Social exclusion in adult informal carers: A systematic narrative review of the experiences of informal carers of people with dementia and mental illness

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A B S T R A C T

Social exclusion has a negative impact on quality of life. People living with dementia or mental health disorders as well as informal carers have been separately described as socially excluded. The objective of this systematic narrative review was to examine the extent to which social exclusion experienced by adult informal carers of people living with dementia or severe mental health disorders has been identified and described in research literature. It synthesised qualitative and quantitative evidence and included the perspectives of carers themselves and of professionals. Eight electronic databases (1997–2017) were searched. Five relevant studies published between 2010 and 2016 were identified. All were qualitative and used interviews and focus groups. Study quality was variable and most were European. Two focused on carers of people living with dementia and three on carers of people with mental health disorders. Four investigated carers' perspectives and experiences of social exclusion directly (total of 137 carer participants, predominantly parents, spouses and adult children), while the fifth focused on the perceptions of 65 participants working in health and social care. Stigma, financial difficulties and social isolation were highlighted in four studies and the challenges for carers in engaging in leisure activities were described in the fifth. Most conceptualised social exclusion as a form of stigma, or as resulting from stigma. One presented social exclusion as an element of carer burden. Two explicitly discussed the negative effects of social exclusion on carers. The dearth of research and the lack of specificity about social exclusion in carers was surprising. Future research should investigate aspects of social exclusion that may adversely affect carer well-being.

1. Introduction

Social exclusion is generally acknowledged as negative and is associated with the experiences of marginalised groups such as people with dementia, severe mental illness and informal often family carers. Social exclusion comprises a wide range of domains including limited or non-participation in economic, educational, political and leisure or cultural activities and social relationships. It is a multi-faceted concept and can be defined in a variety of ways. For clarity we have adopted the following definition:

'Social exclusion is a complex and multi-dimensional process. It involves the lack or denial of resources, rights, goods and services, and the inability to participate in the normal relationships and activities, available to the majority of people in a society, whether in economic, social, cultural or political arenas. It affects both the quality of life of individuals and the equity and cohesion of society as a whole' [1]. Social exclusion can also incorporate

other areas, such as exclusion from politics (e.g. voting), unemployment and poverty [2].

Amongst the many available definitions of social exclusion, it is possible to identify some key features; social exclusion is multi-dimensional and dynamic – people may move between being socially included and socially excluded at different times of their lives. It occurs on multiple levels, not only affecting the individual but also families and communities [3]. It is also clear that people can be both socially included, for example included within certain sub-cultural populations, whilst at the same time being excluded from the wider community. However, the concept's complexity and overlap with poverty have led some to regard social exclusion as a 'contested concept' [4].

One example of the challenges of understanding social exclusion, its impact and causal relationships is the role played by stigma and discrimination. Some authors [5] have argued that stigma is a key driver to social exclusion whilst others view stigma and discrimination as

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Table 1
Example electronic search strategy conducted in Medline.

	Concept	Search terms
1	Carers	*Caregivers* OR caregiver$ OR care giver$ OR care-giver$ OR carer$ OR informal caregiver$ OR informal care giver$ OR informal care-giver$ OR informal carer$ OR family caregiver$ OR family care giver$ OR family care-giver$ OR family carer$ OR primary caregiver$ OR primary care giver$ OR primary care-giver$ OR primary carer$
2	Social exclusion/inclusion	Social exclusion OR social inclusion
3	Health condition	*Dementia* OR dement$ OR *Alzheimer Disease* OR Alzheimer$ OR *Substance-Related Disorders* OR *Alcoholism* OR addiction OR substance misuse OR *Mental Disorders* OR mental illness$ OR *Psychotic Disorders* OR psychosis OR personality disorder$ OR bipolar disorder$ OR schizophreni$ OR depress$ OR *Anxiety* OR *Anxiety Disorders* OR anxiety OR schizoaffective OR post-traumatic stress disorder OR PTSD

Note: The MeSH (Medical Subject Heading) terms used are reported in italics and key words with truncation where appropriate.

mediators to social exclusion [6].

Despite the challenges in defining and conceptualising social exclusion, it is generally accepted that social exclusion is both a risk factor for and a consequence of poor mental and physical health [7–9] and poorer quality of life [10]. Reducing social exclusion and improving social inclusion are therefore policy priorities in countries such as England and Wales – for example, the National Dementia Strategy [11] for people living with dementia, the National Carers Strategy [12] for unpaid, informal carers, and strategies for people with mental health disorders [13].

