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Translation and validation of the Schizophrenia Caregiver Questionnaire – Japanese version (J-SCQ)

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ABSTRACT

The Schizophrenia Caregiver Questionnaire (SCQ) was developed to evaluate the state of family members caring for schizophrenics. Our study aimed to construct a Japanese version of the SCQ (J-SCQ) based on its English version and verify its reliability and validity. We conducted forward and backwards translations and cognitive debriefing to draw up the J-SCQ. A total of 1229 survey sheets were mailed, together with the Japanese versions of the Medical Outcomes Study Short-Form version 2 (SF-12v2) and World Health Organization Quality of Life Scale (WHOQOL-26) questionnaires. A total of 305 survey sheets (valid response rate: 68.2%) were analyzed. The Cronbach's alpha coefficients of various supra-domains and subdomains of the J-SCQ were over 0.71, establishing its internal consistency. Pearson's correlation coefficients between the various domains of the SF-12v2 and WHOQOL-26 was used to establish concurrent validity. The results show that the J-SCQ may be a useful Japanese questionnaire that can compare Japanese caregivers to those across different countries and measure the effects of support and intervention provided to caregivers.

1. Introduction

The unexpected onset of schizophrenia and chronic health conditions disrupt the family system's critical balance in relationships, goals, expectations, aspirations, and hopes [1]. Schizophrenia has long been treated by hospitalization worldwide. The length of hospitalization often extends over several decades, and as symptoms become chronic, many schizophrenics lose the ability to function in their daily lives and are unable to live in the community. The circumstances surrounding Japan's mental health and medical welfare have changed since the 2000s. In its "Visions in Reform of Mental Health and Medical Welfare" [2], the government indicated a policy of shifting the focus from hospitalized medical treatment to community-based care. A committee of personnel in charge of promoting psychiatric patients' transition-to-community [3] has also been formed, aimed at establishing a community-based integrated care system that also caters to mental disorders, to ensure that individuals with psychiatric diagnoses can live independently as members of the community. In this system, a support setup is planned for development by health, healthcare, and welfare personnel in collaboration with psychiatric and other medical institutions, community support operators, and municipalities. However, in community psychiatric treatment, attention has been drawn to the role of families as caregivers who carry heavy burdens since early on [4].

For family caregivers who live with people with mental illness, the development of mental illness in a family member is clearly a difficult and painful life experience, which may put these individuals in a chronically stressful situation [5]. In particular, families with

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schizophrenia experience a heavier burden than those with other mental disorders because of their greater role in supporting community life [6]. Many families with schizophrenia experience significant cognitive, psychological, social, and economic burdens, including psychiatric symptoms such as anxiety and depression, social stigmatization, and financial constraints [7]. It is possible, however, that family caregivers who feel burdened will persist in the situation without being aware of the stress they are under. This can cause impairments in their physical health, emotions, behaviors, cognition, and interpersonal relationships [8]. Family members caring for schizophrenics play a demanding role in supporting community living [9–11]. They face mental and physical burdens, as well as the difficulties and stress associated with caregiving, and experience depression and anxiety associated with such care and overload arising from their lack of knowledge of the disease [9,12–14]. Assistance for patients' parents to alleviate their sense of burden with caregiving is essential to prevent the relapse of patients' disease [15]. For that purpose, caregivers need a place where they can readily engage in daily consultations. Social assistance to caregivers helps families maintain their physical and mental health and lead meaningful lives [16]. Furthermore, support for family members caring for schizophrenics is needed because the burden on family caregivers results in huge social costs, such as their unemployment, loss of productivity resulting from missed work, and increased dependence on fee-based medical care [17].

Past studies evaluating family caregivers' sense of burden mainly used the Zarit Caregiver Burden Interview (ZBI) [18] as a survey sheet and assessed it alongside quality of life (QOL) and depression. However, the ZBI was developed to evaluate the sense of burden experienced by family caregivers of elderly patients with Alzheimer-type dementia. It does not target the family members caring for schizophrenics. This prompted a group led by Steven H. Zarit, who created the ZBI in 2012, to revise its scale. They developed the Schizophrenia Caregiver Questionnaire (SCQ) specifically for family members caring for schizophrenics [19]. It has been translated into 11 languages in ten countries across Europe [20]. However, there is no Japanese version of this scale.

