,42] and most used convenience sampling. No very recent studies were identified. The oldest was published in 1993 [39], the most recent in 2009 [41]. The research investigated both attitudes to formal support (e.g. day centres or home care) and informal support. Four investigated formal services only [38,40,41,43], one only investigated informal support [42]. The remaining two studies investigated both [37,39] (Table 1).

In the seven studies a total of 301 carers (mean: 43, median: 24, range: 9–169) participated. Of these 145 were males. Qualitative studies included between nine and 34 participants whilst the two quantitative studies involved 30 to 169 participants. Five studies only included male carers [37,38,39,41,42]. Carer participants were mostly husbands, generally older and over working age, although the age range in one study was 33–97 years [38]. Where participant ethnicity was described, white or Caucasian carers dominated [37,39,40,43] but three studies did not report carer ethnicity [38,41,42]. In all but two studies [40,43], care recipients had dementia (Table 2).

Study aims were broad with some focussing on general exploration of male carers' experiences of and attitudes towards formal or informal support. However, the two studies including both male and female carers focussed on identifying gender differences in perceptions or experiences [40,43].

4.2. Quality ratings

Using the quality rating scale [36], all but one study [39] scored more than 70%. Five studies scored between 70% and 75% [38,41,37,40] and one quantitative study achieved 85% [43] (Table 3). Where points were lost, this generally related to limited methodological descriptions, using convenience sampling and for

Table 2
Participant characteristics.

Authors	Total sample size; Age (years) (Mean (SD), Median, Range)	Carer gender (% male)	Carer ethnicity	Carer relationships to care recipient	Conditions of care recipient	Urban or rural
Brown et al. [37]	9 Mean: 79(NR), Median: NR, Range: 65-87	100%	9 Caucasian	All husbands	All dementia	NR
Coe & Neufeld [38]	24 Mean: NR, Median: NR, Range: 33-97	100%	NR	17 husbands 7 others including sons & sons-in-law	Alzheimer's disease, vascular dementia & cognitive impairment	Urban
Harris [39]	15 Mean: 73(NR), Median: NR, Range: 68-88	100%	14 Caucasian 1 African 1 American	All husbands	All Alzheimer's disease	NR
Laditka et al. [40]	169 Mean: 69.7(7.1), Median: NR, Range: NR	18.3%	168 Caucasian 1 NR	115 children 32 wives 9 husbands 33/NR others	All 'relatively impaired'	NR
Neufeld & Kushner [41]	5 to 34 Mean: NR, Median: NR, Range: Husband- 63–89, Range: Sons- 45 - 65	100%	NR but had emigrated from several countries	24 husbands 10 sons	All Alzheimer's or related dementia	Urban
Sanders [42]	20 Mean: 73(10.6), Median: NR, Range: 41-84	100%	NR	17 husbands 3 sons	All dementia, plus 1 or more chronic condition (e.g. emphysema, diabetes)	Rural
Zodikoff [43]	30 Mean: 75.6(8.35), Median: NR, Mean: NR	40%	24 Caucasian 5 Latino 1 Indian	18 wives 12 husbands	All 'Chronic medical condition' & 'physical health problems'	Urban

NR= Not reported

the qualitative studies, not describing the study context or considering researcher reflexivity.

4.3. Main findings

The qualitative studies reported that male carers were committed to their role and felt it was their responsibility to carer help [38,39,42]. They often felt ambivalent or guilty about asking for help [38,42]. Expectations of support were mixed and previous negative experiences of support influenced help seeking especially for informal support [37,39]. Insufficient information about available services was frequently highlighted [37,38,41].

Only three of the seven studies [37,38,41] described facilitators to accessing support for male carers. Positive past experiences and availability of both informal and formal support (including gender specific education) were described as facilitating service access [37]. Two studies described the importance of professional or voluntary sector support in providing information and helping access services [38,41].

Quantitative studies highlighted similar service related obstacles to those identified in the qualitative studies including lack of awareness of services, incomprehensible systems and male carer attitudes to service use including preference for informal support, lower confidence in services and higher worry compared to females [40,43]. These studies also revealed some gender differences in attitudes to services with males preferring formal services over informal support [40,43]. However, more male than female car-

ers reported that they were proud to care without using formal services [40].

