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Participation of nurses and care workers in the decision-making process for people with dementia in Japan: Discussion paper

Rio Miyanaga[a], Hemant Poudyal[b,*]

[a] Department of Nursing, Faculty of Medicine, Kyoto University, Kyoto, Japan
[b] Medical Education Center, Department of Diabetes, Endocrinology and Nutrition & Department of Cardiovascular Surgery, Graduate School of Medicine, Kyoto University, Kyoto, Japan

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ABSTRACT

Numerous socio-legal factors make the process of surrogate decision-making for people living in dementia very complicated in Japan. In this discussion paper, we argue that the lack of early consultation between patients, surrogate decision-makers and healthcare providers and the overreliance of patients and their families on doctors to assume the decision-making role lead to healthcare practices that may not align with the patient's wishes. Further, we argue that lack of laws on surrogate decision-making, changing family structure and the liabilities associated with the care of people living with dementia contribute to the complexity of the decision-making process in Japan. Finally, given the rapidly changing social and healthcare norms in Japan, we call for greater involvement of nurses and care workers in the decision-making process to ensure patient-centric treatment and care are adopted.

What is already known about the topic?

- In Japan, there is a greater reliance on others to assume the decision-making role for lifestyle, healthcare, medical treatments and end-of-life care of people living with dementia.
- Changes in family structure and increasing fear of litigation for caregivers have resulted in an ever-increasing number of older people living alone.
- Consequently, there is a greater reliance on nursing and care homes for the care of people living with dementia.

What this paper adds

- We argue that nurses and caregivers can play an important role in understanding the patient's perspective.
- Greater involvement of these healthcare professions will be instrumental in providing patient-centric treatment and care to people living with dementia in Japan.

1. Introduction

Japan has the highest proportion of older people in the world with 27.7% of its population (34 million people) aged over 65 years in 2017 (Ministry of Internal Affairs and Communications, 2018). The percentage of older people is expected to further rise to 35.3% by 2040 (Ministry of Internal Affairs and Communications, 2018). With an increasing ageing population, Japan has experienced numerous social challenges such as solitary deaths (Cabinet Office Government of Japan, 2018; Morita et al., 2015), accidents involving older people (Cabinet Office Government of Japan, 2018; Oshima, 2017), long-term care (Cabinet Office Government of Japan, 2018; Hayashi, 2015) and abuse of older people (Haruna and Ochi, 2018). In 2016, 6.6 million older people in Japan were living alone and many were at the risk of isolation and solitary death (Cabinet Office Government of Japan, 2018; Fukukawa and Kawaguchi, 2011; Kanawaku et al., 2010; Ueda et al., 2010).

The ageing population significantly adds to the burden of healthcare in Japan with sharp increases in the prevalence of age-related diseases such as dementia. In 2012, there were 4.62 million people living with dementia in Japan representing 15% of the older population at that time and the number is estimated to increase to over 6 million by 2020 (Cabinet Office Government of Japan, 2017a, b). Due to the nature of the illness, diseases that produce dementia such as Alzheimer disease, in particular, present unique medico-ethical challenges (Hughes and Common, 2015; Johnson and Karlawish, 2015). In 2013, Strech et al. highlighted the full

* Corresponding author at: Medical Education Center/International Education Section, Kyoto University Graduate School of Medicine, Yoshida Konoe-cho, Sakyo-ku, Kyoto, 606-8501, Japan.
E-mail address: hpoudyal@kuhp.kyoto-u.ac.jp (H. Poudyal).

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spectrum of ethical issues in dementia care (Strech et al., 2013). These issues were broadly categorized as diagnosis and medical indication, patient's decision-making competence, information and disclosure, decision-making and consent, responsible surrogate decision-making, social and context-dependent aspects, care process and process evaluation and special situations for decision-making (Strech et al., 2013).

