



# Developing a Social Capital Scale for Family Caregivers of People with Dementia

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# 博 士 論 文

## Developing a Social Capital Scale for Family Caregivers of People with Dementia

(認知症家族介護者におけるソーシャルキャピタル測定尺度の開発)

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## **Abstract**

Although several scales have been designed to measure social capital, none have been specialized for caregivers of people with dementia, even though social capital is important in terms of continuing care provision. Therefore, a 17-item measure to assess social capital among caregivers of people with dementia developed and validated. The responses from a questionnaire survey that included a draft of a social capital scale were assessed psychometric properties. Factor analysis identified three factors involving 17 items with a Cronbach's alpha of .85. The intra-class coefficient for test–retest reliability was .71. The correlation with positive aspects of caregiving was .62 ( $p < .01$ ). The results suggest that this scale could be a useful tool to assess social capital among caregivers of people with dementia.

**Keywords:** Social capital, Scale development, Caregivers of people with dementia, Reliability, Validity.

## **I Introduction**

It is estimated that 47 million people are currently living with dementia on a worldwide scale, and the cost of dementia care was estimated to be 604 billion USD in 2010 and 818 billion USD in 2015 (Prince, Comas-Herrera, Knapp, Guerchet, & Karagiannidou, 2016). In addition, the global incidence of dementia doubles with every 5.9-year increase in age (Prince, 2015). Dementia impacts not only developed, but also developing countries because the increasing incidence of dementia translates to higher medical and social costs.

It is necessary for people with dementia to continue to live in their community as long as possible because of the profound benefits associated with their physical and psychological health, quality of life, and dementia cost (Jokinen et al., 2013; Nikmat, Hawthorne, & Al-Mashoor, 2015; Wübker et al., 2015; Olsen et al., 2016). Family caregivers are one of the most important resources for this process to be feasible (Farina et al., 2017) because the majority of people with dementia primarily receive help and support from them, especially from spouses and children (Stokes, Combes, Stokes, 2015; Ying et al., 2018).

However, it is well known that family caregivers of people with dementia are bound to experience significant levels of stress and burden compared to caregivers of physically-impaired elderly individuals (Tremont, 2011). Caregivers need to be attentive and to provide care for various symptoms, especially pertaining to behavioral and psychological symptoms of dementia (BPSD).

Formal and informal support is useful for caregivers of patients with dementia for them to take care of their family, and to minimize the level of stress and the unavoidable financial burden experienced. In fact, caregivers have been found to use formal types of support (Lethin, Hallberg, Karlsson, Janlöv, 2016; Elmståhl et al.,

2018), whereas they tend to perceive informal support as a safety net (Gibson, Holmes, Fields, & Richardson, 2019). In addition, social support plays an extremely essential role in terms of enabling caregivers to have an enhanced quality of life (Clare et al., 2019). Consequently, social ties that provide support to these individuals will, therefore, provide distinct benefits to all caregivers.

Social ties, or social networks, if you will, are investigated and evaluated in various academic fields. Patterns of relationships between individuals and groups are intimately tied to the idea of social capital (Barnes-Mauthe, Gray, Arita, Lynham, & Leung, 2015). Therefore, and considering the support required by caregivers of people with dementia to facilitate their well-being within community settings for as long as possible, the social capital theory can help us understand the nature and the benefits stemming from their interactions. In addition, and although social capital is often hypothesized as a distinct determinant of health (Rodgers, Valuev, Hswen, & Subramanian, 2019), little is known regarding the effect of social capital scale on caregivers of people with dementia. Therefore, this study was conducted to investigate the development of social capital scale for caregivers of people with dementia.

## **II Literature Review**

### **II-1 Merits of living in community for people with dementia**

It is important that people with dementia live in their community as long as possible because changes in their residential environment, such as moving to an unfamiliar out-of-home residence, can facilitate increased difficulties, including the development of anxiety and disorientation (Jokinen et al., 2013). The majority of people with dementia on a worldwide level tend to live at their home rather than in institutional facilities, and the rate of people with dementia living at home is significantly higher in rural areas (Pot & Petrea, 2013). Olsen et al. (2016) conducted a cross-sectional study based on baseline data acquired from two RCT studies with 78 and 115 patients with dementia. The authors concluded that individuals with dementia who reside at their home demonstrate a significantly higher quality of life (QOL), a greater ability to perform daily activities, and a higher level of social connectedness compared to individuals living in institutional facilities (Olsen et al., 2016). In addition, individuals with dementia living in communities exhibited a lower prevalence of depression. According to a cross-sectional survey performed by Nikmat & Almashoor (2013) on 111 dementia patients living in institutions, 71% of individuals with dementia suffered from depression. In addition, Bhattacharjee, Oh, Reiman, & Burke (2017) used data from a nationally representative cohort of community-dwelling individuals, and reported that the prevalence of depression among community-dwelling elderly individuals with dementia was 21.59%. Furthermore, Wübker et al. (2015) examined the total costs of care and individual cost components in 383 community-dwelling patients of dementia. Their results showed that the costs associated with dementia are significantly lower for people receiving home care compared to those receiving long-term institutional nursing care. Therefore, living in the community as long as



possible is bound to be highly beneficial for people with dementia not only in terms of QOL, but also in terms of the cost of future dementia care.

## **II–2 Family caregivers of people with dementia**

Families of people with dementia consist one of the most important resources for dementia care (Farina et al., 2017) because many individuals with dementia receive care from their spouses or children at home (Stokes, Combes, & Stokes, 2015; Ying et al., 2018). However, it is a well-established fact that family caregivers of individuals with dementia are susceptible to experiencing high levels of mental distress, and they are at high risk for developing health problems, such as depression and anxiety that are caused by the caregiving burden (Boots, de Vugt, Kempen, & Verhey, 2016). In fact, it has been shown that the provision of care to individuals with dementia is significantly more stressful than the caring for a physically-impaired older adult (Tremont, 2011).

Consequently, it is extremely essential to identify novel means to maintain and improve the QOL and social well-being of people living with dementia and their families, such as keeping them physically, mentally and socially active (Swan, 2012; Heward, Innes, Cutler, & Hambidge, 2017). Thus, in addition to long-term care and welfare services, dementia-friendly communities that enable people with dementia to remain active and maintain control over their own lives for as long as possible (Wiersma & Denton, 2016) are being created around the world (Lin & Lewis, 2015). However, communities that aspire to becoming dementia-friendly are more likely to build on and facilitate the development of social capital and community capacity for their local populations of residents, workers, and visitors (Crampton, Dean, Eley, AESOP Consortium, 2012). Elderly individuals who have higher quality family social capital, increased social trust, and a greater number of organization memberships are

more willingly to choose to live in local communities (Jiang, Lou, & Lu, 2018). Social capital provides increased opportunities for social interaction, cooperation, and prosocial behaviors, which may benefit aging older adults (Versey, 2018).

### **II-3 Social capital**

Caregivers of people with dementia have diverse interactions in their communities because they receive both formal and informal support; and social capital theory can help us understand these interactions. In addition, social capital is often considered as a determinant of health, and it is one of the important factors that promoted the well-being and harmony of caregivers of people with dementia (Rodgers, Valuev, Hswen, & Subramanian, 2019).

#### **II-3-1 Definition of social capital**

Social capital is a complex and multidimensional concept (Alipour et al., 2015), thus several definitions have been proposed (Alvarez, Kawachi, & Romani, 2017).

Table 1 exhibits the definition of social capital. Durkheim, a famous French sociologist, was the first person who stated the correlation between social connect and health. Durkheim linked modern urban life to decreasing birth rates, increasing alienation, and worsened gender role tensions, which, he believed, facilitated negative health consequences, evidenced by increased suicide (Kushner & Sterk, 2005).

Hanifan was the first user of the word ‘social capital’. Hanifan defined social capital as “*goodwill, fellowship, mutual sympathy and intercourse among a group of individuals and families who make up a social unit.*” (Hanifan, 1916, p. 130). Furthermore, he exclaimed that an accumulation of social capital could be succeeded by means of public entertainments, “*sociable,*” picnics, and a variety of other

community gatherings (Hanifan, 1916).

On the other hand, Bourdieu (1986) identified three dimensions of capital: the economic, cultural and social capital. He defined social capital as “*the aggregate of the actual or potential resources which are linked to possession of durable network of more or less institutionalized relationships of mutual acquaintance and recognition*” (p. 248). Bourdieu’s approach is derived from the viewpoint that actors are engaged in a struggle to pursue their own interests. In addition, he perceived social capital as having two characteristics linked to group member and social networks, and which were based on mutual cognition and recognition (Siisiäinen, 2003). Bourdieu also stated that “*institutionalized relationships of mutual acquaintance and recognition*” was a significantly more important resource (Farr, 2004).

Moreover, Coleman (1994) mentioned that social capital consisted of the social relationships within the family and the community members in the development of children and youth. Coleman (1994) thought that “*social capital was defined by its function*” (p. S98), and he said that “*it is not a single entity but a variety of different entities, with two elements in common: they all consist of some aspect of social structures, and they facilitate certain actions of actors—whether persons or corporate actors—within the structure*” (p. S98). Coleman emphasized on the fact that social capital was a capital of social and not individual structure, and hence tended to draw community into the family tree (Farr, 2004).

Putnam states that “*social capital refers to connection among individuals – social networks and the norm of reciprocity and trustworthiness*” (Putnam, 2000, p. 19). He placed trust and norms to the social network core (Sato, 2013). In fact, Putnam's core thesis is that when a community has a well-functioning economic system and a high level of political integration, then the accumulation of social capital

is bound to occur in communities (Siisiäinen, 2003).

Lin (2001) adopted an individualistic perspective of social capital by adding resources to the social network core, and defined social capital as “*resources embedded in a social structure that are accessed and/or mobilized in purposive actions*” (p. 29).

Burt (1997) noted that “*social capital is contextual complement to human capital*” (p. 339). He defined social capital as “*friends, colleagues, and more general contacts through whom you receive opportunities to use your financial and human capital*” (Burt 1992, p. 9).

As mentioned above, social capital was defined as individual level by Bourdieu (1986), Burt (1992), and Lin (2001), while was defined as social level by Coleman (1990) and Putnam (1993) (Sato, 2013).

Other researchers have also defined social capital. Baker (1990) defined social capital as “*a resource that actors derive from specific social structures and then use to pursue their interests; it is created by changes in the relationship among actors*” (Baker 1990, p. 619). Belliveau, O’Reilly, & Wade (1996) stated social capital as “*an individual’s personal network and elite institutional affiliations*” (p. 1572). Furthermore, Portes (1998) noted that social capital was “*the ability of actors to secure benefits by virtue of membership in social networks or other social structures*” (p. 6). Hence, they all considered social capital as internal relations.

On the other hand, several researchers have focused on external relations. Brehm & Rahn (1997) defined that social capital was “*the web of cooperative relationships between citizens that facilitate resolution of collective action problems*” (p. 999), whereas Fukuyama focused on trust and stated that social capital was “*the ability of people to work together for common purposes in groups and organizations*” (Fukuyama 1995, p. 10). Thomas noted that social capital was “*those voluntary means*

*and processes developed within civil society which promote development for the collective whole” (Thomas 1996, p. 11).*

In addition, other researchers have focused on the association of social capital with both internal and external relations. Nahapiet & Ghoshal (1998) noted that social capital was *“the sum of the actual and potential resources embedded within, available through, and derived from the network of relationships possessed by an individual or social unit. Social capital thus comprises both the network and the assets that may be mobilized through that network”* (Nahapiet & Ghoshal 1998, p. 243). Schiff (1992) stated that social capital was *“the set of elements of the social structure that affects relations among people and are inputs or arguments of the production and/or utility function”* (p. 160).