5. Discussion

We identified few studies investigating male carers' experiences in accessing formal and informal support. This was surprising given the enormous role played by male carers and the evidence suggesting that they are less likely than female carers to access support [24,25]. Furthermore, all the included studies came from North America and we found nothing fitting our criteria published after 2009, highlighting the need for more new international research in this important area.

Barriers to accessing support were described in all seven studies. These barriers were similar both to those identified in other research looking at carers in general [21] and also to those identified for other more specific demographic groups such as black and minority ethnic (BME) carers [23]. These barriers fell into two broad categories. Firstly, service related issues which included insufficient information, poor awareness of services and service costs and secondly, male carers' attitudes to accepting support including their sense of responsibility or duty and unwillingness to relinquish responsibility to formal support services and sometimes to other family members. The reasons for this are unclear and more needs to be known about how male carers perceive the available support. For example, some evidence suggests that male carers do not find support groups as useful as females [16]. Unhelpful or unsat-

Table 3
Study findings

Authors	Quality rating	Experiences of accessing services -overall findings	Barriers	Facilitators	Conclusions
Brown et al. [37]	Quality: 70%	Largest category- 'intervening conditions' Core category- 'doing the best I can'. Action/interaction strategies- 'making choices'. Intervening conditions: 'hindering & facilitating conditions' Consequences: 'continuing on'. Accessing services included 'making concessions for care'. This category included 4 stages: resisting; giving in; opening the door; making the match. Before seeking help, it often took e.g. a critical experience or series of challenging behaviours leading to carers being unable to cope with caring.	Barriers related to 'intervening conditions' category: Prior negative experiences or interactions; potential cost of involving formal services; inadequate information & knowledge on sources of help; attitudes & values; closeness to family, friends, neighbours & church. Desire to maintain independence; sense of personal responsibility; pride; difficulty admitting need outside help; valuing family privacy; feeling obligated to do something in return; lack of service information; not knowing where to go for help; unwilling to relinquish care to formal services.	Past positive experiences; availability of willing informal sources of help; availability of gender-specific education; household management & respite care programmes. Information & help with access from e.g. health professional or Alzheimer's Society; carer actively seeking out support.	Help-seeking by older husbands is complex & gender specific. Interventions must be gender specific & complement already existing help-seeking patterns.
Coe & Neufeld [38]	Quality: 75%	Common themes: e.g. commitment to caring; social isolation; coping strategies e.g. control, a structured routine with respite, problem solving; sense of accomplishment; need for specialist services for men; limited expectations of help from children.	Specialised services for males needed; reluctance to relinquish caring role; sense of responsibility & duty; difficulty asking friends for help; social isolation from family & friends.	NR	Closer attention needs to be paid to male carers' needs as more men take on caring roles. Services need to be put in place to support male carers.
Harris [39]	Quality: 40%	CSAI data showed significant gender differences in perceived barriers to service use and in attitudes to services.	Compared to females, males statistically more likely to prefer to use community services than ask family for help ($p < 0.05$). Females statistically more likely to say the government should support more community services for carers	NR	Carers' attitudes to service use are multi-dimensional & complex. They are more likely to express interest in services than to use them
Laditka et al. [40]	Quality: 72%	Male carers experienced non-supportive interactions including: lack of orientation to the caregiving situation; unsatisfactory linkage to support sources; insufficient support; hurtful interactions.	Lack of awareness of resources; lack of information about dementia; uncertainty about what they need; uncertainty about service access due to lack of information or complex application processes; not fitting criteria; insufficient resources.	Support from voluntary sector.	Male carers' experiences of non-supportive interactions are complex & variable. Professionals may make assumptions about needs of male carers.
Neufeld & Kushner [41]	Quality: 75%	2 main themes with sub-themes were identified: 1) male carers' perception of the willingness of informal support networks to provide help: not involved with care; emergency assistance only; felt free to call if could actually help; part of the caregiving team. 2) willingness of male carers to ask informal networks for assistance: asked for assistance; did not ask for help felt guilty asking for help.	Lack of informal support meant male carers were unable to participate in activities potentially providing support, e.g. attending church; informal network willing to help but carers responsible for asking for help; want pro-active offers of help; felt guilty or uncomfortable asking for help; perception of informal support as only providing assistance as illness progressed; felt caring situation not yet bad enough; want to protect others from caring burden; felt caring their responsibility.	NR	Male carers experience unique relationships with their informal support networks dictated by perceptions of the willingness to provide help & their willingness to ask for help. More research on male carers is needed.
Sanders [42]	Quality: 75%	There were few gender differences in attitudes to services using the CSAI and none were statistically significant at $p < 0.05$.	On the CSAI, higher (n.s.) levels of fear, worry & lower confidence in the service systems were reported by male carers compared to females ($p = 0.889$). Female carers had greater confidence in services ($p = 0.049$) than males.	NR	Assessment of gender-related attitudes to service use of older spousal carers is needed. Understanding their attitudes & beliefs about the appropriateness of services for their needs is required.
Zodikoff [43]	Quality: 85%				

