Enferm Clin. 2018;**28(Supl 1 Part A)**:102-111

ELSEVIER

Enfermería Clínica

www.elsevier.es/enfermeriaclinica

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

Herni Susanti[a], **Karina Lovell**[b] **and Hilary Mairs**[b]

[a] *Faculty of Nursing, Universitas Indonesia, Depok, Jawa Barat, Indonesia*
[b] *Faculty of Biology, Medicine and Health, University of Manchester, Manchester, United Kingdom*

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.

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 illness[1]. 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 support to mentally ill individuals[2]. It has been argued that without carers, the cost to the social health care budget in the UK would exceed £1.24 billion a year[3].

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 of carers and their right to

---

*Corresponding author.
Email: herni-s@ui.ac.id (H. Susanti).

1130-8621/© 2018 Elsevier España, S.L.U. Todos los derechos reservados.

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 research[13]. 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, PSycINFO, 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 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.

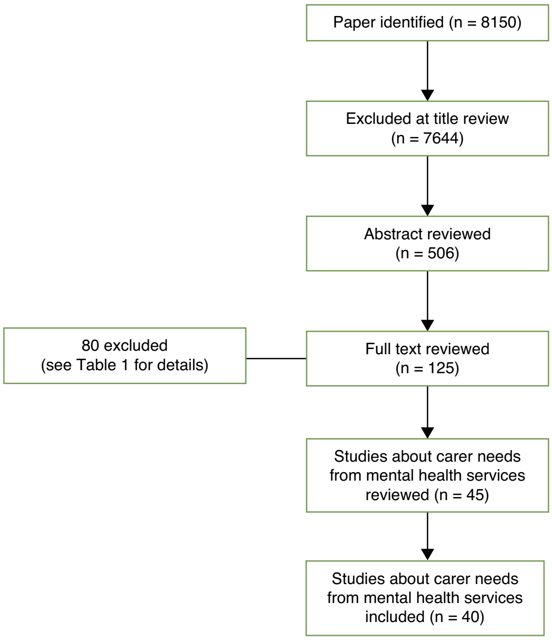

Figure 1 Process and outcome of the literature search.

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

Table 1 Reasons for studies' exclusion

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

involve the carers only in speaking on behalf of their relatives' wellbeing[5]. Discussions with the research team were conducted throughout the data extraction process until consensus was reached regarding the information retrieved. The summaries resulting from this extraction were helpful for synthesizing the reviewed studies.

A thematic analysis approach was adopted in the review to synthesize the data from the included studies[15]. The synthesis comprised two stages based upon the principles outlined by Thomas and Harden[16], which offer a relatively clear and replicable process for addressing questions related to the participants' perspectives.

The first stage was the development of descriptive themes, where free line-by-line coding was applied to the findings of the included studies. The coding was undertaken on extraction sheets to identify recurring themes surrounding carers' needs from, and expectations of, mental health services. This procedure resulted in several categories of carer needs.

The second phase was developing analytical themes, where the previous descriptive themes were drawn to provide a new interpretation that went beyond the original studies. It involved collapsing some themes into another existing theme.

Results

Of the 40 included papers, the majority concerned Western countries—the US, the UK, Australia, the Netherlands, Norway, Italy, Canada, Germany, and Sweden. Only 6 articles concerned non-Western countries—China, Taiwan, Japan, and South Africa.

Of these studies, 25 had samples of carers only, and 15 used mixed samples including carers and service users (n = 7); carers, service users, and professionals (n = 7); and carers and professionals (n = 1). The total sample size of carer participants in all studies was 3,099. Samples of the carer participants varied from four carers in 2 studies[17,18] and 746 carers[19].

