

**LIVING WITH DYING:
FROM THE PATIENT'S PERSPECTIVE**

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Dedication

I dedicate this dissertation to my father,

Paul Moses Kiyoshi Ono

(January 14, 1921 – April 11, 2009)

who inspired me to explore the meaning of the lived experience of dying

and the meaning of quality dying and

whose loving presence is with me always.

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Abstract

There are few descriptive studies on the experience of dying from the patient's perspective. The existing studies were conducted mostly on Caucasians, in the continental United States, or in other countries. Very little research has been conducted to explore the Pacific Islanders' perspectives on dying. Cultural differences may have an effect on the research results. The purpose of this research is to: (a) understand the lived experiences of residents in Hawai'i, with serious, progressive illnesses; (b) identify their values and preferences for the remainder of their lives; and (c) describe their ideas and beliefs of "good quality of dying."

The population consisted of nine terminally ill adult Asian/Pacific Islanders living in rural Hawai'i. After informed consent was obtained, data was collected through in-depth, face-to-face, open-ended interviews. The recordings of the interviews were transcribed verbatim. The data were examined for themes and concepts utilizing interpretive phenomenology.

The participant interviews resulted in rich descriptions of each individual experience framed within the context of the four existential life worlds (temporality, relationality, spaciality, and corporeality). Four distinct themes emerged: Higher Being or spirituality, family or healthcare provider support, symptom management, and mission and attitude. Cultural aspects were also examined.

Implications included: (a) Effective patient pain control and symptom management are essential for quality of dying, (b) Open communication and loving support of the patient are essential to the quality of dying, and (c) Cultural characteristics should be used only as guidelines for care.

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Chapter I. Exordium

Scope of Problem

Dying is one of the few things everyone has to face (Byock, 2012; Teno, Byock, & Field, 1999; Yedidia & MacGregor, 2001). Still, society is uncomfortable and unwilling to discuss dying openly (Byock, 2012). Dying has been described as a difficult event for both the dying person and his family (Byock, 2012; Teno et al., 1999). In the United States, nearly everyone who is asked wants to die at home, yet only approximately 20% die at home. The reality is that over 30% die in nursing homes and approximately 50% die in hospitals. In Hawai'i, only 29% of the population has executed living wills (Braun, Onaka, & Horiuchi, 2001), in which the person indicated whether or not he or she wanted life-sustaining measures in the event of an irreversible condition when one cannot speak for oneself. Thus, there may be a difference between the way an individual dies and how he or she had hoped to die.

Adams (1990) drew parallels between birth and death. Both are seen as transitions. In the past, birth was seen as a horrible, painful experience. In our culture, it was not until the advent of preparatory education about the birth process that birth became a celebration. With education and guidance throughout the childbirth experience, birthing became regarded as an exhilarating event. Can the death and dying process also become a positive experience?

Are there opportunities for personal growth when dying (Teno et al., 1999)? Is it possible that life and the dying experience can take on a new meaning? How can nurses improve end-of-life care? What do nurses need to know to support Asian/Pacific Islander

Americans (APIAs) on Kauaʻi through the dying process? These questions drove the need to explore the experience of dying for this study.

Statement of Problem

There are few descriptive studies on the experience of the dying (Kayser-Jones, 2002; Teno et al., 1999; Yedidia & MacGregor, 2001). With limited data, it is difficult for healthcare providers to support the dying patient and the family through this potentially positive experience.

Research Questions

What is the lived experience of dying APIAs on Kauaʻi? What are their values and preferences for the remainder of their lives? What is their perception of “good quality of dying”?

Purpose of the Study

The purpose of this research was to: (a) understand the meaning of the lived experience of dying as a consequence of serious, progressive illness for APIAs in Hawaiʻi; (b) identify the values and preferences of those who are dying with regard to care during their illness trajectory and the remainder of their lives; and (c) describe their ideas and beliefs of “good quality of dying.” With additional knowledge, healthcare providers may be able to assist in improving the quality of the dying experience or allowing the patient to die with dignity.

