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Assessing the structural characteristics of the Japanese version of the Adult Social Care Outcomes Toolkit for Carers

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Abstract

As there are no standardized measures of Quality of Life (QoL) of informal carers impacted by use of long-term care (LTC) in Japan, the development or translation and cross-cultural adaptation of LTC outcomes measures for carers is needed for LTC research and evaluation. In this study, we assessed the validity and reliability of the factor structure and response system of the translated and cross-culturally adapted Japanese version of the Adult Social Care Outcomes Toolkit for Carer (J-ASCOT-Carer). Participants were 872 informal family caregivers of adults with LTC services, living at home. Almost half (46 %) were aged between 50 and 59 years and 60 % took care of their mother . We used a combined factor analysis and item response theory approach. Model fit indices considered were factor loading, path coefficients, root mean square error of approximation, standardized root mean square residual, and comparative fit index. This study confirmed the one factor structure of the original English version of the ASCOT-Carer. The values for the model fit indices indicated a good fit. The validity and reliability of the response system were confirmed. The J-ASCOT-Carer is a promising assessment instrument to measure QoL of Japanese caregivers of adults with LTC.

Keywords : quality of life, long-term care, caregivers, Adult Social Care Outcomes Toolkit for Carer

Introduction

In 2000, the long-term care (LTC) system was introduced in Japan to provide care recipients necessary services at home with autonomy and dignity.[1] LTC is expected to improve and maintain the quality of life (QoL) of care recipients as well as their informal family caregivers. However, a standardized measure for LTC-related QoL was lacking when the LTC system was introduced in Japan.[2] Outcomes of LTC in Japan are typically evaluated based on activities of daily living (ADLs) and instrumental activities of daily living (IADLs), which are measured by LTC professionals.[1] However, effectiveness and quality of LTC should not only include ADLs and IADLs but also the QOL of care recipients and caregivers.[3]

A national survey reported that caregivers of LTC recipients included residing spouse (25%), residing child (22%), professional service providers (13%), children, living separately from care recipients (12%), residing a spouse of own child (10%), others (3%), and unknown (15%).[1] LTC recipients who live at home are heavily reliant on informal family caregivers.[4-6] Major diseases among LTC recipients in Japan include dementia and stroke.[1] Informal family caregivers of adults with dementia struggle with care recipients' disruptive behavior such as agitation, aggression, and disinhibition.[7] Informal family caregivers of adults with stroke experience psychological distress and physical burden.[8,9] Therefore, psychological counseling and education for caring skills are provided to those caregivers for the maintenance of their health.[10] An epidemiological study in Japan found that regardless of the degree and type of functional limitation of LTC recipients, their spouses as informal family caregivers experienced a significantly high risk of psychological distress as well as limitations in social participation.[11] Moreover, a systematic review suggested that caregiving burden was determined more by the characteristics of the caregiver and the provision of caregiving tasks than by the characteristics of care recipients.[12] Therefore, every caregiver needs interventions to address their needs and strains.[13]

The Adult Social Care Outcomes Toolkit for Carers (ASCOT-Carer), developed by a research group at the University of Kent, England, captures aspects of LTC-related QoL for informal caregivers of adults requiring LTC at home.[14] The ASCOT-Carer was developed to reflect the social care policy and legislative focus on informal caregivers' wellbeing and QoL,[15] which recognizes that caregivers are co-clients of LTC along with the people they support.[16-19] The ASCOT-Carer is included in the Adult Social Care Outcomes Toolkit (ASCOT),[3] a suite of instruments designed to measure LTC-related QoL of recipients[20-22] and informal caregivers.[14,16-19] The ASCOT-Carer and an instrument for LTC recipients incorporate multiple dimensions of QoL that can be improved by LTC, for example, control over daily life, personal safety, and social participation.[14,16-22] The ASCOT-Carer and LTC recipient instruments have four overlapping QoL dimensions: control over daily life, social participation, personal safety, and occupation ("doing things I find value in and enjoy"). Other QoL domains are specific to caregivers (e.g., feeling supported and encouraged in the caring role) or LTC recipients (e.g., food and drink). In England, the ASCOT-Carer's psychometric properties have been established in a study on caregivers[14,16] and it has been used in LTC evaluation.[23] The ASCOT-Carer has been cross-culturally adapted and translated into Japanese.[24]

In this study, we examined the validity and reliability of the factor structure and the response system of the Japanese version of the ASCOT-Carer (J-ASCOT-Carer) using the data of informal family caregivers of adult recipients of LTC services who lived at home in Japan. This is an important step toward establishing whether and how the measure can be used in evaluation studies and home-based care research in Japan. This study had two research questions.