NR = Not reported; ns = non-significant; CSAI = Modified Community Service Attitude Inventory.

isfactory experiences with support services may well reduce the likelihood of carers attempting to access services in the future [23].

Two included studies [37,39] argued for gender specific services for males but our synthesis suggests that male carers' experiences of accessing support are very similar to the those of other demographic groups. There is some evidence that male carers can benefit from informational or skills-based interventions and distance-based interventions when they are targeted at specific problems [44] but more research directly comparing male and female carers is needed. The perspective of carers as a whole, with their unwillingness to relinquish their responsibilities to others, whether to formal services or families, is important here. Despite the known challenges to the role, carers often gain satisfaction from their role and take pride in what they do [4,5]. However, this does not mean that information about available services should not be improved or that services could not be made more acceptable to all carers—perhaps by increased flexibility and personalisation of the support offered.

Further high quality research needs to be undertaken to investigate male carers' experiences. This is not only because male carers represent a significant number of people, who play an essential role and often need support. It is also because the over-representation of female carer participants in research [45] may have led to a bias in the selection of interventions and outcomes in support provided for carers. Available evidence suggests male carers report lower burden and distress than female carers [46,7] and adopt more task orientated as opposed to emotion focussed strategies [7,26]. However, possibly because of the dominance of female carers in research, supportive interventions often focus on reducing carer burden and distress. If male carers generally suffer less from these challenges, any impact on them is likely to be less than for females [47].

5.1. Limitations of the included studies

Sample sizes of the included were mostly small and the reliance on convenience sampling limited the generalisability of the findings [48]. Caring often takes place over long periods and more long-term research is required. Furthermore, if understanding of carers' experiences is to be improved, more studies are needed that directly compare male and female carers' experiences and perceptions. This would help determine whether gender specific carer services would benefit male and female carers.

The small scale nature of these studies means that it is impossible to identify the influence of carer age and relationships with the care recipients. The majority of participants here were husbands or partners and there remains little research focussing on the experiences of sons who are likely to be younger than spouses and more likely to have additional roles and responsibilities.

Another limitation in the studies was the lack of ethnic diversity. Evidence shows that carers from BME groups are less likely to access services [23] despite the fact that they express greater need for services than their white counterparts [49,50].

The review highlights a number of possible avenues for future studies. More research focussing on male carers from a greater range of countries and health and social care systems is needed. Similarly more needs to be known about younger males from diverse ethnic groups caring for people with health conditions other than dementia. Ideally future research should directly compare male and female carers within the same studies. The evidence suggests that many barriers encountered by male carers are similar to those of carers in general [21] and carers from minority ethnic groups [23]. However, without within study cross-gender comparisons, it is difficult to know if these barriers are, for example, more significant for one demographic group than another. Finally there needs to be a move away from cross-sectional research using con-

venience samples. More longitudinal research with sampling aimed at ensuring a wider range of carer participants is required.

5.2. Strengths and limitations of the review

The review's strengths include its extensive, comprehensive and reproducible search strategy and rigorous assessment of study methodological quality using a scale developed specifically to evaluate qualitative and quantitative studies simultaneously [35]. However, it was limited by only including studies published in English, thereby potentially excluding research highlighting cultural differences. Systematic literature reviews are influenced by publication bias, where studies are more likely to be published if results are statistically significant [51]. As a result, research not identifying gender differences in the experiences of caring may not have been published and therefore will have not been identified. Finally, given the few studies specifically focussing on barriers and facilitators to male carers accessing services, we sometimes categorised the findings into these groups and may have oversimplified the complexity of the experiences of accessing services.

Conflict of interest

The authors declare no conflict of interest.

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