PERCEPTIONS OF FUTURE AND ADVANCE CARE PLANNING FOR JAPANESE WOMEN WITH EARLY STAGE GYNECOLOGICAL AND BREAST CANCER

by

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ABSTRACT

Advance care planning (ACP) is the process that allows individuals to choose a path of care in the event that they are unable to make a decision for themselves. The concept of advance care planning is much broader than merely putting wishes in writing; however, misconceptions exist. The purpose of this study was to gain understanding of perceptions of Japanese women with early stage cancer about ACP. A theoretical model for ACP was developed from review of current knowledge. This study was significant to developing culturally sensitive intervention in supporting ACP in this Asian population.

This study utilized ethnography guided by phenomenology. Fifteen semi-structured qualitative interviews were conducted between January 2009 and March 2010 with ten Japanese women with breast or gynecological cancer, recruited from Kochi (rural) and from Tokyo (urban) prefectures in Japan. The mean age of the study participants was 46.6 years: range was 37 to 59 years. The audio-recorded interviews lasted from 21 to 110 minutes (M=65.1). The time from diagnosis to interview ranged from 3 months to 18 months (M= 11 months).

Data were transcribed and analyzed in Japanese language to preserve cultural meanings and contexts. Data were coded and categorized, and then were analyzed in
both language in a way to derive cultural themes. Quotations in Japanese and English
illustrated findings.

Data analysis yielded a set of rich findings including cultural descriptive and
contextual themes, and themes specific to ACP. Overall, the concept of palliative care
was not well diffused in Japanese society and participants had demonstrated difficulty
grasping the concepts. Regardless, participants expressed a willingness to learn about
ACP and recognized the significance of developing advance directives. Enryo, sashhi
and amae were identified as concepts grounded in Japanese culture and can be found
in their communication style. The overarching theme was “Culture and Dynamics in
Japanese Communication influencing advance care planning: Sasshi and Amae”.
Significant cultural implications related to the importance of families in the ACP
process were identified. Through the perspectives of these participants, Japanese
fundamental concepts were found to have significant influence on decision-making
process in ACP.

The form and content of this abstract are approved. I recommend its publication

Approved: Joan K. Magilvy
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LIST OF GLOSSARY

Glossary

**sasshi** (n.) [sa-shi:察し] An interpersonal guess work about the quality and quantity of amae that the communicator engage in before she or he encodes meanings and decodes message in the communication process (Miike, 2003) Dictionary translations: conjecture, surmise, a guess, judgment, understanding, sensitivity, comprehension, consideration

**amae** (n.) [a-ma-eh:甘え] Behavior to depend and presume upon another’s benevolence (Doi, 1956), Dictionary translations: [a child's] attention-seeking [behavior], reliance on others, dependence

**amaeru** (v.) Behavior of amae

**omonbakaru** (v.) Same as Sassuru that is a verb form of Sasshi. Dictionary translations: consider, deliberate, take careful thought, think over, ponder


**Yome** (n.) [yo-meh: 嫁] Dictionary translations: a wife, a bride, a daughter-in-law

**kaigo** (n.) [ka-ee-go:介護] Dictionary translations: nursing care, care-giving, caring, nursing service

**mawari** (n.) [ma-wa-ree: 周り] In this interview context, participants used this term to describe "people around the person". Dictionary translations: circumference, girth, the border, the fringe, neighborhood, the vicinity

**nodomoto- sugireba (atsusa-o-wasureru)** [喉元過ぎれば熱さを忘れる] A thing happened has become past, people forget how hard it was. Similar expression: The danger past and God forgotten

**Uchi** Inside, internal, private (Maynard, 1997)
<table>
<thead>
<tr>
<th><strong>Soto</strong></th>
<th>Outside, external, public (Maynard, 1997)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>kangoshi</strong>(n.)</td>
<td>Registered nurse(RN)</td>
</tr>
<tr>
<td>看護師</td>
<td></td>
</tr>
<tr>
<td><strong>Jyun-kangoshi</strong>(n.)</td>
<td>Licensed practical nurse</td>
</tr>
<tr>
<td>准看護師</td>
<td></td>
</tr>
<tr>
<td><strong>ACP</strong></td>
<td>Advance Care Planning</td>
</tr>
<tr>
<td><strong>EOL</strong></td>
<td>End-of-Life</td>
</tr>
<tr>
<td><strong>PC</strong></td>
<td>Palliative care</td>
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CHAPTER I
BACKGROUND AND PURPOSE

Cancer is the leading cause of death in Japan with more than 367,000 deaths annually (Ministry of Health Labor and Welfare, 2012), and in the United States (US) cancer leads to more than 577,000 deaths annually (American Cancer Society, 2012), thus, the development of high quality cancer care is a critical need in both countries. To plan high quality, patient-centered cancer care, an advance care planning is essential, including aspects of desired treatment such as palliative care and advance directives.

Advance care planning is necessary to provide quality care tailored to the patient and family’s needs and wishes. Nursing plays an integral part in caring for patients throughout the course of their illness. Nursing care is holistic, patient and family-centered, and respectful of the dignity and life of individuals. Ethically, nursing has a role in assisting patients and their families in expressing their wishes related to their cancer treatment and to introduce palliative care as early in the course of disease as possible; therefore advance care planning is an essential first step toward identifying what patients want and need.

Advance directives and living wills are the written documents most commonly used in the process of ACP. In the United States, the Joint Commission for Accreditation of Health Care Organizations requires that all patients be offered information about ACP (Patel et al., 2004), yet the advance directive completion rate is still reported to be between 13% to 29% (Braun, Onaka, & Horiuchi, 2001; Hanson & Rodgman, 1996; Jezewski, Meeker, Sessanna, & Finnell, 2007). In Japan, while private efforts to disseminate advance directives have been made, advance directive (AD) does not have
legal authority. The situation in Japan indicates an urgent need to promote the introduction of advance care planning in the early stages of illness.

**PALLIATIVE CARE AND ADVANCE CARE PLANNING**

Advance care planning (ACP) is an essential part of palliative care, and may occur prior to provision of palliative care. ACP is defined as “discussions (that) promote shared decision making among patients, their families, and healthcare providers, as providers can educate patients and families about viable treatment options and patients can share their values and goals for treatment” (Moore, 2005, p. 39). While an AD is a document to describe the patient’s wishes at a given moment, ACP is a much broader process of assisting, developing, and reassessing the patient’s wishes as the patient’s condition changes their ACP wishes may change. Because of the reasons, promoting ACP at the early stage of life-threatening illness is necessary. Another essential component of care of persons with cancer and others with serious illness in ACP are reviewed in following sections.

Palliative care is an integral part of cancer care because of its holistic and humanistic approach. Palliative care is defined as:

An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through preventions and relief of suffering by means of early identification and impeccable assessment, and treatment of pain and other problems- physical, psychosocial and spiritual (WHO, 2007, p.3).

Palliative care consists of an interdisciplinary team, such as physicians, nurses, social workers, and chaplains. In palliative care, nursing plays an important role in advocating for patients and families and in developing and educating communities in order to promote palliative care (Stanley & Zoloth-Dorfman, 2001). Palliative care is a
very unique inter-professional discipline in which professionals such as physicians, nurses, social workers, and chaplains engage in patient and family-centered care, assisted by other professionals and lay people such as pharmacists, dieticians, and volunteers.

A palliative care team is an ethically responsible entity that advocates a patient’s autonomy. This holistic and multidimensional approach is also one of the prominent components of palliative care. Palliative assessment involves not only physical but also psychosocial, spiritual, and cultural aspects. Although cancer remains a life-threatening illness, many people live with cancer for a long time because of the improvement in treatment, creating a need for long term support for cancer patients, similar to a chronic illness. As palliative care intends to maximize patient symptom management and quality of life, integration of palliative care for cancer patients early in the course of the illness is desired. Development of ACP is an essential component of introducing palliative care, as ACP includes awareness of quality of life. PC would be part of the ACP and treatment plan for these patients.

The World Health Organization (WHO) recommends that the trigger point to start palliative care is at the time of diagnosis of life-threatening illnesses such as cancer and cardiac disease (WHO, 2007). Today, advanced medical technologies have become widely available in Japan. Whereas over-utilization of technologies to prolong life has escalated, a question of providing such care at the end-of-life (EOL) has been raised. A similar trend can be found in other developed countries, such as in the United States (US) and United Kingdom (UK). Recognizing the principles and ethical implications
embracing palliative care is important for determining the future direction of this care modality worldwide.

Awareness of ACP as a concept of palliative care has become prominent. Palliative care was introduced to the US in the late 1960s as hospice care. Currently, hospice care is a part of palliative care, yet the concept of palliative care is much broader than hospice care and not limited to EOL care. Currently palliative care is widely available in the US, yet not enough governmental or systematic support exists; thus, private and organizational efforts are sustaining palliative care in this country. In Japan, a country that utilizes a universal insurance health care system, hospice care first started in 1973, and financial reimbursement for palliative care was implemented in 1990. The Japanese government financial reimbursement was raised significantly in 1997 (Kotani, 2004) accelerating the increase in number of certified palliative care facilities. In Japan, palliative care is gradually becoming more popular among health care professionals, and utilization is growing; however there are political views around it.

The growing interest in palliative care is believed to result from the public’s increased awareness of human rights. The patients’ rights movement beginning in the 1960s that contributed to drastic legislative changes (Berg, Appelbaum, Lidz, & Parker, 2001). Since then, consumerism in healthcare further promoted a patient’s right to choose, right to explanations about their illness and care, and is now an accepted in and exemplified by informed consent. The component of palliative care that respects a patient’s autonomy is congruent with this movement. Palliative care providers are particularly conscious and sensitive about ethical issues, especially over-utilization of unnecessary life support at the end-of-life.
The underlying philosophy of palliative care is different from the modern medical model; thus palliative care can be employed inclusively with active treatment. To implement this inclusive care model, advance care planning is needed and should be initiated early in treatment, when the patient is capable of making such decisions. In reality, however, late development of ACP and late referral to palliative care is common and a serious issue. For this reason, despite the WHO’s recommendation, ACP is not as effectively utilized in Japan or in the US. Early decision making is the purpose of ACP, and understanding the Japanese perspectives on ACP is the focus of this study. First, a description of Japanese culture may provide essential content to the description of ACP.

CULTURAL DIFFERENCES: JAPAN AND THE US

Although political ideologies are different in the US and Japan, they do share some similarities. One similarity in both countries is the significant economic growth in the last 60 years, enabling the availability of advanced medical technologies in both countries. While technology has improved public health dramatically, an ethical question is raised concerning over-utilization of advanced technology for people who are in an irreversible condition. Another commonality between these countries is the location of care at the end-of-life. In Japan, the location where most terminally ill people die has changed radically in the last fifty years. In 1960, less than 20% of all deaths occurred in a hospital compared to more than 80% of deaths in 2001 (Iwasaki, 2004). This finding is very similar in the US, and most people die in the hospital (Kinzbrunner, 2005). Accordingly, both countries are facing similar ethical issues regarding end-of-life care.

As palliative care involves extreme consciousness about ethics, a necessity of promoting palliative care is evident in people with cancer as a life-threatening illness.
However, barriers exist to initiation of ACP. Curtis & Patrick (1997) identified one of the barriers as reluctance by physicians to initiate a discussion about AD, despite the public’s expectation that physicians should lead the discussion of advance care planning (Sahm, Will, & Hommel, 2005). In Japan, initiation of a discussion on palliative care is even more difficult because Japanese physicians tend to recommend aggressive treatments even for patients with incurable cancer (Motohiro, Hirota, Komatsu, & Yanai, 1994). Furthermore, in Japan a diagnosis of a life-threatening illness is not always conveyed to the patient. Gabbay et al. (2005) conducted a survey of 244 Japanese and 103 US resident physicians. Although 99% of physicians surveyed in both the US and Japan answered that they would provide a true diagnosis of incurable cancer to the patient, only 76% of Japanese physicians answered that they would inform the patient they were “dying” of cancer, compared to 96% in the US. Current conventional end-of-life care is developed based on frank diagnosis and conversation, and it is apparent that educating physicians to communicate frankly and truthfully with patients is necessary for development of an appropriate patient-centered palliative care plan although the patients’ cultural background should be carefully considered. In addition, it is evident that early introduction of ACP by physician has been challenging.

In general, public opinion has shown favorable attitude toward ACP in both Japan and the US (Iwasaki, 2004; Sahm, Will, & Hommel, 2005), yet the perceptions and attitude of cancer patients about ACP remains largely unknown. Understanding how cancer patients accept, and experience palliative care and ACP, is crucial for early initiation of palliative care for this population as recommended by WHO. Being diagnosed with cancer is a life changing experience (Stanton, Bower, & Low, 2006),
and understanding this population’s perspectives and opinions is necessary in evaluating early initiation of ACP. Further, this knowledge will be useful to health care providers in planning such care. Uncovering and describing concerns unique to different cultures are essential for viewing not only cultural differences but also finding universal themes. An ultimate research goal will be comprehensive understanding of patient’s perspectives of ACP through various populations, and cultural comparison and contrast would serve comprehensive theory of ACP. However, in this study, as a first step, I have perused cultural understanding of ACP in Japanese women with cancer. An implication of this study is to draw future directions for gaining understanding of patient’s perspectives regarding ACP.

**PURPOSE OF THE STUDY**

The purpose of the study was to describe the meaning of how Japanese cancer patients experienced ACP and palliative care from their perspectives and to explore future direction and strategies to integrate palliative care into the early course of life with cancer. In addition, this study included an exploration of how the Japanese cultural context influences patients’ perceptions and attitudes toward palliative care.

**Specific Aims**

Guided by the purpose of the investigation, the following specific aims were identified:

1. To explore the experiences of Japanese women with early stage breast and gynecological cancer regarding ACP and palliative care.
2. To describe patients’ and their family members’ previous experiences with ACP and palliative care.
3. To identify factors that might facilitate or impede patients’ comfort levels in discussing ACP and palliative care.

4. To identify factors that determine and/or modify patients’ decision about ACP

5. To describe cultural influences on ACP and palliative care.

To address these specific aims, an ethnographic study design, informed by phenomenology, was used to explore the perspective of Japanese cancer patients and their experiences with ACP and palliative care. This subjective approach was essential to provide an in-depth understanding of the perceptions and experiences of patients in each culture and explore universal themes.

**SIGNIFICANCE OF THE STUDY TO NURSING**

Palliative care is an important part of total care for cancer patients. Consistent with the holistic nature of palliative care, nurses play a significant role in palliative care. Watson (2008) has emphasized a significance of humanistic care and ethical consciousness in nursing. She cited the importance of and gaining an ethical and holistic understanding of human experience is in the interest of nursing, to seek an appropriate direction for practice. Thus, a holistic understanding of cancer patient’s perception of ACP and PC is necessary for nursing practice.

Leininger (2002) contributed a transcultural nursing perspective, emphasizing a need for nurses to gain in-depth knowledge of cultural influences on health and illness. Taking an anthropological view, Leininger advocated that nursing practice from a cultural perspective can prevent “cultural biases, cultural clashes, cultural pain and
imposition practices, plus a host of major cultural conflicts and unethical care practices” (Leininger, 1997, p. 33).

In palliative care, a patient’s autonomy and cultural perspectives are significantly respected; therefore a cultural understanding of phenomenon of cancer patients’ perspectives on ACP and palliative care was determined to be necessary and congruent with Leininger’s approach. Despite recognition of the problem of late referral to palliative care and limited ACP, an effective strategy has not been identified by previous research. To develop an appropriate strategy to promote palliative care and ACP during the early stages of cancer treatment, understanding of patients’ perceptions, experiences, and attitudes is vital to planning care and influencing quality of life of cancer patients.

**SUMMARY**

Cancer as a life-threatening illness has a significant impact on patients physically, psychologically, and socioeconomically. A holistic approach to palliative care needs to be integrated to cancer care, but introduction of palliative care interventions must begin in early phases of cancer treatment; thus a need exists for advance care planning (ACP). Nurses play an important role in palliative care and ACP, as nurses are integral to planning and providing quality care for cancer patients. To develop effective strategies to introduce palliative care and ACP at an early stage of cancer, an in-depth understanding of patients’ perceptions and attitudes toward palliative care and ACP is necessary. Further, because ACP is an ethical decision and culturally-linked, cultural perspectives must be considered. This topic has not been studied in Japan with Japanese cancer patients and is the focus of the research.
In this first chapter, a proposed study to address the identified problem was presented, the purpose of which was to describe the meaning of how Japanese female cancer patients experienced ACP and palliative care from their perspective. This study was conducted with the hope of informing future interventions both in Japan, and to improve introduction of ACP and palliative care earlier in cancer treatment. In the next chapter, a concept analysis of ACP is introduced in addition to a theoretical framework for the investigation, demonstrating the state of the science of perceptions and attitudes toward palliative care and ACP. In Chapter III the design and methods for the proposed investigation are described. The remaining chapters IV, V, and VI are the findings of the research. Chapter VI presents a discussion of the findings and implications for further research, education, and nursing practice.
CHAPTER II
REVIEW OF LITERATURE, DEFINITIONS, AND CONCEPT OF ADVANCE CARE PLANNING

In this chapter, supporting information for this study is presented, including definitions of terms, current knowledge and state of the science. The literature review consists of three sections: 1) concept analysis of advance care planning (ACP), 2) palliative care and ACP in Japan and the USA, and 3) state of science on ACP. The most relevant definitions of terms for this study are discussed; including palliative care, hospice care, advance directives, and advance care planning. At the end of the concept analysis, a theoretical conceptual model of ACP is presented. Empirical literature is incorporated to examine current knowledge on palliative care and ACP. Finally, issues promoting palliative care and ACP for early stage cancer patients are presented.

Literature review was initially conducted in October 2008; updates were searched in February 2011 and October 2012. Literature search was done using keywords: advance care planning, advance directive, palliative care, and hospice care. Search engines used for this study were Medscape, CINAHL, PubMed, and Cochrane library for English and Japanese articles. In addition, I used Medical Online ® to search for Japanese articles. Articles were screened, and relevant articles were saved in the software EndNote®.

CONCEPTUAL MODEL OF ADVANCE CARE PLANNING

Advance Care Planning is not well understood, either in Japan or the US\(^1\). Evidently, many health care providers perceive advance care planning (ACP) as developing advance directives. Advance directives (AD) are an important tool to

\(^1\) The US refers to the United States of America in this thesis.
communicate with significant others and health care providers. However, the concept of ACP is broader than writing an AD. Currently, ACP discussions support for AD writing, and palliative care intervention have not been occurring until a patient’s death was imminent. People have a little or no exposure to either ACP information or palliative care interventions until end-of-life. The primary cause of this has been identified as late referral to palliative care. Palliative care team members often successfully assist people in making end-of-life decisions. At the same time, it is more difficult for people to make decisions when they are in crisis, which also raises ethical questions. Health care providers often consider ACP and palliative care most appropriate for people who are dying. This fact is evidence of a narrow concept that is misleading current practice.

As mentioned earlier, ACP is often perceived as only the completion of an Advance directive (AD) (Fried et al., 2012). Furthermore, it is sometimes considered as refusal of available life-prolonging medical technologies (Levinsky, 1996). Wide use and misuse of the term ACP is evident. In order to resolve these misconceptions, close examination of ACP is essential. In this section, the concept of advance care planning is reviewed, and later the model of advance care planning is presented.

**CONCEPT OF ADVANCE CARE PLANNING**

The concept of advance care planning (ACP) is broad and poorly understood, even by the health care providers (Teno & Lynn, 1996). The concept still remains under construction scientifically, because the emergence of the concept is relatively new. However, awareness of the importance of ACP has increased significantly, and clinicians and researchers are more interested in ACP. The increase of interest has occurred only recently. Ovid keyword search on "advance care planning" (search}
performed on April 6, 2012) found a total of 531 articles. Of those articles, only 21 articles were published before 2000, then 189 articles placed ACP as a keyword between 2001 and 2005. The number soared to 415 between 2006 and 2010. Simply looking at these numbers clearly demonstrates a recent increase in interest in this area.

Despite interest by the health care providers and researchers, the focus tends to be on writing advance directives (AD) and a living will (Allen & Ventura, 2005; Aw et al., 2012; Jeong, Higgins, & McMillan, 2010; Schubart et al., 2012; Sharma & Dy, 2011; Tobler et al., 2012; Yung, Walling, Min, Wenger, & Ganz, 2010). Advance care planning as a process has been proposed, but in reality scientific knowledge around it seems to be fragmented. This holistic concept analysis serves to capture the theoretical framework of ACP. In order to derive a theoretical framework for the study and model of ACP, a concept analysis was conducted based upon a method by Walker and Avant (2005). The concept analysis identified areas that need further investigations as presented in the following discussion.

**CONCEPT ANALYSIS GUIDE BY WALKER AND AVANT**

Understanding the concept of advance care planning (ACP) is vital to construct a theoretical framework for this study. It serves as a map of the attributes and categories, so that objectives and limitations of this investigation become clear. Without a framework, the locus of discussion would be ambiguous. In this section, I have used the concept analysis guideline by Walker and Avant (2005). According to these authors, "concepts are mental constructions; they are our attempts to order our environmental stimuli. Concepts, therefore, represent categories of information that contain defining attributes" (Walker & Avant, 2005, p. 63). The processes of concept analysis are:
1. Select a concept
2. Determine the aims or purpose of analysis
3. Identify all uses of the concept that you can discover
4. Determine the defining attributes
5. Identify a model case
6. Identify borderline, related, contrary, invented, and illegitimate cases
7. Identify antecedents and consequences
8. Define empirical references

(Walker & Avant, 2005, p. 65)

As a first step, I selected advance care planning (ACP) as a concept to examine.

The second process was to determine the aim or purpose of this concept analysis.

**Purpose of Concept Analysis**

The purpose of this concept analysis was to determine where fragments of current knowledge lie, so that a comprehensive understanding of the phenomena of ACP could be achieved. Understanding of the concept of ACP was expected to derive a theoretical framework for this study. This process also facilitated understanding of proposed interventions and theories proposed by other researchers, as a body of knowledge. The end product of the concept analysis was a model useful for organizing contributing constructs, and clarifying their relationships.

**Identifying Uses of the Concept**

ACP has been used in literature, mostly in the past ten years, because the concept is relatively new. Many recent studies and palliative care books mention ACP. Some examples in these studies and literature approach ACP as a process (Bomba, 2005; Fried et al., 2012).

In a palliative nursing textbook, Ferrell & Colyle (2010) discussed ACP as follows: "meeting the patient and family's preferences for EOL care requires advance
care planning that occurs early in the course of illness, or preferably in the primary health care setting while people are well and healthy” (p.79). In addition, Bomba (2005) emphasized that advance care planning is more than a document.

Literature supported the introduction of ACP in conversations with health care providers when people are in good health (Ahluwalia, Levin, Lorenz, & Gordon, 2012; Aitken, 1999; Bomba, 2005; Coyle, 2010; Teno & Lynn, 1996). Other statements proposed that ACP is for patients with life-limiting illnesses (Ackerman, 1997; Cohen, McCannon, Edgman-Levitan, & Kormos, 2010). While variety of perspectives was found in existing literature, in regard to the introduction of ACP discussion, I am accepting that earlier introduction is preferred. This decision was related to ethical problems with late introduction of ACP discussions.

Defining Attributes

The process of identifying defining attributes is the heart of concept analysis, and is similar to the criteria for making differential diagnoses (Walker & Avant, 2005). Many attributes and constructs are related to ACP. This step found on terms: palliative care, hospice, and advance directives.

Palliative Care

Palliative care is an active total care. Palliative care can be any care provided to treat the symptoms of any illness without curing that illness, such as appropriate analgesics for osteoarthritis or treatment for heart failure with digoxin and furosemide (Kinzbrunner, 2005). Therefore, palliative care can be provided to any patients who are in a chronic or acute condition. World Health Organization (WHO) defined palliative care as:

...
An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through prevention and relief of suffering by means of early identification and impeccable assessment, and treatment of pain and other problems—physical, psychosocial and spiritual (WHO, 2007, p.3).

The goal of palliative care is “neither to hasten nor postpone death” (McHale, 2002, p. 193). This concept needs to be recognized because most diseases are not curable, and “70% of currently available medical treatment should be considered palliative, focusing on the management of chronic illness” (Beltran & Coluzzi, 1997, p. 50).

Because of the recent advance in technologies, cancer patients are now considered as having a chronic illness. Palliative care ensures appropriate pain relief and abatement of other distressing symptoms (McHale, 2002), and the approach is also holistic, so that the care measures are not only pharmaceutical but also psycho-social and spiritual.

Palliative care is delivered by an interdisciplinary team, including physicians, nurses, social workers, and chaplains. In palliative care, nursing plays a critical role in advocating for patients and families, and in educating communities in order to promote palliative care (Stanley & Zoloth-Dorfman, 2001).

Palliative care has been discussed in the context of cancer care from the earliest days of hospice care, because of the recognition of cancer as a life-threatening disease. In the present day, further need for palliative care for people with cancer is evident, as the 5-year relative survival rate for all cancers is 62%. This represents the majority of individuals living with cancer (Gullatte, Kaplow, & Heidrich, 2005).

Hospice Care

Hospice care WAS FIRST STARTED in Great Britain by Dame Cicely Saunders during the 1960s (Kinzbrunner, 2005). Although palliative care and hospice care share
the care foci on quality of life and symptom management, the major difference is that hospice care is provided at the end-of-life; thus eligibility for a hospice program includes a life expectancy of six months or less. “Hospice is an interdisciplinary model of care for those who have reached the final stages of a terminal illness” (McHale, 2002, p. 147).

Patients’ and family’s wishes are valued over health care providers’ interests in hospice care, and prolonging life is not often intended. Developing achievable goals for a patient is vital, and palliative care teams work with the patient and family to achieve these goals. Hospice care is provided for people whose life expectancy is short, therefore the goal needs to be achievable in a relatively short time. Kinzbrunner’s table (2002) is helpful to see the differences between palliative care and hospice care in the US (Table 2.1).

Advance Directive

The definition of an Advance Directive (AD) is “a written document that informs healthcare providers of their medical management requests in the event they are unable to do so themselves” (C. Taylor, 2002, p. 1). Ditto and Hawkins (2005) described AD as “any statement given in advance [originally italic] of decisional incapacity directing [originally italic] the provision of life-sustaining treatment in incapacitated states” (p.S63). Because ADs are declarations of desired treatment and care developed in advance by patients prior to health conditions that lead to an inability to communicate, those wishes must be expressed when the person is competent. Waiting until a patient is near the time of being unable to express one’s self is contrary to the intent of writing ADs.

An AD should be written by a person who is in good health and is able to make appropriate decisions for himself (Teno & Lynn, 1996). The most common formal AD
documents that have been developed as a result of ACP discussions are living wills and durable medical powers of attorney. AD can be as simple as choosing durable medical power of attorney or as complex as expressing details of care. In the US, Five Wishes®, developed by Aging with Dignity (2008), is widely used in hospital and hospice settings as an AD. Five Wishes starts with discussing durable medical power of attorney, then addresses whether the person wants to receive life-prolonging measures or not, and how those measures should be provided (Appendix A).

The document also discusses pain relief versus sedation, and how health care providers can support the person’s spiritual needs. Five Wishes is significant because it addresses the issues that need to be addressed during ACP. The nature of palliative care is holistic, thus comprehensive guides such as the Five Wishes are extremely helpful. Verbal directives may be ethically valid; however, most patents and health care providers prefer written documentation (Pearlman, 1998).

Identify Model Cases of Advance Care Planning

ACP discussions promote shared decision making among patients and providers (Moore, 2005). Good communication among patients, families and care providers is essential during ACP. A definition of ACP is a “process aimed at extending the rights of competent adults to guide their medical care through periods of decisional incapacity” (Pearlman, 1998, p. 1). Additionally, decisions about treatment preference should be discussed in the context of a patient’s history, lived experiences, social support systems, cultural norms, and resulting values (Moore, 2005). ACP provides a significant opportunity to educate patients and their families. It may involve discussions about
Table 2.1: Comparisons of Hospice and Palliative Care Services

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Hospice</th>
<th>Palliative care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eligibility</td>
<td>Prognosis ≤ 6 months</td>
<td>None Required</td>
</tr>
<tr>
<td>Professional services</td>
<td>Interdisciplinary team:</td>
<td>Interdisciplinary or multidisciplinary team:</td>
</tr>
<tr>
<td></td>
<td>Physician</td>
<td>Physician</td>
</tr>
<tr>
<td></td>
<td>Nurse</td>
<td>Nurse</td>
</tr>
<tr>
<td></td>
<td>Social Worker</td>
<td>Social worker</td>
</tr>
<tr>
<td></td>
<td>Pastoral counselor</td>
<td>Others as needed</td>
</tr>
<tr>
<td></td>
<td>Certified nursing assistants</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other as need</td>
<td></td>
</tr>
<tr>
<td>Other services</td>
<td>Medications</td>
<td>No required services</td>
</tr>
<tr>
<td></td>
<td>Durable medical equipment (DME)</td>
<td>Determined by program</td>
</tr>
<tr>
<td></td>
<td>Bereavement care</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Others</td>
<td></td>
</tr>
<tr>
<td>Location of services</td>
<td>Comprehensive:</td>
<td>Based on program:</td>
</tr>
<tr>
<td></td>
<td>Home care</td>
<td>Some comprehensive</td>
</tr>
<tr>
<td></td>
<td>Long-term care facility (LTCF)</td>
<td>Some inpatient only</td>
</tr>
<tr>
<td></td>
<td>Inpatient</td>
<td>Some LTCF-based</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Some require networking between hospital and hospice or home-based home health programs</td>
</tr>
<tr>
<td>Funding</td>
<td>Medicare Hospice Benefit</td>
<td>Traditional hospital coverage</td>
</tr>
<tr>
<td></td>
<td>State Medicaid programs</td>
<td>Traditional home care coverage</td>
</tr>
<tr>
<td></td>
<td>Health maintenance organizations (HMOs) and commercial insurers</td>
<td>Support from hospitals and hospice partner or organizations</td>
</tr>
<tr>
<td></td>
<td>Charity (non-for-profit hospices)</td>
<td>Grants</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Charity</td>
</tr>
</tbody>
</table>


benefits from health care, available social support, power of attorney, and the importance of documenting their wishes (Sherman, 2001). ACP reveals, and designs, an individual’s wishes for providing appropriate and uniquely tailored palliative care for the duration of their illness. ACP is also sometimes called a palliative care plan. During ACP, the discussion proceeds with open-ended questions to explore patients’ values related to health care (Table 2.2), as well as asking about their wishes and goals.
Table 2.2: Questions to Explore Patients’ Value on Health Care Decisions

- What makes life worth living?
- What would have to happen for your life to be not worth living?
- How do you feel about quality of life versus quantity of life?
- How much input do you want your family/loved ones to have in decisions that are made about your health care?
- What are your thoughts about pain control? Would you want your pain controlled even if it means that you might not be as alert?

(Moore, 2005, pp. 39-40)

Moore (2005) also emphasized the importance of continuation of discussions over time, and care providers’ obligation “to ensure that patients understand their options as the disease trajectory progresses” (p.39). Thus ACP is a prolonged engagement and a process of palliative care. ACP can initially be introduced at diagnosis as an educational element of palliative care in more general terms, but then evolve more specifically when professional involvement occurs. The nature of ACP allows patients to make decisions about their future. ACP discussions may start before palliative care is formally initiated, or made concurrently with palliative care service.

Identify Borderline, Related, Contrary, Invented, and Illegitimate Cases - Relationship among Palliative Care, Hospice Care, Advance Directives and Advance Care Planning

Palliative care can be provided for people in any stage of their disease. Palliative care embraces patients and family education to provide information regarding their options related to their disease. The largest difference between education during palliative care and conventional medical care is the multidimensionality. While conventional medical care is obligated to provide information regarding its expertise, mostly physical aspects, palliative care is holistic and attempts to capture the patient and family’s value on their
health and quality of life. This requires physical, psychosocial, and spiritual assessment (Gullatte et al., 2005). Therefore, palliative care can be provided with active medical treatment concurrently. An implication of this notion is that ACP discussions can be introduced in any health care setting, including primary care. Some researchers and clinicians have attempted to promote discussion in the primary care setting (Ahluwalia et al., 2012; Aitken, 1999; Boyd et al., 2010). WHO provided a model to show the relationship between palliative and hospice care (Figure 2.1).

Figure 2.1: A Model of Palliative Care by WHO

In the figure, palliative care right before death indicates hospice care. Palliative care starts at the diagnosis and the involvement increases as disease progresses. Hospice care and bereavement care are parts of palliative care, yet palliative care is not limited to end-of-life care.

ACP starts at the diagnosis or earlier, ideally. ACP is oriented towards the individual’s values, and disease nor other health problems need not to be present. Rather ACP is developed by personal decisions, based on personal past experience and

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2 WHO=World Health Organization. This Figure is from World Health Organization (2007) “Cancer Control: Knowledge into Action: WHO guide for Effective Programs: Palliative Care”, Geneva, Switzerland.
education. Education involves explaining how an individual could be treated in a situation where they cannot express their own wishes. AD is documentation of an individual’s wishes, as a result of ACP. As “patient preferences are not static” (Moore, 2005, p. 39), ADs allow revision if a patient’s wishes change. Health care providers need to ensure that current wishes are documented in the AD.

Although ACP directs palliative care, ACP discussions can be initiated before palliative care is formally provided. Presence of diagnosed disease is not required to develop AD through ACP.

As mentioned earlier, ACP reserved only for people who have life-threatening illness is an example of illegitimate use of ACP because it excludes making decision in advance for healthy adults. ACP and AD are sometimes called end-of-life decisions in literature (Boyd et al., 2010). This expression led to the misconception that ACP is limited to people who have life-threatening illness, or someone facing an imminent death. Furthermore, misconstructions "by the detractors of health care reform as 'death panels' or 'death squads' and portrayed as a means for the government to get rid of old people or others who were judged to be non-productive” (Flaskerud, 2011, p. 720), resulted in false and negative images of ACP.

**Identify Antecedents and Consequences**

In this step, antecedents and consequences of ACP are visited. According to the National Consensus Project for Quality Palliative Care (2009), ACP is “based on the identified and expressed preferences, values, goals, and needs of the patient and family” (p.15). This implies that prior to ACP discussions with health care providers, people already possess preferences, values, and goals. These elements can be considered as some
of the antecedents. However, theoretically, people are not necessarily clear regarding goals of care, especially when ACP discussion is initiated without imminent death. This discussion should to be left until adequate and sufficient research investigations are completed. Personal preferences and values are considered to be influenced by life experiences. City and Labyak (2010) discussed that personal decisions and responses are different because “this response reflects the diversity of an individual’s life experiences” (p.26). Other antecedents related to ACP did not often appear in existing literature. I found a lack of knowledge before actual intervention by health care providers regarding ACP in the current literature. City and Labyak (2010) also discussed cultural influence; however, how culture related to ACP has not been thoroughly discussed.