This study aimed to use the American English version of the SCQ as the basis for developing a Japanese version (J-SCQ) and to verify its reliability and validity. This would make it possible to objectively show the influence and sense of burden felt by family members caring for schizophrenics based on their experiences. The advantages of using the J-SCQ include generating awareness of the sense of burden associated with caregiving and understanding the caregivers' burden of care. The J-SCQ may also help in evaluating support received by the caregivers.

2. Materials and methods

2.1. Ethical considerations

The survey items were presented in writing and explained to the research participants along with the study's purpose and specific methods. In addition, they were advised that participation was completely voluntary, their privacy would be strictly protected, and no disadvantages would occur in their medical treatment or daily life. Finally, they were advised about the system for contacting the researchers. This study was conducted after receiving approval and permission from the Tokyo Medical University Institutional Review Board (approval ID: T2020-0425) with which the researchers are affiliated.

2.2. Schizophrenia Caregiver Questionnaire (SCQ)

The SCQ is based on the following eight domains: [Humanistic Impact (HI, 17 items)], [Exhaustion with Caregiving role (EC, 2 items)], [Lack of Support (LS, 1 item)], [Patient Dependence (PD, 2 items) Patient Dependence (PD, 2 items)], [Worries for the Patient (WP, 3 items)], [Perception of the Care provided (PC, 2 items)], [Finance (F, 2 items)], [Overall Difficulty of caregiving role: (OD, 1 item)], and two other items (Item 19 and Item 26) for a total of 32 items. In addition, the sub-domains are classified as follows; [Humanistic Impact: (HI, 17 items)] consisted of "Physical functioning: (HI-P, 3 items)", "Emotional functioning: (HI-E, 6 items)", "Social functioning: (HI-S, 3 items)" and "impact on Daly Life: (HI-DL, 5 items)" and [Finance (F, 2 items)] consisted of "Financial Dependence of the patient: (F-D, 1 item)" and "Financial impact of caregiving: (F-I, 1 item)".

The SCQ is the 11-point numerical rating scale. Responses are recorded to a 0 to 4 scale [21]. The final SCQ score is a linear transformation of the recoded item scores multiplied by 25, with the total ranging from 0 to 100. Higher scores indicate greater impact.

2.3. Translation

Using the best practices for translation as our basis, we conducted forward and back translations, as well as cognitive debriefing. Forward translation involved two translators whose native language is Japanese and are familiar with American English (one was familiar with mental health and medical welfare), while back translation involved a translator who was not involved in forward translation work. Before the cognitive debriefing, the researchers evaluated the translation. Cognitive debriefing was then conducted on five individuals whose native language was Japanese. The aim was to discover any problems that had gone unnoticed in the forward and back translations and to investigate actual users' ease of understanding of the J-SCQ (i.e., the caregivers who are the participants of this study) and its cognitive equivalence. The criteria for selecting the participants for debriefing were individuals who were familiar with the users of the scale and could predict the understanding of the users who could answer the scale.

2.4. Verification

2.4.1. Research subjects

We randomly selected 150 groups from 1171 associations registered with the National Federation of Associations of Families with Mental Illnesses in Japan. The organization was formed by families of people with mental illnesses and has been in existence for almost 50 years. Between May 1 and August 31, 2021, telephone numbers were available for 120 of the 150 organizations. Of these, representatives and office staff of 113 organizations were contacted by the researcher. Of these, 30 were no longer active as family associations due to dissolution, termination, or suspension of membership. The main reasons were aging and novel coronavirus infection (COVID-19). As a result, 68 family associations with research cooperation were selected as research target groups. The research participants were caregivers who belonged to these groups. The survey sheets were handed out by group. The researcher explained the research objectives and methods, respect for free will to participate in research, confidentiality, privacy protection, absence of disadvantages in medical care and daily life, contact system for researchers, etc., in writing. Participants who returned the completed form were considered to have given consent. The target number of questionnaires to be collected was set to 400–500, which was sufficient for statistical analysis and feasible in terms of the research period and budget. Considering the results of past surveys conducted by the National Federation of Associations of Families with Mental Illnesses in Japan and method of selecting subjects for this study, the response rate was predicted to be approximately 30%. Therefore, 1500 copies were sent to the research participants' groups to get the expected response rate.