Some of these ethical issues, particularly ones involving patient or surrogate decision-making are more pronounced in Japan. Capacity to make their own decision is one of the central issues with people living with dementia due to the detrimental impact of the disease on multiple components of decision-making and communication process including thinking, memory, reasoning, and language. The four key components assessed in a decision-making capacity evaluation of a people living with dementia include understanding, communicating a choice, appreciation, and reasoning (Hegde and Ellajosyula, 2016). Although cognitively impaired individuals may gradually lose the capacity for self-determination, the concept of autonomy as a basic right is not extinguished with the diminishment or loss of decision-making capacity (Young et al., 2018). Older people maintain their autonomy by making small decisions in their lives and this process is important to them (Komatsu et al., 2018). Family members and care providers of persons living with dementia are typically expected to facilitate and support autonomous decision-making from early stages and gradually assume the responsibility of surrogate decision-making as the decision-making competency of persons living with dementia declines (Fetherstonhaugh et al., 2017).

However, the already challenging process of making medical or end-of-life decisions for people suffering from dementia is further complicated by socio-legal factors in Japan. In the subsequent sections, we argue that the lack of early consultation between patients, surrogate decision-makers and healthcare providers and the overreliance of people living with dementia and their families on doctors to assume the decision-making role leads to healthcare practices that may not align with the patient's wishes. Further, we argue that lack of laws on surrogate decision-making, changing family structure and the liabilities associated with the care of people living with dementia contribute to the complexity of the decision-making process in Japan. Finally, given the rapidly changing social and healthcare norms in Japan, we call for greater involvement of nurses and care workers in the decision-making process to ensure patient-centric treatment and care is adopted.

2. Method

Pubmed, CiNii and Ichushi-Web databases were searched for relevant papers using the following combination of keywords in English and Japanese languages: "Dementia, Autonomy, Japan", "Dementia, Consent, Japan" and "Dementia, Decision, Japan". Reference list of key articles was also screened. Articles in English or Japanese that reported original data from Japanese people with dementia or healthcare professionals were included in this study. Systematic reviews and meta-analysis with a clearly defined method were also included. Reviews, commentaries, responses to authors and letters to the editor were excluded. Full-text articles were retrieved from the Kyoto University library or through direct communication with the corresponding author.

3. Role of people living with dementia, family and healthcare professionals in the decision-making process

The progressively declining cognitive and communicative abilities and loss of the ability to communicate thoughts, needs, and preferences severely affect the decision-making capacity of people living with dementia (Woodward, 2013). However, people living with dementia cannot be assumed to lack the capacity to reason, self-evaluate, communicate or making decisions (Hegde and Ellajosyula, 2016). It is important to consider that people living with dementia make decisions not just on logical thoughts but also based on personal values and relationships (Smebye et al., 2012).

An analysis of the diaries of a centenarian Japanese woman living alone showed that despite progressing dementia, she was able to understand her cognitive decline, conceive basic emotions of grief, gratitude and loneliness, self-evaluate and consider positively coping with the situation (Suwa et al., 2018). Further, in a survey of Japanese people receiving long-term care, 73.7% of people with dementia were somewhat capable of making decisions (32.4% were reported as being "always capable"; 41.3% were reported as being "sometimes capable") (Mitoku and Shimanouchi, 2014). Also, 93.7% of people living with dementia felt they were somewhat capable of communicating with others (78.3% were reported as being "always capable"; 15.4% were reported as being "sometimes capable") (Mitoku and Shimanouchi, 2014). However, the decision-making capacity at baseline declined to about half of what they were after one year and to about one-third of what they were after two years (Mitoku and Shimanouchi, 2014). These findings emphasize the importance of early consultation with people living with dementia while they retain the capacity and competency for decision-making and express their wishes and preferences. Numerous cases, where the preference for end-of-life care or life-prolonging treatments of people living with dementia could not be confirmed due to their advanced dementia, have been reported in Japan (Nishikawa et al., 2013; Shintani, 2013).

In addition to reduced mental capacity, lack of available choices or not being given the opportunity to participate are two major factors that led to the non-involvement of people living with dementia in the decision-making process (Smebye et al., 2012). Although the long-term care insurance aims to promote autonomy in the decision-making process, this rarely happens in practice due to low health literacy of the patient and/or the healthcare professional will only promote autonomy at the request of the patient or the family (Mizuno, 2004). Earlier studies have indicated that participation in the decision-making process can greatly improve the perception and satisfaction of older people. A survey of older women who attended and received some health care and/or welfare service at different facilities in Tokushima prefecture showed that people whose opinions were considered in the general daily life aspects were more satisfied with their lives than those whose opinions were poorly or not considered (Onishi et al., 2010). Further, low levels of life satisfaction of older women were positively correlated with the prevalence of depression in those living with dementia (Onishi et al., 2010).