Consequences of ACP are more apparent. The goal of ACP is preparing for a situation where one cannot express their wishes. One of the tools to communicate with family and health care providers is an advance directive (AD), so it is clear that AD should occur after ACP. Although a written AD is the most accepted form to communicate to family and others, informal discussions can serve as a consequence of ACP as well. AD can vary broadly, from the appointment of durable medical power of attorney (DMPOA), to detailed advance directives such as Five Wishes® (Aging with Dignity, 2012). Appointment of DMPOA, and any decision-making tools regarding end-of-life can result from ACP as well. Following these attributes, palliative care, hospice care, or a tailored treatment plan would occur.

**Define Empirical Referents**

“Empirical referents are classes or categories of actual phenomena that, by their existence or presence, demonstrate the occurrence of the concept itself” (Walker & Avant,
In this phase, I organized these attributes in order and by relationship, to best explain current knowledge. As a result, I am proposing a model of ACP.

A gap that I have found during this process of concept analysis was that in many uses, ACP has been described as health care provider (HCP) centered. The stakeholder who makes decisions is an individual. Advance care planning occurs with the individual, not the HCP. An appropriate expression should be “ACP discussions need to be initiated by HCP…” rather than “ACP needs to be initiated by HCP…” because the later expression implies that no preference exists before a HCP’s intervention starts. HCPs can assist individuals to communicate their preferences, which may exist prior to the HCP’s intervention. This notion is important to resolve chronological conflict of attributes. Life experience is an antecedent of ACP, and preferences may exist based on individual’s life experiences. A client-centered model of ACP is necessary to grasp the concept well. Existing models ignore an individual’s pre-contemplations, or developed preferences that already existed before the HCP’s intervention starts. The new model increases awareness of pre-contemplations and possible developed-preferences related to life experiences and values.

I am proposing a client-centered model of advance care planning. I incorporated the WHO model so that it is easy to see the relationships with curative care, palliative care, and hospice care. The developing process of this model can be found in Figure 2.2.

In this model, Advance Care Planning is a process that needs to be re-visited by health care providers over time. As ACP discussion becomes mature, an individual is able to more clearly communicate her/his health care preferences, and put them in writing. Contemplation occurs through his/her life experiences and from health care information.
received formally and informally. The distinguishing features of this model are: 1) health care provider's action is not ACP, 2) any thoughts and perceptions contributing to an individual's preference are comprised as ACP, and 3) AD is a part of ACP but ACP is a broader concept than AD. I use this model to map existing knowledge in a later discussion.

In summary, a concept analysis was conducted leading to development of a conceptual model of ACP. Related attributes were organized in the model to show relationships. This model serves as a theoretical framework of this study. The proposed model was developed with the intention of being client-centered, rather than being dependent on the HCP's action. In the following section, empirical knowledge is presented, and later this model serves as a map to examine the locus of current knowledge.

**Cultural Dimension and Advance Care Planning**

Cultural values are highly respected in palliative care, with emphasis on psychosocial and spiritual considerations. However, cultural contexts in advance care planning are not well described in the literature, as these studies merely described the tendency of choices made by certain ethnicities (Bullock, 2011; Melhado & Bushy, 2011; Zager & Yancy, 2011) rather than how they make decisions. Cultural values need to be addressed with a culturally sensitive research design. Loseth, Moor, Mulder, and Peterson (2005) recognized cultural sensitivity as:

Characterized by awareness and acknowledgement of the central role that culture plays in modeling patient’s worldviews and values, made apparent by a nonjudgmental attitude when encountering belief systems and customs that vary from one’s own. … Cultural competence involves developing a knowledge base about patient’s cultural values, beliefs, and behaviors, which can empower
health care professionals to communicate with patients and families in an appropriate and respectful manner. (pp.309-310)

They also identified a framework of cultural influence to assist in sub-cultural understanding: ethnic culture, religious culture, regional culture, and other influences.

The purpose of comparing and characterizing differences by ethnicity is not labeling people by ethnicity. Rather, by acknowledging ethnic differences, health care providers involved with ACP can be reminded to be sensitive and respectful to other cultures that are different from one’s own.

Struthers and Eschiti (2004) described Native Americans’ beliefs about health behavior. Their study on indigenous people with cancer revealed a culturally respected role of the traditional healer and a traditional way to heal, following a diagnosis of cancer. Indigenous people wanted to integrate modern and traditional medicine. Findings suggested that cultural foundations influenced health care behavior, so there is a need for health care providers to raise awareness of cultural perspectives related to decision making and health behavior.

Kiely, Mitchell, Marlow, Murphy and Morris (2001) compared racial differences of 283,763 residents of nursing homes in four states in the US: California, Massachusetts, New York, and Ohio from a national database. They found that the percent of those holding living wills was highest in whites and American Indians/Alaskan natives compared to Hispanics, Asians, and blacks. This finding implies possible disparities to access to palliative care can be found in ethnicities. Further studies are needed in the area to discover why these disparities exist.
Perkins, Geppert, Cortez, and Hazuda (2002) also conducted a content analysis from structured interviews to observe the perception on advance care planning, also called palliative care planning, among 58 European-Americans, Mexican-Americans, and African-Americans in Texas. Findings included perceptions such as "the patient deserves a say in treatment" and "advance directives (ADs) improve the chances a patient's wishes will be followed" (Perkins et al., 2002). However, differences were seen in the findings among ethnicities, such as Mexican-American and African-Americans believed "the health system controls treatment", while this view was not prominent in European-American views. Instead, European-Americans believed ADs helped staff to know and implement a patient's wishes. Perkins and colleagues also found an unwillingness to discuss ADs among African-American patients (2002). The reason why African-Americans were not willing to discuss ADs was not pursued in the study.

Although theoretically aggressive treatment and palliative care are integrated, dichotomous perceptions of aggressive treatment and palliative care persist. In Japan, initiation of a discussion on palliative care is difficult because Japanese physicians tend to recommend aggressive treatments, even for incurable cancer patients (Motohiro, Hirota, Komatsu, & Yanai, 1994). Further, worth mentioning is that in Japan a diagnosis of life-threatening illness is not always conveyed to the patient. Gabbay et al. (2005) conducted a survey of 244 Japanese and 103 US resident physicians. Although 99% of physicians both in the US and Japan answered that they would provide a true diagnosis of incurable cancer to the patient, only 76% of Japanese physicians answered
Step 1: The WHO model (2007) was placed on the right end as time moves left to right. The WHO model describes time of death, need to be right end.

Step 2: Life experiences embrace the model.

Step 3: Clients acquire health information before they receive diagnosis.

*Figure 2.2*
Step 4: Clients develop their preference of care (ACP) as they acquire health information and have life experience with their family and others.

Step 5: Documentation, such as advance directive, can happen before clients receive diagnosis. Documentation is more necessary and becomes concrete as clients are close to death.

Figure 2.2
Step 6: Health care providers need to discuss ACP periodically to support clients.

**Figure 2.2: Six-Step Model Development Process for Client-Centered Model for Advance Care Planning**
that they would tell the truth to a patient if the patient were dying from cancer, compared to 96% in the US. Current conventional end of life care is developed based on truth telling, and it is apparent that educating physicians to communicate truthfully with patients is necessary for them to develop an appropriate palliative care plan. However, the patients’ cultural background needs to be carefully considered in these communications.

In summary, viewing ACP through a culturally sensitive lens means not only relying on an individual’s preference, but also acknowledging traditionally developed social sub-cultural influences. Evaluating acceptance of palliative care in Japan is difficult because of the persistent problem of health care providers avoiding truth telling, and a reluctance to identify and discuss a patient’s prognosis. A study to investigate perception of ACP and palliative care in non-hospital setting would help to understand patient's perspectives without destruction by health care providers.

**RELIGIOUS DIMENSION IN JAPAN**

Religious background and cultural influences on human behavior and beliefs do not have finite boundaries. Although in the US, many different religions are identified, the Judeo-Christian influence cannot be ignored. Only 26% of Japanese reported being religious, yet 30% of the total population believed in reincarnation, a typical belief of Buddhists (Anonymous, 2008). Generally, most Japanese people keep a distance from identifying with a specific religion. However, a strong religious influence does influence all aspects of Japanese culture. The majority of Japanese people practiced Buddhism and Shinto traditions in ancient Japan. These combined beliefs persist today; 94% of the people surveyed expressed a respect for ancestors, one of many principles
of Buddhism (Anonymous, 2008). Because culture and religious influence are integrated, to understand people’s perceptions, an integrative approach of inquiry would be needed.

**REGIONAL CONTEXT IN PALLIATIVE CARE**

Regional influences on palliative care can be seen, informed by subculture or residential circumstances. At the end of life, the place to die is one of the decisions to be made by patients and families. Based on literature review, regional context can be identified. In a secondary analysis on US urban and rural residents with a sample size of 13,562, Burge, Lawson and Johnson (2005) argued a need to consider rural residency as a culture. They reported that cancer patients in rural areas died in hospital significantly more frequently than patients who resided in urban areas. The study left a question of “whether a ‘culture of caring’ in rural community is different than in urban setting” (Burge et al., 2005, p. 237). It was one of this study’s questions.

On June 6, 2008, the Japanese press reported results of a survey conducted in Kanagawa prefecture and Aomori prefecture stating that only 10% of Japanese people wished to spend time at home until the end of their life (Carrier Brain, 2008). This result differed from the Japanese government’s estimate of 60% (Furuhashi, 2007), and the finding baffled policy makers. According to the survey, the major concerns expressed about dying at home included increased family burden, anxiety over a sudden change in physical condition, and disbelief that dying at home was feasible. Whether these inconsistent results were due to residential differences is unknown, and a need is indicated for studies designed to pursue this question. As a direction of future palliative care, Japanese government is still promoting palliative care at home (Kudo &
Hasegawa, 2012). Quantitative surveys are good to assess community as a group, but difficult to describe the cause or details. Early introduction of ACP may provide better understanding of utilization of palliative care for patients, yet a little is known regarding ACP. A culturally sensitive and qualitative study on ACP is needed.

In summary, a firm cultural understanding is necessary to assist in health care decisions in different populations and settings. Cultural perspectives were evident looking through ethnic, residential, and religious lenses. Before interventions are developed to influence health care decision making, health care providers involved in palliative care need to understand how culture influences patient and family perceptions and preferences. Further, health care providers must be culturally capable, humble, and sensitive, to practice excellent palliative care.

**PALLIATIVE CARE AND ADVANCE CARE PLANNING IN JAPAN AND THE US**

Review of the current status of palliative care and advance care planning in Japan and the US is presented here. This review exposes explicit cultural contrasts and systematic and historical differences between the two countries. Literature review and assessment of existing knowledge are conducted by discussing both palliative care and advance care planning, because advance care planning includes the notion of palliative care as an end-of-life option.

Japan and the US utilize different health care models, yet there are some commonalities between the two countries. In Japan, modality of place of death has changed radically in the last fifty years. In 1960, less than 20% of all deaths occurred in a hospital compared to more than 80% of deaths in 2001 (Iwasaki, 2004). The shift
accelerated between the 1970s and 1980s simultaneously with rapid economic growth, similar to the US.

Hospice care started in Great Britain in 1960s and was introduced to Japan and the US early 1970s. The concept of palliative care emerged following the hospice movement. Health care systems are very different in Japan and the US, thus palliative care has grown differently.

**Palliative Care and Advance Care Planning in Japan**

Understanding the public’s perception and acceptance of palliative care is essential for promoting utilization of palliative care, as well as advance care planning (ACP). Dissemination of a correct understanding of palliative care and hospice care has been a challenge both in the US and Japan, because palliative/hospice care is often misperceived simply as refusing care and giving up hope for recovery, rather than maximizing symptom management through palliative care. In the Japanese language, introducing the term “Kanwa (palliative) care” was significant to public acceptance. Kanwa consists of two Chinese characters: 緩 (kan: ease, relax) and 和 (wa: harmony, peace, circle). Literally, Kanwa means relief, alleviation, to ease, to relax, and mitigation (Aiba et al., 1998; Collick, Hinata, & Tanabe, 1983). This word Kanwa is taught in the school systems by the ninth grade and is commonly used by lay people. Kanwa care, through the implication of the Chinese characters, directly conveys the image of relieving, the fundamental nature of palliative care.

When first introducing the concept of palliative care in Japan, the phonic term, Pa-ri-a-ti-bu ké-a パリアティブケア, was used, but its use now has been replaced with Kanwa care, for its more acceptable implication of symptom management. On the
contrary there is no translation for hospice in the Japanese language, and the phonic term *Ho-su-pi-su* ホスピス is spelled in the Japanese alphabet *katakana*, which is used for words in a foreign language. In the past any treatment that included antibiotics, hydration, and palliative radiation was not provided in hospice care in Japan. Therefore, the Japanese image for hospice became a place in which one waits for death, with a deficient recognition of alleviating a patient’s symptoms. In contrast, *Kanwa* care represents the meaning of holistic wellness in the Japanese language, making the genuine meaning of palliative care more publicly acceptable than hospice care in Japanese society. As a result, palliative care units have become more available than hospice care in Japan.

In Japan, hospice care was first started in 1973, and reimbursement for palliative care was implemented in 1990. In 2008, over 200 hospice/palliative care units have been certified officially by the government, not including private efforts for palliative/hospice care in Japan (Kato, 2012).

An increased interest in palliative care is also evident in Japanese medicine, as demonstrated in the medicine and healthcare literature. Medline® includes an extended collection of journals in foreign languages, although not all foreign journals are incorporated in the compilation. A literature search on the keywords palliative care in Medline® found only 154 articles written in Japanese published between 1965 and 1990, but 283 articles were cited between 1991 and 2008. Additionally by 2008, MedicalOnline®, a Japanese medical article search engine, indexed approximately 2000 articles published on palliative care. Today, the number of publications related to this area is increasing even more.
Further, in April 2007 the Japanese Ministry of Health, Labor and Welfare initiated a national campaign for the public, through the Japanese Society for Palliative Medicine, called the Orange Balloon Project (Japanese Society for Palliative Medicine, 2007). A significant objective of the project was to educate the public about palliative care, thereby dispelling the former concept of a hospice as a place to wait for death. Through this initiative, Japanese enthusiasm for palliative care is currently more vigorous, and the movement was accelerated further when government reimbursement was raised significantly in 1997 (Kotani, 2004).

On the other hand, proper utilization of palliative care remains challenging in Japan. Although palliative care can be reimbursed, 20 out of 47 prefectures have never requested palliative/hospice care reimbursement from the health ministry (Hospice Palliative Care Japan, 2006). This statistic implies even greater efforts are needed for establishing palliative/hospice care utilization.

The concept of advance care planning is not currently promoted in Japan. Using the keywords advance care planning, a search of literature in MedicalOnline, which is a comprehensive Japanese literature search engine, found only seven articles published as of November 2012. Of these, two were general opinion and one was a review article (Hotta, 2007; Nishikawa, 2012; Nishikawa et al., 2011). Some articles focusing on elderly populations were found, including two research articles (Hayakawa & Sugisawa, 2008; Nishikawa, 2012), and two studies had been done on people receiving home care.

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3 Keywords used for the literature search were Japanese translations of advance care planning: advance care planning, アドバンスケア プランニング, and 事前ケア計画.
for chronic illnesses (Hayakawa & Sugisawa, 2010; Hirakawa, Uemura, & Katsuya, 2007).

In summary, the concept of ACP is not established in Japan. The consensus on the translation has not been attempted yet. There was no study on a younger population, or on a healthy population. Research is necessary to develop knowledge and achieve WHO's notion of early introduction of ACP.

**Palliative Care and Advance Care Planning in the US**

Despite the need, and private efforts to promote palliative care, palliative care benefits are not well established in the US. Medicare covers patients with a life expectancy of less than six months for hospice care. The certification of determining a life expectancy of less than six months has to be completed by two physicians, in order to receive reimbursement (Kinzbrunner, 2005). Although palliative care is a much broader concept, only the very limited service of hospice care is well supported, systematically. Patients who survive longer than 6 months may continue to receive hospice care.

Palliative service in the US is mostly hospital-based. Because inpatient care is interdisciplinary, hospital-based palliative care teams utilize primary team members, such as nurses and medical social workers. Hospital-based palliative care is traditionally initiated by the oncology care team. Palliative care programs are still underdeveloped in the US, and funding for non-hospice palliative care is one of the major challenges. Current methods used most frequently to sustain palliative care are receiving private funding and utilizing the International Classification of Diseases (ICD) - 9 as a reimbursement mechanism (Kinzbrunner, 2005).
US Studies on ACP can be found; however, most of these are heavily skewed toward end-of-life populations and the elderly. For studies on the elderly regarding ACP, most research was conducted on populations of nursing home residents (Alano et al., 2010; R. S. Allen et al., 2003; Benham-Hutchins & Kyba, 2005; In der Schmitten et al., 2011; Yung et al., 2010). This focus was based on the assumption that the elderly have a shorter life expectancy; therefore they would be more likely to write an AD. However, this is another contributor to the false assumption that ACP is only for the elderly. In der Schmitte et al. (2011) noted the importance of community efforts to promote ACP.

Little attention specific to Asian populations in research was found. Kwak and Salmon (2007) did a study on end-of-life decisions in an elderly Korean-American population. They described the tendencies of Korean-Americans as expecting family to ask HCPs to do everything possible to prolong their lives. It implies an important role of family in the culture; however, details about how these preferences were developed, was out of scope of the study.

In conclusion, I have found a gap between recommendations by professional organizations such as WHO, and current research and practice, in both Japan and the US. Little research on ACP has occurred, except where end-of-life was imminent or the population was elderly. Figure 2.3 shows the current research focus. Most research now, explores the yellow oval area. In order to develop comprehensive knowledge on ACP, more studies on additional populations in various stages of life are needed.
SUMMARY

In this chapter, the concept of advance care planning (ACP) and an examination of current knowledge were presented. The purpose of the concept analysis was to determine a theoretical framework for ACP. Based on this concept analysis, I proposed a conceptual model of ACP. This model is client-centered. The model serves to assess current knowledge, and the gap in knowledge, by assessing current literature. A brief history of palliative care and ACP in Japan and US was reviewed.

Based on the review, a major gap between recommendations to introduce ACP earlier, and a heavy focus on end-of-life and elderly populations was exposed. According to the model, even though ACP is not currently promoted well in Japan, it is valuable to understand patient's perspectives before they formulate advance directives. Cultural studies have been categorizing tendencies of choices by ethnicity rather than by patient perspectives. A study is needed on a younger population, with a design that captures that group's perspectives.

I discuss a methodology to capture Japanese patient's perspectives related to ACP in the next chapter. Philosophical background, research design and research methods are included.
A Model for Client-Centered Advance Care Planning based on Concept Analysis

State of the Science Shown in the Model of ACP as Yellow Oval

Figure 2.3
Focus of this Study Shown as Pink Oval

Figure 2.3: State of Science and a Focus of this Research in the Client Centered Model for Advance Care Planning
CHAPTER III

METHODS

The purpose of this study is to explore cancer patients’ perceptions, experiences, and attitudes toward ACP and palliative care. The investigation utilizes an ethnographic design guided by phenomenology. The methodology for conducting this investigation, including design, methods of sampling, data generation, analysis, and interpretation are described in this chapter.

RESEARCH DESIGN

Ethnography is a qualitative research design used to describe a social and cultural scene from the emic, or insider’s, perspective (Fetterman, 1989b). Epistemology of ethnography can be derived from different paradigms, such as phenomenology and positivistic paradigms. The underlying philosophy defines the epistemology and guides the methodology. As the meaning of the lived experience of cancer patients with ACP is totally subjective, phenomenology served as an underlying philosophy for the investigation.

OPERATIONAL DEFINITION OF CULTURE

According to Fetterman (2010), there are two different ways to define culture. The first definition is the classic materialist interpretation of culture, where "culture is the sum of a social group's observable patterns of behavior, custom, and way of life" (p.16). The other definition adopts a cognitive approach and "culture comprises the ideas, beliefs, and knowledge that characterize a particular group of people" (p.16). Because this ethnographic study adopted phenomenology as its philosophy, the second definition is utilized in this study.
PHILOSOPHY AND CONTRASTING METHOD

In this study I attempted to develop an in-depth understanding of cultural differences or influences in a Japanese cancer patient’s perceptions and attitudes toward ACP and palliative care. Contrasting with other cultures is useful to enhance interpretation of cultural differences. I have used the transcultural contrasting method between Western culture represented as American culture, and Japanese culture. However, in this thesis only a Japanese perspective is explored, to be followed later by description of American perspectives and transcultural content. In this research, cultural contexts of ACP are integral, and participants from rural and urban settings were included. Because this study specifically utilizes ethnography informed by phenomenology, the philosophical backgrounds of phenomenology and ethnography are discussed at the beginning.

Phenomenology

Phenomenology as philosophy was first argued by Edmund Husserl in the early 1900s. “Phenomenology holds that reality consists of the meanings in a person’s lived experience (Erlebnis)” (Omery & Mack, 1995, p. 141). The aim of phenomenology as a research approach was to transform lived experience into a textual expression of its essence, and hermeneutic significance derived from meaning of the lived experience (van Manen, 1990). Merleau-Ponty said “phenomenology is the study of essence… the essence of perception, or the essence of consciousness, for example” (Merleau-Ponty, 1962, p. vii).

4 “American” in this thesis refers to the United States of America
Essence in phenomenology refers a linguistic construction or a description of a phenomenon (van Manen, 1990), and he further articulated:

A good description that constitutes the essence of something is constructed so that the structure of a lived experience is revealed to us in such a fashion that we are now able to grasp the nature and significance of this experience in a hitherto unseen way. (van Manen, 1990, p. 39)

Although the term phenomenology is used in various ways, such as methodology and philosophy, Munhall (2007) claimed phenomenology as the underpinning of most qualitative studies. In phenomenology, understanding meaning of the life experience is the way to gain knowledge of its reality, and subjective perception is imperative. Phenomenology is an inductive approach; and whereas some qualitative methods possess a theoretical component, such as grounded theory, phenomenology is atheoretical (Munhall, 2007). Phenomenology informs this ethnographic inquiry, as patients’ lived experiences were explored though cultural lenses.

**Ethnography**

In this study, ethnography was adopted as the research design. In this study ethnography operationally and specifically refers to ethnography as a phenomenology oriented approach. Ethnography derives from anthropology, but the technique has been utilized in other disciplines, such as sociology and nursing. Ethnography inquires *emic* (insider’s) perspectives. “An *emic* perspective compels the recognition and acceptance of multiple realities” (Fetterman, 1989c, p. 20). The *emic* notion was crucial to understand different cultural interpretations and "why people think and act in the ways they do" (Fetterman, 1989c, p.20). Exploring how women with early stage cancer perceive ACP, and describing their past experiences with ACP and palliative care, might identify
differences among the individuals. This study identified Japanese women's perceptions of
cultural influences and universal themes. The differences of perceptions among
individuals were honored in this inquiry, because variations of perspectives are believed
to be helpful to gain understanding of the phenomenon. Although cultural tendencies
were examined, the aim of the study was not to generalize in this population. Richness of
data from diverse perspectives was desired for the purpose of a deeper description.

ACP involves personal decisions based on personal experiences and beliefs.
Understanding emic perspectives enabled the researcher to grasp how cancer patients
construct their perspectives and decisions. This approach was beneficial because it
brought a deeper understanding of lived experience, rather than simply identifying
favorable or unfavorable attitudes towards ACP.

This study also employs etic (outsider’s) perspectives through photographs and
field notes to analyze the congruency of data. Leininger (2006) addressed that both emic
and etic methods are necessary to obtain a more complete understanding of the
phenomena of interest to nursing. Photographs taken with a digital camera were used to
record the physical environments of participants. Recording actual life scenes suggested
more culturally specific questions that I did not notice at the time of the first interview.
These etic tools, photographs and field notes, were simply used to enhance my
interpretation during this study. This study was focused on a specific phenomenon, and
does not attempt to describe an entire culture. Fetterman (1989c) recommended using key
actors. “Key actors can provide detailed historical data, knowledge about contemporary
interpersonal relationships…, and a wealth of information about the nuances of everyday
life” (Fetterman, 1989c, p.48). In this study, nurses in Japanese communities who take
care of the population were asked to be the key actors or participants. These key actors were asked to confirm interpretations from photographs and field notes to increase the credibility (Figure 3.1).

Plausible interpretations are imperative in ethnography, and photographs and field notes were also employed for this reason. Fetterman (1989d) articulated the importance of a long term relationship with the community, yet also said,

Ethnographic research in one’s own culture may not require as much time to reach this point as ethnographic work in a foreign culture: language and customs are familiar, and the researcher is already an insider in many respects (p.39).

In this study I, as the researcher, took the advantage of being born and raised in Japan, in addition to living in the US for twelve years. My past experience with qualitative interviews in both counties also supported an efficient study process.

In summary, this qualitative study utilized ethnography along with an underpinning philosophy of phenomenology as the research design. These methods were used because of the excellent fit with the nature of the phenomenon explored through this study: cancer patients’ perceptions of ACP and palliative care. This study also explored the cultural contexts influencing this phenomenon, and ethnography facilitated illuminating the differences and universal themes.

**BRACKETING**

Preconceptions and presuppositions are often criticized in qualitative analysis. Bracketing is the technique most commonly used to argue against that criticism. Bracketing is “the act of suspending one’s various beliefs in the reality of the natural world in order to study the essential structures of the world” (van Manen, 1990, p. 175).
Although the researcher suspends one’s beliefs, unlike idealism, phenomenology admits the impact of an investigator’s preconceptions and presuppositions. Phenomenologists do not attempt to eliminate or ignore preconceptions and presuppositions, since it is not realistically possible. Rather, the investigators try to be conscious of the preconceptions or presuppositions they possess.

The following information is presented to guide the reader in understanding my own experience and perspectives. I was born and lived in Japan for 29 years. I have had many opportunities to take care of cancer patients, and this interest led me to conduct this study. I have witnessed many cases in which ACP was not supported by health care providers systematically. Patients and family had to make difficult decisions at the time of imminent death that were extremely stressful for both patients and families. I have started to think that we must address and support these patients and families to develop ACP much earlier in the course of illness.

Bracketing is necessary in naturalistic inquiry, as the environment and conditions are not controlled. In this study, the condition and environment were not controlled, as I was interested in a specific phenomenon of the lived experience with ACP and palliative care in patients with early stage cancer. I did not intend to change the participant’s perspectives, but instead listened to their stories about their life experiences. My values were not presented during the interview. However, because of the nature of topic, participants started to realize the importance of ACP while constructing their own concept of ACP and verbalizing their thoughts.
Figure 3.1: Some Examples of Several Photographs Taken in the Public Domain

**DATA GENERATION**

Consistent with ethnographic terminology, data collection was referred to as data generation. The process of data generation included participant interviews and participant observations, with data recorded on digital audio devices. The audio recordings were then transcribed into text and saved as secure electronic files, and field
notes were also converted to electronic files. Photographs were used to illustrate life and the lived experiences of cancer patients. In the following sections, the setting, description of intended sample, procedures for recruitment and consenting of potential participants are described. Then procedures for data generation are presented.

**Setting**

The setting of this study was two communities in Japan: Tokyo (urban) and Kochi (rural) prefectures. People living with cancer in both rural and urban communities were interviewed. Culture is often discussed with a notion of ethnicity, but current knowledge suggests cultural effect exists not only by ethnicities, but also residence and other perspectives (Moore, 2005). Specifically, Tokyo prefecture as an urban setting and Kochi prefecture as a rural setting were selected. The Japanese population is approximately 128,057,000, and resides in an area of 377,930 km² (Ministry of Internal Affairs & Communications Statistics Bureau, 2011). The area of mainland is 227,945 km². Populations of the selected prefectures of Tokyo and Kochi were approximately 13.2 million and 764,000, respectively (Ministry of Internal Affairs & Communications Statistics Bureau, 2011). Prefectures are like states in the US. In order to obtain diverse samples, Tokyo, which is the largest prefecture in population in Japan, and Kochi, which has one of the smallest, were selected. The settings facilitated a variety of participants and residences (urban or rural) to produce rich data.

**Sample**

To recruit participants, convenience sampling was employed. I have been an oncology nurse for 20 years and have been interested in oncology patients to improve care for this population especially women. This population was chosen based on my
interest and gap in knowledge. This sampling method was useful to challenge the
group’s presumptions and maximize the chance to determine various points of views
by accepting any eligible participants. It was considered appropriate and consistent with
the goals of an exploratory study to understand emic perceptions of a phenomenon. In
future studies, including or studying a predominantly male population or persons with
different types of cancer would help to understand perceptions in the different
populations.

To be eligible for recruitment into the sample, a participant must have been
diagnosed with an early stage cancer, as my ultimate goal was the intention of
introducing ACP at an earlier stage of cancer diagnosis. Early stage of cancer was
defined as stages I or II, as diagnosed by their primary oncologist. The ultimate goal of
this study was examining the introduction of palliative care for women in the earlier
stages of cancer, and including populations having stage III or IV cancer was beyond the
scope of the study. Diagnosis had to be made after July 1, 2007 operationally for initial
participation.

Women who had gynecological or breast cancer were invited to this study. Types
of cancer were not a primary concern for this study because this study was not treatment
dependent. Rather, this study explored Japanese women's perspectives after a cancer
diagnosis, and their thoughts about ACP. As the leading cause of death in Japan, the
literature supports that cancer was perceived as a life-threatening illness (Stanton, Bower,
& Low, 2006). Therefore, for these stage I and II cancer patients how their cancer
experience affected their life and perspectives on their future were explored.
Previous exposure to palliative care or ACP was not examined at the time of enrollment of this study, as previous exposure to palliative care could occur in various ways. Exposure raged from watching media such as television to profound exposure such as having a family member who had received palliative care. Also, the extent of previous exposure to palliative care and ACP, and which types of exposure affected cancer patients’ decisions, were unknown. Thus consistent with the purpose of this study, the influence of previous exposure to palliative care and ACP to patients’ lived experience was explored. Further, a variety of perspectives and experiences were desired and respected in this study because of the underlying phenomenological philosophy.

Participants were selected based on whether or not they were in active treatment. Active treatment means a treatment recommended by the oncologist or physician, or requested by patient and provided by their health care providers to eliminate, or slow the progress of cancer. Active treatment included chemotherapy, surgery, radiation, or other treatment. Only two participants were undergoing active treatment. They were in the phase after surgery and were receiving oral hormonal therapies.

Inclusion criteria for this study were:

1) Adult women between the ages of 21 and 60 years old, who were living with cancer in one the two study areas (Tokyo or Kochi)
2) A stage I or II cancer diagnosis
3) The diagnosis was made after July 1, 2007
4) Participants must understand and speak the Japanese language
5) Participants must agree to be interviewed at least once and possibly twice
Exclusion criteria were:

1) People with life expectancy less than 6 months as estimated by their primary oncologist

2) Recurrence of cancer found at the time of recruitment

3) People with stage III or IV cancer

4) Pregnant women with a cancer diagnosis

5) People not cognitively able to communicate effectively and discuss their perceptions and experiences.

Sample Size

Sample size in qualitative research is not simply a matter of the number of participants; rather the size of the sample is determined by the complexity of phenomena and relating factors (Marshall & Rossman, 2006; Morse & Richards, 2002). Marshall and Rossman stated: “An unknown culture or profession studied in-depth over time may be composed of one case study or ethnography…a small sample would be useful as thick cultural description” (Marshall & Rossman, 2006, p. 63). In this study, the in-depth description of culture was explored and the total sample size was ten participants, of which five participants were formally interviewed twice for a total of fifteen interviews. In this qualitative study, purposive sampling was employed, meaning participants were purposefully sought out who have experienced the phenomenon of interest.

During the sample recruitment, I actively sought to include individuals who had responded to recruitment fliers, and who represented a variety of experiences related to palliative care. This sampling procedure was known as maximum variation sampling (Morse & Richards, 2002; Polit & Beck, 2004). Participants ranged in age from 37 to 59
years (mean age was 46.6). Seven participants had gynecological cancer and three participants had breast cancer. More detail for patient demographics can be found in the Table 3.1 (Description of Sample). An additional detail of participant’s characteristics is in Appendix C.

RECRUITING METHODS

Participants were recruited from Tokyo and Kochi, Japan, using flyers approved by the Colorado Multiple Institutional Review Board (COMIRB). Some participants were recruited from the gynecology and breast clinic at the Japanese Red Cross Medical Center in Tokyo, and the Kochi Red Cross Hospital in Kochi. In addition, participants were sought through the posting of fliers, in places like clinics at these hospitals with permission of clinic directors, physicians and charge nurses. In clinical settings, only nurses or physicians who had a treatment relationship with patients identified and approached prospective participants. The designated nurse or physician then presented patients with a flyer describing the study. The prospective participants were directed, if interested, to contact the investigator voluntarily and independently. The flyer was developed in Japanese (Appendix D) and was translated into English and submitted for approval by COMIRB. Interested parties contacted the investigator by phone.

In the designated hospitals: the Japanese Red Cross Medical Center in Tokyo and the Kochi Red Cross Hospital in Kochi city, approval from their institutional review boards and permission to recruit were obtained following submission of the required documents and COMIRB approval for review upon their request. The research proposal and informed consent forms were translated into Japanese to be used for the participants.
Interviews proceeded and new information was obtained. Qualitative protocol was employed to determine a need to end interviewing. “When ongoing analysis reveals no new information appearing and no new categories emerging (saturation), sampling may cease” (Marshall & Rossman, 2006, p. 535). The end point of recruitment was by my decision, based on saturation.

Table 3.1: Description of Sample and Interview Details

<table>
<thead>
<tr>
<th>Participant*</th>
<th>From</th>
<th>Age**</th>
<th>Diagnosis</th>
<th>Diagnosis date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Yoshii Kochi</td>
<td>53</td>
<td>Endometrial Ca*** Stage I</td>
<td>October 2008</td>
<td></td>
</tr>
<tr>
<td>2 Takei Kochi</td>
<td>40</td>
<td>Cervical Ca Stage I</td>
<td>November 2008</td>
<td></td>
</tr>
<tr>
<td>3 Kotani Kochi</td>
<td>37</td>
<td>Breast Ca Stage I</td>
<td>May 2008</td>
<td></td>
</tr>
<tr>
<td>4 Yamada Kochi</td>
<td>59</td>
<td>Endometrial Ca Stage I</td>
<td>July 2008</td>
<td></td>
</tr>
<tr>
<td>5 Murai Kochi</td>
<td>50</td>
<td>Breast Ca Stage II</td>
<td>October 2007</td>
<td></td>
</tr>
<tr>
<td>6 Ito Kochi</td>
<td>56</td>
<td>Endometrial Ca Stage I</td>
<td>July 2008</td>
<td></td>
</tr>
<tr>
<td>7 Sasaki Kochi</td>
<td>45</td>
<td>Breast Ca I</td>
<td>January 2008</td>
<td></td>
</tr>
<tr>
<td>8 Asao Tokyo</td>
<td>40</td>
<td>Endometrial Ca Stage I</td>
<td>September 2008</td>
<td></td>
</tr>
<tr>
<td>9 Sato Tokyo</td>
<td>49</td>
<td>Ovarian Ca Stage I</td>
<td>December 2008</td>
<td></td>
</tr>
<tr>
<td>10 Kawai Tokyo</td>
<td>37</td>
<td>Cervical Ca Stage I</td>
<td>March 2008</td>
<td></td>
</tr>
</tbody>
</table>

Note. *Pseudonym. **Age is the participant’s age at the time of interview, ***Ca=cancer

Telephone Screening of Potential Participants

Individuals contacted were screened for the eligibilities over the telephone by me. After the participant-initiated contact, I contacted the potential participants by telephone to answer questions related to eligibility, participation, and the study in general. A registry of all phone and email contacts was kept in a locked file to be used for contacting
the participant again if necessary. These files will be destroyed at completion of the study and dissemination.