2.4.2. Survey items

The survey collected the following basic attributes of subjects: sex, age, relationship with the person with schizophrenia, place of residence, caregiver status (primary or not), and residence status (living or not living with a person with schizophrenia). For persons with schizophrenia receiving care, the following survey items were collected: sex, age, age of onset, and method of taking oral medications. The J-SCQ and Japanese versions of the Medical Outcomes Study Short-Form version 2 (SF-12v2) and World Health Organization Quality of Life Scale (WHOQOL-26) were used to develop the questionnaire. It was predicted that there would be a negative correlation between the J-SCQ and SF-12v2 and between the J-SCQ and WHOQOL-26.

2.4.3. SF-12v2

The Japanese version of the SF-12v2 is classified into the following 8 subscales: [Physical Functioning (PF)], [Role Physical (RP)], [Bodily Pain (BP)], [Social Functioning (SF)], [General Health (GH)], [Vitality (VT)], [Role Emotional (RE)], and [Mental Health (MH)]. The higher the score, the higher the quality of life.

2.4.4. World Health Organization Quality of Life

The Japanese version of the WHOQOL26 consists of 26 items, including 24 items in the 4 domains of [physical health (7 items)], [psychological health (6 items)], [social relationships (3 items)] and [environmental health (8 items)], and 2 items asking about [overall]. The questionnaire is a self-assessment type, and the items are subjective judgments, using a 5-point response scale with "not at all" as 1 and "very much" as 5, with higher scores indicating a higher quality of life.

2.4.5. Collection of data

The number of questionnaires collected was predicted to be between 400 and 500, and the rate of collection was approximately 30%. The target number of questionnaires was 1500 copies, which were distributed to the research participants via representatives and business offices of the research participants' groups. The questionnaires were collected after the participants had answered the questions; completed questionnaires were enclosed in an anonymous return envelope provided by the researchers and returned to them.

2.4.6. Statistical analyses

The reliability and internal consistency of the J-SCQ was evaluated according to the calculated Cronbach's alpha coefficient for each J-SCQ item. Concurrent validity was evaluated according to the calculated correlation coefficient between the J-SCQ and SF-12v2/WHOQOL-26 scores. Exploratory factor analysis (EFA) was conducted to examine the structure of the J-SCQ. Statistical analyses were conducted after receiving advice from math and statistical specialists. IBM SPSS Statistics ver. 24.0 was used for the statistical analysis.

3. Results

3.1. Translations

During the cognitive debriefing, we scrutinized the translated version of the SCQ to see if there were any terms and/or content that were difficult to understand and if the understanding of the content and concept of the items was appropriate. If the expressions and content were within the range that the caregiver could understand, literally translated sentences were adopted. Questions asking about the degree and frequency are described such that they can be clearly understood. For instance, it was clarified whether the participant is the caregiver (you) or schizophrenic (she/he). Cognitive debriefing did not result in any modification of the representation.

The J-SCQ was developed according to the following process: in the questionnaire, the term "caregivers" was written as "carers" (in

katakana), not "family care providers" or "caregivers" (in English). In this study, the term "carers" is defined as "individuals who provide care, such as nursing care, education/support, care/assistance, and/or considerations, to family members with schizophrenia free of charge regardless of whether they live together or separately."

3.2. Verification

After sending two to 90 copies per association to 68 associations that agreed to participate in the research, the total number of questionnaires sent was 1229. Of the 447 copies collected (rate of collection: 36.4%), we analyzed 305 copies that had answers written for all the questions (valid response rate: 68.2%).

Table 1 lists the basic attributes of the participants. Over 70% of the carers were women, with those in their 60s and 70s accounting for approximately 70%. Approximately 60% of the individuals receiving care were men, and those between their 30s and 50s accounted for approximately 80%.