The process of decision-making in Japan usually results in decisions being made for people living with dementia mainly due to the lack of early discussion between the patient, family and healthcare professionals and importantly, patient's overreliance on others to assume the decision-making role. A cross-sectional survey of middle-aged and older adults in Tokyo showed that over 80% of the respondents preferred to decide treatment preferences in consultation with others (22.2% with their surrogate decision-makers, 11.0% with the doctor, and 47.8% with both their surrogate decision-makers and the doctor) (Miyata et al., 2006). Another survey of middle-aged and older adults showed that only 12.7% had decided preference of their own care, 31.9% had ever thought but not yet decided and 52.3% had never thought of advance care planning (Arai and Arai, 2008). Importantly, only 39.5% of those who had decided had discussed their decisions with their family (Arai and Arai, 2008). This survey also showed that there was a positive correlation between awareness of dementia (anxiety and

knowledge) and if they have advance care planning (Arai and Arai, 2008). Further, in people at the end of their lives who presented signed documents stating their wishes regarding end-of-life care, only 2% of the documents were signed by self, 10.2% by their spouse and 81.6% were signed by their children suggesting an overreliance on the family to assume the decision-making role (Sato et al., 2011).

Although people may rely on family to assume the decision-making role, there are studies to indicate that the family may be reluctant to take up this role. A recent study of people receiving home medical care and their families who were expected to prepare for end-of-life decision-making showed that 32% were entrusting all decision-making to the doctor or their families (Tsuda et al., 2018). In turn, most of the surrogates preferred doctors to assume the decision-making responsibility (Tsuda et al., 2018). The reluctance of family to shoulder the decision-making role was also demonstrated in a study aimed to evaluate the decision-making process in driving cessation by older people from Ehime prefecture (Mizuno et al., 2008). The study reported that 54% of family caregivers preferred older people to determine whether to cease driving by themselves and of those family caregivers who doubted the driving ability of people in their care, only half attempted to encourage driving cessation (Mizuno et al., 2008).

In addition to this overreliance on others to assume the decision-making role of both older people and surrogate decision-makers, there is also a disconnect between the wishes of people living with dementia and the decisions made by the surrogate decision-maker. For example, in a retrospective cross-sectional study of people living with dementia in group homes, 90% of the family members preferred group home as the place of death whereas 45.5% of people living with dementia wished their death to be at their own homes (Nakanishi and Honda, 2009). This discrepancy in preferences of people living with dementia and their family is largely contributed by the difficulty in providing care and monitoring especially when the patient refuses to take the treatment (Sugihara et al., 2016). Such scenarios render decision-making support difficult and often lead to the prioritization of the family's preference by healthcare professionals (Sugihara et al., 2016; Takeshita et al., 2018).

Furthermore, the priorities of healthcare outcome for older people appear to differ between patients, families and healthcare providers. In the largest survey ever conducted to describe health outcome prioritization in Japanese geriatric medicine, improvement of the quality of life, patient satisfaction with care and improved mobility emerged as top priorities for geriatricians, physicians involved in the care of older people and adult day-care staff (Akishita et al., 2013). However, family members of people living with dementia and older patients living in the community, adult day-care centres or geriatric outpatient clinics all prioritized effective treatment, improved mobility and reduced caregivers' burden (Akishita et al., 2013). Improving social functioning, avoiding institutional care and reduce mortality were the lowest priority for all groups of health care providers, families and patients (Akishita et al., 2013).

