



International Reflections on Caring for People with Advanced Dementia

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Running Head: Dementia care in two countries

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3 Dementia care in two countries
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7 **International Reflections on Caring for People with Advanced Dementia**
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11 **ABSTRACT**
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14 Dementia is causing global concern with its massive impacts upon affected individuals, families,
15 society and national economies. As the disease progresses, patients' needs increase in number,
16 depth, and breadth, covering physical, psychological, social, and spiritual domains. Care varies
17 from place to place, from country to country and from East to West. To learn from some of
18 these variations, we explored advanced dementia care in UK and Japan. Informed by an
19 overview of literature on care of people with advanced dementia, we reflected upon direct non-
20 participant observations of care in urban areas of Northern Ireland and Japan. Whilst we
21 identified a common purpose: to address the complex needs of people living with dementia, there
22 were differences in the approach to care. Broadly, dementia care in UK tends towards person-
23 centred care with a strong interest in Advance Care Planning as part of a palliative care
24 approach. In Japan, we found less evidence of early stage palliative care and more of family-
25 based decision making to inform care of older people. In both countries, dementia care varies
26 regionally, being more available in some areas than others. International knowledge exchange
27 and further comparative studies will help to improve care for people with advanced dementia,
28 everywhere.
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48 **Key words:** Dementia; Palliative care; Cross-Cultural Comparison; Japan; Northern Ireland
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6 Almost 50 million people around the world are living with a dementia diagnosis and the
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8 number of new cases is increasing by about 7.7 million per year (World Health
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10 Organization, 2012). The condition affects mostly older people and has a long trajectory
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12 (Li et al., 2017; Verlinden et al., 2016). It starts off with the characteristic symptom of
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14 memory loss and ends with an inability to live daily life independently. Dementia has a
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16 huge impact on social, economic and medical systems worldwide (World Health
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18 Organization, 2012). Many countries are attempting to address the challenge of dementia
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20 in their national strategies and action plans (Nakanishi et al., 2015; World Health
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22 Organization, 2012). Although the approaches within these national plans and strategies
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24 vary from country to country, reflecting different social structures and policy situations,
25
26 the worldwide priority actions are agreed to be: awareness-raising and prevention; early
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28 diagnosis; commitment to good quality continuing care and services; caregiver support;
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30 workforce planning and effective training; research to better understand the disease and
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32 inform evidence-based care (World Health Organization, 2012).
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38 Dementia is recognised as a long-term life-limiting illness: as yet there is no cure
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40 or effective treatment (Koller et al., 2012; Lee & Chodosh, 2009). With such a lengthy
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42 deterioration, patients often develop comorbidities and at the same time, lose the ability
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44 to communicate (Prince, Comas-Herrera, Knapp, Guerchet & Karagiannidou, 2016).
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46 Pain and discomfort are common concerns, but poor communication makes it difficult to
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48 identify, locate and treat chronic pain and other symptoms. It is important that healthcare
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50 professionals around the world understand the complexity of dementia, so they can better
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3 support those affected in different settings, particularly towards the end of life. In this
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5 paper, we review approaches to the care of people with advanced dementia in UK and
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7 Japan, based upon appraisal of current evidence combined with non-participant
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9 observation in both countries.
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11 **Background**