Table 2 shows the average scores for each J-SCQ item, Cronbach's alpha coefficients, and Cronbach's alpha coefficients for the SCQ original version. The total scores for the J-SCQ as well as the Cronbach's alpha coefficient of each supra-domain and subdomain exceeded 0.71.

Table 3 shows the total J-SCQ score and Pearson's correlation coefficient between the various supra- and subdomains and each SF-12 domain. Those in bold font have correlation coefficients exceeding 0.4. Correlation coefficients between scores of J-SCQ domains and SF-12 domains ranged 0.01–0.06 (low to moderate correlation). HI scores were moderately correlated with scores in 'Vitality', 'General health', 'Role emotional', 'Mental Health' scores, and 2MCS_U. EC, LS, PD, WP and PC scores were also moderately correlated with scores in MH and 2MCS_U.

Table 4 shows the Pearson's correlation coefficient between the J-SCQ total score and each of its supra- and subdomains and between each domain of WHOQOL-26. Those in bold font had a correlation coefficient exceeding 0.4. Correlation coefficients between scores of J-SCQ domains and WHOQOL26 domains ranged 0.01–0.06 (low to moderate correlation). HI scores were moderately correlated with scores in 'Total Score', 'Physical domain', 'Mental domain', 'Environment', and 'Overall' scores. EC, LS, WP, PC, F_I and OD scores were also moderately correlated with scores in 'Physical domain', 'Mental domain', 'Mental domain', and 'Environment' scores.

The structure of the J-SCQ was explored by a principal factor method with Varimax rotation and Kaiser normalization. Table 5 lists the items in order of factor loadings for each factor. Factor I consisted of 19 items from No. 2 to No. 9, Factor II consisted of 8 items from No. 31 to No. 26, and Factor III consisted of 6 items from No. 20 to No. 8, and each factor was named as follows; Factor I: "Impact on Life and Relationships, and Burden of Psychological and Physical"; Factor II: "Difficulties and Emotional Burden"; Factor III: "Sense of Failure and Concerns of life".

The SCQ is a measure that asks about the past four weeks, with "Over the past four weeks," at the beginning of every item.

In J-SCQ, each item is described in Japanese. In this study, each item was described in American English as it was in the SCQ original version [19,21].

4. Discussion

The purpose of this study was to use the original American English version of the SCQ as the basis to develop a Japanese version. The items in the original version were developed based on a review of the literature on ZBI, experts' opinions, and semi-structured, qualitative interviews with family members caring for schizophrenics whose native language was American English (free answers, given face to face) [19,22] and whose content validity had been fully secured. In our study, translations were conducted based on a report by the ISPOR Task Force [23], similar to those conducted on 11 European-language versions [20]. Content validity was therefore established, and the J-SCQ took the form of a questionnaire that the caregivers could understand and answer appropriately.

Previous studies comparing caregivers of different races and regions in various countries [24,25] with varying levels of

| | | Carers | | Schizophrenics | |
|-----|----------|------------|------|----------------|------|
| | | n (people) | % | n (people) | % |
| Sex | Male | 81 | 26.6 | 178 | 58.4 |
| | Female | 223 | 73.1 | 121 | 39.7 |
| | Other | 1 | 0.3 | 6 | 2.0 |
| Age | Under 10 | 0 | 0 | 0 | 0 |
| - | 10s | 0 | 0 | 1 | 0.3 |
| | 20s | 0 | 0 | 16 | 5.2 |
| | 30s | 3 | 1.0 | 72 | 23.6 |
| | 40s | 8 | 2.6 | 109 | 35.7 |
| | 50s | 25 | 8.2 | 65 | 21.3 |
| | 60s | 79 | 25.9 | 19 | 6.2 |
| | 70s | 139 | 45.6 | 12 | 3.9 |
| | 80s | 43 | 14.1 | 2 | 0.7 |
| | 90s | 3 | 1.0 | 0 | 0 |
| | Unknown | 5 | 1.6 | 9 | 3.0 |

Table 1Basic attributes of carers and care recipients (N = 305).