1.1. Social exclusion, mental illness, dementia and informal carers

People with severe mental health disorders are regarded as some of the most socially excluded in society [14–15] and there is a substantial body of literature investigating social exclusion in this group [4,7,16]. Similarly, people living with Alzheimer's disease and other forms of dementia [17–20], are also regarded as socially excluded.

Informal carers are often family members and have been defined as someone who "*spends a significant proportion of their life providing unpaid support to family or potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems*" [12]. These carers are often at risk of being socially excluded, with many reporting having to give up employment, suffering financial difficulties and worsening mental and physical health problems [21].

Given this combined evidence that people with severe mental health conditions and dementia are two of the most socially excluded groups and it is also believed that informal carers can suffer from social exclusion, it is important to identify the available evidence specifically for social exclusion in carers of people with these conditions. However, we have been unable to identify any such synthesis.

This review therefore aims to examine the extent to which social exclusion in informal carers of individuals with severe mental health disorders or those living with dementia has been identified and described in the research literature

1.2. Aims and review questions

The aims of this review are to investigate and synthesise the evidence for social exclusion amongst informal, unpaid carers. More specifically, the research questions are:

1. How is social exclusion described and what dimensions of social exclusion are identified in research with informal carers of people living dementia and carers of people with severe mental health disorders?
2. Is there any evidence that social exclusion in informal carers has an impact on their wellbeing?

2. Methods

The review followed the Centre of Reviews and Dissemination (CRD) guidelines [22] and was reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines [23].

2.1. Electronic search strategy

Eight electronic databases were searched from 1997 until November 2017. The Social Exclusion Unit is a United Kingdom (UK) government body set up to oversee the development of projects to reduce social exclusion among disadvantaged people in England [14]. This start date for including papers was selected because this is when the Social Exclusion Unit was established and reducing social exclusion became a national policy priority. This cut off was also selected because it covered the last two decades, a reasonable period of time that is both comprehensive and more likely to be relevant to current situations worldwide. The following data bases were searched: Medline; Embase; PsychINFO; Cumulative Index to Nursing and Allied Health Literature (CINAHL Plus); Social Sciences Citation Index (SSCI); Allied and Complementary Medicine (AMED); Scopus and Applied Social Sciences Index and Abstracts (ASSIA).

The search strategy for Medline is provided in Table 1 as an example. Similar search strategies were developed according to specific database requirements and consisted of both keywords and Medical Subject Heading (MeSH) terms. Keywords and combinations applied were the same throughout database searching. In order to keep the review focussed and increase the number of relevant papers retrieved by the electronic searches, we specifically limited the search to include only 'social exclusion' or 'social inclusion' as described by the study authors.

2.2. Inclusion criteria and study selection

Inclusion criteria:

1. Primary research published in peer-reviewed journals (between January 1997 and November 2017)
2. English language
3. Qualitative, quantitative or mixed methods
4. Describing or measuring social exclusion in informal, adult or young carers of people with diagnosed severe mental health disorders (including psychoses and addictions) and dementia living in the community.

Exclusion criteria:

1. Grey literature
2. Not peer reviewed
3. Reviews, commentary and opinion publications

Following duplicate removal, all authors screened the titles and abstracts to identify those potentially fitting the inclusion criteria. Full texts of these articles were then scrutinised. Where there was uncertainty about inclusion, consensus was achieved by discussion.

2.3. Other sources

Authors of the included articles were contacted to ask if they were able to identify any additional literature fitting the inclusion criteria. Reference lists of relevant systematic reviews and the included studies identified from the electronic database searches were also searched.

2.4. Data extraction and management

Data were entered into standardised tables which included study aims, methods, findings and overall conclusions.

2.5. Data synthesis

Given the broad research questions and studies reporting qualitative findings, narrative synthesis was selected [24].

2.6. Quality appraisal

The quality of included studies was assessed independently by two members of the research team using the Critical Appraisal Skills Programme quality appraisal tool [25]. Any differences in ratings were identified and consensus achieved through discussion. No studies were excluded based on quality scores but quality assessment allowed interrogation of the methodological quality.

