



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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ABSTRACT

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	<i>Caregivers</i> 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	<i>Dementia</i> OR dement\$ OR <i>Alzheimer Disease</i> OR Alzheimer\$ OR <i>Substance-Related Disorders</i> OR <i>Alcoholism</i> OR addiction OR substance misuse OR <i>Mental Disorders</i> OR mental illness\$ OR <i>Psychotic Disorders</i> OR psychosis OR personality disorder\$ OR bipolar disorder\$ OR schizophre\$ OR depress\$ OR <i>Anxiety</i> OR <i>Anxiety Disorders</i> 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.

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