Twenty-five of the 40 studies were qualitative, 12 were quantitative, and 3 were mixed studies. Out of the 25 qualitative investigations, 16 did not report the specific methodology adopted. The remaining studies employed various methodologies, including grounded theory (n = 3), content analysis (n = 2), ethnography (n = 2), case studies (n = 2), and symbolic interactionism (n = 1). In terms of the methods for collecting the qualitative data, 15 used individual interviews, 9 adopted focus groups, and 1 study examined written qualitative data from carer participants.

Of the 12 quantitative studies, all involved the use of surveys. Most of the 12 surveys used recognized instruments, such as the Educational Needs Questionnaire (ENQ), the Camberwell Assessment of Need Short Appraisal Schedule (CANSAS), the Family Assessment of Needs for Services (FANS), the Relatives' Cardinal Needs Schedule (RCNS), Needs Assessment of Caregivers/Families questionnaire from Salford Mental Health Project 1985, the Friedrich-Lively Instrument to Assess the Impact of Schizophrenia on Siblings (FLIISS), the Degree of Congruence between Attributes of Home Care Services Desired and Received Questionnaire (DCAHCSDRQ), and a standardized Carer assessment by Gloucestershire Partnership NHS Trust (2003). Some modified/self-developed instruments were also used: Chinese Modified Educational Needs Questionnaire (CENQ), Italian version of Camberwell Assessment of Need (ICAN), and the Carers' Needs Assessment for Schizophrenia (CAN-S). All of the three mixed studies also employed surveys for their quantitative investigations. For example, Jubb and Shanley[20] and Lloyd and Carson[21] posted written open-ended questions in a survey to obtain data for their mixed methods studies.

Relationships of the carer participants and their family members with a serious mental health problem were identified in 25 studies. Most of the carer participants were siblings (n = 1,061), followed by parents (n = 1,051), spouses/partners (n = 171), adult children (n = 79), and others (n = 47). Six studies used specific participants to investigate the needs of a specific group of carers, such as female carers, siblings, spouses, or parents.

The first stage of the synthesis (i.e., the development of descriptive themes) resulted in some categories of carer needs including informational, emotional, practical, and professional support. The need for information was dominant, and it was found in 32 of the 40 studies. This need focused on carers needing knowledge about mental health problems (e.g., signs, symptoms, and treatments), the progress of their relative with mental health problems, and the mental health services available. In addition, carers in 3 studies[22-24] suggested that information should be individualized and tailored to the specific circumstances of each family and offered at an appropriate pace, particularly in the early stages of the mental health problem. Twenty-one studies revealed data outlining the need for emotional and practical support. Six studies uncovered the need for professional support and emphasized that carers wanted to be respected and listened to, and for health workers to demonstrate empathy. Finally, the need for carer involvement emerged in 9 of the 40 studies, specified as carers' desire to be treated like part of the care team and, accordingly, be acknowledged as experts and consulted regarding decisions made for service users.

The similarities and differences between the categories were then identified and grouped into a hierarchical structure. Seven major themes including their sub-themes were revealed to describe what carers needed from healthcare services, as depicted in Table 2. Other similarities and differences were identified regarding the needs of carers across some cultures, described as Western (represented by carers living in North America, Europe, and Australia) and non-Western (represented by carers living in Asia and Africa). Several needs including needs for information, emotional support, supportive attitudes from professionals, and practical support were voiced in the studies in both Western and non-Western contexts. Nonetheless, while the carers' needs for adequate wellbeing and involvement in the services were expressed profoundly in the US, Canada, and Europe, these needs did not emerge from the investigations with Asian and African subjects.