3. Results

Electronic searches identified a total of 274 articles before duplicate removal: Medline – 32; Embase – 37; PsychINFO – 45; SSCI – 58; CINAHL Plus – 16; AMED – 0; Scopus – 32 and ASSIA – 54. After duplicate removal, the titles and abstracts of the remaining 180 articles were scrutinised and 24 full texts were retrieved. From the searches, only one relevant systematic review was found and retrieved for reference checking (Novais et al.) [26]. *No literature reviews were found which specifically explored social exclusion in informal carers.* Reference list searching of studies, contact with experts in the field of research and hand searching the Journal of Mental Health and Social Inclusion revealed eight new potentially relevant articles. Of these, one was retrieved as full-text but it did not fit the inclusion criteria. In total five studies fitted the inclusion criteria, all of which were qualitative (Fig. 1).

Three studies were subject to considerable deliberation by the review team but were finally excluded. Fernando et al. [27] discussed stigma in detail but did not explicitly relate it to social exclusion and although Forbes et al. [28] mentioned social exclusion in carers, its focus was on social exclusion of the people with dementia and gave too little detail for inclusion. For example, it only included a very brief discussion of exclusion of families in decision making for the people they care for. Similarly, Moore et al. [29] also provided insufficient data for inclusion in the review, for example, giving only one brief quote discussing stigma surrounding caring for parents with substance misuse difficulties.

3.1. Included studies

Five studies fitting the inclusion criteria were identified (Table 2). All investigated adult carers. Four investigated the perspectives of carers directly and included a total of 137 carer participants. One, Daly et al. [30] focussed on the perspectives of 65 health and social care volunteers and professionals. Carer gender was not always identified but overall there appeared to be more female carers. None of the five studies reported participant ethnicity. Carers were predominantly parents, spouses and adult children. Two studies focussed on carers of people living with dementia and three on carers of people with mental health disorders. Two were undertaken in the UK, with one each in

Sweden, the Netherlands and West Africa. All were qualitative and employed interviews or focus groups, with a mixture of analysis including thematic and content analysis. Publication dates ranged from 2010 to 2016.

Study quality was assessed using the CASP (2017) and scored out of 10 as has been conducted in other systematic reviews [31]. Study quality was variable and ratings ranged from four (Gray et al.) [32] to nine (Daly et al.) [30] (Table 4). None of the studies included sufficient discussion of researcher reflexivity and several studies received lower scores because the appropriateness of the design was not made explicit.

Four studies [30,32–34] focused on stigma, carers' financial difficulties and social isolation, whilst Innes et al. [35] focused entirely on challenges for carers in engaging in leisure activities.

One of the aims of the review was to identify how study authors described social exclusion and what dimensions were included. All studies apart from Innes et al. [35] conceptualised social exclusion as a form of stigma, or as the result of stigma [32,34]. For example, van der Sanden et al. [34] concluded that informal carers of people with mental health problems suffer social exclusion due to stigma by association. Others described social exclusion as resulting in marginalisation and isolation [32] and barriers to accessing leisure activities [35]. Ae-Ngibise et al. [33] presented social exclusion as an element of carer burden whilst Innes et al. [35] described social exclusion solely in terms of restrictions in leisure participation as a result of caring for someone with dementia (Table 3).

In relation to our second research question, only two studies [33,34] explicitly discussed social exclusion in relation to carer wellbeing. Ae-Ngibise et al. [33] stated that carers who were socially excluded reported reduced wellbeing. Van der Sanden et al. [34] who described social exclusion as a type of stigma, also claimed that stigma affected carers' mental wellbeing, social life, and social networks.

4. Discussion

Carers of people with dementia or mental health disorders were selected for the review because both these health conditions are recognised as stigmatising [8,37] and people with the conditions are often said to be socially excluded [37,38]. It was therefore anticipated that their carers may also be socially excluded. The dearth of studies investigating social exclusion in these carers was therefore unexpected.

As a result of the lack of available research and the wide range of contexts in which it was undertaken, we have been unable to identify any universal or central dimensions of social exclusion for carers. The fact that there is so little research in this area is perhaps a reflection of the complex and multi-faceted nature of social exclusion. We found that many authors used the term loosely and it was not explicitly defined. Furthermore, the included studies here tended to look at only one aspect of exclusion, or referred instead to specific difficulties experienced by carers, particularly in terms of social relationships, work and leisure activities, rather than considering social exclusion as a broader concept.