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13 From a global perspective, dementia is understood and addressed within many different
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15 social, economic, organisational and cultural dimensions. The way people deal with
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17 these challenging situations and the variable support provided, reflects local cultural
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19 influences. Broadly stated, individualism is predominant in Western society, whilst
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21 collectivism is more dominant in decision-making in the East (van der Steen et al., 2013;
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23 Matsumura et al., 2002). These and many other cultural differences offer an opportunity
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25 to compare the actual situation between countries, in order to identify potential
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27 improvements in quality of care.
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33 Japan and UK have broadly similar health care systems based upon universal
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35 health coverage, with essential health services made available to those who need them,
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37 either free or at low cost. Generally, health services are controlled by central or regional
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39 government, whilst social care services are often provided through the local authorities.
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41 Subtle differences persist between and within each region. In Japan, the universal
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43 coverage for elders is supported through Long-term Care Insurance (LTCI) (Campbell &
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45 Ikegami, 2000; Matsuda & Yamamoto, 2001). A similar National Insurance scheme
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47 operates in UK, with a small proportion of care being privately funded, although
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3 arrangements vary across the UK nations, as the governance arrangements are devolved
4 to local government in England, Scotland, Wales and Northern Ireland (Doheny, 2015).
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8 Even though the multiple differences make comparison within and between
9 countries complex, the two countries address elder care within a similar health insurance
10 system, in other words, care for older people is provided based on universal coverage.
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12 This broadly similar organisational approach makes it possible to focus on the cultural
13 differences (other than funding systems) which directly affect decision-making regarding
14 care to address the primary and common concerns; i.e. to maintain the quality of life of
15 the people with dementia and their families.
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24 People living with dementia have unique needs, because the distinctive nature and
25 course of disease leads to physical and psychological deterioration. Professional carers
26 must meet the complex needs of those with dementia and their families. People living
27 with dementia need help with many aspects of daily life: professional care to provide
28 comfort, nutrition and symptom control; specific help with communication and decision-
29 making; care to address emotional and psychosocial needs (Lawrence, Samsi, Murray,
30 Harari & Banerjee, 2011; Lee et al., 2017).
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40 The social and cultural differences between regions provides a rich opportunity to
41 explore natural variation in the way services are provided. Thus, the aim of this study
42 was to examine and compare the care provided to people living with advanced disease in
43 selected settings in Japan and United Kingdom. Cognisant of global consensus upon the
44 twin goals of (1) person-centred care, communication and shared decision-making; and
45 (2) optimal treatment of symptoms and providing comfort (Lawrence et al., 2011; Lee et
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3 al., 2017; van der Steen, et al. 2014), we set our focus upon these two aspects in our two
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5 countries.

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8 Hence, this comparative study included an overview of relevant literature and
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10 direct non-participant observation in urban areas in both countries, with a focus upon
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12 physical aspects of care, communication and decision making. Our purpose was to better
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14 understand dementia care across UK and Japan, in order to inform practice development.

15 16 17 **Methods**

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19 To gather existing knowledge on care of people with advanced dementia, an exploratory
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21 overview of published papers, including policy documents and reports relating to both
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23 countries was completed (September 2017). Relevant literature was identified through
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25 MEDLINE and CINAHL. The search terms used were “dementia”, “end-of-life”,
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27 combined with “United Kingdom” or “Japan”. Our focus was mainly on “communication
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29 and decision making”; “care for comfort” and “symptom management”; these were the
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31 search terms. The same terms were also used to access grey literature (using google and
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33 google scholar) to obtain reports or guidelines issued by government, professional societies
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35 or private research institutions. We restricted the search to English language or Japanese.
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37 No formal restriction on publication date was applied. Titles and abstracts were screened
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39 and the articles which focused on disease other than dementia and those with unreachable
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41 full-text sources were excluded.
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47 The literature was supplemented with information derived from visits to clinical
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49 sites located in urban areas in both countries; non-participant observation of care facilities
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51 in Northern Ireland, UK and reflection upon experience in practice settings in Tokyo, Japan.
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Findings

Results are presented according to two main themes: (1) decision-making and (2) symptom management. These are presented below, each with a UK and Japan perspectives.

Decision making in UK

Thorough communication with patients is mandatory in UK for consent purposes and in making decisions about individual care. However, effective communication is made difficult in cognitive decline as the disease progresses. In such cases where the patient loses the ability to make decisions, maintaining their autonomy on decision making is difficult.

In UK, there are several strategies and Acts of Parliament which address decision-making for the patients whose ability to decide is lost. The 2005 Mental Capacity Act (Ministry of Justice, 2007) allows a family member to make decisions, only where they have been given lasting power of attorney. Taking the legal aspects forward, the End-of-Life Care Strategy (Department of Health, 2008) and the Prime Minister's Challenge (Department of Health, 2015) called for the autonomous decision-making, promoting Advance Care Planning (ACP). It is intended to be an effective tool to identify patients' needs and preferences early in the disease process in order to mitigate family conflict that often arises later, when making decisions on behalf of patients.