The second stage of the synthesis (i.e., the development of analytical themes) involved an advanced interpretation of the original studies. It included collapsing some themes into another existing theme, as presented in the previous Table 2. To illustrate, the needs for information and emo-

Table 2 Themes from the descriptive stage of synthesizing the reviewed studies

No.	Main themes	Sub-themes
1	Information	• Method for giving information • Content of the needed information
2	Emotional support	• Emotional support for other family members and friends • Consultation with, or therapy from, professionals to express concerns associated with caregiving • Involvement in support groups • Spiritual support
3	Adequate wellbeing of service users	• Mental, physical, and social wellbeing • Improving services for service users
4	Supportive attitudes of professionals	• Being respectful of carers • Listening to carers • Having empathy for carers
5	Carer involvement	• Carers as part of the care team • Carers being consulted regarding decisions for service users • Being acknowledged as experts
6	Adequate wellbeing of carers	• Emotional, physical, and social wellbeing
7	Practical help in performing caring role	• Respite care • Practical help for daily life • Practical help during a crisis • Easy access to services • Housing assistance • Financial assistance • Legal assistance

tional support were grouped under the theme of carers' need for adequate wellbeing; ultimately, this theme was labelled as carers' need for holistic wellbeing. In addition, this phase involved a re-examination of the data to ensure that the themes were represented. For example, the data related to improving services were re-examined and grouped together with the data of the need for practical support under a new theme: the need for the service users' holistic wellbeing. The result at this stage was the identification of four major carer needs: (1) holistic wellbeing of service users, (2) holistic wellbeing of carers, (3) supportive attitudes of professionals, and (4) carer involvement. Further analysis resulted in the grouping of needs (1) holistic wellbeing of service users and (2) holistic wellbeing of carers, which were respectively closely associated with the wellbeing of service users and carers, and needs (3) supportive attitudes of professionals and (4) carer involvement, which have indirect connections to the wellbeing of carers or service users, as shown in Figure 2.

Finally, the synthesis could describe the relationship between the emerging themes. A deeper analysis of the data related to the needs for supportive attitudes of professionals (3) and carer involvement (4) suggested that these needs were voiced because the carers wanted their ill relatives to receive the best services. Likewise, many carers reported that they required information because they wanted to be more knowledgeable and skilled in caring for the service users. Therefore, it can be assumed that all four carer needs uncovered in this review were actually dedicated to the carers' ill relatives, as illustrated in Figure 3.

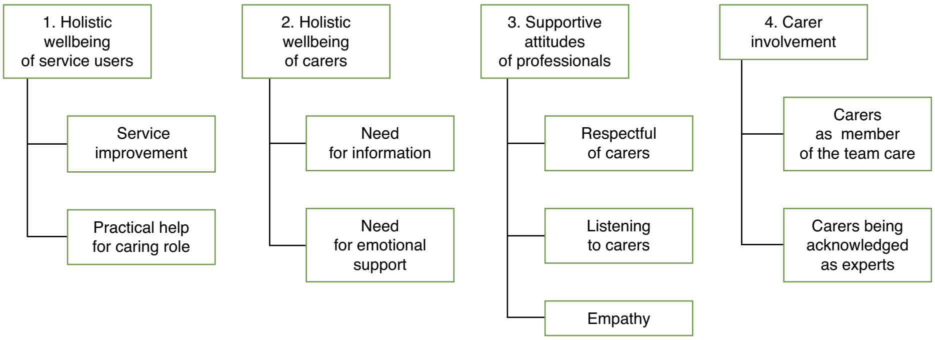

Figure 2 Four needs of carers resulting from the synthesis of the reviewed studies.

Discussion

The 40 studies reviewed suggest that carers have a range of needs. The findings from the qualitative studies were meaningful for their rich and thick descriptions of the needs, which augmented the data from the survey studies. However, several considerations should be taken into account before attempting to apply the findings in other contexts. First, the reviewed studies were mostly carried out in Western countries, such as the UK, the US, Australia, and the Netherlands, and these countries are culturally different from the non-Western countries represented (e.g., the country of origin of the first author was sometimes located in Asia). Investigations into carer needs in Asian countries were mostly conducted by administering surveys, which resulted in limitations in terms of their small sample size and response bias from the respondents. Moreover, Asian carers were only represented by participants from a Chinese cultural background. Only one Asian-based qualitative study was included in this review[25], and it explored the experience of a homogeneous group of carers belonging to community family associations in Japan. As stated earlier, there was a significant gap between the needs of carers from Western and non-Western countries, especially relating to the views about carer involvement and carers' wellbeing. In addition, the reviewed studies were mostly conducted in circumstances where the value of carers has been legally recognized, followed by substantial development of services for those with mental health problems. Consequently, the reported carer needs might have been different if the studies had been conducted in Indonesia, for example, where services for carers are less developed.