Villalonga-Olives & Kawachi (2015) proposed that the definition of social capital should focus on the individual and the collective. They defined social capital as *“1. The resources – for example, trust, norms, and the exercise of sanctions – available to members of social groups. The social group can take different forms, such as a work place, a voluntary organization, or a tightly-knit residential community. The salient feature of this approach is that social capital is conceptualized as a group attribute. 2. The resources – for example, social support, information channels, social credentials – that are embedded within an individual’s social networks. In this approach, social capital is conceptualized as an individual attribute as well as a property of the collective”* (p. 63).

Japanese researchers have also researched social capital. Inaba and colleagues (2015) used a broad concept of social capital that they defined as *“trust, norms of reciprocity, and networks with externalities through human minds”* (p. 169). Inaba has further stated that externality of mind was the good will of a person who induced

positive effects on other people.

However, and although various researchers have defined social capital, the most accessible definition of this term was developed by Putnam, who stated that “*social capital refers to connections among individuals – social networks and the norm of reciprocity and trustworthiness*” (Putnam, 2000, p. 19). As seen in the discussion above, social network is contained in all definitions because social capital exists between actors (Sato, 2013).

### **II-3-1-1 Network**

Network is explained as “*a group of people, organizations etc. that are connected or that work together*” (Della, 2003, p.1287). Social network is a set of ties among people who have similar interests or interactions (Shushtari, Hosseini, Sajjadi, Salimi, Latkin, & Snijders, 2018), and indulge into cooperation for mutual benefit purposes (Putnam, 2000). Therefore, social networks, and the patterns of relationships between individuals and groups, are intimately tied to the idea of social capital (Barnes-Mauthe, Gray, Arita, Lynham, & Leung, 2015).

A number of research studies related to the idea and essence of social networks have been conducted. There are three methods of research that contributed to the development of its theory: the sociometric analysis tradition, interpersonal relations tradition, and anthropology tradition. The sociometric analysis tradition relies on graph theory methods, whereas the interpersonal relations focuses on the (number of) cliques in the group, and the anthropology tradition explores the structure of community relations (Liu, Sidhu, Beacom, & Valente, 2017). Centrality, cohesion, and structural equivalence are key network concepts that have organized research on network effects (Liu, Sidhu, Beacom, & Valente, 2017). On the other hand, degree, closeness, and

betweenness are different measures to indicate structural centrality, whereas network cohesion measures the degree of interconnections among a group, and structural equivalence shows two or more network positions that share a similar pattern of connections (Liu, Sidhu, Beacom, & Valente, 2017).

Social network impacts health among members of the network. This is, in turn, based on structural networks such as size (the number of members of the network), density (the range to which network members are connected to each other), degree (number of people of direct ties), betweenness (frequency of ties with an individual who is on the shortest path connecting pairs of others), centrality (extent to which an individual occupies a central position in the network), and homogeneity (similarity among network members) (Shushtari, Hosseini, Sajjadi, Salimi, & Latkin, 2018).

There are contradictory opinions with respect to network ties. Friedkin (1993) highlighted that social cohesion was an important factor that could explain the frequency of actors' communications on specific issues. On the other hand, weak ties are important resources in realizing mobility opportunity (Granovetter, 1973). Weak ties, in or bridging ties, if you will, are connections that link two otherwise unconnected network groups (Liu, Sidhu, Beacom, & Valente, 2017).

Regardless of the size of social ties, if the caregivers of people with dementia fail to recognize the usefulness of social networks, then social ties will not function beneficially for caregivers.

Social support refers to a qualitative and functional aspect of the social network (Faquinello & Marcon, 2011). This is a broad, multidimensional concept that is often measured in terms of being either perceived or enacted, structural or functional, and has multiple components such as emotional, instrumental / tangible, appraisal, and informational support (Langford, Bowsher, Maloney, & Lillis, 1997; Nolan, Hendricks,

Ferguson, & Towell, 2017). Clare et al. (2019) concluded that social support plays an important role in terms of enhancing caregivers' well-being. Caregivers of people with dementia have been found to use formal types of support (Lethin, Hallberg, Karlsson, & Janlöv, 2016; Elmståhl et al., 2018) and perceive informal support as a safety net (Gibson, Holmes, Fields, & Richardson, 2019). Therefore, measuring these types of social support as part of the social network could be a very essential process for evaluating caregivers' well-being.

### **II-3-1-2 *Reciprocity***

Reciprocity is interpreted as the give and take, and is defined as repayment for the giving act (Perls, 1953), mutually gratifying relationships (Hirschfeld, 1983), and the act of give and receive (Zabielski, 1984). The social exchange theory suggests that individuals are driven by the desire to maximize rewards and minimize costs through social interactions, thus seeking exchanges with others (Cook, 1987).

There are two types of reciprocity: generalized and specific. Generalized reciprocity is the norm where the mutual exchange of benefits may be imbalanced, yet it involves the intrinsic expectation that future transactions could level potential imbalances (Rönnerstrand & Sundell, 2015). Therefore, the norms of generalized reciprocity are the ones which facilitate collective action (Putnam, 2000). On the other hand, specific reciprocity is defined as doing something others under the condition that they will also do something 'equivalent' for you (Emmering, Astroth, Woith, Dyck, & Kim, 2018).

It is well known that caregivers of people with dementia are willing to help other caregivers. Lu, Jiang, Sun, & Lou (2019) found that the provision of support to other residents in the community is associated with positive aspects of caregiving, and



that caregivers, who use their acquired caregiving knowledge and skills to support others, recognize their personal strengths and resources, and encourage their confidence and self-efficacy. Both types of reciprocity can help encourage caregivers of people with dementia to continue providing care.

### **II-3-1-3 *Trust***

Trust is considered as an important condition for the smooth and optimal functioning of complex systems such as the health care ones (Groenewagen, Hansen, & de Jong, 2019). In general, social trust can be described as the expectation that people will act on good will, that they attempt to honor their commitments, and that they will avoid inflicting damage or harm on others (Freitag & Bauer, 2013). There are two types of trust: particularized and generalized (Freitag & Bauer, 2013; Glanvill & Story, 2018). Both types of trust are important in terms of helping caregivers to maintain their health and hence continue to provide care to patients with dementia.

Particularized trust or knowledge-based trust (Yamagishi & Yamagishi, 1994) involves trust at close social range and is primarily showed toward people that the individual knows personally from his/her daily interactions such as friends, neighbors, and coworkers (Freitag & Bauer, 2013; Glanville & Story, 2018). Because particularized trust is considered as the trust in familiar to the subject people, this type of trust is of the same nature as the cognitive dimension of bonding social capital (Glanville & Story, 2018). Furthermore, particularized trust facilitates additional access to social support when needed, such as instrumental and emotional support (Glanville & Story, 2018).

On the other hand, generalized trust is an abstract attitude to all people, including strangers (Freitag & Bauer, 2013). This type of trust is characterized by the

absence of a specified receiver of trust and of a specific regard in which the receiver is trusted (Frederiksen, 2019). Therefore, it corresponds to the cognitive component of bridging social capital (Glanville & Story, 2018). However, and although generalized trust has been widely used in public health literature, Glanville & Story (2018) stated that currently published studies have inadequately focused on the validity of the standard measurements of generalized trust.

Measuring particularized and generalized trust can provide a more robust social capital proxy (Giordano, Björk, & Lindström, 2012). Efforts performed in terms of building and maintaining trust can significantly help to improve local health care management, enhance trust in physicians, and access to and the quality of health care (Ahern & Hedryx, 2003). Health care professionals can focus on enhancing residents' trust to encourage and facilitate social capital within the community, which can, in turn, become a key strategy for health promotion and disease prevention (Hsieh, 2008).

### **II-3-2 Forms and types of social capital**

There is a distinction of social capital into different forms and types. One of the classifications of social capital involves the differentiation between cognitive and structural social capital. Cognitive social capital contains norms, values, attitudes and beliefs (Islam, Merlo, Kawachi, Lindström, & Gerdtham, 2006). Cognitive social capital involves people's perceptions on interpersonal trust as well as norms of reciprocity within the group (Villalonga-Olives & Kawachi, 2015). Cognitive social capital impacts behavioral norms, including control of risky behavior, mutual aid and support, and informal ways of informational exchange in relation to health (Cullen & Whiteford, 2001).

On the other hand, structural components of social capital are observable

aspects of social organization, such as social network density, or patterns of civic participation (Islam, Merlo, Kawachi, Lindström, & Gerdtham, 2006). Both cognitive and structural social capital can be analyzed at individual or collective levels (Villalonga-Olives & Kawachi, 2015). Structural social capital at the macro level is molded by comprehensive health policies, mechanisms that enable its implementation, and the institutional implementing actors related to health (Cullen & Whiteford, 2001). Impacting factors include the effectiveness and efficacy of various networks in service delivery and diffusion mechanisms for health-related information at the meso level (Cullen & Whiteford, 2001).

Within the framework of structural social capital, there are two distinct dimensions: the horizontal and the vertical one. Horizontal social capital reflects ties that exist among individuals or groups of equals, whereas vertical social capital stems from hierarchical or unequal relations that reflect differences in power (Cullen & Whiteford, 2001). Horizontal social capital is called the ‘bonding social capital’, whereas the vertical social capital is called the ‘bridging social capital’. However, several researchers have proposed that another type of social capital is required to capture the power dynamics of vertical associations (Claridge, 2018).

Bonding social capital involves connections within a group or community that is characterized by high similarity in demographic characteristics, attitudes, and available information and resources. Bonding social capital refers to mutual trust and cooperative relationships between members of a network who perceive themselves as being similar to one another, in terms of their social identity (Szreter & Woolcock, 2004). Bonding social capital exists among ‘*people like us*’ and in strong close relationships: family members, close friends, and neighbors. Putnam noted several examples of bonding social capital which include ethnic fraternal organizations,

church-based woman's reading groups, and fashionable country clubs (Putnam, 2000). Bonding social capital can be an extremely beneficial social function by providing a resource of support to people who suffer from socio-economic problems or poor health. Bonding social capital tends to help people to '*get by*', thus providing the norms and the trust that, in turn, facilitate collaborative action (Claridge, 2018).

Bridging social capital is a connection that links people who belong in different parts of society such as different races, classes, or religion. Bridging social capital involves relationships based on respect and mutuality between people who know that they are not alike in certain socio-demographic perspectives or sense such as age, ethnic group, class, and so on (Szreter & Woolcock, 2004). Furthermore, these associations tend to 'bridge' together groups, organizations, or communities (Claridge, 2018). Some examples of bridging social capital include the civil rights movement, youth service groups, and ecumenical religious organizations (Putnam, 2000). The benefits stemming from this concept are far-reaching and can include increased ability to gather information, ability to gain access to power or better placement within the network, or ability to better recognize new opportunities (Adler & Kwon 2002). Granovetter underlines that benefits stemming from the formation of weak relationships were superior to strong ones for accessing new resources (Granovetter, 1973; Riemer, Finke, & Hovorka, 2015). In addition, Burt proposed the theory of structural holes, and argued that information advantages obtained from weak ties depend on the structure of the network (Riemer, Finke, & Hovorka, 2015).

Linking social capital is defined as norms of respect and networks of trusting relationships between people who are interacting across formal or institutionalized power or authority in society (Szreter & Woolcock, 2004). This refinement sought to incorporate a distinction into the bridging social capital. Szreter & Woolcock (2004)

considered that social ties connect people across explicit vertical power, although bridging social capital was an act of bridging individuals that were more or less equal in terms of their statuses and power differentials.

