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## **Issues and Challenges in comparing Carers' Quality of Life in England and Japan: Lessons from developing a Japanese-version of the ASCOT-Carer**

Mai Yamaguchi, PhD, Professor <sup>1</sup>  
Stacey Rand, Research Fellow <sup>2</sup>

<sup>1</sup> Japan Lutheran College, Mitaka, Tokyo, Japan

<sup>2</sup> University of Kent, Canterbury, Kent, United Kingdom

### **Introduction**

Improving the quality of life of carers is the ultimate goal of carers' policy and support services. This paper discusses issues and challenges in conceptualising and comparing carers' quality of life in England and Japan, based on developing a Japanese-version of the self-completion Adult Social Care Outcomes Toolkit for Carers (ASCOT-Carer). Since supporting carers in employment is a key concern in both countries, we particularly focus on this group of carers.

### **Contextual similarities and differences between England and Japan**

Before comparing carers in England and Japan, it is important to understand contextual similarities and differences. In Japan, 27.7% of the population is aged over 65 years, with 13.8% aged 75 years or over. An important societal and political question is how to support this ageing population. In 2000, Japan established a Long Term Care Insurance (LTCI) system to fund institutional and community-based care services for eligible older adults. The LTCI system is funded by insurance premiums paid by people aged 40 years or older and by taxation. LTCI users also directly contribute between 10% and 30% of the service costs.

The LTCI system aims to facilitate the provision of long-term care to older citizens with health and support needs. This is, in part, a response to the fact that the number of LTCI service users increased from 1.8 million to 5.2 million between 2000 and 2017. Many are supported by a family carer. Japan has more than six million carers which represents about 5% of the total population. 55% of Japan's carers are of working age, and working carers represent 5.2% of the total Japanese working population; this proportion is expected to increase as the population ages. Many Japanese family carers adopt a caring role due to cultural expectations, duty and obligation though this expectation seems to be changing. Many struggle with the demands of caring, an issue that is made worse by the fact that there are few formal LTCI services (Yamaguchi, 2011).

Around 100,000 people in Japan give up paid work each year to provide care to a relative with (often) negative consequences for the carer, the employer and the wider economy. Prime Minister Shinzo Abe and his cabinet have developed a number of policies to support carers. For example, the 2016 amendment to the *Child Care and Family Care Leave Act* offers carers more flexibility regarding 'care leave', time off and reduced working hours (Minister of Health, Labor, and Welfare, 2018). Under the Act, the employer is obliged to 'consider exemption from overtime or longer hours' to enable employees to balance work and caring roles. This is a particular challenge in Japan where there is a culture of long working hours; 20% of employees work 49 hours per week or more (Cabinet Office, 2018).

The benefit rate from Employment Insurance<sup>1</sup> for 'care leave' has also increased from 40% to 67% of the carer's wage to promote the uptake of care leave.

These initiatives are viewed as positive in terms of supporting working carers but there is still a long way to go. Support for carers is not mandated within the LTCI system, there is no legislation to protect carers' rights, nor is there a national carers' strategy. Policy discourse still primarily conceptualises carers as unpaid resources rather than citizens with individual rights. 'Supporting carers' is widely understood to mean supporting the carer (and wider family) to provide care to the dependent relative for as long as possible.

In England, family and other unpaid care is also a pivotal dimension of the long-term care system; 48% of carers providing 20 hours of more of care per week (NHS Digital, 2010). There are more than five million carers in England, representing over 12% of the population (NHS Digital, 2010). Formal community-based and/or residential care services can be self funded (privately) or publicly-funded or a mix of the two. Public funds for carer support and (most) care of people who have support needs are administered by local authorities<sup>2</sup>. Publicly-funded care of this type is subject to strict eligibility criteria and is means-tested. Despite England's ageing population increasing, between 2008/09 and 2012/13 the number of adults receiving state-funded care and support fell from 1.8 to 1.3 million due to a policy-driven reduction in public spending (National Audit Office, 2014).