Second, the needs of carers revealed in this review were mainly related to the service users' needs, such as improving/maintaining the service users' health status. This does not mean that the carers' own needs were not revealed. After following the data extraction and synthesis procedures, the researcher was eventually able to identify the carers' needs for their own wellbeing. This identification was quite toiling because the reviewed studies failed to offer straightforward information about the carers' own needs. This contradicts the existing perspective that carers and service users have very different needs[5].

Figure 3 Relationships between the themes that emerged from the synthesis of the reviewed studies.

Regarding the data collection method, the studies employed varied approaches to elicit information about carers' needs. These included surveys, in-depth individual interviews, and focus groups. When conducting surveys, asking carers to fill out survey might have numerous benefits, including minimizing costs, saving time, and involving large samples. Nevertheless, even with the assistance of reliable and valid surveys, such as the the Relatives' Cardinal Needs Schedule (RCNS)[26], the adoption of the instrument must be treated with caution when it is used in countries where English is not people's first language. The main issues of the current tools for investigating carer needs surround translation and the limited needs covered[27]. Moreover, as affirmed by some researchers, the survey method has several flaws that can also present issues in qualitative works, such as potential bias from the respondents and the researcher/interviewers; inability to capture extensive, complex, and sensitive information; and the issue of social desirability[23,26,28-31]. Alternatively, most investigators in the reviewed studies favored qualitative methods, especially in-depth individual interviews and focus groups. As expected, the one-on-one dialogues and focus groups were able to elicit information about carers' needs that was rich, deep, and extensive. Such methods allowed carers to express their needs in detail and sourced from their own experience of caring for ill family members[32]. Moreover, regarding focus groups, some investigators affirmed that this method was excellent for encouraging the carer participants to reflect on the stories of others when expressing their needs based on their contacts with services and experiences in caregiving[33,34]. The focus groups could also promote a safe environment for the carer and service user participants to discuss a topic that in other circumstances might be sensitive because of stigma, marginalization, or a lack of opportunity[33].

This review provides a broad overview of what carers require from mental health services. The description given is comprehensive, sourced from qualitative and quantitative investigations undertaken in different regions of the world. However, there are several limitations to this review. First, publication bias might have been introduced, since the findings reflect data reported in academic journals, but do not represent unpublished literature, such as conference proceedings, theses and dissertations, and other grey literature. In addition, the review excluded non-English studies and studies published before 1990, which means that the review might have excluded some relevant studies.

To summarize, this paper presented the results of a synthesis of what carers need from mental health services from the extant literature. Due to the limitations of the reviewed studies, the application of the evidence to other contexts, which are culturally different, can be problematic. Likewise, as the studies were mainly conducted in places where the caring role has been formally supported, the findings might be dissimilar if the needs of carers were explored in areas where services targeting them are underdeveloped.

Conflicts of interest

The authors declare no conflicts of interest.