One of the challenges of the review was synthesising study findings where the authors conflated exclusion with stigma and burden. Unlike, for example, Ae-Ngibise et al. [31], we would argue strongly that social exclusion should not be subsumed under carer burden. The concept of burden is already very broad and includes the emotional, social, physical, and financial consequences of caring and is increasingly criticised for being vague and over-inclusive [37]. To include social exclusion as part of burden would only compound this further.

Government policy in the United Kingdom (UK) refers to social exclusion in informal carers [12] but there appears to be very little research evidence for this. We identified no research specifically investigating paid employment and social exclusion in carers. This is surprising given the evidence that being an informal carer affects carers' employment with many moving to part-time paid employment or leaving work altogether with considerable loss of income [40]. This clearly has not only consequences for carers and their families but also
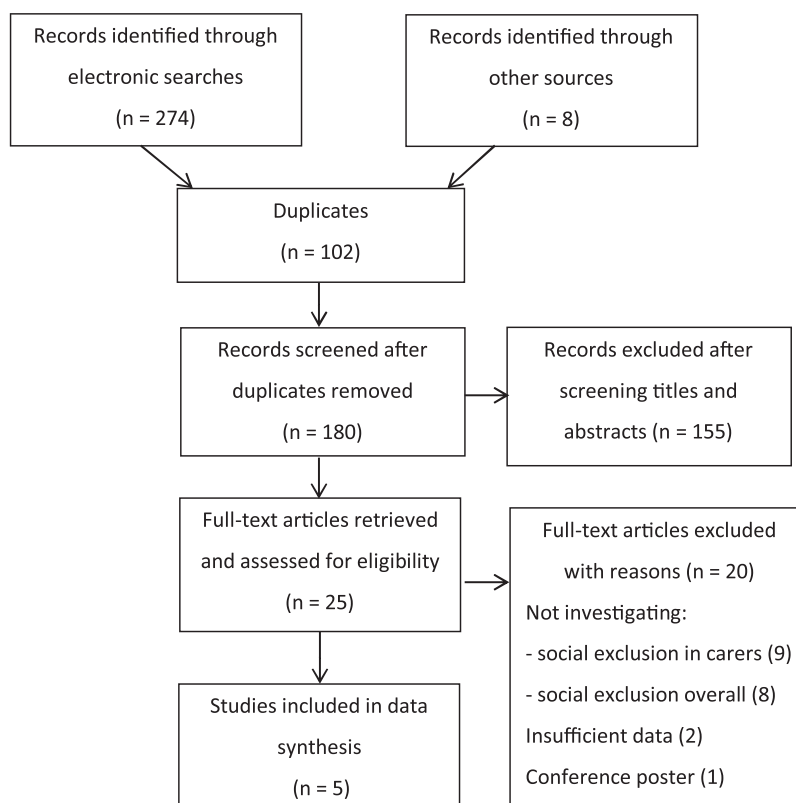
Fig. 1. PRISMA (Moher et al., 2009) [23] flow diagram showing the process of article identification and selection.

for society as a whole – estimated to be an annual loss to the UK economy of £5.3 billion [41]. Further, there is a dearth of evidence surrounding how social exclusion affects carers' wellbeing. This is surprising given, that for example, the UK 2014 Care Act highlights the need for local authorities to promote carers' wellbeing through participation in work, training, education or recreation [42]. Therefore, there is a need for future research.

Like the concept of burden [39], care must be taken to ensure that the term social inclusion is not too inclusive and used too generally, which would make it difficult to both measure and change. To make it more relevant and useful when trying to improve the lives of carers, it may be more appropriate to focus on specific domains of social exclusion, such as paid employment, leisure activities or socialising.

4.1. Limitations of the included studies

The studies were small and of variable quality. Although participant recruitment was usually described as purposive, sampling was often unclear and authors, for example, failed to identify why potential participants did not take part. In addition, in general neither the carer participants nor the specific cultural or economic contexts were sufficiently well described. Insufficient recognition and discussion in these studies relating to the impact of cultural understandings of dementia and mental health disorders also raise questions about the generalisability of the findings.