Social capital can also be conceptualized from two distinct components: collective, such as the characteristics of the community, and individual, such as social supportive sources (Coleman, 1990; Putnam, 1993; Lu, Jiang, Sun, & Lou, 2019). Support from the community is helpful to facilitate and maintain optimal dementia care, and a mismatch has been identified between the supply and demand of social support from the community (Dam, Boots, van Boxtel, Verhey, & de Vugt, 2018).

It is important that health care providers have an understanding of the sources of social support to help caregivers of people with dementia on the individual level. As reviewed above, social capital is additionally classified into two types: cognitive and structural. A meta-analysis of social capital literature revealed that cognitive social capital is more significantly related to health compared to structural social capital (Xue & Reed, 2019). Positive appraisals of cognitive social capital could be beneficial for caregivers of people with dementia in terms of promoting and enabling improved health, thus allowing them to feel more self-efficacious and continue providing care to the community. Social capital, therefore, was conceptualized as an individual perspective and focused on its cognitive aspects in this study.

### **II-3-3 Effects of social capital on health**

Previous studies have reported on the role which social capital can play in promoting and maintaining individuals' health. Recent studies evaluating the connection between social capital and health are conducted in various fields of health. Social capital would

be beneficial to facilitate individuals' well-being, although the 'dark side' of social capital is also reported (Campos-Matos, Subramanian, & Kawachi, 2015; Villalonga-Olivesa & Kawachi, 2017).

Pertaining to physical health, self-reported health is frequently used in social capital studies. Emmering, Astroth, Woith, Dyck, & Kim (2018) demonstrated a relationship among social capital and self-reported mental and physical health, health behaviors, healthcare utilization, and mortality among older adults. Yap, Mohan, Stephan, Warren, Allotey, & Reidpath (2019) identified that social capital was directly associated with poor self-reported health. Chong, Koh, Nazri, Ibrahim, & Rahim (2020) found the significant positively correlation between generalized social capital and subjective well-being among young Malaysians. Yiengprugsawan, Welsh, & Kendig (2018) showed that low levels of trust were significantly associated with greater odds of transitions into poor physical functioning. In addition, the authors found that this transition into low levels trust was a predictor of poor self-rated health. Glanville & Story (2018) identified that particularized trust is more strongly associated with self-rated health than generalized trust. Hung & Lau (2019) found that bonding social capital exhibited a beneficial effect on self-rated health. The authors also found that the positive effect of cognitive social capital on self-rated health became weaker at higher levels of bridging social capital. Pan & Woo (2020) identified that a significant correlation was exhibited between trust and self-rated health in the old-old group. Cain, Wallace, & Ponce (2017) exhibited an association between neighbors who are helpful and feel safe and improved self-reported health. They also found that trust was negatively correlated with self-reported health among lower income residents, and that social capital dimensions tend to function differently when it comes to the health of elderly individuals.

Researchers have also used additional outcomes pertaining to health in their social capital studies, such as physical health, obesity, mortality, and others. Buck-McFadyen, Akhtar-Danesh, Isaacs, Leipert, Strachan, & Valaitis (2019) found that high levels of trust in institutions, sense of belonging, and civic engagement were all associated with improved physical health, and that high levels of trust in people and trust in the respective institutions were associated with improved mental health. Kim (2018) reported that bridging networks were significantly linked with better health outcomes, however, bonding networks were negatively associated with health among marriage migrants in Korea.

Researchers have also evaluated the potential association between social capital and obesity. Wu, Moore, & Dube (2018) found that the higher the number of kin ties in a person's network, the greater the risk of obesity, whereas higher network capital and trust were key factors in preventing the development of obesity. Kamphuis, Oude Groeniger, Poelman, Beenackers, & van Lenthe (2019) reported that bridging social capital, such as having friends with a higher educational level, could significantly reduce the likelihood to report overweight among low-educated adults. On the other hand, bridging social capital, such as friends with a lower educational level, increased the likelihood to report daily smoking, lack of leisure time for cycling, failing to meet dietary recommendations for vegetable intake, and high meat intake among high-educated adults compared to high-educated adults with bonding social capital. Child, Kaczynski, Walsemann, Fleischer, McLain, & Moore (2019) identified a negative association between social cohesion and body mass index among black Americans.

Several papers have focused on evaluating the relation between social capital and functional ability. Noguchi, Kondo, Saito, Nakagawa-Senda, & Suzuki (2019)

found a significantly negative relation between social cohesion and risk of onset of functional disability. Amemiya et al. (2019) suggested that community social capital could affect functional ability improvements. Furthermore, a study performed by Ke, Jiang, & Chen (2019) revealed that middle-level network density was associated with reduced rates of depression, and that a higher level of participation and network density were associated with elevated basic activities of daily living. Lestari, Ng, Kowal, & Santosa (2019) identified that inability to access social capital was significantly associated with activities of daily living disability in China. Kim et al. (2018) found that the general network was significantly associated with the poor chewing function, whereas social capital, such as a poor social network, is associated with poor chewing function. Moreover, Tariq, Beihai, Ali, Abbas, & Ilyas (2019) found that interpersonal trust, reciprocity, and physical disability were significantly correlated with one another, and that reciprocity mediated the relationship between physical disability and depression in Pakistan.

With respect to mortality, Gontijo, Firmo, Lima-Costa, & Loyola Filho (2019) reported that the social participation dimension of social capital's structural component was significantly associated with mortality in elderly Brazilians. In addition, Giordano, Mewes, & Miething (2019) identified an association between individual-level and contextual-level trust and mortality, whereas Nakamura et al. (2019) found a significant negative association between the received emotional support and suicide standardized mortality ratio in Japan. Moreover, Steelesmith et al. (2019) underlined that high levels of social capital were associated with lower suicide rates compared to low levels of social capital. Peng, Yang, & Rockett (2019) mentioned that social capital, measured as network connection, embedded-resource, and generalized trust, was negatively associated with self-reported suicidal thoughts or ideation.



In addition, social capital has been found to impact on various psychological aspects including mental health, depression, cognitive function, and others. Kaur, Chakrapani, Newtonraj, Lakshmi, & Vijin (2018) reported that social capital in India was a significant mediator on mental health. Also, An & Jang (2018) found that social capital induced a direct effect on mental distress, whereas Luo & Menec (2018) found that social networks and support as structural social capital indicators were significantly positively associated with mental health, and that civic participation was also associated with mental health among older Chinese female immigrants in Canada. In addition, a study performed by Lin, Lu, Guo, & Liu (2019) pinpointed an association between low contextual civic trust and self-rated mental health. The authors also found that civic and political trust and mental health were positively correlated at both individual and community level reciprocity, and that the individual level of political trust had a significantly positive impact on mental health in urban areas. Furthermore, the community level of political participation was also found to contribute to mental health. Zhu, Gao, Nie, Dai, & Fu (2019) identified that high social cohesion and social participation were significantly associated with a low ratio of poor mental health. Finally, Paiva Souto et al. (2020) found that women with lower social support dimension of social capital had a greater chance of presenting common mental disorders compared to women with higher social capital.

When it comes to evaluating the association between social capital and depressive symptoms /depression, Wu, White, Fleischer, Cai, Chen, & Moore (2018) reported that greater scores of composite cognitive social capital and structural social capital were associated with a lower likelihood of developing depressive symptoms, and that there was no association between network social capital and depressive symptoms among Taiwanese adults. Clark, Williams, Schulz, Williams, & Holt (2018)

found that higher social capital was related to lower ratio of depressive symptoms. Zhou et al. (2018) reported a significantly negative association between the manifestation of depressive symptoms among primiparas and social trust. Furthermore, Yang et al. (2018) exhibited the association between depressive symptoms and poor social capital. Yamaguchi et al. (2019) highlighted a significant association between community social capital and a lower risk for developing depressive symptoms. Archuleta, Prost, & Golder (2019) showed that higher trust and fewer depressive symptoms were negatively correlated, whereas Lu & Peng (2019) identified that cognitive social capital had a mediation effect on the association between structural social capital and depressive symptoms. In addition, Han et al. (2018) showed that low interpersonal trust and reciprocity were significantly associated with the manifestation of depressive symptoms, and reciprocity mediated the association between household income and depressive symptoms in community-dwelling elderly individuals. The authors also found a significant association between cognitive social capital and depressive symptoms. Nonetheless, Yamaguchi et al. (2019) concluded that community civic participation was inversely associated with the onset of depressive symptoms. They also found that community social capital components were significantly associated with lower risks for the development of depressive symptoms. Zhang & Lu (2019) reported that family social capital exhibited a moderation effect on the relationship between community-based cognitive social capital and depressive symptoms. Cohen-Cline et al. (2018) pinpointed that cognitive social capital was associated with the development of lower rates of depressive symptoms in between-twins. Urzua et al. (2019) found that adjusted odds rates of depressive symptoms were 1.13 in men and 1.05 in women respectively in social cohesion score. Zhu, Li, Wang, & Mao (2018) showed an inverse association between social capital

and depression among migrant hypertensive patients in China. Chen, Gao, Xu, Wang, & Li (2018) demonstrated that social capital including total, bonding and bridging social capital, was negatively associated with depression. Chum, O'Campo, Lachaud, Fink, Kirst, & Nisenbaum (2019) reported that low levels of linking social capital was independently associated with depression in Canada. Moreover, Hall, Pangan, Chan, & Huang (2019) found that cognitive social capital was significantly negatively associated with depression, and that cognitive social capital could modify the association between discrimination and depression and anxiety. Lee, Lee, & Song (2019) exhibited the significant relation between trust in social capital, social capital satisfaction, and self-esteem and depression. Rugel, Carpiano, Henderson, & Brauer (2019) identified that higher levels of sense of community belonging were associated with improved mental outcomes, including improvements in major depressive disorders, negative mental health, and psychological distress. In addition, Carr (2020) conducted a multi-level 2-wave longitudinal analysis at both the between- and within-person levels over a 7-year period in the Wisconsin Longitudinal Study. Results showed that social capital was negatively related with depressive symptoms.

Social capital is also capable of decreasing negative mental aspects, and increasing positive mental ones. Han (2019) showed that some components of social capital were negatively associated with perceived stress, and the correlation between social capital and perceived stress varied depended on the levels and types of social capital. Himanshu, Arokiasamy, & Talukdar (2019) identified a positive association between QOL and strong social capital components such as being married, civic engagement, social-actions, trust solidarity, and strong psychological resources. Walsh & LaJoie (2018) found a moderate and positive correlation between social capital and mental health, and a distinct association between social capital, happiness and

self-rated QOL. Ward, McGarrigle, Carey, & Kenny (2020) reported that social cohesion was associated with the QOL among urban Chinese older adults. Finally, Lane, Wong, Močnik, Song, & Yuen (2019) revealed that social cohesion and associational membership were both associated with a higher QOL. Additionally, Boen et al. (2019) identified that specific indicators of social capital were positively related to health and well-being at baseline and at 3-year follow up. Joe, Perkins, & Subramanian (2019) concluded that personal community involvement was positively associated with all outcomes involved in self-rated health, but also with psychological well-being, subjective well-being, memory skills, and daily and instrumental activities.

Social capital can promote the positive aspects of psychological health. Simons et al. (2019) found the significant positive associations between bonding social capital and social, emotional, and psychological well-being in Dutch elderly individuals. Tsuruta, Shiomitsu, Hombu, & Fujii (2019) exhibited the positive relationship between social capital and happiness in relation to factors of social capital such as trust, connections and interaction, and social participation. Furthermore, Ramos, Su, Correa, & Trinidad (2018) revealed that bonding and bridging social capital were significantly associated with self-efficacy among Latina immigrants in Nebraska, US. Finally, Pan (2018) showed that trust and family support were significantly positively associated with life satisfaction.