Appendix 1 Summary of the reviewed studies about carer needs from mental health services

No	Authors	Country of Origin	Number of carer participants and relationship with service user	Setting	Recruitment of carer Participants	Data analysis
1	Glendy and Mackenzie (1998)	China	8 carers (3 parents, 3 spouses, 2 siblings)	All aspects of mental health services	Not stated	Content analysis
2	Johnson (2000)	USA	180 carers (70% parents 13% siblings, 6% spouses, 8% adult children)	All aspects of mental health services	Contacts with potential participants already involved in a project for carers	Not stated
3	Smith et al. (2001)	USA	45 carers (23 spouses, 16 adult children)	Mental health hospital services	Not stated	Not stated
4	Domboos (2002)	USA	76 carers (no information of the relationship with service user)	A wide range of mental health services	Postal invitation from researcher and gatekeepers (managers of support groups of carers)	Content analysis
5	Bowes and Wilkinson (2003)	UK	4 carers ((no description of their relationships with service user)	Community mental health services	Used gatekeepers (professionals and leaders of community groups of carers)	Thematic analysis
6	Bollini et al. (2004)	Italy	13 carers (no description for their relationships with service user)	Community mental health services	Used gatekeepers (psychiatrists of the service users)	Not stated
7	Rose et al. (2004)	USA	31 carers (14 parents, 5 siblings, 4 children, 6 spouses, 2 others)	A wide range services	Used gatekeepers (professionals, leaders of community groups for carers and church services)	Content analysis in combination with thematic analysis
8	Lakeman (2008)	Australia	86 carers (parents 59%, spouse 17%, siblings 9%, adult children 5%, and grandparent 1%, others 8%)	All aspects of mental health services	Dissemination of the study in carer meetings, postal and phone invitations	Content analysis
9	Askey et al. (2009)	UK	22 Carers (No description for their relationships with service user)	All aspects of mental health services	Dissemination of the study in the local mental health services and carer support groups	Thematic analysis
10	Lyons et al. (2009)	UK	57 carers of people with mental illnesses (No description for their relationships with service user)	Mental health crisis services	Postal invitation	Thematic analysis
11	Mavundla et al. (2009)	South Africa	8 carers (5 mothers, one sister, one father, one wife).	Community mental health services	Contacts with potential participants in outpatients	Unspecified qualitative analysis
12	McAuliffe et al. (2009)	Australia	31 carers (25 parents, 3 partners, 3 siblings)	All aspects of mental health services	Poster display, and used gatekeepers (staff of mental health services and carer support groups)	Thematic analysis
13	van der Voort et al. (2009)	Netherland	15 carers (all spouses)	Community mental health services	Pamphlet display and contacts with potential participants in organisation of carers	Coding techniques by Strauss and Corbin

(continue)

Appendix 1 Summary of the reviewed studies about carer needs from mental health services *(cont.)*

No	Authors	Country of Origin	Number of carer participants and relationship with service user	Setting	Recruitment of carer Participants	Data analysis
14	Nordby et al. (2010)	Norway	18 carers (15 parents, 3 siblings)	Mental health hospitals services	Used gatekeepers (hospital staff) to contact service users to obtain consent from their carers	Content analysis
15	Thomas et al. (2010)	UK	7 carers (No description for their relationships with service user)	7 Community health services and 1 prison	Used gatekeepers (staff of mental health services and organisations of carers)	Not stated
16	Van de Bovenkamp and Trappenburg (2010)	Netherland	18 carers (No description for their relationships with service user)	All aspects of mental health services	Contacts with potential participants involved in organisations of carers	Content analysis
17	Copeland and Helleman (2011)	USA	8 mother carers of adult children with mental illnesses	A wide range of mental health services	Dissemination of the study in community groups of carers, and used gatekeepers (nurses and social workers) for recruiting potential participants in the hospitals	Coding techniques by Strauss and Corbin
18	Jonsson et al. (2011)	Sweden	17 carers (7 mothers, 3 fathers, 1 child)	Mental health hospitals	Postal invitation, followed with phone contacts for further explanation	Content analysis
19	Weimand et al. (2011)	Norway	216 carers (156 parents, 18 partners, 27 siblings, 10 adult children, 5 others)	All aspects of mental health services	Postal invitation	Content analysis
20	Hacketal et al. (2012)	USA	7 carers (No description for their relationships with service user)	A community mental health centre	Not stated	Content analysis
21	McHugh et al. (2012)	Germany	14 carers (all spouses)	Mental health hospitals	Not stated	Grounded theory analysis
22	McNeil (2013)	Canada	4 carers (No description for their relationships with service user)	A mental health hospital	Not stated	Line by line coding, arranged into themes
23	Mizuno et al. (2013)	Japan	11 female carers (8 parents, 3 siblings)	Community mental health services	Dissemination of the study in support groups of carers	Content analysis
24	White et al. (2013)	USA	17 carers (all parents)	Assertive community treatment service (ACT)	Used gatekeepers (team leaders of ACT teams)	Content analysis
25	Wood et al. (2013)	UK	9 carers (No description for their relationships with service user)	Mental health hospitals	Used gatekeepers (staff of services/organisations for carers)	Thematic analysis