Table 2

Average score for each J-SCQ item and Cronbach's alpha coefficient (N = 305).

| Domains | Sub-Domains | No. of items | Av. score (points) | Standard deviation | Cronbach's α | Cronbach's α for the SCQ original version [21] |
|--|-------------------------|-----------------|-----------------------|--------------------|-----------------|---|
| Total Score | | 32 | 36.82 | 27.14 | 0.979 | ND |
| Humanistic Impact | Total Score | 17 | 33.72 | 28.54 | 0.974 | 0.96 |
| | Physical | 3 | 35.16 | 31.96 | 0.909 | 0.85 |
| | Emotional | 6 | 37.65 | 30.70 | 0.941 | 0.89 |
| | Social | 3 | 29.54 | 29.49 | 0.865 | 0.80 |
| | Daily Life | 5 | 30.64 | 28.62 | 0.921 | 0.87 |
| Exhaustion with Caregiving role | | 2 | 40.45 | 34.57 | 0.791 | 0.69 |
| Lack of Support | | 1 | 34.02 | 36.00 | NA | NA |
| Patient Dependence | | 2 | 40.45 | 32.34 | 0.801 | 0.57 |
| Worries for the Patient | | 3 | 49.26 | 33.30 | 0.878 | 0.70 |
| Perception of Caregiving | | 2 | 37.91 | 31.44 | 0.907 | 0.79 |
| Finance | Total Score | 2 | 35.94 | 31.36 | 0.716 | ND |
| | Dependence | 1 | 40.25 | 37.07 | NA | NA |
| | Impact of caregiving | 1 | 31.64 | 33.91 | NA | NA |
| Overall Difficulty of caregiving role | | 1 | 46.15 | 36.44 | NA | NA |

ND: No Description.

NA: Not Applicable as single-item dimension.

development [26] are rare. Therefore, an international evaluation is important. In addition, factor structures were not taken into consideration and remained the same as in the original version during the course of developing the 11 European-language versions [20]. As the purpose of this study was to draw up a Japanese version of the SCQ, we kept each domain of the J-SCQ the same as that of the original version. Internal consistency and concurrent validity were also analyzed.

For the J-SCQ, Cronbach's alpha coefficient ranged between 0.72 and 0.97. In the original version, the Cronbach's alpha for Patient Dependence, Exhaustion with Caregiving, and other domains were 0.57, 0.69, and over 0.70, respectively [21]. The results in the current study show better results for internal consistency as compared those of the original version, thus establishing J-SCQ's internal consistency.

Regarding Pearson's correlation coefficient between the J-SCQ and SF-12v2, statistically significant correlations (p < 0.01 and 0.05) were observed between domains, except for those between the J-SCQ's "Patients' Financial Dependence (F-D)" and SF-12v2's "Bodily Pain," (r = -0.099), and between the J-SCQ's "Patients' Financial Dependence (F-D)" and "Physical Component Summary," (r = -0.105). These results are close to the results of the original version of the SCQ and SF-36 (MOS 36-Item Short-Form Health Survey) [21], which claim correlations in the low- to medium-range coefficients (0.1–0.6). A comparison with the result of the original version [21] revealed greater and equal correlations. Pearson's correlation coefficient between the J-SCQ and WHOQOL-26 also showed a correlation exceeding 0.4 between numerous domains. Thus, these results confirm the concurrent validity of the J-SCQ.

Furthermore, factor analysis was conducted and the J-SCQ was structured in 3 domains. However, based on the factor loadings, there were items that were included or could not be included in any of the factors. This was similar to the fact that the SCQ original version was structured with 8 domains, and Item 19 and Item 26 were not included in any domain when the construct validity of the SCQ original version was verified. Therefore, it was difficult to show a clear structure of the J-SCQ. In the validation of the original version of the SCQ, consistent floor effects were observed by Rasch modeling for all items of the questionnaire. One reason for this is that the SCQ may not accurately measure caregivers who are completely unaffected or only very mildly affected [21]. Another reason is that caregivers with very strong impacts may not be able to answer questions. The latter may have affected the response rate and thus the results of the study.