Definitions of Quality Dying and Death

The Committee on End-of-Life Care of the Institute of Medicine defined a quality death as “a death that is free from avoidable distress and suffering for patients, families, and their caregivers; in general accord with the patients’ and families’ wishes; and

reasonably consistent with clinical, cultural, and ethical standards” (Field & Cassel, 1997, p. 4). Madan (1992) defined dying with dignity as a holistic paradigm incorporating cultural values, individual autonomy, and familial responsibility. Madan further described the loss of dignity as loss of autonomy and being under the control of others with a loss of self-assessment, expression, and choice. Patrick, Engelberg, and Curtis (2001) defined quality dying as “the degree to which a person’s preferences for dying and the moment of death agree with observations of how the person actually died” (p. 717) and a “personal evaluation of the dying experience as a whole, including a subjective evaluation of concepts according to expectations and values” (p.718).

Comparative and surrogate terms. Throughout the literature, many terms are utilized to connote quality dying and death: peaceful death; quality end-of-life closure; quality of life; quality care at the end of life; good death; dying well; and dying with dignity. They are similar but have subtle differences. Some look only at quality of life/wellness, or at one component such as pain, the care, or the moment of death and are not all-encompassing as quality dying and death. The terms may all be components of quality dying and death.

In 2000, the American Association of Colleges of Nursing (AACN) and the City of Hope (COH) National Medical Center defined a peaceful death as “addressing all the dimensions of quality of life (QOL) that creates the opportunity to experience tremendous growth and healing even when facing death or witnessing the death of a loved one” (p. M1-14). In a 1997 project, the AACN described the knowledge and competencies needed of nurses to provide a “peaceful death.” Both Matzo’s and Sherman’s book (2001) and AACN’s document describe what nurses or healthcare providers can do for

the patients or their families to make them more comfortable. Peaceful death was essentially equated with comfortable death.

Quality end-of-life closure refers to the positive experiences in the face of suffering. Patients and families can find meaning and reach personal goals prior to and after the death of a family member (Egan & Labyak, 2001).

Quality of life (QOL) includes all dimensions of a person's life: the physical, emotional, spiritual, and social (AACN & COH National Medical Center, 2000). Venes and Thomas (2001) defined quality of life as "the worth, meaning, or satisfaction obtained from living . . . may evolve over time" (p. 1812). Quality of life is "a measure of the optimum energy or force that endows a person with the power to cope successfully with the full range of challenges . . . regardless of illness" (Anderson, 1994, p. 1319). This phrase is most often linked with living. When used with dying, most times a descriptor is added such as "quality of life at the end of life."

Quality care at the end of life is sometimes used interchangeably with quality dying and death. In their book, Matzo and Sherman (2001) provided practice guidelines to achieve quality care at the end of life. Patrick et al. (2001) distinguished quality care at the end of life (EOL) from quality dying and death. "Quality of life emphasizes activities and experiences while living with a life-threatening or terminal illness, and the quality dying emphasizes experience of preparing for, facing, and experiencing death itself" (p. 718).

Often the phrase *good death* is used in the literature to describe the goal of terminal care. It has the disadvantage of connoting something that is static and formulaic. Moreover, while a good death depends on the perspective of the individual, common

criteria include: (a) the patient was free from pain and other distressing symptoms; (b) adequate time was spent addressing important patient or family concerns in order to achieve quality EOL closure; (c) all possible treatments aimed at curing the illness were exhausted; (d) the patient died at home surrounded by family and friends; (e) the patient was able to live long enough to finish unfinished business; and (f) the patient lived long enough to witness a particular event, e.g., a birth or a graduation (AACN & COH National Medical Center, 2000).

The phrase *dying well* describes the positive end-of-life experience that people desire (Byock, 1996).

[It is the] subjective experience of personal growth, embodying a sense of renewed (at times enhanced) meaning and a sense of completion, at times even fulfillment in life. Personal growth is rarely easy at any stage of life, and a growthful dying may actually be difficult. It probably must entail a measure of suffering. The touchstone of dying well -- the sense of growing in the midst of dying -- is for the experience to be important, valuable and meaningful for the person and their family. (pp. M1-75)