26	Ascher-Svanum et al (1997)	USA	197 carers, (40% mother = 80,15% sister = 30,15% father = 30,9% brother = 20)	A wide range mental health services	Postal invitation	118 item survey questionnaire, the name of questionnaire was not specified
27	Gasque-Carter and Curlee (1999)	USA	80 carers (28 parents, 26 siblings, 9 daughters/sons, 3 spouses, 5 kins and 9 others)	A mental hospital services	Not stated	Cross sectional questionnaire using 52 items and 2 open ended questions (developed by the researchers), questioned via telephone
28	Chien and Norman (2003)	China	240 carers (no description their relationships with the service user)	All aspects in mental health services	Phone and face-to-face invitation	Cross sectional questionnaire using 45 items of Chinese Modified Educational Needs Questionnaire (CENQ)
29	Sung et al. (2004)	Taiwan	100 carers (39% parents, 36% spouses)	All aspect s in mental health services	Used gatekeepers (nurses and physicians)	Cross sectional questionnaire using 45 items of Educational Needs Questionnaire (ENQ)
30	Cleary et al. (2005)	Australia	50 carers (50% parents, 32% spouses, 16% girlfriend/boyfriend/others)	All aspects of mental health services	Carers were recruited based on consent from the service users	Face-to-face interview using 3 open ended questions
31	Gregory et al. (2006)	UK	36 carers (22 parents, 2 partners, 2 siblings, 2 friends)	Assertive community Services	Hospital professionals distributed questionnaires as a part of an assessment program for carers	A standardized Carer assessment by Gloucestershire Partnership NHS Trust (2003)
32	Tung and Beck (2007)	Taiwan	75 carers (42 parents, 13 spouses 7 children, and 13 others)	Mental hospitals	Initiated with phone contacts, then face-to-face contacts for further information of the study	Cross sectional questionnaire of the Degree of Congruence between Attributes of Home Care Services Desired and Received Questionnaire (DCAHCSDRQ) to assess 19 attributes of carers unmet needs from services
33	Drapalski et al. (2008)	USA	308 carers (234 parents, 28 siblings, 9 adult daughters/sons, 18 spouses, 10 others)	All aspects of mental health services in the community	Postal information to service users to obtain consent for carers' participation	Cross sectional questionnaire using 16 items of FANS (Family Assessment of Needs for Services), via mails

(continue)

Appendix 1 Summary of the reviewed studies about carer needs from mental health services *(cont.)*

