‘Departure’ from a long life

End-of-life care in Japanese nursing homes
An ethnographic study

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Master thesis
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Amsterdam Master’s in Medical Anthropology
August 2009
Dedication/ 献辞

遠藤様（仮名）のご冥福を心からお祈り申し上げます。遠藤様の意味深い人生を教えて頂いた事は、
私に人間の存在価値を探求する機会を与えて下さいました。深く感謝の意を表します。
I want to express my deepest sympathy on Mr Endo’s departure and my sincerest gratitude to him for
sharing his profound meaning of life with me. His departure made me more aware of what it means to
be a human being. His death put his stamp of life on my thesis.

佐藤様（仮名）に深い感謝の意を表します。佐藤様から生きる価値を学ばせて頂き、また、内なる強
さは、私にエネルギーを与えて下さりました。ここに佐藤様の好きな相田みつを氏の書を載せたいと思
います。
I also want to express my deepest appreciation to Ms Sato for sharing with me her rich tapestry of inner
values and strength. Her example gave me energy and made me conscious of the worth of my life. She
liked the calligraphy of Mituo Aida. This is her favourite calligraphy.

Our life continues, although we are suffering
by Mituo Aida (1984)
# Table of Contents

Acknowledgements i  
Abstract iii  

## Chapter 1  Introduction: End-of-life care of older people in Japan 1  
1-1  Japan: A super ageing society 1  
1-1.1  Demographic data 1  
1-1.2  The policy of caring for older people in Japan: The long-term care insurance system 3  
1-1.3  The situation of caring for older people in Japan 4  
1-2  Japanese older people’s attitudes towards death 5  
1-2.1  The preferred way of dying 6  
1-2.2  Acceptance versus fear of death 6  
1-2.3  Concept of a good death among older people 8  
1-3  The importance of end-of-life care in the Japanese nursing home 9  
1-4  The research questions 12  
1-5  Conclusion 13  

## Chapter 2  Methods 15  
2-1  The research setting 15  
2-2  Data collection 17  
2-2.1  Phase one: Building a relationship and understanding the socio-demographic background of older residents 17  
2-2.2  Phase two: Participant observation: insider accounts 18  
2-2.3  Phase three: Case studies: caring dying older residents 19  
2-2.4  Phase four: In-depth interviews: the meanings of life and death 20  
2-3  Ethical Considerations 21  
2-4  Personal reflections 22  
2-4.1  Position 22  
2-4.2  Introspection 24  
2-4.3  Limitations of the study 25  
2-5  Conclusion 25
Chapter 3  Meaning in life and death: An inner journey  
3-1 The meaning of the past  
3-1.1 Accomplishments  
3-1.2 Loss  
3-2 Meaning of the present  
3-2.1 Independence versus dependence  
3-2.2 Loneliness  
3-3 The meaning in death  
3-3.1 Preparation for dying  
3-3.2 Preferred place and circumstances to die  
3-3.3 Concerns about dying  
3-4 Conclusion  

Chapter 4  Dignity at the end-of-life care: Respect for inner journey  
4-1 Dignity in daily care  
4-1.1 Eating  
4-1.2 Bathing  
4-1.3 Toileting  
4-2 Dignity in the decision making process in end-of-life care  
Case 1: An advanced dementia resident  
4-2.1 Incapability of making decisions  
4-2.2 Surrogate decision making  
Case 2: A terminally-ill cancer resident  
4-2.3 Non-disclosure  
4-2.4 Ambiguity of dignity at the end  
4-3 Conclusion
Chapter 5    Spirituality in end-of-life care: a boat for departures

5-1    Older people’s yoridokoro or ‘spiritual resources’
5-1.1    Deceased loved ones
5-1.2    Religious belief
5-1.3    Harmony with Nature

5-2    Spirituality at the end of life: A case study of Ms Sato
5-2.1    Transcendence of the self: the case of Ms Sato
5-2.2    A conceptual framework of spirituality at the end of life

5-3    Conclusion

Chapter 6    End-of-life care: Companionship during life’s journey

6-1    Perceptions of end-of-life care
6-1.1    Older residents’ perspectives of end-of-life care
6-1.2    Families’ concerns about older residents’ end-of-life care
6-1.3    Nursing assistants’ perspectives on end-of-life care
6-1.4    Nurses’ perspectives on end-of-life care
6-1.5    The doctor’s perspective on end-of-life care

6-2    Important components of quality in end-of-life care
6-2.1    Introspection
6-2.2    Compassion
6-2.3    Intuition
6-2.4    Interpretation
6-2.5    Sharing time

6-3    Conclusion

Chapter 7    Conclusion: Departing from a long life

References
Acknowledgements

My research and the writing of this thesis would not have been possible without the help and support of many people. I would like to express my gratitude to all of them.

I would like to first thank all the older residents in the Noboru nursing home. Spending time with them was a profound experience for me, as they shared many personal experiences in their long life journey with me. Their humour and strength gave me energy. I deeply appreciate the staff’s and the doctor’s willingness to speak with me about their difficulties, ideas, and feelings in relation to the care of their residents. I learnt so much from working with them. I am also grateful to the director for allowing me to conduct this study and in supporting me throughout this work.

I am thankful to the older residents in the Haruka nursing home and the older people in the Saitama day care centre who I interviewed. They openly told me their life histories. It was a precious experience to be able to listen to them. I am grateful to Ms Iijima and the director of the Haruka nursing home for giving me the opportunity to conduct the interviews.

I would like to express my sincerest gratitude to my supervisor, Professor Sjaak van der Geest. He supported, guided and encouraged me with great care and consideration. He made me aware of the diverse meanings and implications of end-of-life care. I deeply appreciate his persistent commenting on many drafts of the thesis and his precious advice.

I would also like to express my gratitude to Mr. Euan Sadler for his valuable comments and patient editing of my English within an extremely short time frame.

Furthermore, I am indebted to my AMMA friends, teachers, staff and classmates. Studying Medical Anthropology has brought me to explore my own inner values in life. I also gained invaluable tools for working as a nurse with older people and patients who depend on the care and compassion of others.

I am thankful to my parents who encouraged and inspired me in my caring for older people. Finally, I deeply appreciate the support of Kazuhiko who was my spiritual resource that gave me strength and insight to complete this thesis.
Abstract

Japan has the world’s highest number of older people as a proportion of the total population. The aging of Japan’s society raises significant public health and social welfare concerns. Due to a decrease in the number of available family members able to provide care for older people, the traditional system of informal care-giving by the family is said to be in crisis. In the year 2000, in order to cope with the expected rapid increase in the number of older people requiring long-term care in old age, the long-term care insurance system was established. The availability of long-term care facilities may lift the anxieties older people have about becoming a burden on their families. Due to the difficulties of dying at home and in hospital in Japan, nursing homes in particular are becoming a common setting for end-of-life care among older people.

Although nursing homes are afforded a growing responsibility to care for dying older people, only a few qualitative studies have explored end-of-life care in Japan. Taking an ethnographic approach to investigate end-of-life care in a nursing home provides an important contextualization of the psychosocial, cultural, spiritual, and organizational factors shaping end-of-life care for older people in Japan. The aim of this study is to explore how Japanese older people living in a particular nursing home in Japan experience end-of-life care.

This study is a qualitative institutional ethnography by a researcher as ‘an insider’- a nurse working in a private nursing home in Tokyo, Japan. In my attempt to strike a balance between ‘an insider’ and ‘an outsider’ perspective, I conducted in-depth interviews in a second nursing home and a day care centre. Data was collected over a 6-month period between December 2008 and May 2009. Triangulation of methods was used; participant observation, case studies, in-depth interviews, and narrative life-histories. For ethical reasons, I used pseudonyms in the write up of this thesis to protect the identity of specific persons and places.

This study focuses on three themes in the life of older residents, namely: meaning in life and death, dignity, and spirituality. It does so by contextualizing important components of end-of-life care in the three nursing institutions.

The aim of end-of-life care is to support and maintain the dignity of older residents until their death. The residents expressed that they were ready to depart from their life in the nursing home after they had left their own home. Moving into the nursing home brought with it significant changes in the older resident’s everyday lives. They discovered their human worth through exploring meaning in life and death, and by making life in the nursing home worth living.
Older residents’ dignity was influenced by their relationships with others and the institutional environment. Staff expressed time pressures in their daily care schedules and residents expressed that they were waiting to be cared for by staff. There were two ‘cultures’ in the nursing home: one was the ‘time-pressed culture’ of the staff; the other ‘the waiting culture’ of the residents. This gap sometimes shaped care among residents which lacked the prescribed dignity.

In the collectivist Japanese culture, the family has a central position in decision-making about medical treatment at the end of older relatives’ lives. The family is responsible for surrogate decisions regarding advanced dementia among residents. The culture also has an ethos of non-disclosure of terminal illness as part of the family centred decision-making process. Although relatives understood that medical treatments could bring further suffering to older residents, they often decided to continue treatment because they felt sadness regarding the separation of their loved ones. They needed more time for spiritual preparation and to accept their relative’s departure from this life. It is, therefore, essential that residents, families, the doctor and care staff openly communicate about the older resident’s departure in the early period of his or her stay in the nursing home. Profound empathy for the family’s suffering is an essential part of care and family support at the residents’ end of life.

The centrality of spirituality in end-of-life care was a key finding in this study, with a conceptual framework of spirituality in old age emerging. This framework is composed of three layers: the self, relationships to others, and transcendence of the self, as well as five key components (i.e. meaning in life and death; relationships with others; spiritual resources; transcendence of the self; and inner resources). These components interacted to varying degrees in shaping older residents’ spirituality more profoundly in old age and at the end of life. It is important to draw attention to the opportunities older residents had for further developing and nurturing their spirituality, with their spiritual resources shaping their power of living and inner peace before departing from this life.

This study has shown that end-of-life care is an extension of the care of daily activities. Thus, end-of-life care should start as soon as older residents enter the nursing home. The nursing home staff play an important role in accompanying them during the preparations for their ‘departure.’ However, the staff had difficulties in providing the quality of care to the satisfaction of residents’ needs, due to a lack of experience, knowledge, and skills in terms of end-of-life care. Recommendations are provided in this thesis for staff education and training in issues related to end-of-life care. The staff need to develop a sensitivity to sharing meaningful time with, and profound empathy for the older residents at the end of their lives. Essential elements of quality of end-of-life care are, namely: observation, introspection, intuition, interpretation, carefulness, and compassion. Furthermore, the older people in this ethnographic study valued companionship on their last journey, and opportunities to share their profound meaning of life and death with the care staff. This experience shaped a profound depth of care from the staff to and for the older residents.
Chapter 1
Introduction: End-of-life care of older people in Japan

Over 50 years ago, Japanese older people died at home surrounded by their family. The traditional Japanese view, life is continued from ancestor to descendant, and considers death as a natural process of the life course (Sakurai et al., 2009). However, in contemporary Japan, over 80% of older adults die in hospital (MHLW¹, 2007). What has emerged is the stark contrast between the Japanese ideal of older people dying peacefully at home, surrounded by their family, and the modern day reality of older people dying alone with nameless masked faces in sterile hospital rooms, surrounded by tubes, machines, monitors. Today’s reality of death in old age within contemporary Japan is far from the traditional and religiously based ideal. In this thesis, I will begin to examine older people’s experiences with end-of-life care in contemporary Japan.

1-1 Japan: A super ageing society

1-1.1 Demographic data

Japan has the world’s highest number of older people as a proportion of the total population. Trends have shown that by 2050 it is expected that one in every three adults will be aged 65 years or over (see Figure 1: MHLW, 2007). Furthermore, life expectancy at birth is currently the highest in the world. Figures in 2006 indicate that men can expect on average to live 79 years and women 86 years (MHLW, 2007).

The aging of Japan’s society raises significant public health and social welfare concerns. Many researchers and public health officials fear that an increase in adult life expectancy without a corresponding reduction in the incidence of chronic disease will lead to a

¹ MHLW: Ministry of Health, Labour and Welfare
considerably significant increase in the number of disabled and dependant individuals in later life (MHLW, 2007). At the same time, there has also been a decrease in the number of available family members able to provide informal care for such older people. Although Japan is unique among industrialized nations in that 36% of the older people currently live in three-generation households, a large and growing proportion of women (i.e. daughters and daughters-in-law who are traditionally expected to fulfil the role of caregiver to an older parent) now work outside of the home (CAO\textsuperscript{2}, 2008). As a consequence, the traditional system of informal care giving by the family is said to be in crisis.

**Figure 1: Changes in the ageing population and future prospects**

Welfare policy for the older people 2007: MHLW, p.7

\textsuperscript{2} Cabinet Office, Government of Japan
1-1.2 The policy of caring for older people in Japan: The long-term care insurance system

In order to cope with the expected rapid increase in the number of older people requiring long-term care in old age, the long-term care insurance system was established in April 2000 (MHLW, 2002). This new insurance system aims to promote the ‘socialization’ of care through mandatory social insurance. Specifically, this means that all adults aged 40 years and over pay premiums, and that those aged 65 and over are eligible for benefits based on their physical and mental disabilities. Following an application procedure of care requirements, a care manager assigned to a particular case is responsible for assessing the extent of the older person’s care needs. The municipal certification committee subsequently renders a final judgment of the degree of his or her physical or mental disability, based on a computer-generated classification and the opinion of the primary care physician. Following the assessment of physical and cognitive functioning, the older individual’s eligibility status for benefits is classified into one of six levels. These reflect, namely, a support level, in which the person is generally deemed to be capable, albeit with some assistance, of conducting basic daily activities of living; and five care levels, ranging from care level one (i.e. those requiring partial care) to care level five (i.e. those whose ability to conduct daily activities is almost impossible without extensive assistance).

One of the main aims of the long-term care insurance system in Japan is to promote the use of home care rather than institutional care (MHLW, 2002). However, many older people in need of care avoid using home care services under the long-term care insurance system because of various restrictions on the use of services (Shibusawa et al., 2001). Instead, the majority prefer to use the more readily accessible medical care insurance system: the health service system for older people, which provides the option of long stays in hospitals (Ikegami et al., 2003). However, under the medical care insurance system, older adults are
not allowed to stay in hospital longer than three months. Furthermore, the implementation of the long-term care insurance system has resulted in an increase in the number of applications to nursing homes, resulting in longer waiting list times for beds in these homes. For example, it is estimated that waiting lists for nursing home beds have risen three to five fold since the implementation of the long-term care insurance system (Hirakawa et al., 2009).

1-1.3 The situation of caring for older people in Japan

Older people in contemporary Japanese society may prefer to use long-term care facilities rather than rely on their adult children to care for them. This seems to be confirmed by the high suicide rate among Japanese older people; in 2007 12,107 people over the age of 60 years committed suicide, and of these 95% were living with their family (CAO, 2008). Arguably, the action of committing suicide might be a strategy employed by older people to reduce their children’s obligation to care for them.

Furthermore, Japan also has one of the highest rates of bedridden older people (see Figure 2: MHLW, 2007). In recent years, the term netakiri rojin, meaning ‘bedridden older people,’ has been replaced by some with the word nekasekiri, which means ‘older people who are forced to stay in bed,’ reflecting a growing awareness that some bedridden older people are victims of societal and familial conditions.

At the same time, Japan has also witnessed an increase in the number of older people with dementia, placing a greater burden on family caregivers (MHLW, 2007). Care giving fatigue (kaigo zukare) is a term which often appears in the mass media. In addition, murders of older people are increasing due to care-giving fatigue during the last decade. The availability of long-term care facilities may lift the anxieties older people have about
becoming a burden on their families. In other words, by easing potential burdens of care giving among adult children, long-term care facilities may have a role to play in facilitating closer family ties rather than inhibiting intimate social relationships. Consequently, a growing number of older adults now prefer to spend their final years in care homes or other long-term care facilities; a choice which their families support (Hirakawa et al., 2009).

**Figure 2: Future estimations in Japan of bedridden older adults/elderly suffering from dementia**

![Future estimations graph](image)

Welfare policy for the older people 2002: MHLW, p.4

### 1-2 Japanese older people’s attitudes towards death

Changing societal and cultural attitudes away from caring for older people in their own homes towards being cared for in long-term care facilities, raises the question as to how older people themselves might perceive life and death as the final stage of the life-course. Several studies have been explored Japanese older people’s attitudes towards life and death, and several themes emerging from such studies are now considered.
1-2.1 The preferred way of dying

Japanese older people’s preferred way of dying is by sudden death (pokkuri) (Hattori et al., 2006; Kinouchi and Yoshida, 2004). In English this might be phrased as to ‘just fall over dead,’ for example, following a heart attack (Long, 2001). In Japan, since the 10th century, special temples exist where older people can pray for pokkuri. Underlying reasons for pokkuri as the ideal death relate to the avoidance of becoming a heavy burden to the family, as well as avoiding being bedridden, pain and suffering in old age (Kinouchi and Yoshida, 2004).

A further Japanese ideal way of dying among older people is to experience a peaceful death or daiojo (Long, 2001). Originally, the meaning of daiojo denotes becoming a Buddhist, in order to achieve spiritual enlightenment in old age (Kawashima, 2005). Daiojo implies that dying is natural, where the individual is with others who love them, leading to freedom from all pain and suffering. Moreover, a gradual death (rosui) reflects the view by Japanese older people that they want to die gradually and naturally without life-sustaining treatment (Hattori et al., 2006; Long 2001). In Japan, it is generally believed that those who die with rosui experience no physical and psychological pain and suffering in death, which itself represents a peaceful process (Hattori et al., 2006). Compared to pokkuri then, rosui means that older people have time to prepare for their death and the dying process.