Location of Consent Procedures and Interview

After prospective study participants were screened, they were asked to set an interview appointment. As principal investigator, I reviewed the consent form with participants to consider their participation in the study. Care was taken to arrange for an interview setting that was both comfortable and private for the participant. An appointment was made for the consent process and interview to occur at the same meeting. This process worked well for all participants.

Location of Interview

The setting for the interviews was a private place of the participant’s choice. The rational for this choice included: 1) the interview setting needed to be comfortable enough for the participants to talk about their personal experience, and 2) the comfortable setting was expected to be a familiar place for the participants, and would help me to understand their actual life. The settings included a designated private consultation room or other private rooms (number of interviews= 7); in participant’s homes (number of interviews= 4) and also in a neutral, quiet, public places upon the participant’s request (number of interviews= 4). For the interviews scheduled in a public setting, participants and I scanned the area for a comfortable and private corner of the setting or a private area. I informed the participant that the possibility of the chosen location may not be private enough, and that the interview may be overheard. Participants chose public places and were aware of the concern. However, they confirmed that they wanted to have the interview at these sites, such as a restaurant or cafe.
CONSENTING PROCESS

Each potential participant was provided with a copy of the consent form at the interview and asked to read it thoroughly and formulate any questions they had. The prospective participant met me in a quiet, comfortable setting, and the consent form was reviewed. Comprehension was assessed by asking the participant to explain the study in her own words.

As the participant demonstrated comprehension, the participant and I signed the consent. The participant received a copy of the signed consent for her records. The Japanese consent was my complete translation of the English version, as I am fluent in both Japanese and English. Once translated, the Japanese version of the consent form was back translated by an independent, native Japanese speaker, and the two versions were compared to confirm the content and wording were equal. The two versions of the consent forms are in Appendix E and F. I obtained informed consent for all participants. As the principal investigator, I was aware of the procedures for obtaining informed consent and had completed required Colorado Multiple Institutional Review Board training (Collaborative Institutional Training Initiative training) and the Health Insurance Portability and Accountability Act research training. No volunteers or research assistants were used to obtain informed consent.

PROTECTED HEALTH INFORMATION

Protected health information (PHI) was not collected in this study. Additionally I obtained permission to exclude HIPAA Form B by COMIRB because HIPAA only applies in the US, and the form was not appropriate for Japanese participants. A pseudonym was assigned to each participant, and at the time of transcription, this
pseudonym replaced the person’s real name. During transcription, any information that could be linked to the participant’s identity (i.e., names, specifics about treatment, specific hospitals, and dates) were edited out of the data or changed to pseudonyms.

In order to contextualize the information collected during the interview, I collected non-identifiable information from each participant. This information included: sex, age (all participants were younger than 60 year-old), type of cancer, months/years since cancer diagnosis, stage of cancer, treatment status (active/complete), area of residence (urban, rural), and living status (by self, with spouse/significant other, with children or other family members, or in a setting such as an assisted living facility or long-term care setting).

**INTERVIEWS**

Interviews were conducted between February 2009 and March 2010. Interviews were conducted in a quiet, private place as described earlier. The interview was semi-structured. Open-ended questions allowed the participants to choose words and expressions, and using both open-ended and closed questions were valuable to describe their lived-experience and perceptions. Closed questions were used mainly to confirm that my interpretation was appropriate and plausible from the participants. Retrospective interview was also used to grasp contexts of past events and personal-historical/cultural meanings. The detailed interview guide is in Appendix G. The order of questions was modified as necessary because as Fetterman (1989d) stated: the “ethnographer has a series of questions to ask the participant and will wait for the most appropriate time to ask then during the conversation (if possible)” (p. 49). I attempted to ask all the questions unless the participant was unwilling to answer.
At the beginning of each interview, I as the researcher had asked the participant for permission to audio-record the interview. Average interview time for each participant was 65.1 minutes. Participants were informed of the voluntary nature of participation in the study, and the freedom to withdraw anytime, although no participants withdrew from the study.

**OTHER SOURCE OF DATA**

Field notes and photographs were used as other source of data. With permission from the participants, I took field notes and photographs. Photographs were taken without individual identifiable information. I also took photographs in the community to assist with cultural description. Photographs were taken only when the scene belonged to public domain, if permission could not be obtained. The photographs served to support the cultural interpretation of the interview. Field notes were taken in the community and at the interviews. Field notes and photographs were transferred to password secured flash drives designated for this study. Security of the data is described in the Data Management section in detail.

**DATA ANALYSIS**

Before presenting the data analysis method used in this study, data management is discussed.

**Data Management**

Audio-recorded data, photographs, and observations were considered as data in this study. Interviews were audio-recorded with a participant’s permission. An electronic IC audio-recording device was used to capture audio data. The digital audio-recorded data were converted to WAV data files in a computer immediately after each interview.
WAV data files are digital audio files that can be listened to on a computer. Once audio-recorded data were converted WAV data files, data on the electronic IC device were erased. WAV data files were stored in a USB flash drive with password security. The USB flash drives were designated only for this study. Transcriptionists agreed to confidentiality and signed confidentiality agreements. Each transcriptionist had access to a copy of audio recordings with different passwords assigned by the researcher. All WAV data files were typed and stored as Microsoft Word ® documents. When WAV data files were transcribed, all identifiable data, such as person’s names and institute, were converted to pseudonyms. Transcriptionists saved the transcribed data in the same USB flash drive and returned it to the researcher.

Photographs were taken upon participant’s permission. Photographs were taken using a digital camera. Photographs were transferred to a password-protected USB flash designated for this study, at the end of each day or as soon as access to a computer with appropriate security was possible. When photographs were safely transferred, data in a digital camera were deleted. If a participant agreed to have her photograph taken, she was informed of the privacy risk, and then signed a consent form. Otherwise, only photographs considered as belonging to public domain were used at disseminations of study results.

Field notes were recorded in a notebook at both community assessments and interviews. Field notes were typed and stored as Microsoft Word ® documents by the end of each day, or as soon access to a computer with appropriate security was possible. After field notes were stored as Word documents, physical documents, such as memos and
paper notes, were shredded. No individual identifiable field notes were made, and pseudonyms were used as needed.

Designated USB flash drives were considered as secured storage because no one can open or see the files without passwords.

**Data Analysis**

Transcribed data were organized utilizing the qualitative software Atlas ti. Version 6®. This study was analyzed using an analysis method developed by Leininger (2006). Leininger developed an analysis guide for ethnography in nursing to enable rigorous, in depth, and systematic analysis in 1987. The analysis consists of:

- **Phase I:** Collecting, describing, and documenting raw data
- **Phase II:** Identification and categorization of description and components
- **Phase III:** Patterns and contextual analysis
- **Phase IV:** Major themes, research findings, theoretical formulations and recommendations

(Leininger, 2006)

I also followed analytic strategies described by Fetterman (1989e). The detail of Leininger’s analysis method is described in Appendix H. According to Leininger (2006), “At all times, research findings from the data analysis can be traced back to each phase and to the grounded data in the first phase” (p. 62).

The first phase is called “collecting, describing, and documenting raw data”. In this phase, I entered transcriptions, photographs, and field notes in Atlas ti ®. I consciously attempted to preserve relevant verbal statements, meanings, and interpretations from the participants with fidelity, and not reduce data to spurious or
questionable themes (Leininger, 2006). I also carefully preserved each participant’s own wording and expressions to prevent over interpretation. In order to achieve this process, I kept the transcripts in Japanese until a later stage. Initial coding was also done in Japanese to preserve cultural expressions and meanings. In this process, I used a strategy to prevent loss of meaning that could be caused by translating at an earlier phase of analysis.

In the second phase, I assigned codes to the raw data. Japanese words were used for code names. Examples are shown in Appendix I. I grouped similar codes appearing to belong to the same family, and developed family names. Characteristically, in ethnography many quotes were double coded because the meanings were found to contribute to multiple families. According to Leininger (2006) the process is called “identification and categorization of descriptors and components” (p.62). “Categories” is the term generally accepted in ethnographic research. However, the term “families” is used in the qualitative software Atlas ti®, and I use these terms interchangeably. I tried to be inclusive with codes representing the families, so that I could identify any indirect influence on themes developing during later phases of analysis.

According to Fetterman (1989a), the researcher needs to look for patterns of thought and behavior by collecting pieces of information, comparing, contrasting, and sorting gross categories and minutiae until a discernible thought or behavior becomes identifiable. Leininger (2006) called this third phase “pattern and contextual analysis”. During the process, key events are also useful as some images from key events are clear representations of social activity (Fetterman, 1989a). Participants discussed key events during the interviews to give me examples of their experiences. These discussions
regarding their experiences were very helpful, and I was able to identify why they think the way they do and understand the meanings of their perceptions. Visual representations, such as maps, flowcharts, organizational charts, and/or matrices can be used as the researcher finds appropriate. I used Google Earth® for each city to see their geological features to help gain an understanding of the places where the participants lived (Figure 3.2). Contents were examined carefully for the consistency of interpretations (Fetterman, 1989a).

After this phase, I derived the major themes. This process followed Leininger’s phase VI “major themes, research findings, theoretical formulations, and recommendations” (Leininger, 2006). In this synthesis phase, I looked at all categories as a whole rather than fragments, to derive appropriate cultural meanings. Then, the relationships of each of the categories and cultural implications of the components were closely examined. Preliminary themes were named in Japanese to preserve cultural implications. Themes were organized and reorganized multiple times to derive the themes in the most culturally appropriate manner. These themes were then translated into English in a way that western readers could understand. This process was completed in discussion and consultation with my advisor and committee members. The translation was done deliberately, to preserve original meanings. I have used Japanese words for some terms, where there was no direct English translation. Original words with phonic expression and translation were used along with representative descriptions in English to present these themes. If terms were preserved as Japanese, the meanings were presented in the results.
Figure 3.2: Utilization of Google Earth®: Susaki City is a Rural and Fish Culturing City.
In this way I attempted to ensure the authenticity of the results of the analysis. A Japanese reader can then follow the logic and content of these findings.

**TRUSTWORTHINESS**

A study requires appropriate evaluation criteria, depending on the philosophical underpinning. Unlike evaluation criteria for quantitative studies that are controlled by specific assumptions, evaluation criteria for a qualitative study need to be utilized cautiously. Although assuring trustworthiness was necessary, “the rigid following of procedures in attempts to ensure the trustworthiness of the study may actually threaten validity” (Mackey, 2007. p. 557). The statement represents that the authenticity of data should be ensured rather than strictly following evaluation steps during a research process. Mackey further argued that “one set of criteria may not be appropriate for all types of qualitative research” (p.555). However, for sake of legitimacy of the study, maximizing trustworthiness was pursued.

Lincoln and Guba (1985) introduced four criteria to achieve trustworthiness: credibility, transferability, dependability, and confirmability. Each criterion and a description of how I attempted to satisfy the criteria in my study are presented below.

**Credibility**

Credibility is a discussion about truth value and replaces internal validity (Mackey, 2007). Direct and repeated involvement in the scenes of the culture enhances credibility (Germain, 2001). In this study, I visited the community and held live interviews in the community with the participants. I also had multiple contacts with each participant to increase credibility. I also used informal member checking as a strategy to establish the credibility of the findings and interpretations. Informal member checking
was achieved by providing a summary of the information captured in the interview back to the participant during my second interview (Lincoln & Guba, 1985). I also used the technique of confirming that my interpretations were appropriate and accurate, during the interview. As a member checking process, I also asked a question to later participants to confirm if what I learned from other participants was true for the later participants.

I have also asked multiple nursing faculty who are Japanese to concur if my findings were plausible. Dr. Misuzu Gregg, a qualitative expert and a professor at Kobe City College of Nursing, was asked to read this entire thesis. She is an experienced nurse, qualitative researcher, and a Japanese woman. After Dr. Gregg read through the thesis, she wrote a letter to confirm credibility and authenticity of interpretation (Appendix J).

**Transferability**

Transferability replaces external validity and regards applicability to another setting or group of people (Marshall & Rossman, 2006). “The researcher should argue that his finding will be useful to others in similar situations, with similar research questions or question of practice” (Marshall & Rossman, 2006, p. 201). Because the purpose of this study was “providing the widest possible range of information for inclusion in the thick description” (Lincoln & Guba, 1985, p. 316), this qualitative approach and thick description serve to establish transferability. During the recruitment, I attempted to select representative samples from each area to facilitate my ability to grasp a modality of the culture although it was challenging due to the difficulty of recruiting research participants in Japan. To ensure a thick description of data and appropriate processes in the study, I consulted frequently with my PhD committee members. This procedure promoted precise and detailed descriptions and invited readers to understand
the population and phenomenon under study. Transferability of the study findings are discussed in Chapter VI.

**Dependability**

Dependability replaces reliability in a positivist framework, and is discussed as consistency (Lincoln & Guba, 1985; Mackey, 2007). Consistency of findings can be confirmed over time or by replicating a study although in the qualitative paradigm the term replication is not used. Although the phenomenological paradigm does not assume an unchanging universe as positivism, I hope universal themes would arise if a scholar chooses to repeat this study. However, literature on Japanese culture was found to be supportive of my interpretations and the themes found in this study. These aspects are discussed in Chapter VI. The exploratory nature of this study precludes firm confirmation of dependability. Therefore my responsibility was to provide a precise description of methodology so a future researcher could engage in similar investigation.

**Confirmability**

Confirmability argues the neutrality of a study, and replaces objectivity (Mackey, 2007). “Confirmability audits are conducted when the project is nearing completion” (Germain, 2001. p. 302). The process requires auditing, to confirm that findings, interpretations, and conclusions were supported by the data. Preserving verbatim field notes and photographs throughout this process allows the researcher to justify confirmability. In this study, I have committed to present results based on actual data. Most of the themes were also derived from actual quotations by participants. I have created a reference for the process and examples of the actual data so that readers can see the process of analysis (Appendix I and K).
SUMMARY

In this chapter, the research design and methods were presented, including philosophical justification of use of ethnography informed by phenomenology; study settings; recruiting methods; interview data management; and analysis methods; and trustworthiness of the study. Participants were recruited from two different sites; Japanese rural and urban cities. The study population was women with gynecological or breast cancer stage I or II. Fifteen interviews were conducted with the women. Their lived experience with advance care planning was explored through this qualitative inquiry. Sources of data were interview recordings, field notes, and photographs. All data were stored electronically in password-protected flash drives until data was analyzed. Data were analyzed using methods described by the Leininger (2006) and Fetterman (1989d). Lincoln and Guba’s criteria (1985) were utilized to increase trustworthiness. In the next two chapters results of the investigation are presented.
CHAPTER IV
RESULTS: JAPANESE CULTURE

INTRODUCTION

In this chapter, research findings related to Japanese culture are discussed. The cultural context is an essential component of this ethnographic investigation and provides the Western reader with a foundational understanding of the findings related to ACP. Language carries culture and this investigation was conducted in the native language of the Japanese participants who lived in rural and urban Japan.

Not all Japanese expressions are easy to understand for English readers because expressions may comprise culturally different meanings. Without understanding the cultural implications, the interpretation may be inappropriate. Direct literal translation may also cause one to miss significant cultural contexts. Although I, as the researcher, encouraged the participants to be clear about their meanings on each expression, the participants also naturally assumed the researcher, a Japanese native, would understand Japanese cultural contexts by common sense and life experience. The participants repeatedly used expressions of "ですね [desuyone]" or "じゃないですか [jyanai-desuka]" , which means "isn't it?" and "you would agree" respectively. I was trusted to understand Japanese culture because of my almost 30 years of life experience and cultural observation in Japan. During the dialogue, I asked some probing questions to confirm that my interpretations were accurate. The findings are presented with pseudonyms of participants’ last names because it is natural for Japanese people to call each other by their last names.
For these reasons, certain symbolic expressions and core cultural concepts are presented in this chapter to support the American reader's understanding of Japanese culture. Symbolic expressions and cultural concepts supported to develop the themes related to advance care planning.

Themes are presented as a whole by utilizing phenomenological interpretation rather than a common ethnographic analysis method to enhance Japanese cultural meanings and interpretation. This method was helpful for the readers to understand concepts that do not exist in English language. Participants’ verbal and non-verbal expressions shown in the data were interweaving, and data were interpreted as a whole to derive the profound cultural meanings with rich descriptions of emic perspectives. The study results are presented in Chapter IV and V in this same manner.

The symbolic expressions and concepts discussed in this chapter are: 1) **Perception of Their Own Lives**; 2) **Perception of Their Bodies and Organ Donation**; 3) **Care Giving and a Status as a Wife in Japan - 介護 [kaigo] & 嫁 [yome]** ; 4) **Medical Knowledge and EOL Issues**; 5) 遠慮 [Enryo] - Self-Restraint and Holding Back. Those concepts more directly related to the participant's perception of ACP are presented in the Chapter V. However, first, the concepts presented in Chapter IV provide a cultural foundation and context for the major findings of this investigation.

**PERCEPTION OF THEIR OWN LIVES**

Japanese people have a unique communication style. They prefer to have indirect communication. Culturally, explicitly expressing an individual's own thoughts are considered impolite and evidence of self-centeredness, and people are uncomfortable explicitly expressing their own thoughts.
Many of the Japanese participants described their perception of their life as "a life cured [by the doctor]". When they talked about their life and body, they expressed their life as a passive existence, ontologically. While they acknowledged their life was their own, at the same time they described it as if they were alive by the force of an external entity. The participants used an expression of "I am lived by [something] 自分は生かされている [jibun-wa ikasarete-iru]" or "because this life was cured by [someone], I don't want to expose to risks to lose 助けていただいた命なので、失う危険にさらしたくない [tasukete itadaita inochi nanode, ushinau kiken ni sarashi takunai]". The expression of "I am lived by something" cannot be easily translated into English. It was a participant's feeling of external locus of control. In Japanese, there is clear distinction between active person and passive person in the dynamics within the sentence, which is not clear in the English language. Another feature of Japanese language is that possessive expressions, such as “my”, are used much less than the English language. Unless it's necessary to specify or have special emphasis on the possession, often possessive adjectives are omitted. Japanese people are simply not comfortable with expressions and a communication style with emphasis on self. Consequently it was expected to see minimal use of possessive adjectives. However, I have found that the perception of their lives with minimal emphasis on one’s own possession was even less than usual in conversations with women who had early stage cancer.

The expression "お任せするしかない [Omakase surushika nai]" was found repeatedly. It means that there is nothing I can do other than depending on a person/something. This implies significant dependence on their physicians. This notion
reflects a hierarchal structure between patients and health care providers. In the last ten years, a growing emphasis has been observed on patients' rights and patient-centered care in the Japanese culture (Imamura, 2001). On the other hand, people's perspectives of the hierarchal structure remains. They believe that the health care provider has control over their body.

It is noteworthy that they express minimal emphasis on possessiveness of their body. It is not necessary that they perceive their body as shared with their community either. Japanese participants were educated and had their own thoughts on their health. A participant, Mrs. Asao [pseudonym] from Tokyo challenged the physician on her treatment plan. She had cancer before and it went into remission with hormonal therapy. Because she wanted another child, she had asked the physician not to remove her uterus if the cancer recurred.

When I found [the cancer] the second time... no way, no way... Recurrence... Doctor, you told me probably 2 years [for recurrence]... it's too soon. It's only been a year.” [The doctor said] "it depends on the person, but we have to cut [the uterus] out this time." [I said that] I wanted to take medicine; I wanted to have one more child. However, I was totally scolded. [He said] rather than dreaming about a child that you even don't know if you get, you have to raise a child you already have. [The doctor continued,] there is no way the child can be raised without its own mother. It was more shock again...because I wanted to have two or three children... I still had embryos to bring back [to my uterus]... there was a possibility to have a child by in-vitro fertilization...his recommendation of taking [my uterus] out means there is no place for [the child]. It was so shocking. I can't make siblings for my child anymore... However, I was told to raise the child here already, so I just had to accept it. Actually, as we cut it out, it was stage 1b. Until they actually cut the cancer out, which might be stage 0, Stage Ib, Ia...The doctor told me we would never know until we actually cut repeatedly. Then, as he actually cut, it was stage 1b, which was the borderline of metastasis: no lymph node metastasis. Although I had to receive lymph node dissections, I didn't have to take any chemotherapy or medication. I feel now that I was really lucky.
ですってやっぱりもう一人欲しいからって話をしたんだけど、それはもう完全に先生に叱られました。授かるかどうかはわからない子どものことよりも、今いる子どものことをきちんと育てなさい、お母さんいなかったら子どもは大きくなれないんだだって、でもそれはまたそれでショックで、二人、人と欲しいと思っていたのでまだ受精卵が残っていたのでもう一人戻して、また体外受精で授かるかもしれないっていう可能性があったので、それでその戻す場所がなくなっちゃうというのはとてもショックで、兄弟を作ってあげることはできない、だけど今いる子どもをきちんと育てなさいといわれたので、もうだからそれを受け入れるしかなかったですね。
ただ実際に、切ってみたら1b期で、それは切ってみないと最終的な判断はできないから0期かもしれないし1期、1b、1aかもしれない、それは本当に切ってみないとわからないからってことは再三言われていて、で、切ってみたら本当に1b期、ぎりぎりのラインで転移してないで、リンパ節郭清はしたけれども、その後の化学療法とかお薬だとか飲まずにすんでいて、本当にラッキーだと今は思えます。

Mrs. Asao continued...

At the time [of diagnosis], it was soon after I went back to work [after maternity leave], so I was working. Because I had to arrange my work and taking care of my child, I've asked to delay [my treatment], which was an incomprehensible request [for the doctor]. So the doctor scolded me as "this is about your life! You are going to die [without treatment]"; "You have no choice. Surgery has to happen as soon as possible. It's cancer. There is no work that would tell you to work if you tell them you have cancer. You have to explain to your work that you have cancer, then they should tell you to be in the hospital." Well... as I told my work [about the cancer, my boss] told me that it's okay to go to the hospital [for inpatient treatment].

そのときはもう復職して間もないということで仕事をしていましたので、その仕事の段取りのこととか、子どものこともあるしできれば延ばしてくださいっていう訳のわからないお願い事をしたんですけど。そしたらもう本当に先生には命に関わるんだよね、死んじゃうんだよって本当に叱られて、選べない、できるだけ早く手術したほうがいい、癌ならだよ、職場に癌だって言って働けなんていう職場はいないっていって、きちんと職場に説明して癌だって言いなさい、そしたらすぐに入院していってくれるはずだからって。ま、本当にそういったらすぐに入院していいからって言われましたけど。

Japanese people tend to talk humbly about their health. They use the phrase "お蔭様で[okage-samade]" quite often in usual conversation. It means "because of
It reflects their cultural expectation to describe their body and health with minimal emphasis on power over their own health/body, although not necessarily thinking their body belongs to someone else. This perception of life as their own, yet kept in privacy, was observed throughout the study findings.

**PERCEPTION OF THEIR BODIES AND ORGAN DONATION**

Although I did not ask about their thoughts on organ donation specifically, some of the participants drew a relationship between decisions on organ donation and advance care planning. Organ donation has been a very active discussion in the Japanese media related to end-of-life (EOL), and an EOL discussion seemed to remind participants about organ donation. Wishes regarding organ donation can be included in the ACP but is not necessary. Participants expressed their perspectives on organ donation, as something not well accepted in Japanese culture. Some of the expressions were "hmm...Something like...ripping the organs out for someone else...It's hard to think something like that."

うーん、人の為にえぐって使ってとかってそういう事、考えがたいと思いますよね。

Mrs. Sasaki said that taking an organ away reminds the Japanese of homicide.

All the organs... Old people think that as everything is there, it's a whole body, so there should be all [organs together]. Such as homicide, if such a thing happened, there is no way to avoid autopsy though. Japanese people who hate getting autopsy for small reasons. [People] hate being cut, being chopped. Feel sorry, even if [the person] is dead, they still feel sorry. 全部臓器が、全部揃っておいて一つの体っていうのが古い人は考えますから、やっぱり全部。殺人事件とか、あんななら解剖されても仕様がない。何か、ちょっとした事で解剖されるのも嫌な日本人がいますからね。切られる、刻まれるのが嫌。可哀想って。死んでても可哀想だっていう。

[She continued] Japanese [people] are difficult. Very few [people] are willing to give their organs. If the person wants, the person would have to talk to
the family very well. Only for each person who wants to donate an organ, there is a family member who feels that it is not the [same] person anymore after taking [an organ] away. なかなか日本人はね。少ないですよね、なんか臓器の提供というのはね。する人は、ちゃんともって家族で話し合って、後、自分だけこうやでも、それを取られたら本人じゃないみたいに思う家族もいるみたいなんで。

[Mrs. Sasaki concluded] I believe there are only a few people who think [they would donate their organ] if [their or family's organ] can be used to help [others]. Not so many people would donate for the future of medicine or being a part of research. Yeah...not yet... 何かの役に立てばっていう考える人がなかならないでしょうね。研究材料、今後の医療の発展の為に提供するっていう人はそんなにいないと思う。なかなかまだ、、、、。

Mrs. Asao recognized the meaning of giving an organ, but on the other hand she also acknowledged possible resistance from the family, and an individual would obey the family decision to act with harmony. She stated:

As I die, it would be my pleasure if a part of my body helps in any way, somewhere; but on the other hand, I'd never know what happens as I am dead. I have never talked with my family and other people how they would feel about me being cut. Not yet, maybe [my family] would respect my wishes, or my family may say no and resist. Because I have not talked [with my family] yet, I don't feel I want to write about that [in AD] yet. 自分が死んで、その別のところで自分の体が臓器がどんなかたちでも役に立つのはやっぱり嬉しいなって思える半面、自分は死んでしまってるわけだからわからないわけですよね、家族や他の人たちが自分の体が切り刻まれていくっていうのはどういうふうに感じるのかというのは話したことがないので。まだ、まだ、自分の意見を尊重してくれるのかもしれないし、家族は嫌だと抵抗するかもしれませんねし、それは話せていないので、あんまりそういうことは書く気にはならないと思います。

Mrs. Asao expressed more acceptance of organ donation, but this participant also said she did not register as a donor. She explained:

Such a thing is shown on the media, isn't it? As I heard news that we can prioritize next of kin's transplant [if the person was registered], ah...[this] makes sense. For example, [a mother on the TV said] "my daughter has died, but my daughter's eyes are still alive in someone else's [body]". As the mother said [such
a thing, I felt] "yeah, make sense", but [if you asked me if] I have such a thing
[like donor card], there is no active force to register [as a donor] yet. メディアで
そういうの報道されていますよね、そのドナーカードを近親者を優先して移植
することができるようになったとかいうのをニュースなんかで聞いて、ああ、そうなんだって。例えばその自分の娘は死んじゃったけど、別の人の
ところで娘の目が生きていますなんて、お母さんが言うとなるほどのねという
ことは思いますけど、じゃ自分はそういうものを持つ、登録するまでの
行動力はないです。まだ。

These participants perceived organ donation as not very well accepted in the
Japanese society. They felt that way because there was a social norm of unity of person -
one has to have all the organs together in life and death. They also have certain feelings
about a body after death. Japanese think they should pay respect to the body after death
and feel terrible if the body was not treated well, such as with the cutting out an organ.
Some people were open to the idea of donating their own organs after death; however,
they also cared about how the family would feel if their body were cut and the organs
taken out. Other cultural concepts related to ACP which were emphasized by participants
are discussed in the following section.

CARE GIVING AND STATUS AS A WIFE IN JAPAN - 介護

[KAIGO] & 嫁 [YOME]

The simplest and usual translation of the term 介護 [kaigo] (pron. ka-ee-go) is
"care-giving." However, it embraces specific implications beyond just care-giving. In
English, care giving applies to various care receivers, such as children, adolescents,
adults and elderly people. In Japanese, this term is specifically used in relation to people
who are ill or elderly. It is never used for infants or children unless they are ill. In this
section, the culturally specific meaning of *kaigo* is explained because of its importance on cultural perspectives related to EOL decision making.

Similar to people in the United States, EOL issues remind people about aging. Most of the participants' personal experience with EOL was with family, typically their parents or parents-in-law. Throughout the interviews, participants implied that natural death was acceptable in the elderly population. Their perception on natural death will be described in detail in Chapter V; however, some cultural perspectives and their related implications unique in Japanese culture and other Asian populations, are presented in this chapter.

Japanese women are expected to take a specific role in *kaigo*. The expectation is closely related to another concept that describes a Japanese wife - 嫁 (*Yome*). *Yome*, in the simplest translation, is a wife or a daughter-in-law. An historical view of women, especially married women, in the Japanese society helps to understand their role in the family.

Mrs. Yoshii was at the family meeting for her father-in-law's EOL. She related this story:

> When [my father-in-law was] moved to a palliative care unit, my husband and his sister went to see the facility that has the best reputation and was the place I had seen [previously] due to [my] work. They talked to the doctor and agreed it would be a good place [for their father]. If I [participate to] decide, things get complicated. Yeah, it was good that his biological daughter and son decided. Still I am just a *Yome*; I'd better not decide.
A good *Yome* is expected to be patient, not complain, work hard, and obey her husband. A *Yome* is expected to serve the family and is in a low hierarchical rank in a family (Abe, 2009). Because *Yome* is supposed to be a primary caregiver for her parents-in-law, married women experience pressure and criticism from relatives who do not share this responsibility.

Mrs. Yoshii described conflict between relatives who live with the elderly and relatives who do not live together. She also talked about change in Japanese society:

For example, a long-term-care institution [for elderly]. Well, since approximately 10 years ago, a long-term-care institution or facilities using long-term-care insurance for elderly [have been more utilized]. Until a little more than 10 years ago, if [we] placed [old people], there was a resistance. Because family feel the burden, the family want to place [the old person] in a facility...[at an institution, they] take care of [the old people] very well. However, relatives get grumpy and say 'why don't you take care of her [by yourself]’... but... In Kochi, a two-income family [is common]...[because] income is very low for both men and women compared to the national average. So, there are many two-income families, and if [a person] gets dementia or ill, [we] have to rely on facilities. [Since] 10 years ago, people have not felt resistant to place their family in such a place [facility], I guess. 例えば、その老人福祉施設ですよね。まあ、老人保健全施設とか、老人のいわゆる介護保険を使った施設に入れるのも１０年位前、１０年ちょっと前位かな、は、凄くその、そういった所に入れると抵抗がある。家族は大変だから入れたいんだけど。よくお世話もして下さるし。だれでも、親戚がちょっと機嫌が悪くなったり、何でちゃんと見てあげないのとっかつて、。。。ですけれども、やっぱり高知は、共稼ぎが、あの、とても収入が低いんですよね。男性も女性も。全国平均からいうと。だから共稼ぎが多いので、やっぱりボケたり、病気になったりしてしまうと病院とか施設に頼らず終えないって所もあるので、１０何年かいうとそういった所に自分の身内を預けたりするのは、あまり皆さんん抵抗が無くなって来たんじゃないか？

Mrs. Sasaki also had the experience of taking care of her parents-in-law while taking care of her children. She said:

Well, at the same time of raising children, my husband's parent's *kaigo* is waiting for me...so really...she had dementia and other things. ...mother-in-law already had dementia, atrophy of brain. Since [we were] married, there was
a bit of significant forgetfulness. My father-in-law had laryngeal cancer, which he already had more than ten years; several tumors came back. Then, gradually, he has become aphasic and forgetfulness got worse. [Because of that, I] had to take him to day-services et cetera and it was really so much work. Yeah, until he's got into the hospital, I had to drive him around. Although my father-in-law has already passed away, my mother-in-law is in a nursing home, since a bed that we've applied before has become available...yeah, the vacancy. I've applied to the place that their waiting list was the shortest. Yeah, there are many people who have to wait very long time, I guess. If we want somewhere close [and convenient], [the number of the] people waiting would be big. [So.] we've applied the place smallest [of their waiting list]. We were notified relatively quickly. We still waited almost one year though. If it was a nursing home, they would do everything. If that was a hospital and don't take care of laundry, it would be so expensive. It would be very different [between a nursing home and a hospital]; the unit of the difference is 100,000 yen [approximately $1000 if the conversion rate was $1: ¥100]. その子育てと同時に、主人の親の介護が待ってますから、本当 に、、、、。痴呆症とか色々あったんで。…義母は、もう痴呆、脳の 萎縮。結婚した時から、多少物忘れがひどいかなっていう感じで。お 義父さんは、喉の癌もあって、まあ１０年以上経ってたんですけど、 何個か出来て、血管が弱ってる中、お風呂入れたんですよ。自分[義 父]が入ってる時に、孫を一緒に入れて、その後に脳出血を起こして。 それから、段々、出なくなって、物忘れとかこうなったんで。デイサ ービスとか色々送っていったたりとかやったり色々大変でした。もう入 院間際までね、車運転してましたから。もう、お義父さんは亡くなっ たけど、おばあさんは老人ホームに。丁度、空きが、申し込んでたん で、空きがね。私の場合は、一番人数が少ない所へ申し込んだんで。 もう、何年も待つ人が居るでしょうね。人数が多い所、近くでって願 むと。一番空きが少ない所に頼んで。わりかし、早めに言ってきまし たね、よかったって。１年もかくは待ちましたけどね。老人ホームに 入ったらある程度、全部やってくれるんですよね。病院なんかは、全 部、洗濯物から持って来てなくちゃ金額が高くなるから、大変みたいで すね。まぁ、１０万違うでしょうかね。

Mrs. Yoshii talked about recent problems related to the significant increase of the elderly population in Japan. Although her mother-in-law was getting old at the time, she was still expected to take care of the mother-in-law's mother-in-law who was even older. So, the family expressed an unwillingness to place this participant's husband's grandmother in a facility.
I: So, do you feel the change gradually [regarding utilizing institutions for elderly people]?
Mrs. Yoshii: Yes, I can feel it clearly. And, the proportion of elderly population is even higher now, so no doubt [about the change of utilizing the facilities]
I: So you said it started about 10 years ago? Was it around the time that the long-term care insurance system started?
Mrs. Yoshii: I guess so, because it's been about 10 years since my husband's grandmother passed away. [She was] in the facility few years before [she passed away], and it might be about 15 years ago. At the time, [my husband's] mother got complaints from relatives, but if [she didn't use the facility], she would break down from Rou-rou-Kaigo [elderly taking care of elderly].

Mr. Yoshii's mother had to serve as yome, as she was the daughter-in-law of Mr. Yoshii's grandmother. Mrs. Sasaki continued to talk about a yome's responsibilities, and the difficulties for a yome to have support in kaigo.