In addition, social capital can be beneficial in terms of maintaining optimal cognitive function. Ito et al. (2019) demonstrated a significant association between cognitive function and individual cognitive social capital in men, and between cognitive function and structural social capital in women. Jiang, Wu, Lu, & Dong (2020) identified that neighbors trust was positively associated with cognitive function in India, Russia, and Ghana, yet it was negatively associated in South Africa and no

effect was revealed in China. Murayama et al. (2019) reported that lower amounts of district-level emotional and instrumental support were associated with cognitive impairment among men in Japan, and that district-level emotional support was associated with a greater cognitive impairment among women. The authors additionally found that district-level social network could mediate the relationship between low-education status and cognitive impairment.

Moreover, social capital can trigger corresponding health behaviors. Herberholz & Phuntsho (2018) reported that individual social capital was positively related to the tendency to seek treatment when ill or injured, whereas strategizing and organizing social capital may support the necessary improvement in healthcare utilization. Peng & Lin (2018) reported that social capital, with regard to social network and social participation, is significantly associated with an increased use of National Health Insurance general preventive care services. Walsh, Kolobov, & Harel-Fisch (2018) reported that three forms of social capital (form of parental monitoring, friend and teacher support) were negatively related to substance use or abuse such as alcohol and cannabis. Ransome et al. (2018) demonstrated that social capital was an important health determinant in HIV/AIDS prevention, transmission, and treatment outcomes.

Pertaining to the relationship between social capital and sleep, Win, Yamazaki, Kanda, Tajima, & Sokejima (2018) conducted a study in which they highlight that the lowest group of neighborhood social capital was found to exhibit higher prevalence of insufficient sleep compared to the highest one among Japanese adults. Robbins et al. (2019) showed the association between a decreased sense of belonging and short sleep, and between decreased trust and moderate-severe insomnia.

Systematic reviews evaluating the effects and benefits of social capital have

also been conducted and identified the usefulness. For instance, Noel, Cork, & White (2018) systematically reviewed 15 studies acquired in literature, and found an inverse association between individual cognitive social capital and post-traumatic stress disorder, anxiety, and depression. The authors also found a positive association between the ecological cognitive social capital and mental well-being. Furthermore, Rodgers, Valuev, Hswen, & Subramanian (2019) reviewed 145 research studies and found that the most frequently investigated health condition involved self-reported health, followed by mortality, cardiovascular diseases, obesity, diabetes, infectious diseases, and cancers and that partial support for protective association between social capital and health. Moreover, Ehsan, Klaas, Bastianen, & Spini (2019) identified that social capital could predict better mental and physical health in patients, and also that it was an efficient protective measure against mortality. Carrillo-Álvarez, Kawachi, & Riera-Romaní (2019) found an association between neighborhood social capital and obesity. Flôr et al. (2018) reviewed three studies pertaining to the development of diabetes mellitus and found that some elements of social capital were related diabetes mellitus. Pérez et al. (2019) conducted a systematic review of review associated with community social capital and found that a consistently correlation between social cohesion and physical activity, a trend in the relationship between social cohesion and healthy weight, and a positive association between neighborhood community life and several population health outcomes.

### **II-3-4 Measurement tools of social capital**

Measurement tools of social capital have been developed in the world. The World Bank developed the social capital measurement tool during the 1990s. The World Bank's Social Capital Initiative was specifically established to improve the greater

understanding of social capital, and hence create an enabling environment in which social capital can be strengthened (Stone, 2001). Its work sought to provide detailed insights regarding various survival and mobility strategies utilized by poor populations (Grootaert, Narayan, Jones, & Woolcock, 2004). The purpose of the Integrated Questionnaire for the Measurement of Social Capital (SC-IQ) was to provide a core set of survey questions for individuals interested in generating quantitative data on various dimensions of social capital as part of a larger household survey (Grootaert, Narayan, Jones, & Woolcock, 2004). This scale focused on six distinct sections: groups and networks, trust and solidarity, collective action and cooperation, information and communication, social cohesion and inclusion, and empowerment and political action.

The Social Capital Assessment Tool (SCAT) was developed to measure the levels of cognitive and structural social capital. The SCAT uses qualitative and quantitative data to measure baseline levels of social capital and to subsequently monitor the respective progress over the course of the implementation of the project (Krishna & Shrader, 1999). This scale was constructed by three components: community profile, household survey, and organizational profile. The household survey part of this scale consists of over 60 questions and requires individuals to dedicate sufficient time to respond to all questions. In addition, this tool has not been tested in terms of its reliability and validity (Harpham, Grant, & Thomas, 2002).

Harpham, Grant, & Thomas (2002) developed an adapted version of SCAT (A-SCAT) which consists of seven questions on structural social capital and 11 questions on cognitive social capital. This scale incorporates the concept of support which can theoretically catch concepts such as measuring emotional, informational, and instrumental support. This scale is designed for application on low income developing countries, and the time to respond to all questions is only 15 minutes.

Onyx & Bullen (2000) developed a 36-item questionnaire to measure social capital, provided with a 4-point Likert-type response scale ranging from 1 (no, not much or no, not at all) to 4 (yes, definitely or yes, frequently). This scale consists of eight subscales: participation in the local community, social agency, feelings of trust and safety, neighborhood connections, family and friend connections, tolerance of diversity, value of life, and work connections. This scale was modified for use in telephone surveys with a United State-based sample (O'Brien, Burdsal, & Molgaard, 2004). Exploratory factor analysis revealed a similar factor structure to the original Onyx and Bullen model (O'Brien, Burdsal, & Molgaard, 2004). In addition, this scale was translated to Greek, and the Greek version of social scale also showed a similar construct to the original model (Kritsotakis, Koutis, Alegakis, & Philalithis, 2008).

Putnam (2000) measured social capital using five distinct components: community organization life, engagement in public affairs, community volunteerism, informal sociability, and social trust.

A measurement tool focusing on the presence of social resources is called a "*position generator*" (Kawachi, Subramanian, & Kim, 2008). In this tool, a sample of positions with valued resources (e.g., occupational statuses, authority positions, industrial sectors) is used. Respondents are then asked to indicate if they know anyone having that job or position (Lin, 1999).

Kouvonen et al. (2006) developed an 8-item questionnaire to measure social capital at work. Cronbach's alpha of this scale was .88 and the  $r_{wg}$  index by .88 showed a significant within-unit agreement. The authors reported that a lower social capital at the work unit level was associated with poor self-rated health.

Looman (2006) created the social capital scale for caregivers of children with special health care needs. The value of Cronbach's alpha below which internal



consistency of the common range is low was .84. The computed test–retest reliability for the total score level of this scale was .90 ( $p < .01$ ). Factor analysis demonstrated the 5-factor construct: common good, sense of belonging, spiritual community, school connection, and informing/asking. Concurrent validity was tested using a support function scale, and the respective scores were significantly correlated with this scale ( $r = .25$ ,  $p < .05$ ). These psychometric tests exhibited sufficient internal consistency, stability over time, and construct validity.

Chen, Stanton, Gong, Fang, & Li (2008) aimed to develop and evaluate a novel instrument, i.e., the Personal Social Capital Scale, which was designed specifically for use in survey studies to assess personally owned social capital. The researchers developed a scale that consisted of 10 items (five items were associated with bonding social capital and the remaining five were associated with bridging social capital) with a total of 42 sub-items. Consequently, the authors stated that this scale was extremely useful for cross-cultural research studies in order to assess personally owned social capital. On the other hand, Wang, Chen, Gong, & Jacques-Tiura (2014) developed a 16-item and an 8-item version of this scale.

Takakura, Hamabata, Ueji, & Kurihara (2014) developed 12-item social capital scale for young people. The internal consistency, stability, criterion-rerate validity were tested and results were adequate. Paiva et al. (2014) devised a 12-item questionnaire on social capital for adolescents with four subscales: school social cohesion, school friendships, neighborhood social cohesion and trust (school and neighborhood). The Cronbach's alpha of overall was .71, whereas the Kappa coefficient was higher than .72 for the majority of items. Hence, the authors concluded that this scale could indicate the validity and reliability of the Social Capital Questionnaire for Adolescent Students.

Primack et al. (2014) aimed to develop a brief scale to assess social capital among early-career clinical investigators. The authors developed a 3-item assessment tool based on a conceptual framework and measurement tools of social capital from other fields. Internal consistency using of alpha coefficient was .71. Bivariable regression analysis exhibited a significant association between seven of the nine expected constructs: sex, age, confidence in research skills, intrinsic and extrinsic motivation, burnout, and social support. Multivariable regression also demonstrated that the score of this scale was most strongly associated with higher research confidence, higher extrinsic motivation, and lower burnout rates. This study concluded that this brief assessment could be valuable to benchmark social capital of clinical research trainees.

Furthermore, Saito et al. (2017) developed a health-related social capital scale at community level based upon the assumption that their scale would be used to conduct community diagnosis. Eleven community level variables, including participation in volunteer groups, sports groups, and hobby activities, trust, norms of reciprocity, and attachment to one's community, were selected. Factor analysis indicated that the variables selected could be further distinguished into three subscales: civic participation, social cohesion, and reciprocity. Confirmatory factor analysis showed that the root mean square error of approximation was .089, whereas the comparative fit index was .925. The authors stated that this scale might be useful for future studies on elderly individuals residing in community settings.

Therefore, it can be concluded that there are several existing tools that can measure social capital as presented above. However, none of these existing tools can accurately measure social capital among caregivers of people with dementia, and some cannot measure general and specific reciprocity separately because they measure reciprocity

as a single item (Kouvonen et al., 2006; Primack et al., 2014; Saito et al., 2017). Likewise, several scales cannot measure generalized and particularized trust separately because they do not measure trust or only consider it as a single (Primack et al., 2014; Saito et al., 2017). Some scales have been developed at a single or a few cities (Chen, Stanton, Gong, Fang, & Li, 2008; Primack et al., 2014; Takakura, Hamabata, Ueji, & Kurihara, 2014), or using of convenient samples (Looman, 2006), and most of these do not include reverse items (Kouvonen et al., 2006; Chen, Stanton, Gong, Fang, & Li, 2008; Paiva et al., 2014; Primack et al., 2014; Takakura, Hamabata, Ueji, & Kurihara, 2014; Saito et al., 2017). Including negative and positive items on a scale would be desirable (Polit & Beck, 2017). Social capital scale that solved above and specialized for caregivers of people with dementia would be hoped to be developed.

### **III Purposes of This Study**

A novel social capital scale that encompasses the three theoretical domains (social networks, reciprocity, and trust) is required to describe and measure the physical and psychological health of caregivers of people with dementia. The development of this scale could help health care professionals to assess the personal social capital of these individuals, and, consequently, implement appropriate interventions, but also to clarify whether caregivers of people with dementia recognize and accept their communities as dementia-friendly or not. This would, in turn, be highly critical and helpful for health care professionals and for policy-makers, in their attempts and processes of developing dementia-friendly communities. Therefore, the aim of the present study was to develop and assess the validity and reliability of a social capital scale for caregivers of people with dementia.

## **IV Methods**

### **IV–1 Recruitment and procedures**

The study participants were caregivers of people with dementia living in the Kinki region of Japan. Based on the recommendation of Gorsuch regarding a minimum sample size of at least 100 for conducting exploratory factor analysis (Gorsuch, 1983), 1,373 facilities related to the caregivers of people with dementia were randomly selected, including 872 community general support centers, 101 daycare centers, 94 Alzheimer cafés, 206 home-visit nursing stations, and 100 federations for families with dementia, to participate in the study. These facilities were asked to disseminate a questionnaire that included an explanation of the study purpose, methods, and ethical considerations to caregivers for people with dementia. A total of 2,825 questionnaires were then distributed to these facilities through postal mail.