No	Authors	Country of Origin	Number of carer participants and relationship with service user	Setting	Recruitment of carer Participants	Data analysis
34	Friedrich et al. (2008)	USA	746 carers (all siblings)	All aspects in mental health services	Postal invitation, advertisement in newsletter, and used gatekeepers (leaders of carer support groups)	Cross sectional questionnaire using 19 items of Friedrich-Lively Instrument to Assess the Impact of Schizophrenia on Siblings (FLIISS) to rate the importance carer needs and mental health services
35	McPherson et al. (2008)	UK	32 carers (no description their relationships with the service user)	Assertive Outreach team services	Not stated	Cross-sectional questionnaire using 22 items of CANSAS (Schedule Camberwell Assessment of Need Short Appraisal Schedule)
36	Absalom-Hornby et al. (2011)	UK	18 carers (12 parents, 5 siblings, 1 other)	Forensic mental health services	Postal invitation	Cross sectional interview using 48 items of FQ (Family Questionnaire) and 14 items RCNS (Relatives Cardinals Needs Schedule), questioned via telephone
37	Lasalvia et al. (2012)	Italy	120 carers (no description their relationships with the service user)	Community mental health services	Contacted service users to obtain permission for their carers	Cross sectional questionnaire using 22 items of the Italian version of Camberwell assessment of Need
38	Winefield, and Harvey (1994)	Australia	121 carers (68.6% parents, 17.4 % siblings, 7.4% spouses, 4.1% adult child	All aspects of mental health services	Face-to-face contacts with service users to obtain consent for carers' participation	Structured interviews
39	Jubb and Shanley (2002)	Australia	14 carers (no description of their relationships with the service user)	A mental hospital	Postal invitation	Cross sectional questionnaire of Needs Assessment of Caregivers/Families questionnaire from Salford Mental Health Project 1985, delivered via mails
40	Lloyd and Carson (2005)	UK	40 carers who attended 3 support groups	Community mental health services	Postal invitation to complete survey questionnaires and direct contacts with carers in support group meetings	Questionnaire and discussion meetings