1-2.2 Acceptance versus fear of death

Asami (2006) has pointed out that a polarization of attitudes towards death among older people leads to either an acceptance of death or a fear of death in old age. Furthermore, Asami (2006) describes omukae wo matu, translated as waiting for a ‘welcoming death’ is often expressed by older adults even among those who are fit, healthy and active.
Originally, *omukae* refers to the Buddha escorting the deceased to the next world inhabited by ancestors and loved ones who have died. They are welcomed by Buddha and the ancestors in the next world. Therefore, *omukae wo matu* is a metaphor for the acceptance of death in the final stage of life. It implies that older people expect to go on to the next world after death where they are reunited with their loved ones. Ushida and colleagues (2007) have also noted that *omukae wo matu* is commonly expressed by older people in nursing homes (“I can prepare for dying since I enter the nursing home”). Therefore, one positive aspect of *omukae wo matu* is an acceptance of death among older people in the life cycle.

On the other hand, a fear of death among older people means a fear of pain of illness and suffering from the deterioration of activities of daily living, with the resultant loss of self-respect in old age (Asami, 2006; Ushida et al., 2007). Moreover, older people in Japan fear *kodokusi*-dying alone (Kinouchi and Yoshida, 2004). In the last decade, a number of older people have been found dead alone in their own homes (Sasaki et al., 2007). The reasons for *kodokusi* are not as a result of committing suicide, but from social isolation, poor health and economic situation (Sasaki et al., 2007). Japanese older people often express “I want to avoid especially *kodokusi*, when I am dying.” Fear of death leads to a negative reflection of life, is seen as a burden to the family, and reflects the meaninglessness and loneliness of their lives (Asami, 2006). In a collective society such as Japan, the loss of role within their family and in society at large underscores a strong sense of feeling a burden to others in life. In addition, such older people hold regrets or express unfinished business in their lives (Ushida et al., 2007).
1-2.3 Concept of a good death among older people

To summarize, the literature highlights that Japanese older people’s ideal of death is a natural one, peacefully surrounded by loved ones and not alone, without physical and psychological pain and suffering, and not burdensome to the family. Furthermore, a belief and expectation to move into the next life to join their ancestors underlay their positive attitudes towards death. In addition, the process of acceptance of death (omukae wo matu) means that they prepare for death through a reconsideration of the meaning of their life at the end of the life-course.

Discourses in the sociology, anthropology, and nursing literature focus on arguments regarding the meaning of a good or bad death (Hattori et al., 2006). These arguments lead me to further question what a ‘good death’ actually means. In this literature there is so far no clear consensus on the definition of a good death. Pool (2004, p. 960) has argued that a ‘good death’ involves overlapping characteristics which fall into three main categories, namely:

1) related to the patient’s experience of dying (mild, painless, peaceful, dignified, brief); 2) refers to the social context (family involvement, good relationships, communication, conflicts resolved); and 3) relates to the patient’s autonomy and control over the dying process.

Long (2004, p.918) suggests that the Japanese notion of good death is similar to the American view of death and summarizes Japanese notions of a good death as:

(1) a dying that is peaceful; (2) the basis of such a peaceful death is that the last stage of life is pain free; (3) that a good death is one in which the dying person is surrounded by a caring family; (4) a recognition of a continuity from living through dying; (5) a belief that death was, or should be, a personalized experience appropriate to that person’s values and life conditions; and (6) a strong concern that one does not become a burden on family, reflecting and creating an ambivalence about the social nature of dying.
In the nursing literature, Hattori et al. (2006) assert that a good death leads to family satisfaction, a positive bereavement process for the family and healthcare professionals, as well as work satisfaction for healthcare professionals. However, Pool (2004, p. 961) argues for institutional control is part of the in the notion of a good death:

Hart, Sainsbury, and Short (1998) speak of an ideology of a good death that “legitimizes a new form of social control within which socially approved dying and death are characterized by proscribed and normalized behaviours and choices.” This form of institutional control obviously impedes the patient control…

Perceptions of a good death are constructed under social circumstances. The question is raised whose perception of a good death is it: dying older people or others? Long (2004) argues that individuals differentially draw upon scripts for a good death, and multiple scripts serve as alternative models for how to die ‘well.’ I shall return to this question in chapter six.

### 1-3 The importance of end-of-life care in the Japanese nursing home

Although several studies have investigated Japanese older people’s attitudes towards death, little attention has been given to what is appropriate care of older people at the end of their lives. As mentioned previously, due to the difficulties surrounding dying at home or in hospitals in Japan, nursing homes in particular are becoming a common setting for end-of-life care for older people.

In order to provide end-of-life care to older people, nursing homes are confronted with a number of obstacles (IHEP\(^3\), 2002; Hirakawa et al., 2007; Hoshishiba, 2009). According to the IHEP survey (2002), 64% of older nursing home residents were transferred to a hospital when their health deteriorated and where they subsequently died. Furthermore,

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\(^3\) IHEP: Institute of Health, Economic and Policy
only 19.4% of all nursing homes provide end-of-life care, and the majority (79.8%) of these have no guidelines and policies in place for end-of-life care (IHEP, 2002).

The literature points to two possible obstacles and one major challenge in providing end-of-life care in nursing homes. The first obstacle points to the lack of human resources is a barrier to the adequate provision of end-of-life care for older people (Hirakawa et al., 2009). Nursing home care is heavily reliant on nursing assistants. Due to heavy burden on nursing assistants to provide care in nursing homes in Japan, the rate of the staff turnover is very high. Most qualified nursing assistants in nursing homes report ‘burn out,’ both mentally and physically, within three years (CWSCF\textsuperscript{4}, 2008). Moreover, physicians or nurses are not available 24 hours. Physicians work to a contract in nursing homes and visit to examine older residents only on a once weekly basis. At night, 54% of nursing homes employ nurses on the ‘on-call’ system (IHEP, 2002). Hirakawa et al. (2007) report that nurses feel they lack sufficient time to care for older people, and end-of-life care provision may impose a great burden on nursing staff. According to the 2002 IHEP survey, most nursing assistants and nurses report poor confidence in providing end-of-life care, which stems from a lack of knowledge and skills around end-of-life care. However, nursing assistants and nurses are also eager to be educated on end-of-life issues, such as pain and symptom control, physical, as well as spiritual care (Hirakawa et al., 2009).

The second obstacle points to the difficulties in making decisions on medical treatment in relation to end-of-life care among older residents, families, health professionals and organizations. According to a report from the United States, advanced directives is one of the most significant factors related to nursing home deaths among older people (Carlson, 2007). In Japan, however, neither advanced directives, which includes a living will, nor the

\textsuperscript{4} CWSCF: Care Work Support Centre Foundation
attorney system for medical decisions are legally binding (Takezako et al., 2007). Unlike in Western countries, there are no guidelines in place for systemic advanced directives in relation to end-of-life care within Japanese nursing homes. Furthermore, Kwak and Halley (2005) assert that Japanese physicians are more likely to support aggressive life support treatment measures for patients who are not informed of the diagnosis, as the highest priority in the past few decades has been towards medical advancements and the goal of saving lives. Long (2004) claims that decision-making is paternalistic among professional health care experts in Japan. In addition, the Japanese prefer group surrogate decision making regarding end-of-life treatments in the event that they can not make decisions for themselves, over choosing a single individual to make the decision on their behalf (Kwak and Halley, 2005).

Family facilitated decision making underpins collectivism in Japanese society. Whereas independence and autonomy is valued in Western cultures, interdependence is particularly valued in Japanese cultures. The anatomy of dependence by Doi (1971) is noteworthy for its application of the concept of *amae* (mutual dependence) to the character of Japanese society. Doi describes a uniquely Japanese cultural value is the need to be in good favour with others and to be able to depend them in times of need. He also explains *amae* means to depend and rely upon another person’s benevolence. The notion of mutual dependence shapes non-disclosure or partial disclosure of a medical diagnosis to the dying person’s family member, and is considered to be a way of protecting loved ones from potential harm, as well as maintaining an atmosphere of calm and an attitude of hope (Hattori et al., 2006). Telling the truth is considered cruel (Long, 2004). This is a key problem in respecting older people’s autonomy under circumstances of mutual dependence. However, Hattori et al. (2006, p.167) point out that “four factors have been shown to contribute to patients’ autonomy and to control over the dying process: a natural way of dying, physical and
mental comfort, clear decision-making, and advanced care planning.” The importance of respecting older people’s autonomy as part of end-of-life care cannot be overemphasized in contemporary Japan.

Arguably the major challenge to improving the quality of end-of-life care among older people is to what extent can nursing homes come close to creating an atmosphere of living at home. Sakurai et al. (2009) assert that end-of-life care is an extension of the care of daily activities; and it is essential to support older people living in nursing home settings in ways they themselves might chose. The importance of end-of-life care reflects the quality and dignity in which older people want to live, while waiting for ‘welcoming death.’

1-4 The research questions

Although nursing homes are afforded a growing responsibility to care for dying older people, only a few qualitative studies have explored end-of-life care in such a setting in Japan. Taking an ethnographic approach to investigate end-of-life care in a nursing home provides an important contextualization of the psychosocial, cultural, spiritual, and organizational factors shaping end-of-life care for older people in Japan. Thus, the main aim of this thesis explores how Japanese older people living in a particular nursing home in Japan experience end-of-life care, and seeks to address the following four research questions:

- What are the psychosocial, cultural, spiritual, and organizational circumstances affecting end-of-life care among older people in a nursing home setting?
- How do older people, their families and health care providers perceive end-of-life care?
- What does decision making about care between older people, their families and health care providers affect their end-of-life care?
- How does relationship between health care providers, older people and their families influence the experience and quality of care of older people who are dying?

1-5 Conclusion

In this first chapter, drawing on the literature, I have introduced the problems regarding end-of-life care in Japan. In such a culture, Japanese older people’s ideal is to die naturally and peacefully surrounded by loved ones and not alone, without physical and psychological pain and suffering, and not to become a burden to family. Due to the difficulties of dying at home and in hospital in Japan, nursing homes in particular are becoming a common setting for end-of-life care among older people. In order to provide adequate end-of-life care to older people, nursing homes are confronted with a number of obstacles, such as the lack of human resources, knowledge and skills related to end-of-life care among staff, and difficulties surrounding decision making at the end of life. The need to respect older people’s autonomy in a collective society such as Japan is paramount. In this thesis I will focus on the meanings of end-of-life care among older people living in a nursing home setting, centred on four main themes emerging from ethnographic data. These are, namely: the meaning of life and death, dignity, spirituality, and quality end-of-life care. Before considering such themes, the next chapter considers the methods used in this study and my reflections from this research.
Chapter 2
Methods

This study is a qualitative institutional ethnography by a researcher as ‘an insider’-a nurse working in a private nursing home in Tokyo, Japan. Institutional ethnography examines how everyday scenes in life are shaped by forms of social organization which cannot be fully understood from within those scenes (Smith, 2006). Institutional ethnography takes associated work processes as a point of entry (Campbell, 1998). There has been a lack of institutional ethnographies in health care facilities, such as hospitals and nursing homes. Arguably, this is related to a defensive attitude among authorities of health care facilities towards institutional ethnographic studies (Van der Geest and Finkler, 2004; Campbell, 1998). A major difficulty and ethical dilemma in institutional ethnographic approaches in care homes, is the extent to which the researcher remains an anonymous figure to all (i.e. the residents, their families and staff members), in order to maintain an individual’s privacy and autonomy (Brady, 2002). In this research study, pseudonyms are used to protect the identity of individuals, as well as the name of the particular nursing home. Brady (2002) points out that researchers as insiders are confronted with the dilemma of maintaining a balance between subjectivity and objectivity. In this second chapter, I will describe how I carried out the research as ‘an insider’ within this exploratory ethnographic study.

2-1 The research setting

The research took place in two private nursing homes and one day care centre for older people in Tokyo, Japan. I worked predominantly in one private nursing home. In my attempts to strike a balance between ‘an insider’ and ‘an outsider’ perspective, I conducted in-depth interviews in the second nursing home and day care centre.
To begin with, I asked a nursing agency to find a suitable nursing home to carry out the research whilst working as a nurse. The Noboru nursing home was chosen and here I conducted the research working as a nurse for six months. The Noboru nursing home is owned by the same company which also runs a school of nursing assistants, and has been in operation since 2006. It is located in a suburban region of Tokyo and houses 57 residents (14 men and 43 women). The residents live in a western style private room (23 m²) with their own toilet. The building has five floors and there is a dining room, bathroom, and living room—all with tatami mat (traditional Japanese flooring)—on each floor. The age distribution of the residents is between 74 and 99 years. Specifically, nine (16%) residents are in their 70s, 27 (47%) in their 80s, and 21 (37%) in their 90s (see Table 1). Furthermore, eight (14%) residents are independent, 34 (60%) need some care, and 15 (26%) need full assistance in personal and daily activities. In addition, fifteen (26%) residents suffer from dementia.

The working staff composition consist of seven nurses; four full time—including the researcher of this study—and three part time/only night shift nurses; 25 nursing assistants (20 full time: 5 part time); one care manager, one administrator, and one director. The Noboru nursing home has contracts with a local clinic. One doctor (a geriatrician) has sole responsibility of examining residents once a week. Any changes in their condition are reported. This doctor is also on-call 24 hours for emergencies.

Table 1: Age distribution in the Noboru nursing home

<table>
<thead>
<tr>
<th>Sex</th>
<th>Age</th>
<th>70s</th>
<th>80s</th>
<th>90s</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>70s</td>
<td>2(4%)</td>
<td>8(14%)</td>
<td>4(7%)</td>
<td>14(25%)</td>
</tr>
<tr>
<td>Female</td>
<td>70s</td>
<td>7(12%)</td>
<td>19(33%)</td>
<td>17(30%)</td>
<td>43(75%)</td>
</tr>
<tr>
<td>Total</td>
<td>70s</td>
<td>9(16%)</td>
<td>27(47%)</td>
<td>21(37%)</td>
<td>57(100%)</td>
</tr>
</tbody>
</table>
The second nursing home is known as the Haruka nursing home which is also situated in suburban Tokyo, and I asked a nurse working in this nursing home if I could also conduct research there. At the Haruka nursing home there are 48 residents (seven men and 41 women). The average age of the residents is 85 years, ranging between 72 to 100 years. Here, I visited the nursing home in total four times and conducted in-depth interviews with the residents. Furthermore, I also conducted in-depth interviews at a day centre for older people, which is located in Saitama prefecture near to Tokyo. I used to work part-time at this day centre as a nurse, so I asked the director there for permission to conduct my research. The purpose of the interviews was to explore the meaning of life and death among older people who used the day centre, but still lived at home and mostly needed some care and support from family and home care services due to physical and cognitive impairments. Approximately 15 older adults used this day centre every day (total capacity = 78 older adults).

2-2 Data collection
Data was collected over a six- month period between December 2008 and May 2009. Overall, this consisted of four phases of data collection.

2-2.1 Phase one: Building a relationship and understanding the socio-demographic background of older residents
In the beginning, in order to work as a nurse managing the everyday care of residents in the Noboru nursing home, I needed to understand and get to know the residents by face and name, which rooms they lived in and what their living space was like, their medical history, current health status, medication, and treatments. I also needed to assess their level of
independence in functional Activities of Daily Living (ADL)\(^5\). In the first two months, I also spent a time to getting to know the social background of the residents, their family, the reasons why they had entered the nursing home, their hobbies, personality and characteristics, habits, and their likes and dislikes through talking with different residents and colleagues (e.g. the care manager, nursing assistants, and nurses). I developed a database or a nursing care summary from the data I collected and each staff member could access and update this database. This initial period of data collection was important for building up a relationship with the residents and other work colleagues.

2-2.2 Phase two: Participant observation: Insider accounts

Although participant observation in the Noboru nursing home had already started from the point when I began to work as a nurse, I experienced an initial phase or transitional period when I changed from an outsider to an insider among residents and colleagues. After two months, I had more time to observe while participating in daily activities, events, a doctor’s visit to examine residents, and various meetings to discuss care plans with families. Simultaneously, I also witnessed a sudden worsening of health among several residents for example, those suffering from condition such as miss-swallowing, falls resulting in fractured limbs, myocardial infarction, cerebral infarction and pneumonia. Available medical treatments were limited in the nursing home, geared towards particular health problems, and some residents needed to be transferred to the hospital. The decision making process for transferring residents to hospital in emergency cases involved the family, doctor, care manager, as well as the director. It largely excluded the older residents who were in a severe health condition. These emergency cases allowed me to consider different aspects or problems regarding the end-of-life care in the nursing home.

\(^5\) Activities of Daily Living (ADL): the basic ADL consists of these self-care tasks; bathing, dressing and undressing, eating, transferring from bed to chair, and back, voluntary control urinary and faecal discharge, using the toilet, walking
2-2.3 Phase three: Case studies: caring dying older residents

I witnessed a few residents who gradually deteriorated in their condition before their death. In this section, I will introduce three cases, and later on I will describe their end-of-life care. Mr Endo was a 76-year-old man suffering from oesophageal cancer. One year ago he started to have difficulties eating. The doctors found the oesophageal cancer, and he underwent an operation to insert an oesophageal stent to help him to eat. He was not informed of the diagnosis due his family wishes. When I met him for the first time, he could eat a pasted meal, talk, and sometimes walk to the local café. However, he has gradually found it increasingly more difficult to eat and suffers from pain.