Facilities were asked to distribute the questionnaire to caregivers who met the following criteria. The inclusion criteria for the caregivers were being a family caregiver of people with dementia living in a community, who was self-identification as a primary caregivers of people with dementia, and who has the ability to read and understand Japanese. The exclusion criteria were having diagnosis of serious psychological disease or dementia performed by a physician diagnosis. Distribution of questionnaire to the caregivers by staffs of facilities was considered to represent consent to cooperate with this study. Completing and return a questionnaire by caregivers was considered to represent consent to participate in this study.

### **IV–2 Ethical aspects**

This study was approved by the Ethical Committee of the Kobe University Graduate School of Health Sciences (No. 716) and Kansai University of Nursing and Health

Sciences (No.80). All participants received a full explanation of the purposes and ethical considerations of this study, and voluntarily provided written informed consent to participate.

#### **IV–3 Measures**

##### ***IV–3–1 Social capital scale for caregivers of people with dementia***

Based on a review of the literature and previous studies on social capital, 41 items were generated using the following three theoretical components of social capital: social networks, reciprocity, and trust. To assess content validity, two experts in the areas of dementia nursing, one psychologist, and two gerontological nursing educators rated the relevance of each item on a four-point Likert scale. A content validity index (CVI) was computed based on the proportion of experts who rated each item as 3 or 4. The CVI for the entire scale, which included all items with a  $CVI \geq .8$  ( $N = 35$ ), was calculated as .94 based on the mean of all individual CVI values (Polit and Beck, 2017). To assess face validity, a draft questionnaire was conducted on a convenience sample ( $N = 5$ ) of caregivers of people with dementia, and items that were found to be unclear were revised. The social capital scale for caregivers of people with dementia was scored on a five-point Likert scale ranging from “1 = strongly disagree” to “5 = strongly agree”. A higher score indicated greater social capital.

##### ***IV–3–2 Positive aspects of caregiving (PAC) scale***

PAC is related to socio-emotional support (Koerner, Kenyon, & Shirai, 2009). The three components of social capital are considered to be associated with PAC, in that higher social capital reduces the stress and burden associated with caregiving, which leads to high PAC. The PAC scale, which was developed by Tarlow et al. (2004), has

shown promise as a valid and reliable instrument. They proposed a nine-item, two-factor solution composed of “*self-affirmation*” and “*outlook on life*” (Tarlow et al., 2004). A higher score on the PAC scale indicates higher PAC. Cronbach’s alphas for all items and the two PAC subscales used in this study were .895, .851, and .885, respectively.

#### **IV–3–3 Demographic data**

The following demographic data were collected: gender and age of caregivers, relation with care recipient, highest level of education, duration of caregiving, gender and age of care recipient, and long-term care level of the care recipient (Table 1).

#### **IV–4 Data analyses**

Cronbach’s alpha coefficient was used to assess internal consistency. An alpha coefficient over .70 indicates acceptable internal consistency (George & Mallery, 2003). Four weeks later, a second test for the social capital scale for caregivers of people with dementia was conducted on 50 caregivers. Then, intra-class correlation coefficients (ICCs) were used to estimate test–retest reliability. An ICC over .70 indicates acceptable reliability (Ware Jr & Gandek, 1998). For construct validity, exploratory factor analysis with maximum likelihood estimation was used. The components of the social capital scale were assumed to be correlated with each other. Promax rotation, which relaxes the assumption of orthogonality of the resultant components, was used. The extracted number of factors was decided as three based on the three theoretical components of social capital: social networks, reciprocity, and trust. The criterion for estimating the number of factors to retain was a factor loading of .4 or higher. Concurrent validity was assessed using the PAC scale. All data were analyzed using

SPSS (version 24; IBM Corp., Tokyo, Japan).



## **V Results**

### **V-1 Participants' characteristics**

In total, 199 responses were received. After excluding 21 caregivers who did not answer one or more items on the social capital scale, 178 caregivers (43 males [24.2%]; mean age  $\pm$  SD,  $63.7 \pm 12.1$  years) were finally included in the analytical sample. Table 2 exhibits the participants' characteristics. Most caregivers were daughters (37.1 %) or spouses (29.8%), and the mean length  $\pm$  SD of caregiving was  $5.5 \pm 4.2$  years. Furthermore, and considering care recipients (60 males [33.7%]; mean age  $\pm$  SD,  $83.7 \pm 10.2$  years), 152 (85.3%) individuals required support or care, and four were not certified for long-term care insurance (2.2%).

### **V-2 Selecting items from the item pool**

In total, 35 of the original 41 items (18, 9, and 8 items from the social network, reciprocity, and trust components, respectively) were retained based on a content validity index.

### **V-3 Test of psychometric properties**

#### **V-3-1 *Ceiling and floor effects on the social capital scale***

Eight of the 35 items demonstrated ceiling effects; however, no floor effects were observed.

#### **V-3-2 *Item-total correlation analysis***

After excluding the eight items for which ceiling effects were observed, the correlation coefficients between the total score for all items and those for the remaining 27 items were estimated. All items showed significantly positive relations, ranging from  $r = .23$

to  $r = .68$ .

### **V-3-3 Exploratory factor analysis**

The Kaiser–Meyer–Olkin index was .83, and Bartlett’s test of sphericity was significant ( $\chi^2 = 2261.43$ ,  $df = 351$ ,  $p < .001$ ), indicating that the sample fulfilled the prerequisites for conducting factor analysis. Exploratory factor analysis using maximum likelihood estimation with oblique rotation for three factors identified 17 items. The three-factor solution showed an eigenvalue greater than 1. The items contained in the three factors had factor loadings higher than .4. Ten items with a factor loading lower than .4 were eliminated. These 17 items explained 46.5 % of the total variance before promax rotation.

Table 3 shows the results of the exploratory factor analysis. Factor 1 consisted of six items, and was called “*Support for people with dementia and their caregivers*”. The items included in this factor related to helping others, such as teaching, helping, and counseling people who have trouble in dementia care. This factor also included items about improving the community and helping people understand dementia. These items reflected giving support and help to other caregivers regardless of direct rewards were received.

Factor 2 consisted of seven items, and was called “*Trust in providing dementia care*”. The items included in this factor related to trust among medical staffs, members of the community, and others. In addition, in this factor contained an item related to feeling like a part of the community. Therefore, this factor was interpreted as involving reciprocal trust.

Factor 3 included four items, and was called “*Support from neighbors*”. The items included in this factor related to neighbors and included the words “help” or

“kind”. These items reflected the perception of support from people in the community.

#### **V-3-4 *Internal consistency***

Cronbach’s alpha was .85 for all 17 items, and .86, .74, and .78 for Factors 1, 2, and 3, respectively.

#### **V-3-5 *Concurrent validity***

It was assumed that a higher social capital scale score would be associated with a higher PAC scale score. The correlation coefficient between social capital and the PAC scale was computed, and a significant correlation was found ( $r = .62$ ,  $p < .01$ ). Each factor on the scale was significantly correlated with the PAC scale (Factor 1:  $r = .42$ ; Factor 2:  $r = .58$ , and Factor 3:  $r = .40$ ).

#### **V-3-6 *Test-retest reliability***

In total, 50 respondents were reexamined 4 weeks after the first survey. The ICC was .71, which indicated adequate stability (Ware Jr, & Gandek, 1998).

## VI Discussion

To my knowledge, the social capital scale developed in the present study is the first for caregivers of people with dementia. Caregivers of people with dementia require considerably more social resources compared with the general population. Health care providers should understand whether the social resources provided to caregivers can reduce their burdens and encourage care provision, so an assessment tool that can measure social capital among caregivers of people with dementia is needed. This scale could help health care professionals gain a better understanding of the strengths and weaknesses of caregivers of people with dementia in terms of social capital. This scale could also help policy-makers foster communities where people with dementia can live well as long as possible.

The exploratory factor analysis showed that the three extracted factors corresponded almost perfectly with the conceptual components of reciprocity, trust, and social support. Factor 1, *Support for people with dementia and their caregivers*, is interpreted as reciprocal behavior between people with dementia and their caregivers. This factor contained items regarding caregivers of people with dementia who have trouble in dementia, such as in helping, teaching care, and counseling. These items were considered to indicate specific reciprocity because caregivers who used their acquired caregiving knowledge and skills to support others recognized their personal strengths and resources and encouraged their confidence and self-efficacy (Lu, Jiang, Sun, & Lou, 2019). In addition, this factor also included items related to the community and helping people understand more about dementia. These items were interpreted as indicating general reciprocity because generalized reciprocity is the norm of mutual exchange and motivates people to care for unknown others (Adams & Sharp, 2013; Rönnerstrand & Sundell, 2015). This factor can therefore measure both

types of reciprocity, specific and generalized.

Factor 2, *Trust in providing dementia care*, is useful for helping health care providers and policy-makers know two types of trust: generalized and particularized (Freitag & Bauer, 2013; Glanville & Story, 2018). This factor included items related to others and the community. Some items (e.g., “In general, I trust others”, “The community where I live is safe for taking care of people with dementia”) reflected generalized trust, because generalized trust is an abstract attitude toward people in general (Freitag & Bauer, 2013). Additionally, two items in this factor were related to medical staffs (“I trust medical staffs to care for people with dementia” and “I feel like I can consult medical staffs for anything in regard to dementia care”). These items were interpreted as particularized trust, because particularized trust is directed at people the individual knows personally (Freitag & Bauer, 2013).

Factor 3, *Support from neighbors*, can assess help and support in regard to dementia care from neighbors. Social support was defined as the network accessible to an individual through social ties to family, friends, neighbors, and the community (Lin, Ensel, Simeone, & Kuo, 1979). Gibson et al. (2019) reported that most caregivers in a rural setting found strength from their community, which was beneficial as a safety net of support. This factor can measure such networks through social relationships with neighbors. In addition, the items included in this factor can assess social cohesion in the community, because social cohesion refers to interdependence among neighbors (Cramm, Van Dijk, & Nieboer, 2012).

As mentioned above, the social capital scale developed in this study can measure three dimensions of social capital: reciprocity, trust, and social networks. This scale is beneficial for health care professionals and policy-makers in that it provides information on whether caregivers of people with dementia are perceived in their

community as being rich in social capital. For example, health care professions might be able to facilitate mutual group help for a caregiver with a low score for Factor 1 or 3 that could allow him or her to listen to and share care experiences, help others, or perform voluntary work. When the area where caregivers with low scores of Factor 2 live exist on jurisdiction, policy-makers might strengthen developing the dementia friendly community.

The development process of this measurement tool described here has several strengths. First, whereas few studies have assessed the content and/or face validity of such a scale, both the content and face validity of this scale were tested by experts in dementia nursing and actual caregivers, who represent the intended population for its use (Kouvonen et al., 2006; Looman, 2006; Paiva et al., 2014; Primack et al., 2014; Saito et al., 2017; Agampodi et al., 2019). Evaluating content validity is a critical early step in enhancing the construct validity of the measurement (Polit & Beck, 2017). Face validity is important if respondents' resistance to being measured reflects the view that is not relevant to their situations (Polit & Beck, 2017). Overall, 14 of the original 41 items were excluded because of poor content validity and ceiling effects, leaving 27 to be entered into the exploratory factor analysis; from these 27 items, 17 were extracted. These 17 items showed that the model almost fit the component of social capital. Additionally, the correlation coefficients between the social capital scale, all three factors, and the PAC scale indicated significant moderate positive correlations. The PAC scale has been reported to be positively related to social support (Yu, Wang, He, Liang, & Zhou, 2015). These results suggest that this newly developed scale has sufficient validity.