References

1. Carers UK. Facts about carers: Who are carers? May 2014 [accessed 2016 Aug 10]. Available at: http://www.carersuk.org.
2. Shah AJ, Wadoo O, Latoo J. Psychological distress in carers of people with mental disorders. Brit J Med Pract. 2010;3:a327.
3. The Schizophrenia Commission. The abandoned illness: A report by the schizophrenia commission. London: The Schizophrenia Commission; 2012.
4. Goodwin V, Happell B. Conflicting agendas between consumers and carers: The perspectives of carers and nurses. Int J Ment Health Nurs. 2006;15:135-43.
5. Kuipers E. Time for separate psychosis caregiver service? J Ment Health. 2010;19;401-4.
6. Lobban F, Postlethwaite A, Glentworth D, Pinfold V, Wainwright L, Dunn G, et al. A systematic review of randomised controlled trials of interventions reporting outcomes for relatives of people with psychosis. Clin Psychol Rev. 2013;33:372-82.
7. Australian Health Minister. National mental health policy 2008. Canberra: Australian Government. 2009. Available at: http://www.health.gov.au.
8. Care Act Assessment and eligibility: Assessing needs and determining eligibility [accessed 2015 Feb 4]. Available at: http://scie.org.uk/care-act-2014.
9. Gasque-Carter KO, Curlee MB. The educational needs of families of mentally ill adults: the South Carolina experience. Psychiatr Serv. 1999;50:520-4.
10. Nordby K, Kjønsberg K, Hummelvoll JK. Relatives of persons with recently discovered serious mental illness: in need of support to become resource persons in treatment and recovery. J Psychiatr Ment Health Nurs. 2010;17:304-11.
11. Green S. Systematic reviews and meta-analysis. Singapore Medical Journal. 2005;46:270.
12. Ryan F, Coughlan M, Cronin P. Step-by-step guide to critiquing research. Part 2: qualitative research. Br J Nurs. 2007;16:738-45.
13. Aveyard H. Doing a literature review in health and social care. 3rd ed. McGraw-Hill Education; 2010.
14. Steadman HJ, Osher FC, Robbins PC, Case B, Samuels S. Prevalence of serious mental illness among jail inmates. Psychiatr Serv. 2009;60:761-5.
15. Dixon-Woods M, Agarwal S, Jones D, Young B, Sutton A. Synthesising qualitative and quantitative evidence: a review of possible methods. J Health Serv Res Policy. 2005;10:45-53.
16. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. BMC Med Res Methodol. 2008;8:45.
17. Wood VJ, Curtis SE, Gesler W, Spencer IH, Close HJ, Mason J, et al. Creating ‘therapeutic landscapes’ for mental health carers in inpatient settings: a dynamic perspective on permeability and inclusivity. Soc Sci Med. 2013;91:122-9.
18. Wilkinson C, McAndrew S. ‘I’m not an outsider, I’m his mother!’ A phenomenological enquiry into carer experiences of exclusion from acute psychiatric settings. Int J Ment Health Nurs. 2008;17:392-401.
19. Friedrich RM, Lively S, Rubenstein LM. Siblings’ coping strategies and mental health services: a national study of siblings of persons with schizophrenia. Psychiatr Serv. 2008;59:261-7.
20. Jubb M, Shanley E. Family involvement: the key to opening locked wards and closed minds. International Journal of Mental Health Nursing. 2002;11:47-53.
21. Lloyd M, Carson A. Culture shift: carer empowerment and cooperative inquiry. Journal of Psychiatric and Mental Health Nursing. 2005;12:187-91.
22. Ascher-Svanum H, Lafuze JE, Barrickman PJ, Van Dusen C, Fompa-Loy J. Educational needs of families of mentally ill adults. Psychiatr Serv. 1997;48:1072-4.
23. Drapalski AL, Marshall T, Seybolt D, Medoff D, Peer J, Leith J, Dixon LB. Unmet needs of families of adults with mental illness and preferences regarding family services. Psychiatr Serv. 2008;59:655-62.
24. Askey R, Holmshaw J, Gamble C, Gray R. What do carers of people with psychosis need from mental health services? Exploring the views of carers, service users and professionals. Journal of Family Therapy. 2009;31:310-31.
25. Mizuno E, Takataya K, Kamizawa N, Sakai I, Yamazaki Y. Female families’ experiences of caring for persons with schizophrenia. Arch Psychiat Nurs. 2013;27:72-7.
26. Absalom-Hornby V, Gooding P, Tarrier N. Coping with schizophrenia in forensic services: The needs of relatives. J Nerv Ment Dis. 2011;199:398-402.
27. Wancata J, Krautgartner M, Berner J, Scumaci S, Freidl M, Alexandrowicz R, et al. The “carers’ needs assessment for Schizophrenia”: an instrument to assess the needs of relatives caring for schizophrenia patients. Soc Psychiatry Psychiatr Epidemiol. 2006;41:221-9.
28. Winefield HR, Harvey EJ. Differences according to recruitment method in subjects who care for a relative with schizophrenia. Aust N Z J Psychiatry. 1994;28:239-43.
29. Chien WT, Norman I. Educational needs of families caring for Chinese patients with schizophrenia. J Adv Nurs. 2003;44: 490-8.
30. Tung WC, Beck SL. Family caregivers’ satisfaction with home care for mental illness in Taiwan. Int J Ment Health Nurs. 2007; 16:62-9.
31. Lasalvia A, Boggian I, Bonetto C, Saggioro V, Piccione G, Zanoni C, et al. Multiple perspectives on mental health outcome: needs for care and service satisfaction assessed by staff, patients and family members. Soc Psychiatry Psychiatr Epidemiol. 2012;47:1035-45.
32. Kersten P, McLellan L, George S, Mullee MA, Smith JA. Needs of carers of severely disabled people: are they identified and met adequately? Health Soc Care Community. 2001;9:235-43.
33. McAuliffe D, Andriske L, Moller E, O’Brien M, Breslin P, Hickey P. ‘Who cares?’ An exploratory study of carer needs in adult mental health. Australian e-Journal for the Advancement of Mental Health. 2009;8:57-68.
34. Nordby K, Kjønsberg K, Hummelvoll JK. Relatives of persons with recently discovered serious mental illness: in need of support to become resource persons in treatment and recovery. J J Psychiatr Ment Health Nurs. 2010;17:304-11.