Second case was Mr Kawata, who was an 83-year-old man, living with advanced Alzheimer’s disease. Before I met Mr Kawata, he was agitated and aggressive. Then he started to use Aricept and several kinds of tranquilizers. My first impression of him was of a quiet and a bloodless man. Over time, he has become incontinent and refuses to eat or get dressed.

The third and final case was Ms Sato, a 74-year-old woman diagnosed with Chronic Obstructive Pulmonary Disease (COPD), who received oxygen therapy for her condition, allowing her to continue to be independent with activities of daily living (ADLs). Her condition was worsened last January when she was admitted to hospital with pneumonia. This resulted in deterioration of her respiratory function and independence in ADLs. Although the doctor in charge did not give permission to discharge her from hospital, this happened because she and her family expressed a strong desire to return the nursing home.

I recorded several conversations with the above three older residents and their families,  

6 Aricept: Its main therapeutic use is in the treatment of Alzheimer’s disease where it is used to increase cortical acetylcholine in the brain.
observed the care and reviewed the written nursing records of colleagues. Whilst I was caring for these residents and during conversations with their families, this gave me an opportunity to start to reflect upon what a ‘good death’ in old age meant to them.

2-2.4 Phase four In-depth interviews: the meanings of life and death

In the final phase of data collection, I conducted informal and in-depth interviews with a number of people on the meanings of end-of-life care in the nursing home. I had several informal discussions with the visiting doctor when he came to examine the above three residents and others in the nursing home. I also had daily informal discussions and in-depth interviews with two nurses and eight nursing assistants who worked in the Noboru nursing home regarding their perceptions towards end-of-life care in the nursing home setting. In addition, I conducted informal and in-depth interviews with three residents who were physically and cognitively independent, together with their families who often visited them, regarding their perceptions of end-of-life care in the Noboru nursing home.

Furthermore, as a researcher (or outsider), I undertook in-depth interviews with three female residents (aged 78, 82, and 86 years) who lived in the Haruka nursing home. Here, the semi-structured questionnaire included topics on: 1) their preferred way of dying (i.e. place, environment, and circumstances); 2) their preferred lifestyle prior to death; 3) what constitutes the beginning of end of life; 4) what is essential care at the end of life; 5) what are unnecessary medical treatments at the end of life; and 6) their views on life-after-death. In addition, I conducted narrative life-histories with three older people (i.e. one male and two females; aged between 82 and 91 years of age) who attended the older people’s day care centre. Such participants were independent and lived alone in their own homes. During these interviews, they were asked to tell their life stories and to discuss the meaning of life in old age. As I knew the three older people well prior to the interviews, I was able
to build up a good rapport with them and to talk openly with them about their lives. All interviews were tape-recorded. Moreover, the reason why I conducted interviews in different geographical places was in order to gain experience as ‘an outsider’ researcher and to gain analytical distance from my collected data in the Noboru nursing home.

2-3 Ethical considerations

Talking about someone’s approaching death in public is a taboo subject in Japan. My research topic was a very sensitive issue for residents and families in the nursing home. Before I worked at the Noboru nursing home, I explained the purpose of research and methods to the director of the nursing home and the nursing care manager working at the headquarters of the company. Both gave me their permission to undertake the research, on the conditional provision that I did not inform the residents and families about my research. Thus, I could not obtain informed consent of residents and families for the interviews, however, I did get informed consent from the nurses and nursing assistants in the Noboru nursing home.

As ‘an insider’ researcher, I experienced ethical dilemmas due to the sensitive nature of issues related to death and dying in old age. Green and Thorogood (2004, p.66) assert that

Covert methods, in which the researcher does not disclose their role to those in the field, clearly raises a number of particular ethical dilemmas. Not only is the autonomy of the participants not respected, but informed consent is impossible to secure at least before the fieldwork.

As previously discussed, in order to protect the privacy of older residents and their families, in this thesis I used pseudonyms and not real names of participants and the nursing homes in which they lived. Campbell (1998) highlights the importance of securely storing experiential data such as minutes from meetings and nursing care staff records. As ‘an
insider’ researcher, I had open access to such data, however, I made sure (through the use of pseudonyms) that identification of specific persons and places from this data could not be made. On completion of the study, I disclosed to residents and some families that I was a researcher. At this point, one of residents positively commented that it had been good to talk to me so openly about the meaning of end of life. Throughout, I felt that it was not possible to conduct the research without the mutual cooperation of residents and their families. On reflection, ethically, building up a good relationship under a covert position with those taking part in the study was an essential part of respecting the autonomy of individuals involved in the research process.

2-4 Personal reflections

2-4.1 Position

My position as a researcher represented ‘an insider status’ within the Japanese nursing home. Personally, I often struggled to strike a balance between aligning myself as either an ‘insider’ or ‘outsider’ throughout the research. Green and Thorogood (2004, p.137) echo the difficulties of conducting ethnographic studies with one’s own professional group in nursing:

Nurses, for instance, have carried out many studies of nursing care based on ethnographic methods for data collection. This poses particular methodological problems for maintaining a productive balance between outsider and insider perspectives and making the familiar ‘strange’. The advantages are clearly that access is much easier, and the researcher is already familiar with the emic perspective.

Brady (2002), however, argues that balancing the distance between subjectivity and objectivity in analyzing the collected data is difficult as ‘an insider’ researcher. I had worked as a nurse in a Japanese nursing home more than ten years ago. On my return I
experienced a strange feeling resembling a ‘reversed’ culture shock. In the first two months of my return to Japan, I made an effort to adapt again to the ‘new’ culture by understanding the cultural context of the Japanese nursing home. During this period, I maintained a balance between the ‘emic’ and ‘etic’ perspectives. Adopting an ‘emic’ perspective as a nurse, meant that I communicated with residents as much as possible. Adopting an ‘etic’ perspective as a researcher, meant that I could spend more time observing the nature of the interactions between residents and staff and the structure of the organization. After two months of involvement in the study, I felt that I could not keep a balance between ‘participation’ and ‘observation.’ It was difficult to keep an analytical distance, and sometimes I could not ‘see’ objectively. It was noteworthy, however, that I had opportunities to maintain more of an outsider position when carrying out research in the second nursing home and in the day centre for older people. I could re-examine my observation in the Noboru nursing home through carrying out interviews in there.

Green and Thorogood (2004) suggest that insider researchers may have to work much harder to treat the data theoretically and to achieve analytical distance from collected data. As a result, my position as an insider researcher was informed by the theory of ‘relative subjectivity’ posited by Slingsby (2004, p.342): this theory leads me to maintain balance of seeing objectively and subjectively.

... ‘relative subjectivity’ is interdependent on one’s ability to contextually understand. Individuals who are relatively subjective take into account, either unconsciously or consciously, the tides of each situation and the nuances of another’s speech. Relative subjectivity maintains our understanding of another’s behaviour rest on the very act of interpretation, and that this interpretation is not only relative to our own subjectivity but also to our relationship with the other.

Slingsby (2004) thus suggests that important human senses related to ‘relative subjectivity’ are intuition, interpretation, introspection and responsiveness to others, and this theory
facilitated my attempts to maintain a balance between the role of researcher and the role of nurse by acting interpretation of my observation.

2-4.2 Introspection

As Japanese citizen, a nurse, a researcher, and a daughter with older parents, this ethnographic study meant that I had to reflect on my own inner values related to life and death, caring for parents, and Japanese spirituality. Ultimately it provided me with an opportunity to exploring my inner values. When listening to older people’s own life stories, I felt that I was accompanying them on their life journeys. They had own dramas in their life and they expressed life experiences which were fruitful, but also involved suffering. I was deeply touched by their immense inner strength and I wondered how they could continue to hold such inner strength to overcome adversities in their lives. They often expressed watashi no yoridokoro: (my spiritual resources supports me when suffering). Individual spiritual resources varied shaped, for example, by the death of their partner, religious beliefs, ancestor worship and other family and friend relationships. Their life stories seemed to provide me with a mirror to reflect on the meaning of my own life and future destiny. Moreover, their behaviour and sense of values reminded me of certain lost Japanese cultural value, for instance in relation to the importance of the harmony of nature.

Involved in the process of decision making for medical treatments at the end of life, forced me to consider the question “what I could do, if I were this resident or relative of this resident in this situation?” Sometimes, I was struggled to understand the different decision making processes and wishes of residents, family members, doctor and director of the nursing home. I could see and feel the contradictions and differences in the meaning of suffering. I also had ambivalent feelings towards balancing the prolongation of life or respecting the autonomy of individuals. Overall, I felt that I had to respect the older
residents’ decisions around end-of-life care.

Furthermore, when I returned to the nursing profession in Japan, I experienced a changing nursing culture. Nursing records were computerized and the necessary documents had increased under the long-term care insurance system. Nurses and nursing assistants need to record the time they spent documenting care records in front of the computer. Ironically, advanced technology and a more complicated social welfare system also caused more stress and burden to staff members.

2-4.3 Limitations of the study
Clearly, this study involved a very small group of people and was exploratory in character. I intended to conduct interviews with more residents; however this was limited by the time and scope of the study. Although there are different types of long term care facilities in Japan, this study only focused on private nursing homes and most of the residents were of an upper middle class background. It excluded older people faced with economic difficulties who were eligible to enter government-funded nursing homes. Thus, the impact of economic factors affecting the meaning of end-of-life care in this study could not be examined.

2-5 Conclusion
In this second chapter, I have described the methodological aspects of the study, which was conducted in two private nursing homes and in one day care centre for older people. I conducted an ‘institutional ethnography’ working as a nurse in one nursing home in Tokyo. This approach was conducted as an insider-researcher position; and there were positive and negative aspects to this. The positive aspects were arguably related to the possibility of collecting valuable experiential data by becoming embedded in the culture of nursing home
and the benefit of having an insider's perception of reality in describing situations and behaviours. On the other hand, negative aspects reflected the difficulties in balancing analytical distance between an insider perspective and that of a researcher and the ethical considerations of adopting a covert position to the research. As an insider researcher, this position allowed a greater level of introspection of my own values in relation to the meaning of end-of-life issues and questions around life and death. In the next chapter, I will describe older people’s meanings of life and death as reflected through their own inner life journeys.
Chapter 3
Meaning in life and death: An inner journey

Life is like a long journey of searching for our worth of existence. Older people are nearing the end of a long journey. They often experience losses, such as the death of a spouse or peers, the loss of social roles, physical or cognitive health limitations and independence (Dwyer et al., 2008). One question which comes to my mind is how do older people justify their existence at the end of their life. Kotre (1975, p.433) describes the existence of a human being in a poem:

We need a rope to hold onto,
extending deep into the past,
reaching far into the future,
We cannot afford to be static,
but we do need a place to stand.

Observing the almost universal need for human beings to find meaning and purpose in life, Kotre (1984) explores the issues of generativity, a term originally coined by Erik Erikson (1950). Erikson (1950, p.267) defined generativity as “the concern in establishing and guiding the next generation,” whereas Kotre (1984, p.7) subsequently defined it as “a concept that invites us to see the entire range of ways human beings leave their stamp on the future.” Kotre (1984, p.12) describes four types of generativity; biological, parental, technical and cultural:

1) Biological generativity is begetting, bearing, and nursing offspring; 2) Parental is nurturing and disciplining offspring, initiating them into a family’s traditions; 3) Technical is teaching skills-the “body” of a culture-to successors, implicitly passing on the symbol system in which the skills are embedded; 4) Cultural is creating, renovating, and conserving a symbol system-the “mind” of a culture-explicitly passing it on to successors.
Saunders and Kastenbaum (1997) state that the inner journey is a way for individuals to seek meaning in life and death and provides hope. In relation to those that are dying, such individuals might turn towards their own inner values in search of existential meaning in their lives. This leads me to the question: *How do older people search their inner journey at the end of life?* In this chapter, I describe the meanings older people attribute to their past and present, and their views of death, through their own narratives, as reflected in informal conversations, in-depth interviews, and observations.

### 3-1 The meaning of the past

In Erikson’s (1950) life stage psychosocial model of human development, he describes the final stage of development in old age is depicted by reaching a sense of ‘integrity versus despair.’ Takenaka (2000) explains that ‘integrity’ is when the older individual seeks value in his or her accomplishments and previous contribution in their life, develop a detached concern for the whole of life, and accept death as the completion of life. On the other hand, those that experience ‘despair’ focus on their perceived failures in life, fear death and struggle to find a purpose to their lives. In this sense they may wonder *“was the journey worth it?”*

#### 3-1.1 Accomplishments

When older people started to talk about their accomplishments in their life, I could see in their face a sense of liveliness. Ms Nakata was 93 years old and suffered from dementia. She had delusions that someone wanted to steal her possessions. She had previously worked as a midwife and had even managed a private birth centre in her 70s. When she began claiming that someone had been stealing her stuff she became agitated. When I asked her how she found her job as a midwife, suddenly her face changed to become more
gentle and serene as she started to tell the story why she had become a midwife:

I went to the school of midwives. It was rare that women had their own job but I wanted to get a qualification to survive after the Second World War was over. I worked harder and harder. I assisted delivery and held many babies. Was I great?

She repeated this story many times, and she asked me the same question at the end of our conversation: “Was I great?” I answered that I respected her as a forerunner of working women, to which she smiled with great satisfaction. She was proud of her work and she wanted to confirm that her work as a midwife brought her great worth in her life and to her very existence by asking “Was I great?” Kotre (1984, p. 13) describes such skills as a form of technical generativity:

Skills are not transmitted in isolation. They bring in their wake systems offering initiates something more than a sense of competence: a map of existence, a view of a place to settle on that map.

Ms Yamada was an 86 years old woman who currently had no living family of her own. Her husband had died in the Second World War. Prior to entering the nursing home, she had managed a boarding house near to the University. She was very proud of her boarders, who were university students who had subsequently become successful in their working lives:

I was happy to take care of boarders. Today’s children have changed a lot, but my boarders were sincere and diligent. That’s why they could get good jobs and were doing to well. They often visited my house, even after they graduated from the university. I felt like they were my children.

One of her boarders became her guardian and his family often visited and took care of her. Although she had no children of her own, in taking care of her boarders she found her sense of human worth.
Mr Suzuki was 84 years old and used to work at an electric appliance company until the age of 60. After retirement, he started to trace his ancestors and travelled many places in search of his roots. When he was 81 years of age, he suffered a stroke and paralysis down the left side of body. He entered the nursing home after he had been discharged from the hospital. Despite his paralysis he continued he started to write about his ancestral roots using his typewriter. When I visited his room in the nursing home, he was always facing his typewriter. I asked him “Do you need break?” Laughing, he retorted, “you know I have a limited time, don’t you?” and further commented:

I spent a time searching for my ancestors since 20 years ago. I enjoyed travelling around Japan. I wanted to compose a book posthumously of my work in my life, but I had stroke. Fortunately, I could still use my right hand, so I started to write slowly at first. I hope to publish a private book this year.

His daughter said to me that she was worried he was depressed after his stroke, but he managed to recall what he wanted to do by himself. She proudly described her father in the following way:

He worked hard until his retirement. I rarely met and talked to him at home. He was livelier after he was retired. He looks to finding out *ikigai*-reasons for living by starting to search his ancestors. It is interesting for me as well, because I can begin to know my ancestors too.

She supports the idea that her father will publish his book. Mr Suzuki had found out *ikigai*-his reasons for living by overcoming his stroke. The Japanese often express *ikigai* or their reasons for living. There is no direct English word, but *ikigai* is that intangible quality that makes life seem worth living. *Ikigai* is nothing in particular: it can relate to a job, a loved one, a past time, or anything else. Mr Suzuki wanted to leave his stamp on life by publishing a book of his ancestors, representing generativity and a sense continuity for the future generation.
3-1.2 Loss

The generation over the age of 70 devoted their work to the growth of the economy after the Second World War. They worked to achieve a wealthy life for their children in their personal life, which stemmed from their experience of poverty during the Second World War. When older people lost children or broke relationships with them, they might have questioned: “What is the meaning of my past efforts to achieve a wealthy life for my children?”

Ms Kanda was 82 years old and was very talkative and cheerful with the other older people at the day care centre. She lived alone and her daughter lived near her apartment. She suffered from chronic heart failure and her independence with ADLs was deteriorating. She had a home care worker to help with cleaning and shopping three times a week. The relationship with her daughter was difficult. The care manager informed her daughter that “Ms Kanda would find it difficult to manage living by herself. Someone is needed to support her especially during the night.” However, her daughter refused to provide such support to her mother. Currently she was on the waiting list for another nursing home. She told me:

My daughter was a very good girl when she was a child. I was a working mother because my husband’s salary was low. I did not spend much time with my daughter but I provided her with most of what she wanted. I know why she does not want to live with me. I would be a burden for her now as she is also working mother with two children. I took care of my grandchildren and I supported her for she could work when I was healthy. Maybe my role of mother was over. I enjoyed coming here (the older people’s day care centre). My heart is rusty and would stop soon. I don’t know whether my welcoming death will come (omukae ga kuru) at home or in the nursing home. I prefer to depart from this life when I get up and my heart stops suddenly at home.
She regretted the relationship with her daughter. I felt that she needed a reward from her daughter at the end of her life because of what she had done in her life for her. Her daughter told the care manager why she could not care for her mother:

My mother is very strict in what she wants to do. I cannot handle to care for her. I know she supported me a lot, but now I do not have time to spend with her.

The different cases of adult children-parent conflicts, like that of Ms Kanda, stemmed from their unfinished business, which is hard to understand from as an outsider. Ms Kanda had a deep sense of loss of meaning in her life in old age.