(1) Was the original factor structure of the ASCOT-Carer observed in the J- ASCOT-Carer?

(2) Was the original response system of the ASCOT-Carer effective for Japanese informal family caregivers?

Methods

Study design

This study employed a cross-sectional survey. The participants included informal family caregivers of recipients of LTC services who live at home. The second author conducted an online survey using Google Forms® (Google LLC, Los Angeles, CA, USA) from April 1 to September 30, 2018. After obtaining permission from an organization (where the second author was a member) that supports informal family caregivers, the recruitment information was sent to informal family caregivers through emails. Since the study was conducted using an online survey, potential participants were expected to have internet access, comprehend instructions written in Japanese, and respond according to instructions. The survey system allowed participants to submit their responses after completing all question items. Meeting rooms were provided in big cities, including Tokyo and Osaka for participants who needed assistance to complete the survey. A total of 872 participants provided informed consent for their data to be analyzed in this study.

The participants were not randomly selected. We intended to represent the national distribution of care need levels of LTC recipients.[1] The levels are examined by LTC professionals by assessing the extent of help required in performing ADLs and IADLs.[1] In this study, the levels were categorized into the following four groups, from the least dependent to the most dependent. In the least dependent level, recipients required LTC services to perform homemaking activities. In the moderate dependent level, recipients required LTC services for bathing, toileting, managing medication, and financing. In the highly dependent level, recipients required LTC services to perform all basic ADLs. In the most dependent level, recipients required LTC services for all ADLs and were not able to perform ADLs by themselves. In this study, the aforementioned four levels were expected to comprise 23%, 26%, 29%, and 22% of the population, respectively.

Ethical procedures

All participants provided informed consent. The study was conducted according to the World Medical Association Declaration of Helsinki. The study protocol was reviewed and approved by the research ethics committee of the Japan Lutheran College (2016-IBRA #01).

Measures

Demographic and caregiving characteristics

A self-report demographic questionnaire was used to gather caregivers' information, including gender, age, paid employment status during the data collection period, whether they resided with the care recipient, whether they were a primary family caregiver of the recipient, self-rated health status (good, fair, neither good nor bad, relatively bad, and bad), and duration of caregiving. Their care recipients' information, including age and kinship (own mother, own father, wife, husband, mother-in-law, father-in-law, grandmother, siblings, and others) was also collected,

The Japanese version of the ASCOT-Carer

The assessment instrument covers the following seven question items: *occupation (doing things with value and enjoyment), control over daily life, self-care, personal safety, social participation, space and time to be yourself,* and *feeling supported and* *encouraged*. Each item is rated on a 4-point Likert scale. The description of each level depends on the item; however, generally, the following descriptions are used; they demonstrate the range from the most satisfying to the least satisfying state: "I can do as I want," "I can do adequately," "I cannot adequately do" and "I cannot do at all".

Data analysis

The validity and reliability of the factor structure and response options of the J- ASCOT-Carer were evaluated using the combined factor analysis and item response theory (IRT) approach. These approaches helped investigate the dimensionality, validity, and reliability of the measure.[25-27] Prior to applying these approaches, the response options were converted into numbers as follows: 1 = "I can do as I want," 2 = "I can do adequately," 3 = "I cannot adequately do" and 4 = "I cannot do at all.