The results suggest that this newly developed scale has sufficient internal consistency and test-retest reliability. Cronbach's alphas for the total items and each

factor were  $> .70$ , which indicated acceptable internal consistency (George & Mallery, 2003). This result suggested that the retained items measured the same constructs of social capital. Additionally, test–retest reliability was assessed using ICCs. The ICC in the present study was  $.71$ , indicating acceptable reliability (Ware Jr & Gandek, 1998). This result suggested that the score of this scale was stable for 1 month among caregivers of people with dementia.

The construct of this scale is different from those of other social capital scales. Although some of the recently developed social scales have a reciprocity component, it is constructed based on provided and received support (Primack et al., 2014; Saito et al., 2017). An aspect of receiving support protect and help people in their daily lives (Trepte S & Scharkow, 2016). On the other hand, the aspects of providing support allow caregivers to recognize their personal strengths and resources and encourage their confidence and self-efficacy (Lu, Jiang, Sun, & Lou, 2019). This scale can measure aspects of providing and receiving support separately. Therefore, compared with other scales, this scale might help provide a better understanding of the aspects of providing and receiving support among caregivers of people with dementia.

The trust component on this scale can measure general trust using the item, “*In general, I trust others.*” Some of other social capital scales have a similar item (Chen, Stanton, Gong, Fang, & Li, 2008; Paiva et al., 2014; Takakura, Hamabata, Ueji, & Kurihara, 2014). Trust is the foundation of personal relationships and is considered to be a key factor in terms of social outcomes (Musson & Rousselière 2017). Generalized trust is one of the important resources for caregivers of people with dementia because generalized trust is a rather abstract attitude toward people in general (Freitag & Bauer, 2013). In addition, this scale can measure particularized trust using items, such as “*I trust medical staffs to care for people with dementia.*” Particularized

trust is trust at close social range directed at people the individual knows personally through daily interactions (Freitag & Bauer, 2013). Some of other social capital scales similarly have items in relation to particularized trust (Chen, Stanton, Gong, Fang, & Li, 2008; Paiva et al., 2014; Takakura, Hamabata, Ueji, & Kurihara, 2014), but do not have items for caregivers of people with dementia. Both of generalized and particularized trust are important for helping caregivers to maintain their health and continue providing care. This scale might help provide a better understanding of trust among caregivers of people with dementia.

This scale can also measure social capital without placing a great burden on respondents. Recently developed social capital scales have more than 10 items (Looman, 2006; Chen, Stanton, Gong, Fang, & Li, 2008; Paiva et al., 2014; Takakura, Hamabata, Ueji, & Kurihara, 2014; Saito et al., 2017). This scale is composed of 17 items, which is not larger than other social capital scales and can measure the multi dimensions of social capital.

This scale might be useful as a new outcome measure for interventions among caregivers of people with dementia. A number of intervention studies in relation to caregivers of people with dementia have been conducted using the following variables as research outcomes: burden, stress, anxiety, depression, well-being (Blom, Zarit, Zwaafink, Cuijpers, & Pot, 2015; Huis in het Veld, Verkaik, Mistiaen, van Meijel, & Francke, 2015; Gilhooly et al., 2016; Hopwood et al., 2018), QOL, competence, physical and mental health,<sup>61</sup> and the usefulness of web-based platforms (Dam, de Vugt, Klinkenberg, Verhey, van Boxtel, 2017). Social relationship have rarely used as a research outcome.

Here, the development and validation of a new social capital scale specialized for caregivers of people with dementia were described. This scale can measure the



social capital of caregivers of people with dementia, and is therefore beneficial for both health care providers and policy-makers.

## **VII Limitations**

This study had several limitations. First, the low response rate may limit the generalizability of the results. A total of 2,825 questionnaires were sent to 1,373 facilities; however, because of the difficulties associated with directly distributing questionnaires to caregivers of people with dementia, only 199 responses were received. Staffs of facilities might have hesitated to distribute questionnaires to caregivers because the numbers of questions were not little. Moreover, they may not have distributed the questionnaire to caregivers because they did not want to impose additional burdens in addition to the daily care they were already providing for their family members with dementia. Furthermore, it was considered that caregivers did not have much time to complete and return the questionnaire because they were too busy providing daily dementia care. Therefore, the possibility of selection bias could be not rule out.

Second, results of this study may not be representative of caregivers for people with dementia in general, because this research was carried out only in the Kinki region, which involves but six of the 47 prefectures of Japan. A more representative sample may be needed for further study.

## **VIII Conclusion**

The results of the present study confirm the reliability and validity of this newly developed social capital scale for caregivers of people with dementia by assessing the three elements of social capital: social networks, reciprocity, and trust. In addition, social capital was negatively associated with depression among caregivers of people with dementia. This scales developed in the current study can assist health care professionals in gaining a greater insight and understanding of the strengths and weaknesses of caregivers of people with dementia in terms of social capital, but also policy-makers in terms of developing dementia-friendly communities.

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Table 1 Definitions of social capital

| Author                         | Definition of social capital   |
|--------------------------------|--|
| Hanifan                        | <i>“goodwill, fellowship, mutual sympathy and intercourse among a group of individuals and families who make up a social unit”</i> (Hanifan, 1916, p. 130).  |
| Bourdieu                       | <i>“the aggregate of the actual or potential resources which are linked to possession of durable network of more or less institutionalized relationships of mutual acquaintance and recognition”</i> (Bourdieu, 1986, p.51).   |
| Coleman                        | <i>“social capital was defined by its function. It is not a single entity but a variety of different entities, with two elements in common: they all consist of some aspect of social structures, and they facilitate certain actions of actors—whether persons or corporate actors—within the structure”</i> (Coleman, 1988, p. S98). |
| Putnam                         | <i>“social capital refers to connections among individuals – social networks and the norm of reciprocity and trustworthiness”</i> (Putnam, 2000, p. 19).   |
| Lin                            | <i>“resources embedded in a social structure that are accessed and/or mobilized in purposive actions”</i> (Lin, 2001, p. 29).  |
| Burt                           | <i>“social capital is contextual complement to human capital”</i> (Burt, 1997, p. 339).<br><i>“friends, colleagues, and more general contacts through whom you receive opportunities to use your financial and human capital”</i> (Burt, 1992, p. 9).  |
| Baker                          | <i>“a resource that actors derive from specific social structures and then use to pursue their interests; it is created by changes in the relationship among actors”</i> (Baker 1990, p. 619).   |
| Belliveau,<br>O’Reilly, & Wade | <i>“an individual’s personal network and elite institutional affiliations”</i> (Belliveau, O’Reilly, & Wade 1996, p. 1572).  |

Table 1 Definitions of social capital (continued)

| Author             | Definition of social capital   |
|--------------------|--|
| Portes             | <i>“the ability of actors to secure benefits by virtue of membership in social networks or other social structures”</i> (Portes,1998, p. 6).   |
| Brehm & Rahn       | <i>“the web of cooperative relationships between citizens that facilitate resolution of collective action problems”</i> (Brehm & Rahn 1997, p. 999).   |
| Fukuyama           | <i>“the ability of people to work together for common purposes in groups and organizations”</i> (Fukuyama, 1995, p. 10).   |
| Thomas             | <i>“those voluntary means and processes developed within civil society which promote development for the collective whole”</i> (Thomas, 1996, p. 11).  |
| Nahapiet & Ghoshal | <i>“the sum of the actual and potential resources embedded within, available through, and derived from the network of relationships possessed by an individual or social unit. Social capital thus comprises both the network and the assets that may be mobilized through that network”</i> (Nahapiet & Ghoshal, 1998, p. 243). |
| Schiff             | <i>“the set of elements of the social structure that affects relations among people and are inputs or arguments of the production and/or utility function”</i> (Schiff, 1992, p. 160).   |

Table 1 Definitions of social capital (continued)

|                                |   |
|--------------------------------|---|
| Villalonga-Olives<br>& Kawachi | <p><i>“1. The resources – for example, trust, norms, and the exercise of sanctions – available to members of social groups. The social group can take different forms, such as a work place, a voluntary organization, or a tightly-knit residential community. The salient feature of this approach is that social capital is conceptualized as a group attribute.</i></p> <p><i>2. The resources – for example, social support, information channels, social credentials – that are embedded within an individual’s social networks. In this approach, social capital is conceptualized as an individual attribute as well as a property of the collective” (Villalonga-Olives &amp; Kawachi, 2015, p. 63).</i></p> |
| Inaba                          | <p><i>“trust, norms of reciprocity, and networks with externalities through human minds” (Inaba, 2015, p. 169).</i></p>   |

Table 2 Participants' characteristics ( $N = 178$ ).

| Variable  | $N$ (%)    | Mean $\pm$ $SD$ |
|---|------------|-----------------|
| Sex of caregiver                                    |            |                 |
| Male  | 43 (24.2)  |                 |
| Female  | 135 (75.8) |                 |
| Age of caregiver (years)                            |            | 63.7 $\pm$ 12.1 |
| Relation with care recipient                        |            |                 |
| Spouse  | 53 (29.8)  |                 |
| Brother/sister                                      | 3 (1.7)    |                 |
| Daughter  | 66 (37.1)  |                 |
| Son   | 16 (9.0)   |                 |
| Daughter-in-law                                     | 25 (14.0)  |                 |
| Grandson/granddaughter                              | 5 (2.8)    |                 |
| Other   | 8 (4.5)    |                 |
| N/A   | 2 (1.1)    |                 |
| Educational attainment of caregiver                 |            |                 |
| Junior high school                                  | 15 (8.4)   |                 |
| High school   | 71 (39.9)  |                 |
| Junior college/technical school                     | 51 (28.7)  |                 |
| University  | 39 (21.9)  |                 |
| Graduate school                                     | 2 (1.1)    |                 |
| Duration of caregiving (years)                      |            | 5.5 $\pm$ 4.2   |
| Age of care recipient (years)                       |            | 83.7 $\pm$ 10.2 |
| Sex of care recipient                               |            |                 |
| Male  | 60 (33.7)  |                 |
| Female  | 113 (63.5) |                 |
| N/A   | 5 (2.8)    |                 |
| Long-term care level of care recipient <sup>a</sup> |            |                 |
| Requiring support 1                                 | 8 (4.5)    |                 |
| Requiring support 2                                 | 6 (3.4)    |                 |
| Requiring long-term care level 1                    | 29 (16.3)  |                 |
| Requiring long-term care level 2                    | 44 (24.7)  |                 |
| Requiring long-term care level 3                    | 31 (17.4)  |                 |
| Requiring long-term care level 4                    | 20 (11.2)  |                 |
| Requiring long-term care level 5                    | 28 (15.7)  |                 |
| Not certified for long-term care insurance          | 4 (2.2)    |                 |
| Other   | 2 (1.1)    |                 |
| N/A   | 6 (3.4)    |                 |

Note. N/A = not available.

a: A higher long-term care or support level indicates a worse condition.