3-2 Meaning of the present

According to a study by Dwyer and colleagues (2008) among older residents of two nursing homes in Sweden, the meaning of their daily life was shaped by having a sense of physical and cognitive capabilities, feeling needed and having a sense of belongingness. They also asserted that enabling older people to tell their life stories and experiences helped to bring vitality and meaning back into their everyday life. As described earlier, the older residents in this study discovered their human worth through their past experiences, making life in the nursing home worth living. Moving into a new environment—the nursing home—the next question I shall consider is how older residents discovered and created sense of meaning in light of their present situation.

3-2.1 Independence versus dependence

The residents who were independent who had moved into the nursing home had ambivalent feelings about themselves, such as “Am I an independent or dependent person?” This was the case especially for women who were homemakers as they no longer needed to cook, wash clothes and clean up their rooms in the nursing home. Ms Seya, who
was 83 years of age, had previously lived alone. She had managed daily life despite mild cerebral vascular disease. Her children, however, worried about her living alone, which resulted in her entering the nursing home. In a way she had accepted the nursing home environment, because it provided security for her:

When I came here at the first I was happy to be free from housework. Meals were provided and my room was cleaned up every day. But now I am getting tired of doing nothing. When I lived alone I needed to go shopping to buy daily foods and groceries, and I chatted with my friends at the shop. Of course I enjoy talking with other residents and younger staff who look like my grandchildren in here. But I feel something is missing.

She lost her role of homemaker when entering the nursing home since one year ago. Currently she expressed a deep sense of emptiness. Moving to a different environment in old age, some residents tried to find something which validated their existence and human worth in the new environment. Ms Seya started a tea ceremony in the living room (a Japanese traditional tatami room). Some also taught other residents special skills such as Japanese calligraphy and flower arranging. Overall, the meaning of older people’s daily lives in the nursing home was closely related to their earlier lives. This was expressed as a desire to still feel needed, having a sense of belonging and having communication and relationships with others.

Residents who had previously managed to live independent lives and then had become dependent on others, struggled to find a positive sense of identity. Franklin et al., (2006) describe the dignity of identity is hindered if there is an unrecognizable body, or through frailty or dependency. Ms Ono was an 88 year old previously independent woman who had fractured her pubic bone after a fall when visiting her daughter’s house. Currently she had to stay on bed rest with a corset and needed full assistance in using the toilet:
I feel bad. I thought I should not go to my daughter’s house. I cannot go to the toilet and cannot move by myself. I have to stay in bed all day. It is painful when I move and I’ve never experienced such a pain. My body looks like it is not mine! Oh, what a shame… The doctor said it will take three months to cure and I worry whether I can walk again or not.

She voiced that she had lost her physical freedom in her daily life and was irritated and felt anxious about her current physical health problems, feeling estranged from her body. The nurses and nursing assistants often visited her in her room and talked to with her. At night she would press the assistant button every half an hour requesting to be moved or complaining about pain for two weeks. Following this period her pain decreased.

I am sorry that I call many times in the night. I did not like to ask for help but I get scared in the darkness of the night. I feel pain, I’m sleepless and feel hopeless. So I cannot stay alone so I press the button for help. I am relieved when the staff come and say to me “Are you alright?” This touches me. I feel I am not alone, and someone watches me in the darkness. Now my pain has decreased I feel I can get out from the darkness. I have only one further wish; I want to go to the toilet by myself as much as possible.

She felt embarrassed about her behaviour at night in the last two weeks. Eriksson and Andershed (2008) write that people’s experiences of being dependent may bring about feelings of guilt and shame if control of bodily functions fails. Being care-dependent involves a radical change in people’s life and affects the relationship both with oneself and with others. Ms Ono was struggling with being care-dependent, but she also made a constant effort to adjust to her new situation, helped by the support she received from others. Eriksson and Andershed (2008) point out that control over when care is provided and the type of care which that is provided are key to positive wellbeing.
3-2.2 Loneliness

Loneliness may be experienced by everyone at some point in their lives and, as such, is a temporary state that dissipates when a person’s circumstances change (Victor et al., 2002). When the older residents started to live in the new environment of the nursing home, some were able to easily adjust and make friends. However, others found it more difficult to make new relationships and were isolated. Hicks (2000) reports that factors which increase levels of loneliness among older residents in a nursing home include a lack of intimate relationships and increased dependency. Mr Hara was 93 years old and independent, but had difficulty with his hearing. As a result, his vehicle of communication was writing. He was a pharmacist and had a very high level of intelligence. When I met him for the first time, he was sitting all alone in the dining room. I asked the staff why he was sitting alone and the staff explained that he did not like sitting with other residents and said that they teased him because he could not hear. Since then he had become physically isolated from the other residents. Sometimes we talked about medical issues which he really enjoyed. He took care of plants in the garden everyday. However, I never observed him talking with other residents, only with the staff. I asked him “Are you comfortable to stay in here?” to which he replied:

I have been here for two years. I had a slight stroke in the last year. I have been scared to go out since then. I used to have more freedom than now. At the time I felt that three women teased me and were saying things about me. I could not hear what they said and they were laughing. They are rude. I don’t believe them. They are old enough to understand morals aren’t they? I am 93 years old and I don’t care for them. I am comfortable to take care of the plants. The plants are honest and calm. I am going back to the nature soon so I am omukae wo matsu-waiting a welcoming death. I am asking the plants ‘When are you inviting me?’
I asked the staff again what had happened between Mr Hara and the three women. I told them that Mr Hara was misunderstood that these women had teased him. The staff explained they had not teased him or laughed at him, but they could not clear up the misunderstanding with him. He stayed in his own world and the other residents expressed that he seemed lonely. Victor et al. (2002) highlight that loneliness is a subjective feeling and the amount loneliness can only be described by the individual who is experiencing it. In discovering his role and pleasure in taking care of the plants in the nursing home, this seemed to afford a sense of protection against his sadness and isolation in his daily life. When taking care of his plants, his face seemed peaceful rather than sad, expressing *omukae wo matsu*-waiting for a welcoming death. Kamiya (1966) describes that Japanese older people who are aware of *ikigai*-reasons for living find useful roles to play in life.

3-3 The meaning in death

When I talked with the older people about their life stories, they often expressed openness about dying. In the narratives of the older people I spoke to, they searched for the meaning in their life, which also extended to the meaning of death through a process of reviewing their life. While I interviewed them about their life, they expressed *omukae wo matsu*-waiting for a welcoming death. Another common expression was: *omukae ga kuru*-a welcoming death is coming. The meaning *omukae* (welcoming death) stems from the Buddhist’s view that death is an entry to the next world. Since ancient times, it has been believed that a river (*sanzu no kawa*) flows at the border between this world and the next. The Japanese express dying as *omukae ga kite sanzu no kawa wo wataru*-we can across the river when a welcoming death is coming). As mentioned in the Chapter one, *omukae wo mastu* implies a process and a way of accepting death. In asking older people in the nursing home setting questions on the meaning of death, and their understanding of
37

omukae wo mastu, their responses could be categorized into three sub-themes: 1) preparation for dying; 2) a preferred place and circumstance to die; and 3) concerns about dying.

3-3.1 Preparation for dying

Most of the older people expressed that they were prepared for a welcoming death. They often expressed that the end of their life started when they entered the nursing home:

I am ready to die whenever the welcoming death is coming. When I entered the nursing home I cleared up my stuff and I brought memorable stuff of my life in here. When I die I want this stuff to put in my coffin (Mr Suzuki).

In reviewing and contemplating on their life, many voiced that they had been ready to die when having to pack and clear up their possessions when departing from their own home.

As discussed previously, several older people also expressed spiritual resources (yoridokoro). Their spiritual resources were considered to support and guide them in their preparation for death; like a compass of a boat. Religion was one of their spiritual resources. Some residents found comfort in reading and writing down hannya sinkyo-old Buddhist sutras.

I spend time writing down hannya sinkyo-old Buddhist sutras for dying peacefully. I would like to experience a state of perfect selflessness while I am writing down old Buddhist sutras, but it is difficult. It means a welcoming death has not come to me yet (Ms Yamada).

It is believed that a sutra brings merit to the person just by reading it and even greater merit if it is recited and transcribed, just as in the saying “one Buddha appears as one word transcribed.” It is considered extremely venerable to devotedly transcribe sutras without any desires. Like with Ms Yamada, transcribing a sutra was because the older people
wanted to be close Buddha to renounce all worldly desires. In a reality, it is difficult to renounce any desires in their daily life, but by transcribing *hannya sinkyo* meant they could live calmly and peacefully.

Another common spiritual resource among the older people was ancestor worship. Japanese religious faith is based on Buddhism and Shinto which are based on the idea that the human soul continues to exist after death and that the deceased continue to watch over the living. For some it was customary to pray to the ancestors in their everyday life:

> I pray and give offering (foods) to my ancestor every morning and before sleeping as my welcoming death is coming soon and I will meet my husband in the next world (Ms Abe).

The meaning of praying to the ancestors is that older people expect to be reunited with their loved ones. In recent years, the song *sen no kaze ni natte* or ‘a thousand winds’ (see later) has been very popular in Japan. This lyric indicates that people who have died exist in nature. The older residents also preferred to listen to and sing this song. Popularity of this song indicates that a belief about the continuity of human existence after death is deeply embedded in the meaning in death among older people:
Sen no kaze ni natte: A thousand winds

Do not weep at my grave.
I am not there. I am not sleeping.
As a thousand winds. As a thousand winds.
I blow in the great sky.
In the autumn I am the light that falls upon the crop fields.
In the winter I am the falling snow that shines as a diamond.
In the morning I am the bird to whose song you awake.
At night I am the stars that watch over you.
Do not cry at my grave.
I am not there. I did not die.

Modified Japanese version by Man Arai: Original poem by Mary Elizabeth frye

3-3.2 Preferred place and circumstances to die

Most of the residents in the nursing home had made a decision when they entered the nursing home that it was the place where they would see out the last days of their life:

I want to wait for a welcoming death in the nursing home. Of course I wanted to die in my home, but my home was far away from Tokyo. This nursing home is close to my son’s house. If I died in my home my children could not come to see me at the end. So I prefer to spend time in here at the end. I do not want to be admitted to the hospital. I want to die naturally without any resuscitation (Ms Hayami).

I decided to come here and that the nursing home is the last place to live.” So I want to die in here surrounded by young care staff and my family (Mr Goto).

I want to die in my room while I am sleeping and listening to music peacefully after taking a bath. My body is already cleansed when I die (Ms Yamada).

Residents expressed ideally that they wanted to die at home, however, they were ready to die in the nursing home when they left their own home because they were aware of the

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The lyric of Sen no kaze ni natte (A Thousands Winds):

Author of original lyric was Mary Elizabeth frye in the USA and the title was “Do not stand at my grave and weep.” Japanese singer song-writer Man Arai translated and modified in Japanese and composed music as A Thousands Winds. See webpage:

http://en.wikipedia.org/wiki/Do_not_stand_at_my_grave_and_weep#A_Thousand_Winds
difficulty dying at the home due to family issues or physical health problems. Older people expected that they would be surrounded by family and others when they were dying, and not to die alone when departing their life in the nursing home.

3-3.3 Concerns about dying

Although the residents often expressed that they were prepared to die, they had ambivalent feelings of accepting their own death and some were regretful of their life:

I am concerned about my family giving me a proper funeral. When I started to talk about my funeral my daughter said it is ominous, and please can I stop talking about my funeral. But it is important for me. I cannot die until I have arranged my funeral (Mr Goto).

My great grandchildren will be born in six months. I wonder if I will live or not until then. I want to die after I see my great grandchildren. If I saw them, my next life would be happier (Ms Seya).

I do not want to be a burden to my children. It is better that the welcoming death comes soon for them. But my son's factory is now busy. The factory cannot be bankrupt because I inherited it from my husband. If I died now, it is also a heavy burden to them. So I would like to die when I can see the factory will be fine (Ms Abe).

Several residents try to find reasons for living to extend the time waiting for a welcoming death. These reasons are shaped by their spiritual resources. For some like Ms Seya her great grandchildren bring her a reason to live and keep him lively. Others still cling to life to resolve unfinished business, as can be seen with Mr Goto’s need to have his funeral preparations in place. In addition, Ms Abe wanted to see the factory which she inherited from her dead husband. In doing so she wanted to confirm her husband’s stamp (i.e. the factory) will continue through her descendants.
3-4 Conclusion

The residents considered that the nursing home was the last place for them to live out the end of their lives. They reconstructed their existence or new identities in this last place through seeking meaning in life and death. This study shows that older people’s generative beliefs and values related to personal continuity in which they tried to leave their stamp in life through their descendants were varied. Their spiritual resources supported and guided them to live in a lively manner and allowed them to be prepared for dying, like a compass of a boat. Dwyer et al. (2008) assert that the inner dialogue and inner strength, as well as having contact with others, seems to facilitate older people’s creation of meaning in life as a whole, including both the past and the present. Flanklin et al. (2006) assert that in an everyday care context of strain, supportive relationships with others could help older people to maintain or reconstruct a new identity with which it is acceptable to live. Especially among those who have lost other relationships in their lives and those who are physically dependent or frail, such individuals searched for their identity in order to keep a sense of dignity. They needed to be seen and respected for who they actually were as individuals. In this chapter I have shown that it is important to explore how older individuals’ viewed themselves and how the values they attributed to the meaning of life and death within the nursing home context. In the following chapter, I will explore how the older residents maintained a sense of dignity and how the staff respected their dignity within the nursing home.
Chapter 4
Dignity at the end-of-life care: Respect for inner journey

While I was sharing older people’s inner journeys in seeking the meaning of life and death, I was aware how important it was for them to maintain respect and keep their dignity. I noticed that some of them had problems maintaining their dignity in the care culture of the nursing home. I had many questions in my mind. What does dignity mean in a nursing home? How much can we (the nursing home staff) respect older people’s dignity in their daily care? Why do dying older people not have a key role in making decisions concerning their death?

Historically, ‘individual dignity’ first appeared in the Japanese Constitution after the Second World War and this ethos has been used within a health care context since the 1980s, especially within the hospice movement (Hamanabe, 2008). The policies for caring older people declare to respect older people’s autonomy and dignity in health care facilities and government social welfare services, however, a clear definition of dignity does not exist in Japan. Dignity is often referred in Japanese as sonohitorasisa wo sonyou suru (respect older people as being themselves). This means helping them to keep their values, intentions, and ways of living (Hisada, 1996). The concept of ‘individual dignity’ has not been embraced in the Japanese collectivist cultural context. Rather, an individual’s behaviour and ways of living are based on the approval of others or what appears to be appropriate to society. If an individual behaves in ways that are considered to be disrespectful or inappropriate to the community, he/she will be subject to social sanction in the form of shame. In fact, as early as 1946, the American anthropologist Ruth Benedict coined the Japanese culture as a ‘shame culture.’ In contrast, individual dignity and autonomy are embedded in a Western individualistic cultural context.
There have been discussions in the literature about the notion of dignity both in Europe and
the US (Carlson, 2007; Dwyer et al., 2008; Flanklin et al., 2006; Pleschberger, 2007). Flanklin
et al. (2006, p.134) reviewed and summarized fourteen publications on the current
definitions of dignity and concluded:

Current definitions of dignity indicate it as being subjective, multidimensional and
influenced by our socio-cultural environment and personal histories. Dignity
comprises an internal aspect, which is one’s personal, subjective valuing of oneself,
and an external aspect, which is the valuing of oneself by others.

Based on the above definition of Flanklin and co-authors, Pleschberger (2007) categorized,
two aspects of dignity, namely: intrapersonal dignity as an internal aspect and relational
dignity as external aspect. She also reports that the understanding of dignity in the nursing
home context is not solely individualistic and personal, but rather has a closer relationship
to social ideas of value, which ultimately shapes the basic requirements of institutions in
which ‘frail old people’ live. In this chapter, I shall explore the question: How do older
people experience dignity at the end of life? Drawing on my observations in the nursing
home and participant two case studies I will describe older people’s dignity in their daily
care and in decision making at their end of life.

4-1 Dignity in daily care
Moving into the nursing home brought many older residents great changes to the structure
of their everyday lives. Although respecting residents’ autonomy and dignity is declared
within the policy of the nursing home, residents were not totally free to do what they
wanted and they needed to adapt from their home life pattern in order to live under the new
circumstances of the nursing home setting. Ordinarily, time was scheduled by meal and
bathing times in the Japanese nursing homes. The staff were expected to work within these
time schedules and staff caring for residents were under pressure of time. It is open to
question whether the staff providing the daily care to residents in the nursing home respected their dignity or not. Flanklin et al. (2006) claim that there is a risk that dedicated staff who are not given the opportunity to care for older people in accordance with the aims set out in guidance documents, as well as in line with their own values, are exposed to moral stress. Dignity in daily care leaves room for a variety of interpretations under the circumstances of the nursing home. Next, I describe the residents’ experiences of dignity in the nursing home during the basic daily care activities of eating, bathing and toileting.

4-1.1 Eating

Eating is a basic human need and a source of enjoyment for older people. It is an essential part of care in the nursing home. Residents’ changes in their ways of eating were shaped by their mental and physical limitations and their relationships with others. Eating habits also highlighted residents’ aspects of their past life. How did the staff deal with individual needs related to eating?