Webster (1988) defines *dignity* as “the quality or state of being excellent, worthy, honored, or esteemed” (p. 354). Madan (1992) defined *dying with dignity* as a holistic paradigm incorporating cultural values, individual autonomy, and familial responsibility. Madan described the loss of dignity to be due to the healthcare professionals’ control of the dying person, loss of self-assessment, expression, and choice. For Filipinos, “a dignified death commonly meant a peaceful death free from pain and not being burdensome to others” (Yeo & Hikoyeda, 2000, p. 112). Frankl (1984) believed that

while the patient loses autonomy and independence, dignity is preserved if the patient retains the freedom to choose one's outlook on life and to search for meaning. In 1959, Victor Frankl (1984), a psychotherapist and concentration camp survivor wrote:

We must never forget that we may also find meaning in life even when confronted with a hopeless situation, when facing a fate that cannot be changed. . . . When we are no longer able to change a situation . . . we are challenged to change ourselves. (p. 135)

Summary

Death is an inevitable event, though many fear death and avoid discussing it. The meaning of quality of dying or dying with dignity is different for each person. As a healthcare provider, the researcher believes that the phrase coined by Patrick et al. (2001), “quality of dying and death,” and its definition are the most encompassing and, ultimately, the most important in the dying person’s self-evaluation. This research explored the perception of “good quality of dying” from the perspective of APIAs in Hawai‘i who were dying as a consequence of a serious, progressive illness. In Chapter I, the scope of problem, statement of the problem, and the purpose of the study were presented. Chapter II describes the literature review on quality dying.

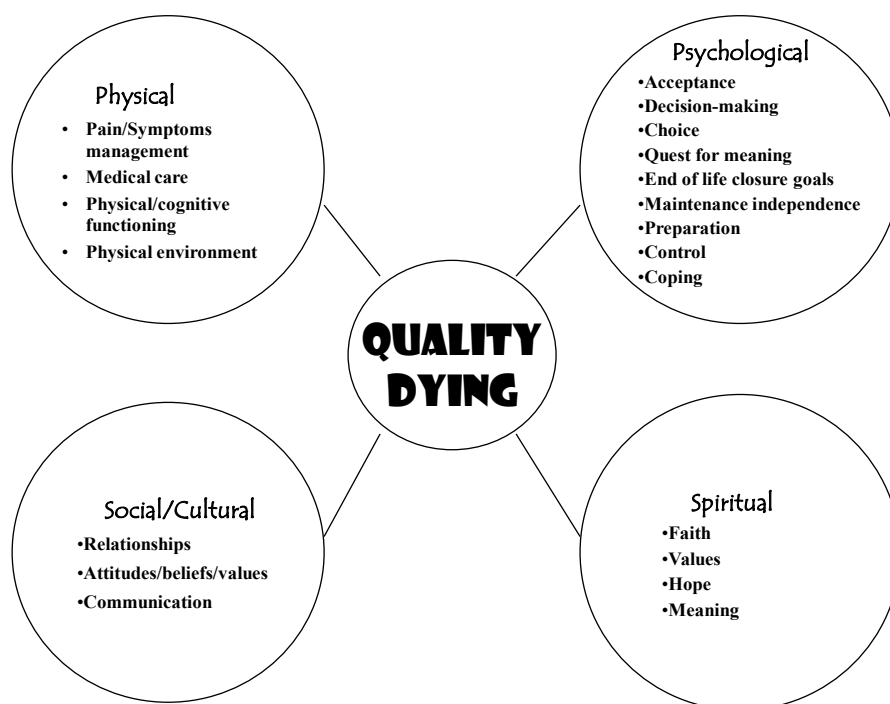
Chapter II. Review of Literature

A systematic review of the literature was conducted using the EBSCO HOST search engine and the Academic Search Premier, Health Source – Consumer Edition; Health Source: Nursing/Academic Edition, Alt HealthWatch, CINAHL, MEDLINE, Pre-CINAHL, Psychology and Behavioral Sciences Collection, and Religion and Philosophy Collection databases. Utilizing key words, “death” and “quality,” yielded 19,046 results. The keyword “death” was interchanged with “death and dying” and “terminally ill.” These keywords were linked with “acceptance,” “attitude,” “spirituality,” and “culture,” with and without another keyword, “perspective.” “Dignity” as a keyword yielded fewer articles but the same ones as the term “quality” did and, thus, was eliminated from the search. Journals on health, psychology and behavioral sciences, religion, and philosophy were included in the search due to the nature of the topic. To retrieve as much information as possible, the time frame option in the search was not utilized. Where applicable, the search was limited to review or research articles, and/or peer-reviewed journals. Not all databases had these options. Through the “snowballing” technique, additional resources including books and presentations were obtained.

