



What does the literature suggest about what carers need from mental health services for their own wellbeing? A Systematic Review

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KEYWORDS

Carer;
Need;
Mental health service

Abstract

Objective: The aim of this study was to examine prior studies relating to carers' needs from mental health services for their own wellbeing.

Method: A systematic approach was adopted for the literature review. The databases searched included MEDLINE, PSycINFO, EMBASE, and CINAHL, involving the use of search terms such as carers, mental health, and needs. The search was conducted in April 2012 and updated in December 2015. In total, 40 published papers were included in the review and were subsequently assessed for quality. For the data synthesis, a thematic analysis approach was employed to integrate the quantitative and qualitative evidence relating to carers' needs.

Results: Twenty-five of the reviewed studies were qualitative, 12 were quantitative, and 3 were mixed. Four major carer needs emerged from the synthesis: (1) holistic wellbeing of service users, (2) holistic wellbeing of carers, (3) supportive attitudes of professionals, and (4) carer involvement. All four of these needs, in fact, revolved around the carers' ill relatives.

Conclusions: The studies reviewed suggest that while carers of people suffering from mental illness have a range of needs, they generally fail to offer straightforward information about their own needs.

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Introduction

Carers have been defined as people who deliver unpaid care to a family member or friend who needs support due to limitations of age, physical or learning disability, or illness¹. Carers play a significant role in the treatment and support of relatives living with an illness, including those suffering from a mental health problem. In addition to providing practical help and personal care, carers give emotional sup-

port to mentally ill individuals². It has been argued that without carers, the cost to the social health care budget in the UK would exceed £1.24 billion a year³.

It has been recognized that carers have specific needs owing to their caring role, including maintaining their own physical and mental health as well as receiving financial and practical assistance for supporting their caregiving duties^{4,6}. For this reason, both the UK and Australian governments have acknowledged the roles of carers and their right to

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receive appropriate support to care for their ill relatives^{7,8}. There has also been recognition that more research is required to evaluate the benefits of support provision for carers and to explore whether health and social care services are meeting the needs of carers^{9,10}. Numerous studies have been conducted to investigate carers’ needs, but reviews of the literature aimed at understanding their needs from mental health services have been scarce. Furthermore, there is inadequate literature suggesting what carers need in terms of ensuring their own wellbeing. This review was intended to address the following question: What does the literature suggest about the needs of carers from mental health services for their own wellbeing? More specifically, the objective was to search, identify, synthesize, and appraise the relevant studies on carers’ needs.

Method

A systematic approach was adopted to conduct the literature review. Such an approach offers a more rigorous synthesis method than a traditional review does. Systematic reviewers undertake activities to locate and synthesize research related to a particular question comprehensively, using organized, transparent, and replicable procedures at each step in the process^{11,12}.

One of the principles employed in this review was limiting bias from the process of selecting the published research¹³. This involved using explicit, rigorous criteria for selecting the articles. These criteria enabled the researcher to ensure that only papers that were relevant to the research question were included in the review. Specific inclusion and exclusion criteria were determined prior to the commencement of the review. The inclusion criteria specified that the studies had to examine carers’ needs or expectations of mental health services; it had to be stated that the recipient of the care (service user) was experiencing a serious mental illness (i.e., long-term illness, such as schizophrenia, schizoaffective disorders, bipolar disorders, and chronic or persistent depression)¹⁴; the recipients of care (service users) had to be adults (over 18 years of age); the studies needed to employ qualitative, quantitative, or mixed methods aimed at gathering data about carers’ needs; they had to be published in English; and the studies needed to have been published in the last two decades. The review excluded studies in which paid carers had been recruited as participants.

The search strategy involved the use of a number of search terms including carers, mental health, and needs. Synonyms were identified, such as need OR expectation; carers OR caregivers OR family. Truncation was also employed to detect a wide range of term endings, such as need*, to locate need and needs; and carer* for carer and carers. The search was conducted through MEDLINE, PSYINFO, EMBASE, and CINAHL.

The search was conducted in April 2012 and was updated in December 2015. The initial search yielded a total of 8,150 publications, and a title search excluded 7,644 papers. Abstracts of the remaining 506 papers were then retrieved. A further inspection of the abstracts excluded 381 papers. Full texts of the remaining 125 articles eliminated another 80 studies. The research team then discussed the 45 remaining papers. In total, 40 published papers were included in

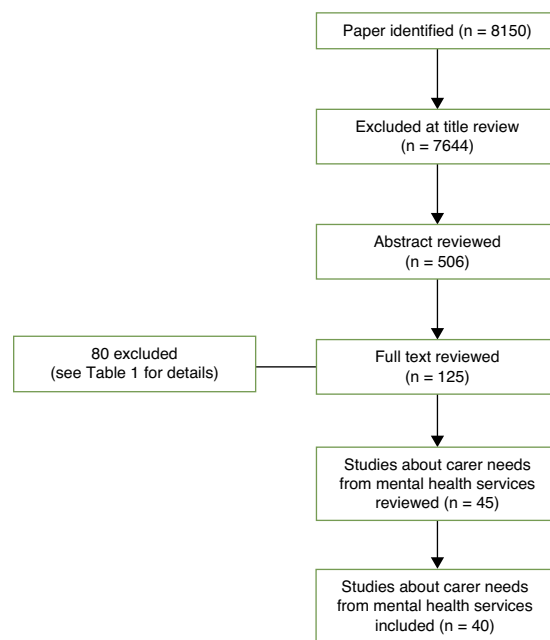


Figure 1 Process and outcome of the literature search.

this review and were subsequently assessed for quality. A summary of the process as well as the reasons for exclusion are detailed in Figure 1 and Table 1.

Further, detailed information was extracted on the characteristics of the participants, study settings, recruitment approaches, and data analysis methods (Appendix 1). The extraction procedure also involved summarizing all data in the included studies that were relevant to the review question (i.e., major findings relating to what carers need from services). The procedure continued to identifying whether the research yielded data on carers’ needs for their own wellbeing. This identification is important, as existing mental health services often disregard the carers’ interests and

Reasons for exclusion	Number of studies excluded	Number of studies retained (from 125 studies)
Involving older service users	2	123
Involving children service users	7	116
Not using carer participants	3	113
Using non-mental illness cases	5	108
Not yielding carers’ needs	65	43
Report paper	3	40
	Total: 80 excluded	Total: 40 retained

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