English social policy has a mixed view of carers variously conceptualising them as unpaid 'resources' (like Japan), 'co-workers' or 'co-clients' (Twigg, 1989; Rand et al, 2014). In the past twenty years, national carers' strategies have explicitly recognised the need to identify and support carers to maintain their own health and wellbeing and help those of working age to remain in employment, education or training (Department of Health and Social Care, 2018). Three quarters of family carers are of working age (NHS Digital, 2010). Under the *Care Act* (Department of Health, 2014), carers may be eligible for support in their own right. Local authorities have a legal responsibility to assess carers' needs in relation to specified outcomes (e.g. maintaining personal relationships) and to meet 'eligible support needs'. The number of carers who access a needs assessment and carers' support services, however, remains persistently low even though an increase had been projected with the implementation of the *Care Act*.

### **Measuring carers' quality of life**

The ASCOT-Carer is a measure of care-related quality of life. This is defined as aspects of quality of life that are important to carers and may be the target of long-term care services (in the UK, social care services) for carers (e.g. carer support groups) or for care-recipients (e.g. home care, residential care) (Rand et al, 2015). The instrument was developed in England for use in research and evaluation of service effectiveness (Rand et al, 2015).

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<sup>1</sup> Employment insurance is funded by a premium from employers, workers and government to protect workers who become unemployed or who have difficulties in maintaining employment for example due to caring.

<sup>2</sup> Local authorities administer the legal duties and functions of local government. The 151 local authorities in England with Adult Social Services departments are responsible for publicly-funded adult social care services.

The ASCOT-Carer includes one item for seven care-related quality of life attributes (see Box 1). Each attribute is rated by the carer as one of the following four outcome states - an 'ideal state', 'no needs', 'some needs' or 'high-level needs' ([www.pssru.ac.uk/ascot](http://www.pssru.ac.uk/ascot)).

#### Box 1. ASCOT-Carer attributes

Occupation ('doing things I value and enjoy')
Control over daily life
Self-care
Personal safety
Social participation and involvement
Space and time to be yourself
Feeling supported and encouraged in the caring role

To develop a Japanese-version of ASCOT-Carer, we followed a translation and cultural adaptation process of concept elaboration, 'forward and back' translation and cognitive debriefing (i.e. clarification of understanding of the questionnaire wording and tone). This took place in December 2016 and was followed up by a pilot study ( $n=272$ ) in March 2017. There were iterative amendments throughout the process to develop a final-version translation. The pilot study results indicated that the Japanese version of the ASCOT-Carer is broadly comparable to the English version, whilst also being culturally appropriate and acceptable to Japanese carers.

#### Issues and challenges

Several issues and challenges were experienced in conceptualising and comparing quality of life in translating the ASCOT-Carer into Japanese.

First, the results showed that respondents understood the meaning of all the translated questions except those on 'personal safety'. This related to the carer *feeling safe* in relation to fear of abuse, physical harm or accidents that may arise as a result of caring. Cognitive debriefing with carers in England indicated that carers understood this question to refer to the risk of physical harm due to care tasks (e.g. lifting) or as a consequence of behaviours by the care-recipient, including physical, verbal or emotional abuse (Rand et al, 2015). Japanese respondents seemed to have difficulty understanding the concept of safety in the context of the caring relationship. Because 'Anzen' (safety) conveys the meaning of not being at risk of crime, it is difficult for respondents to conceptualise 'safety' as relating to caring. Due to the different cultural context and discourse around elder abuse in Japan, Japanese carers may never before have considered their exposure of abuse or harm in the context of a care relationship.

Elder abuse is a key social concern for older adults living in care institutions and private households in Japan. The *Act on the Prevention of Elder Abuse, Support for Caregivers of Elderly Persons and Other Related Matters* enacted in 2005 (Ministry of Justice, 2018) was introduced to address this issue. In 2016/17, more than 16,000 cases of elder abuse or

neglect by family carers were reported; this includes 25 deaths. We decided to delete the word 'Gyakutai' (abuse) in the final Japanese translation of the ASCOT-Carer 'Personal safety' question because at the present time abuse is viewed as directed *towards* the care-recipient by the carer not the other way around.