Table 3 Results of the exploratory factor analysis.

|   | 1      | 2      | 3      |
|---|--------|--------|--------|
| Factor 1: Supports for people with dementia and their caregivers  |        |        |        |
| I sometimes teach people who have trouble in dementia care how to care for people with dementia.                        | 0.952  | -0.073 | -0.044 |
| I sometimes help people who have trouble in dementia care.  | 0.890  | -0.169 | 0.009  |
| I sometimes counsel people who have trouble in dementia care.   | 0.881  | -0.217 | 0.071  |
| In general, I try to help people understand dementia.   | 0.601  | 0.165  | 0.002  |
| I want to improve my community for people with dementia.  | 0.503  | 0.251  | -0.019 |
| I participate in an organization or association for families affected by dementia (i.e., a dementia family association) | 0.467  | 0.098  | -0.060 |
| Factor 2: Trust in providing dementia care  |        |        |        |
| In general, I trust others.   | 0.017  | 0.636  | 0.068  |
| I trust medical staffs to care for people with dementia.  | -0.049 | 0.614  | 0.021  |
| The community where I live is safe for taking care of people with dementia.   | -0.007 | 0.606  | 0.020  |
| I think my community has adequate health, medical, and welfare services for people with dementia.                       | -0.146 | 0.567  | -0.029 |
| I feel like I can consult medical staffs for anything in regard to dementia care.                                       | 0.094  | 0.509  | -0.047 |
| I feel that I am a member of my community.  | 0.113  | 0.507  | 0.054  |
| I feel lonely when I take care of my dementia family. <sup>a</sup>  | 0.005  | 0.448  | -0.079 |
| Factor 3: Support from neighbors  |        |        |        |
| I think that my neighbors help each other.  | -0.096 | -0.06  | 0.993  |
| I can get help from my neighbors in daily life.   | 0.109  | 0.063  | 0.466  |
| I feel that my neighbors are kind.  | -0.047 | 0.311  | 0.462  |
| I can ask my neighbors when I need help in dementia care.   | 0.081  | 0.182  | 0.436  |

Note. <sup>a</sup>: reverse item. Exploratory factor analysis with promax rotation using maximum likelihood estimation.



## **XI Additional documents**

### **Validation of the Positive Aspects of Caregiving scale among Japanese caregivers of people with dementia.**

#### **Abstract**

The Positive Aspects of Caregiving (PAC) scale is an essential tool for health care professionals who wish to intervene in caregiving. This study aims to validate the psychometric properties of the PAC scale among Japanese informal caregivers of people with dementia. A cross-sectional research design was used. In total, 194 participants responded to questionnaires that included the Japanese version of the PAC scale and the Geriatric Depression Scale (GDS). Translation and back-translation were performed to acquire the optimal translation of the PAC scale. Cronbach's alpha coefficients for all nine items and two subscales were .895, .896, and .823, respectively. The intraclass correlation coefficient for test-retest reliability was .721, indicating acceptable reliability. Exploratory factor analysis revealed that all 9 items were retained but extracted 2 factors were different from original model. This study concluded that the Japanese version of PAC scale was adequate except for factorial validity.

**Keywords:** Positive aspects of caregiving, caregivers of people with dementia, scale development, Japan

## **1. Introduction**

The number of people with dementia is increasing around the world. The Organisation for Economic Co-operation and Development (OECD) estimated the number of older people with dementia and reported that Japan has one of the highest prevalences among the OECD member countries (OECD, 2017). The population of older individuals (aged 65 years or above) living with dementia in Japan is expected to increase from 3.3 million in 2020 to 5.3 million in 2070 (Fukawa, 2018). The increasing number of people with dementia is expected to lead to increasing costs for dementia care, such as medical and social costs (Prince, Comas-Herrera, Knapp, Guerchet, & Karagiannidou, 2016). Therefore, the increasing number of people with dementia in Japan is likely to present serious challenges.

Living in the community as long as possible is important for people with dementia. The costs associated with dementia care tend to be high because people with dementia generally require a high level of care (de Labla et al., 2015). However, compared with nursing home residents with dementia, people with dementia living in community show a better quality of life (Olsen et al., 2016), a greater ability to carry out activities of daily living, and a higher level of social connectedness (Nikmat, Hawthorne, & Al-Mashoor, 2015). Thus, living in the community as long as possible is beneficial for people with dementia in terms of a better quality of life and a lower cost of dementia care.

Families are one of the most important resources for people with dementia to continue living in their community. However, it is well known that family caregivers of people with dementia tend to experience high levels of mental distress and be at high risk of developing health problems caused by the caregiving burden, such as depression and anxiety (Boots, de Vugt, Kempen, Verhey, 2016). Additionally,

providing care to people with dementia is not only time-consuming, but also very stressful (de Labla et al., 2015). Therefore, one of the most important aspects of dementia care is supporting family caregivers.

## **2. Backgrounds**

A number of studies have been conducted to support family caregivers of people with dementia. Research has primarily focused on the negative aspects of caregiving, such as unavoidable burdens (Chiao et al., 2015; Liu et al., 2017; Cheng, 2017; Sinha, 2017; Besser & Galvin, 2018; Cheung et al., 2018; Riffin et al., 2018; Donath et al., 2019; Jütten, Mark, & Sitskoorn, 2019), depression (Liu et al., 2017; Donath et al., 2019; Jütten, Mark, & Sitskoorn, 2019; Liew, Tai, Yap, & Koh, 2019), anxiety (Liu et al., 2017; Jütten, Mark, & Sitskoorn, 2019), and anticipatory grief (Cheung et al., 2018). While many studies have been conducted to identify caregiving burdens (Papastavrou et al., 2007; Pallent, 2014; Tay et al., 2016; de Labla et al., 2015; Kajiwarra et al., 2015; Yu et al., 2015; Vaingankar et al., 2016; Liu et al., 2017; Besser & Galvin, 2018; Scott, Clay, Epps, Cothran, & Williams, 2018; Donath et al., 2019), several others have focused on the positive aspects of caregiving (PAC).

Studies to identify the construct of PAC started to be conducted from the late 1980s. Lawton et al. (1989) proposed the term “caregiving appraisal” to refer to all cognitive and affective appraisals and reappraisals of potential stressors and the efficacy of individual coping efforts. Peacock et al. (2010) identified five themes that emerged from interview data on PAC: an opportunity to give back, personal growth along the journey, the discovery of inner strengths by connecting with others, a sense of competence in the role, and an opportunity for a closer relationship and commitment to the care receiver. Lloyd et al. (2016) reported on the following

conceptualizations of PAC for people with dementia: role satisfaction, emotional rewards, personal growth, competence and mastery, faith and spiritual growth, relationship gains, and a sense of duty and reciprocity. Furthermore, Tarlow et al. (2004) devised a valid and reliable two-factor model—“*self-affirmation*” and “*outlook on life*”—based on psychometric analyses of data from “The Resources for Enhancing Alzheimer’s Caregiver Health” project. The perspectives of PAC emphasize the role of caregivers’ values, capacity, resources, and hopes in coping with the caregiving journey, and assume that individuals are capable of growth (Lou et al., 2015). Therefore, PAC are an important component of strategic planning to support family caregivers.

In addition, some studies have clarified the usefulness of PAC among caregivers. PAC reduce the stress associated with caregiving and improve outcomes for caregivers (Kinney & Stephens, 1989). A positive association has been identified between PAC and both well-being and life satisfaction among caregivers of people with dementia (Quinn et al., 2019), and a negative association with a desire for the institutionalization of people with dementia (Fields, Xu, & Miller, 2019). Furthermore, PAC has been reported to be significantly correlated with behavioral bother, burden, daily care bother, and depression (Harris, Durkin, Allen, DeCoster, & Burgio, 2011). As PAC are an important factor in allowing people with dementia to live in their community as long as possible, they need to be quantified to identify the positive aspects of dementia caregiving.

Some scales have been devised to measure the positive aspects of caregiving. Lawton et al. (1989) developed a scale composed of dimensions of what they termed “*caregiving appraisal*”, which included subjective burden, caregiving mastery, caregiving satisfaction, cognitive reappraisal, and perceived caregiving impact. Based

on this scale, Tarlow et al. (2004) developed a PAC scale, which has shown promise as a valid and reliable instrument. The PAC scale has been used in a number of Western countries, including the USA (Riffin, Van Ness, Wolff, & Fried., 2004; Tarlow et al. 2004; Hilgeman, Allen, DeCoster, & Burgio, 2007; Las Hayas, López de Arroyabe, & Calvete, 2014; Roth, Dilworth-Anderson, Huang, Gross, & Gitlin, 2015), and in a number of Eastern countries (Lou et al., 2015; Siow, Chan, Østbye, Cheng, & Malhotra, 2017). Additionally, the PAC scale has been used to assess caregivers with different cultural backgrounds, such as Whites, Hispanics, African-Americans, and Chinese (Roff et al., 2004; Lou et al., 2015). A systematic review reported that the PAC scale was the most commonly used tool to measure PAC (Quinn & Toms, 2019). However, to our knowledge, few studies have attempted to validate the psychometric properties of the PAC scale in Japan. Considering the increasing number of people with dementia worldwide, the difficulties experienced by caregivers of people with dementia should be anticipated and solved through knowledge of dementia care worldwide, despite cultural differences. The objectivity of the PAC scale, as well as its ability to facilitate comparisons among countries when needed, favors its use on a global scale; therefore, the PAC scale is expected to be increasingly helpful in the near future. With this background, the aim of this study was to develop, and subsequently test the reliability and validity of, a Japanese version of the PAC scale.

### **3. Methods**

#### **3.1 Study design**

A cross-sectional study design was used to develop the Japanese version of the PAC scale.

### **3.2 Recruitment and procedures**

We obtained permission to use and translate the PAC scale from the coauthors of the original article.

Based on the recommendation of Gorsuch (1983) in relation to a minimum sample size at least 100 for conducting exploratory factor analysis, data were collected from the Kinki region of Japan. In total, 1,373 facilities related to dementia care, 872 including community general support centers, 101 daycare centers, 94 Alzheimer's cafés, 206 home-visit nursing stations, and 100 federations for families of people with dementia, were randomly selected. We asked these facilities to disseminate a questionnaire, which included explanations of the study purpose, methods, and ethical considerations, to caregivers for people with dementia. A total of 2,825 questionnaires were distributed to these facilities by postal mail. The distribution of the questionnaire to family caregivers by facility staffs was considered to represent consent to cooperate with this study. We asked facilities to distribute the questionnaire to caregivers who met the following inclusion criteria: being a family caregiver of a person with dementia living in the community, being a self-identified primary caregiver, and having the ability to read and understand Japanese. The exclusion criteria were a diagnosis of a serious psychological disease or dementia by a physician. Completing and returning the questionnaire was considered to indicate consent to participate in this study.

### **3.3 Ethical aspects**

Institutional review board approval was obtained for this study (Kobe University [No. 716] and Kansai University of Nursing and Health Sciences [No. 80]). The study purposes and ethical considerations were explained to all participants. All participants

were also informed that their participation in the study was voluntary.

### **3.4 Measures**

#### **3.4.1 Japanese version of the Positive Aspects of Caregiving (PAC) scale**

The English items on the PAC were translated into Japanese by the first author of this study. A native English speaker at a translation company back-translated the Japanese version into another set of English items. Following a comparison between the original and back-translated PAC items, a revision was made to one item on the Japanese version of the PAC.

#### **3.4.2 Geriatric depression scale (GDS)**

PAC reduce the stress of caregiving and improve outcomes for caregivers (Kinney & Stephens, 1989). It was considered that the higher PAC would make caregivers less depressive. The Japanese version Geriatric Depression Scale (GDS) short-form, is composed of 15 items and requires respondents to answer dichotomous (“*Yes*”/“*No*”) questions. This scale was validated in outpatients (Herrmann et al., 1996), inpatients (Leshner & Berryhill, 1994), nursing home residents (McGivney, Mulvihill, & Taylor, 1994), and medically ill inpatients (Lyons, Strain, Hammer, Ackerman, & Fulop, 1990). It has been translated into not only Japanese, but also other languages and is currently used worldwide (Fountoulakis et al., 1999; Kasahara, Kada, & Yanagawa, 1995; Wancata, Alexandrowicz, Marquart, Weiss, & Friedrich, 2006). Scores between 0–5 are normal, whereas scores higher than 5 suggest depression, and scores higher than 10 almost always indicate depression.