By developing a scale that can comprehensively measure caregivers' burden, we were able to secure the reliability and validity of the J-SCQ, which used a factor structure similar to that of the SCQ. Therefore, the J-SCQ can be considered a useful questionnaire that can compare Japanese caregivers with those across different countries and measure the effects of any support and interventions they receive.

4.1. Limitations

The original American English version of the SCQ was translated into Japanese based on best practice. Therefore, the validity of the content is believed to have been established. However, it is possible that the impact of caring for schizophrenics may differ due to differences between the cultures of Asian countries, including Japan, and that of the US and European countries. For instance, during cognition debriefing, the participants confessed that they felt fear when schizophrenics were in the acute stage of the disease, and that this affected them. At the same time, it affected their relationship with the patient to whom the caregivers subsequently provided care. However, the SCQ does not contain item asking respondents about their fear. Another limitation of this study is that it did not include caregivers of non-schizophrenics and the low response rate.

The J-SCQ shows favorable internal consistency and concurrent validity. Because of COVID-19, it was not possible to perform a

Table 3 Pearson's correlation coefficient between the J-SCQ and SF-12 (N = 305).

| Scale | Domains | J-SCQ TS, Domains and Sub-Domains | | | | | | | | | | | | | | |
|-------|------------------|-----------------------------------|---------------------------|---------------------------|---------------------------|--------------------------|---------------------------|---------------------------|---------------------------|---------------------------|--------------------------|---------------------------|--------------------------|----------------|--------------------------|---------------------------|
| | | TS | HI_TS | HI_P | HI_E | HI_S | HI_DL | EC | LS | PD | WP | PC | F | F_D | F_I | OD |
| SF-12 | PF | 208** | 200** | 198** | 179** | 144* | 226** | 170** | 199** | 136* | 168** | 205** | 201** | 129* | 230** | 150** |
| | RP BP | 381** 297** | 377** 284** | 355** 282** | 334** 264** | 321** 239** | 413** 288** | 284** 264** | 313** 286** | 327** 205** | 314** 245** | 301** 265** | 285** 184** | 211** 099 | 297** 231** | 309** 266** |
| | SF | 347** | 362** | 397** | 318** | 305** | 366** | 247** | 305** | 271** | 283** | 196** | 248** | 196** | 245** | 275** |
| | GH | 459** | 467** | 474** | 473** | 380** | 424** | 355** | 420** | 344** | 416** | 307** | 272** | 236** | 246** | 361** |
| | VT | 457** | 458** | 445** | 406** 401** | 458** | 451** | 298** | 443** | 328** | 397** | 367** | 278** | 217** | 277** | 380** |
| | MH | 638** | 644** | 495*** 621** | 491** 631** | 473** 578** | 600** | 374*** 463** | 484** 559** | 38/** 462** | 463** 583** | 391** 437** | 411** | 240** 350** | 349** 377** | 401** 537** |
| | 2PCS_U 2MCS_U | 200** - .614 ** | 192** - .624 ** | 201** - .602 ** | 158** - .605 ** | 135* - .581 ** | 230** - .577 ** | 174** - .429 ** | 180** - .562 ** | 155** - .450 ** | 144* - .563 ** | 186** - .422 ** | 179^{**} 362^{**} | 105 307** | 217^{**} 333^{**} | 159** - .501 ** |
| | | | | | | | | | | | | | | | | |

TS: Total Score; HI: Humanistic Impact; HI_TS: Humanistic Impact_Total Score; HI_P: Humanistic Impact_Physical; HI_E: Humanistic Impact_Emotional; HI_S: Humanistic Impact_Social; HI_DL: Humanistic Impact_Daily Life; EC: Exhaustion with Caregiving role; LS: Lack of Support; PD: Patient Dependence; WP: Worries for the Patient; PC: Perception of Caregiving; F: Finance; F_TS: Finance_Total Score; F_D: Financial Dependence of the patient; F_I: Financial Impact of caregiving; OD: Overall Difficulty of caregiving role; PF: Physical Functioning; RP: Role Physical, BP: Bodily Pain; SF: Social Functioning; GH: General Health; VT: Vitality; RE: Role Emotional, MH: Mental Health; 2PCS_U: A two-physical component summary score that shows the QOL of physical aspects using a 0–100 point method; 2MCS_U: A two-mental component summary score that shows the QOL of mental aspects using a 0–100 point method.

