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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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the Fundamental study on effective
community services for people with
severe mental disorders and their families.

Abstract

Aims: This study investigated outcomes in community mental health research that were important to caregivers of people with schizophrenia.

Methods: Using an online survey conducted from August 1 to 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 selfreported 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.

Conclusions: 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.

KEYWORDS
caregivers, clinical, community mental health, outcomes, schizophrenia

1 | 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,

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