Whilst over a third (36%) of the UK population has written a will, only 8% of people in England and Wales have completed ACP (South East Coast Clinical Senate, n.d.). Generally medical doctors take responsibility for initiation of ACP (van der Steen,

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3 Galway, Carter, & Brazil, 2016), ideally at diagnosis, or soon thereafter (Dening, King,
4 Jones, Vickerstaff, & Sampson, 2016) including for people with dementia (Poppe,
5 Burleigh, & Banerjee, 2013).
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10 After many years of development, the Mental Capacity Act (Northern Ireland)
11 gained Royal Assent in May 2016 (Lynch, Taggart, & Campbell, 2017). It will
12 encourage a less paternalistic and more person-centred approach to decision-making so
13 that everyone's wishes are respected, as far as possible. The new law is unique in that it
14 makes it possible for specific safeguards at the time when someone "lacks capacity"
15 regarding a specific decision. During our visit, we heard from senior staff that the new
16 law has yet to be fully implemented, as associated papers are needed to guide practice. It
17 will also need a significant change in thinking and culture; a move away from a
18 paternalistic view that the professional knows best, towards an emphasis on the choices,
19 rights, feelings, values and beliefs of the person being cared-for.
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33 ***Decision making in Japan***

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35 In Japan, it is common for decisions about end-of-life care, especially regarding an older
36 patient when they become frail, to be made mainly by family or sometimes by medical
37 professionals (Ito, Tanida, & Turale, 2010; Konishi, Davis, & Aiba, 2002; Nakanishi &
38 Honda, 2009). Only half of Japanese doctors give priority to their patients' wishes for
39 medical care, regardless of the patient's competency (Asai, Miura, Tanabe, Kurihara, &
40 Fukuhara, 1998; Miyata, Shiraishi, & Kai, 2006).
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49 In our experience it is challenging to apply the decision-making process, elicited
50 through collective preference, not only for patients and their family but also medical
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3 professionals, who themselves experience difficulties. There is a widespread reluctance
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5 to engage in advance care planning. Hence, The Government of Japan now also promotes
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7 the participation of patients in decision making regarding end-of-life and requires the
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9 implementation of such decision-making process as part of the reimbursement fee
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11 schedule of LTCI (Japanese Council of Senior Citizens Welfare Service, 2015). Several
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13 guidelines state how the decisions should be made when the patients are incapable of
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15 making their own decisions (All Japan Hospital Association, 2016; Japan Medical
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17 Association, 2007; Ministry of Health, Labour and Welfare [MHLW], 2015; The Japan
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19 Geriatrics Society, 2012): decisions should be made in the patient's best interests, in
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21 discussion with the families or relatives and medical professionals. However, recent
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23 guidelines refer to ACP as the decision-making principle in respect of a patient's right
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25 (MHLW, 2018). Although substitute decision-makers such as families and medical
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27 professionals have the ultimate responsibility on the final decision, there are no
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29 regulations to validate such decisions.
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35 *Symptom management in UK*

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37 The palliative approach is increasing in importance in UK to benefit those diagnosed with
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39 chronic illness through person-centred, comfort care as well as continuity and optimal
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41 symptom control (National Collaborating Centre for Mental Health (UK), 2007).
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43 However, even with a high level of public interest and debate in UK, people with
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45 dementia tend to experience suboptimal symptom management, in spite of them enduring
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47 a similar burden to other life-limited illness such as cancer (Davies et al., 2014; Sampson,
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49 2010).
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3 Initially UK hospices began with a focus upon cancer, but are now expanding the
4 palliative approach to other non-malignant diseases including dementia. At the same
5 time, they are moving to provide palliative care in various care settings, including at
6 home and at outpatient clinics known as “Day Care”. For example, we visited one
7 hospice in Northern Ireland that runs a special palliative care program for people with
8 dementia. In special dementia-friendly facilities, they provide services specialised for
9 dementia, with interior design used effectively for less confusion, employing staff who
10 are skilled and specialised in dementia care. Nevertheless, care for the person with
11 dementia can be challenging due to wide variation in context, with practical complexities
12 in addressing a wide range of symptoms that have been described as “chaotic” with
13 highly variable needs that require a flexible approach (Davies et al., 2014) with
14 interdisciplinary collaborations (Ryan, Gardiner, Bellamy, Gott, & Ingleton, 2012) across
15 a wide range of settings: those in remote rural settings can be particularly disadvantaged.
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33 In UK, the majority of people with a cause of death recorded as dementia die in
34 hospital, care-home, nursing home or in the community, with very few (0.3%) in a
35 hospice (Sleeman et al., 2014). “The gold Standards Framework” (Hansford & Meehan,
36 2007), which offers educational modules about palliative care, provides guidance for
37 optimal care in those settings and several evidence-based interventions or protocols are
38 under development in England (Davies, Manthorpe, Sampson, & Iliffe, 2015; Jones et al.,
39 2012).
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49 *Symptom management in Japan*