### **3.5 Demographic data**

The following demographic data were collected: the caregiver's gender and age, relation with the care recipient, highest level of education, and duration of caregiving (Table 1).

### **3.6 Statistical analyses**

Internal consistency was measured using Cronbach's alpha coefficient for the PAC scale and subscales. An alpha coefficient over .70 indicates acceptable internal consistency (George & Mallery, 2003). A second PAC scale was conducted on 53 caregivers of people with dementia 4 weeks later. An intraclass correlation coefficient (ICC) was used to evaluate test–retest reliability. An ICC over .70 indicates acceptable reliability (Ware Jr, & Gandek, 1998). Exploratory factor analysis was performed to assess the structure of the PAC scale. Maximum likelihood estimation and oblique rotation were used. All data were analyzed using IBM SPSS (version 24; IBM Corporation, Tokyo, Japan) and IBM SPSS Amos (version 24; IBM Corporation).

## **4. Results**

### **4.1 Participants' characteristics**

In total, 199 responses were obtained (response rate, 7.0%). After excluding five caregivers who did not answer one or more items on the PAC scale, the analytical sample consisted of 194 caregivers.

Table 1 shows the characteristics of the study participants. Among the 194 participants, 46 were male (24.2%), and the mean age was  $64.0 \pm 12.1$  years. The majority of participants were daughter caregivers (35.6%) or spouse caregivers (30.9%). Regarding education, 74 caregivers had graduated high school (38.1%), 58



junior college/technical school (29.9%), and 41 university (21.1%). The average length of caregiving experience was  $68.7 \pm 56.0$  months.

## **4.2 Psychometric properties**

### **4.2.1 Construct of PAC Japanese version.**

The Kaiser–Meyer–Olkin index was .88 and Bartlett’s test of sphericity was significant ( $\chi^2 = 987.09$ ,  $df = 36$ ,  $p < .001$ ), indicating that the sample fulfilled the prerequisites for conducting factor analysis. The EFA employing maximum likelihood estimation with oblique rotation identified two distinct factors. Factor 1, *Outlook on life and self-affirmation*, was composed of items 2 and 6–9, and Factor 2, *Affirmation from the perspective of care recipients*, was composed of items 1 and 3–5 (Table 2). These factors explained 69.5% of the total variance before promax rotation.

### **4.2.2 Concurrent validity**

It was assumed that a higher score on the PAC scale was associated with positive feelings among caregivers. The correlation coefficient between the PAC and GDS scores was significant ( $r = -.548$ ,  $p < .01$ ).

### **4.2.3 Internal consistency**

Cronbach’s alpha coefficients for all nine items and two subscales were .895, .896, and .823, respectively.

### **4.2.4 Test–retest reliability**

In total, 53 participants responded to the second measurement performed 4 weeks after the first. The ICC was .721, indicating acceptable reliability.

## 5. Discussion

To our knowledge, the Japanese version of the PAC scale developed in the present study is the first in Japan to enable comparisons using data from other countries. It is well known that caregivers of people with dementia also experience positive aspects of caregiving (Lawton et al., 1989; Lloyd et al., 2016; Peacock et al., 2010). We believe that our scale could allow health care professionals to gain a better understanding of the PAC.

Our results indicate that the psychometric properties of the Japanese version of the PAC scale were adequate, and similar to those obtained in the original validation study. EFA showed that all nine items were retained; this was same as that in previous studies (Tarlow et al., 2004; Las Hayas et al., 2014; Siow et al., 2017). Therefore, the nine items on the Japanese version of the PAC scale enable comparisons with other countries and cultures.

Cronbach's alpha for all nine items was .895; this value is almost identical to Tarlow's complete scale ( $\alpha = .89$ ). This result suggests that the Japanese version of the PAC scale has sufficient internal consistency, similar to the original scale. In addition, the ICC was .721, indicating acceptable test-retest reliability (Ware Jr & Gandek, 1998). This finding suggests that scores on this scale among caregivers of people with dementia are stable for 1 month. Taken together, these indices suggest that the Japanese version of the PAC scale has sufficient reliability.

As expected, the correlation coefficient between the PAC and GDS showed a significant negative correlation; this result is consistent with previous studies (Tarlow et al., 2004; Harris et al., 2011; Las Hayas et al., 2014; Siow et al., 2017). This supports Japanese version of PAC scale as a factor that meet with satisfactory

caregiving outcomes among Japanese caregivers of people with dementia.

However, the EFA outlined different constructs compared with Tarlow's original scale. The factor '*Outlook on life and self-affirmation*' was composed of 'Enabled me to develop a more positive attitude toward life', 'Enabled me to appreciate life more', 'Made me feel strong and confident', 'Strengthened my relationships with others', and 'Made me feel good about myself', while the factor '*Affirmation from the perspective of care recipients*' was composed of 'Made me feel important', 'Made me feel needed', 'Made me feel appreciated', and 'Made me feel more useful' on the Japanese version of the PAC scale in this study. On the other hand, Factor 1 in Tarlow's original and the Eastern version of the scale was composed of 'Made me feel important', 'Made me feel needed', 'Made me feel appreciated', 'Made me feel more useful', 'Made me feel good about myself', and 'Made me feel strong and confident', and Factor 2 was composed of 'Enabled me to develop a more positive attitude toward life', 'Enabled me to appreciate life more', and 'Strengthened my relationships with others' (Tarlow et al., 2004; Las Hayas et al., 2014; Siow et al., 2017). That is, 'Made me feel good about myself' and 'Made me feel strong and confident' were taken from Factor 1 of Tarlow's original scale, "*Self-affirmation*", and included in Factor 2, "*Outlook on life*". In this study, Factor 1 included three items: 'Enabled me to appreciate life more', 'Enabled me to develop a more positive attitude toward life', and 'Strengthened my relationships with others'. These items were the same as the "*Outlook on life*" factor on Tarlow's original scale (Tarlow et al., 2004). This result suggested that Factor 1 in this study can measure the construct of "*Outlook on life*" on the original scale. However, Factor 1 in this study also contained two additional items: 'Made me feel good about myself' and 'Made me feel strong and confident', which differed from the construct of the original scale (Tarlow et al., 2004). These items identify whether

caregivers perceive themselves as good, strong, and confident. These findings suggest that Factor 1 in this study focuses on self-affirmations from caregivers' perspectives and their outlook on life

Factor 2 in this study, '*Affirmation from the perspective of care recipients*', was composed of four items: 'Made me feel important', 'Made me feel needed', 'Made me feel appreciated', and 'Made me feel more useful'. These items identify whether caregivers perceive themselves as important, needed, appreciated, and useful for care recipients. The majority of Japanese people consider individualism as a negative ideology or perception because they believe that individualism contaminates close interpersonal relationships (Ogihara, 2017). Instead, they primarily care about how they are perceived by others. Therefore, Japanese people try to look at themselves from the perspective of others. For this reason, the two items in Factor 1 of Tarlow's original scale were divided.

In this study, we developed a Japanese version of the PAC scale and validated its psychometric properties. While studies in relation to the PAC have been conducted in the USA, Canada, New Zealand, Europe, including the United Kingdom, East Asia, the Middle East, and Africa (Quinn & Toms, 2019), cross-cultural comparisons of the PAC are rare (Lou et al., 2015). We believe that our version of the PAC scale will not only help clarify the strength of caregivers in Japan, but also allow researchers to compare different cultures and assist health care professionals who wish to intervene in caregiving.

## **6. Limitation**

This study had several limitations. First, the response rate was low. A total of 2,825 questionnaires were sent to 1,373 facilities; however, only 199 responses were

received. We think the reason for this was the difficulty experienced in distributing the questionnaires directly to caregivers of people with dementia. In addition, facility staffs might have been reluctant to distribute questionnaires to caregivers because of the relatively large number of questions, which they could have feared would place additional burdens on the patients during daily care, since they were already taking care of their family members with dementia. Furthermore, it was considered that caregivers did not have time to complete and return the questionnaires because they were too busy from daily care. Therefore, the possibility of a selection bias cannot be ruled out.

Second, we conducted this study only in the Kinki region of Japan, which involves six of the 47 prefectures of Japan; therefore, our results may not be representative of caregivers for people with dementia in general. Further studies with a more representative sample are needed.

## **7. Conclusion**

We developed and confirmed the reliability and validity of a Japanese version of the PAC scale. Our 9-item PAC scale consists of two components: “*Outlook on life and self-affirmation*” and “*Affirmation from the perspective of care recipients*”. This scale could be expected to enable comparisons with other countries regarding PAC among caregivers of people with dementia.

## **8. Relevance to clinical practice**

Japanese version of scale can assist health care professionals in effectively assessing PAC among caregivers of people with dementia in Japan. This scale could help health care professionals to assess their intervention for caregivers to live well.

**Author Contribution:**

Study design: CG, HF

Data collection: HF

Data analysis: HF

Manuscript preparation: CG, HF

**Reference**

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Table 1 Characteristics of study sample ( $N = 194$ )

| Variable                            | n (%)      | Mean $\pm$ SD   |
|-------------------------------------|------------|-----------------|
| Sex of care giver                   |            |                 |
| Male                                | 46 (23.7)  |                 |
| Female                              | 148 (76.3) |                 |
| Age of caregiver (year)             |            | 64.0 $\pm$ 12.1 |
| Relation for care recipient         |            |                 |
| Spouse                              | 60 (30.9)  |                 |
| Brother / Sister                    | 3 (1.5)    |                 |
| Daughter                            | 69 (35.6)  |                 |
| Son                                 | 17 (8.8)   |                 |
| Daughter in law                     | 29 (14.9)  |                 |
| Grandson / Granddaughter            | 5 (2.6)    |                 |
| Other                               | 9 (4.6)    |                 |
| N/A                                 | 2 (1.0)    |                 |
| Educational attainment of caregiver |            |                 |
| Junior high school                  | 17 (8.8)   |                 |
| High school                         | 74 (38.1)  |                 |
| Junior college / Technical school   | 58 (29.9)  |                 |
| University                          | 41 (21.1)  |                 |
| Master course and over              | 3 (1.5)    |                 |
| Other                               | 1 (.5)     |                 |
| Period of caregiving (months)       |            | 68.7 $\pm$ 56.0 |

Table 2 Two-factor model of the Japanese version of the Positive Aspects of Caregiving (PAC) scale

| Providing help to (CR) has . . .                              | Factor 1    | Factor 2    |
|---|-------------|-------------|
| 8. Enabled me to develop a more positive attitude toward life | <b>.919</b> | −.003       |
| 7. Enabled me to appreciate life more                         | <b>.918</b> | −.120       |
| 6. Made me feel strong and confident                          | <b>.797</b> | −.037       |
| 9. Strengthened my relationships with others                  | <b>.625</b> | .223        |
| 2. Made me feel good about myself                             | <b>.576</b> | .168        |
| 5. Made me feel important                                     | −.112       | <b>.899</b> |
| 3. Made me feel needed  | .089        | <b>.753</b> |
| 4. Made me feel appreciated                                   | −.021       | <b>.721</b> |
| 1. Made me feel more useful                                   | .167        | <b>.535</b> |

*Note.* Exploratory factor analysis with promax rotation using maximum likelihood estimation.

CR = care recipient

Factor 1 was called “*Outlook on life and self-affirmation*” and Factor 2 was called “*Affirmation from the perspective of care recipients*”.