Depending on family's demand and degree of kaigo needs, the [kaigo] service would change some extent, wouldn't it? Even when there are siblings close by, while there are [some family] to take care of [the parents-in-law], there are [people who] don't help [to take care of the parents-in-law] at all. Japanese men rarely help. Long time ago... changing diapers, [she] had to feed [the parents-in-law], and [she] had to change the meals to be soft. [She] had to cook meals separately [for the parents-in-law]. The most difficult thing was bathing. [We] felt sorry [for the care receiver] if she didn't get bathing at least once a month. Still co-pay is quite expensive [because] the bathing car comes to our house. Such as a couple of thousand yen. It's quite expensive. There are a few bathing cars [available] as well. 家族が希望したい内容と介護度によってある程度サービスが違って来るでしょ、今。それによって全然合わない時もあ る。周りに同じ兄弟がいても、交代で見てくれる所もあれば協力して全然 見てくれない所もありますからね。日本人の男性はなかなか手伝ってくれませんからね。昔...もっとオムツ交換とか食事もやっぱり食べさせなくちゃいけないし、食事の内容も柔らかくしなくちゃいけない。別に作らん
Even in a rural area like Kochi, facilities have been utilized progressively in the last decade. However, the availability of beds is limited because of the drastic increase in the elderly population of Japan. Despite an increasing acceptance of long-term care facilities, family burden still remains because of the waiting time. A *yome*, women in Japan, are still expected to carry out most of the responsibilities in care-giving, *kaigo*. Although the women interviewed in this research had cancer diagnoses, the topics of *kaigo* and *yome* were so embedded in their cultural experiences that they related their advance care planning to the situations of caring for older family members that they had observed or performed. The participants were cancer survivors but at the same time some of them had to continue the role of *yome* while going through cancer treatment. Their life experiences of *kaigo* responsibilities as a *yome* showed physical burden while they received cancer treatments.

**MEDICAL KNOWLEDGE AND EOL ISSUES**

Knowledge regarding their own health status and EOL issues developed from various internal and external sources. Participants discussed how they acquired knowledge from their own life experiences and also from books, TV programs, commercials, the Internet, and conversations with others.

**From Women's Own and Family's Life Experience**

Many of the participants had some exposure to EOL issues in their own life experience and this shaped their thoughts about EOL. Life experience refers to the
experience with family members and loved ones. These experiences largely influenced their perspective on how to perceive their own or their loved one's possible EOL issues.

Mrs. Yoshii witnessed her father's EOL in a hospice and reported:

Well, of course, in my father's case, because any aggressive treatment was not available at all anymore, [we focused on] relieving pain and eating whatever he wants... although as within a scope of hospital care, [we] let him do whatever he wanted as much as possible. A male nurse was assigned to him. Because of that, it seems he was able to talk [to the nurse] easily; he talked about many things, such as his travel experiences. まあ、勿論、うちの父の場合は積極的な治療はもう一切出来なかったので、まあ後は痛みを取って、好きな物を食べて、もう好きなことを病院に居る範囲内ですけど、してくれるっていう形で。父には男性の看護師さんが付いていたんですよ。だから父も話しやすかったみたいで、旅行の事とか色々話していたんで。

Mrs. Yoshii described a cultural implication of the preference of having a nurse of the same gender. After the experience with her father in hospice, she has found a preference regarding her own EOL. Despite developing this preference, she still has not had an explicit discussion with her family, nor has she put her wishes in writing. Instead, there is some expectation that her family would treat her the way she wants to be treated. Her wishes at the EOL have taken form through the personal experience of observing a family member receiving hospice care.

From The Media

Many documentaries and news stories have provided medical information, including information about EOL issues. Mrs. Sasaki had seen a TV program reporting the benefits of utilizing hospice care and said:

It was on a TV; there was a person who was told he was able to live only a few months, but as pain was [controlled and] stopped, he was able to go home and spend good time [at home]. So, torture...pain is the priority, I think as [we] stop the pain, it would be possible to spend the day comfortably.
家に帰って暮らせるようになったしっていう人も居るから、苦しみを、やっぱり痛みが一番ですから、痛みを止めたら気分的に楽で一日が過ごせるっていうのもあるって思いますね。

Such stories presented on television make it easier for lay people to understand EOL issues. Depending how the information is presented, people become aware of alternative or integrative care to make an individual more comfortable at the EOL. It speaks to people's values about quality of life.

Society has changed and so have the methods in which we obtain information about EOL issues. Until just over a decade ago, the main sources for medical information were newspapers, television, and books. In more recent years, however, the Internet has become widely available, and it has become a significant source of medical information. This shift has occurred in many developed countries including Japan and the US. In Japan, use of the Internet has increased dramatically in the last decade. The dissemination rate is as high as 75.3 percent of all households (Japanese Ministry of Internal affair and communication, 2009). Almost all participants said that they have used the Internet to gather medical information about their diagnosis and treatment, but no participants explicitly expressed that they had researched ACP. The same phenomenon was found with the acquisition of information from books.

Information gathering methods largely depend on individual preference. Mrs. Yamada went to the library to read books.

Well, like symptoms of cancer stage I are like these can be found in a book or ask someone. [That kind of information] can be found on TV, media, some books, being in society, and on the newspaper; and it cannot be hide. What I have changed [after my diagnosis] was that I went to the library and read book page by page. まあ、大体、癌の1期だったらこんな症状って、大体、本とか、本人に聞いてもですけど、テレビで報道とか色々本とか社会、新聞とかで報
Mrs. Kawai said she found that blogs and personal stories were very helpful:

I’ve also researched. [I was] frantic and look though the computer from cover to cover. Because something... now [I feel] very much like...[I understood] it would be like it. There were many of those written as blogs from diagnosis to surgery and after surgery; and it was very helpful. [Because of those blogs] I would be like that. Because I was able to guess it would be like this next, yea, I probably felt much easier. 私も調べました、がむしゃらだったし、パソコンも隅から隅まで見ました、だからなんか、今すごく、こうなんだ、告知から、手術から、術後からってブログ形式で掲載されてるのも多かったしそれは参考になったんですけど、それでこうなるのかな、こうなるのかなっていう次の予想がつくのは、うん、多分気持ちが大分楽になるのかなって思いました。

External information sources were often the media. Depending on the nature of this media, people received information in very different ways. For example, with books and the Internet, people need to have some idea what they are looking for. If they have no concept of the topic, they do not display information seeking behavior. On the other hand, information from a movie or television can reach people who have no basic knowledge about the topic. An abundance of information is available to Japanese people as the dissemination rate for media and the Internet in particular, are high. Japanese literacy and education levels are among the highest in the world. This was consistent with participants’ descriptions of a variety of sources they used to obtain health and EOL information. In the next section, an important concept unique to Japanese culture, *Enryo*, is described to provide a context for the ACP perspectives and care experiences of participants.


遠慮 [ENRYO] - SELF-RESTRAINT AND HOLDING BACK

遠慮 [enryo] (pron. ehn-ryo) is a phenomenon that cannot be directly translated into English. Enryo is the behavioral phenomenon of “not having to ask” because of assumed cultural empathy. It has also been explained as polite hesitation (Arnault, 2002). In Japanese culture, asking directly for something, clearly accepting an offer, or causes someone else’s effort is considered impolite. For this reason, people tend not to directly express what they want. It may be evidenced in a manner where they say "No thank you. I am okay" when they actually need help (see Appendix L). This phenomenon is very common in Japanese culture, and it was prevalent in participants’ interactions with family, healthcare providers and others.

Enryo was extended as compassion to their nurses during the participants’ hospitalizations as well. Mrs. Yoshii couldn't say what she wanted after surgery, but said

Well, the nurse would have done it if I told her, but as I see how busy they were, I couldn't tell [about my needs]... ま、あの言ったらしてくださったらかもしれませんけれども、あまりにも看護師さんたちの忙しさを見ればちょっとといえなかったなっていう。

Mrs. Takei had vomited after surgery. She said she vomited three or four times overnight, but could not call a nurse because she knew all the nurses were busy, so she felt reluctant to call them.

[As I vomited, a nurse] brought a basin, so I vomited [in it]. I felt [bad] to call [a nurse] right away and left [the basin]. I thought "[a nurse] would come next [soon]", and I asked when [the nurse] came the next time. 一応、ガーグルベー ス持って来てくれたのでも、自分で吐いて。それを直ぐに呼ぶのもあれだ なって思って、置いてみたいな感じで、「次来るのでかん」と考えて、 次来た時に頼んだりとかいうのはして。
Mrs. Yoshii stated similarly: “Well, [when nurses say] tell them anytime for anything, everyone would enryo anyway. で、あったらいつでも言ってくださいっていてもね、みなさん遠慮というか。” and

If I say so, it's a complaint though... Doctors are too busy. Really busy. Yeah, really busy. So, there is some pressure that I can't say nothing. I am not sure if it's a good thing or bad thing. ま、不満といえば不満ですが、先生もあまりにもお忙しいので、本当に忙しいので、この方本当に忙しい、だからもう言えない雰囲気がありますね。それがいいことか悪いことかわかりませんけども。

This hesitation of verbalization is ingrained in the Japanese culture, and can be found in some other Asian countries as well. Although it is more prominent in Japanese culture, this phenomenon can be found in Western cultures as well. Because there is explicit language to express this phenomenon in Japanese, they are very conscious of this concept and phenomenon (Miike, 2002).

This cultural phenomenon affected a participant's medical decisions. Mrs. Asao thought of getting a second opinion for her cancer, but explained:

Eventually I couldn't make an action to go to such a hospital [that would provide second opinion]. Since I have to obtain all the data from this hospital and go to get a second opinion [at the different hospital]...then if I have to get cut [receiving a surgery] anyway, I have to come back here. Then I felt enryo [to my doctor here]. 最終的には、そういう病院に行くっていうふうなところまでは行動はしませんでした。というのはここからすべてのデータをもらって別に病院にいて、セカンドオピニオンに聞くわけですから、それでも切ってもらうだったら、何かをするんだけど売らなくちゃいけないというのがあって、なんとなく自分の中では遠慮みたいなので。

She was thinking about the doctor's feelings in regard to her receiving a second opinion. It might imply distrust or disrespect to her doctor. She wanted to avoid any possible conflict with the doctor because he would be the one who would perform
surgery, if she ended up needing a surgery. Although getting a second opinion has become more common in Japan, people still feel the act is a betrayal or distrustful to the person who originally offered them help.

*Enryo* has been introduced as a typical Japanese communication style by many researchers in sociology. During the interview process, this participant's fundamental psychology had to be carefully respected to avoid being culturally disrespectful. The participants consciously and unconsciously used the communication style in every-day life. I carefully presented questions and engaged in dialogue with the participants, taking both an emic (insider) and etic (outsider) perspective. This approach helped obtain clarity in the meanings of their expressions, while respecting their cultural beliefs.

**SUMMARY**

In this chapter, several important cultural perceptions and phenomenon that appeared in the interview data were presented. The themes introduced in this chapter were: 1) **Perception of Their Own Lives**; 2) **Perception of Their Bodies and Organ Donation**; 3) **Care Giving and a Status as a Wife in Japan -介護 (kaigo) & 嫁 (yome)**; 4) **Medical Knowledge and EOL Issues**; 5) **遠慮 (Enryo) - Self-Restraint and Holding Back**. Visiting these important phenomena was vital for deeper understanding of Japanese women, specifically these participants living with cancer. Their communication style and fundamental beliefs were closely related to how they perceived society and what they expected of other people with whom they interacted. These phenomena were a representation of their consciousness of community. In addition to their community awareness, they have a specific ontology related to their body. Japanese look at the body as a respected entity, even after death, and a recent movement to promote organ donation
has been a difficult for people to accept. Despite the fact that the focus of this research was not organ donation, it seemed EOL decisions and organ donation decisions were intertwined in the minds of participants.

A review of living as a married woman in Japan or Yome, is important, as the hierarchal structure still remains and it influenced participants’ decisions about themselves and their families. Although the hierarchal structure is not as strict as it was in the past, how they acted and what they were expected to do were always done with the intentional recognition of their status in life.

More importantly, the Japanese term enryo was described because this phenomenon is so profoundly embedded in Japanese culture. Sometimes described as a communication style, enryo exists as expected behavior in the Japanese culture. This cultural concept serves Western readers to better understand Japanese women's perceptions of ACP.

In this chapter, several prominent cultural themes that emerged during the interviews were introduced. Those themes are embedded in Japanese culture and were repeatedly encountered in the interviews. Based on these cultural understandings, derived themes from interviews regarding the research question of perception of advance care planning are discussed in Chapter V.
CHAPTER V
RESULTS: ADVANCE CARE PLANNING

INTRODUCTION

The purpose of an ethnographic study is to acquire a perspective broadened beyond her or his ethnocentric one (Germain, 2001). In this study I used ethnography as a method of inquiry to understand Japanese cultural perspectives on advance care planning. This work was achieved in learning about Japanese culture through the lenses of Japanese women living with cancer. Although there are different types of ethnographic inquiries, phenomenology was defined as the underpinning philosophy of this study. Phenomenological inquiry highly regards the individual's own perspectives. Phenomenology is the study of essences: the essence of perception or essence of consciousness (Merleau-Ponty, 1945). Through the participants’ lenses, their perceptions of Advance Care Planning (ACP) were pursued. The derived themes were: 1) discomfort to express one's own will, 2) limited knowledge of advance care planning, 3) dependence on family, and 4) willing learn. After these four themes are presented, an overarching theme “culture and dynamics in Japanese communication influence advance care planning: sashii and amae” is discussed.

My observational data was not limited to the visits to Japan during the formal study period, but also from my longitudinal life experience in Japan, including living in the city where some of the participants resided, for two years. Because ACP is not limited to simply writing an advance directive, I also explored extended interpretations of ACP in the Japanese culture. During this process, emic perspectives of culture needed to be
preserved (Germain, 2001), and I attempted to derive symbolic and central themes regarding ACP through participants' own perspectives.

During the ethnographic interviews, participants expressed their perspectives on Japanese culture and the communities in which they lived. Their lived experiences of early stage cancer largely contributed to their own perspectives on ACP and end-of-life (EOL) issues. However, the research did not lead to a simple conclusion as to whether a cancer patient might write an advance directive. The perceptions of ACP were complex, and facilitated a philosophical and fundamental discourse.

This effort to describe the Japanese culture is not intended to generalize Japanese women's behavior. Rather, I hoped to understand what would be perceived as norms within the cultural context. Cultural norms are extremely relevant to the level of comfort of individuals. They also relate to how easily an individual can accept an event or someone else's behavior. These points are important to this investigation as the comfort with which women living with cancer influenced their ability to describe their wishes and hopes about their advance care planning. In this chapter, results of the ethnographic investigation related to the primary research question are described. Analysis of data led to the identification of cultural themes describing the meaning and experience of ACP. The themes included: 1) discomfort to express one's own will, 2) limited knowledge about advance care planning, 3) dependence on family, 4) willingness to learn, and 5) Sasshi and Ameae. The first theme is discussed in the following section.
Participants directly and indirectly described their perceptions of how Japanese culture impacted their cancer experience and how they thought about the future. Participants showed discomfort in expressing personal opinions and preferences; thus, talking about their illnesses and plans for ACP was particularly difficult. This theme surfaced across all the interviews and was determined to be culturally important. It was shown in the data in different ways. One way was characterized by participants verbalizing their perceptions about how Japanese people generally feel. This theme was expressed by the participants, through an unconscious tendency to use phrases that make the possessive voice of statements vague.

Figure 5.1: Client-Centered Model for Advance Care Planning

Japanese people are in the habit of indirectly expressing their own wishes. Since expressing one’s own thoughts in such a direct manner was not common, participants felt
it was odd to be asked to explicitly state what they want. Insensitively asking to clarify their statements can be intrusive or intimidating for Japanese people, and I had to be cautious about the way I asked questions. I used inquisitive phrases, such as "you mean...?" in order to clarify their thoughts.

Mrs. Sasaki brought up the example of organ donation to explain why Japanese people did not typically express their personal thoughts and decisions. Japanese individuals were assumed to have the same or similar beliefs as the community. At the time of interviews, if a person does not have legal documentation, the person cannot donate her/his organs in Japan. Because organ donation was legalized in 1997 and has a relatively short history in Japan, it has not been widely accepted by Japanese people. Mrs. Sasaki conveyed a common belief about organ donation to me. Her method of expressing her perception was to articulate the community's common belief rather than her own opinion. I found many similar expressions during the interview. Mrs. Sasaki said:

[An organ donation] is not diffused...Since old days, Japanese are... Because it was an isolated island...[Japanese] hardly accept foreigners. This is a Japanese unique belief. [Japanese are] somewhat old fashioned too. 普及してませんよね。...日本人は昔から、孤立の島だったから、なかなか外国人をなかなか入れなかったから。日本独特の考え方。古くさい考え方って所もあるし。

As reported by Mrs. Sasaki, historically Japanese people tended to be resistant to foreign cultures and persist in keeping their fundamental culture. She acknowledged this could be an outdated way of thinking, but insisted this feeling remains in Japanese society. Because of this underlying fundamental belief, people simply do not feel it’s worth substantial effort to have an explicit conversation about ACP. This finding implies that ACP or advance directives (AD) represent topics that Japanese people would not typically discuss. In essence, expressing personal opinions about the topics would make
them extremely uncomfortable. Further, people tended to perceive that their own beliefs were parallel to the general understanding of the community.

I noted references to various levels of sense of community. Mrs. Sasaki brought up an example of the community at large and used the expression "Japanese people are…日本人は". Some other times the study participants talked about their family as a community that shared common opinions, representing a different level of the general community. A strong sense of belonging to the culture comforts Japanese people. Generally, participants did not feel they would have to have an explicit conversation or written documentation of ACP because people expected that their family would hold the same opinions.

Because a sense of community is so grounded in Japanese culture, an over-expressing of one’s own wishes or thoughts can be perceived as being self-centered. While Mrs. Yoshii had developed her EOL preference, she had no plans to put it in writing or to have an explicit conversation about it with her family, due to this unwillingness to express her own will directly. Mrs. Yoshii commented:

If we were in the same situation as my father, and there is no treatment available, probably it is our common understanding in the family that [a hospice] would be [our best option] as a choice. まあ同じ状態になればという事ですね。父と同じ状態になっても、その治療の方法が無くなれば、もう選択肢の一つとしてもうかなり大きい部分を占めるなっていうのは、たぶんうちの家族の中では共通認識だと思っています。

Mrs. Yoshii had previously cared for both her father and her father-in-law. As described in Chapter IV regarding women's status as yome, she did not participate in her father-in-law's EOL decisions. However, because she had known about hospice care from her work, Mrs. Yoshii made the suggestion of utilizing hospice care to her husband. After
a family meeting led by her husband, Mr. Yoshii and his sister decided to place her father-in-law in the hospice at the EOL. She explained that she did not participate in the decision making process, saying: "Because I am yome, it is not my place to decide. やっぱり私は嫁ですので。私が決めない方がいいですよね。"

Later, the family reflected upon the decision to place her father-in-law in hospice and felt it was the right decision. Mrs. Yoshii's father-in-law took comfort in the time that he could spend with his family. Although she had her preference about the possible EOL issues based on these experiences, she did not feel that is was necessary to have her wishes put in writing. Instead, she told me that it was important that all her family members shared the same opinion so that they would treat each other the same way at the EOL. These types of assumptions are common in Japanese culture and consequently, most people believe it is unnecessary to talk about a matter perceived as common sense.

Despite an explicit preference for hospice care, Mrs. Yoshii has not yet had a discussion to express her wishes to her family, nor has she expressed her wishes in writing. Rather, she expected that her family would anticipate her wishes. Her wishes related to the EOL have developed through the experience of actually seeing a family member receiving care at the hospice. However, because of the cultural sense of community in Japan, Mrs. Yoshii perceived it was the whole family learning together, rather than a necessity for developing a personal preference. Japanese people humbly perceive that when the individual learns, people who share the experience would learn in the same way.

Clarification by an individual might be considered rude in Japanese culture because a clarifying statement challenges the notion that people learn the same way and
have a common understanding. Due to these cultural dynamics, and despite never discussing ACP specifically at home, Mrs. Yoshii concluded: "probably it is our common understanding in the family. たぶんうちの家族の中では共通認識だと思っています."

**Speaking of Death**

While it is not a taboo to discuss death in Japanese culture, it is taboo to utter one’s own will and express one’s own wishes. This Japanese trait is different from the American feeling of discomfort in talking about death because it is considered morose. Many Americans tend to avoid talking about death because they hold the belief that if they don’t speak of death, somehow it is not going to happen.

In contrast, Japanese are fundamentally uncomfortable to talk about themselves and do not necessarily avoid speaking of death. The Japanese are not necessarily uncomfortable talking about EOL, as evidenced by the willingness they expressed to learn more about ACP or AD.

Participants understood the need to explore an issue when the issue could not be handled by the culture’s common sense. During interviews, many participants expressed a willingness to learn more about ACP and even about writing AD. Several participants said that they had never thought about ACP before; whereas many who had experienced the terminal illness of a family member admitted the necessity of ACP.

Some participants told me that they had never thought very much about such issues. Mrs. Kotani remarked: "Well, I've never thought [regarding the EOL issues] so profoundly そうですね。深く考えた事ないんですけれども"
Mrs. Kotani also said:

Because my parents' family has been relatively healthy, really…friends and people around me were surprised [that I] became ill...so [thinking about EOL is] not something close to me. 本当に私の両親の家系とかも比較的に健康で長生きの系統なので、あまりその身近で、友人とも本当に周りも私が病気になってビックリされる位だし、余り身近ではないんですけれども。

While participants said they had never seriously thought about EOL issues before, many acknowledged the necessity of explicitly discussing their wishes, and writing AD.

Mrs. Kotani recognized that expressing one’s own wishes is not easy for Japanese people, but at the same time, she realized the necessity of ACP and AD, saying:

Japanese people cannot do so much such a thing like expressing one’s own will. Yes, such a thing [AD] is needed...As I talked about this issue [with someone, I thought] 'yeah, that's right'; ... for anyone who lives, death will come someday, so I feel that I have to write my wishes in advance. やっぱり日本人って自分の意志を表現するというか、そういうのがあまり、出来ないですね。そうですね、そういうのは必要というか、。。。自分も今、話してて、“あと、それ”というか。生きている限り、いつかは死はあるので、やっぱり考えを書いて置かないといけないなーとちょっと思いませんね。

Although Mrs. Murai did not know AD was available in Japan and that it had legitimate legal power, she believed putting a person’s wishes in writing was important.

Mrs. Murai continued:

I'd like to do it [writing an AD]. Yeah, well... because [others would know my ] written words, "yeah, that was what she has written." As the person who reads can confirm "this is her will" and [everyone] understands; so such a way to express... for just in case I am dead...I want to leave something like [AD] somehow. それはしたいなとは思ってます。うん。あの、やっぱこういう風に言いよったと言っても、文章で言葉で書いてたら、“ああ、こういう風に書いてるから”って、また本人も読んだ人も再確認して、だから“これが意思だな”っていう事が分かるから、そういうアピールの仕方。あの、亡くなってからの。それは何だかの形でいきたいなとは思っています。
Additionally Mrs. Ito discussed the importance of written documents as they related to legal issues:

[Mrs. Ito remarked], such a thing [one’s own will]...We have to record such things. Such a thing is not something related to me, but I sometimes feel I should record regarding doctors and attorneys [legal things]...so, "yeah, like, we should do this to each other"...We could get a trouble from [an argument of] you said that or not. ...Or someone else intervenes to the argument, preposterous! Regardless, I was in an either status [of for prolonging life or anti-prolonging life]... In either status, writing or recording is an important thing. Well, I would hate if it gets complicated. I don't want to use my energy for such an unnecessary thing [arguments]. それは、そういう事はとっとかなくちゃね。私達ってでも、全く関係ないけど、ドクターと弁護士関係はちょっととっとかなきゃねっとか思う所ありますからね。...うん、だからお互いにこうしたいんじゃないとかか、、、、、お互いに言った、言わないは困るからね。後、第三者を必ず入れるとかね。とんでもないですよね。どっちの立場でも。...やっぱりどっちにしろ、書くか録音ですね、大事な事は。もう、本当にややこしいのは困りますよね。余計な事でエネルギー使いたくないからね。

Mrs. Ito concluded this conversation by saying she believed her family’s written wishes should be placed on the refrigerator door or somewhere people could easily find them. From her statement, it can be observed that she had a concrete idea about what needed to be done. It might be related to her personal experience of taking care of her own mother who had dementia. Again, however, while she has not taken any action personally on ACP, and she expressed that she knew how her husband would like to be treated at the EOL.

Possessive Voice

The second type of evidence behind the theme of expressing one’s own will was participants’ tendency to use an unspecified possessive voice in the conversation. Reluctance to explicitly express one’s own wishes around EOL exists in Japan, but the phenomenon of reluctance to clearly state one’s own wishes was not found to be limited
to EOL decisions. This action is shown in other aspects of their communication style as well. As briefly mentioned in Chapter IV, participants used linguistic expressions to make their statements appear to be common perceptions rather than their own thoughts, such as "isn't it?" and "you would agree..." Participants tended to use expressions to make the possession of the statement vague. This element of communication style appeared prominently during conversations with the participants.

Participants repeatedly stated that Japanese people were not used to expressing what they thought as individuals. Participants were uncomfortable to participate in conversations beyond the accepted common sense of the community. It should be noted that accepted common sense in this context was not common sense as defined by the actual community. An accepted common sense here means the perception of the individuals who were interviewed. In this study, perceived common sense was similar among these participants but might vary beyond this population. Participants tended to use this collective phrase, Japanese are…, to generalize the thoughts and statements they presented. This action was taken to avoid presenting their own thoughts, which again, would make them uncomfortable. This action therefore relieved them of responsibility for their statements.

Difficulty in speaking beyond accepted cultural perception was demonstrated when participants talked about organ donation as described in detail in Chapter IV. Mrs. Yoshii stated:

You know, [the concept of] volunteer has just to take firm hold [in the Japanese culture] since it has just started to diffuse in the foundation [of the society]. Yeah, [nothing like that in] the foundation of Japanese people. So, even regarding to organ donation, we kind of feel like "[we have to] treat the body properly"; you know, there is such an expectation.
近やっと根付き始めたばかりで、そういう、根底にないですよね。日本人の根底に。やっぱり、だから臓器移植にしてもその“体ちゃんね”みたいな所あるじゃない?

To Mrs. Yoshii, "treating the body properly" was taken to mean considering all organs together, as was discussed in Chapter IV. She told me that discussing organ donation as a part of EOL decisions was difficult because in the Japanese culture, the common understanding was to regard “all organs together” as a shared fundamental belief and expectation of Japanese people.

Understanding what individuals perceive as a common sense, or shared and accepted beliefs, is extremely important in approaching this population. Without this sensitivity, asking such questions can be perceived as extremely offensive, or at a minimum could make a Japanese person very uncomfortable. This finding provided an important insight into the culture and has many implications for practice, as discussed in Chapter VI.

In summary, the difficulty for Japanese people to express their own will and their own wishes was the essence of this theme. This phenomenon is expressed as a general cultural discomfort about expressing one’s own wishes, rather than a reluctance to discuss death and dying. Thus, because of the strongly held belief that wishes are supposed to be anticipated, being asked to express one’s own wishes, explicitly, causes Japanese patients cultural discomfort. This learning implies health care providers need to be aware of this notion while supporting patient’s decisions for AD.

**LIMITED KNOWLEDGE OF ADVANCE CARE PLANNING**

Through the course of my interviews and analyses, I have found that generally, Japanese people have no organized concept of ACP. The concept of ACP is not well
understood by health care providers or the lay population either. While participants admitted that they had heard of ACP and thought about issues related to possible ethical dilemmas, the conceptualization was not well organized nor did it lead to a tangible action around ACP. According to Walker and Avant "concepts are mental constructions" (2005, p.63). I found that participants had fragmented thoughts about ACP, and no concrete mental constructions. Participants were only able to convey to me fragmented information and thoughts pertaining to ACP. These fragmented thoughts were often derived from their personal experiences. Thus, the theme of **Limited Knowledge** reflects the uncertainty expressed by participants, who verbalized thoughts similar to Mrs. Yoshii: “rather than resisting, I don’t know. 抵抗があるというよりわからない。” By expressing this, Mrs. Yoshii was trying to explain that she was open to the information, and she was not resisting learning about ACP or palliative care; she was pointing out that ACP was not a concept Japanese people knew about at all.

Mrs. Sasaki’s story provides a clear example of this situation. Mrs. Sasaki described caring for her husband's parents as they became older. She spent an extended period of time taking care of her husband's parents while raising three children including a developmentally challenged son. Later, they decided to send her husband's mother to a long-term-care facility. Mrs. Sasaki reflected that while it was accepted to allow a natural death in Japan, and even after a long period of institutionalization as in her mother-in-laws case, the family still struggled with idea of her being in a long-term care facility.

Mrs. Sasaki said:

We felt so sorry to make her live longer. She even couldn't talk. Just sleeping all the time. Just sleeping in the bed all the time, and [we felt] so sorry to prolong her life. [A change in her mother-in-law's condition was not] a sudden change… ....
she didn't deteriorate all of a sudden. もう延命処置は可哀想だし、話も出来ない。ただ寝るばっか。ベッドの上で寝るばっかりで、これ以上可哀想だから延命処置は、もうやらない様にって。急変、急に悪くなった分じゃないから。

As Mrs. Sasaki witnessed with her mother-in-law’s EOL, she felt that prolonging life was not always a good thing. She felt that prolonging life could make people miserable in some cases. Through this experience Mrs. Sasaki acquired an understanding of EOL care, along with concerns about quality of life. For her, the concept of EOL care was no longer limited merely to extending the length of time a person can live. Mrs. Sasaki had an experience with writing an AD, and said:

Now, it's also in the nursing homes; in case the condition changed acutely, [these nursing homes required us to write] where we want him/her to be seen at or if we want to have measures to prolonging life; all of such [decisions] has become being kept as a documents. 今、老人ホームでもそうなんですけど、急変して何処で見てもらいたいかとか、延命処置を取るかとか、そんなの全部、書類で残す様になって来たんですよ。

Mrs. Sasaki was the only participant who had had experience with a written form regarding advanced directives at EOL for a loved one, but it was a family agreement rather than the patient's individual wishes, the latter of which is more common in the US.

Palliative Care

Without having an EOL care experience for a family member or someone close to them, participants expressed difficulty in grasping what they would need to consider or address in EOL decisions. Palliative care as a part of patient care is utilized in Japan, but the term “palliative care” is not well understood. Some people had heard about PC before. Some people stated they have never heard the term at all. Mrs. Kawai had heard of PC
before, but only had a vague idea about what it was, because there was no one around her who had utilized PC.

Mrs. Kawai said:

I don’t know other than [that palliative care is] for someone at the end of life. I guess something like taking pain away or providing psychological care. Yeah, there is no one [I know who has used palliative care before]. 末期がんの方の対するケアだということしかわからない、痛みをとったりとか心のケアをしたりとかってことなのかって、はい。周りには[利用した人は]いないですね。

Ms. Sato was a single woman, and she expressed that she did not want to receive futile care at the EOL. She did not want to be a burden on her parents and sister, and she thought she would be, if she put them in the situation of debating the prolonging of life versus quality of life. She thought she was going to die when she was diagnosed with cancer, and she imagined how it would affect her family.

Ms. Sato said:

In my understanding, [palliative care is] just stopping pain and no more aggressive treatment. I’ve thought about it because I thought I might have been in advanced stage… it was [actually] not though. There is a palliative care unit [in the hospital], isn’t there? There is something like a palliative care unit there, isn’t there? なんかもう痛みとかを止めるだけで、積極的な治療はしないという認識ですけど。考えましたよ、私ももし末期だったらと思ったもん、たらそんな末期でもなかったんですけど。緩和ありますよね、緩和病棟みたいなありますよね、あそこに。

Mrs. Kawai had a difficult time grasping concepts of AD, PC and ACP. While Mrs. Kawai was describing her understanding of palliative care, she started to talk about the pink ribbon, which has become a universal symbol of the fight against breast cancer.

This is the first time to hear [about a palliative care]. It’s become common hearing about a Pink Ribbon, but [about PC] was first time. 私も初めて聞きました。ピンクリボンなんて良く聞くようになったんですけど、初めてです。
It seemed that she related cancer with end of life care, and when we discussed palliative care, she related that term with cancer also.

Mrs. Sasaki talked about her knowledge of palliative care. She had developed the idea that palliative care was about long-term care for the elderly, saying:

Well, yes [I have heard about palliative care]…I have not been working and I don’t know the details, though. Target populations? It’s been said that it has started with dementia [care]. It is difficult to take care of [people with dementia] by family only, isn’t it? あい、はい。私も、働いてなかったから詳しい内容は分からないですけど。対象?大体、認知症から始まったりとか言われてましたし。なかなか家の者だけではケアは難しいですよ。

Mrs. Sasaki stated that she did not work and considered herself a housewife. She implied that housewives did not have access to information to the same extent that working women do.

**Hospice**

Interpretations of palliative care by the participants were often limited to EOL care. Mrs. Takei was a type of nurse called *jyun-kango-shi*: 准看護師 whose credentials were similar to a licensed practice nurse in the US. She told me she used to work on the palliative care unit:

I was working a little bit at a hospital that specialized in palliative care. [Actually, the place] was not a palliative care unit and an internal medicine unit; it was mixture of internal medicine and orthopedics. Mostly orthopedics was rehabilitation though. No post-op and rehab. For [those] people [need] palliative care, there were a few rooms, so I worked on the unit that was a place for those people who were waiting for the [palliative care] rooms as a place in between. Well...such as... relieving pain for people at the end-of-life and how to enhance their end [-of-life]. I thought palliative care and hospice care were the same. ...hospice and palliative care are different? 緩和ケアを結構専門にしてる病院に、あのちょっと仕事で行っていた事はあって。で、緩和病棟じゃなくて、自分は、その内科の病棟で、内科と整形と混合の。まあ、リハビリやけど整形はね、術後とかこなくてリハビリ。緩和ケアの人は、部屋が少ないので、部屋待ちでワンクッション置く様な感じの病棟にあった事があ
Although the Mrs. Takei stated that she had been involved with palliative care, she was not able to differentiate between palliative care and hospice care. Since an abrupt expansion of interest in palliative care in Japan in recent years, many hospitals now have palliative care units. However, this form of palliative care is focused on inpatient care, and shortage of beds became a serious issue. Mrs. Takei described an internal medicine unit that also functioned as a palliative care unit. Additionally, she was confused palliative care with hospice care, when trying to define palliative care.

A diffusion of terminology is another challenge in the population. Mrs. Sasaki vaguely knew about hospice care, but instead of saying "hospice" she said "hospital". Mrs. Sasaki also brought up the shortage of health care providers specializing in the field.