50 To our knowledge, symptom management in advanced stages of dementia has not been
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3 actively discussed in Japan, such that symptoms at end-of-life might be more
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5 appropriately managed. In our experience, residents in Japanese nursing homes tend to
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7 undergo somewhat burdensome interventions such as tube-feeding, cardiopulmonary
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9 resuscitation and hospital transfer at the end of life (Nakanishi & Miyamoto, 2016).
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12 A private-sector survey reported that over 60% of long-term care facilities
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14 provide end-of-life care for older people (Mizuho Information & Research Institute, Inc.,
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16 2014). Staff are often highly motivated to provide good end-of-life care and establish
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18 systems and policies to ensure quality care, such as care manuals with training
19
20 programmes for all staff. End-of-life care is not specific to dementia, rather the focus of
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22 end-of life care in long-care-facilities is on the patient's quality of life with appropriate
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24 symptoms control, which is called *Mitori care*. (Japanese Council of Senior Citizens
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26 Welfare Service, 2015). *Mitori care* is similar to Palliative care but its application is
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28 limited to the terminal phase (Japanese Council of Senior Citizens Welfare Service,
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30 2015). Quality of care at the end of life in those facilities has recently been promoted by
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32 a financial bonus system which regulates the eligibility criteria on the facilities and
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34 patients to receive *Mitori care*. Payment starts 30 days before death and is claimed
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36 retrospectively (Nishiguchi, Sugaya, Sakamaki & Mizushima, 2017). This reflects the
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38 fact that more resources are required to meet the needs of people with terminal illness.
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44 Few articles regarding palliative care focusing on people with dementia in Japan
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46 were found in our research. One of them reports the implementation of palliative care to
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48 people with chronic disease, including dementia, in one hospice (Nishikawa et al., 2013);
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50 the other was a large-scale cross-sectional study which examine the correlation between
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3 staff knowledge about palliative care and their attitudes (Nakanishi & Miyamoto, 2016).
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5 Implementing palliative care for people living with non-malignant disease is not yet
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7 common in Japan; under the public health insurance scheme, most hospice services are
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9 reserved for patients with advanced cancer (Nakanishi & Miyamoto, 2016).
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12 **Discussion**

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14 We reviewed approaches to the end-of-life care of people with advanced dementia in UK
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16 and Japan, based upon literature, other relevant documents and non-participant
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18 observations, in both countries. We focused on the critical elements of end-of-life care
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20 for advanced dementia: *Communication & decision making* and *Care to provide comfort*.
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22 Although these elements are only part of end-of-life care, we used them to focus attention
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24 upon quality care of patients with dementia in both countries. There were differences in
25
26 the approaches of both countries: some approaches to care in UK are highly specialised
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28 for dementia, led by government strategies or local agencies. Although our study
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30 reviewed practices in a limited way, we find that Government Acts and regional policies
31
32 help to guide services and promote good quality end-of-life care for people with
33
34 dementia. However not many people benefit from such specialised services for dementia.
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36 In Japan, we found a highly systemised provision of care for older people who need
37
38 support in all care settings, under the LTCI scheme that covers medical and welfare
39
40 services including end-of-life care both in community and in-patient facilities (Campbell
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42 & Ikegami, 2000). Care for people with dementia in Japan is provided within the
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44 existing services for older people with any diagnosis: though services are organised
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46 within a good infrastructure, they are not developed specifically for people with
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3 dementia.