**p < 0.01, *p < 0.05.

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| Table 4 |
|---|
| Pearson's correlation coefficient between the J-SCQ and WHOQOL26 ($N = 305$). |

| Scale | TS and Domains | J-SCQ TS, Domains and Sub-Domains | | | | | | | | | | | | | | |
|--------------|---|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|
| | | TS | HI_TS | HI_P | HI_E | HI_S | HI_DL | EC | LS | PD | WP | PC | F | F_D | F_I | OD |
| WHO QOL26 | TS Physical domain Mental domain Social relationship Environment Overall | 622** 576** 595** 362** 541** 485** | 618** 571** 596** 376** 525** 496** | 611** 571** 592** 348** 521** 484** | 586** 542** 588** 358** 477** 471** | 555** 502** 527** 354** 488** 432** | 592** 548** 544** 364** 517** 488** | 479** 443** 448** 269** 439** 346** | 588** 529** 576** 378** 514** 425** | 455** 424** 438** 229** 398** 376** | 527** 499** 515** 295** 439** 421** | 440** 415** 417** 245** 401** 286** | 454** 408** 386** 241** 464** 336** | 337** 313** 294** 155** 342** 232** | 470** 412** 393** 276** 484** 367** | 526** 487** 501** 285** 461** 425** |

TS: Total Score; HI: Humanistic Impact_Total Score; HI_P: Humanistic Impact_Physical; HI_E: Humanistic Impact_Emotional; HI_S: Humanistic Impact_Social; HI_DL: Humanistic Impact_Daily Life; EC: Exhaustion with Caregiving role; LS: Lack of Support; PD: Patient Dependence; WP: Worries for the Patient; PC: Perception of Caregiving; F: Finance; F_TS: Finance_Total Score; F_D: Financial Dependence of the patient; F_I: Financial Impact of caregiving; OD: Overall Difficulty of caregiving role.

**p < 0.01, *p < 0.05.

 \checkmark

Table 5

Factor loadings resulting from a principal factor method with Varimax rotation from the J-SCQ.