As discussed above, there is a high expectation in Japan for the doctor to assume the decision-making role (Miyata et al., 2006; Tsuda et al., 2018) despite differences in priorities of healthcare outcome with patients and families. Moreover, an earlier survey administered to 450 dialysis patients in 15 hospitals as well as their family members and physicians revealed that neither family members nor physicians more accurately predicted their patients' wishes about life-sustaining treatments than expected by chance alone (Miura et al., 2006). Therefore, the preferences of healthcare professionals for treatment options and care for people living with dementia may not necessarily address the patient's wishes. This is best exemplified by the use of life-sustaining treatments such as ventilators, drip infusions, and gastrostomies. In Japan, tube feeding and drip infusion are considered part of "routine care" and physicians worry that not providing a feeding tube and drip infusion can be perceived by the patients' families as allowing the patients to starve (van der Steen et al., 2013v). This may also be contributed by the fact that both active and passive euthanasia are prohibited by Japanese laws (van der Steen et al., 2013v). Over 90% of Japanese geriatricians view neurological disorder and stroke and 46.8% consider dementia as indications for tube feeding (Mitoku and Shimanouchi, 2014). However, the current guidelines from the Japanese Society for Parenteral and Enteral Nutrition and the Japan Gastroenterological Endoscopy Society on parenteral/enteral nutrition and percutaneous endoscopic gastrostomy (PEG) tube feeding, respectively, does not describe the indications for tube feeding in older patients, especially in those with dementia (Ogita et al., 2012). Nevertheless, a cross-sectional study of people in hospital care or long-term care reported that over 60% of people living with dementia with PEG tube placement had advanced dementia (Nakanishi and Hattori, 2014).

In cases where experts from the United States, for example, would consider tube feeding and drip infusion as medically ineffective and unnecessarily prolongs the dying process, Japanese physicians' feel that it is "socially important that the patient be kept alive as long as the patient has family or grandchildren who wish for such" and would consider the psycho-social benefits of tube feeding and drip infusion that could be used to satisfy the family's needs (Nagao et al., 2008). However, not starting or withdrawing treatment is considered appropriate if the patient wishes so as there is no intention to terminate life (van der Steen et al., 2013v). The Japan Geriatrics Society guidelines of 2012 on the decision-making process for the health care of older people noted that withholding or withdrawing feeding tubes are treatment options that should be discussed with the patients and their families during the decision-making process (The Japan Geriatrics Society, 2012; Tsoh et al., 2015).

It is noteworthy that PEG tube feeding in patients at the hospital was expected to improve quality of life (QoL) in only 39.1% of patients with advanced dementia and 60.7% in patients with non-advanced dementia and prolonged survival without improving QoL was expected in 51.1% of patients with advanced dementia (Nakanishi and Hattori, 2014). However, very few Japanese patients prioritize prolonged survival (Akishita et al., 2013; Miyata et al., 2007,2006) and greater emphasis is placed, by both families and patients, on improved QoL (Akishita et al., 2013). Among long-term patients with advanced and non-advanced dementia, the most common benefits of PEG tube were the administration of medication was ensured (60.9% & 61.4%) and the relatives were satisfied with the QoL of patients' lives (58.6% and 62.2) (Nakanishi and Hattori, 2014). However, only 4.2% of those with advanced dementia and 16.4% of non-advanced dementia could enjoy their own lives (Nakanishi and Hattori, 2014). Furthermore, in a survey of outpatients aged 75 years or older without dementia, only about 5% wished to receive any artificial nutrition and hydration during end-of-life care (Yamaguchi et al., 2016). Nevertheless, in a survey of families of dementia patients, over 60% felt that the decision to choose PEG was good for the patient, 13.3% felt that PEG resulted in poorer outcomes and the rest were undecided (The Japan Geriatrics Society, 2010). Together these studies indicate the disconnect in the preferences of treatment options and experience of the course of treatment among patients, families and healthcare provider.

Laypeople and healthcare professionals (physicians and nurses) in Japan reported different preferences and expectation on life-sustaining treatments such as a ventilator or gastrostomy (Kawasaki et al., 2015). More than half of the laypeople did not