Basically all the residents ate the same meals; however, their preference for and dislikes of particular foods were taken into account by the staff in the nursing home. The Japanese are very sensitive about seasonal changes and residents preferred to eat fresh seasonal foods. The chef cooked decorated seasonal meals for them especially on the days of seasonal events. Furthermore, meals were regionally varied among residents; they missed the foods of their hometown, so sometimes they were provided with their hometown meals. Some residents at times dined out with their families or friends, and families brought in certain foods which they knew they liked. Respecting individual eating habits was important to the residents in the nursing home. However, variations in food were also shaped by therapeutic diets. When the act of swallowing was a problem, the form of the meal changed to make it easier for the person to swallow, for example, in the provision of porridge or chopped and
pasted meals. Residents typically expressed:

When I cannot eat, *omukae ga kuru* (welcoming death is coming for me). I do not want to eat a meal which does not keep its original forms. It looks like pet food.

Commonly, it was the residents’ view that their ability to eat symbolized independence and living, whereas on the other hand eating with a disability represented dependence and dying.

The question raised in my mind was whether the staff should accept the residents’ care needs despite having difficulties swallowing. Ms Shimada was 94 years of age, and her swallow was deteriorating, as a result of suffering from mild stroke. She did not want to eat chopped-up meals and ate ordinary meals with the assistance of the staff. One day, however, she ate a chunk of beef without their help and choked. Fortunately she recovered, but after this incident, her son complained to the staff:

Although my mother said she did not like to eat ordinary meals, the chopped meal should be provided for her condition.

However, Ms Shimada expressed to her son

I could not eat such baby foods. I wish for *omukae ga kuru* –a welcoming death had better come when I choked. I can go *pokkuri*-sudden death. Why do I survive? I am already 94 years old. It is enough to live for me. I do not want to live any longer if I cannot eat.

Here there seemed to be a contradiction between the dignity of respecting life and the dignity of respecting autonomy. My own personal view was that I respected her desire to want to eat an ordinary meal. In this case, Ms Shimada was provided an ordinary meal and the staff needed to pay more attention to prevent her from choking. The staff in the nursing home worked under pressure and often confronted ambivalent dignities among residents.
Among residents who had difficulties eating but could at least eat by themselves, although they often spilling their foods, staff need to devise ways of allowing them to eat by themselves to enhance their independence. Ms Kimura suffered from dementia and Parkinson’s disease. She could eat by herself but spilt her food, so one staff member brought her an apron which looked like a pinafore. She got angry: “Why do I put on a pinafore? I am not a child. I am alright, I can eat by myself.” Using such an apron she considered, infantilized her and made her feel undignified. This had a negative effect on her identity and independence. As a compromise, the staff devised a special serviette which looked more elegant and she was happier to use this.

Most of the residents who needed full assistance whilst eating were difficult to talk to and had problems expressing what they wanted to say. I observed different ways in which the assisted their eating. Some of the staff assisted the by careful observation and in talking to these older residents. Other staff helped them to control their pace of eating without any communication. Ms Ishiya who had suffered a stroke, resulting in limb palsy and aphasia, needed full assistance to eat. Sometimes she did not eat at all or ate very little. I found out that she did not eat when the staff controlled her pace of eating. Refusing to eat her meals was a strategy she adopted to express her anger towards the staff. She would say: “I want to eat my own pace, please pay attention to me carefully!” Thus, when some residents lost their appetite, this highlighted problems in their relationships with others rather than being related to their physical condition.

4-1.2 Bathing

Bathing is also a very important care activity undertaken in the Japanese nursing home. Some of the residents entered the nursing home partly so that they could take a bath because they were unable to take a bath on a daily basis at the home due to physical
limitations or frailty. Why is bathing important for Japanese older people? For the Japanese, bathing is not simply a matter of maintaining personal hygiene. It also reflects Japanese cultural values around purity, relaxation, and social connection. Even though they have private bathrooms in their own home, public bathing is common in Japan, either at onsen (hot springs) or at sentou (public bathhouses), which are separated for men and women. The Japanese visit the hot springs or public bathhouses with friends, family, and colleagues. Here they remove all of their clothing, which is an expression of social bonding: hadaka no tukiai (naked association). Bathing is seen as a way to enhance social bonds and to strengthen a sense of camaraderie. In the home, bathing is also an important act of family bonding: Japanese parents bathe their children and this provides them with an opportunity to communicate with their children.

In the nursing home there were private bathrooms on each floor and one public bath. Residents preferred to use the public bathroom because they felt more relaxed and could communicate with other residents whilst bathing in a big bathtub together. Bathing in the public bathroom created a sense of social bonding among the residents and it was a continuity of the bonding they once had with others in the hot spring or public bathhouse before entering the nursing home.

Residents took a bath every day and bathing was a separate activity for men and women. Those who were bed-ridden also took a bath with assistance in a special bathtub. Although it is common to be naked in a public bath, staff assisting older residents in bathing, such as in changing clothes and washing bodies needed to pay particular attention to respecting their privacy. Some female residents were unwilling to be assisted in their bodies being washed by new male staff. At times that this occurred, rather than refusing to bath, it was a matter of trust that such male staff respected their privacy and comfort, rather than refusing
to be assisted to bathe by them. Overall, the residents were concerned that staff had the appropriate skills and an attitude of respect for their privacy and dignity.

Some of the older residents expressed a special meaning in life and death in relation taking a bath:

I am happy that I can take a bath every day; it is worth to come here at the end of life.

I want to take a bath until omukae ga kuru (a welcoming death is coming).

I wish I can go pokkuri (sudden death) after taking a bath.

Taking a bath lets bygones be bygones. Cleansing my body and cleansing my kokoro-soul

Water as the purification element in the bathing cleans, refreshes, relaxes, and invigorates not only their body but also the kokoro-soul. Taking a bath carried with it a sense of cleaning one’s inner self. Bathing provided time and space for older people’s inner journey in terms of waiting for a welcoming death.

4-1.3 Toileting

Toileting is a sensitive care activity in which the staff in the nursing home especially need to respect the residents’ privacy. Dependency in toileting made older people feel shame and led to a loss of identity. Japanese older people commonly expressed shimono sewani natte made ikitakunai hazukasi: “I do not want to live with someone who needs to provide care of my private parts; it is shameful.” When Ms Yasu, who suffered from advanced dementia, was assisted by the nursing assistants to go to the toilet, she always said to the staff “I am sorry, I am sorry. It is a shame, it is a shame. Thank you, thank you…” whilst bowing at the same time. Sometimes, she defecated on the floor in her room, but she did not seem to
care about that. Her feeling of shame centred around someone else assisting her to use the
toilet. Okano (1994) writes that this sense of shame among the Japanese is evident from
early childhood and is constructed by interaction with others, especially in terms of public
manifestations of the person’s inferiority and inadequacy as a person. It is deeply grounded
in older people’s sense of values.

Deteriorating physical conditions among residents sometimes led to incontinence. When
older people started to suffer from incontinence, they hardly accepted themselves. Mr
Konishi was 92 years old and a retired doctor. His symptoms of Alzheimer disease had
progressed rapidly. However, he still kept his identity as a doctor and refused to be assisted
to use the toilet or admit he had an incontinence problem. The floor of toilet was often
messed with urine and faeces, and his clothes were soiled. He explained to the staff:

Who did such a thing? Maybe, the old lady who lives next door did it, ahh….she is
sick, you know?

The staff accepted his opinion and asked: “Doctor, shall we go to take a bath?” He loved to
take a bath, so the staff in order to respect his sense of identity asked to him to take a bath
rather than to change his clothes or to clean up his room.

The staff assisted residents to go to the toilet as much as possible as part of their everyday
care, although some of the residents found it hard to walk. Although the staff made efforts
to respect residents’ dignity, sometimes the staff cared in alternative ways. Residents who
needed assistance to walk to the toilet often pressed a call button when they wanted to go.
Sometimes two or three residents called at the same time and the nursing assistants often
used to say “Could you wait a minute. I am coming as soon as possible,” but many of the
residents claimed that “it was not a minute, and I feel I have waited for a long time.” Ms
Hayashi typically expressed:

I do not want to ask for assistance to go to the toilet during the night time because one time I was waiting for a long time after I called the nursing assistants. So I try not to drink during the night time to reduce asking to go.

When the staff said “please wait a minute,” residents perceived this as a means of disrespecting them or of not pay attention to them. I observed the staff often using the phrase “please wait a minute” without being aware of residents’ uncomfortable feelings about this phrase. It seemed like the staff responded very quickly in terms of minutes, but residents would often feel like it was more like ten minutes. Dwyer et al. (2008, p.15) describe different sense of time between residents and the staff same as I observed,

Everyday life seems to have been controlled more by staff routines than by residents’ needs…the nursing home environment is both a place where older people are living the last days of their life and a workplace for the staff. The older people and the staff are described as living in two different cultures. The staff live in a hurried or pressed culture and the older people live in a waiting or expecting culture. These two cultures rarely interact.

Similarly, the underlying ‘pressed culture’ of daily care among the staff in the nursing home was a ‘syndrome of wait a minute’ and shaped undignified care among the residents in the nursing home. It remains an unsettled question to what extent the staff could overcome this ‘strategy of waiting a minute’ in order to respecting residents’ dignity in their daily care.
4-2 Dignity in the decision making process in end-of-life care

Changing physical limitations after moving to the nursing home meant that residents and their families were confronted with making tough decisions in their medical treatment in the course of end-of-life care. Residents were often did not occupy a central position in the process of their decision making. The question raised is why did their family or others make a decision for them without involving the dying older people? Some ideas are suggested by Davis and Konishi (2000, p. 90) who write:

Traditionally in Japan the individual is viewed as the socially embedded self and part of several groups ranging from the family to the nation. It then follows that groups tend to make decisions, not individuals. This certainly is the case with the terminally ill older people.

How do older people feel that their end-of-life decisions are made without involving them?
In the following section I describe the family centred decision making at the end of life among the older residents drawing upon two cases; one resident suffering from advanced dementia and the other who was terminally ill.

Case 1: An advanced dementia resident

4-2.1 Incapability of making decisions

Mr Kawata was 83 years of age and suffered from advanced Alzheimer’s disease. He became incontinent and refused eating and changing his clothes. He lost weight and his physical condition and cognitive ability was getting worse. Family, doctor, and staff held a meeting to take a decision about his end-of-life care.

The doctor explained to his family Mr Kawada’s condition, the possibility of medical treatment and what would happen if medical treatment were not given to him. Possible medical treatment included tube feeding or percutaneous endoscopic gastrostomy (PEG)
which is generally placed into a patient’s stomach as a means of feeding him when he is unable to eat. His older daughter said that about this procedure:

It is difficult to say, but I think I do not want to give him tube feeding. I know he will die soon, but he looks like he is suffering now and it is painful. We will give him more suffering by feeding him this way. He does not know I am his daughter. It is very sad.

His second daughter further commented:

I hesitate to end my father’s life. If he can be alive by tube feeding then he will pass way. It is a shame that my relatives might consider we do not do anything for my father. Maybe I will be able to accept he is dying. I understand my sister’s feelings, I also feel sad to see him changing.

At the meeting a decision could not be made among the family and they spent a week deliberating. Finally the family decided to give tube feeding to their father. Mr Kawata was admitted to the hospital for PEG operation. After he was discharged from the hospital back to the nursing home, he could not walk anymore, and became bedridden. His older daughter visited him every week, and expressed her feelings of sadness.

I wonder how long he can alive under this condition. The decision making about his life was painful for the family. I did not want to give tube feeding but I could not take responsibility for ending his life. I always feel sorry for him when I see his face.

4-2.2 Surrogate decision making

There are convincing arguments in the literature for surrogate decision making of older individuals with advanced dementia at the end of their life. Monteleoni and Clark (2004) claim that the quality of life of older people with advanced dementia can be adversely affected when a feeding tube is inserted. The daughters of Mr Kawata struggled in their decisions in how to best provide their father with dignity at the end of his life. The family
were overburdened with the surrogate decision making of their father’s end-of-life care. His daughters had ambivalent feelings about prolonging his life. They felt a strong sense of guilt in acting on behalf of their father about his life. Tanida (2000) reports that the concept of ‘being natural’ in both Shinto and Buddhist teaching may contribute to less favourable attitudes toward the involuntary act of the dying process, such as in euthanasia. Long (2001) asserts that Buddhist, Shinto, and other religious or spiritual messages remain part of the cultural environment in which decisions are made about the dying process. Furthermore, Pool (2004, p.963), writing about the Netherlands, posits whether versterving (voluntary death by fasting) is a natural process of dying or not:

Versterving was controversial because of the ambiguities and connotations of the term itself; ambiguity about the nature of tube feeding, uncertainty about whether or not it was painless, and the extent to which the dying person was in control, and uncertainty about what constitutes natural death.

It is difficult to define what a natural death means. In the Buddhist and Shinto views, fasting is a way to attain spiritual enlightenment, however, involuntary initiation of dying process is regarded as unnatural. Ambiguity around involuntary versterving as a natural death underlay his daughters’ sense of guilt. However, how is it possible to explore the autonomy of advanced dementia residents like Mr Kawata who are incapable of making decisions for themselves? Advanced care planning is one possible way to respect such individual’s autonomy.

**Case 2: A terminally-ill cancer resident**

**4-2.3 Non-disclosure**

As introduced in chapter two, Mr Endo was 76 years old and suffered from oesophageal cancer. Overtime, he found it gradually more difficult to eat and suffered from pain. He asked the staff:
What’s happening to my body? What is my disease? I heard that I have an oesophageal ulcer from my doctor. Is it true?

His family decided not to tell him the truth about his diagnosis, and the staff said to him:

“_Your oesophageal ulcer was getting worse again, so you lost appetite and felt pain._”

However, he started to ask about his condition obsessively and needed a blood transfusion and pain control by using narcotics, which were difficult to manage in the nursing home. His son, the doctor, and several members of the staff had a meeting to discuss his end-of-life care in the nursing home. His son expressed his wishes as follows:

> If we told my father he has cancer, I think he will be depressed and he cannot accept it. I do not want to give him to have advanced medical treatment such as a blood transfusion, although his life would be shortened. Because I do not want to see that he is suffering. If it is possible I do not want to refer him to the hospital. My mother died surrounded by medical equipment in the hospital. He often tells me: I do not want to die in the hospital like your mother.

The doctor told his son:

> I understand you do not want your father to suffer. However, your father is suffering from severe pain now, although we need to relieve his pain with analgesics. I would like to use narcotics but it is difficult to use in the nursing home under the medical law. One possible option is that we refer him to the hospice but we should tell him he has cancer.

The son replied:

> Of course I want to relieve his pain. Maybe it is better to admit him to the hospice. But I still do not want to tell him that he has cancer.

After the meeting the doctor tried to find out about referring his father to the hospice but found out that the hospice had no beds and he would need to wait at least one more month. He had not known what treatment they had decided and the doctor explained to him that the ulcer was getting worse and he needed to take several pills to cure it. Overtime, he was
unable to eat and could only drink a cup of coffee; something he really liked. He took analgesics and tranquilizers as often as he could for the relief of his severe pain. While his physical condition was getting worse, it seemed that there was no-one he could ask about his disease. When his condition was better I took him to the garden. He told me:

I wonder whether I can see cherry blossoms blooming this year. Cherry blossom is beautiful but it is wistful when the petals are falling. Do you know Fumiko Hayashi? She made a famous haiku 8 “The life of a flower is short and full of suffering” If I composed a haiku, what about: “My life is neither long nor short with a part of happiness and a part of suffering.” How is it?

He talked calmly with a smile and it seemed that he realized that he was going to die. It was a difficult moment for me and I was moved when he posed the question: “I know I am dying. Let me know how long can I live?” I replied:

I wish we can go to see the cherry blossom together in April. I think your haiku describes the world of chudo-middle path that “there is a happy medium in everything including life.” If the person finds out chudo-middle path, it is said that person would attain spiritual enlightenment in his life, doesn’t it?

Indirectly I thought I had answered this question, and he laughed. A week later we had another conversation. It was getting more difficult for him to talk as his condition became more critical. The doctor asked his son whether his father should be referred to the hospital or not. His son was upset and he could not accept that his father was dying, although he said “I do not want to give my father advanced medical treatment.” I said to his son “your father knows he is dying and he looks like he is accepting it.” The staff wanted to care for him until the time of his death in the nursing home. However, eventually his son decided to refer him to the hospital. After two weeks Mr Endo died in the hospital having not seen the cherry blossom tree blooming.

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8 haiku: Japanese poetry
4-2.4 Ambiguity of dignity at the end

Mr Endo was not told that he had cancer as a strong wish from his son. His son assumed that his father’s perception towards disclosure of cancer was based on his interpretation on the behaviour of his father without communicating with him directly. However, the autonomy of Mr Endo was not respected; his decisions were shaped by others. The self of Japanese is described as ‘interdependent’ which emphasizes attending to and fitting in with others and the importance of harmonious interdependence with them (Marcus and Kitayama, 2001). Interdependent selves favour an implicit style of communication which is sensitive to contextual factors such as people’s facial expression, body postures, roles, and relationships of communicators (Slingsby, 2004). The interdependent self underpins the norms of nondisclosure in the process of family centred decision making. The Japanese norms of nondisclosure render little possibility of informed consent with older people.

However, I observed that Mr Endo also expressed other dimensions of the self; that of the ‘independent self’ which stresses attending to the self, the appreciation of one’s difference from others, and the importance of asserting the self. Slingsby (2004) asserts that independent and interdependent selves are often coexisting to varying degrees within cultures and within individuals. However, there is ambiguity of autonomy and individual dignity under the circumstances of an interdependence culture. There would be a conflict between the views from others and views from oneself like between Mr Endo and his son. It was difficult for his son to be aware his father’s independent self. Moreover, it is a challenge that the views from others and oneself interact together.

