INTRODUCTION

Outcome selection and participant involvement are important in modern clinical and research work [1]. This appears to apply to studies of caregivers of people with mental illness since they have specific needs and require effective support [2]. Importantly, caregivers appear to have different concerns from people with mental illness. For example, they tend to bear significant physical, mental, and economic burdens as a result of caring for those with mental illness [3]. In short, we need to identify proper research outcomes for caregivers themselves.

A previous systematic review reported outcomes from the past three decades that were considered important to caregivers [4]. These outcomes were mainly divided into three dimensions, namely negative aspects of caregiving (e.g., strain, stress, and worrying), positive aspects of caregiving (e.g., personal growth, strength, support,
rewards, and satisfaction), and caregivers’ perceptions and attitudes toward people with mental illness (e.g., insight, stigma, and efficacy). Most studies primarily assessed the negative aspects of caregiving, while positive aspects of caregiving have received less attention [4]. Other systematic reviews also pointed out that few studies have focused on caregivers’ recovery and well-being [5,6]. Therefore, further research is expected to explore outcomes meaningful to caregivers.

Despite an increasing emphasis on outcomes important to caregivers, the outcomes in most individual studies may still be determined by researchers rather than caregivers [7]. Focusing on caregivers’ experiences, needs, and interests in the outcome selection process appears to be important for identifying meaningful goals and sharing research findings. In fact, people with mental illness and researchers often recognized different needs and goals for treatment [8], and this may also be true for caregivers and researchers. In addition, caregiver involvement has been accelerated by a recent trend toward patient public involvement (PPI), or coproduction [9,10]. Therefore, exploring outcomes that caregivers consider important can be essential to promote future studies that meet their needs. Although several systematic reviews have summarized experiences or views of caregivers regarding caring for people with mental illness [5,11-14], few studies have directly asked caregivers about important outcomes in research, particularly in community-based mental health research settings. This study preliminarily investigated what outcomes are deemed by caregivers of people with mental illness to be important for community-based mental health research.

2 | METHODS

2.1 | Study design and participants

An online, cross-sectional survey was conducted from August 1 to 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).

2.2 | 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

![Study flowchart]

FIGURE 1 Study flowchart
burden as evaluated using the Japanese version of the Zarit burden interview, short version (J-ZBI-8) [15]. 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.” We created the questions through discussion with caregivers to enable them to easily understand the term “outcome” which was unfamiliar to them. We also worked with caregivers to modify the online survey screens in order for participants to answer each question easily. We held an online conference for the participating caregivers to share the results of our research on March 20, 2021. We then confirmed their supportive comments on the results and no requests to change the results.

2.3 | Analyses

Two researchers (NY and TS) independently extracted outcomes based on participants’ survey responses and 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. We shared the analysis results with several caregivers who participated in the survey to obtain their feedback. We then incorporated it into our analysis. 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 [16], and the criterion for good reliability was set at 0.8 [16]. Finally, the number of responses corresponding to each category was calculated. The categories are presented in Table 2.

3 | RESULTS

A study flowchart is shown in Figure 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.

| Demographic characteristics of caregivers and people with schizophrenia (N = 132) |
|---------------------------------------------------------------|
| ![Table 1](https://example.com/table1.png) |
This study suggested 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.

Caregiver burden is considered as the main outcome identified by previous studies, and positive aspects of caregiving, namely caregiver recovery and well-being, have been recognized less frequently [4–6]. Since caregiver burden captures the degree of multifaceted burden that caregivers experience from caring for family members and partners over time [17], the results of this study may not cover all aspects of caregiver burden. However, the overall trend toward family burden as an important outcome appears to be similar to previous studies.

The reason for these results may be related to weaknesses in the community-based mental health system in Japan. For example, 90% of health professional work in inpatient settings in Japan, and the number of psychiatric beds is still the highest across the world [18]. In addition, for almost 100 years until 2014, Japanese family members statutorily were obligated to provide care for people with mental illness. A study suggests feelings of care burden of family in Japan is higher than those in Korea [19]. Although there has been a gradual increase in services for people with mental illness, the community-based mental health system is mainly designed to provide facility-based services in Japan [20]. In other words, community services are inadequate, particularly for those with severe mental illness or those in the acute phase of recovery who have difficulty going out. Consequently, caregivers often play a major role in supporting their daily lives. The common outcomes identified in this study may reflect this situation. Specifically, they may indicate that caregivers need a community-based mental health system in which they do not bear so much responsibility for caring for people with mental illness.

The strength of this study is that we worked with caregivers in the development stage of the question and online survey screens
based on the concepts of PPI [9,10], although the PPI could not be performed in all the stages of this study. This could lead to future interventional studies whose primary outcomes are based on what caregivers consider to be highly important, as well as additional, implementable, evidence-based practices for caregivers. On the contrary, this study had several limitations. First, the study was not conducted by the family caregivers themselves. While we obtained the feedback from the caregivers, it was still impossible to avoid the researcher's interpretation of the analysis. Second, the amount of interview data may be inadequate. Although this study included over 100 caregivers and obtained a wide variety of statements, more in-depth interviews using semistructured methods might have yielded more information than this study. Third, outcomes were ranked by numbers of responses, but this approach may be inadequate to determine which outcomes are most important. Fourth, we did not consider covariates related to caregiver characteristics and circumstances because we could not link participants' statements with their personal characteristics in this online survey. Further research employing a more rigorous qualitative design is needed to confirm the findings of this study and to assess covariate influence.

Despite these limitations, this exploratory study suggested 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.

AUTHOR 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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CONFLICT OF INTEREST
The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT
Not all data are freely accessible because no informed consent was given by the participating agencies for open data sharing. However, the data are available from the corresponding author on reasonable request, following approval by the Research Ethics Committee at the National Center of Neurology and Psychiatry.

ETHICAL APPROVAL
The study was approved by the Research Ethics Committee of the National Center of Neurology and Psychiatry (No. A2020-036).

INFORMED CONSENT
Informed consent was obtained from all subjects.

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