What Outcomes in Community Mental Health Research Are Important to Caregivers of People With Schizophrenia? An Exploratory Qualitative Analysis of an Online Survey

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Research note

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Abstract

Objective: This study investigated outcomes in community mental health research that were important to caregivers of people with schizophrenia. Using an online survey conducted from August 1–31, 2020, data were collected from caregivers belonging to the LINE Schizophrenia Family Association. Caregivers identified outcomes important in community mental health research. Two researchers categorized caregivers' statements into research outcomes.

Results: A total of 132 caregivers completed the online self-reported questionnaire, and 296 caregiver statements were identified. Qualitative analysis identified 17 outcome categories. The caregivers tended to value having more free time, maintaining an appropriate relationship with people with schizophrenia, and being able to cope with their symptoms. This exploratory study newly demonstrates the outcomes that caregivers of people with schizophrenia consider important in community mental health research. The findings may be useful in selecting outcomes for future studies of caregivers.

Introduction

Outcome selection and participant involvement are important in modern clinical and research work. This also applies to studies of caregivers of people with mental illness since they have specific needs and require effective support [1]. Importantly, caregivers appear to have different concerns from people with mental illness. For example, they bear significant physical, mental, and economic burdens as a result of caring for those with mental illness [2]. In short, we need to identify proper research outcomes for caregivers themselves.

Caregiver-related outcomes have gradually changed due to the development of community mental health services over the past 30 years [3]. Early studies mainly assessed the family functions as a good caregiver, such as care experiences, attitudes toward people with mental illness, and knowledge about mental illness [4, 5, 6]. In contrast, recent studies have focused on aspects of emotional satisfaction and self-fulfilment, for example well-being, self-efficacy, and quality of life [7, 8]. In other words, subjective personal matters have become progressively more valued in caregiver research.

Despite an increasing emphasis on outcomes important to caregivers, study outcomes may be still be defined by researchers rather than by caregivers [9]. Few intervention studies of caregivers have defined primary outcomes based on issues considered important to caregivers themselves, which ultimately means that evidence-based practices for caregivers are not fully developed [10]. Thus, focusing on caregivers' experiences, needs, and interests in the outcome selection process is becoming increasingly important for identifying meaningful goals and sharing research findings. Indeed, caregiver involvement has been accelerated by a recent trend toward patient public involvement (PPI), or coproduction, in which people with mental illness participate in research in order to develop effective interventions [11, 12]. Therefore, exploring outcomes important to caregivers is essential to promote future studies that meet their needs. However, such studies have not been performed in community mental health settings. This

study used an online survey and qualitative analysis to preliminarily investigate outcomes deemed by caregivers of people with mental illness to be important for community-based mental health research.

Methods

Study design and participants

An online, cross-sectional survey was conducted from August 1–31, 2020. Participants were recruited from the LINE Family Association of Schizophrenia, which had 238 registered members as of August 1, 2020. The association offers a platform for information exchange and peer support for caregivers of people with schizophrenia using the “LINE” online software. Eligibility criteria were as follows: (a) caregiver of one or more people with schizophrenia and (b) age over 20 years. For example, a caregiver might care for a family member with schizophrenia and look after his or her daily needs. Respondents were invited to participate on a voluntary basis, and provided fully informed consent through the internet. The study protocol was approved by the Research Ethics Committee of the National Center of Neurology and Psychiatry (No. A2020-036).

Data collection

We collected sociodemographic data of participating caregivers, such as age, gender, education, and annual household income. We also assessed care experiences, such as relationship with people with schizophrenia, time spent providing care, and caregiver burden as evaluated using the Japanese version of the Zarit burden interview, short version (J-ZBI-8) [13]. The data on family members with schizophrenia were obtained from their caregivers, including age, gender, duration of illness, and lifetime number of hospitalizations.

We defined the following open-ended question to capture outcomes in community mental health research that are important to caregivers of people with schizophrenia: “What benefits do you (i.e., caregivers) wish to gain from support services? Please enter up to three ideas.”