It was a difficult time for the family when Mr Endo fell into a critical condition. It was hard for his son to accept that his father was dying. His son’s decision was difficult when faced with determining the length of his father’s life. He was not prepared to accept his
father’s death, and expressed his feelings about it as follows:

I felt so ashamed that I broke down at that time. I did not want to refer my father to the hospital, but I could not imagine he was going to die within two or three days. I asked by myself: what have I done to him? Although my father accepted *omukae ga kuru* (a welcoming death is coming), I needed time to spend with him before his departure. I stayed beside my father in the hospital and I talked to him even when he was unconscious. I wonder whether we could have talked about his departure openly, if I had told him he had cancer.

Mr Endo’s son tried to come to terms with his father’s death in order to heal his own grief. The family needed to spend time for the spiritual preparation of accepting their father’s departure from this life. It is essential to have communication regarding resident’s departure openly at the early periods between residents, family and the staff.

At the end of Mr Endo’s life, he struggled with severe pain from the cancer. He would have liked to confirm with others whether “he was dying or not” in order to search for the meaning in his life and death. He might have been disappointed that no one had told him the truth about his diagnosis. I felt the sadness and frustration in his eyes when I explained the false diagnosis. I often found I was caught between Mr Endo, his family, and the doctor. I struggled with the idea that we should tell him the truth and discuss the best way of dying. However, the family’s decision was decisive and given priority under the circumstances of the nursing home. I could not tell him the truth directly. We could only just listen and accept what he had to say as much as possible. At the end, he described his life as “*neither long nor short with parts of happiness and suffering.*” His description implied *chudo*: a middle path which was spiritual enlightenment in the teaching of Buddhism. I felt that he might have been able to search for his inner journey before his death.
4-3 Conclusion

The concept of ‘individual dignity’ has not embedded in the Japanese collectivist context. Although respecting residents’ autonomy and dignity was declared by the policy of the nursing home, residents tried to adapt to living under the circumstances of the nursing home by constructing their own life pattern. The residents showed their autonomy in non-verbal ways, such as through their facial expressions, ways of eating and asking to be assisted to go to the toilet as part of their everyday care. The staff made efforts to respect resident’s sense of self, however the strategy of ‘wait a minute’ in the course of resident’s daily care shaped undignified care among residents under the pressed culture.

Residents and their families were confronted with making tough decisions about medical treatment for residents at the end of life. They were overburdened with surrogate decision making for those with advanced dementia. The interdependence culture underlay the notion of non-disclosure for terminal illness in a family centred decision making process. Much still remains to be done to guarantee respect for residents’ dignity at the end of their life in the nursing home circumstances. This study shows the importance of respecting residents’ dignity; it involves exploring their inner values, the meaning and dynamics of their relationships with others (i.e. family, friends, and staff), environment influences (i.e. care culture and society) on residents. Spirituality in end-of-life care would enhance residents’ dignity. In the next chapter, I shall further explore residents’ dignity and spirituality in interpreting their inner values.
Chapter 5
Spirituality in end-of-life care: A boat for departures

In sharing time with residents, I found that their expressions contained profound reflections of their past and present life. Their inner strength through searching for their meaning of life and death touched me. I asked myself “Where does their inner strength come from?” They spoke about yoridokoro: spiritual resources in times of suffering. Different spiritual resources were expressed by individuals, such as in the context of deceased loved ones, in their religious beliefs and relationships with family and others. Takeda and Futoyo (2006) assert that yoridokoro is an important concept of spirituality for maintaining older people’s sense of oneself in old age.

In Japan, spirituality has been discussed in the social science, theological and nursing literature. In 1984, the World Health Organization (WHO) produced a new definition of health which included a focus on spiritual well-being (Takeda and Futoyo, 2006). In particular, there have been arguments regarding the meaning of spiritual needs in palliative care among terminally ill cancer patients. The word ‘spirituality’ is difficult to translate into Japanese; it is called supirichutarithi in Japanese English. Furthermore, there is no clear definition of spirituality within a Japanese health care context. Takeda and Futoyo (2006, p.57) have reviewed and summarized definitions of spirituality in the Japanese literature. They describe common features of spirituality as follows:

1) a concept relating to primordial human existence which all human being have;
2) operating when people face crisis in life, although it is usually latent in their everyday life; 3) an ethos of searching for meaning and purpose in life and the meaning of death and suffering based on relationships with the self, others and the transcendence of self; 4) includes a religious factor, but is distinct from religion and 5) provides power of living for human beings. [translated from Japanese].
Compared to the English literature on spirituality, of particular note are the definitions of spirituality by Japanese scholars: spirituality is overtly present when people face a turning point, crisis and the challenges of life (Kubodera, 2005; Okamoto, 2003; Yamazaki, 2005). Such authors focus on the meaning of spiritual pain in terminally ill cancer patients in the palliative care literature, and describe that an individual’s spirituality is most apparent when confronting an awareness of finitude in life.

In the English literatures of the nursing science, spirituality is a phenomenon which is shaped throughout the life-course (Hicks, 1999; Wallace and O’Shea, 2007). For instance, this is the case in Hicks’ (1999, p.144) following definition of spirituality:

Spirituality can be defined as the dynamic principles developed throughout the lifespan that guide a person's view of the world, which influence his or her interpretation of a Higher Power, hope, morals, loss, faith, love, and trust, and provide structure and meaning to their everyday activities.

Spirituality is of particular importance in the lives of older people at the end of their life: because they may have particular spiritual tasks to carry out, such as in confirming one’s human existence, in the acceptance of death as a reality of old age and in attaining integrity over despair (Takenaka, 2000). However, spirituality in the care for older people has received little discussion in Japan. In this chapter, I will explore: What role does spirituality play during older residents’ approaching end of life? I will describe, based on one case study, older residents’ spiritual resources and elaborate on their spirituality at the end of life.
5-1 Older people’s yoridokoro or ‘spiritual resources’

Kawa (2005) discusses that yoridokoro is a multidimensional phenomenon; the backbone of one’s life, which provides comfort and directions throughout the lifespan, and shapes meaning and power in life. As I noted in chapter three, at the end of life older people in the nursing home reconstructed their existence by searching for the meaning of life and death in the context of yoridokoro. In this section, I describe older people’s yoridokoro terms of being shaped by deceased loved ones, religious beliefs and their harmony with nature.

5-1.1 Deceased loved ones

Most older residents had loved ones in their life. Older women who had lost their husbands in the Second World War had viewed them as anchors to their own existence. As Ms Yamada echoed:

I live a long life because I feel that my deceased husband protected me. I talked to him when I was suffering. I felt that he might say I should live for a portion of his lost life. I survived despite many people losing their lives in the War. While I was taking care of my boarders (university students), I reflected on my husband who wanted to go to university. I appreciate him, and I pray for him everyday.

Her deceased husband was the backbone of her life. Her belief that she was living a part of his lost life gave her great inner strength. She discovered her reason for living in taking care of university students. This stemmed from her husband’s unfulfilled dream of going to university. He influenced her direction and way of life. She said that she had completed his unfulfilled life and expected to be reunited with him after her death:

I am 86 years old now. I feel I have already lived his lost life. Now my boarders take care of me. It is time now for him to send me omukae: a welcoming death. I look forward to seeing him again.
Her *yoridokoro* was her deceased husband. Her inner values were shaped by her interactions with her boarders, supported by the existence of her deceased husband throughout her life following his death after the Second World War. When she felt that her role was fulfilled, she came to accepted a greater awareness of own death. Waiting for a welcoming death shaped her sense of hopefulness and comfort in her expectation to be reunited with him. The *yoridokoro* plays an important role in accepting and preparing dying older residents.

### 5-1.2 Religious belief

Although the Japanese rarely express religious beliefs and practices in public, I observed older residents following their own religious beliefs. In general, Japanese religious beliefs are based on a mixture of Buddhism and Shinto: and it is said that the Japanese are born Shinto and die Buddhist. Buddhists view death as a natural process in the life cycle and death signifies rebirth and reincarnation of the spirit (Keown, 2005). Older residents prayed and gave offerings to the *butsudan*: a small family of Buddhist altars each day. Deceased loved ones and ancestors were enshrined in the *butsudan*. Older residents believed that deceased loved ones remained available to their families to support and protect them in life, as was in the case of Ms Yamada’s discussed previously. Daily prayers and offerings at the *butsudan* were an important ritual for communicating with deceased loved ones and their ancestors in every their life. The *butsudan* created time and space for older people in the nursing home to practice their spirituality.

Older residents read *hannya sinkyo* or old Buddhist sutras whilst praying at the *butsudan*. Ms Sakota explained why she had read and wrote down *hannya sinkyo*:
I was not a religious person but I started to read and write down hannya sinkyo since I lost my husband. I went to the Buddhist temple and it provided a place for writing done hannya sinkyo. It relieved my pain and suffering from my feelings of loss. Hannya sinkyo taught me that suffering was not static and moving. Life is like a flow of a river, as in Hibari Misora’s song. While I am reading and writing down hannya sinkyo, I can forget the anger or sadness and whatever happened in life.

As mentioned earlier in chapter three, it is believed that writing down and reading hannya sinkyo brings spiritual enlightenment. The aim of hannya sinkyo is to attain selflessness.

Arai (2005, p.28) explains selflessness as:

No permanent self because the nature of reality is impermanence and everything (including ourselves) is changing moment to moment. When you resist this change, and try to be a separate self apart from the flow of life you suffer. No permanent self applies to the dimension of time. We are part of the eternal present moment; always moving; always changing. The Buddhist takes the middle way between the self and it is not something fixed or permanent. It is not nothing or not existence [translated from Japanese].

Like Ms Sakota, hannya sinkyo supports and gives relief to her suffering. Although it would be difficult to attain full of spiritual enlightenment, she could maintain her sense of self by being aware that “life is like a flow of river.” By describing life as a flowing river, is part of a fundamental Buddhist concept-'selflessness’ that our being is always changing and moving like a river.

5-1.3 Harmony with nature

Kubodera (2005) points out that Japanese spirituality is strongly influenced by the belief of one’s existence as a part of the nature. As previously introduced in chapter three, Mr Hara described death as going back to nature. In the same vein, Ms Tateno said:

Trees, flowers, weeds, insect and birds live and die. In the same way human beings live and die. So we are tsuchi ni kaeru-going back to the soil with other living things after death.
The Japanese expression *tsuchi ni kaeru*—going back to the soil—is a Japanese metaphor for dying. It is believed that one’s body is laid in the soil and becomes part of nature after death.

The older residents in the nursing home were in awe of nature. Ms Tateno was a survivor of the Great Kanto earthquake in 1923, where more than a hundred thousand people died in the Tokyo area.

I was so scared and it was so sudden. My house completely damaged, but fortunately my family and I stayed at the rice paddy field at the time. My family survived. I lived in a suburb of Tokyo and I saw the centre of Tokyo in a blaze from my place. The War was scary, but the earthquake was a greater threat. We should not make nature angry. We are living with the nature. Our family survived because we prayed to nature. I pray to nature every day to appreciation our life. My life was saved by nature, so nature will also tell me when it will invite me to *omukae*: a welcoming death.

The belief in a greater power of nature underlay her awe of nature. Harmony with the nature is believed to protect individual lives. There are different kinds of shrines for the divine worship of nature, such as in relation to thunder, winds, rains, waters and soils in Japan. It is believed that individuals are protected by many divines in the nature. The belief in nature’s divinity protects one’s life. Nature provides safety and peace, and leads to an appreciation of life, as was the case with Ms Tateno. Viewing one’s human existence in harmony with nature represents older people’s *yoridoko*. It supports their positive attitudes towards death and dying and shapes their meaning in life.
5-2 Spirituality at the end of life: A case study of Ms Sato

Takeda and Futoyo (2006) write that the framework of Japanese spirituality is composed of three layers: the ‘self,’ ‘others/environment,’ and ‘transcendence’ beyond life. Spiritual resources are an essential part of the conceptual framework of spirituality among older people. In this thesis, I describe three layers of spiritual resources based on the narratives of previous cases (see Figure three). The self searches for one’s existence in the meaning of life and death, and in relationships with others, including their environment, supported by one’s spiritual resources. Furthermore, the self is aware of the continuity of life through relationships with a greater spiritual presence beyond life, such as with nature and in their religious beliefs (e.g. Buddhist discipline). Ultimately the self experiences transcendence beyond life. Older people at the end of life in the nursing home setting, experience transcendence of the self through reenacting their spirituality in the process of adapting to a new environment, reconstructing and confirming their existence, and accepting/preparing for death. I describe how spirituality involves the transcendence of the self, using Ms Sato’s story as a case study.

Figure 3. The conceptual framework of Spirituality

Adapted from Takeda and Futoyo (2006, p.61)
5-2.1 Transcendence of the self: The case of Ms Sato

Ms Sato was 74 years of age and suffered from Chronic Obstructive Pulmonary Disease (COPD). She was currently independent using oxygen cylinder to assist her to breath. She and her husband entered the nursing home three years ago. Their reason for entering the nursing home was that they could not manage to live by themselves; especially because her husband’s physical condition, who also suffered from COPD, was getting worse. Her husband passed away three months after they had both entered the nursing home. She expressed feelings of loss after his death:

My husband was calm, sincere and kind. I was happy to walk along side him in my life. I knew my husband was dying, but it was difficult to accept his death at that time. We suffered from similar diseases. I became deeply depressed after his death. I wanted to depart with him. My daughter said: “You are the wife of my father, but also you are my mother. If you die, I lose my father and mother at the same time. My father would say that you should live for your children and it is not yet time for your departure.” My daughter, son, and grandchildren visited me and supported me after his death. I know that someday I will die like my husband, but not now. My life is extended for my children, my husband and my ancestors. I pray to my husband and ancestors by reading hannya sinkyo every day to express my appreciation for life.

She also described her suffering from the loss of her husband. When I met her for the first time, I felt her power and strong will for living because she made efforts to be as independents much as possible, although she was using an oxygen cylinder. I could not believe she had depression. She told me that she discovered her meaning of life after her husband’s death was through the support she received by her family. Photographs of her husband and family, drawings from her grandchildren and calligraphy of Japanese poetries were hung up over the wall of her room. These seemed like a rich tapestry interwoven within her inner values. I could see how she constructed the meaning of her life in those Japanese poems (see below). The poems showed her appreciation for the continuity of life,
(in terms of reincarnation), when she knew she would meet her deceased husband and other loved ones. She wrote down Japanese poems using calligraphy on postcards and sent them to her relatives and friends when her condition was stable. She liked to talk with other residents and staff and was popular in the nursing home. She always said to them:

“happiness is always decided by one’s own heart.”

<table>
<thead>
<tr>
<th>My turn</th>
<th>Meeting</th>
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<tbody>
<tr>
<td>Being born again.</td>
<td>“I am really glad to come across to you.”</td>
</tr>
<tr>
<td>Dying again.</td>
<td>Even if only one person in the world.</td>
</tr>
<tr>
<td>Inheriting the past lives of eternity.</td>
<td>was to say this to me.</td>
</tr>
<tr>
<td>Now I am living.</td>
<td>From bottom of heart.</td>
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<tr>
<td>My turn.</td>
<td>It is blissful.</td>
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<tr>
<td>This is what your life is.</td>
<td></td>
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<tr>
<td>This is what my life is.</td>
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Ms Sato transcribed Mituo Aida’s poetry [translated from Japanese]

Unfortunately, last January, she had a complication and was admitted to hospital with Pneumonia. Her independence in ADL deteriorated and her respiratory function worsened. Although the doctor in charge did not give permission to a discharge her from hospital, Ms Sato and her family expressed their desires for her to return to the nursing home. Her daughter said:

My mother is not herself in the hospital. Everything is controlled by treatment. I feel I want to respect her wish that she wants to come back here. She said I want to depart from the nursing home not in the hospital. I do not want to lose her like my father who stayed in the hospital.

In the hospital, under medical treatment, she lost her dignity and spiritual place, unlike in the nursing home where she had created her own tapestry on the wall in her room. The nursing home’s doctor and staff decided to accept her back to the home although they know it would be difficult to manage her medically. She returned, bed ridden and in need of full assistance in her ADL function. Physical movement caused her dyspnea on exertion and severe fatigue. However, she was conscious and had good appetite. Her family brought
her food and whatever she wanted to eat. Two weeks after she was discharged from the hospital to the nursing home she made a dramatic recovery and was able to sit out and partially eat by herself. Her family, doctor and staff were impressed by her energy. They wondered where her power had come from. I asked her and she replied:

I am not strong. I am protected by my husband and family and great deities. I am comfortable to stay in here because the staff support me. I felt lost by myself and had become a nameless patient in the hospital. When I came back, I felt my spirit was still in this room! My deceased husband told me I should not die now. I still needed to live especially for my daughter. As you know, she was very upset when I suffered from pneumonia. I wish that I can live six months more, for the third anniversary of my husband’s death. He will tell me whether I can depart or not on his anniversary.

She lost her human worth of existence in her life after the death of her husband, and when she was admitted to the hospital. However, supported by her family nearby, she searched for reasons to live. She was also aware that her life was extended by the support she received from her deceased husband and greater existences such as deities. She created the rich tapestries and hung them on the wall in her room. This tapestry highlighted the flow of her spirituality since the death of her husband. She felt his spirit was present in her room when she returned to the nursing home. She created her own space of to express her spirituality, which has become her spiritual resource. The self had rediscovered a sense of human worth in life. She could experience transcendence of the self supported by her own spiritual resources. Ultimately, the transcendence of self shaped a more profound sense of meaning of life and death, and inner strength in her life.