Second, there are cultural differences around the meaning of social participation with regard to family relationships. In the original English version of the ASCOT-Carer, 'social participation' is defined as being able to maintain meaningful relationships with friends and family, as well as feeling part of their community. In Japanese, 'Shakai Sanka' (social participation) may not immediately be understood to include everyday relationships between family members. Cultural expectations of family members with regard to caring is another important consideration. When caring issues arise familial conflict is common; this is particularly the case among siblings regarding parental care. A decrease in the average size of families and a rise in single (never-married) and divorced people has affected the pool of available carers; more women being in employment is also an issue that has affected it. Traditionally, daughters-in-law would have lived with parents-in-law and undertaken the caring role. Today, fewer than 10% of main carers are co-resident daughters or sons-in-law, a quarter (25.2%) are spouses, and a fifth (21.8%) are co-resident daughters or sons. The role of formal services and extra-resident adult children is increasing; 12.2% and 13.0% of all carers are extra resident families and formal services, respectively. The remaining proportion are 'unknown' (15.2%), 'others' (1%) or 'other co-resident families' (1.9%). A mix of demographic and social changes has disrupted assumed patterning of familial care.

Third, structural systemic differences between the countries need to be considered. In England, the healthcare and long-term care systems are funded, administered and accessed separately, despite sustained efforts to integrate them. The ASCOT-Carer was designed to measure care-related quality of life in relation to *long-term care services*. Nevertheless, the measure inevitably captures aspects of quality of life that *may* be affected by healthcare interventions. This is relevant to the translation and adaptation of the ASCOT-Carer for use in Japan, since the Japanese LTCI system covers health and long-term care without distinguishing between the two types. In addition, although some home care services are included in the LTCI programme, long-term services, especially for carers, are rather limited. It is therefore challenging to identify carers who benefit from long-term support.

Furthermore, the Japanese care management system in LTCI - the mechanism by which need is assessed and support provided - only focuses on the person with dependency needs not family carers. To address this, Japanese researchers and carer organisations are seeking to introduce carers' assessments. Our research team is seeking to develop a comprehensive carers' assessment, including the ASCOT-Carer. While this tool was originally designed to measure long-term care-related quality of life for carers in England, the tool may be useful for identifying needs and promoting long-term care support for Japanese carers.

Finally, demographic differences that affect the experience of caring need to be considered. As the number of single older person households and households consisting of elderly couples increases in Japan, more attention is being paid to the diverse and complex nature of caring. Increased incidence of carer burnout, elder abuse, and acknowledgment of unmet need amongst (mainly) frail elderly people is becoming more prevalent and more visible. A reduction in the number of middle aged and younger adults may exacerbate these issues.

Not only will it create labour shortages - including in the care industry – but it is likely to have a significant impact on the availability of unpaid carers. The results of a web-based survey among ex-working carers in 2013 (N=994) revealed that more than one in four left their job due to a deterioration in their health; it is likely that some of the health problems are linked to care demands (MUFG Research and Consulting, 2013). Although caring is still undertaken predominantly by women, the working carer issue has highlighted the fact that the number of male carers is increasing (Ikeda, 2017). In 2016, more than thirty percent of co-resident primary carers were husbands or sons (15.5% and 17.2%, respectively). There is a particular need to explore the profile and needs of male carers in Japan.

Although the process of translating the ASCOT-Carer into Japanese identified some shared challenges in relationship to carers in England and Japan, it also exposed a number of key differences. In England there is some policy recognition of carers needs and a reasonably well developed formal care service, albeit severely under-funded. This is not the case in Japan. The process also highlighted the importance of taking account of socio-cultural distinctions when interpreting and studying the dimensions of carer quality of life in different countries. By using the ACOT-Carer in Japan the authors hope to explore carers' quality of life and compare it with evidence from England. More work is needed to understand the complex nature of caring in Japan, raise awareness of carers' needs and develop effective support for both carers and the person they look after.

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