For the first research question, we used exploratory factor analysis (EFA) and confirmatory factor analysis (CFA) to evaluate the factor structure of the J-ASCOT-Carer. This ensured confirmation of the robustness of the factor structure in the same study.[27] The original instrument was found to have a one factor structure.[14] In the EFA, to assess whether the measurement had a one factor structure, we needed to confirm a contribution ratio at above 20%.[28] We used a robust weighted least squares estimation with no missing data. Model fit indices included factor loading, path coefficients, root mean square error of approximation (RMSEA), standardized root mean square residual (SRMR), and comparative fit index (CFI). A RMSEA value close to .06 and a CFI of above .95 represented good fit.[29] A SRMR value less than .05 represented a well-fitting model.[29]

For the second research question, an IRT approach was employed to investigate the response system of the J-ASCOT-Carer with maximum likelihood estimation and robust standard errors. An advantage of the IRT approach is the fact that the question items and response options' properties are not sample dependent.[25-28,30] When a response option system is not effective, the factor structure cannot be verified.[25-28] The IRT method is appropriate to analyze a response system, such as the effects of item location, item discriminating power, and item information functions.[28,30] Additionally, it shows whether participants were able to differentiate between the response options for each question item.[28,30] Therefore, we examined item discrimination and item difficulty to explore validity. The former parameter indicates the items' effectiveness by identifying respondents at different levels of the latent variable; its values range from .5 to 2.5. The latter demonstrates difficulty in achieving a .5 probability of a correct response for a specific item, given the respondent's score on the latent variable, and its values range from -4.0 to 4.0.[31]

To analyze participants' characteristics, the response distribution, and EFA, we used the Statistical Package for the Social Sciences version 25 in Japanese (SPSS, Inc., Chicago, IL, USA). For the CFA and IRT analysis, we used *M*plus version 8.1 (Muthén and Muthén, Los Angeles, CA).

Results

Participants' demographics

Table 1 shows participants' demographics. Of the 872 informal family caregivers, 59% were men, 46 % were between 50 and 59 years old, 85% were employed, 69% resided with the care recipients, 76% were primary family caregivers of the care recipients, 42% indicated "fair" self-rated health status, 32% were caregivers between three and six years. Among the care recipients, 54% were between 80 and 89 years old and 60% were the caregiver's mother.

(Insert Table 1 around here)

Response distribution to the Japanese version of the ASCOT-Carer

Figure 1 displays the response distribution according to the question items. Nearly 10% of the participants responded to "I can do as I want" across the question items. For the item on *personal safety*, 31% of the participants responded to the response option as an exception. The response option, "I can do adequately" occupied the highest frequency of responses in the *control over daily life, self-care, personal safety,* and *feeling supported* (41%—57%) items. The response option "I cannot adequately do" occupied the highest frequency of responses in the *occupation, social participation,* and *space and time* (approximately 42%) items. Approximately 13% participants responded to "I cannot do at all" across the question items. As an exception, 5% participants chose to the response option in the *control over daily life* and *personal safety* items.

(Insert Figure 1 around here)

Factor structure of the Japanese version of ASCOT-Carer

According to the EFA, the contribution of the first factor was 57.3% and the eigenvalue of the first factor was 4.013. The contribution of the second factor was 10.4% and the eigenvalue was .722, supporting one factor structure.

Values in factor loadings, obtained by the CFA, were from .850 (standard error .039) for *space and time to be yourself* to .533 (.049) for *personal safety* (all $p < .001$) (Table 2). The CFA found that all standardized path coefficients in the model were statistically significant, showing .62 for *occupation*, .46 for *control over daily life*, .65 for *self-care*, .43 for *personal safety*, .59 for *social participation*, .71 *space and time to be yourself*, and .55 for *feeling supported and encouraged* (all $p < .001$). The values for RMSEA, SRME and CFI were .062, .023, and .982, respectively, indicating a "good" fit.

(Insert Table 2 around here)

Response options of the Japanese version of ASCOT-Carer

Table 3 shows item discrimination and item difficulty values for each question item in the response options. All values were within the expected ranges, indicating between .720 and 2.072 for item discrimination and between —1.824 and 2.929 for item difficulty.

(Insert Table 3 around here)

Discussion

This study identified that the factor structure and response system of the J-ASCOT-Carer was valid and reliable for informal family caregivers in Japan. Similar to the original English version of the ASCOT-Carer,[14] the Japanese version is a unidimensional instrument to measure family caregivers' LTC-related QoL. The factor structure does not obtain values at the good fit level, if the response system of an examined measurement is poor.[25-28] Moreover, the IRT approach allows for sample independent response option properties.[25-28,30] Thus, it was important to confirm the validity and reliability of the response system to promote the use of the J-ASCOT-Carer in future studies.