5.2.2 A conceptual framework of spirituality at the end of life

As Ms Sato highlighted, her spirituality became more profound and matured in old age. She experienced a transcendence of the self to overcome her despair at the end of her life.
journey. Dossey et al. (in Wallace and O’Shea, 2007 p.285) describe spirituality as:

The essence of our being which permeates our living and infuses our unfolding awareness of who and what we are, our purpose in being, and our inner resources; and shapes our life journey.

Older people’s spirituality in the nursing home played an important role in helping them to re-discover their human worth, even though they experienced a sense of despair. In further clarifying the conceptual framework of spirituality at the end of life (see Figure three above), there are five important concepts involved in this conceptual framework of spirituality: 1) the meaning of life and death; 2) relationships with others; 3) spiritual resources; 4) transcendence of the self; and 5) inner resources (values, strength, and peace).

First, self meaning in life and death among older people is a fundamental concept of their existence. It holds a core position in the concept of spirituality. The self searches for the meaning of existence by exploring and reviewing a sense of human worth, reasons and purpose of living in the past and present, and by searching for meaning when faced with death and dying. Second, self is surrounded by others (family, friends, staff and residents), the nursing home environment and society at large. The self discovers one’s existence in relationship with others which boosts older residents’ sense of spirituality as supporters. However, the relationship with others, the environment and society also might lead to loss of dignity and a decreases sense of spirituality when, for example, Ms Sato was admitted to hospital and Ms Kanda broke ties with her daughter.

Third, spiritual resources support the self in discovering ones’ human existence, especially when the self is in crisis and despair, and when the environment changes. Spiritual resources were shaped by older residents’ beliefs and values in the family, the loss of loved ones, divine beings, nature, past accomplishments and sacred texts. Older residents
discovered and created their own diverse spiritual resources by overcoming despair, for instance, in Ms Sato’s constructing of her tapestry. I have already described the spiritual resources of some of the older residents in detail, however the importance of spiritual their resources cannot be overemphasized in the conceptual framework of spirituality.

Fourth, the self is also surrounded by greater powers beyond life such as ancestors and deceased loved ones, divine beings and with nature. The older residents were aware of these greater spiritual powers beyond life, as well as the continuity of their life (i.e. in terms of reincarnation, finding harmony with nature). Older residents experienced a unity of self with such transcendent realities. They believed that they are not alone, whatever happened to them at the end of their life, because they were supported by such greater existences, as was the case with Ms Sato and Ms Yamada described previously. This unity of self with a greater transcendent reality led to transcendence of the self. Fifth, transcendence of self shaped inner resources such as inner strength and peace for the older residents. These inner resources influenced more profoundly their power of living and meaning in life and death in old age.

This framework parallels some aspects of the theory of gerotranscendence (Tornstam, 1989, 1997). Gerotranscendence is regarded as the final stage of a possible natural progression towards maturation and wisdom. Tornstam defines this process as “a shift in meta-perspective from a materialistic and rational view to a more cosmic and transcendent one, normally followed by an increase in life satisfaction” (Hyse and Tornstam 2009, p.4). However, gerotranscendence has also been found to be not only influenced by ageing perse. Ahmadi (2000) found that spiritual development can be essential for nurturing certain qualities of gerotranscendence, such as self-transcendence, changes in the meaning and importance of relationships, and in aspiring to transcendent sense of wisdom. This study
found that older people’s spirituality and attainment of transcendence of self is also influenced by ones’ experience of earlier life crises (e.g. health limitations, the loss of a family member) and religious beliefs throughout life.

5-3 Conclusion

In this study a conceptual framework of spirituality in old age emerged, based on the narratives of older residents in a nursing home setting. It is composed of three layers: self, in relation to others, and transcendence of self, as well as five key components (i.e. meaning in life and death; relationship with others; spiritual resources; transcendence of the self; and inner resources). These components interact to varying degrees in shaping older residents’ spirituality more profoundly in old age and at the end of life.

Based on the qualitative findings from this study, I would like to offer a definition of spirituality as: “an intrinsic boat (i.e. an essence of human being) of one’s life journey for discovering transcendence of the self and one’s own existence. Spiritual resources allow people to search for their meaning in life and death and provide an anchor and a compass for them, shaping their inner values, strength and peace.” The study demonstrates that the older residents were aware of greater powers beyond life such as ancestors and deceased loved ones, divine beings and with nature based on religious belief of a mixture of Buddhism and Shinto: and these great powers supported them. Older residents’ spirituality is influenced and nurtured by their belief of these great powers. At the end of life in the nursing home, it is important to draw attention to the opportunities older residents had for further developing and nurturing their spirituality, with their spiritual resources shaping their power of living and inner peace before departing from this life. In the next chapter, I shall focus on the question: How does spirituality become integrated in the end-of-life care
of older residents in the nursing home?
Chapter 6
End-of-life care: companionship during life’s journey

As discussed in chapter one, perceptions of ‘good death’ are differ between individuals. Long (2004) finds that many people draw on their personal notions about choice, time, place, and personhood when dying, and use multiple scripts or shift their frame of reference in different contexts. In this study, older residents perceived the nursing home as the last place of their life, with many expressing that the end of their life started when they entered the nursing home. They have been searching the meaning of life and death since then. This study found that spirituality played an important role in their lives and brought them power in their lives and added profound meaning to death. However, the quality of end-of-life care was found to be still open to question in the nursing home. The definition and standardization of end-of-life care for older people has been discussed since it was first suggested by the American Geriatric Society (AGA) in 1995, however, there is room for further discussion (Ushida et al., 2007). The definition of ‘end-of-life care’ by Ross et al. (2000, p.9) is commonly used in manuals:

End-of-life care requires an active compassionate approach that treats, comforts and supports individuals who are living with or dying from progressive or chronic life threatening conditions. Such care is sensitive to personal, cultural and spiritual values, beliefs and practices and encompasses support for families and friends up to and including the period of bereavement.

In Japanese, end-of-life care is called mitori care. Originally, mitori means ‘to attend to one’s departure.’ Sakurai et al. (2009, p.39) write about mitori care in the nursing home:

Quality daily care of older residents leads to quality mitori care. Mitori care is to respect older residents’ worth and ways of living, to maintain older people’s sense of oneself until their end, and to care for their physical, psychological, social and spiritual pain. Profound empathy for them brings their departures peacefully and comfortably [translated from Japanese].
Sakurai et al. (2009) also assert that end-of-life care is an extension of the care of daily activities in the nursing home. What kinds of care are essential for older residents’ departure at the end of their lives in the nursing home? In this chapter, based on interviews with older residents, I shall describe the perception of end-of-life care and important components of quality of end-of-life care.

6-1 Perceptions of end-of-life care

In chapter three, older residents described their preferred ways of dying: *omukae wo matu* - a welcoming death which is peaceful, with family and others around them, and not to die alone. Most residents expressed that they wanted to die naturally and did not want to be resuscitated. They also did not want to be taken to a hospital. In reality, however, there were obstacles to respecting older residents’ preferred ways of dying in the nursing home. I shall describe the perceptions of end-of-life care from different angles: from the perspective of older residents, relatives, nursing assistants, nurses, and the doctor.

6-1.1 Older residents’ perspectives of end-of-life care

Older residents wanted to stay in the nursing home until the end of their life. What kind of care do they want to receive? Ms Seya voiced:

> Some young staff members are insensitive and do not understand my feelings. Sometimes I am lonely, especially when my family has left after a visit. Some staff members feel my sadness and they take time to talk to me. But not all staff are like this. I try to be cheerful in front of people but it makes me tired when I feel sad.

I observed some residents seemed lonely, sad, or angry when their family came. Most were happy to see their family, however, they missed their family when they left the nursing home and their emotions were imbalanced. It is important to keep in mind that they had deep sadness on separation from their family, although they appeared to look like they had
adjusted to life in the nursing home. It is important to be sensitive to understand the older residents’ feelings in caring for their relief of emotional pain and supporting their feelings that they are not alone.

Ms Hayami had a right hand impairment due a pervious fracture. She still had severe pain when she moved her hand. She needed assistance to dress and to go to the toilet. She complained about the different ways of caring among the staff:

Some staff assisted to change my clothes without paying attention to the pain in my right hand. They do not understand how pain I feel. I wonder if my pain gets better or not, and whether I must live with this pain until my death?

Older residents have physical pain due to the after effect of various diseases. Unrelieved physical pain may itself cause emotional suffering. Relief of physical pain is part of basic care and comfort at the end of life. Furthermore, being sensitive to understanding the older residents’ pain is essential to their caring.

Some of the older residents complained of pain, however, their pain was not only physical in origin. Physical pain itself can be made worse by psychological and emotional causes, such as fear, anxiety, and depression. Cicely Saunders, founder of the modern Hospice movement coined the phrase ‘total pain’ to refer to physical, spiritual and emotional kinds of suffering commonly experienced by persons with life-limiting illnesses (Metha and Chan, 2008). Older residents also experienced this ‘total pain’ at the end of their life, as in Mr Endo’s case. Takeda and Futoyo (2006) state that spiritual pain stems from the loss of identity and loss of one’s meaning in life in old age. Older residents’ spirituality can be a resource for the relief of their spiritual pain. I shall discuss spiritual care later on in this chapter.
6-1.2 Families’ concerns about older residents’ end-of-life care

Families expected that their relatives live the same way in the nursing home as they used to do in their own home. Some families were remorseful that they had made their father or mother to enter the nursing home: they felt their lack of physical capacity had brought them to the nursing home. Ms Aoki’s daughter expressed:

I wanted to take care of her until she died. But my physical condition was worse. I could not take care of her. I always worried whether she could live comfortably and happily in here. When I saw that she looked like she was enjoying herself with other residents and staff I felt relieved.

The family’s sense of remorse led to worry about the care their relative would receive in the nursing home. The staff reported to families any change in residents’ physical and emotional status, or any trouble they had with other residents. Some families were not able to visit regularly. Families were upset when they saw that their relative’s condition had changed when entering the home. Sharing residents’ information with families is very important so that they had an opportunity to understand the situation. Mr Konishi’s son voiced:

I was shocked when I saw my father had messed his toilet…I heard his condition from my wife, but I could not believe his dementia had progressed. He still remembers he was a doctor. Then he was orderly and, he was respected by his patients...

Families found it difficult to face their father or mother’s changed physical health status, and found it difficult to accept that they were dying. As described in chapter four, families had difficulties in making decisions on treatment on behalf of their relatives. Although they understood that medical treatments brought suffering to older residents, families themselves also felt sadness and suffered from the separation of their loved ones. They suffered chaotic feelings of devotion for their loved ones and feared losing them, as was
the case with Mr Endo’s son and Mr Kawata’s daughters. Frequent communication with
family members and sharing with them about any difficulties is important for the decision
making process of around treatment for their older relative at the end of their life.

Metha and Chan (2008) assert that the family also experiences ‘total pain’ like their dying
parent. Ms Sato’s daughter, as mentioned in chapter five, was devoted to her mother and
she supported Ms Sato’s wishes as much as possible. She was a teacher and had two
children herself who were in junior school. She created time to spend with her mother,
whilst also making the effort to manage her working life and family life. One day she came
to the nursing home and looked exhausted. I asked her “Are you alright?” and she replied:

I am Ok but I am a bit tired. My son will take an examination to enter a high
school. He is very sensitive now. I spend time with my mother, but I also really
need take care of my son. But I do not want to regret not caring for my mother. I
could not do anything for my father when he departed.

Her eyes filled with tears when she talked. She suffered physical pain and fatigue caring
for her mother and her son; social pain in balancing time with her mother, son and in her
work; emotional pain through her suffering by herself which she could not express to
others; and spiritual pain because she blamed herself whether she was able to care for her
mother enough. Profound empathy for these different types of pain among families is an
essential part of providing support to older residents in their end-of-life care.

6-1.3 Nursing assistants’ perspectives on end-of-life care

Most of the nursing assistants were in their 20s and the average length of work experience
was less than three years in the Noboru nursing home. I interviewed eight nursing
assistants; only two of which had close experience of death, and only one had experienced
the death of a resident. They expressed difficulties in caring for older residents who were
dying. I asked them what their picture of death was and they replied:

Death is darkness, scary, fear, destiny, disappearance from this world, loss of one’s existence, painful separation, and sadness.

The nursing assistants held negative ideas about death and replied that it was difficult to imagine death itself. A lack experience of death among young nursing assistants led to difficulties in caring for dying residents. When Mr Endo who, as discussed in chapter four, suffered from terminal cancer, entered a terminal stage of his disease, the nursing assistants voiced:

I do not know how I can talk with him. He asked me “What kind of disease do I have?” I could not look him in his eyes and I said “I do not know, please ask the nurse.” I ran away from him because I was scared to care for him (Nursing assistant A).

When I saw him he was in pain. I only could touch and massage his back. I could not relieve his pain. After some time he asked me “Can you stay with me?” but the assistant call was ringing and I had to leave him. I wanted to stay with him, but I should care for other residents too (Nursing assistant B).

When I was on night duty I was afraid he would die. I checked him every hour. He could not sleep in the night. He told me night time was when he felt more pain. I called the nurse and she gave him painkillers but he was still in pain. I felt it was not only physical pain but also sadness (Nursing assistant C).

Nursing assistants struggled to face the pain of terminally ill older residents. They wanted to support him, but felt powerless. I asked them: “if your father or mother were in the same situation as Mr Endo what would you do for them?” Two replied:

If my parents suffered cancer, I would tell them the truth and I would discuss with them how they wanted to spend the rest of their life. I would relieve their pain as much as possible to comfort them until they departed from their life (Nursing assistant B).
If my parents were in the same condition as he was, I would help them wherever they want to go or whatever they want to do with effective pain control at the end of life (Nursing assistant C).

Two nursing assistants also expressed other difficulties around end-of-life care:

I was trained in daily care but I did not learn how to care for dying residents. Dying residents need medical treatments. Caring for dying residents is the task of nurses not of nursing assistants. I think nursing assistants find it difficult to care for dying residents (Nursing assistant D).

We are always concerned about time. There are many things to do in a short time. I feel sorry that I cannot spend more time for each resident. Some nursing assistants can manage well. They talk with residents. But I still have difficulties with time management (Nursing assistant E).

Some of the other nursing assistants also mentioned a lack of knowledge and skills regarding end-of-life care and the time pressures they had in daily care. They perceived end-of-life care to be only for dying residents, and those in need of medical treatments were difficult to care for.

I asked the nursing assistants if they were residents in the nursing home, “how would they want to be cared for at the end of their lives?” Three expressed:

I want be free and go to my memorial place before I die.
I want to be surrounded by things and people I like.
I want to be calm and peaceful without pain and suffering.

Attitudes towards life and death is altered by the personal experience of death, and one’s own experiences of loss and suffering. Becker (2003) asserts that one’s understanding of death is developed through one’s experience of the death of a close relative or friend and this experience shapes one’s search for meaning in life. Sakurai et al. (2009) suggest that nursing assistants’ understanding of death is developed by caring for dying older residents, which gives them an opportunity to reflect on their own human worth in life.
6-1.4 Nurses’ perspectives on end-of-life care

I interviewed two nurses; Nurse Kita who was in her early 40s, had ten years of experience working as a nurse in a hospital, and had worked in the Noboru nursing home for three years; and nurse Abe, who was in her early 30s, and had five years experience working in hospitals; and who had worked for three months in the Noboru nursing home. Nurse Abe expressed her lack of confidence concerning end-of-life care in the nursing home:

In the nursing home it is difficult to control the pain of residents. I have a lack of experience of providing pain control to terminally ill patients here. Unlike in the hospital, in the nursing home there is a lack of medical equipment and the doctor is not here all the time. I feel the nurse’s responsibility is very heavy. I still feel I have little confidence to care for terminally ill residents in the nursing home since I started to work in here.

She did not have experience caring for older people and those that were terminally ill, and so expressed her difficulties caring for them.

In contrast, Nurse Kita described her experience of caring for one resident who was dying in the nursing home:

I learnt a lot from caring for Ms Tani who was dying. She was 94 years old and she and her family did not want to any medical treatment at the end of her life. She suffered from oedema because of heart failure and took only oral medicine. I had a difficult time because I wondered whether we could have given her more medical treatment. In the hospital, we try to resuscitate the patients’ life as much as possible and often have to checking the monitors. I had never experienced caring for dying patients without a monitor. I had to pay close attention to observing her physical and mental condition. On the day she died, she ate lunch as usual. After one hour her breathing changed and the doctor and her family came to the nursing home. Gradually her heart stopped. It was very calm. I felt, how can I say, I could see her depart from this world.

Through her experience of caring for Ms Tani, she saw how important it was to respect the dying older person’s needs of how it was to ‘die well.’ Her experience reflected her sense
of nursing care; she always said to other care staff that “observation is very important—what residents want to do, we really need to pay attention to them; to see, listen, touch, and feel.” She further expressed her difficulties as a nurse around end-of-life care:

The needs of Ms Tani and her family were same. In an ideal situation, nurses often adopt a middle position between residents and their family. I regretted Mr Endo had to die in the hospital. He wanted to please their family. The nurses explained his real intention to the family. However, his family was not aware of his real needs. Ultimately, he followed the family’s decision. I should have communicated with his family more often. When residents enter the nursing home, we do not discuss their end-of-life care with them and their family. It was difficult to ask this question when they started to live here. However, it is very important for residents to die well to find out how they want to spend their time in the end.