want to use either a ventilator or gastrotomy for themselves although a greater number indicated that they would choose a ventilator or gastrotomy for their family (Kawasaki et al., 2015). Similar to laypeople, many healthcare professionals had less desire to use either intervention for themselves but would recommend the use of these medical interventions for their family members more than for themselves and for their patients more than for their family members (Kawasaki et al., 2015). When participants envisioned themselves as the patient, the recognition of the interventions as life-sustaining treatment was a significant predictor of not using either of them (Kawasaki et al., 2015). Both laypeople and healthcare professionals recommended the use of the ventilator and the gastrostomy tube less frequently in cases in which an advance directive to "Do not perform futile LST (life-sustaining treatment)" was present (Kawasaki et al., 2015). However, very few people in Japan use advanced directives and rely on others to make medical decisions. In a cross-sectional survey of middle-aged and older adults in Tokyo, less than 10% of the participants had advanced directives despite over 60% of respondents agreeing that it is better to express their wishes regarding advance directives (treatment preferences in writing, appointment of proxy for care decision-making, appointment of legal administrator of property, stating preferences regarding disposal of one's property and funeral arrangements) (Miyata et al., 2006). Consistent with these observations, a recent study of people receiving home medical care and their families who were expected to prepare for end-of-life decision-making, showed that only 1.9% of the deceased left written advance directives (Tsuda et al., 2018). Currently, there are no clear laws on advanced directives in Japan, which also carries a negative perception among the public, often producing dilemmas for medical professionals to make healthcare decisions when the family opposes the plan suggested in an advanced directive (Tsoh et al., 2015).

There are also some differences in the preferences for the treatment of dementia amongst community residents, nurses and care workers (Miyata et al., 2007). Fewer community residents preferred active treatment under high burden treatment-poor chance of success scenario (3.5–4.4%) compared to low burden treatment-high chance of success scenario (73–76%) (Miyata et al., 2007). In the low burden-high chance of success scenario, >98% of healthcare professionals preferred active treatment for both moderate and severe dementia, but only 7.5% of care professionals preferred active treatment under high burden-poor chance of success scenario for moderate dementia compared to 1% in severe dementia (Miyata et al., 2007). Less than one-third of the community residents preferred life-sustaining treatment for moderate and severe dementia in contrast to health care professional, a majority of whom preferred life-sustaining treatments (Miyata et al., 2007). Regarding preferences about medical treatments based on the American format for advance directives, 72.7% of respondents did not want life-sustaining procedures that served only to prolong the process of dying, 81.6% did not want cardiac resuscitation and 78.5% of them did not want artificial nutrition and hydration if they were in an irreversible or incurable persistent vegetative state, and only 6.9% of respondents wanted their life to be prolonged to the greatest extent possible (Miyata et al., 2006).

4. Emerging challenges for decision-making for people living with dementia in Japan

Since Japan does not have a law or clear guidelines on surrogate decision-making in medical practice (Narumoto, 2013; Tsoh et al., 2015), physicians typically obtain consent from family for patients who are unable to provide consent (Tsoh et al., 2015). Interestingly, in Japan, the role of the surrogate decision-maker is limited to providing consent and the person who has a close relationship with the patient is considered as the key person for surrogate decision-making (Mizuno, 2003; Ogawa, 2014; van der Steen et al., 2013v). This is in contrast with practices in other countries such as the United States where an individual is considered as a surrogate decision-maker from a legal standing. This was exemplified in a case study by American and Japanese physicians and ethicists of a 92-year-old female patient with late-onset Alzheimer's disease who was under the primary care of the daughter-in-law (Nagao et al., 2008). The Japanese experts chose the daughter-in-law as the surrogate decision-maker whereas the American team opined on the inclusion of the grandson as a surrogate decision-maker despite the grandson not being very close to his grandmother or taking interest in her care, was living overseas and only occasionally visited the patient (Nagao et al., 2008). The American team recognized the grandson as having a better legal standing due to the blood relationship with the patient (Nagao et al., 2008). The Japanese approach of allowing a close relative, even if unrelated by blood, does not have any legal basis but has legal precedent and is supported by traditional family structure in Japan (Tsoh et al., 2015).