Using these techniques, 2,943 articles were listed. Articles from non-peer-reviewed journals that did not deal with quality of dying, the dying process, or the dying persons’ or their families’ perspectives were excluded. Preliminary elimination, using these exclusion criteria while scanning the abstracts, yielded 130 articles. After reading the articles, an additional 99 articles were eliminated because they were irrelevant. The remaining 31 articles have been included in the literature review.

The synthesis of the literature reviewed will be discussed in the context of four major categories: physical, psychological, spiritual, and social/cultural (Figure 1). The physical domain includes pain/symptom management, medical care, physical/cognitive functioning, and physical environment; the psychological domain involves acceptance, decision-making, quest for meaning, end-of-life closure goals, maintenance of independence, preparation, control, and coping; the spiritual realm contains faith, values, meaning, and hope; and the social and cultural realm deals with relationships, attitudes, beliefs, values, and communication. The dying individual's physical, psychological, spiritual, and social/cultural values and beliefs shape the whole perspective of quality (see Figure 1). Instruments used that try to capture the patients' perspectives will also be discussed.

Figure 1. Concept of Quality Dying



Physical Attribute

In the physical domain, a common theme was the dying patients' need for control over pain and symptom management (Cohen & Leis, 2002; Espinoza Venegas & Sanhueza Alvarado, 2010; Goodridge, Duggleby, Gjevre, & Rennie, 2009; Johnston & Smith, 2006; Pierson, Curtis, & Patrick, 2002; Singer, Martin, & Kelner, 1999; Steinhauser, Clipp, et al., 2000; Tanaka, Iwamoto, Kaneyasu & Petrini, 1999). A focus group of Canadian cancer patients was asked what was important to their quality of life (Cohen & Leis, 2002). Three "physical" determinants were identified: the patient's physical and cognitive functioning; quality of palliative care; and the physical environment. Johnston and Smith (2006) interviewed 22 registered nurses and 22 dying patients over a 5 year period in Scotland. The patients were asked about their care and the nurses were asked about palliative care. Their answers were compared. Both the patients and the nurses acknowledged the importance and desire to have the patients' needs met, especially for comfort. Symptom control was only mentioned by the nurses. In the interviews of 35 patients with Acquired Immunodeficiency Disease, 29 patients identified symptom control and five identified quality medical care as components of a "good death" (Pierson et al., 2002). In the 1999 study of 126 patients on renal dialysis, with human immunodeficiency or who resided in a long-term care facility, Singer and colleagues (1999) discovered that 22.5% identified adequate pain and symptom management as important for quality care. This component was also cited by many of the focus group participants, which consisted of healthcare providers, patients, hospice volunteers, and bereaved family members (Steinhauser, Clipp, et al., 2000), and by the eight terminally ill patients in Japan (Tanaka et al., 1999).

Psychological Attribute

Yedidia and MacGregor's (2001) qualitative study utilizing an ethnographic approach involved serial, in-depth, semi-structured interviews of 30 dying patients. The researchers identified the emotional patterns in the dying experience including: struggle, dissonance, endurance, coping, incorporation, and volatility. Wilson's (2000) grounded theory study of 49 senior citizens' preferences for end of life care was conducted in Canada. The participants believed they would be dependent when dying and worried if they would receive the appropriate end-of-life care to meet their basic needs. The patients' distress scores, as measured by a tool developed by Jones, King, Tookman, and Walsh (2000), increased as death approached. Distress from death and dying was closely related to health status, especially mental health status (Sullivan, Ormel, Kempen, & Tymstra, 1998). Distress was also related to the fears of death and dying.

Achieving a sense of control over medical care (Pierson et al., 2002; Singer et al., 1999) and maintaining the power to make decisions (Fowler, Coppola, & Teno, 1999; Kelner, 1995; Steinhäuser et al., 2001; Steinhäuser, Clipp, et al., 2000) were very important. Kelner (1995) interviewed 38 hospitalized elderly patients and found that 71% of them wanted a voice in the decision making about their care, while 29% wanted to delegate that responsibility to other family members or to the physician.