She suggested that it is important to discuss how residents spend their time at the end of their lives when they enter the nursing home. I asked her what her opinion was of ‘advanced directives’ and ‘advanced care planning.’ She answered:

‘Advanced directives’ and ‘advanced care planning’ are very important in making decisions for respecting residents’ autonomy. I know some nursing homes have started to write these directives. I asked the director to introduce ‘advanced care planning,’ but guidelines for end-of-life care have not been produced yet and are under discussion in the company’s policy. I do not know when we can utilize them…

Organizational structures shaped barriers to improving quality end-of-life care among nurses and nursing assistants in the nursing home setting. Davis and Konishi (2000, p.91) highlight the nurses’ difficulties in being involved in the decision making of older people’s end-of-life care:

Japanese nurses often find themselves between the patient and the family, the family and the physician, or the patient/family group and the physician…Japanese nurses have neither laws that protect patients’ rights nor clear-cut ethical principles to guide them. They grapple with their own notions of ethics within their own culture.
6-1.5 The doctor’s perspective on end-of-life care

The doctor visited the nursing home once a week to examine the residents. He was a geriatrician and always tried to respect the residents’ and family’s needs. For instance, one diabetes resident wanted to eat whatever he liked at the end of his life and the doctor allowed him to stop a calorie-restricted diet. The doctor gave as an example the case of a terminally ill cancer resident (Mr Endo):

I think that I should communicate more with him and his family when he was diagnosed with cancer. Pain control is important in the terminal stage. But pain control of the cancer resident in the nursing home is difficult due to management of narcotics. Care of terminal cancer residents needs to cooperate with the hospice.

Furthermore, he expressed his perspective of end-of-life care in the nursing home:

I think the role of a doctor in end-of-life care in the nursing home is assessment of the residents’ condition, explanation of possible treatments and life prognosis, and provision of appropriate pain and symptom control using non or minimally invasive treatments. Some older residents and family ask me: “What is the best way to do this?” or say “I’d like to leave the choice to the doctor.” They might have their own preferred way of treatment. But some residents hide their real intention of treatment. I come here only once a week so I can’t grasp all residents’ condition. The nurse’s report is very important to assess residents' real condition and needs.

Older residents tend to hide their real needs in front of the doctor. Since the older generation grew up under the umbrella of medical paternalism, they considered they should follow the doctor’s decisions on treatment. However, they did express their real needs to the nurses. Nurses played an important role as a messenger or mediator of the older residents’ real needs of treatments to the doctor.
6-2 Important components of quality in end-of-life care

As the previous discussion has shown, different people hold different views of end-of-life care. Before discussing the components of quality of end-of-life care, there is a fundamental point which needs to be clarified, namely, “what is care?” An exact equivalent of the English word ‘care’ does not exist in the Japanese language. The term ‘care’ is used in health care and social welfare since the introduction of Western medicine into the Japanese culture. Kleinman and Van der Geest (2009) elaborate that ‘care’ consists of emotional and technical/practical acts. They argue that the emotional act of caring involves special devotion on the part of the caregiver, whereas technical acts of caring focus on the practical daily tasks of caring for someone who is more dependent than themselves, due for example, to a physical disability. In their phenomenological account of caring, Kleinman and Van der Geest (2009, p. 160) also draw upon an existential view of ‘care’ based on Heidegger’s ideas:

the act of caring for oneself and for others and the attitude of ‘care-fullness’
typifies being a ‘human being’; to ‘care’ is the essence, the structure of being.

Matsuoka (2007, p.44) also discusses in his theory that “care is equivalent to the will or the motivating force of life.”

As described previously, older residents’ spirituality in the nursing home setting is important resource to help them to discover their human existence in life and shapes their inner strength. In considering the role of ‘care’ for one’s spirituality, ‘care’ would be an essential and fundamental spiritual resource. Care in this broader sense would imply companionship with other older residents in their journey to the end of life.

Spiritual care has been discussed as an integral part of quality of end-of-life care for older
residents (Hicks, 1999). However, as is the case with definitions of spirituality, the meaning of ‘spiritual care’ is still open to question. Touhy et al. (2005) argue that spiritual care is described within the context of deep personal relationships, and holistic care, including physical, psychosocial and spiritual comfort, and support for residents. Bush and Bruni (2008) report that introspection of one’s self’s beliefs and values and the awakening realization of one’s sense of spirituality is essential in order to recognize the spiritual needs of others in spiritual care. Searching for one’s own sense of spirituality and experience of relationship with older and dying residents would allow staff to provide a more profound depth of care.

Matsuoka (2007, p.44) discusses Mayeroff’s theory: “Caring is the antithesis of simply using the other person to satisfy one’s needs; it is not an isolated feeling or a momentary relationship, but a process of helping another grow and actualize him/herself through mutual trust and through a deepening and qualitative transformation of the relationship.”

Caring older residents who have accumulated life experiences at the end of a long life is an opportunity for the nursing home staff to encourage their personal growth. Sakurai et al. (2009, p. 47) assert that

A care person who is attending to a dying one’s departure receives ‘meaning of life’ from the dying one: the care person explores and discovers one’s own ‘meaning of life’ received from dying one throughout the life span, and the care person will give their ‘meaning of life’ to others when they depart: one’s ‘meaning of life’ is continuing from the dying one to living one [translated from Japanese].

End-of-life care should imply a process of inheriting the older people’s meaning of life. What is more, based on findings of the study I shall now further elaborate on important components of quality of end-of-life care, namely: introspection, compassion, intuition, interpretation and sharing time.
6-2.1 Introspection

Most of the nursing assistants expressed a lack of experience in facing one’s death in their life. In searching for one’s view of life and death supports staff by leading to a greater awareness of older residents’ feelings, such as their suffering, fears, anxieties, loneliness, and the loss of their existence at the end of life. In this study, older residents were willing to talk about their views of life and death with staff in order to search for their own meaning of existence in life. Accompanying them on their life journeys, staff have opportunities to explore for themselves existential questions such as: “what is death?,” “what is life’s worth?,” “what is life?,” and the relationship between self and others, and with a wider transcendent reality beyond life. Discovering one’s view of life and death also leads to introspection of one’s own spirituality.

6-2.2 Compassion

Development of one’s spirituality and view of life and death brings compassion between staff and the older residents. Compassion consists of ‘com’ meaning sharing and ‘passion’ meaning ‘to suffer’ so compassion can represent sharing one’s suffering. Sensitivity of the self and others generates compassion. Older residents feel relieved by the presence of someone to share their suffering with. Rather than offering advice or opinions, it is important that the staff off a silent ear and listen empathetically. Hicks (1999, p. 146) describes the “silent witnessing which occurs when care staff serve as a sounding board.” Kleinman and Van der Geest (2009, p.161) state that “caregiving is an interpersonal experience; it is concern and compassion, and, in a larger sense, love.”
6-2.3 **Intuition**

Sensitivity of the self and others leads to a cultivation of one’s own intuition. Intuition is an essential part of care. Enabling staff to be aware of older residents’ changes in physical and mental functioning ensures they recognize their physiological, psychosocial, and spiritual needs, and older residents feel the staff’s carefulness towards them. One of the nursing assistants had a high sense of intuition and he always discovered and reported any slight changes in the functioning and wellbeing of the older residents she was caring for. As a result, they trusted and opened up their feelings towards her. Furthermore, agitated dementia residents also opened up her. She was in her mid-20s and had been working in the nursing home since two years. I asked her “How do you find out whether the residents are changing?” She replied:

> I just observe the atmosphere in their room and if they have a different attitude, movements, expression, and countenance from usual. I can feel if something is changing, but I cannot explain exactly what is different, so I report this to other nursing assistants and nurses.

In this quotation she highlights the use of all her senses, such as seeing, listening, touching, and smelling when observing the older residents she was caring for.

6-2.4 **Interpretation**

Attentive observation of older residents lead by the care staff leads shapes the building up of a supportive and mutual relationship. The process of ‘interpretation’ is also essential for understanding older residents’ real needs. For instance, residents sometimes hid their real intentions, but tried to show some metaphorical expressions, or countenance. It is essential to interpret what their attitude and behaviour meant to understand their real intentions. Sensitive interpretation plays an important role in the interaction between residents, family, staff, and the doctor. In the ‘interdependent culture,’ as Slingsby (2004) suggests a
‘relatively subjective’ style of behaviour and communication is shaped by what seems to be most appropriate to one’s relationship with the other and the particular.

6-2.5 Sharing time

Staff expressed time pressures in their daily care, but residents expressed that they were willing to take time with them. This meant that there was a led to a disparity between the residents’ and staffs’ priorities and the meaning of spending time with one another. The question raised was, how can this disparity between them be overcome? This solution is not only by having an adequate number of human resources or appropriate time management. A fundamental solution is how can the staff create an interactive meaningful time spent with the residents. One’s sense of time is influenced by one’s own perceptions of time, their relationships with others and is dependent on one’s circumstances. Sharing time without interaction, carefulness, or compassion leads to older residents feeling a loss of identity, a sense of loneliness and meaningfulness. Furthermore, sharing meaningful time means that staff are enabled to share time with residents using their senses of observation, intuition, interpretation, carefulness, compassion and spirituality. Sharing time with older residents in end-of-life care means that staff come to value the worth of older residents’ time in the nursing home, which is both precious and limited.

6-3 Conclusion

Older residents experienced physical, emotional, and spiritual pain due to the loss of loved ones and social roles, physical or cognitive health limitations and independence in their end-of-life journey. Spiritual resources among older residents acted to overcome such pains through allowing a space to explore their meaning of life and death. Care represents companionship with older residents in their journey through their end of life: a
The nursing home care staff play an important role in attending to older residents’ departures from life in a meaningful way. However, this study found that there was a gap between the staff’s expectation of providing care and the residents’ actual received care. This gap caused shaped undignified care among the residents. The staff had difficulties in providing good quality of care to satisfy the needs of residents under a ‘time pressed culture’ in the nursing home. The staff need to develop their sensitivity in sharing a meaningful sense of time with the older residents and to nurture a profound sense of empathy for them. The essential senses of quality of end-of-life care are observation, introspection, intuition, interpretation, carefulness, and compassion. Furthermore, companionship with older residents on their last journey from life would create opportunities to share a profound sense of meaning in life and death among the staff. This experience provides staff with a profound depth of care for the older residents they are caring for. In the next chapter, I shall offer some conclusions and discuss some recommendations based on findings of this ethnographic study.
Chapter 7
Conclusion: Departing from a long life

The older residents in this study have had a long life’s journey; like the flow of river passing the peaks and troughs of the valleys, they arrived at the nursing home for the last place in their life’s journey. The role of the last place of their end of life is to support the older people to living meaningfully until the end and to attend of their departures peacefully and comfortably. However, in the new environment of the nursing home, older residents experienced a loss of identity, physical and cognitive impairments, and dependence. They searched for two fundamental questions related to their existence: “who am I?” and “what am I?” They reviewed their life history and they discovered their reasons and worth of living, and ultimately reconstructed new identities for adapting to the circumstances of the nursing home.

Spirituality played an important role in the process of reconstructing older residents’ new identities. The centrality of spirituality in end-of-life care was a key finding in this study. The centrality of spirituality as a holistic framework shaping healthcare was also found in the study by Bush and Bruni (2008), who report that the nurturing of one’s spirituality is fundamental to the maintenance of one’s health and the promotion of healing. This study illustrates that spirituality is “an intrinsic boat (i.e. the essence of being human) of one’s life journey for discovering transcendence of the self and one’s own existence: spiritual resources allow a person to search for one’s meaning in life and death, and provide an anchor and a compass for the individual in shaping their inner values, strength and peace.”

Older people’s spirituality and attainment of transcendence of self was influenced by the experience of earlier life crises (e.g. health limitations, the loss of a family member), and beliefs in greater powers beyond life, such as towards ancestors and deceased loved ones,
divine beings and with nature. Awareness of the importance of spirituality in the process of caring among the nursing home staff was essential for the healing of older residents’ pain: and promotes dignity despite experiencing crises or despair.

Following Sakurai et al. (2009), this study highlights that end-of-life care is an extension of the care of daily activities. Older residents’ experiences of everyday life were often related to their body and its decay. They complained about pain, which was not only physical in nature. Physical pain was made worse by psychological causes, such as, fear, anxiety, and depression. They expressed their pain indirectly, metaphorically, and non-verbally. Furthermore, they hid their real needs and showed their autonomy through non-verbal ways, such as, in their facial expressions, ways of eating and asking for assistance to go to toilet. Being sensitive to recognizing and understanding the older resident’s pain and real needs is an essential part of their care, and shapes compassion between residents and staff.

Families shared physical, social, emotional, and spiritual pain with dying residents. They had to make difficult decisions about their relatives’ medical treatment at the end of their life. Relatives were overburdened with surrogate decision making concerning advanced dementia among their aged parents. Although they understood that medical treatments brought suffering to older residents, families themselves felt sadness and suffered from the separation of their loved ones. They needed time for spiritual preparation to accept their relative’s departure. It is essential older residents, their families, the doctor and the care staff are able to openly communicate with one another in the early stages of entering the nursing home about their departure and end-of-life care. Nurturing profound empathy for their pain is part of essential care to support the family support at the older person’s end of life.
End-of-life care for terminally ill older people in the nursing home leaves room for a variety of interpretations. This study showed that an interdependent culture underlay the notion of non-disclosure for terminally ill in the context of family centred decision-making. On the one hand, disclosure was considered cruel; on the other hand non-disclosure was considered to be a way of protecting loved ones from potential harm as well as maintaining an atmosphere of calm and an attitude of hope (cf. Long, 2004; Hattori et al., 2006). There was ambiguity of autonomy and individual dignity under this culture. Mr Endo’s case demonstrated that his autonomy was not respected and his decisions were shaped by others. There was a conflict between the views from others and those of the older residents, for example, between Mr Endo and his son. The very act of interpretation of the viewpoints of families and residents’ is important to overcome potential conflicts. It is noteworthy to interpret what the attitudes and behaviours of different social actors mean in order to understand their real needs. Sensitive interpretation plays an important role in the interactions between residents, family, care staff, and the doctor.

The findings from the study highlighted the generative concerns of the older residents in that they tried to leave their stamp in life through their descendants in demonstrating their existence. The nursing home staff had an important role in their end-of-life care by accompanying them on their final life journey until departing from this life. The staff supported the older residents by enabling them to leave their stamp behind in life before their death. The experience of companionship with dying older people shaped a profound sense of meaning in their life which staff could sensitively nurture and cultivate.

In conclusion, based on the findings of this study, I would like to make some recommendations on end-of-life care in the nursing home setting (see Table 2). Addressing and respecting older residents’ spirituality is the core aspect of end-of-life care. Spiritual
resources are essential anchors for individuals to overcome despair at the end of life. Care staff need to be encouraged to discover what spiritual resources mean to the dying older person. The staff play an important liaison role for activating those spiritual resources, for example, through the family. They support residents to create their own spiritual resources, like the tapestry displayed in Ms Sato’s room. In supporting the development of their spirituality, the care staff nurture and cultivate sensitivities in terms of intuition, interpretation, introspection, compassion, and the sharing of time.

Staff education and training is essential for providing quality of end-of-life care. Issues around death and dying should be an integral component of the training program of care staff in order to encourage them to reflect on their own spirituality and views regarding life and death. Appropriate pain and symptom control for the terminally ill is important to relieve their physical, emotional and spiritual pain, and to live comfortably at the end of their life. Staff expressed that they had insufficient knowledge of pain and symptom control in the terminal stage of older resident’s illnesses. Thus, teaching pain/symptom control should be an essential part of their end-of-life care. Furthermore, discussion of end-of-life treatment decisions in staff training programmes is important so that they understand how to maximize dying older people’s dignity and are sensitive to the suffering of their families.

Finally, it is necessary that nursing homes develop clear guidelines in end-of-life care, including advance directives. This is a much debated subject which needs to be given greater attention to as there is currently no law relating to advance directives in Japan society.
Table 2. Recommendations on end-of-life care in the nursing home

Developing older residents’ spirituality
- To explore residents’ spiritual resources
- To have a liaison role for activating spiritual resources
- To support, develop and create residents’ spiritual resources
- To explore and support residents’ meaning of life and death through sharing their life experiences and in life reviews

Family support
- To communicate frequently with the family of older residents
- To allow opportunities for the family to share their difficulties
- To have profound empathy for their pain in relation to their dying relative

Important senses in end-of-life care among staff
- Intuition- to be aware of slight changes in the condition of older residents
- Interpretation- to understand older residents’ real needs
- Introspection-to nurture one’s own sense of spirituality
- Compassion-to share in the suffering of residents and their families
- Sharing time-to attend to the quality of meaningful time spent with residents and their families

Staff education and training
- To cultivate a sense of sensitivity
- To explore one’s views on life and death
- To explore one’s own spirituality
- To be educated on pain and symptom control in the terminal stage
- To be trained in communication skills for nurturing an important sense of care
- To discuss surrounding end-of-life treatment decisions

Organizational interventions
- To develop clear guidelines of end-of-life care
- To provide education and training for staff
- To discuss end-of-life care with older residents, their family, the care staff, and doctor when entering the nursing home

This exploratory ethnographic study has described and contextualized important components of end-of-life care for older residents in three Japanese homes for older people. As the recommendations indicate, much still remains to be done to enhance the respect and dignity of older residents in the nursing home setting when they are about to depart from a long life. It is important to keep in mind that the nursing home is a place in which older people can pass on profound meaning to following generations.
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