It's still [underdeveloped] in Kochi. There are hospitals [hospice] but how much [it's utilized]... It has not reached yet [to utilize hospice] in Kochi because there are [specialized] nurses there. [Their care is] like natural, no more [aggressive care], and [the patient is able to] spend [good] time. It is like sustaining mentally. まだまだ、高知では。ホスピタルはありますけど、どこまでがあれなんか、、、また高知がそこまでいってないがと思います。その看護婦さんがおる状態やないんで。こう自然体でもう何も、時を過ごして。精神的に支える感じっていう感じ。

These participant's quotes show they had some understanding of hospice and palliative care, and they recognized the benefits and purpose of hospice and palliative services. However, no participants interviewed were able to clearly explain the difference

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5 The Japanese translation of the word "hospital" is "病院 [byo-inn]". Because there is no translation for the word "hospice", the phonic term "ホスピス [ho-su-pee-su] " is used. Because foreign terms are difficult for Japanese people, this participant misused the term "hospital" when she meant to say hospice.
between palliative care and hospice care, and the confusion became evident in the
conversations. Mrs. Yoshii explained how palliative care units were thought of in Japan:

The place [where I have visited] was also called "palliative care unit" because if
we write [on the sign at the ward] "hospice" clearly, it brings an image of "this is
the end," so all the hospice [floors] in Kochi are called a palliative care unit, I
think. そこも、緩和ケア病棟っていうって名前で、全部ホスピスって書い
ちゃうと“そこでおしまい”っていうイメージを与えるから、全部、緩和ケ
ア病棟ってなってると思うんですよ、高知のホスピスも。

Mrs. Yoshii also had an opportunity to interview staff at a local hospice. She
talked with people working there and witnessed residents actually receiving care in the
hospice. Mrs. Yoshii said, describing her interviewing experience and learning what a
hospice was like:

Mrs. Yoshii: It was like end-of-life medicine. Actually, [we] don't know what
[they] are doing there [in the hospice], do we? So, [I] have interviewed the head
nurse and a physician. Because they are close to their death, [the residents] don't
look very healthy. Some people look smiley. [For example, I saw a person] at a
cafeteria, he probably had short life-expectancy but was doing very well. As I saw
it, I thought this is already a choice; I thought [hospice] is one of the choices [for
me].
I: So, until you saw it [hospice], did you feel resistance?
Mrs. Yoshii: Rather than resisting, I didn’t know [about that kind of care] at all. I
couldn’t even imagine.

吉井さん: 終末医療みたいな形であるけれども。実際じゃ、どんな事をし
ているのかって事を知らないですよ。だからそこの師長さんとかお医者
さんとかを取材して。まあ、やっぱり、そこに居らっしゃる方は死が近い
ので、そんなに元気には見えないんだけども。中にはとても朗らかな人
もいらっしゃって。こう喫茶コーナーにいらっしゃる、まあ老人の方が凄
い余命は少ないんだけども元気にしていらっしゃるのかを見て、そう
いうのを見て、これはもう選択肢、選択肢の一つだと思いました。
私: やっぱり、それを見るまではちょっとそういう場所っていうのは抵抗
がありましたが？
吉井さん: 抵抗があるというよりも、分からない。やっぱり全然分からない。
想像がつかない。
In summary, the levels of knowledge about ACP, particularly EOL care and AD, were different with each individual participant. Their level of understanding depended on their life experiences and exposure to EOL care for a family member or someone close to them. Confusion related to terminology was observed, such as “hospice” and “hospital”, or conceptual interpretations of palliative care and hospice care. This confusion was prominent during the interviews. Although these women learned much about their medical conditions and had received active and aggressive treatments, a perspective about the future that might lead to writing AD was limited. They said "I even can't imagine" or "I've never thought that profoundly before". Whereas an individual's wishes are respected and are expected to be expressed in the US, these participants who were Japanese women, were not certain about AD or who should be the person to write AD. This is probably associated with the community-oriented nature of the Japanese. Thus, this theme conveyed the confusion around, and even the novelty of, the idea of advance care planning and advanced directives. The next theme described the women’s dependence upon their family.

**DEPENDENCE ON FAMILY—家族に任せて**

Mrs. Kotani, who had no previous family EOL experience, actually had a conversation with her mother. She understood her mother's wish to avoid futile care, in case her mother became incapacitated and was unable to make decisions for herself. Mrs. Kotani also shared these same values and wishes. However, she expressed uncertainty about what she would do for her mother in that situation. This example demonstrated the theme of Dependence on Family. Mrs. Kotani said:
I was told by my mother that in case she's gotten sick or became older, and she has to be in a hospital, she doesn't want life-prolonging treatment. Such as ventilators... without consciousness during life-prolonging treatment... as live unnecessarily long and become a burden to [other people] around her; she doesn't want such a thing. Although she said, she has just told me verbally, and I [am] still young and she is still 60s too, and we don't feel reality [of the possible situation]. [My mother] is healthy now, working, and has no reality [to think about the situation], I think. If [a situation of dying were to] happen to her, I don't think I can do it [to carry out her wishes]. Even though [my mother] herself is saying [what she wants], I still cannot do it. 私、母に言われてるのが、私が病気になったりとか、自分も歳がいって、もし病院で入院する事になったととしても、延命治療はしなくていいと。何か、そんな呼吸器とか延命治療で意識もないままというか、ずっと居て周りに迷惑を掛けるらんだったら、そういうのは要らないって言われているんですけど、口頭で言われてるだけですし、まあ私も、まだ母も60代なのでそんなに実感がない。今は、健康で働いてるので、実感がないですけど。もしそうなっても、多分私は出来ないと思います。本人がそういう風に言っていても、やっぱり無理だと思います。

There are two implications to Mrs. Kotani’s statements. The first is a Japanese belief that we are supposed to do everything possible to prolong life. Another is that no matter what her/his condition would be I want her/him to live and remain a part of the family. A conflict of ideas was found here: refusing futile care versus not being able to carry out the family’s wishes. Often, how a participant admitted she would like to be treated, and how she would treat a family member was different. Mrs. Kotani expressed that about herself:

I’ve never thought about [EOL issues] so deeply, but if like brain death or something, if I have to keep living in such a condition, I don't want to be a burden for people around [me]; and then a decision...I’d like to rely on a decision made by people around [me]. 深く考えた事ないんですけれども、でもその、そうですね。でも、脳死とか、まあ、そういう状態で意識がないまま生きて続けるっていうのであれば、もう、周りに迷惑を掛けたくないので、それはその時に判断。周りの判断に任せたいかなとは思いますね。

Participants acknowledged that prolonging life without hope of recovery would burden the people around them. They used a common expression of "people around [me
which typically indicates family. However, even if they were not directly speaking about family, they preferred to use this term. Mrs. Kotani's expression implies a cultural assumption that "people or family would know what I want and do what is right for me."

Mrs. Yoshii said:

Well, if the family has good communication among family [members], even if you don't write it, they would [provide care] appropriately. If [the family] does not [have good communication] but you want [care] exactly as you want, [writing AD] might be necessary. Well...it depends on economic status and so on, and this can't be generalized. まあ、家族とのコミュニケーションが上手くいってる所は、そのまま何も書き置かなくても、ちゃんとやってくれるでしょうけど。そうじゃない人は、そういう事が自分の思いどおりやって欲しければ必要かもしれませんね。まあ、その時の経済状態とか色々な事があるから一概には言えませんけど。

Mrs. Yoshii felt that, the decision whether a written form was necessary or not depended on the family’s level of communication, and believed AD is not always necessary. Mrs. Sasaki tried to imagine potential situations and how she would act in them, saying:

As the care goes on for a long time, it would be a burden for the family; and [it is a burden for] for the person [patient] as well. So, I strongly feel that I want to let [my family] sleep [pass away]. Well, if [something] acutely happened, such as accident or stroke, then I would still watch how it goes [with aggressive treatment]. ある程度長い事看たら、家族にも負担になるし、本人もそうだし、あれやけ、安らかに眠らせてあげたいなっていう気持ちは高いですけど。まあ、急になって、事故とかの脳梗塞とか、あれやったら、まだあれかな、ね。しばらくは様子を見てっていうあれもあります。

Mrs. Sasaki described her thoughts based on common sense and speculation. In Japan, people tend to associate taking care of someone, both in the hospital and at home
and including *kaigo*\(^6\), as the family’s burden. At the same time, they were also conscious of the possibility that such care could be futile. Mrs. Sasaki implied her wishes were clear but, at the same time, she did not have the desire to communicate her wishes directly to family or health care providers. Mrs. Asao felt uncertainty in regard to these themes. One belief was that family could obtain a consensus to refuse futile care. Another belief was, that because she did not have a sibling, she might keep using life-sustaining measures even if a loved one did not experience much quality-of-life.

I won't say I've never been in the situation like that, and when my grandfather passed away, my mother talked to her brother asking if they wanted to carry out life-prolonging measures. My grandfather left nothing [like AD]; he didn't say what he wanted. So siblings [participant's mother and her brother] thought about their father's personality, and [thought] he would accept his [imminent] death and wouldn't choose to prolong his life for no reason; it was their consensus, and something special... I heard that they have asked [the doctor] not to take special measures. My mother... She had a sibling and was able to talk [about the situation] and was able to obtain consensus, which was good, but I don't have any siblings; I would never know until the time comes, but even with a machine's help and even if she can't talk anymore, if she feels still warm and I was there, I would say don't stop [the machine]. Even if the figure looks like the way people say 'no more living,' [I would still think] maybe she would come back to alive and would take care of her. そういう場面にあったことが、なくはないですけど、祖父が亡くなったときにはやっぱりうちの母はどうするかってことを兄弟と話をしていましたので、延命治療をするかしないかって、祖父はまったく残していなかったので、どうするっていうのはいっていなかったんですね、そのときにただ兄弟たちはやっぱり祖父の性格を考えたときに、やっぱり自分の死はしっかりと受け止めてむやみやたらにだらだら延ばすということはあの人はしないだろうということは全員一致したみたいで、特別にそういう、特別な処置はしないでくださいということをお願いはしたみたいですねけど。... 母は兄弟がいてそういう話ができるて一致を結論をだせたらよかったんだと思うんですけど、私は兄弟がいないのでそういうのはそのときになってみたいわからないです、仮に機械の力借りていても、なにもしゃべってくれないのであればあったかくてその場にいたらとめないでくださいって私は言うんじゃないかなと思います。それが生きて

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\(^6\) See Chapter IV, theme #3 for more detail.
ないっていうように世の中で言われるような形であっても、もしかしたら生き返るかもしれないとか、きっとと思って看護するんじゃないかなって。

The two perspectives Mrs. Asao provided were conflicting: futile care was not preferred, versus the thought that she should utilize technology with a hope for recovery. She stated that her thoughts might change if she actually faced a situation where she had to make a decision for a family member. The way she expressed it was that family was in charge of making decisions rather than the patient. This implies that Mrs. Asao expected family to make decisions for her if she was unable to make them for herself, and, she assumed that family would do the right thing.

In contrast, Mrs. Yoshii had an opportunity to see actual care in hospice and felt that hospice care can be one of the most important choices to make at the EOL. Mrs. Yoshii felt she would want to utilize hospice care, and that her wishes would be anticipated by her family, therefore AD was not necessary. This belief was prominent in the theme of dependence upon family.

Participants had a difficult time understanding how AD comes into play at the EOL, and they did not actively feel a necessity for AD. A quote by Mrs. Kawai was

I thought [AD] was a [a document] written by family. I didn't know that it should be written by the [patient her/him] self, yes...”家族が書くものかなって、本人が書くっていうのは知らなかったです、はい。

She thought AD was to be written by the family. When we ask Americans about putting their wishes in writing, they assume that the individual would be the one who would make a decision. However, this presumption does not apply in Japanese culture because of the family’s expectation of responsibility. Mrs. Kawai’s quote represents this implication.
Mrs. Yoshii expressed the advantages of AD vaguely:

If we had a written thing [such as AD], it would be respected. So, I kind of feel like if [the person] wants [this] strongly, the family would follow the wishes as much as they can as it was [prepared] to be understood [by others]. でも、はっきり書いた物があると、やっぱそれは尊重されると思うので。絶対そうして欲しかったら書き残して、ちゃんと分かる様にしたら、やはり可能な限り遺族はそれに従ってくれるんじゃないかってっていう気がしますね。

Without explicitly stating their responsibility for healthcare decisions, many participants talked casually about what they would do for their family and what their family would do for them. They thought that the act of making a decision for their family was not only accepted in the culture but also was expected. Therefore, the participants did not believe that as patients, they would need to put their wishes in writing. The pre-contemplation of ontology of the self as a part of a family, demonstrated a boundary of ownership for decisions and provided evidence for this theme of Dependence upon Family.

WILLINGNESS TO LEARN

During the interviews, participants expressed their understanding of the urgency of introducing ADs, but on the other hand, they also expressed that they needed some time to think about it. The urgency around ACP faded as the immediate threat of cancer was now in the past.

Nodomoto Sugireba- Once It Has Becomes the Past

Some participants used the expression 喉元過ぎれば- nodomoto-sugireba to present the change in their feelings. Their expression nodomoto-sugireba comes from a Japanese idiom of nodomoto-sugireba astusa-o-wasuresru 喉元過ぎれば熱さを忘れる. Direct translation is once [an object] passes the throat, one forgets how hot it was. It
means that when an event has become the past, people forget how hard it was to endure. A similar English expression is "The danger past and God forgotten." An example was given by Mrs. Kotani, who had been in a traffic accident, and suffered an injury to her neck. She said she wanted to appreciate every moment of life, but at the same time "as nodomoto-sugite happens, I had forgotten... but still it was somewhere deep in my mind.

Mrs. Yoshii recognized the importance of thinking about ACP through her family's EOL experience but said, “Although nodomoto-sugite was already happened, I had got to think [about ACP] when my father died. 喉元過ぎちゃってるんですねけど、やっぱり父がそこで亡くなった時に思いましたね。”

Mrs. Yoshii also told me that it was acceptable for her to engage in ACP because she has had cancer twice, and those experiences made her recognize the importance of addressing EOL issues in advance. Mrs. Yoshii described her status as a survivor, as nodomoto-sugite had already happened. She made a distinction about herself from other cancer survivors. This point is illustrated as Mrs. Yoshii discussed her assumptions about other cancer survivors, and expressed that they might not be as conscious of nodomoto-sugite as she was:

Especially for people who nodomoto-sugite happened [who’s cancer is the past already], [it would be difficult to think about ACP]; but me, it was the second [cancer] and it’s easier [to talk about ACP]. [It is] still depending on the person though. 特にあの喉元過ぎてる人には。私は2回目なんで、まだあれかと思いますけど。まあ、人にもよると思いますが。

She discussed how it might be difficult for some people to talk about ACP if their
cancer is not in the past yet. She added the phrase “depending on the person” however, to avoid imposing her own thoughts explicitly. Again, this illustrates the Japanese trait of discomfort to clearly express one’s own thoughts. Mrs. Yoshii implied that she herself might not find it difficult though. She just did not take any action related to ACP because the experience of her cancer treatment feels like the past, and it was not closely connected to her life anymore. Her expression further suggests that sometimes people neglect to address ACP, as they become distanced from a life threatening illness, due to the passage of time.

**Perception of Natural Death**

Allowing natural death at the EOL and opposing futile care have increasingly become preferences in developed countries, although definitions of futile care can be vague. The issue of EOL can cause ethical dilemmas and conflicts when it is raised. Japanese people are highly educated (Research and Planning Division for Lifelong Learning Policy Bureau, 2005) and conscious of EOL issues. Although highly advanced medical technologies are available, participants expressed their perceived norms about use of technologies in an ethically acceptable manner. Mrs. Sasaki characterized this thought, saying:

> If we keep [them alive] too long, we feel bad... see? [She continued, saying: If] some length of time passes and there is no possibility to recover after several months have passed, then probably it [withdrawing life sustaining devices] is better. そんなに長い事やったら、可哀想っていう、、、。ね、ある程度も何ヶ月か経ってるのに意識が戻る可能性がほとんど無かったら、もう、あ れなんでしようけど。

Mrs. Sasaki’s quote implies that prolonging life without consciousness might result in prolonged misery for the patient. She believes that if this type of condition were
to continue for more than few months, life support to prolong the patient’s life should be stopped.

Mrs. Ito stated:

Well, such as my husband and sister. Our generation doesn't want to receive life-sustaining treatment unnecessarily. It seems clear. ああ、まあ。主人とか姉は。もう、今の私達の世代は、やたらとね、延命治療を受けたくないから。それはもうはっきりしてるみたいですね。

The preferences of these women seemed to have been developed largely from their experience with their families. Mrs. Sasaki continued:

Because my son [lives] in out of prefecture, placing tubes, what you call it? Do you call it a ventilator? I feel it is too much to use [such a device] to live. So, I feel I have to write it in advance; but in Kochi, when my husband's father passed away several years ago, a doctor asked his son. [The doctor] asked him 'do you want to place many tubes?' He said "no it's okay [no more invasive interventions]", and it was okay [for everyone]. Because of that, I don't feel it would be a big deal [to have a written form]. That was not placed because of the family's will, and it went smoothly. [But it was still] scary if some [troubles] had happened. 私も息子、県外だから、やっぱり管付けてまで、結局何ていったんだった？人工呼吸器っていうんですか？それを付けてまで、生きたくないというのは思いますし、だから書いて置かなきゃと思うけど、でも高知では、何年か前に主人の父が亡くなりましたけど、ドクターは、あの息子、彼に聞きましたからね。“こんなに管付けますか？”って言って、“いや、もう結構です”って言ったらそのままオーケーでしたから、そんなに大変な事だとは思ってないですけど、家族の意思で付けなかったってだけの事でスムーズにいきましたけど。怖いですね、色々あったら

Ms. Sato said:

If I were dying anyway, I don't want to have difficult time. If I had a child or someone I have to protect, no matter what figure I would be, I wanted to live, didn't I? [But] I am not, and I don't want to be on the ventilator as I looked like a branch stick [extremely thin]. As becoming that much, there is no one who would like to live. ...Because of that [I don't want that much treatment]. It is just my opinion, and there might be a lot of people not like that though. どうせ死んでし

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7 She described “tubes” here represent tubes and cables of life support devices. An expression of “spaghetti syndrome” is translated into Japanese and widely understood by the public.
Ms. Sato further expressed her wishes to refuse futile care, as she had witnessed other patients at the EOL when she was in the hospital. According to her account, some people would also pay for very expensive folk remedies with the desperate hope of being cured. As Ms. Sato observed those patients, she concluded that she would not want to pursue futile care and accumulate unnecessary costs. Ms. Sato continued:

...but I want to write [AD]. The [responsibilities belong to] my family: my sister and parents so far. That's all my family and I feel bad to make them decide. [If I had a child and] if it were my child, it might be [okay], but it's pitiful to make my sister to decide. So if I decide myself, [my family would be able to say] "because my sis said this and we should do it [although it's hard to let her go]", so I want to do it [AD] myself. うまくなら自分をつらい思いしたくないし。なんか子どもとか守らなければならないものがいっぱいあったっていっていうのあるじゃないですか。そういうのではないので、そんなに枝のようになってまで、人工呼吸器をつけたくないんですね、私は。そこまでになって生きていくことを求めている人はいないと思うので。...だからそんなにね、それはあくまで私のあれなので、そうじゃない人も多いと思いますけどね。

Mrs. Kotani recognized the importance of a written form, but at the same time, expressed uncertainty about it, saying:

[I have to ask my mother] to write or I will be in [a trouble]. However, even if it were written, I can't do it [to refuse futile care]. If it was my mother...it's a difficult question. 一筆書いてもらわないとあれですよね。でも、私は、書いてても何か出来ないですね。母がもし、 рамках。難しい問題ですね。

Mrs. Kotani continued:
Even for very young [people], we never know what would happen next\(^8\) and [I] may get in an accident. We never know what would happen to us, and even young people need to express own wills, yeah...as we talked, I thought this is very important. やっぱり、でもどんなに若くても、一寸先は闇じゃないですけど、交通事故に遭わない訳でもないですし。何があるか本当に分からないので、やっぱり若い人も、その意思表示っていうか、本当、、、今伺って凄く大切だなと思いました。

Mrs. Kotani acknowledged the importance of writing AD for herself, but it seemed she felt differently about that decision for her family. She also said she may not follow her family's wishes based on the legitimacy of authorization of AD in Japan. At the time of interview, she was living in Kochi, which was her hometown, but she also had the experience of living in Tokyo and overseas as well. Although she had experience outside of her community, it did not result in her having more knowledge about ACP. Participants did not have a good understanding of the legal authority of AD either.

Mrs. Ito had a conversation with her family about ACP. She repeated that she felt it was important to express her wishes in writing in advance. She also mentioned audio or visual recording, or having the third person present to avoid miscommunication. Mrs. Ito explained:

If actually I get close to death, I never know, but so far... [this is] my plan for my future. [For example,] my sister - her husband is already passed away and she is always telling me [what she wants]. So, eventually [I will] get into a facility. [Discussion] about money and what [I want] for my EOL will have to be told [in advance] to someone, and I am telling my wishes frequently. I haven't written that yet, though. I have to write... [Telling only] verbally is bad, definitely. もっと死が近くなったら、どうか分かりませんけどね。今の所は…。もう身の振り方は。姉なんか、もう主人も亡くなったから、ちょっと言う言ってますからね。だから、結局、施設に入った時には、やっぱりお金と自分の最後は誰かに言っておかないといけないから、それはちょっと言う意思表示はし

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\(^8\) The participant used the word 一寸先は闇 (issun saki wa yami). The direct translation is "an inch ahead is blackout". This is a Japanese idiomatic expression and mans "no one knows what may happen next."
Mrs. Ito has been taking care of her mother who had dementia. She was taking care of her mother (*kaigo*) at home and had become knowledgeable enough to see possible conflicts during *kaigo* and at EOL. Because of that, she was conscious about legally legitimate communication regarding an EOL decision.

Mrs. Murai had faced EOL issues with her aunt, and that made her think about the necessity of a written form of AD. Her aunt had died unexpectedly in her home and was not found for over two weeks. No one had checked to see how she was doing. Because the aunt did not have a living will or any materials expressing her wishes, the family, including Mrs. Murai, had a difficult time considering how they should treat her after her death. In Japan, treating the dead with respect is very important. Even when someone who has died leaves a hospital, nurses are responsible for making the corpse tidy in appearance so that the body can be seen at the funeral. In Japan, a corpse never leaves the hospital in a plastic bag with a zipper. To Mrs. Murai, knowing how her aunt wanted to be treated was important. However, there was no way for her to know what to do because her aunt did not have a will.

Mrs. Murai had also observed another incident in which her twenty-year-old son's classmate had died accidentally. These incidents made her think about mortality and the importance of expressing one’s own wishes in advance as she said "Such a system to write so that [my wishes] are understood is really good. 書いて、理解してもらえるっていう仕組みは本当に良いと思います。." Mrs. Murai continued: "[AD is] really good. If [we do] so, without doubt at all, really [I can] pinpoint to carry out [what my
family] wants. I think it is a great strategy.凄く良いと思う。その方が、全然迷いも無く、本当ピンポイントでしたい事をしてあげられるから、凄い良い方法だと思いません。："

Mrs. Ito has had casual conversations with her husband and sister regarding importance of writing down wishes regarding EOL. Mrs. Ito stated:

[I said to my husband] you have to write in advance that "If I [have to use] tubes [to sustaining my life], don't do such a treatment." My sister says "I will place [my AD] on the refrigerator [door] for sure. As [other people] can understand my wishes clearly; it would be bad [if we] did not know where the AD was placed … and we will tell [each other] that [I] will post it somewhere [where my family] can find it. 「管をあれだったら、そういう治療はしないでくれ」っていうのは書いて置いてよって。姉は、「私は、冷蔵庫に必ず貼って置く」とかね。もう自分の意思をはっきり分かる様に、何処に置いたか分からないじゃないけないから、一番分かる所にいつも貼っておくからみたいな事は言ってますね。

In summary, participants were very conscious about ethical issues at EOL. Many participants expressed the importance in Japanese culture, of natural death and treating the dead with respect. One participant expressed consciousness about the possible family burden of making an EOL decision for them. Some participants were highly aware of the risk for using advanced technologies in an inappropriate or unethical manner, in the Japanese health care system. Since natural death is well accepted, and at the same time advanced medical technologies are available in Japan, participants expressed necessity of some kind of written communication for their EOL.

Willingness to Write an AD

Despite that many people who were interviewed expressed the value of discussing an emergency EOL decision in advance, they encountered different opinions from other people. This is typical in Japanese culture. Culturally Japanese people are not
comfortable expressing their own thoughts; however, this does not mean individuals do not have their own thoughts. Because of the discomfort in expressing their own thoughts, when they do express their personal thoughts, they incorporate a guess as to how other people may think.

Ms. Sato stated: "I am not sure, I am fine [with writing my own wishes in advance], but there might be people don't want to... I feel the way. どうでしょうね、私はいいですけど、やな人もいるでしょうね、って感じですよね。"  Ms. Sato also said: "It would depend on the person. For me, it is no way to receive life-sustaining treatments [at the EOL]...in my case. So, if there is such a thing, I will be the first to write. 人によりますよね。よくはなれない。私だから延命治療なんかとんでもないって感じなので。私はね、そういうのがあれば書きますよ、率先して書く。"

Some participants said they would like to write an AD if available, similarly as Ms. Sato exclaimed: "Absolutely, I'd like to write [an AD]! Absolutely! Absolutely! 是非書きたいですね。是非、是非".

Not all, but some of the participants clearly expressed their willingness to write advance directives if the option was available. It implies a patient barrier does not necessarily exist for all patients who have early stage cancer. Inviting discussion by the health care provider would be beneficial to promote AD.

**Timing of the Advanced Directive**

Many participants said they would take an action to write AD because they were not sick anymore. They have even admitted they believed there is nothing wrong with their health at the present time, determining themselves as survivors. In addition to
discussing how they felt about writing their own ADs, participants provided their perspectives about when would be good time for other people to write ADs.

Ms. Sato said before surgery might not be a good time because it would add stress for people facing surgery. Mrs. Kawai said:

The time which we can write [ADs] the most calmly would be when I am healthy, isn't it? When [someone becomes ill, there is a possibility to change [their wishes]; but it doesn't change? ... Is it like changeable? 一番落ち着いてかけるのは健康なときですよね、病気なってからだとまた変わる可能性もありますからね、でも変わんないのかな。変更可能な感じなんですか？

Mrs. Kawai expressions showed a concern about changing one's mind, which is an important point emphasized related to the ACP process.

On the other hand, Mrs. Asao expressed that writing AD before surgery would not be comfortable for her.

Mrs. Asao said that:

If I was asked to write [AD] voluntary, it might be acceptable. [However, if I was told] I must [write], it sounds like it was presumed I was dying. …I don’t want to think. I guess I would decline. 任意で書いても良いですよって言うくらいだったら受け入れられるかもしれませんが。ねばならない、必ず書いてくださいねって言われたら、なんか死ぬのが前提になっているようで気がして。…考えたくない。たぶん反発すると思います。

Mrs. Asao thought asking to write AD before surgery would make people feel they were dying. She had solid belief of any kind of procedure to prolong life at any situation would be valuable. Mrs. Asao was the only one who said she would keep her family alive in any situation.

Mrs. Kawai also brought up the regulatory problem and lack of legal authority of AD in Japan. She talked about her thoughts on the necessity to write ADs: "[such as
ADs] need to be introduced absolutely urgently [in Japan]. andsは日本にも是非、早急に取りいれて欲しいと思います。" and Mrs. Kawai continued: "I would think [the Japanese government change the regulation] urgently so that one self can write [an AD]. 早く本人が書けるようにしていただきたいと思います。"

Mrs. Kawai continued with her opinion about the Japanese government:

Really, it needs to be appealed to the ministry of Health and Labor urgently. Such as medicine [approvals], like everything is slow. Such as influenza and immunization...and the medicine to prevent cervical cancer was just approved. I had a friend who worked at a hospital and it's has been said it should be approved from long time ago; it has been discussed from long time ago, then finally this year or last year [the medicine] was approved. Slow... "the [Japanese] government is [slow]" is the only word [to describe], isn't it? In Japan...we are...本当にそれは厚生労働省にね、早急に訴えて。薬にしてもそうですし、なんか全てが遅いなって、インフルエンザのなんだ、予防接種のあれなんかにしても、あと子宮がんの予防する薬がやっと認証されたんですかね、。随分前から認めてるって、病院に勤めてる友達がいたので、随分前からやってるって話、やっと今年だか去年ですよね、認可が下りたのが。遅い、役所が、その一言ではないでしょうか、日本は、われわれは。

Because Japanese people are educated and knowledgeable enough to imagine issues related to EOL based on personal experiences and information from various sources, they see the value of an AD to express their wishes. This theme of an urgent need to make this change is especially important at present in Japan, since medical technologies are widely available to almost everyone because of the universal health insurance system. The following overarching theme is comprised of the critical cultural concepts of sasshi and amae. The theme is overarching because it brings together the many themes described previously to a more full understanding of the ACP phenomenon.
CULTURE AND DYNAMICS IN JAPANESE COMMUNICATION

INFLUENCING ADVANCE CARE PLANNING: 察し [SASSHI]

AND 甘え [AMAE] (OVERARCHING THEME)

*Sasshi* and *amae* are culturally significant concepts and symbolic of Japanese communication styles; thus, this theme demonstrates overarching traits to the findings presented thus far. In American culture, when a person is asked to express her opinion but cannot articulate well, the questioning person would think the person has a lack of ability to express their opinion. In contrast, in Japanese culture, people are expected to kindly presume how the other person would be feeling without asking a direct question. Japanese people believe that it is neither intelligent nor polite to make the other person say how they feel. This cultural phenomenon is called "*sasshi* [察し]", and such expectation is grounded in the Japanese culture. An example of this expectation was expressed by Mrs. Yoshii:

[People] tend to think "needless to say"...how [we] feel... [In Japanese culture, people would think that] you should *omonbakatte-agenasai* [understand without asking directly]. However, I feel it is getting to the era [in our society] that things don't happen without saying. 話さなくても分かるだろう”みたいな風潮もあるし、思い、心の気持ちを慮って[おもんばかって]あげなさいみたいな所もあるし、[でも]もう言わないと自分の思いどおりにならない時代にはなって来てるとは思いますね。

Mrs. Yoshii expressed her understanding that the Japanese society has changed and she is expected to express her wishes clearly. On the other hand, she implies that it is culturally difficult to express what she wants. *Omonbakaru* [慮る] comprises the meanings of "to consider", "deliberate", and "take careful thought" (Watanabe, 2005). Mrs. Yoshii used *Omonbakaru* as an equivalent meaning to *Sassuru* contextually, which
is a verb form for *sasshi*. The concept requires the person who asks to have an ability to make the best guess of the other's situation and feelings related to it. Even regarding ACP, Mrs. Yoshii said, "because of that, without explicitly saying, everyone [in my family would] think the same way [about detailed wishes].だから、そこはもう言わなくても、みんな同じ事を思ってるっていう様な感じはしますね。"

Many of the themes previously presented are significantly relevant to these concepts of *sasshi* and *amae*: discomfort to express one’s own will and also depending on family. It is unusual for one to explicitly express their own wishes, and family is the responsible entity for someone who is unconscious.

In the theme of "discomfort to express one’s own will", Japanese people are described as not being in the habit of expressing their own thoughts explicitly. People are expected to *sassuru*9 (guess carefully about how people would feel) in the Japanese culture. The *sasshi* receivers expect that how they feel needs to be read by others. The act is called *amae*. *Amae* was initially introduced to the US by Takeo Doi in 1970, but the term was not new to the Japanese. Because there was no parallel term or concept in English, Doi introduced the concept at global conferences and published a book to explain this phenomenon. As described in Chapter IV, participants didn't expect people to explicitly express what they want.

They recognized the necessity of AD to clearly understand one's wishes, but as they felt distanced from the threat of death, the urgency disappeared from participants.

For example, Mrs. Yoshii said:

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9 *Sassuru* is the verb form of *sasshi*. See Glossary.
It's difficult. Well, like me at the bottom line, now...there is nothing wrong [in my health] now, isn't it? Everything [wrong] was taken out, even cancer. I even don't get any treatment, then [I] have forgotten [the importance of ACP]. At the time [of surgery] I have thought 'how I would be if I died'.難しいですね。まあ、ねえ、私なんかも結局、今、今現在もうどこも悪くない状態じゃないですか？全部取っちゃってね、癌も。治療もしてない訳だから。そうなると忘れちゃうんですよ。その時は、「死んだらどうなるんだろう？」とか思いますけどね。

One notion Mrs. Yoshii expressed was that the urgency of what she would have done if facing imminent death faded, as she had acquired more knowledge regarding her health and experienced her recovery. As a result, Mrs. Yoshii had also lost the feeling of urgency in providing for these contingencies. Mrs. Yoshii said that she had forgotten about the importance of ACP because she was no longer receiving cancer treatment.

Japanese people easily revert to the way of feeling that family would take care of them even if “I do not express, explicitly, what I want.” This happens because they hold the presupposition that family would do what’s best. This situation is evidence of the cultural concept of *amae* or dependence.

Mrs. Sasaki expressed the dilemma of wanting to live in *amae* and postponing thoughts about ACP, but at the same time realizing the importance of explicitly expressing one's wishes because those wishes may not be carried out otherwise. Mrs. Sasaki explained:

From the beginning, [I don't think people] would talk [about ACP] since they are healthy. Something at some extent, getting older, as [they] realize that [they] will not going to [live] longer, then, so... [People can think about ACP]. However, even if [we already] have heard [what they want], it wouldn't work if there was no [written] words left because [their wills] cannot be believed.始めから、元気な時から話す事は無いでしょうね。ある程度何か、歳を取って、もう自分は長くないんだって分かってからこう。でも、それを聞いてても、言葉で何かで残ってないとなかなかダメなんでしょうよね。信じてもらえないから。
To summarize this overarching theme, participants were conscious about ethical issues at the EOL and value of discontinuing futile care. Their knowledge about ACP and palliative care was limited, and I have found that the longer the time since their cancer diagnosis, the less they thought about these issues. However, because *sasshi-amae* dynamics are deeply ingrained in the Japanese culture, participants expected their family to make the best decision for them in the case of a need for these types of decisions. It is difficult for Japanese people to ignore *sasshi-amae* dynamics because they are expected to respect others and being in harmony. At the same time, they realized possible issues at the EOL without communicating about their wishes with others. As a consequence, they experience a dilemma between respectfully being ama eru [*dependent on the family*] and explicitly writing their own wishes to reduce family burden. This theme represents, then, the ultimate understanding that addresses the primary problem of this research.