4.2. Limitations of the review

Despite a comprehensive search in eight electronic databases, very few studies explicitly investigating carers' social exclusion were found. None directly answered the review questions. One of the unexpected challenges of the review was discovering that, although social exclusion was alluded to, it was often neither explained, defined nor elaborated upon, making it impossible to know precisely what the authors meant

by the term. Indeed, even the included studies rarely directly referred to social exclusion, leaving the reader to interpret the findings.

Carer diversity needs to be acknowledged. The two groups of carers and the health conditions of those they support are likely to be different. For example, people diagnosed with dementia are largely older and dementia is a progressively debilitating condition. In contrast mental health disorders are frequently relapsing and remitting conditions, predominantly affecting younger adults. Their carers are therefore also likely to be slightly different, with carers of people with dementia more likely to be either spouses or adult children than those supporting people with severe mental health disorders.

Finally, an important limitation of the review that needs to be acknowledged is that it only included English language research papers.

4.3. Implications and future research

Future research needs to identify precisely what is meant by social exclusion in informal carers and how carer characteristics (e.g. age, ethnicity, gender) may affect this.

We identified no quantitative studies or quantitative scales intended to measure social exclusion in carers. This is clearly an area for future exploration – it could be used to identify socially excluded carers and is a different and arguably more useful concept than, for example, 'burden'. Understanding social exclusion in carers might help identify issues that could potentially be improved with interventions. However, the lack of conceptual clarity about social exclusion makes measurement challenging. Mixed-methods research is needed to identify how carers are being socially excluded from their perspectives.

Authors' contributions

Nan Greenwood conceived and designed the review.
Gillian Mezey conceived and designed the review.
Raymond Smith performed the literature search.

Table 2
Study characteristics and methods.

Authors and Country	Study aims	Carer participants (n) [% female]	Health professional participants (n)	Age (years)	Urban or rural setting	Health condition of person being cared-for	Data collection methods	Data analysis
Ae-Ngibise et al. [33] Ghana	To explore the experiences of carers of people with severe mental illness living in rural Ghana.	75 [56%} Parent 42.7% Sibling 32.0% Adult child 17.3% Others 8%	N/A	20% 16–34 yrs 60% 35–64 yrs 20% 65+ yrs	Rural	'Serious mental disorders'	In-depth interviews, focus groups	Framework analysis
Daly et al. [30] Ireland	To develop a theory to explain the social processes employed by carers of people with dementia to manage alterations to interactions within their social worlds.	20 [NR] Relationship NR	10	NR	NR	Dementia	In-depth, one-to-one interviews	Coding to identify substantive codes
Gray et al. [32] UK	To explore professionals' experiences and perspectives of patterns of carer social exclusion.	N/A	65 from health, social care, voluntary sectors	NR	Urban and rural	'Mental health problems'	In-depth, semi-structured interviews	Latent content analysis
Innes et al. [35] UK	1) To explore the views and experiences of people with dementia and their family members about to barriers to leisure participation and how this influenced their leisure behaviour. 2) To understand how such barriers might be addressed to maximise opportunities for greater leisure participation among households affected by dementia.	19 [84%] Spouse 68.4% Daughter/son 21.1% Other 10.5%	N/A	NR	Urban and rural	Dementia	Focus groups	Thematic analysis
van der Sanden et al. [34] Netherlands	1) To explore the experiences of stigma by association and burden on the families of people with mental illness. 2) To explore how family members coped with stigmatisation and burden.	23 [52.2%] Family (child, parent spouse, sibling)	N/A	Mean age – 44.3 yrs (SD 12.6) Range – 25–64	NR	Various including depressive/bi-polar/mood disorder; PD and ADHD	Face-to-face, semi-structured interviews	Thematic content analysis

Key: NR: not reported; N/A: not applicable; PD: personality disorder; ADHD: attention deficit hyperactivity disorder; UK: United Kingdom; yrs: years.

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Table 3
Findings relating to social exclusion and health and wellbeing impact on carers.

Authors	Authors' explanations or descriptions of social exclusion and dimensions investigated	Health and wellbeing	Authors' conclusions relating to social exclusion/inclusion
Ae-Ngibise et al. [33]	Social exclusion was included as an element of carer burden.