Johnston and Smith (2006) conducted a phenomenological study with 22 nurses and 22 dying patients regarding their perceptions of expert palliative nursing care. Key themes for the patients were connecting, being in control, and meeting their needs. Maintaining independence was also important. Madan (1992) also described loss of

autonomy, being under other professionals' control, and loss of self-assessment, expression, and choice as loss of dignity.

As the patient approaches death, most individuals strive to complete certain aspects of life, a process that is called life closure. Stages and tasks of life closure are highly variable, usually do not occur in a linear fashion, and affect all dimensions of quality of life (AACN & COH National Medical Center, 2000; Byock, 1996; Espinoza Venegas & Sanhueza Alvarado, 2010; Molzahn et al., 2012; Pierson et al., 2002; Steinhauser et al., 2001; Steinhauser, Clipp, et al., 2000). Life closure involves self-examination, both from the broader, world perspective (the outer perspective) and the inner perspective. This outer perspective includes: sense of completion with worldly affairs; sense of completion with community; sense of meaning about one's individual life; experiencing love of self; and experiencing the love of others. The inner perspective includes: sense of completion in relationships with family and friends; acceptance of the finality of life— of one's existence as an individual; new self (personhood) beyond personal loss; meaning about life in general; surrender to the transcendent, to the unknown; and "letting go." Preparation for death or the dying process was also evident.

During life closure, patients and families are given the opportunity to find meaning through life review and working toward the accomplishment of personal goals. Many find meaning and growth as they explore their relationship with others and with God (AACN & COH National Medical Center, 2000). Suffering is not a prerequisite to finding meaning in life, but it is possible to find meaning in spite of suffering. Finding meaning and purpose to one's life added to quality dying (Espinoza Venegas & Sanhueza Alvarado, 2010).

Another theme of the dying process was acceptance (Fowler et al., 1999; Hinton, 1999; Molzahn et al., 2012; Pierson et al., 2002). “Acceptance of death and the dying process as a natural part of the life cycle is one of the first steps in learning how to view death as an achievement instead of failure” (AACN & COH National Medical Center, 2000, pp. M1-15). Hinton (1999) conducted a study utilizing semi-structured interviews regarding awareness and the progression of acceptance of 76 dying cancer patients and their relatives caring for them. Acceptance was described in terms of inevitability, faith and spiritual values, life’s diminishing rewards, completing life, final benefits, humor, and sharing. Example phrases describing these terms included (Hinton, 1999, pp. 31-32): “If I’ve to go, I’ve to go!” and “You’ve got to come to terms with these things, it’s no use running away from them” (inevitability); “The Lord said it’s my time” and “It’s in God’s hands” (faith and spiritual values); “You sort of give up” and “I don’t want to live if I’m a burden to others” (life’s diminishing rewards); “I’ve enjoyed life” and “I’ve had a life of happy service and no cause to complain” (completing life); “I think of every day as a bonus” and “I was lucky to have Christmas” (final benefits); “I’m overdue already -- that treatment at hospital must have been better than they thought” and “I’ll get measured up by the undertaker – well you must have a laugh even at these things” (humor); and “We’re in the same boat like” and “Not so much more to say about it – I may lie beside him for a little while and just hold his hand” (sharing).

Although these phrases may indicate movement towards acceptance, this supposition may not always be accurate. Some of these statements may have been made to lighten the seriousness of the conversation of dying. This may be done to spare or

protect the friends and family from the harshness of the ultimate end or to assist them in coping.