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6 ***Communication and shared-decision making***

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8 UK policies encourage identification of patients' individual needs and preferences. ACP
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10 is promoted as a way to achieve autonomy, in advance of cognitive impairment. It can be
11
12 an effective tool even for people diagnosed with dementia. Some elements such as the
13
14 timing need to be examined to optimise its use. In many situations, family members are
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16 left to take substitute decisions, on behalf of people who have lost capacity (Dening et al.,
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18 2016; Livingston et al., 2010).
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22 It is true that Japanese families and care professionals tend to make decisions on
23
24 behalf of elders (Kuraoka & Nakayama, 2014). However, recognition of the importance
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26 of involving patients themselves and their families together in decision-making processes
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28 has been increasing (Miyata et al., 2006). These processes are culturally rooted, so it is
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30 necessary to ensure a culturally "fit" and achieve family agreements that honor patient
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32 preference and lead to optimal care for them.
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36 Both UK and Japan struggle with end-of-life decision-making, respecting the
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38 patient's own free choice, whilst avoiding family conflict. However, an effective system
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40 to support decision making is a "must" for good quality end-of-life care. Further research
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42 is needed to examine the effectiveness of timely ACP to promote decision making whilst
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44 ensuring good cultural fit.
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47 ***Optimal treatment of symptoms and providing comfort care***

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49 Globally, high quality palliative care can overcome burdensome and unique physical,
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51 psychological, social and spiritual needs in different ways, in various styles. The
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3 provision of dementia care in Northern Ireland was remarkable because it can provide
4 disease-specific; dementia-friendly care until the end of life. The services we saw cover
5 all the essentials for people with dementia (Prince et al., 2016): continuous, holistic and
6 integrated health care. Here, patients receive palliation earlier in disease trajectory than
7
8 in most other models of care. In Japan, patients can also access continuous and
9
10 standardized care. However, the care is not disease-specific, tends towards *Mitori care*
11 and is less focused upon symptom management or palliation. There is a need to develop
12 optimal palliative care for people in earlier stages of dementia to achieve quality of life
13 throughout the disease trajectory, even from diagnosis.
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24 Indeed, all this assumes that dementia is correctly diagnosed in a timely fashion: a
25 critical first step in addressing specific needs (Nakanishi et al., 2015). But the diagnosis
26 rate is still low, even in high income countries (Prince et al., 2016). By improving
27 diagnosis, engaging with ACP and thereafter addressing symptom control, it may be
28 possible to achieve good quality care for all.
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35 ***Limitations and recommendations***

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37 We explored the situation at end of life for people with dementia in UK and Japan
38 through literature overview and direct observations in Northern Ireland and Tokyo. The
39 challenges of care are similar in both settings: achievement of effective symptom control
40 within a context of clear communication. Recognising the limitations of observational
41 study, which cannot provide evidence of clinical effectiveness, we provide some useful
42 reflections to build a foundation for further comparison and learning. We found many
43 similar situations between the countries: both striving to provide optimal care for end-of-
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3 life care in dementia, albeit using different approaches: UK services being more person-
4 centred and government-driven, whilst in Japan dementia services depend more upon the
5 culture of family-centred support; each with unique local care systems and each
6 influenced by the dominant funding model in the region. Developments in Health
7 Insurance are influential in Japan and the recent inclusion of ACP will promote its
8 introduction in palliative care, which for the moment, still remains focused largely upon
9 people with cancer. ACP in dementia is complex and requires sensitive application,
10 family engagement and evaluation. To advance the quality of care for people with
11 dementia, professionals in public health have an important role: early in the disease
12 process, people with dementia need support, information and access to care near their
13 home. In any setting, access to specialised care is limited, so a better understanding by
14 professionals, carers, and people with dementia is likely to enhance quality of life. We
15 need to help people with dementia and their family to prepare for their upcoming
16 experience and make decisions in advance of cognitive decline (via ACP).
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35 Ongoing knowledge exchange is needed in order to address the needs of people
36 with dementia and their families, across all four palliative care domains of physical,
37 psychological, social and spiritual care (World Health Organization, n.d.). Further
38 research work is needed to underpin this knowledge exchange in order to compare and
39 contrast different components of care. It is important to recognise the value of
40 international comparison and collaboration in this area.
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