**SUMMARY**

In this chapter, five themes regarding ACP derived from data generation through this study were presented. Participant's perceptions of ACP were shown using direct quotes, observations, and other sources. The themes presented in this chapter were: 1) **Discomfort to express one's own will**; 2) **Limited knowledge of advance care planning**; 3) **Dependence on Family**; 4) **Willingness to learn**; and the **Overarching theme: Culture and Dynamics in Japanese Communication Influence Advance Care Planning: *Sasshi and Amae***. These themes are symbolic Japanese concepts, and because Japanese people respect sense of community, they are profoundly rooted in Japanese culture. These themes exist naturally in the culture and sometimes are unconsciously implied by participants. To illustrate the findings in this chapter I utilized direct quotes
and also analyzed the patterns of the participants' views. The participants were well educated, and this sometimes brought up the complex psychology of conflicting thoughts: recognizing the importance of ACP versus social expectations. Some terms that do not exist in English were also discussed. These concepts were not limited to Japanese culture, but were prominently seen during the discussion about existing knowledge and the implications of findings for practice of ACP in Japan, nursing education, and future research needs will be presented in the following chapter.
CHAPTER VI
DISCUSSION AND CONCLUSION

INTRODUCTION

Through this study, I have explored cultural meaning and implications regarding advance care planning from the perspective of Japanese women with cancer. As shown in my revised model, based on study findings, Figure 6.1, advance care planning is largely influenced by personal life experience including exposure to health care information. The emergence of advance care planning is not necessary at the time of diagnosis as it can be found in a theoretical model. Because health care providers (HCPs) often perceive advance care planning as simply an AD producing process, HCPs need to be educated to shift the broader concept of advance care planning (ACP). ACP is a process and phenomenon that is influenced by the social context surrounding the individual. The themes derived from the results were: 1) discomfort to express one's own will; 2) limited knowledge of advance care planning; 3) dependence on family; 4) willingness to learn; and the overarching theme, Culture and dynamics in Japanese communication influence advance care planning: sasshi and amae. In this chapter, I discuss themes derived from my research in context of current knowledge from literature and offer a revision of the original ACP model I developed adapted from the WHO. The current knowledge discussed in the chapter is not limited to nursing literature. Because these themes were interwoven with each other and the last theme serves as the overarching theme, this discussion is presented integratively as a whole, to gain deeper understanding of cultural contexts. At the end of this chapter, the grand summary of this study will be presented.
REVISION OF MODEL OF ADVANCE CARE PLANNING

At the beginning of this study, I developed a conceptual model (Figure 2.2) for client-centered advance care planning (ACP), based on literature review. This model served as a theoretical framework for this study and the focus of the study was shown in Figure 2.3. After the study, I found a significant influence of life experience in the data, confirming the original conceptual model of ACP. Participants had thoughts and preference based on life experiences. As a result of this investigation, I have revised the original model to better reflect my findings (Figure 6.1). As they received more health care information formally and informally, participants were better able to verbalize their own preferences. Although advance directives were not widely available in Japan, some participants were motivated to create documents expressing their preferences. This notion was found in the model: participants' life experiences, along with discussions with health care providers, influenced their desire to explicitly express their wishes. This is shown in the Figure 6.1 as "documentation" becomes darker, as discussion advances.

As a result of this study, I have incorporated cultural influences on ACP, and I am proposing a new comprehensive model of advance care planning (Figure. 6.1). The study results showed the significant influence of cultural beliefs on ACP. Cultural beliefs and implications exist before a health care provider's intervention starts. It is the same with life experiences. There are no clear boundaries between life experiences and cultural beliefs. Rather the relationships are intertwined. Their belief systems largely influenced how the women perceived the decision making process. This model allows us to look at the ACP process comprehensively. Participants' preferences and opinions on health care decisions already existed, before they were able to clearly state or write those preferences.
Acknowledging this pre-contemplation phase is vital. Without this acknowledgement, health care providers may misconceive that they are responsible for determining ACP, but ACP occurs within individuals. In addition, health care providers need to understand how cultural and personal interpretations may influence perceptions about ACP. In the following section, I discuss in detail, how Japanese culture influences perceptions about ACP in Japanese women with early stage cancer.

**Figure 6.1: Revised Client-Centered Model for Advance Care Planning**

**JAPANESE SOCIAL INTERACTION PATTERNS AND ADVANCE CARE PLANNING**

The existence of language to describe this cultural phenomenon brings a higher level of understanding to the culture. Without language to describe it, the phenomenon remains unrecognized or vague. According to Doi (1971) "without doubt, different languages seem to express different types of awareness of reality, and in this respect a language can be said to condition, to some extent, the thinking of those who use it” (p.67).
For this reason, some concepts discussed in these treaties were introduced as unique to Japanese culture; however, the phenomena were not necessarily found only in Japanese culture. My effort to explain these concepts was made with the hope that American readers would become aware of these phenomena, and that awareness would facilitate ways to assess the psychology around advance care planning.

Several fundamental Japanese cultural beliefs were prominently expressed by the participants in this study: amae [甘え], enryo [遠慮], sashi [察し]. These fundamental beliefs were expressed in regard to their lives as Japanese women. In this discussion, their beliefs and their relationships with family are explored.

Understanding language unique to a specific culture is very important as Barnlund (1989) described:

Language, the primary instrument of communication, appears to reinforce these cultural attitudes. The concept of cultural relativity - that every society manifests a somewhat unique system of values and these support a particular social order and manner of behavior - is paralleled by the concept of linguistic relativity. (p.131)

It is important to evaluate how language affects the culture and vice versa. Although some terms are unique to the Japanese language, they do not necessarily define Japanese culture. These phenomena can be found in other cultures as well, but are not as easily recognized because the language to describe them does not exist. Additionally, these comparisons do not suggest what is superior or inferior.

In this section, the concepts are reviewed individually, and then relationships among these concepts are presented.
Amae in Literature

The concept of amae was introduced internationally in the 1970s by Takeo Doi (1971) and has been discussed by many sociologists over the years. Maynard summarized Doi’s work around amae as "physiological and emotional dependence" and “to depend and presume upon another's love” (1997, p.33), and "amae can be seen as that part of the social contract that allows emotions to be freely expressed with approval" (1997, p.35). Psychological dependence here refers to the expectations of an individual. This expectation was expressed by the participants the way that their family would do right thing for them even if they do not clearly express what they want to the family. The ideological background is tightly related to the strong sense of community. Amae can occur in both intimate and non-intimate relationship as shown in Figure 6.2.

The theory of amae explained that it originated in a child-mother relationship according to Doi (1971). As a child develops trust in his/her mother, the child expects the mother to know how the child feels and can provide what the child wants. The mother anticipates that the child would be hungry after a certain amount of time and provides food, or knows that the child would be sleepy and brings him/her to bed. It comes from the trust in the other's ability to care and to be compassionate. The level of trust can vary but it applies to many situations and can exist in an intimate or a non-intimate relationship. If it occurs in an intimate relationship, the person having amae would have higher expectations of another, that he/she would anticipate how the person feels. If the person who is interacting fails to provide what he/she wants, he/she would be disappointed. In a non-intimate relationship, a person may not accept the other's offer even through the person has amae; this behavior is called enryo. Enryo occurs when a
A person did not accept another person's offer honestly, to be polite. Enryo is discussed in detail later.

Doi (1971) discussed his personal experience with amae when he came to the US for medical training as a psychiatrist. He said it was an eye-opening experience to recognize these cultural differences. He was at a home party and offered ice cream. The host, who was an American, asked if he was hungry and said he could have ice cream if he wanted. Although Doi was very hungry and wanted the ice cream, he said no, which was enryo behavior. He, as Japanese, felt it was impolite to accept the offer right away and was expecting the host to offer multiple times until he accepts it, which was amae psychology. This psychology was similarly expressed by the participants as discomfort to express one's own will.

The study participants also expressed enryo and amae behavior as seen in chapter IV and V. A participant was vomiting and wanted the bucket cleaned, but she did not call the nurse and just waited with the anticipation that a nurse would come to see her next. She was expecting a nurse to come to check on her without pressing a call-light, which was amae psychology. At the same time, the participant did not want to bother the nurse because she knew that the nurse was very busy especially at night (enryo).

When amae occurs in intimate relationship, amae is usually greater than enryo. In the non-intimate relationship, enryo is usually greater than amae. Because amae is related to dependence, an intimate relationship fosters amae and brings a sense of security. This is not necessarily reasonable, but rather comes from trust. During advance care planning (ACP), study results showed that some participants had sense of security developed through their life experience. It was supported by fundamental trust in their family, and
they expressed that the family would know what they wanted, and wanted to depend on the family’s decisions: thus the theme identified in my data: dependence on family.

**Enryo in Literature**

In Japanese culture, a relationship with the community in harmony is highly valued. *Enryo* is one of the representative phenomena that demonstrate this relationship. Ontology and epistemology of the self is different from Western ontology and epistemology. Maynard (1997) has made a comparison between Japanese and American culture, but she said these differences did not arise from one culture's superiority, greater value, or sophistication and:

> The Japanese self is a part of society, perhaps a concept existing only in relation to society. Here one must be careful not to view self and society as opposing entities, as Americans tend to do. Self and society can be viewed as interacting and complementary, and placing importance on their relationality is useful for understanding Japan. (p.38)

Japanese people are expected to be conscious of their community and be in harmony with it (Maynard, 1997 & Barnlund, 1989). Japanese culture is uniform as only 1.7 percent of entire population is foreigners and over 50 percent of those foreigners are from China and South Korea (Ministry of Justice, 2009). Miike (2002) found three common themes in an Asian culture: reciprocity, other-directedness, and harmony. This explains that uniformity of Japanese culture is because of the very small number of foreigners, and the majority of whom were Asian. It reflects, heavily, their Asian values. The uniform nature makes people expect to feel similar to others and does not bring the Western urgency to express one's own feeling. The uniformity that I am discussing here does not mean people would act the same. Uniformity as defined here, relates to the epistemological perspective, and conveys that people expect to think similarly. This
Figure 6.2: Enryo-Sasshi-Amae Relationships
perspective is tied to a perception of others. Japanese people expect enryo to occur in non-intimate relationships, and sashi, which considers and guesses the other’s intent, is supposed to occur in response to enryo.

The diagram in figure 6.2 illustrates the enryo phenomenon. Whether enryo occurs or not depends on if the person defines the relationship as intimate or non-intimate: uchi and soto, respectively (Maynard, 1997). Enryo behavior can be found in intimate relationships; however, the degree of sense of intimacy varies conditionally. Often, family is the smallest unit of community and defined as uchi, but depending on the situation, the degree of intimacy can be larger or smaller depending on the situation. When a person defines another person as soto, enryo is dominant. In Japanese culture, modesty is important and greatly valued. Fukada (1998) said modesty is perceived as a virtue in Japanese culture. Modesty is culturally accepted better than assertiveness in Japanese culture. This is one of the factors contributing to the enryo phenomenon. Enryo is a behavioral phenomenon where one feels they should not express their true feelings in response to someone else's verbal or non-verbal offer. It occurs because the recipient did not want to bother the provider, out of politeness. Enryo is one of the ways to show respect to others in the culture, and people are expected to act politely.

Enryo was repeatedly observed during the interviews. Some examples brought up by the participants demonstrated enryo, such as when they did not call nurses in a timely manner because they thought about how busy their nurses were. Some participants also did not obtain a second opinion because they felt it would be disrespectful to their physicians, although they knew that second opinion would be valuable. Enryo is seen in
everyday life in Japan and was experienced and demonstrated by the participants as identified in the theme, dependence on family.

**Sasshi in Literature**

*Sasshi* occurs in relation to *amae* and *enryo* (Figure 6.2). Japanese people are expected to make the best guess as to how another person would feel and what their needs are. This ability is expected of an adult. Miike (2003) defined *sasshi* as “interpersonal guesswork about the quality and quantity of *amae* that the communicator engaged in before she or he encodes meanings and decodes messages in the communication process... (it is) *amae* reading” (p.102). That means a person makes the best guess possible to identify how another person would feel and their needs, without asking directly. This phenomenon strongly relates to an ability to be compassionate. Doi (1971) explained that psychologically, *amae* initially occurs in parent-child relationships. A child *amaeru* (v.\(^\text{10}\)) and cries with an expectation of the mother to pick him up and soothe him. The mother hears the child cry and makes a guess (*sassuru*; v.) that he wanted to be held and picks him up without asking the child directly. When people are in *soto* (non-intimate) relationships, the person providing *sasshi* also needs to assume the *sasshi* receiver would demonstrate *enryo* (Figure 6.2). This very complex pattern is grounded in Japanese culture, and was demonstrated by my participants.

Japanese culture has language to express these phenomena explicitly; therefore, Japanese people are conscious of the phenomena. On the other hand, English does not have the language to describe these phenomena, so it is more difficult to be aware of these concepts. However, these phenomena are not exclusive to Japanese culture. For

\(^{10}\) v. = verb
example, you enter a room and find that everyone in the room is crying. Without having to ask, you already know something is wrong and it’s not appropriate to be upbeat or humorous. You would choose appropriate language and manner, and find out what is going on there. This example of *sasshi* demonstrates intuitive guesswork. Intuition is a thought that comes with vague theory and is difficult to explain. Intuition often comes from the past experiences. *Sasshi* may include this same kind of dependence on past experiences.

In the study, participants described their expectation that family would *sassuru* (v.) their wishes; the psychology may come from their *amae* with family. They also felt that they were expected to *sassuru* family's wishes as well. These Japanese social norms are presumed to determine participants’ feelings and expectations regarding their relationships with family.

**Relationship among Amae, Enryo and Sasshi**

*Amae, enryo and sasshi* are interdependent phenomena. According to Miike (1997), “*enryo* is a counterbalance to *sasshi*. In other words, unless the extent of *enryo* on the part of the speaker meshes with that of *sasshi* on the part of the listener, both *enryo* and *sasshi* will be communicative impediments rather than communicative lubricants” (p.85). Being in harmony with the community is very important in Japanese culture; therefore, being troublesome is seen as inappropriate behavior.

This notion is supported by Barnlund (1989) and Nakane (1970). They observed that Japanese prefer to remain silent rather than utter such words as "no" or "I disagree" and:
The avoidance of such open and bald negative expressions is rooted in the fear that it might disrupt the harmony and order of the group. The underlying dialectic in Japanese social relationships appears to favor preservation of a delicate rapport among the members of a collective rather than a confrontation between independent judgments as in the United States. (Nakane, 1970)

As described in Chapter V, participants demonstrated *enryo* in their relationships with their nurses. Nurses were supposed to *sassuru* (v.) their patient's *enryo* and invite them to an intimate relationship. The necessity of developing this higher level of relationship can be found in Watson's Ten Caritas Processes (Watson Caring Science Institute International Caritas Consortium, 2011).

Caritas comes from the Latin word meaning to cherish, to appreciate, to give special, if not loving, attention to...which make explicit the connection between caring and love...This connection with Love as a source for healing extends from the individual self to nature and the larger universe, which is evolving and unfolding. This cosmology and the worldview of Caring and Love —Caritas—is both grounded and metaphysical; it is immanent and transcendent with the co-evolving human in the universe. (Watson, 2008, pp. 39-40)

Several notions relevant to these research results can be found in the "Ten Caritas Processes" (Appendix L). Caritas process #2: "Being authentically present, enabling faith/hope/belief system; honoring subjective inner, life-world of self/other (Watson, 2008, p.9)" and #9:"Reverentially assisting with basic needs as sacred acts, touching mindbodyspirit of spirit of other; sustaining human dignity” (Watson, 2008, p.9) implies strategies for health care providers to overcome a cultural hesitancy to be in authentic relationship with their patients.

As described in Chapter V, the concept of *sasshi* is clearly defined in Japanese and has a specific meaning. Because *sasshi* is considered deliberate and sophisticated guesswork based on intuitive and empirical analysis, the Japanese Nursing Association has included this notion in their statement on nursing ethics:
It needs to be explained well to patients that their plan of care can be changed, even after making a decision; even if the patient's decision is different from the recommendation, (nurses) need to recommend what the best decision is for the patient and support patient's decisions while sasshuru (v.) the patients subtle change in feeling sensitively. 患者には、一度意思を固めた後も意思が変わったらいつでも変更可能であることを丁寧に伝え、患者の感情の機微や意思の変化を敏感に察しながら、たとえ患者の選択が自分の価値観と相容れないものであっても、患者にとって何が最も良い選択であるかを見極め、患者の選択を支援する。(Japanese Nursing Association Nursing Ethics Commitee, 2012)

This underlying cultural expectation influences the advance care planning (ACP) process. Because this sasshi guesswork is a largely expected, and enryo occurs in order to be polite and maintain harmony, participants didn’t feel a sense of urgency to express individual wishes. This situation resulted in their amae expectation of family, and assumption that this would be best for them. The degree of participants’ relationships with their families also correlated to the urgency in explicitly communicating wishes, where closer relationships produced a higher level of amae. Trust fosters amae because amae originally occurs in relationships with trust, as Doi noted (1971).

Amae, enryo, and sasshi are often described as a Japanese communication style. However, as discussed in this chapter, these concepts are highly complex cultural norms. These concepts were deeply grounded in the Japanese culture, and participants expected others to act accordingly. At the same time they also felt they should act enryo and sasshi to keep the harmony in the community. Taking a metaphysical approach inviting people to have a more intimate relationship, rather than changing their communication style superficially, may enable open discussion with patients to support their knowledge of, and decisions on ACP. In the following section, more detail of knowledge is presented.
MEDICAL KNOWLEDGE AND ADVANCE CARE PLANNING (ACP)

The results showed that Japanese women with early stage cancer obtained medical knowledge not only from HCPs but also through life experience and media. As use of the Internet has become commonplace in Japan, it has revolutionized the way patients gathered medical information.

Utilization of the Internet has increased the dissemination of medical information drastically, and vast amounts of medical information can be found on the web. For example, the National Cancer Institute offers quality information about different types of cancer and the various treatment options on their website (http://www.cancer.gov/). The organization Aging with Dignity is the developer of one of the most frequently used advance directives (AD). The document Five Wishes® (http://www.agingwithdignity.org/) and the related webpage offer information about advance directives. This effort has spread across the US and has begun to spread globally. In Japan, similar to the National Cancer Institute in the US, the National Cancer Research Center provides comprehensive cancer information (National Cancer Research Center; がん情報サービス http://ganjoho.jp/public/index.html). However, because AD has not yet been embraced in Japan, and the awareness is not well established, limited information on options are available to Japanese people. For these reasons, people are not seeking AD information unless directed to do so by a health care provider. Providers should not assume that the public will make an effort to obtain information regarding ADs. As presented in Chapter V, the second theme, limited knowledge of ACP, was supported by the data. For example, only one participant knew about ADs, and other participants had a
difficult time even understanding the use of ADs. Additionally, family is an important player in decision making and participants were not clear about who would write ADs. In the US, individuality is respected, but the concept of \textit{self} is different in Japan. Maynard (1997) said regarding the concept of self:

\begin{quote}

The term usually associated with self in the United States is "individual." Interestingly, the Japanese word for individual - \textit{kojin} - often has negative meanings attached to it, sometime even analogous to "selfishness." ... Anything that violates Americans' right to think, judge, and live their lives as they see fit is considered not only morally wrong, but "sacrilegious." (p.42)
\end{quote}

As described by Maynard, because of the strong sense of community represented by the family unit, individuals do not feel the necessity to make decisions for themselves. Findings in my study supported this work. These Japanese cancer patients had \textbf{limited knowledge of ACP}, not because they were not educated; rather, it was because of significant barriers in dissemination strategies in addition to cultural attitude. In other words, participants did not develop or exert their own preferences regarding end-of-life care. Participant's preference is discussed in the following section.

\textbf{PATIENT'S PREFERENCES}

The study results showed that participants had their own thoughts and preferences about end-of-life (EOL) care. However, due to their Japanese cultural values, they were uncomfortable explicitly expressing their own wishes. Related research themes were: \textbf{perception of their own lives, perception of their bodies and organ donation}, in Chapter IV; and \textbf{discomfort to express one's own will, and culture and dynamics in Japanese communication influencing ACP}, in Chapter V. The participants developed their EOL care preferences primarily through personal experiences with their own families (\textbf{medical knowledge and EOL issues}). Their experiences with family or
someone close to them, along with passive media such as television, were the primary factors for participants in formulating their EOL care preferences. The interviews also revealed that little or no information acquired from the Internet contributed to their preferences, although their use of the Internet was significant (limited knowledge of advance care planning). Instead, participants learned about EOL issues and the utilization of palliative care at EOL through their own experiences with family and loved ones.

Although medical technology and aggressive care options are widely available in Japan, participants expressed their preference for natural death at the EOL, if no effective treatment were available to reverse the disease process (willingness to learn: perception of natural death). As an Asian country, Japan is preserving Eastern philosophy consciously and unconsciously. This notion as described in Chapter V was demonstrated by study participants. Due to their great respect for nature, natural death is accepted at the time when no more effective treatment is available. Participants generally stated that they didn't want unnecessary life-prolonging measures at the EOL; however, one participant mentioned the uncertainty around determining the appropriate time to stop futile care for a family member. The study participants had early stage cancer and considered themselves as survivors; therefore, they maintained a certain distance from EOL (willingness to learn: nodomoto sugireba). This situation contributed to the participants’ inability to imagine complicated issues that arise at the EOL. However, they expressed a general preference against futile care.

Many participants expressed that they had preferences for EOL. They had developed these preferences through past experiences with family. They expressed that
they felt comfortable discussing EOL preferences because their cancer was early stage. They felt a distance from their own EOL. Many participants were able to discuss their preferences casually, but no participants had their own advance directives (AD). Two possible contributing factors for a lack of AD were: 1) Although they were comfortable casually discussing their preferences for EOL, a hesitance to put decisions explicitly in writing was observed, and 2) Due to the strong sense of community, they felt their family could make the decision for them and did not feel they had to actively develop an AD.

Participants’ comfort level in explicitly stating their preferences had a direct relationship to the level of cultural rigidity in their lives, (thoughts, preferences, and decisions).

Another finding was that simply disseminating information about AD on the Internet was insufficient. While the Internet is effective for people seeking specific information, participants were not sufficiently aware of AD or ACP to actively seek information about it. Lack of a national awareness of ACP and AD was found in Japan. In the US, after the tragic story of Terri Schiavo (a woman who lived many years in a coma) and the surrounding controversy became news, social awareness increased significantly. Active involvement of health care providers and different types of dissemination strategies are necessary to increase social awareness of ACP and AD in Japan. Depending on the phase of ACP for an individual, tailored assistance should be available in the next phase.
STRENGTHS AND LIMITATIONS OF THE STUDY

This qualitative inquiry provides knowledge beneficial for health care providers to understand Japanese patient’s perspectives through the ethnographic lens. As in any research, limitations and strengths of the study exist, as discussed in this section.

While a smaller sample size is consistent with the qualitative design selected, richness and depth of understanding are expected results. However, difficulty of recruiting women for this study led to a smaller sample size than expected, and thus limited findings to some degree. Unlike in the US, people have minimal exposure to research activities in Japan, especially exposure to nursing studies. This situation caused unfamiliarity with participation in a study for both health care providers and eligible patients. I made great efforts to explain the significance of study and the process. Fortunately staff at Japanese Red Cross Medical Center and Kochi Red Cross Hospital agreed to the importance of this investigation, and ten people volunteered to participate in the study. The depth of the interviews provided a rich description of participants’ concerns, knowledge, and experiences with ACP.

Another limitation was that of selecting only two locations in Japan. Participants were selected from Tokyo (urban area) and Kochi (rural area), but rather than finding disparities between the rural and urban settings, I found more similarities and universal themes than differences. Further, I identified that a limited research environment existed in both cities. Smaller sample size is a hallmark of qualitative research, and consistent with the exploratory nature of study. The richness of data is evidenced by the description of findings reported herein. Additionally, efforts made to address the trustworthiness of data allow for presentation of findings that are credible and potentially transferable.
One of the strengths of the study was the research design selected. The ethnographic design, guided by phenomenology, enabled me to understand the meaning of participants’ perceptions of ACP. With this design, I was able to look at the data as a whole and the derived meaning of participants’ perceptions. Cultural interpretations and meanings are often lost in fragmentation of the statements and data. This research design supported my interpretations based upon deeper understanding of participant’s emic perspectives.

Another strength is the congruence of cultural concepts discussed in this treatise with those prominent in Japanese culture. Indeed, language exists to describe cultural beliefs and supports understanding of the phenomena. An additional strength of this study was the identification of explicit language to describe participants' perceptions. This explicit language exists in Japanese culture but does not exist in American culture. Using original Japanese text in the quotations will further allow native speakers to catch these cultural nuances and contexts for the study results and interpretations. These phenomena potentially exist in other populations, and further study of other populations will be helpful to examine broader applicability of the notion of advance care planning.

In summary, although limitations existed in the sampling and settings, I believe the consistency of findings and depth of description afforded by this sample led to in-depth understandings. However, further research should include larger and more varied samplings.
IMPLICATIONS FOR NURSING AND A DIRECTION FOR FUTURE STUDY

In this study, perceptions of women with early stage cancer regarding advance care planning (ACP) were explored, to understand patients’ emic perspectives. Although ACP is a process to develop a care plan in the event that an individual becomes incapable of making decisions for himself or herself, ACP is often thought of as simply writing an AD. Results of this research indicated that participants developed their preferences about EOL based on their life experiences and their cultural norms, including their experiences as cancer patients. In this section, implications of this study for practice, education, and research are explored.

Implications for Practice

The implications of this study for practice are extensively applicable for any health care workers who are involved with ACP, because all health care providers need to work to encourage patient-centered decision-making. Cultural sensitivity in practice is one of the most important components of supporting patients and their families. The study results give us a better understanding of Japanese women's perspectives regarding ACP after having a cancer experience. While no participants had prepared an AD, they were not necessarily opposed to writing one. Participants’ knowledge of AD was extremely limited. Therefore, I believe robust strategies to disseminate the information regarding AD are necessary in Japan.

Another implication for practice is that Japanese nurses may need to develop authentically intimate relationships with their patients to understand patients' needs. As the utilization of Watson's theory was discussed in Chapter VI, such transformation of
nurse-patient relationships would be helpful. Nurses may need in-service education to fully implement this recommendation. Providing education about communication skills is essential to promote patients’ verbalization of their needs. For example, nurses may be able to use a question such as “it would be helpful for me to understand your need if you tell me what you would like” instead of asking “Do you need anything?” Developing culturally sensitive communication strategies for this population is essential to nursing and health care practice. Providing care consistent with cultural concepts was identified as having a strong influence on patient thoughts, beliefs, and actions (i.e., amae, sasshi, and enryo) and is a critical element for nursing practice with this population. Nurse scientists can work collaboratively with nurse clinicians and other health care providers in this area of practice to address these needs.

**Implications for Education**

One of the most important foci of nursing education has been cultural competency. Despite this focus, teaching culturally sensitive communication skills has been challenging. Although concepts of palliative care and ACP are advanced level concepts in nursing education, entry-level nurses can be involved with ACP and patient/family decision making in everyday practice. Cultural sensitivity is critical to discussions about ACP in Japan because of social norms, including a strong sense of community. Health care providers such as registered nurses need to be trained and must become skilled in promoting ACP, which would ultimately lead to the development of AD. Awareness of cultural expectations and assumptions assists healthcare providers in developing skills that promote ACP.
Understanding of a patient’s psychology helps us to learn how to approach these patients. The implication here is that rather than stereotyping the Japanese population, nurse educators must assist students to apply a culturally sensitive approach to make patients and their families feel more comfortable. Comfort in communication with the health care provider enables more open discussion and better patient-centered care. The study findings suggest how Japanese women think and interact, and by understanding their thoughts and interactions, health care providers can better facilitate discussions about ACP. Educating entry-level and advanced care providers on how to understand these patients enables them to communicate better.

Disseminating these findings in the Japanese language will contribute to Japanese nurses acquiring the skills necessary to understand their patients’ needs. Publishing in both English and Japanese languages in the professional journals is therefore essential.

**Implication for Future Research**

This study showed that prior to writing an AD, participants held a neutral view of AD, not viewing the concept as either favorable or unfavorable. However, the factors involved in developing their preferences were complex. Most of the previous studies view ACP as "ready for AD or not" or "favorable to AD or not". This study clearly showed that a holistic view is necessary to promote ACP. With a broader population, exploring the phases of ACP before AD would lead to the development of a more holistic and culturally sensitive model.

The results showed that many participants were constructing preferences based on their life experiences, including their experiences with family and loved ones. People are uncertain in this stage, and preferences may not be concrete enough to put into writing.
Understandably, their experiences as cancer patients were a primary influence in the development of preferences. While participants perceived cancer as a life-threatening disease and received successful treatment in early stages, they considered themselves survivors. Consequently, they had less fear, and felt more comfortable about discussing ACP. The opportunity to discuss ACP was a reminder to talk about their preferences with their families.

This finding implies that participants' thoughts about ACP evolve during earlier phases of illness. However, the process remains unclear and development of interventions would be premature. Therefore a need is indicated for further research to explore the phases of developing preferences around ACP. First, a more geographically varied and demographically diverse sample in Japan would be helpful to understand any nuances of the phenomena studied and to provide support or ideas for revision of the model presented. Second, a need is indicated for a comparative sample. In fact, phase II of this study will use the same research question and ask to American women to facilitate international comparison. Including rural and urban comparisons from American study will contribute to completing the model of ACP.

To augment these findings, a future study across multiple cultures exploring how cultural essences influence perceptions regarding ACP will be helpful. To address this need, a study with a cross-cultural comparative design would be appropriate.

**CONCLUSION**

Japanese people embody Eastern culture; a sense of community, harmony, and modesty are very important. Eastern culture is the foundation for Japanese beliefs. Therefore, Japanese people such as these participants have difficulty expressing
preferences, as it would be seen as self-centered or disturbing harmony in the community. Communication and cultural patterns such as amae, sashhi, and enryo, prominent in this research, inform ACP. In Western culture, explicit expression of an individual’s decisions is respected. However, the thought of expressing one's own decisions can be intimidating for Japanese people. At the same time, the participants recognized the importance of discussing ACP, and showed a willingness to express their wishes in writing if it would reduce family burden or make certain they would receive the care they wanted. Legislative efforts to give certain legal authority to AD and disseminate the availability of AD and ACP are still needed. Participants also expressed their perception of family as a significant agent for decision making, thus, family-oriented strategies to promote ACP are essential.

In the future, additional studies with a variety of populations should be conducted to create a complete model of the phases of ACP. A complete model would lead to the development of more effective strategies to promote ACP.

OVERALL SUMMARY

The following is an overall summary of this investigation.

Background and Research Design

Advance care planning (ACP) is the process that allows individuals to choose a path of care in the event that they are unable to make a decision for themselves. Current literature demonstrates that ACP has been often represented as writing an advance directive (AD). However, the concept of advance care planning is much broader than merely putting wishes in writing or examining readiness to write an AD.
In Japan, the highest levels of health care technologies are available to the population because of the Japanese health system of universal insurance. Availability of such technologies has resulted in many ethical issues, such as unnecessary or unwanted care that does not necessarily prioritize quality of life. Although a solution to this ethical issue is creating advance directives for the health care providers to understand patients' individual wishes, current knowledge demonstrated that health care providers (HCP) often fail to communicate with their patients about these preferences.

The World Health Organization and other professional organizations recommend HCPs start introducing palliative care into their practice, and they should begin by supporting patients in developing AD at the time of diagnosis of life-threatening illness. However, literature suggests that Japanese health care problems repeatedly occur due to failure to initiate such discussion with their patients until it's too late.

The purpose of this study was to gain understanding of the gap between recommendations and current practice in terms of patient centered care related to advance care planning in Japan. Cultural sensitivity is vital to understanding my patients' perspectives; therefore, ethnography guided by phenomenology was used as the research design with a sample of Japanese women with cancer to address this purpose.

Method and Participant’s Characteristics

Fifteen qualitative semi-structured interviews were conducted between January 2009 and March 2010 with ten Japanese women in early stages of solid tumor breast or gynecological cancer. This study was approved by the Colorado Multi Institutional Review Board. At the time of the first interview, an informed consent was obtained from
each participant. The consent included agreement to voluntary participation. Privacy and confidentiality were respected when photographs were taken.

The ten participants were interviewed once or twice in a private space of their choice. A total of fifteen audio-recorded interviews were conducted with women who had stage I or II breast or gynecological cancer, recruited from Kochi (rural) and from Tokyo (urban) prefectures in Japan. The mean age of the study participants was 46.6 years: range was 37 to 59 years. The audio-recorded interviews lasted from 21 to 110 minutes (M=65.1). The time from diagnosis to interview ranged from 3 months to 18 months (M=11 months). Three participants had breast cancer and seven participants had gynecological cancer. Second interviews were conducted with five participants to check credibility of findings and in some cases, generate new data.

**Data Analysis**

All interviews were transcribed and entered into Atlas ti® to organize the data. Data were transcribed and analyzed in Japanese language to preserve cultural meanings and contexts, until the phase of deriving themes. Data were analyzed using the Leininger’s (2006) and Fetterman’s (1989e) guidelines, which suited the purpose and design of the study. Data were coded and categorized. The categorized data were analyzed in a way to derive cultural themes. These codes and categories were analyzed as a whole to preserve the cultural meanings. Lincoln and Guba’s criteria (1985) were utilized to address trustworthiness or rigor of the study.

**Results and Discussion**

Data analysis yielded a set of findings: both cultural descriptive themes and themes regarding ACP were identified. The cultural descriptive themes were: 1)
Perception of their own lives; 2) Perception of their bodies and organ donation; 3) Care giving and a status as a wife in Japan - 介護[kaigo] & 嫁 [yome]; 4) Medical knowledge and EOL issues; 5) 遠慮 [enryo] - self-restraint and holding back. The derived themes regarding ACP were: 1) **Discomfort to express one's own will**; 2) **Limited knowledge of advance care planning**; 3) **Dependence on Family**; 4) **Willingness to learn**, and the overarching theme: **Culture and dynamics in Japanese communication influence advance care planning: sashhi and amae**.

**Summary**

Overall, the concept of palliative care is not well diffused in Japanese society and participants had demonstrated difficulty grasping the concepts. Regardless, participants expressed a willingness to learn about ACP and recognized the significance of developing advance directives. Enryo, sashhi and amae were identified as concepts grounded in Japanese culture and can be found in their communication style. Significant cultural implications related to the importance of families in the ACP process were identified. Through the perspectives of these participants, Japanese fundamental concepts were found to have significant influence on decision-making process in ACP.

In conclusion, ACP, the process of developing a care plan, is critical in case an individual cannot speak for themselves when facing a significant illness. For Japanese people, understanding of one's own care needs is a vital element that is dependent upon cultural understanding and sensitivity, and family support. Thus, ACP can be intimidating for the Japanese people, but is possible when these elements are considered. Further research will strengthen these findings and facilitate explanation of interventions and outcomes.
REFERENCES


Carrier Brain. (2008). Only 10 percent said "want to end at home"; divergence with the country's goals *CB News* Retrieved from http://news.cabrain.net/article.do?newsId=16452&freeWordSave=1


APPENDIX A

FIVE WISHES® BY AGING WITH DIGNITY
MY WISH FOR:

The Person I Want to Make Care Decisions for Me When I Can't

The Kind of Medical Treatment I Want or Don't Want

How Comfortable I Want to Be

How I Want People to Treat Me

What I Want My Loved Ones to Know

print your name

birthdate
Five Wishes

There are many things in life that are out of our hands. This Five Wishes booklet gives you a way to control something very important—how you are treated if you get seriously ill. It is an easy-to-complete form that lets you say exactly what you want. Once it is filled out and properly signed it is valid under the laws of most states.

What Is Five Wishes?
Five Wishes is the first living will that talks about your personal, emotional and spiritual needs as well as your medical wishes. It lets you choose the person you want to make health care decisions for you if you are not able to make them for yourself. Five Wishes lets you say exactly how you wish to be treated if you get seriously ill. It was written with the help of The American Bar Association’s Commission on Law and Aging, and the nation’s leading experts in end-of-life care. It’s also easy to use. All you have to do is check a box, circle a direction, or write a few sentences.

How Five Wishes Can Help You and Your Family

- It lets you talk with your family, friends and doctor about how you want to be treated if you become seriously ill.
- Your family members will not have to guess what you want. It protects them if you become seriously ill, because they won’t have to make hard choices without knowing your wishes.
- You can know what your mom, dad, spouse, or friend wants through a Five Wishes living will. You can be there for them when they need you most. You will understand what they really want.