However, the rapidly ageing society, aided by a strong urban migration of the youth to larger cities, has led to the collapse of the traditional family structure in Japan. In the past 3 decades, single member household and households with 2 members have steadily increased with little changes in 3-membered households (Fig. 1). In contrast, households with 4 or more member have reduced by over 50% since 1985 (Fig. 1). These data strongly indicate that fewer older people are likely to live with their children. Indeed, the number of older people living alone has dramatically increased since 1980 (Cabinet Office Government of Japan, 2018). In 2016, 6.6 million older people, representing 27.1% of all people over the age of 65, were living alone (Cabinet Office Government of Japan, 2018). Another 7.5 million older people (representing 31.1% of >65

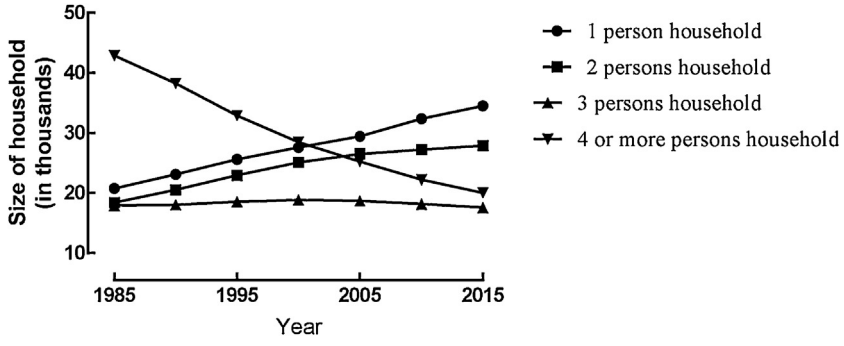

Fig. 1. Changes in the household size in Japan, 1985–2015.
(data source: Japan Statistical Handbook 2018).

years old) were living "in couple" household. The cohabitation rate of older people with their children declined from 69% in 1980 to 39% in 2015 (Cabinet Office Government of Japan, 2017a,b). Consequently, a considerable number of cases of "care for the elderly by the elderly" have emerged. In 2016, 70% of primary caregivers of older people were 60 years or older themselves (Cabinet Office Government of Japan, 2018).

Providing care to people living with dementia is associated with a complex set of responsibilities and liabilities in Japan, therefore, discourages cohabitation with children and also creates legal challenges for older caregivers. This was highlighted in the 2007 case of a 91-year-old Japanese man with dementia who, while in the care of his wife, wandered from home to be hit and killed by a train (Young et al., 2018). The train company successfully sued the wife and the son of the deceased at the local and district courts (Young et al., 2018). However, in March 2016, the Supreme Court pronounced its final verdict denying the responsibility of his wife and son. According to National Police Agency statistics, 15,863 mostly older people with dementia (18.7% of all missing people in Japan) were reported missing in 2017 (National Police Agency, 2017a,b). Most were found within a week, but about one hundred are still missing and 470 were confirmed dead after wandering off from their home or care facility (National Police Agency, 2017a,b).

Numerous cases have now been reported with accidents involving older people with suspected dementia in Japan (Sankei Shimbun West, 2018; The Asahi Shimbun, 2016). Consequently, the Road Traffic Act was revised in 2017 to incorporate stricter rules including taking a cognitive function test for license renewal of older drivers. During the period of March-September 2017, 1,117,876 older people took the cognitive function test out of which 6391 voluntarily returned their licenses and 1964 failed the test (National Policy Agency, 2017). It has been argued that family caregivers, who are more privy of the condition of older drivers, should play a more active role in persuading them to cease driving (Baba, 2017).

5. Involving nurses and care workers in the decision-making process

As a result of the disruption in traditional family structure and the liabilities associated with dementia care, people are increasingly relying on nursing or community care homes (Okuno et al., 2006). In most cases, the decision to move to a care home is not voluntary. According to a survey at a nursing home in Ibaraki prefecture, only 27.8% of people entering nursing home voluntarily did so and 86.1% entered because of reasons of their families or caregivers burden (Okuno et al., 2006). Consequently, repeated appeal to return home in people living with dementia in nursing care facilities is common (Fukui et al., 2011). Only 34.6% of the family caregivers of older people in Ibaraki prefecture who hoped to return home intended to accept them home (Okuno et al., 2006). Person-centred care approach, including providing the personalized environment and greater involvement of people living with dementia in the decision-making process, has been proposed to deal with these issues (Edvardsson et al., 2008; Fukui et al., 2011). However, the fact remains, there is an ever-increasing need for care homes for older people living with dementia in Japan.