Analyses

Two researchers (NY and TS) independently extracted outcomes based on participants’ survey responses, then organized word fluctuation of the responses. Next, related responses were collected and categorized through joint analysis and thorough discussion between the two researchers. Each category whose meaning was ultimately unclear was excluded. For example, responses that discussed the outcomes of people with schizophrenia, rather than those of their caregivers, were excluded. When disagreement occurred between the two researchers, decisions were made based on the advice of SY and MO. The category names were iteratively reviewed to ensure that they reflected the literal meanings of the responses. A co-author (TK) not involved in the analysis fit 30 randomly selected outcome statements into 17 categories. The agreement rate was calculated using Krippendorff’s alpha [14], and the criterion

for good reliability was set at 0.8 [14]. Finally, the number of responses corresponding to each category was calculated. The categories are presented in Table 2.

Results

A study flowchart is shown in Fig. 1. A total of 132 caregivers completed the online self-reported questionnaire and 296 caregiver statements were identified. The categorization agreement rate was 0.82. Caregiver characteristics are presented in Table 1. Most caregivers were middle-aged mothers with a care duration of less than 5 years. The analysis resulted in 17 outcome categories in which the participating caregivers were interested regarding community mental health research. Table 2 shows a ranking of important outcome categories. The category with the highest number of responses concerned the desire to have more free time. This was followed by categories related to maintaining an appropriate relational distance with people with schizophrenia and the ability to cope with these people’s symptoms. Eight of the top 10 items involved caregivers’ personal lives, care burden, and relationships.

Table 1. Demographic characteristics of caregivers and people with schizophrenia (N = 132)

			n (%) or Mean (SD)
Caregivers	Age		52.7 (7.9)
	Gender	Male	11 (8.3)
	Education	Junior high school	2 (1.5)
		High school	21 (15.9)
		Some college	54 (40.9)
		University or higher	55 (41.7)
	Annual household income	≤2.5 million yen	19 (14.4)
		≤5 million yen	25 (18.9)
		≤7.5 million yen	29 (22.0)
		≥ 7.5 million yen	48 (36.4)
		Unknown	11 (8.3)
	Relationship to person with schizophrenia	Parent	111 (84.1)
		Spouse	9 (6.8)
		Sibling	6 (4.5)
		Child	6 (4.5)
	Care duration	≤ 5 years	82 (62.1)
		≤ 10 years	24 (18.2)
		≤ 15 years	16 (12.1)
		≤ 20 years	3 (2.3)
		≥ 21 years	7 (5.3)
	Japanese version of the Zarit burden interview, short version (J-ZBI-8)		15.4 (7.9)
People with schizophrenia	Age		27.7 (11.6)
	Gender	Male	63 (47.7)
	Duration of illness	≤ 5 years	82 (62.1)
		≤ 10 years	20 (15.2)

	≤ 15 years	18 (13.6)
	≤ 20 years	3 (2.3)
	≥ 21 years	9 (6.8)
Lifetime number of hospitalizations		1.6 (1.6)

Table 2. Ranking of outcomes considered by caregivers of people with schizophrenia to be important in community mental health research

Ranking	Item	Description	Number of statements
1	Having more free time	Caregivers want more free time for themselves.	48
2	Maintaining an appropriate relationship with people with schizophrenia	Caregivers want to maintain an appropriate relationship with those they care for.	47
3	Coping with symptoms of people with schizophrenia	Caregivers want to cope well with the symptoms or medical conditions of those they care for.	36
4	Decreasing financial burden of patients with schizophrenia	Caregivers do not want to carry the financial burden of those they care for.	28
5	Decreasing daily care	Caregivers want to reduce the amount of care they must provide.	27
6	Decreasing psychological burden	Caregivers want to feel less of a psychological burden related to their caregiving duties.	22
7	Living their own life	Caregivers want to live their own lives without being influenced by those they care for.	19
8	Living separately from people with schizophrenia	Caregivers want to live separately from those they care for.	19
9	Working	Caregivers want to work without worrying about those they care for.	15
10	Stigma	Caregivers want to live in the community without worrying about stigma related to schizophrenia.	15
11	Obtaining information about schizophrenia	Caregivers want to obtain knowledge and information about schizophrenia.	8
12	Using mental health services	Caregivers want to use mental health and welfare services to ease their care burden.	3
13	Connecting with other caregivers	Caregivers want to be connected with others in the same situation.	3
14	Living together with people with schizophrenia	Caregivers want to be able to live together with those they care for.	2
15	Disseminating information about schizophrenia	Caregivers want to disseminate information about schizophrenia to society.	2
16	Being healthy	Caregivers want to be healthy.	1
17	Having someone to complain to	Caregivers want to have someone to complain to.	1