How Five Wishes Began
For 12 years, a man named Jim Towey worked closely with Mother Teresa, and, for one year, he lived in a hospice she ran in Washington, DC. Inspired by this first-hand experience, Mr. Towey sought a way for patients and their families to plan ahead and to cope with serious illness. The result is Five Wishes and the response to it has been overwhelming. It has been featured on CNN and NBC’s Today Show and in the pages of Time and Money magazines. Newspapers have called Five Wishes the first “living will with a heart.”
Who Should Use Five Wishes

Five Wishes is for anyone 18 or older — married, single, parents, adult children, and friends. Over eight million Americans of all ages have already used it. Because it works so well, lawyers, doctors, hospitals and hospices, faith communities, employers, and retiree groups are handing out this document.

Five Wishes States

If you live in the District of Columbia or one of the 40 states listed below, you can use Five Wishes and have the peace of mind to know that it substantially meets your state’s requirements under the law:

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Alaska</td>
<td>Idaho</td>
<td>Missouri</td>
<td>Rhode Island</td>
<td></td>
</tr>
<tr>
<td>Arizona</td>
<td>Illinois</td>
<td>Montana</td>
<td>South Carolina</td>
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<tr>
<td>Arkansas</td>
<td>Iowa</td>
<td>Nebraska</td>
<td>South Dakota</td>
<td></td>
</tr>
<tr>
<td>California</td>
<td>Louisiana</td>
<td>New Jersey</td>
<td>Tennessee</td>
<td></td>
</tr>
<tr>
<td>Colorado</td>
<td>Maine</td>
<td>New Mexico</td>
<td>Vermont</td>
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</tr>
<tr>
<td>Connecticut</td>
<td>Maryland</td>
<td>New York</td>
<td>Virginia</td>
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<tr>
<td>Delaware</td>
<td>Massachusetts</td>
<td>North Carolina</td>
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<tr>
<td>Florida</td>
<td>Michigan</td>
<td>North Dakota</td>
<td>West Virginia</td>
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<td>Georgia</td>
<td>Minnesota</td>
<td>Oklahoma</td>
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</tr>
<tr>
<td>Hawaii</td>
<td>Mississippi</td>
<td>Pennsylvania</td>
<td>Wyoming</td>
<td></td>
</tr>
</tbody>
</table>

If your state is not one of the 40 states listed here, Five Wishes does not meet the technical requirements in the statutes of your state. So some doctors in your state may be reluctant to honor Five Wishes. However, many people from states not on this list do complete Five Wishes along with their state’s legal form. They find that Five Wishes helps them express all that they want and provides a helpful guide to family members, friends, care givers and doctors. Most doctors and health care professionals know they need to listen to your wishes no matter how you express them.

How Do I Change To Five Wishes?

You may already have a living will or a durable power of attorney for health care. If you want to use Five Wishes instead, all you need to do is fill out and sign a new Five Wishes as directed. As soon as you sign it, it takes away any advance directive you had before. To make sure the right form is used, please do the following:

- Destroy all copies of your old living will or durable power of attorney for health care. Or you can write “revoked” in large letters across the copy you have. Tell your lawyer if he or she helped prepare those old forms for you. AND
- Tell your Health Care Agent, family members, and doctor that you have filled out the new Five Wishes. Make sure they know about your new wishes.
WISH 1
The Person I Want To Make Health Care Decisions For Me
When I Can't Make Them For Myself.

If I am no longer able to make my own health care
decisions, this form names the person I choose to
make these choices for me. This person will be my
Health Care Agent (or other term that may be used in
my state, such as proxy, representative, or surrogate).
This person will make my health care choices if both
of these things happen:

- My attending or treating doctor finds I am no
longer able to make health care choices, AND
- Another health care professional agrees that
this is true.

If my state has a different way of finding that I am not
able to make health care choices, then my state’s way
should be followed.

The Person I Choose As My Health Care Agent Is:

First Choice Name

Address

Phone

City/State/Zip

If this person is not able or willing to make these choices for me, OR is divorced or legally separated from me,
OR this person has died, then these people are my next choices:

Second Choice Name

Address

City/State/Zip

Phone

Third Choice Name

Address

City/State/Zip

Phone

Picking The Right Person To Be Your Health Care Agent

Choose someone who knows you very well,
cares about you, and who can make difficult
decisions. A spouse or family member may
not be the best choice because they are too
emotionally involved. Sometimes they are
the best choice. You know best. Choose someone
who is able to stand up for you so that your
wishes are followed. Also, choose someone who
is likely to be nearby so that they can help when
you need them. Whether you choose a spouse,
family member, or friend as your Health Care
Agent, make sure you talk about these wishes
and be sure that this person agrees to respect

and follow your wishes. Your Health Care
Agent should be at least 18 years or older (in
Colorado, 21 years or older) and should not be:

- Your health care provider, including the
owner or operator of a health or residential
or community care facility serving you.

- An employee or spouse of an employee of
your health care provider.

- Serving as an agent or proxy for 10 or
more people unless he or she is your
spouse or close relative.
I understand that my Health Care Agent can make health care decisions for me. I want my Agent to be able to do the following: (Please cross out anything you don’t want your Agent to do that is listed below.)

- Make choices for me about my medical care or services, like tests, medicine, or surgery. This care or service could be to find out what my health problem is, or how to treat it. It can also include care to keep me alive. If the treatment or care has already started, my Health Care Agent can keep it going or have it stopped.
- Interpret any instructions I have given in this form or given in other discussions, according to my Health Care Agent’s understanding of my wishes and values.
- Consent to admission to an assisted living facility, hospital, hospice, or nursing home for me. My Health Care Agent can hire any kind of health care worker I may need to help me or take care of me. My Agent may also hire a health care worker, if needed.
- Make the decision to request, take away or not give medical treatments, including artificially-provided food and water, and any other treatments to keep me alive.
- See and approve release of my medical records and personal files. If I need to sign my name to get any of these files, my Health Care Agent can sign it for me.
- Move me to another state to get the care I need or to carry out my wishes.
- Authorize or refuse to authorize any medication or procedure needed to help with pain.
- Take any legal action needed to carry out my wishes.
- Donate useable organs or tissues of mine as allowed by law.
- Apply for Medicare, Medicaid, or other programs or insurance benefits for me. My Health Care Agent can see my personal files, like bank records, to find out what is needed to fill out these forms.
- Listed below are any changes, additions, or limitations on my Health Care Agent’s powers.

If I Change My Mind About Having A Health Care Agent, I Will

- Destroy all copies of this part of the Five Wishes form. OR
- Tell someone, such as my doctor or family, that I want to cancel or change my Health Care Agent. OR
- Write the word “Revoked” in large letters across the name of each agent whose authority I want to cancel. Sign my name on that page.
WISH 2
My Wish For The Kind Of Medical Treatment
I Want Or Don't Want.

I believe that my life is precious and I deserve to be treated with dignity. When the time comes that I am very sick and am not able to speak for myself, I want the following wishes, and any other directions I have given to my Health Care Agent, to be respected and followed.

What You Should Keep In Mind As My Caregiver

- I do not want to be in pain. I want my doctor to give me enough medicine to relieve my pain, even if that means that I will be drowsy or sleep more than I would otherwise.
- I do not want anything done or omitted by my doctors or nurses with the intention of taking my life.
- I want to be offered food and fluids by mouth, and kept clean and warm.

What “Life-Support Treatment” Means To Me

Life-support treatment means any medical procedure, device or medication to keep me alive. Life-support treatment includes: medical devices put in me to help me breathe; food and water supplied by medical device (tube feeding); cardiopulmonary resuscitation (CPR); major surgery; blood transfusions; dialysis; antibiotics; and anything else meant to keep me alive.

If I wish to limit the meaning of life-support treatment because of my religious or personal beliefs, I write this limitation in the space below. I do this to make very clear what I want and under what conditions.

In Case Of An Emergency

If you have a medical emergency and ambulance personnel arrive, they may look to see if you have a Do Not Resuscitate form or bracelet. Many states require a person to have a Do Not Resuscitate form filled out and signed by a doctor. This form lets ambulance personnel know that you don’t want them to use life-support treatment when you are dying. Please check with your doctor to see if you need to have a Do Not Resuscitate form filled out.
Here is the kind of medical treatment that I want or don’t want in the four situations listed below. I want my Health Care Agent, my family, my doctors and other health care providers, my friends and all others to know these directions.

**Close to death:**

If my doctor and another health care professional both decide that I am likely to die within a short period of time, and life-support treatment would only delay the moment of my death (Choose one of the following):

- [ ] I want to have life-support treatment.
- [ ] I do not want life-support treatment. If it has been started, I want it stopped.
- [ ] I want to have life-support treatment if my doctor believes it could help. But I want my doctor to stop giving me life-support treatment if it is not helping my health condition or symptoms.

**Permanent And Severe Brain Damage And Not Expected To Recover:**

If my doctor and another health care professional both decide that I have permanent and severe brain damage, (for example, I can open my eyes, but I cannot speak or understand) and I am not expected to get better, and life-support treatment would only delay the moment of my death (Choose one of the following):

- [ ] I want to have life-support treatment.
- [ ] I do not want life-support treatment. If it has been started, I want it stopped.
- [ ] I want to have life-support treatment if my doctor believes it could help. But I want my doctor to stop giving me life-support treatment if it is not helping my health condition or symptoms.

**In A Coma And Not Expected To Wake Up Or Recover:**

If my doctor and another health care professional both decide that I am in a coma from which I am not expected to wake up or recover, and I have brain damage, and life-support treatment would only delay the moment of my death (Choose one of the following):

- [ ] I want to have life-support treatment.
- [ ] I do not want life-support treatment. If it has been started, I want it stopped.
- [ ] I want to have life-support treatment if my doctor believes it could help. But I want my doctor to stop giving me life-support treatment if it is not helping my health condition or symptoms.

**In Another Condition Under Which I Do Not Wish To Be Kept Alive:**

If there is another condition under which I do not wish to have life-support treatment, I describe it below. In this condition, I believe that the costs and burdens of life-support treatment are too much and not worth the benefits to me. Therefore, in this condition, I do not want life-support treatment. (For example, you may write “end-stage condition.” That means that your health has gotten worse. You are not able to take care of yourself in any way, mentally or physically. Life-support treatment will not help you recover. Please leave the space blank if you have no other condition to describe.)
The next three wishes deal with my personal, spiritual and emotional wishes. They are important to me. I want to be treated with dignity near the end of my life, so I would like people to do the things written in Wishes 3, 4, and 5 when they can be done. I understand that my family, my doctors and other health care providers, my friends, and others may not be able to do these things or are not required by law to do these things. I do not expect the following wishes to place new or added legal duties on my doctors or other health care providers. I also do not expect these wishes to excuse my doctor or other health care providers from giving me the proper care asked for by law.

WISH 3
My Wish For How Comfortable I Want To Be.
(Please cross out anything that you don’t agree with.)

• I do not want to be in pain. I want my doctor to give me enough medicine to relieve my pain, even if that means I will be drowsy or sleep more than I would otherwise.
• If I show signs of depression, nausea, shortness of breath, or hallucinations, I want my care givers to do whatever they can to help me.
• I wish to have a cool moist cloth put on my head if I have a fever.
• I want my lips and mouth kept moist to stop dryness.
• I wish to have warm baths often. I wish to be kept fresh and clean at all times.
• I wish to be massaged with warm oils as often as I can be.
• I wish to have my favorite music played when possible until my time of death.
• I wish to have personal care like shaving, nail clipping, hair brushing, and teeth brushing, as long as they do not cause me pain or discomfort.
• I wish to have religious readings and well-loved poems read aloud when I am near death.
• I wish to know about options for hospice care to provide medical, emotional and spiritual care for me and my loved ones.

WISH 4
My Wish For How I Want People To Treat Me.
(Please cross out anything that you don’t agree with.)

• I wish to have people with me when possible. I want someone to be with me when it seems that death may come at any time.
• I wish to have my hand held and to be talked to when possible, even if I don’t seem to respond to the voice or touch of others.
• I wish to have others by my side praying for me when possible.
• I wish to have the members of my faith community told that I am sick and asked to pray for me and visit me.
• I wish to be cared for with kindness and cheerfulness, and not sadness.
• I wish to have pictures of my loved ones in my room, near my bed.
• If I am not able to control my bowel or bladder functions, I wish for my clothes and bed linens to be kept clean, and for them to be changed as soon as they can be if they have been soiled.
• I want to die in my home, if that can be done.
**WISH 5**

*My Wish For What I Want My Loved Ones To Know.*

*(Please cross out anything that you don’t agree with.)*

- I wish to have my family and friends know that I love them.
- I wish to be forgiven for the times I have hurt my family, friends, and others.
- I wish to have my family, friends and others know that I forgive them for when they may have hurt me in my life.
- I wish for my family and friends to know that I do not fear death itself. I think it is not the end, but a new beginning for me.
- I wish for all of my family members to make peace with each other before my death, if they can.
- I wish for my family and friends to think about what I was like before I became seriously ill. I want them to remember me in this way after my death.
- I wish for my family and friends and caregivers to respect my wishes even if they don’t agree with them.
- I wish for my family and friends to look at my dying as a time of personal growth for everyone, including me. This will help me live a meaningful life in my final days.
- I wish for my family and friends to get counseling if they have trouble with my death. I want memories of my life to give them joy and not sorrow.
- After my death, I would like my body to be (circle one): buried or cremated.
- My body or remains should be put in the following location ________________.
- The following person knows my funeral wishes: ________________

If anyone asks how I want to be remembered, please say the following about me:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

If there is to be a memorial service for me, I wish for this service to include the following (list music, songs, readings or other specific requests that you have):

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

(Please use the space below for any other wishes. For example, you may want to donate any or all parts of your body when you die. Please attach a separate sheet of paper if you need more space.)

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
Signing The Five Wishes Form

Please make sure you sign your Five Wishes form in the presence of the two witnesses.

I, ____________, ask that my family, my doctors, and other health care providers, my friends, and all others, follow my wishes as communicated by my Health Care Agent (if I have one and he or she is available), or as otherwise expressed in this form. This form becomes valid when I am unable to make decisions or speak for myself. If any part of this form cannot be legally followed, I ask that all other parts of this form be followed. I also revoke any health care advance directives I have made before.

Signature:________________________________________________________________________

Address:________________________________________________________________________

Phone: ______________ Date: ______________

Witness Statement - (2 witnesses needed):

I, the witness, declare that the person who signed or acknowledged this form (hereafter “person”) is personally known to me, that he/she signed or acknowledged this (Health Care Agent and/or Living Will form(s)) in my presence, and that he/she appears to be of sound mind and under no duress, fraud, or undue influence.

I also declare that I am over 18 years of age and am NOT:

• The individual appointed as (agent/proxy/surrogate/patient advocate/representative) by this document or his/her successor,
• The person’s health care provider, including owner or operator of a health, long-term care, or other residential or community care facility serving the person,
• An employee of the person’s health care provider,

(Some states may have fewer rules about who may be a witness. Unless you know your state’s rules, please follow the above.)

Signature of Witness #1

Printed Name of Witness

Address

Phone

Signature of Witness #2

Printed Name of Witness

Address

Phone

Notarization - Only required for residents of Missouri, North Carolina, South Carolina and West Virginia

• If you live in Missouri, only your signature should be notarized.

STATE OF__________________________

COUNTY OF___________________________

On this _____ day of _____________, 20___, the said ________________________________, and ________________________________, known to me (or satisfactorily proven) to be the person named in the foregoing instrument and witnesses, respectively, personally appeared before me, a Notary Public, within and for the State and County aforesaid, and acknowledged that they freely and voluntarily executed the same for the purposes stated therein.

My Commission Expires: ____________________________

Notary Public
What To Do After You Complete Five Wishes

- Make sure you sign and witness the form just the way it says in the directions. Then your Five Wishes will be legal and valid.
- Talk about your wishes with your health care agent, family members and others who care about you. Give them copies of your completed Five Wishes.
- Keep the original copy you signed in a special place in your home. Do NOT put it in a safe deposit box. Keep it nearby so that someone can find it when you need it.
- Fill out the wallet card below. Carry it with you. That way people will know where you keep your Five Wishes.

Residents of Wisconsin must attach the Wisconsin notice statement to Five Wishes.
More information and the notice statement are available at www.agingwithdignity.org or 1-888-594-7437.

Residents of Institutions in California, Connecticut, Delaware, Georgia, New York, North Dakota, South Carolina, and Vermont Must Follow Special Witnessing Rules.

If you live in certain institutions (a nursing home, other licensed long term care facility, a home for the mentally retarded or developmentally disabled, or a mental health institution) in one of the states listed above, you may have to follow special “witnessing requirements” for your Five Wishes to be valid. For further information, please contact a social worker or patient advocate at your institution.

Five Wishes is meant to help you plan for the future. It is not meant to give you legal advice. It does not try to answer all questions about anything that could come up. Every person is different, and every situation is different. Laws change from time to time. If you have a specific question or problem, talk to a medical or legal professional for advice.

Five Wishes Wallet Card

Important Notice to Medical Personnel:
I have a Five Wishes Advance Directive.

Signature

Please consult this document and/or my Health Care Agent in an emergency. My Agent is:

Name:
Address City/State/Zip
Phone

My primary care physician is:

Name:
Address City/State/Zip
Phone

My document is located at:

Cut Out Card, Fold and Laminate for Safekeeping
APPENDIX B

INITIAL APPROVAL LETTER FROM

COLORADO MULTI INSTITUTIONAL REVIEW BOARD
Certificate of Approval

20-Jan-2009

Investigator: Yukio Akahana
Sponsor(s): 
Subject: COMIRB Protocol #8-1369 Initial Application
Effective Date: 20-Jan-2009
Expiration Date: 15-Jan-2010
Expected Category: 5,6,7
Title: Perceptions

All COMIRB Approved investigators must comply with the following:

- For the duration of your protocol, any change in the experimental design/consent and/or assent form must be approved by the COMIRB before implementation of the changes.
- Use only a copy of the COMIRB signed and dated Consent and/or Assent Form. The investigator bears the responsibility for obtaining from all subjects “Informed Consent” as approved by the COMIRB. The COMIRB requires that the subject be given a copy of the consent and/or assent form. Consent and/or assent forms must include the name and telephone number of the investigator.
- Provide non-English speaking subjects with a certified translation of the approved Consent and/or Assent Form in the subject’s first language.
- The investigator also bears the responsibility for informing the COMIRB immediately of any Unanticipated Problems that are unexpected and related to the study in accordance with COMIRB Policy and Procedures.
- Obtain COMIRB approval for all advertisements, questionnaires and surveys before use.
- Federal regulations require a Continuing Review to renew approval of this project within a 12-month period from the last approval date unless otherwise indicated in the review cycle listed below. If you have a protocol/high risk protocol, specific details will be outlined in this letter. Non-compliance with Continuing Review will result in the termination of this study.

You will be sent a Continuing Review reminder 75 days prior to the expiration date. Any questions regarding this COMIRB action can be referred to the Coordinator at 303-724-1955 or UCHSC Box F-430.

Sincerely,

UCD Panel A
APPENDIX C

DESCRIPTION OF SAMPLE AND INTERVIEW DETAILS
<table>
<thead>
<tr>
<th>Participant</th>
<th>From</th>
<th>Personal characteristics</th>
<th>Age</th>
<th>Diagnosis</th>
<th>Total Interview time (number of interviews)</th>
<th>Diagnosis date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Yoshii</td>
<td>Kochi</td>
<td>A working wife: live with her husband and daughter. Experience with taking care of her own father and father in law at the EOL</td>
<td>53</td>
<td>Endometrial Ca Stage I</td>
<td>95 min (2)</td>
</tr>
<tr>
<td>2</td>
<td>Takei</td>
<td>Kochi</td>
<td>A former LPN: living with two sons and husband. Has experience working at palliative care unit</td>
<td>40</td>
<td>Cervical Ca Stage I</td>
<td>110 min (2)</td>
</tr>
<tr>
<td>3</td>
<td>Kotani</td>
<td>Kochi</td>
<td>Housewife: husband travels overseas often. Living with her parents while getting cancer treatment.</td>
<td>37</td>
<td>Breast Ca Stage I</td>
<td>74 min (2)</td>
</tr>
<tr>
<td>4</td>
<td>Yamada</td>
<td>Kochi</td>
<td>Retired: husband passed away and living alone, but has sons live close to her to support her cancer treatment.</td>
<td>59</td>
<td>Endometrial Ca Stage I</td>
<td>21 min (1)</td>
</tr>
<tr>
<td>5</td>
<td>Murai</td>
<td>Kochi</td>
<td>Owns a restaurant business: participate in breast cancer support group. Live with her husband. Son lives in different city</td>
<td>50</td>
<td>Breast Ca Stage II</td>
<td>76 min (2)</td>
</tr>
<tr>
<td>6</td>
<td>Ito</td>
<td>Kochi</td>
<td>A housewife: lives in Kochi city to take care of her own mother who has dementia. Close to her husband and sister.</td>
<td>56</td>
<td>Endometrial Ca Stage I</td>
<td>70 min (2)</td>
</tr>
<tr>
<td>7</td>
<td>Sasaki</td>
<td>Kochi</td>
<td>Former RN: quit nursing when getting married. Three children, one is mentally challenged. Husband is a fisherman: no family travel. Lived with and took care of husband's parents.</td>
<td>45</td>
<td>Breast Ca I</td>
<td>83 min (1)</td>
</tr>
<tr>
<td>8</td>
<td>Asso</td>
<td>Tokyo</td>
<td>School teacher: a son after long time effort to pregnant. Great support by her husband.</td>
<td>40</td>
<td>Endometrial Ca Stage I</td>
<td>40 min (1)</td>
</tr>
<tr>
<td>9</td>
<td>Sato</td>
<td>Tokyo</td>
<td>Single, never married although has a boyfriend: does office work. Lives with her mother. Close to her sister.</td>
<td>49</td>
<td>Ovarian Ca Stage I</td>
<td>40 min (1)</td>
</tr>
<tr>
<td>10</td>
<td>Kawai</td>
<td>Tokyo</td>
<td>Housewife: lives in the center of Tokyo with her daughter and her husband. Received good support by daughter and her husband's parents to take care of small child at the time of cancer surgery.</td>
<td>37</td>
<td>Cervical Ca Stage I</td>
<td>42 min (1)</td>
</tr>
</tbody>
</table>

*Pseudonym

**Age is the participant's age at the time of interview**
APPENDIX D

ENGLISH AND JAPANESE FLYERS
Your Voice is Needed!

I would like to learn about your experience of living with cancer and your thoughts about your future. I am a doctoral student in nursing who studies cancer nursing. I would like to interview you because your voice is valued to learn patients’ perspectives and perceptions to improve future care for people like you who are living with cancer.

If you have Stage I or II Gynecological or Breast cancer (and your age is between 21 and 60 years) and you are interested in the study or have a question, please contact the investigator Yuki Asakura, RN, MS at [xxx] or e-mail to [xxx]

*This research uses interviews and will not affect your treatment in any way. Your participation is voluntary, and you can withdraw from this study anytime, even after you give consent.

Interest form (English) Version #3, Jan 20, 10; Research title "Perception of Future and Advance Care Planning for Women with Early Stage Gynecological and Breast Cancer: A Transcultural Study between Japan and the US" COMIRB #08-1369; P/I: Y. Asakura
あなたの声を聞かせてください

あなたのがんとともに生きる経験や将来について思うことを
聞かせていただきたいと思います。私は、看護の博士課程で
がん看護を学ぶ学生です。あなたの体験を通して、患者さん
の思うことや体験を知ることにより、今後のあなたのような
患者さん方へのケアを向上するために役立てたいと考えてい
ます。

婦人科系または乳がん (I度またはⅡ度)の患者さん (21 から
60 歳の方)で、ご協力いただけると思う方は、内容について
ご説明いたしますので、研究者 朝倉由紀まで電話 [電話番号]
または、電子メール [メールアドレス] で
ご連絡ください。

*この研究はインタビューでお話を聞くものですので、一切の治療に関わるものではありません。また、協力は自由意志のものですので、同意の後でもいつでも協力を辞退する
ことができます。
APPENDIX E

JAPANESE INFORMED CONSENT
研究協力同意書
日付：

研究課題：　早期婦人科系がんおよび乳がん患者の将来とアドバンス・ケアに対する認識：
日本・米国の国際比較文化研究

研究者名：　朝倉 由紀
COMIRB No: 08-1369
版の版のみ 2010年 9月26日 第3版

あなたには研究への協力をお願いしたいと思います。この同意書はこの研究に関しての情報をあなたに
提供するものです。研究者がこの研究についてご説明しますので、研究参加をお決めになる前、不
明な点についてはどのようなことでもお尋ねください。

なぜこの研究が行われるのですか？
この研究は婦人科系がんおよび乳がんの診断を受けたあとが将来についてどのように考えることが
かを学ぶことを目的としています。
あなたは、早期がんという診断が持ておられるということで、研究者はあなたの話や思いを
伺いたいと思っております。

他にはどのような人がこの研究に参加しているのですか？
他の研究協力者はあなたのような早期の婦人科系がんや乳がんをお持ちの方でです。協力者の総数は
最大80人です。アメリカ、コロラド州と日本の他地域に住む方々もこの研究に協力していただく予
定です。

もし私が研究に参加すると何が起こるのですか？
もしあなたが研究に参加してくださる場合、研究者は2回のインタビューにお答えいただける可能
にします。1回目のインタビューは直接面会をして行われます。インタビューの場所はあなたのご都合の
良い場所で、研究者があなたのプライバシーを守ることのできる場所となります。研究者は、あなた
にどこでインタビューを行いたいか伺うこととなります。この研究の目的は、あなたの将来に対する
認識や思いを伺うことなので、一切の実験的処置はありません。

あなたがもし同意してくださった場合、研究者はインタビューを録音させていただきます。あなたの
希望で、録音を不承することもできます。また、いつでも、録音の一部を消去するよう研究者に聞い
ていくこともできます。録音を拒否された場合も、あなたの研究への参加は可能です。

研究者は、お一人お一人に2回インタビューしたいと計画しております。2回目のインタビューは、直
接お会いする方法の他に、あなたの選択によっては、電話、手紙、電子メールによるインタビューも
可能です。インタビューの時間はおおよそ30分から1時間です。この研究への参加は自由意志のよう
ものですので、もしあなたが恐れたと感じたときには、インタビューを終了いたします。

Page 1 of 4
インタビュー中に、もしあなたの同意があれば、写真を撮らせていただきたいためです。また研究者、あなたの思いを自由に描き表したりできるように、スクラッチペーパーをお渡しします。

1回目のインタビューの締めに、次の面接について直接お話しすることが良いか、電話、手紙、または電子メールが良いか伺います。

もし、あなたが手紙または電子メールと選択した場合、研究者は質問をお送りし、あなたにお答えいただくよう伺います。あなたが、もし手紙を選択した場合、研究者は郵送料支払込み封筒をお渡しまたは郵送させていただきます。もしあなたが希望する場合、電子メールを送っていると良いかもしれません。

あなたからの手紙や電子メールを受け取った後、研究者はあなたの意見することを確認するため、電話をかける、または電子メールで連絡をとさせていただくかもしれません。

最長の場合、2回のインタビューと2回の手紙または電子メールで連絡をとさせていただくことになります。

録音させて頂いたインタビューは、インタビューの後期録音にさせていただきます。逐語録音の際、すべての内容はプライバシーの保護のため別の名前に変えさせていただきます。

この研究により私に得られると思われる利点は何ですか？
この研究は治療やあなたの健康増進のためにデザインされたものではありません。また、可能性としてあなたに不利益となることもあります。可能性としてあり得る不利益は次の2項で説明いたします。

この研究によりあり得る不利益や不敬意はどのようなものがありますか？
あなたのがんについて話すことにより、精神的なストレスや不安を感じる可能性があります。その程度ストレス、不安や傷つかしてしまうかは明らかではありません。もし、あなたがストレスを感じたり疲れたと感じた場合はいつでもインタビューを止めることができます。

もし、あなたが写真を撮ることに同意した場合、その写真が出版物に使われる場合がありますので、その場合あなたが特定されるかもしれないというリスクもあります。もし個人が特定されることが不快な場合は、写真をとることを拒否することができます。もし写真撮影を拒否された場合でも、研究協力は可能です。写真撮影許可は自由意志によるもので、オプションです。

研究者は全ての誠意を持ってあなたのプライバシーを守るよう努めますが、その可能性は極めて低くはありますが、常に守秘義務が破られる可能性として存在します。

誰がこの研究に参加していますか？
この研究には研究者が含みます。研究者は在籍の博士課程の学生であり、この研究はコロラド大学デンバー校看護学部のサポートを受け行っています。
私はこの研究協力により礼金を受けますか？
この研究では協力による礼金はありません。

私がこの研究協力のために支払わなければならないものはありますか？
あなたが、研究に協力したことにより支払わなければならないものはありません。

この研究協力は自由意志によるものですか？
この研究協力は完全に自由意志によるものです。あなたは研究を拒否する権利があります。もし、研究協力をお決めになった後でも、いつでも協力を辞められる権利があります。もし、協力をお辞めになった場合もあなたの得るべき利益や、あなたの持つ権利を損なうことは一切ありません。

質問がある場合誰に連絡すればいいですか？
この研究は朝倉
由記が行っております。どのようなことでも質問があればお聞きください。後に質問、思うこと、苦情などありましたら朝倉由記
(電話番号：)まで、ご連絡ください。説明の後、同意書のコピーをお渡しいたします。

あなたが後に、研究協力者としての権利について質問がある場合があるかもしれません。その場合は朝倉由記までご連絡ください。また、コロラド多施設協同倫理委員会 (Colorado Multiple Institutional Review Board: COMIRB) に電話+1(米国)-303-724-1055にご連絡いただいても結構です。

誰が、私が提供した情報を見ますか？
研究者はできる限りのことをしてあなたの情報に関して秘密を守るよう勤めます。しかし、これは保証されることはありません。
個人を特定される情報およびあなたの氏名を含むこの同意書はこのような人たちは見られる場合があります。

・人権を尊重した研究が行われているかを管理する政府の組織
・COMIRBの人たち（研究協力者の人権を保護するための倫理委員会）
・あなたが治療を受ける施設で研究がルールに沿って行われているかどうかを確認する役割にある人

研究者は会議の場でこの研究について話すことがあるかも知れません。また、研究者は関係者に研究結果を出版するかもしれません。常にあなたのような研究協力者の情報は公開いたしません。
この同意書は期限はありません。しかし、あなたはあなたが提供した情報の使用や発表についてのこの認可を撤回することができ、その場合、研究を続けるための情報としてすでに欠かせなくなった部分を除いて、研究者はこの研究のためにあなたが提供した情報を使用したり発表したりすることはできなくなります。

研究協力をやめることはできますか？
この研究への協力は全面的に自由意志によるもので、あなたはいつでも研究への協力を辞めることができます。また、もし研究者があなた安全性を案じる場合は、研究者の方からあなたの研究への協力を辞退することができます。

研究協力への同意

わたたくしは研究に関してのこの用紙を読みました。もしは読んでもらいました。私はこの研究について可能性のある利点と不利な点について理解しています。私はこの研究参加は自由意志であること

この研究への協力同意:

署名：________________________

氏名：________________________

写真を取ることへの許可（もし写真を撮ることに同意される場合にご署名ください）:

署名：________________________  日付：________________________

氏名：________________________

電子メールの許可（電子メールの交換に同意される場合はご署名ください）:

署名：________________________  日付：________________________

氏名：________________________

同意書について説明した者の署名：________________________  日付：________________________

氏名：________________________

研究者：__________________________  日付：________________________
APPENDIX F

ENGLISH INFORMED CONSENT
Consent Form

Date: ____________

Study Title:
Perception of Future and Advance Care Planning for Women with Early Stage Gynecological and Breast Cancer: a Transcultural Study between Japan and the US

Principal Investigator: Yuki Asakura
COMIRB No: 08-1369
Version Date: September 26, 2010 Version #: 3

You are being asked to be in a research study. This form provides you with information about the study. A researcher will describe this study to you and answer all of your questions. Please read the information below and ask questions about anything you don’t understand before deciding whether or not to take part.

Why is this study being done?

This study plans to learn about women’s perception and thoughts about their future after gynecological or breast cancer diagnosis. The researcher would especially like to learn about women who have early stage cancer.

You are being asked to be in this research study because of your diagnosis of early stage cancer and the researcher would like to listen to your story and your thoughts.

Other people in this study

Other people who would be in the study also have similar conditions that are early stage gynecological and breast cancer. Total number of participants will be up to 80. Women from other regions in Colorado and in Japan will participate in the study.

What happens if I join this study?

If you join the study, you will be asked to have 2 interviews. The first interview will be in person. The place of interview will be at your convenience and somewhere the researcher can protect your privacy. The researcher will talk with you about where you would like to have an interview. The purpose of study is to understand your perception and thoughts about your future, and there is no experimental procedure involved.

If you agree, the researcher will audio record the interviews. You can decline the audio-recording if you prefer. At any time, you can ask the researcher to delete the portion of the interview. Even if you decline for audio recording, you still can be in the study.

Page 1 of 4

Initials: _____
Consent Form

The researcher plans to interview each person two times. The second interview can be held through a telephone, a letter or an e-mail interview instead of an in-person interview if this is your choice. The interview will last approximately 30 min to 1 hour each. Your participation is voluntary and if you feel tired, we will stop the interview.

During the interview, the researcher may take pictures if you agree. The researcher will also provide scratch paper for you if you would like to draw to describe something in your mind.

At the end of the first interview, you will be asked if you would like to have the next interview in person, over telephone, or by sending a letter/e-mail.

If you selected a letter or e-mail interview, the researcher will send the interview question to you by letter or email and ask you to reply. If you choose to send a letter, the researcher will hand or send you a postage-paid envelope so that you can mail it. If you prefer, you may send an e-mail.

After receiving a letter or e-mail, the researcher may call you or send an email to clarify what you said.

Maximum contacts will be two interviews and two letter/e-mails.

The audio-recorded interviews are transcribed after the interviews. At the time of transcribing, all real names will be changed to other name to protect your privacy.

What are the possible benefits of the study?

This study was not designed to treat any illness or to improve your health. Also, there could be risks to being in this study. Possible risks are described in the next section.

What are the possible discomforts or risks?

Emotional distress and anxiety may result from taking about your cancer. The amount of possible distress, anxiety, or harm from this discussion is unknown. If you are distressed or tired, you can stop the interview at any time.

If you agree to take photographs, the photographs may be used in publication, and there is a risk that you may be identified. If you are not willing to be identified, you can refuse to take photographs. Even if you refused to take photographs, you still can be in the study. Agreement to taking photographs is voluntary and optional.

There is always some possibility that confidentiality could be lost, but the researcher will take all the effort to protect your privacy and the risk is minimal.

Who is paying for this study?

There is no outside funding for this research. The researcher is a PhD student in nursing, and the research is supported by the College of Nursing at the University of Colorado Denver.
Consent Form

Will I be paid for being in the study?

There is no payment for participation in this study.

Will I have to pay for anything?

There is no cost to you for participating in this study.

Is my participation voluntary?