| No | Items | Ι | п | III | Communality |
|-----|---|--------|--------|--------|-------------|
| 2. | how often did you feel that because of the time you spent with him/her you didn't have enough time for yourself? | 0.783 | 0.272 | 0.213 | 0.732 |
| 12. | how much did you feel that your social life suffered because you were caring for him/her? | 0.769 | 0.294 | 0.299 | 0.767 |
| 3. | how difficult was it for you to care for him/her and meet your other responsibilities? | 0.763 | 0.279 | 0.295 | 0.747 |
| 10. | how much did you feel that your physical health suffered as a result of caring for him/her? | 0.737 | 0.388 | 0.285 | 0.775 |
| 11. | how often did you feel that you didn't have as much privacy as you would have liked, because of him/her? | 0.686 | 0.357 | 0.279 | 0.676 |
| 1. | how often did you feel that he/she asked for more help than needed? | 0.680 | 0.335 | 0.225 | 0.626 |
| 14. | how often did you feel that he/she was overly dependent on you to help with daily activities? | 0.654 | 0.248 | 0.417 | 0.663 |
| 5. | how frustrated did you feel about his/her behavior? | 0.644 | 0.499 | 0.211 | 0.708 |
| 24. | how tired did you feel due to caring for him/her? | 0.635 | 0.603 | 0.281 | 0.846 |
| 17. | how often did you feel you weren't in control of your life because of his/her schizophrenia? | 0.634 | 0.490 | 0.362 | 0.773 |
| 29. | how often did you feel your sleep was disturbed because of caring for him/her? | 0.608 | 0.503 | 0.257 | 0.689 |
| 7. | how often did you feel that his/her schizophrenia affected your relationship with other family members or friends in a negative way? | 0.604 | 0.501 | 0.272 | 0.690 |
| 6. | how angry did you feel about his/her behavior? | 0.594 | 0.517 | 0.188 | 0.656 |
| 4. | how embarrassed did you feel about his/her behavior? | 0.570 | 0.513 | 0.252 | 0.652 |
| 13. | how uncomfortable would you have felt about having friends over because of his/her behavior? | 0.562 | 0.368 | 0.327 | 0.558 |
| 32. | how often did you feel that caring for him/her affected your work (paid or unpaid) in a negative way? | 0.543 | 0.521 | 0.293 | 0.651 |
| 18. | how often did you wish you could just leave the care of him/her to someone else? | 0.493 | 0.449 | 0.308 | 0.539 |
| 9. | how often did you feel he/she was dependent upon you for financial support? | 0.487 | 0.123 | 0.452 | 0.456 |
| 31. | how often did you experience emotional highs and lows ("an emotional rollercoaster") because of his/her schizophrenia? | 0.424 | 0.696 | 0.355 | 0.791 |
| 28. | how often did you worry that his/her schizophrenia might get worse? | 0.263 | 0.693 | 0.404 | 0.712 |
| 30. | how often did caring for him/her make you feel sad? | 0.357 | 0.691 | 0.386 | 0.754 |
| 27. | how often did you worry that he/she might have an episode? | 0.334 | 0.683 | 0.399 | 0.737 |
| 25. | how stressed did you feel due to caring for him/her? | 0.556 | 0.668 | 0.296 | 0.844 |
| 22. | how difficult was it to care for him/her? | 0.458 | 0.544 | 0.447 | 0.705 |
| 23. | how often did you feel alone in caring for him/her? | 0.456 | 0.465 | 0.402 | 0.585 |
| 26. | how difficult was it to get him/her to take his/her medication? | 0.325 | 0.390 | 0.336 | 0.371 |
| 20. | how often did you feel you should be doing more for him/her? | 0.198 | 0.324 | 0.732 | 0.679 |
| 21. | how often did you feel that you were not able to care for him/her as well as you would have liked? | 0.157 | 0.374 | 0.715 | 0.676 |
| 19. | how often did you feel uncertain about how to care for him/her? | 0.331 | 0.507 | 0.567 | 0.688 |
| 15. | how often did you feel that you didn't have enough money to care for him/her, in addition to the rest of your expenses? | 0.417 | 0.161 | 0.550 | 0.503 |
| 16. | how often did you feel that you would be unable to take care of him/her for much longer? | 0.455 | 0.368 | 0.530 | 0.624 |
| 8. | how afraid were you of what the future holds for him/her? | 0.408 | 0.419 | 0.439 | 0.535 |
| | factor contribution | 9.454 | 7.056 | 4.897 | 21.407 |
| | Cumulative Proportion | 29.543 | 51.593 | 66.895 | |

Note: Factor loadings with absolute values more than 0.4 are boldfaced.

study design to confirm the test-retest reliability of the study. It is necessary to verify test-retest reliability, convergent and discriminant validities, furthermore, the constructs of the impact and burden of family members caring for schizophrenics in Japan need to be examined, in future research.

4.2. Conclusion

The J-SCQ is a scale whose content validity has been established and is easily understandable and answerable for participants. As this study was conducted with the aim of developing a J-SCQ, we verified its reliability and validity using supra-domains, subdomains, and items with the same factor structure as the original version of the SCQ. Thus, we succeeded in ensuring internal consistency and concurrent validity. While the J-SCQ can be used for assessing caregivers' burden in longitudinal and clinical studies, more research is needed to prove its applicability.

Author contribution statement

Naotoshi Kamizawa: Conceived and designed the experiments; Performed the experiments; Analyzed and interpreted the data; Contributed reagents, materials, analysis tools or data; Wrote the paper.

Toshihiro Miyamura: Conceived and designed the experiments; Analyzed and interpreted the data; Wrote the paper.

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Data availability statement

Data included in article/supp. material/referenced in article.

Declaration of interest's statement

The authors declare no conflict of interest.

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