Excluded	37
Total	333

Discussion

This study provided new insight into outcomes that caregivers of people with schizophrenia identified as important in community mental health research. Caregivers tended to value having more free time, maintaining an appropriate relational distance with people with schizophrenia, and the ability to cope with these people's symptoms.

Previous studies revealed that outcomes important to caregivers have shifted from those related to being a good caregiver, such as caregiving knowledge and emotional expression [4, 5, 6], to subjective outcomes such as quality of life and well-being [7, 8]. This study partly supported this trend, since for example reduction of care burden and having more free time are likely to be associated with quality of life and well-being [15]. However, measuring quality of life and well-being is difficult and controversial since these are composite outcomes [16]. The outcomes such as care burden, free time, and coping skills identified in this study are more specific and measurable, and may therefore be helpful for future research.

A novel aspect of this study was that it identified outcomes related to caregiver experiences, needs, and interests based on the concepts of PPI and coproduction [8, 9]. In previous research, outcomes important to people with mental illness were often not the same as those endorsed by experts, even though the outcomes included quality of life and well-being [17]. Furthermore, while a recent study identified a core outcome set for depression that was co-developed by experts and service users, the outcome set did not include quality of life or well-being [18]. Similarly, this study did not evaluate composite outcomes, as caregivers focused on more practical concerns. This could lead to future intervention studies whose primary outcomes are based on what caregivers consider to be highly important, as well as additional, implementable, evidence-based practices for caregivers.

The outcomes in this study (e.g., burden, free time), which were based on caregiver responses, may be related to weaknesses in the community mental health system in Japan. Although there has been a gradual increase in services for people with mental illness, these individuals still have inadequate support in community settings in Japan due to insufficient social resources. Consequently, caregivers often must play a major role in supporting their daily lives [7]. The common outcomes identified in this study may reflect this situation. Specifically, they may indicate that caregivers need a community mental health system in which they do not bear so much responsibility in caring for people with mental illness.

Limitations

This study had several limitations. First, it included only participants who were able to use online software, which may have excluded certain individuals (particularly elderly people) and caused selection

bias. Second, outcomes were ranked by numbers of responses, but this approach may be inadequate to determine which outcomes are most important. In the future, the Delphi method should be used to verify outcomes that are important to caregivers.

Despite these limitations, this exploratory study newly identified outcomes that caregivers of people with schizophrenia considered important in community mental health research. The findings may be useful in selecting outcomes for future studies of caregivers.

Abbreviations

PPI: patient public involvement

J-ZBI-8: the Japanese version of the Zarit burden interview, short version

Declarations

Ethics approval and consent to participate

The study was approved by the Research Ethics Committee of the National Center of Neurology and Psychiatry (No. A2020-036). Participants received information and contact details of the study team at the start of the online study and given sufficient time to read the information, consider any implications, and raise any questions prior to deciding to participate. Participants were informed that they were free to withdraw at any time by closing their browser and were asked to confirm they had read a series of statements on the first web page of the online survey. Consent was then obtained by participants clicking on the "Agree" button.

Consent for publication

Not applicable.

Availability of data and materials

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy and ethical restrictions. Participants were not informed about the public data access during the informed consent process. When we receive a reasonable request for data, they will be made available after approval by the Research Ethics Committee of the National Center of Neurology and Psychiatry.

Competing interests

None.

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Contributions

NY wrote the first draft of the manuscript, and other authors critically revised the manuscript. All authors approved the final manuscript.

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Figures

Figure 1

Study flowchart Flowchart of the caregivers statements inclusion.