Taking part in this study is fully voluntary. You have the right to choose not to take part in this study. Even if you choose to take part, you have the right to stop at any time. If you refuse or decide to withdraw later, you will not lose any benefits or rights to which you are entitled.

Who do I call if I have questions?

The researcher carrying out this study is Yuki Asakura. You may ask any questions you have now. If you have questions, concerns, or complaints, you may call Yuki Asakura at [insert phone number]. You will be given a copy of this form to keep.

You may have questions about your rights as someone in this study. You can call Yuki Asakura with questions. You can also call the Colorado Multiple Institutional Review Board (COMIRB) at 303-724-1055.

Who will see my research information?

The researcher will do everything we can to keep your records a secret. However, it cannot be guaranteed. Both the records that identify you and the consent form signed by you may be looked at by others. They are:

- Federal agencies that oversee human subject research
- People at the Colorado Multiple Institutional Review Board (COMIRB), which is an ethics review board to protect human participants
- Officials who are in charge of making sure that we follow all of the rules for research that are institution where you are receiving your treatment.

The researcher might talk about this research study at meetings. The researcher might also print the results of this research study in relevant journals but will always keep the names of the research participants, like you, private.

This authorization does not expire. However, you may withdraw this authorization for use and disclosure of information you provided, then the researcher will no longer
Consent Form

be able to use or disclose information you provided from this study, except so far as that they have already relied on this information to conduct the study.

Can I be removed from this study?

Participation of this study is fully voluntary, and you can withdraw from this study anytime. Also the researcher can stop your participation if the researcher has any concern for your safety.

Agreement to be in this study

I have read this paper about the study or it was read to me. I understand the possible risks and benefits of this study. I know that being in this study is voluntary. I choose to be in this study: I will get a copy of this consent form.

Consent to participate in the study:
Signature:______________________ Date:_______
Print Name:_____________________

Permission to take a picture (please sign if you agree to take photographs):
Signature:______________________ Date:_______
Print Name:_____________________

Permission to e-mail (please sign if you agree to exchange e-mails):
Signature:______________________ Date:_______
Print Name:_____________________

Consent form explained by:______________________ Date:_______
Print Name:_____________________

Investigator:______________________ Date:_______

Page 4 of 4

Initials____
APPENDIX G

INTERVIEW GUIDE
Interview Guide

I would like to ask you some questions about your life and your experience with your cancer. I also would like to hear about what you think about your future and thoughts about your possible situations in the future. I would like to learn from your personal stories and opinions to understand about being a situation like you are in to support people with cancer. What you think and how you feel about your life and your future is very important to learn about your experience, but individual identifiable information will not be disclosed to identify you when the research results are reported.

1. About your life and diagnosis
   a. Would you tell me how you were diagnosed? How did you find out about your cancer? What was your experience?
   b. Would you describe about your life before your diagnosis?
   How is your life changed after diagnosis?

2. About your future
   a. Are there any thoughts about people around you after diagnosis? What are they?
   b. What have you thought about your future?
   c. Have you talked about your experience and about your future?
   d. Have you heard about palliative care? What do you think palliative care is?
   e. Have you heard about advance directives or durable medical power of attorney? What do you think advance directives are?
      (If the participant never heard about AD or durable medical power of attorney or not sure what they are, some explanations are provided using Five Wishes ® developed by Aging With Dignity® appendix A & K. as standard material to provide basic idea about AD)
   f. Have you thought some issues discussed in Five Wishes before?
   g. Are you comfortable to think about the issues?
   h. Are you comfortable to discuss about these issues with someone else?
      Who was/would be a person you can talk with?
   i. What are your personal opinions on these questions asked in AD?

3. About the place you live and culture
   a. Are your thoughts are related with your life? How do you think it is related to your life?
   b. Would you describe the place you live?
   c. Does the culture have influence to your thoughts and decisions?
4. How you make decisions
   a. What would you think your decisions are influenced by?
   b. Have you had an experience to see someone at the end of life? What the experience made you think about end-of-life care or how you would like to be treated at the end-of-life?
   c. How you feel discussing about the topics like this when you are good enough to think?
APPENDIX H

ANALYSIS GUIDE BY LEININGER

### Fourth phase (Last phase)

**Major Themes, Research Findings, Theoretical Formulations and Recommendations**

This is the highest phase of data analysis, synthesis, and interpretation. It requires synthesis of thinking, configuration analysis, interpreting findings, and creative formulation from data of the previous phases. The researcher’s task is to abstract and confirm major themes, research findings, recommendations, and sometimes make new theoretical formulations.

### Third Phase

**Pattern and Contextual Analysis**

Data are scrutinized to discover saturations of idea and recurrent patterns of similar or different meanings, expressions, structural forms, interpretations, or explanations of data related to the domain of inquiry. Data are also examined to show patterning with respect to meaning-in-context and along with further credibility and confirmation of findings.

### Second Phase

**Identification and Categorization of Description and Components**

Data are coded and classified as related to the domain or inquiry and sometimes the questions under study. *Emic* or *etic* descriptors are studied within context and for similarities and differences. Recurrent components are studied for their meanings.

### First Phase

**Collecting, Describing, and Documenting Raw Data (Use of field Journal* and Computer)**

The researcher collects, describes, records, and begins to analyze data related to the purposes, domain of inquiry, or questions under study. This phase includes: recording interview data from *Key* and *general* informants; making observations, and having participatory experiences; identifying contextual meanings; making preliminary interpretations; identifying symbols; and recording data related to the DOI or phenomenon under study mainly from an *emic* focus. Attention to *etic* ideas is also recorded. Field data from the condensed and full field journal can be processed directly into the computer and coded, ready for analysis.
APPENDIX I

EXAMPLE OF CODING
APPENDIX J

CREDIBILITY LETTER FROM DR. MISUZU GREGG
January 16, 2013

Dear Yuki Asakura dissertation committee,

I am Misuzu Gregg, a professor at Kobe City College of Nursing in Japan. I am specialized in qualitative study, and I was asked to confirm the credibility of Yuki Asakura’s dissertation study. I have lived in Japan for 50 years and in the US for 5 years, and fluent in both Japanese and English.

I have found that Asakura’s interpretation of Japanese culture was appropriate and credible. She had to explain complex Japanese cultural phenomenon, and the analysis was carefully and profoundly done. All the translations placed for quotations by the participants were accurate as well.

As a future study, a transcultural comparison between Japan and US would contribute nursing science to understand patient’s perspectives further. I have found this study to contribute to development of nursing knowledge on Japanese women’s perspectives in advance care planning. Please contact me with any questions.

Sincerely,

Misuzu Gregg

Miszsu Gregg, PhD RN
Professor
Kobe City College of Nursing, Japan
m-gregg@tr.kobe-ecn.ac.jp
APPENDIX K

EXAMPLES OF CATEGORIES
<table>
<thead>
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<th>Name</th>
<th>Group</th>
<th>Description</th>
<th>Created</th>
<th>Modified</th>
<th>Families</th>
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<td>202</td>
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<td>05/11/20</td>
<td>05/37:09</td>
</tr>
<tr>
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<td>202</td>
<td>19/06/20</td>
<td>05/11/20</td>
<td>05/37:09</td>
</tr>
<tr>
<td>202</td>
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APPENDIX L

FIVE WISHES ® JAPANESE VERSION BY AGING WITH DIGNITY
AGING WITH DIGNITY

資料をご請求いただいた皆様へ

これからお読みいただくのは、あなたが重い病気をかかったとき、どうしてほかのかをお考えいただくための資料です。世界中に住む、様々な年齢の方が5つの願いを使用しています。あなたや、あなたの家族が重い病気をかかった前にこの資料をお読みいただき、5つの願いにご自分の意思をご記入ください。あなたの家族や人生、健康を尊重する簡単な手続きです。

手元には次の2種類の資料が用意されています。
1. 日本語に翻訳された「5つの願い」ガイドブック
2. 英語で書かれた「5つの願い」(Five Wishes)

まず、日本語に翻訳されたガイドブックをお読みください。これは「5つの願い」についての説明と考慮すべき意思決定の内容についての説明が記載されています。気のつく点を書き込んでから、読み進めてください。たとえば、Wish 1(願い)では、あなたが意思決定をできなくなる場合、あなたの代わりに意思決定をする人を決めなければなりません。日本語のガイドブックにその人の名前や他の実際の考慮を書き込んでおくと、後で英語版の「5つの願い」に記入するとき便利です。また、日本語のガイドブックは、ご自身の意思について家族と話し合う際にも役に立ちます。

**重要：必要事項を記入し、署名をしなければならないのは「5つの願い」の項目です。日本語のガイドブックは資料と締結内容を理解していただくための参考です。また、ヘルスケアの提供者のある方の意見を考慮してもらうために、記入は英語で行ってください。

英語版の「5つの願い」は日本語に翻訳されたガイドブックと同じ形式で書かれています。たとえば、日本語版のWish 1は、英語版のWish 1と同じ内容なので、日本語のガイドブックのWish 1に同じ内容を「5つの願い」のWish 1に書き込んでください。他の項目も同様に記入してください。よく分からない点はあらゆる人に相談してもらうことを望んでいます。署名するにあたり、締結を正確に把握することは大変重要です。

「5つの願い」にはあなたが自分の意思で意思を明確に記載するための箇所を設けています。「5つの願い」を完成させることは、これらの意思を実現するうえでの目指す英語で記入することが重要です。英語で記入する際には、書類の具合をよく翻訳の手助けを感謝していただきます。

Wish 1から5まで必要事項を記入したら、10ページの下に署名する区間に署名をし、日付も忘れずに記入してください。同時に、同ページにある承収人の署名欄には、1人の署名が必要です。さらに、特別な証人証を設けている州もあります。ガイドブックの署名欄に記載されている、注意事項をお読みください。

書類に署名をした後は、日本語ガイドブックの最後の方のページに記載されている「5つの願い」の記入を終えた後にすべきことは次の説明に従ってください。

この資料がガイドブックが、皆様のご参考になればと思います。「5つの願い」を完成させることは、あなたが希望し、あなたが望ましいケアを受けることを確認するものです。最後に、この場をお借りして、ご家族と話し合うために英語版の「5つの願い」が役に立つことを願っています。
5つの願い

私が意思決定をできなくなったときに、私に代わって意思決定をしてほしい人は。

私が受けたい、あるいは受けたくない医療行為は。

私が心地よく過ごせるようにするためにしてほしいことは。

私が常に求める介護やケアは。

私が愛する人々に知ってもらいたいことは。

[署名と生年月日を記入してください]
5つの願い

人生には、自分の手に負えない事がたくさんあります。この小冊子「5つの願い」は、「重い病気にかかった時にどのようにしてほしいのか」ということも大切な事情をコントロールするために、お使いいただけます。簡単に記入でき、希望する内容を確実に記述できます。必要事項を記入して署名された書類は、ほとんどの州で有効な文書として認められています。

「5つの願い」とは？

「5つの願い」とは、あなたの医療面での希望事項だけでなく、個人的な要望や感情面、精神面のニーズまで網羅した、最初のリビングウィル（生前遺言）です。自分で意思決定ができなくなった時に、あなたに代わって医療上の決断をする人を指名できます。重い病気にかかった時にどういう治療を受けたいか、確実に指定することができます。本小冊子は、米国法曹協会（The American Bar Association）の高齢者法律問題委員会（Commission on Law and Aging）および全米の終末期医療の専門家の協力を得て作成されました。チェックボックスに印をつけ、該当事項を○で囲んで、短い文章を書き加えるだけです。

「5つの願い」を使うことによるあなたとあなたの家族へのメリットは

- あなたが重い病気にかかった時にどのように対処してほしいかについて、家族や友人と話し合う機会が得られます。
- ご家族の皆様は、あなたが何をしてほしいのかを提案してまってほしいです。あなたが重い病気にかかった時に、あなたの本意がわからないままに難しい決断をしなくてよいので、家族を守ることにつながります。
- 5つの願いリビングウィルを通じて、ご両親、配偶者、友人が何を望んでいるのかを知ることができます。彼らが一番あなたを必要としている時にそこにいて、彼らが本当に望んでいることが何かを理解できるのです。

「5つの願い」の始まりは

ジム・トーウィという男性が12年におわたってマザーテレスの近くで仕事をし、1年間をマザーテレスがワシントンDCで過ごしていたホスピスで過ごしました。この直接の経験に触発されたトーウィ氏は、患者と家族が重い病気と戦う以前のより早い段階で計画をしておく方法はないと考えました。その結果生まれたのが「5つの願い」です。これは大反響を呼び、CNNの特集やNBCの「Today Show」、「Time」や「Money」などの雑誌でも取り上げられました。新聞は「『5つの願い』は、魂のこもった最初のリビングウィルである」と賞賛しました。
「5つの願い」は誰が使うべきですか

「5つの願い」は、既婚者、独身者、年齢、青年、友人を問わず、20歳以上の人全員を対象にしており、すでに800万人以上のアメリカ人が使用しています。「5つの願い」は大変使いやすく実用的におできており、弁護士、医者、病院関係者、宗教団体、退職者グループなどがこの小冊子を配布しています。

「5つの願い」を認知している州

リンピア特別区の住民は、認知している40州のいずれかにお住まいの場合、「5つの願い」は実質上州の法律要件を満たしていますので安心して使いいただけます。

アラスカ アイダホ ミズーリ ロードアイルランド
アリゾナ イリノイ モンタナ サウスカロライナ
アーカンソー アイオワ ノースダコタ サウスダコタ
カリフォルニア ルイジアナ ニュージャージー パーマント
コロラド メイン ニューヨーク デンバー
コネチカット マサチューセッツ ニューメキシコ バージニア
デラウェア ナイシン ノースカロライナ ワシントン
フロリダ ミシガン オクラホマ ウエストバージニア
ジョージア ミネソタ ウィスコンシン ワイオミング
ハワイ ミシシッピー ベンシルバニア ワイオミング

ここに記載されている40州以外の州にお住まいの場合は、「5つの願い」は居住州の法律要件を満たしていません。従って、これらの州の医師の多い州には、「5つの願い」の使用に消極的な人もいるかもしれません。しかし、このリストに記載されていない州でもたくさんの方が、その州の法定の書類とあわせて「5つの願い」を記入しています。「5つの願い」を使えば、希望する事柄をすべて記入することが可能、家族や友人、介護者、医師にとって「5つの願い」が役立つ指針となるからです。多くの医師や医療従事者は、どのような形で表現されたものであれ、あなたの意思に耳を傾けなければならないということを理解しています。

「5つの願い」に変更するには

すでに、リビングウィルや医療に関する永続的委任状を作成されているいらっしゃるかも知れません。作成済みの書類に代えて「5つの願い」をお使いになる場合は、「5つの願い」の指示に従って必要な事項をご記入の上、署名をしてください。署名と同時に「5つの願い」が、過去に作成された事前指示書に対して優先権を持ちます。間違いなく正しい書類が使用されるようにするために、以下を行ってください。

- 過去に作成したリビングウィルや医療に関する永続的委任状をすべて破棄するか、お手持ちのコピーに大きな字で「Revoked（取消し済み）」と書き、弁護士が過去の書類を作成した場合は、弁護士に連絡してください。さらに
- ヘルスケア代理人と家族および医師に「5つの願い」の記入を済ませた旨を連絡してください。あなたの新しい希望が何であるかを、よく理解してもらいたいです。
願い1

私が意思決定をできなくなったときに、私に代わる意思決定をしてほしい人は

私自分が医療に関する決定をできなくなった場合は、本書で指定する代理人が私に代わって医療に関する選択を行います。この人物は私のヘルスケア代理人（Health Care Agent，または私の居住する州で指定するProxy，Representative，またはSurrogate，いずれも代理人の意）。下記に記載されている人物が両方とも発生日の場合は、この人物が私の医療サービスに関する選択を行います。

- 私を担当または治療する医師が、私に医療サービスに関する選択を行う能力がないと判断した場合、そして
- 上記の医師とは別の医療専門家が、私には判断能力がないということに同意した場合。

もし、私の居住する州が、医療行為の判断能力の有無を判断するための別の基準や方策を設けている場合は、州の方策に従ってください。

ヘルスケア代理人（Health Care Agent）として私が指名する人物は

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もし、この人物が私のためにこれらの選択をすることができない場合、あるいは選択することを希望しない場合、または、私と離婚したか、法的に別居しているとみなされる場合、または、この人物が死亡した場合は、次の人物を指名します。

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ヘルスケア代理人として適格な人物を選ぶためには

あなたにことを知れていて、あなたのことを大切に考えており、困難な状況ができる人を選んでください。鉄面青の家族は、感情的な好みがあるために、適当な選択をしない場合もあり、最善の選択をする場合もあります。あなたがお知りのことを強く、鉄面青の前に選択できる人物を選びしてください。また、必要な時に援助が得られるように、身近な可能性が高い人物を選ぶことください。ヘルスケア代理人として候補者の家族、友人、いずれかを選ぶ場合にも、あなたの希望についてわかりやすく、その人物があなたの意思を尊重し、それに従うことを確認してください。ヘルスケア代理人は、18歳以上（コロラド州の場合は21歳以上）でなければならないません。また、次に指名する人物は代理人になりません。

- あなたが医療サービスを提供している医療機関・医療提供者（これには、あなたがサービスを提供している医療機関や介護施設、コミュニティケアの所有者や運営者なども含まれます）。
- あなたへの医療サービスを提供している医療機関の職員あるいはその宛去者。
- 10人以上の代理人（AgentまたはProxy）となっている人物。ただし、その人物が宛去者、または近親者の場合は除く。
私は、私のヘルスケア代理人が私のために医療上のの決定を下すことができると理解しています。私の代理人に次のことをできるようにしてください。

- 私のために、検査、投薬、手術などの医療ケアやサービスについての決定を行います。医療ケアやサービスには、私の健康上の問題が何であるのかを調べるための検査や、どのようにして治療するかといったことも含まれます。私の生命を維持するための措置もこれに含まれます。治療や医療ケアがすでに始まっている場合は、私のヘルスケア代理人はそれを継続するか、中断するかを決めることができます。
- 本書面で記載されている、あるいは、他の話し合いを通じて与えた私の指示を、私の意思や価値観についての理解に沿って解釈します。
- 私の病院、ホスピス、介護施設への入院や入所の手配に同意します。私のヘルスケア代理人は、必要な場合には私を助けるため、あるいは私の面倒を見るために必要なヘルスケアワーカーを雇うことができます。
- 人工的な方法を用いた水や栄養の補給や私の生命維持に必要なその他の治療を含め、治療の要求、中断、治療をしないなどの決断をします。
- 医療記録や個人ファイルなどに目を通し、その引き渡しを承認します。これらのファイルを入手するために私の署名が必要な場合は、私のヘルスケア代理人が代わりに署名することができます。

私が必要とする、または私の意思を尊重したケアが受けられるように、私を他の州に移します。

- 苦痛を和らげるために必要な投薬や治療すべてについて、承認または拒否します。
- 私の意思を尊重するために必要な法的措置をとります。

私の置き換えや組織で利用可能かつ合法的に提供できるものがあれば、これを提供します。

- 私のために、メディケア、メディケイド、その他のプログラムや保険の適用申請を行います。これらの書類の記入のために必要であれば、銀行口座などの個人ファイルを閲覧することができます。

次に記載するのは、ヘルスケア代理人の権限についての変更、追加、制限事項です。

ヘルスケア代理人について、私の考えを変えた場合は、次のことを実行します。

- 「5つの願い」のヘルスケア代理人についての記載やそのコピーをすべて破棄します。または
- 私の医師や家族など誰かに、ヘルスケア代理人を取り消したい、または変更したいと話します。または
- 権限を取り消したい代理人の名前のところに、「Revoked（取り消し済み）」と上書きし、そのページに私の署名をします。
願い2

私が受けたい、あるいは受けたくない医療行為

私の命を尊重であり、尊厳のある治療を受けるに値すると考えます。私が重い病気にかかり、
自分のために話をすることもはや不可能になった場合は、次のことを希望します。まで、
私がヘルスケア代理人に与えたこの他のすべての指示を尊重し守るようにしてください。

私の治療者・介護者として覚えておくべきことは

・私は苦痛を感じさせません。医師が
　痛みを緩和するために十分な量の薬を投
　与してくださいることを希望します。薬により、
　眠りが長くなり睡眠時間が長くなる。
　ような場合でも、十分な量を与えてく
　ださい。

・私は、医師や看護師が、私の生命を他
　目的で何かの措置を取ること、あるい
　は、何らかの措置を取ることを望んでい
　ません。

・私は食べ物や飲み物を口から与えてもら
　うこと、清潔で温かくしてもらうこと
　を希望します。

私が意味する「生命維持治療」とは

生命維持治療とは、私の生命を維持するための
　あらゆる医療措置や装置、投薬を意味します。
　生命維持治療において、呼吸を助けるために体内に
　挿入する装置、医療機器（栄養補給チューブ）
　を通じ供給される食物や水、心肺機能蘇生措置
　（CPR）、手術、輸血、透析、抗生物質、そ
　の他、生命の延命を目的とするすべての措置を含
　みます。宗教や信念上などの理由から、生命維
　持治療の意味を下げる場合は、次の余白に制
　約内容を記載します。これにより、私が何をどのよ
　うな状態の後に希望しているのかを明らかにす
　るためです。

緊急事態に備えて

医療上の緊急事態が起こり救急隊員が到
着すると、隊員はDo Not Resuscitate
（蘇生措置を行わないでください）とい
う書類をプレッシャーを捜すことがあ
ります。多くの州では、Do Not Resuscitate
の書類には本人が記入し、医師が署名す
ることが求められています。この書類が
　れば、あなたが死にかけている時には
　生命維持治療を望んでいないということ
　を救急隊員に知らせることができます。
　Do Not Resuscitateの書類の記入が必要か
　どうか医師に確認してください。
死期が近い時

私が短い時間内に死ぬ可能性が高いと私の医師および別の医療専門家の両者が判断し、生命維持治療は死期を遅らせるに過ぎないと判断した場合（下記のうち一つを選んでください）。

- 生命維持治療を希望します。
- 生命維持治療を希望しません。治療を開始した場合は中断してください。
- 生命維持治療が役に立つと私の医師が考えている場合は、生命維持治療を希望します。ただし、私の健康状態または症状の改善につながらない場合には、医師に治療を中断してもらうことを希望します。

昏睡状態に陥り、意識を取り戻したり回復する見込みがない場合

私が昏睡状態にあり、意識を取り戻したり回復したりする可能性がないと私の医師および別の医療専門家の両者が判断し、私の命が損なわれており、生命維持治療は死の瞬間を遅らせる効果しかないと判断した場合（下記のうち一つを選んでください）。

- 生命維持治療を希望します。
- 生命維持治療を希望しません。治療を開始した場合は中断してください。
- 生命維持治療が役に立つと私の医師が考えている場合は、生命維持治療を希望します。ただし、私の健康状態または症状の改善につながらない場合には、医師に治療を中断してもらうことを希望します。

生命維持治療を望まないその他の状況

生命維持治療を望まない別の状況がある場合は次に記載します。この状況下では、生命維持治療の高費用と重い負担のために治療を受ける価値があるとは思えません。（たとえば、ここに「終末期の条件（End Stage Condition）」について記載することができます。これにより、健康状態が悪化することを意味します。精神的にも肉体的にも自分で自分の命を守ることはできません。生命維持治療を回復にはつながりません。記載すべき条件がない場合は、この欄は空白にしてください。）
願い3

私が心地よく過ごすためにしてほしいことは
（同意しない内容がある場合は上から線を引いて消してください）

- 私は苦痛を感じたくありません。医師に
  痛みを軽減するために十分な量の薬を投与
  してもらうことを希望します。投薬に
  より、眠けが増したり顔の皮膚が長くなっ
  るような場合でも、十分な量を投与して
  ください。
- もし私が静虚気、怖い気、息切れ、幻覚
  のなどの兆候を示した場合、私の治療者や介
  護者が私に対してできる限りの処置を施
  すことを希望します。
- 熱がある場合には、冷たい、湿った布を
  陰に当ててください。
- 胸や口が苦しいように溼った息を与える
  ようにしてください。
- 頻繁に苦しいお風呂に入りたいと思います。
  いつも清潔でいられるようにしてください。
- できるだけ頻繁に、温かいお湯を使っ
  てマッサージしてください。
- 可能な場合には、いつも、死の瞬間まで私の
  好きな音楽を流してください。
- 私に苦痛や不快感を与えない範囲内で、
  視覚、聴覚、味覚のブラッシング、歯磨き
  をご指導ください。
- 死期が近づいた場合には、宗教書や人々か
  ら愛されている詩を出して読み聞か
  せてください。
- 私と私の愛する人々が、医療面や感情
  面、精神面でのケアが必要であるため
  になった場合には、ホスピスで受けられるケ
  アについて教えてください。

願い4

私が他人に求めめる介護やケアは
（同意しない内容がある場合は上から線を引いて消してください）

- 可能な場合には、人々が私と一緒にいる
  ようにしてください。いつか助けたくれる
  かもしれないと思う状況になったら、誰かに私と一緒にいてもらいたいと思
  います。
- 可能な場合には、私が人の声や手の感触
  に反応しないように見える場合でも、私
  の手を握って話しかけてください。
- 可能な場合には、他の人に私の側に座っ
  て私のためにお祈りをしてもらいたい
  です。
- 私が信仰をもとにする仲間に私が病気で
  あることを知らせ、私のためにお祈りを
  して私を見舞ってもらえるように伝えてく
  ださい。
- 悲しみながらではなく、明るく、やさし
  く私の面倒を見てください。
- 私の部屋のベッドの側に私の愛する人の
  写真を飾ってください。
- 自分で排尿や排便ができなくなった場合
  は、私の管理者やベッドリネンを清潔に保
  ち、汚れた場合にはできるだけ早く交換
  してください。
- 可能な場合は、自宅で死を迎えたいと思
  います。
願い

私が愛する人々に知ってもらいたいことは
（同意しない内容がある場合は上から線を引いて消してください）

・私の家族や友人に私が彼らを愛していたことを知ってもらいたいと思います。

・私が、家族や友人、その他の人々を傷つけたことを許してもらいたいと思います。

・家族や友人、その他の人々が私を傷つけたことがあったとなると、私が彼らのことを許しているということを知ってもらいたいと思います。

・家族や友人に、私が死を恐れておらず、死は終わりではなく新たな出発であると考えているということを知ってもらいたいと思います。

・もしできれば、私の死の前に、家族全員に伝えてもらいたいと思います。

・私は、家族や友人が、私が重病になる前にどんな様子だったか考えて、私の死後は病気になる前の私の姿を知ってもらいたいと思います。

・家族や友人、介護者が、私が希望することに同意しない場合でも、彼らに私の希望をかなえてもらいたいと思います。

・私は、家族や友人に対して、私の死を、私を含めた全員の成長の時として捉えてもらいたいと思います。それによって、私は最後まで意味のある人生を送ることができます。

・私の死で心を悩ませようなことがあれば、家族や友人にカウンセリングを受けてもらうたいと思います。私の記憶が彼らに悲しみをもたらすものではない、喜びをもたらすものであってほしいと思います。

・私の死後、私の体を（埋葬、火葬のいずれかに○）埋葬または火葬してください。

・私の遺体または遺服は次の場所に安置または埋葬してください。

・次の人物が私のことを知っています。

私のことを、どのようにして記憶にとどめておいてもらいたいかという質問があったら、私について、次のことをお伝えください。

私の葬式を出す場合は、次の事項を計画してください（音楽、唄、朗読その他、特別の希望などを記入）。

（その他の希望があれば、下記の余白に記入してください。たとえば、死後、体の一部、またはすべてを献体したいといった希望があればここに記入してください。余白が十分でない場合は別紙を添付してください。）
「5つの願い」の書類への署名

「5つの願い」の書類への署名は、必ず、二人の証人の前で行ってください。

例：私は、私の家族、医師、他の医療従事者、友人、その他のすべての人達が、私のヘルスケア代理（私を介護する指示を含む）をするよう私に指示することを承知です。私が何を希望するかを把握すべきであると思います。この書類は、私が自分で意思決定を行うか、自分を代行することが不可能になった時点で効力を持ちつづけます。この書類の一部が（どの部分かにかかわらず）不十分であると見なされる場合は、それ以外の記載すべてについて、私の希望をかなえられるように依頼します。また、本書類に記載した、すべてのヘルスケアに対する指示を破棄します。

署名:
住所:
電話番号:
日付:

証人の声明（証人は二人必要です）

私は、証人として、この書類に署名するかを提案した人物（これ以後「人物」と改称）を個人的に知っており、この人物が私の前まで、このヘルスケア代理およびリビングウィル書類（Health Care Agent and Living Will form）に署名し、また、彼または彼女が完全な精神状態にある、要領である。他の不適当な理由下にある者には見受けられなかったことをここに宣言します。

また、私の年齢は35歳以上であり、次の項目に該当しないことを宣言します。

- この文書が代理人、すなわちAgent/Proxy/Surrogate（Patient Advocate）として署名されている個人、または彼または彼女の家族者
- この人物が介護サービスを提供している医療機関・医療提供者（これらは、本人にサービスを提供している施設や施設の持株者や従業員など含まれます）
- この人物が医療サービスを提供している医療機関の職員

(州によっては、証人の資格についての規定が必要な場合もありますが、住所の州の規定をよくご確認ください。)

証人の1の署名
証人の1名前（居所体）
住所:
電話番号:

証人の2の署名
証人の2名前（居所体）
住所:
電話番号:

公証・ミズーリ州、ノースカロライナ州、サウスカロライナ州、ウエストバージニア州にお住まいの場合には公証が必要となります。

- ミズーリ州にお住まいの場合は、あなたの署名のみ公証が必要です。
- ノースカロライナ州、サウスカロライナ州、ウエストバージニア州にお住まいの場合は、あなたの署名および証人の署名の公証が必要です。

STATE OF ____________________
COUNTY OF ____________________
On this ______ day of __________, 20____, the above-mentioned ____________________, appeared before me, a Notary Public, within and for the State and County aforesaid, and acknowledged that they freely and voluntarily executed the same for the purposes stated therein.

My Commission Expires: ____________________

Notary Public
「5つの願い」の記入を終えた後にすべきこととは

- 本書の指示に従って証人が前で署名をし、証人の署名をもってください。これで完了すれば、「5つの願い」の希望は承認され、証人の署名をもってください。

- 家族その他、あなたのことを大切に思っている人々とあなたの希望について話をして、彼らに「5つの願い」のコピーを渡してください。

- 署名入りの原版を、ご自宅の特別な場所に保管してください。貸し金庫には預けず、必要に応じて誰かが見つけることができるように、身近な場所に保管してください。

- 下記の携帯用カードを記入し、いつも持ち歩くようにしてください。あなたご自身で「5つの願い」を保管しているかが、必要な場合にすぐにわかります。

ウィスコンシン州の住人は「5つの願い」にウィスコンシン州発行の通告声明文を添付する必要があります。
通告声明文の詳細は www.agingwithdignity.org を参照してください。

カリフォルニア州、コネチカット州、デラウェア州、ニュージャージー州、ニューヨーク州、ノースカロライナ州、バーモント州に所在がある施設の住人は特別の証人規則に従う必要があります。

上記に記載された州にある特定の施設（ナーシングホーム、その他の認可を受けた長期介護施設、自立した生活者用施設、または精神障害者用施設）で生活している場合、「5つの願い」が法的に効力を有するようにするために、特別の「証人要件」を満たす必要があります。詳細情報につきましては、お住まいの施設のソーシャルワーカーや患者アドバイザーにお問い合わせください。

「5つの願い」の目的は、あなたが将来に対して計画を立てることを手助けすることであり、法的な効力を有することではありません。起こり得るかもしれないすべての事態を想定してそれに回答することを意図しているわけではないからです。人は、みなそれぞれ異なっていますし、置かれている状況もそれぞれです。時間の流れに伴って法律は変わっていきます。具体的な問題や質問をお持ちの場合は、医療や法律の専門家にお相談ください。

「5つの願い」携帯用カード

Important Notice to Medical Personnel: I have a Five Wishes Advance Directive.

Signature 前名

Please consult this document and talk to your Healthcare Agent in an emergency. My Agent is:

物理療法士の名前、等の重要人物の名前を記入する事があります。

Signature 前名

Name: 番号
Address: カーターの住所
Phone: 電話番号

My primary care physician is: 純粋の医師の名前

Name: 番号
Address: 
Phone: 電話番号

My document is located at: ご自身の5つの願いの書類の場所を記入する

カードを切り抜き、安全に保管するために2つに折ってラミネート加工してください。
「5つの願い」に寄せられた声

母が亡くなって5年になります。母は、「5つの願いリピングウィル」を残していましたので、私たちは、母が何を望んでいるのかを知ることができました。母の最後の時が通過したとき、私たちは何をすべきかに明確に指摘されていたので、心の平穏を保つことができました。

Cheryl K.
フロリダ州

「5つの願い」は、すばらしいと思います。はっきりとわかりやすく書かれていますので、簡単に理解することができます。医療の具体的な問題についての詳細ではなく、本当の大切な人間としてのケアについて書かれています。自分自身のために、そして、主人のために「5つの願い」を使いました。

Susan W.
アリゾナ州

私の子供たちは、私が母のために行っているのと同じような決断をさせたくないと思います。これほどたくさんの医療の選択肢があるとは知りませんでした。このように細心の思いやりに満ちた書類のおかげで、私のすべては、書類に記入して子供達のために保護しておけだいのです。

Diana W.
イリノイ州

「5つの願い」は人々が重い病気になかかった時に受けたい医療行為に関する書類を立て、それが受けられるようにするための支援目的とした非営利団体、Aging with Dignityによって作成されました。 「5つの願い」の開発はThe Robert Wood Johnson Foundationからの寄付金によって実現しました。

Aging with Dignity
P.O. Box 1561
Tallahassee, Florida 32302-1561
www.agingwithdignity.org
1-888-394-7477

「5つの願い」の翻訳は下記の団体の支援により実現しました。

United Health Foundation
翻訳は、下記の専門翻訳サービス会社より提供されました。
Language Services Associates
APPENDIX M

WATSON'S TEN CARITAS PROCESSES
**Watson's ten caritas processes**

1. Sustaining Humanistic-altruistic Value by Practice of loving-kindness, compassion & equanimity with self/other.

2. Being Authentically present, enabling faith/hope/belief system; honoring subjective inner, life-world of self/other.

3. Being sensitive to self and others by cultivating own spiritual practices; beyond ego-self to transpersonal presence

4. Developing and sustaining loving, trusting-caring relationship

5. Allowing for expression of positive and negative feelings-authentically listening to another person's story.

6. Creating problem-solving-'solution-seeking' through caring process; full use of self and artistry of caring-healing practices via use of all ways of Knowing/Being/Doing/Becoming

7. Engaging in Transpersonal teaching and learning within context of caring relationship; staying within other's frame of reference-shift toward coaching model for expanded health/wellness.

8. Creating a healing environment at all levels; subtle environment for energetic authentic caring presence.

9. Reverentially assisting with basic needs as sacred acts, touching mindbodyspirit of spirit of other; sustaining human dignity.

10. Opening to spiritual, mystery, unknowns- Allowing for miracles.

(Watson Caring Science Institute International Caritas Consortium, 2011)