The availability of the J-ASCOT-Carer leads to awareness of the LTC needs and outcomes of caregivers in Japan. There are some important contextual differences between Japan and England (i.e., where the measure was originally developed). For example, the traditional cultural norm of filial obligation is still evident in Asian counties. Children are expected to take care of older parents.[32] Female and younger family members, such as daughters and daughters-in-law, are expected to be informal family caregivers.[4-6] However, gradual changes in the cultural norm of filial obligation have allowed daughters-in-law to lessen engagement in caregiving in Japan in recent years.[4] The decreasing working-age population and a rise in the demand for informal family care in Japan have led to policy developments that are designed to prevent employees from leaving the labor force due to caring responsibilities.[33] To this end, sharing caregiving roles among family members (not just daughters-in-law) has been recommended.[4,6] The largest subgroup of Japanese caregivers are adults in their 50s, either living with or in close proximity to aging parents, usually mothers.[1] This is also reflected in the sample for the present study. Friends are considered informal caregivers in England;[17] however, this is not the case in Japan.

Cultural and contextual differences are observed between informal caregivers in Japan and those in England; however, studies have revealed health and wellbeing impacts, especially in social participation and self-care, among caregivers.[34,35] Moreover, the need to support caregivers and promote their health and wellbeing thorough LTC services for care recipients has been acknowledged. Studies on Japanese caregivers have found lower perceived caring burden among those caregivers who spend time on self-care and other enjoyable activities,[36] among those who could share caregiving responsibilities with other family members,[37] among those who could go out and let their care recipients stay at home alone,[38,39] and among those who could maintain good quality sleep even during paid employment.[40] Therefore, short-term breaks, caregiver support groups, or organized activities, may meet the needs and promote health and wellbeing among caregivers of recipients of LTC support. The translated measure of LTC-related QoL and the J-ASCOT-Carer, which captures the important wellbeing impacts of support for caregivers, establish the need for quality assurance and effectiveness of caregiver support by its impact on QoL. Future research should systematically measure caregivers' LTC-related QoL in Japan to assess their LTC-related QoL needs and monitor the effectiveness of caregiver policy at the LTC system level.[16] As does in

England,[41] the J-ASCOT-Carer should also be adapted and used for needs assessment and care planning.

In summary, we found that the J-ASCOT-Carer is a reliable instrument to examine the QoL of informal family caregivers of recipients of LTC services; moreover, the factor structure and response option system demonstrates sufficient reliability and validity. Examining informal family caregivers' LTC-related QoL is important to understand their needs as well as the QoL outcomes of LTC. Study findings using the J-ASCOT-Carer may contribute to quality LTC services for informal family caregivers as well as care recipients, at home. The J-ASCOT-Carer can also be used with an instrument for LTC recipients who live at home[42] to assess the effectiveness of LTC services.

Limitations

This study has some limitations. The participants were not randomly selected. They had internet access, were able to comprehend instructions to complete the survey, responded according to instructions, and could go to the meeting rooms, if necessary. While the study provides initial evidence for the validity and reliability of the J-ASCOT-Carer, further validity studies with a more diverse sample and/or with subsamples of specific groups of caregivers (e.g., caregivers with health issues) are needed to contribute to this evidence. Moreover, studies that compare the ASCOT-Carer with Japanese translations of other standardized measures could provide further insights.

A weighting system was developed for the original ASCOT-Carer.[43] Future studies should develop a weighting system for the J-ASCOT-Carer as well. Using weighting systems for LTC recipients[2] as well as their informal family caregivers can help assess the relationship between care recipients' QoL and caregivers' QoL. Moreover, those assessments may determine the (cost-) effectiveness of the LTC policy and the delivery of services. Furthermore, an international comparative study between Austria, England, and Finland used the ASCOT for care recipients as well as the ASCOT-Carer; it contains measurements of care recipients and informal family caregivers.[21] Similarly, future studies should propose more effective services based on the LTC system in Japan by using international data.

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Declaration of Conflicting Interests

The authors declare no competing interests.

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