To meet the increasing demands, the capacity of nursing care facilities has been increasing with 530,280 special nursing homes, 482,792 paid nursing homes and 370,366 healthcare centre for older people nationwide in 2016 (Cabinet Office Government of Japan, 2017a,b). Long-term care facilities have a disproportionately large number of people living with dementia. In 2016, there were 13,270 facilities covered by long-term care insurance where approximately 97% of the people were living with dementia (Ministry of Health, 2016a,b). Despite the increases in capacity, the demand for care facilities for older people remains unmet. A study from 2011 showed that on an average the capacity of one nursing home was 66.7 and received 227.1 applications leaving 70% of the applicants still in need of a care facility (Ministry of Health, 2011). Furthermore, there is a chronic shortage of healthcare workers for older people largely resulting from the decline in Japanese working population as well fewer young people wanting to engage in health care work due to low wages and the perceived image of hard work. In 2017, the active job opening ratio in nursing care field was 3.50 times, and this number is about 2.3 times the active job opening ratio of all other industries (Cabinet Office Government of Japan, 2017a,b).

The current scenario adds a particularly greater burden on nursing staff and care workers. In the last week of life of people with dementia, the amount of care provided by nursing staff and by care workers increased substantially (by nursing staff, 82.6%; by care workers, 69.7%). Managing directors of nursing or group homes also perform a central role in care planning for end-of-life care (60.6%) (Nakanishi and Honda, 2009). At a hospital confirming patients' treatment intention by signature, 51.6% of signature patients answered nurses are most easily accessible to consult about the condition of their disease followed by doctors (48.4%) and medical social worker (35.5%) (Sato et al., 2011). For most patients, care staffs in group homes were able to anticipate the time of death and unexpected changes in condition were not usual. Deaths occurred under the supervision of care workers (87.9%), attending doctors (69.7%), management directors (63.6%), nursing staff (60.6%) and family members (57.6%). Only about half of the patients (54.6%) were attended by family members who stayed in group homes (Nakanishi and Honda, 2009).

Usually, nurses and care workers are not formally involved in the clinical consultation process for medical decision-making. In the 2005 adaptation of a Canadian booklet that was developed for families of people living with dementia to aid decision-making on palliative care issues to Japanese ethical, legal and medical standards, the Japanese version focused mainly on the physician-patient relationship and on responsibility for medical decision-making, in which nursing staff and care workers play no role (van der Steen et al., 2013v; Yumiko, 2013). However, given the ever-increasing reliance of older people and families on these healthcare providers for dementia care, they are perhaps best suited to understand the needs and wishes of older people living with dementia. This covers one of the truly important aspects in the decision-making process for persons with dementia, the presence of advance care planning (past), understanding the subtle signs expressed by the patients (present) and imagining patients' interest considering merits and demerits (future) (Nishikawa et al., 2013). In particular, the experiences of nurses and care workers with the patients and the knowledge of the day-to-day activities of the patients can play a crucial role in assisting both surrogate decision-makers as well as doctors in making better medical and end-of-life decisions for the patient who lacks the capacity to directly provide consent.

Indeed, studies have shown that nurses can be advocates for older people in the surrogate decision-making process by their family's as they observe patient's expressions and emotions and also bridge the communication gap between the patient, physician, and family members (Sugihara, 2016; Yano, 2015). Studies from the United States suggests that family and surrogate decision-makers for people with advanced dementia are least satisfied with poor involvement of nursing care providers in the process of shared decision-making (Givens et al., 2009; Teno et al., 2004). Furthermore, nursing care providers can play an important role in addressing the emotional needs of the family specially to prepare them to deal with deaths of patients at the end of their lives (Forbes et al., 2000; Teno et al., 2004). Together, these studies highlight the

scope of involving nursing and care workers to provide support to family and surrogate decision-makers to ensure patient-centric care is delivered both in Japanese and international context.