Carers experienced emotional distress, stigma, financial burden, lack of support networks, social exclusion, health impact and absence of decentralised mental health services. | Negative impact | Emotional distress, stigma, financial burden, lack of support networks, social exclusion and health impact were experienced by family carers. Carers are also suffering from emotional distress but support (e.g. counselling and economic support) for carers was lacking. |
| Daly et al. [30] | Carers reported stigma and marginalisation. Carers described 'shrinking worlds' and reductions in social contact. They react to their marginalisation by attempts at 'sustaining place'. Sustained place refers to an enhanced sense of belonging, connection and citizenship. | Not reported | Informal dementia care is embedded in a matrix of social relationships. Living with dementia cannot be isolated from interactions with others, organisations and society. Stigma can lead to depersonalisation, disempowerment and marginalisation. By 'sustaining place' carers challenge disconnection, exclusion and abandonment |
| Gray et al. [32] | Four main themes of exclusion were identified all of which reflected the personal, social and service and financial disadvantage experienced by carers:

1. Social exclusions: isolation, narrowing social networks, time commitments of caring, restrictions in education, training, employment, and leisure. 2. Service exclusions: carers taken for granted, difficulties with access. 3. Financial exclusions: paying for care. 4. Stigma; isolation/ marginalisation; service exclusion; financial exclusion; restrictions in education, training, employment and leisure | Not reported | Carers of people with mental health problems suffer from multiple sources of exclusion and there is pervasive and strong stigma, alienation and isolation. They are a hidden and socially excluded group whose needs should be brought more fully into focus. The implications of carers' exclusion also need to be addressed by policy.p.487
There are complex social, financial and emotional constraints on carers that impact adversely on their lives and wellbeing. Involving carers in defining their own needs and encouraging staff to adopt a carer-centred approach would enhance social inclusion. |
| Innes et al. [35] | The in ability to undertake leisure activities contributes to social exclusion. Accessibility of transport/mobility were barriers to leisure participation. Some carers show 'avoidance behaviours' towards leisure activities due to transportation challenges. Barriers to leisure participation include: Intrapersonal (fear of getting lost); interpersonal (carers' perception of the ability of the person with dementia to engage with activities); structural: accessibility of destinations and cost of travel insurance. | Not reported | '…dementia compounds the access to, engagement in and enjoyment derived from leisure activities spanning across the leisure spectrum from the day trip through to the conventional holiday… "The consequence is leisure by default, where avoidance behaviour, that is taking steps to avoid a situation perceived as potentially challenging, and where opportunity is constrained by the multiple barriers that make any leisure activity extremely challenging in an inter-dependency relationship." (p. 1661). |
| van der Sanden et al. [34] | Social exclusion, being blamed, not being taken seriously, time-consuming care activities and exhaustion appeared the predominant forms of stigma by association and family burden. | Stigma affected carers' mental well-being, social life, and social networks. | Social exclusion is caused by stigma by association p.713 '…participants suffer as a result of stigma by association and family burden. Social exclusion, time-consuming caregiving activities, being blamed, not being taken seriously, and exhaustion were conspicuous features of stigma by association and burden for the family members of people with mental illness.'p.716. They coped with their experiences by using problem- and emotion focused strategies. |

Table 4
CASP (2017) evaluation.

Authors	1	2	3	4	5	6	7	8	9	10	Total
Ae-Ngibise et al. [33]	Yes	Yes	No	Yes	Yes	No	Yes	Yes	No	Unclear	6
Daly et al. [30]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Clear	9
Gray et al. [32]	No	Yes	No	No	Yes	No	No	Yes	Yes	Unclear	4
Innes et al. [35]	Yes	Yes	Yes	Yes	Yes	No	Yes	No	No	Clear	7
van der Sanden et al. [34]	No	Yes	No	No	Yes	No	Yes	Yes	Yes	Clear	6

CASP questions: 1. Was there a clear statement of the aims of the research? 2. Is a qualitative methodology appropriate? 3. Was the research design appropriate to address the aims of research? 4. Was the recruitment strategy appropriate to the aims of the research? 5. Was the data collected in a way that addressed the research issue? 6. Has the relationship between researcher and participants been adequately considered? 7. Have ethical issues been taken into consideration? 8. Was the data analysis sufficiently rigorous? 9. Is there a clear statement of findings? 10. How valuable is the research?.

All three authors contributed to data analysis and drafting of the review.

Provenance and peer review

This article has undergone peer review.

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