However, the current guidelines from Japanese Nursing Association (JNA), International Council of Nurses (ICN) and the Ministry of Health, Labour and Welfare do not provide enough specific details on the role nurses can play in assisting people living with dementia with decision-making. According to the guidelines of the Japanese Nursing Association, nurses can help people living with dementia express their opinions, for example, by suggesting two simple choices after giving enough information (Japanese Nursing Association, 2016). The Ministry of Health, Labour and Welfare recently revised its guideline on the end-of-life medical decision-making process and highlighted the importance of advance care planning and broadened the definition of "reliable person" beyond immediate family members especially in the context of people living in single-households (Ministry of Health, 2018). As evident from the preceding sections, there is a growing need to also include nurses and care workers in the complex decision-making process for people living with dementia who are unable to provide consent.

The proposal to actively include nurses and care workers in the decision-making process of people living with dementia, especially those in care of these healthcare professionals, also requires addressal of other ancillary issues and therefore warrants greater discussion among policymakers, healthcare professionals and other relevant stakeholders in Japan. Firstly, there is an urgent need to increase the number of certified nurses for dementia care in Japan. As of July 2018, there were only 1251 certified nurses for dementia care nationwide (Japanese Nursing Association, 2018). Secondly, nurses and care workers are not trained to assess the decision-making capacity of people living with dementia and this training will be essential (Ogawa, 2016). Thirdly, nursing staff or caregivers may have serious limitations in assessing objective temporal and spatial movement indicators in people living with dementia (Yayama et al., 2013) and this needs to be addressed with additional training (Yamamoto and Aso, 2009). Finally, the added burden on health care provided along with low wages and a serious shortage of employees results in a perfunctory workplace environment, which may paralyze care workers' ethical point of view and may lead to declining quality of care and abuse of older people. In fact, during the period from April 2016-March 2017, 452 confirmed cases and 1723 alleged cases of abuse by care workers at facilities were reported (Ministry of Health, 2016a,b). A survey of 675 Japanese aged care staff from 27 facilities/organizations located in the western and middle parts of Japan showed that staff with negative attitude towards people living with dementia who demonstrate aggression were more likely to use chemical and/or physical restraint and seclusion than staff with positive attitudes (Nakahira et al., 2009). However, the cases of abuse by family caregivers are much higher (16,384 confirmed and 27,940 alleged cases) (Ministry of Health, 2016a,b). In spite of strict laws, reports of abuse have been increasing in Japan.

6. Conclusion

With the rapid decline in the decision-making ability of people living with dementia, family and healthcare professionals are forced to act as surrogate decision-makers. As noted by other researchers, surrogate decision-makers cannot assume the role overnight and have to gradually transition from supporting autonomous decision-making to shared decision-making and ultimately, when the person living with dementia loses decision-making competency, take up the responsibility as a surrogate decision-maker (Fetherstonhaugh et al., 2017; Givens et al., 2009). However, the lack of early consultation between people living with dementia, family and healthcare professionals and the overreliance on others to assume the decision-making role complicate surrogate decision-making process in Japan. This often leads to divergent treatment priorities and preferences among people living with dementia, families and healthcare professionals. Furthermore, the inability to provide adequate care and the liabilities associated with dementia care increases the family's dependency on healthcare providers to assume both care and decision-making roles. Additionally, changing population demographics which has resulted in a very large number of older people living alone or in 2 members "care for the elderly by the elderly" households adds to the increasing dependency on healthcare professionals to assume both care and decision-making roles.

As a direct impact of the limitations of the families of people living with dementia and the increasing dependency on healthcare professionals, there has been greater reliance on nursing homes to assume the role of care provider but not in the decision-making process by the surrogate. Clearly, nurses and care workers, are better positioned to understand the expressions and emotions of people living with dementia and can play an instrumental role in helping families and healthcare professionals in providing the better medical and living environment. This can result in better patient satisfaction as well as fewer discrepancies in the preferences of the people living with dementia and families and the process of surrogate decision-making. Better guidelines and training will be required from key organizations to enable nurses and care workers to adapt to the changing demands and play an active role in helping surrogate decision-makers and doctors to make better decisions for people living with dementia.

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Conflict of interest

Rio MIYANAGA declares that she has no conflict of interest. Hemant POUDYAL declares that he has no conflict of interest.

Ethical approval

This article does not contain any studies with human participants or animals performed by any of the authors.

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