Spiritual Attribute

Several studies have shown that spirituality contributes to the quality of life (Fryback & Reinert, 1999; Georgesen & Dungan, 1996; Steinhauser, Clipp, et al., 2000). Reed (1987) administered the Spiritual Perspective Scale and the Index of Well-Being to 300 adults. The analysis supported Reed's hypothesis that terminally ill hospitalized adults had a greater spiritual perspective than non-terminally ill hospitalized or healthy non-hospitalized clients. The spiritual perspective was positively related to the well-being in terminally-ill hospitalized patients. Fryback's and Reinert's (1999) qualitative study of 10 women with cancer and five men with HIV or AIDS also suggested that spirituality is an important component of feelings of health and well-being. Georgesen and Dungan (1996) described four case studies of people with advanced cancer pain based on the Dungan Model of Dynamic Integration. The Dungan Model viewed individuals in three dimensions: body, mind, and spirit. Individuals needed to incorporate their experiences into these three dimensions to maintain harmony and balance. When a dimension is disturbed, the wholeness and harmony of the individual is affected. Integration may contribute to personal growth and optimal functioning. Nursing interventions can facilitate dynamic integration and healing. In the four case studies, hope and quality of life increased with interventions managing spiritual distress, e.g., grief and spiritual counseling, crisis intervention, cognitive reappraisal, reminiscence therapy, presence, and active listening.

With the realization of an illness being terminal, hope shifts from that of cure to one in which individuals strive to reach personal end-of-life closure goals. Despite the realization that the patient will die, many people, including families, do find new ways to hope (Ersek, 2001).

Many dying people search for a meaning to their life (Yedidia & MacGregor, 2001). Fryback and Reinert (1999) found that people who found meaning in their disease thought they had a better quality of life because of it. Marrone (1999) believed the quest for meaning was more important than finding it. Fear or threat of death contributed to looking for meaning (Holcomb, Neimeyer, & Moore, 1993).

Social/Cultural Attribute

For the dying, spending time with family was important (Espinoza Venegas & Sanhueza Alvarado, 2010). Strengthening or mending relationships was important (Cohen & Leis, 2002; Fowler et al., 1999; Pierson et al., 2002; Singer et al., 1999; Tanaka et al., 1999). Many found meaning and growth as they explored their relationship with others and with God (AACN & COH National Medical Center, 2000). In Ryan's (2005) phenomenologic research with five older adults with advanced cancer, positive social involvement was meaningful. Ryan concluded that the genuine caring and honesty from the healthcare providers; involvement in life activities; and positive interactions with loved ones and the healthcare system were important.

Connecting with someone with whom to talk, who would listen, and who would know them, was important to the dying patients (Johnston & Smith, 2006).

Communication with the healthcare provider is also important (Steinhauser et al., 2001; Steinhauser, Clipp, et al., 2000). Unfortunately, Biola and colleagues (2007) found that

of 440 family caregivers of the dying, 39.9% disagreed that they were informed or received preparatory information (49.8%), or even understood the physician (43.1%).

Nishimoto and Foley's article (2001) focused on the cultural needs of terminally ill individuals, gathering information from research, book chapters, review articles, and clinical practice. Culturally appropriate interventions had an impact on the dying process. Meeting the cultural needs of terminally ill patients improved their quality of life and death (Nishimoto & Foley, 2001). Most studies reviewed on the dying patient's perspective in the literature review did not include APIAs, who are the predominant ethnic group in Hawai'i; or did not specifically mention ethnic groups of participants (Cohen & Leis, 2002; Hinton, 1999; Holcomb et al., 1993; Pierson et al., 2002; Steinhauser, Christakis, et al., 2000; Yedidia & MacGregor, 2001); or included very few APIAs (Steinhauser, Clipp, et al., 2000). Studies that included Asian/Pacific Islander groups were done outside of the United States (Ringdal & Ringdal, 2000; Singer et al., 1999; Tanaka et al., 1999; Wilson, 2000). One study done in the U.S. that did incorporate a significant percentage of APIAs was Kayser-Jones' 2002 ethnographic study of the death experience in a nursing home. The researchers interviewed 35 nursing home residents, their families (n=52), nursing staff (n=66), and physicians (n=36) and observed the care of 117 terminally ill residents. The residents in the study included 28% Chinese and 5% Filipinos. Kayser-Jones noted that there was a lack of attention to cultural needs that influenced the experience of dying.

Since there is little research that has explored the perspective of the dying APIAs, studies of cultural differences related to end-of-life issues in non-dying APIAs were examined. According to Yeo and Hikoyeda (2000), APIAs have several beliefs and

expectations that may potentially affect end-of-life care and decision-making. Family decision-making is the norm and withholding disclosure of terminal illness from the elder may be done to protect him or her from depressing news. For some Native Hawaiians, “Talking about death . . . is taboo (and) therefore, executing advanced directives can become problematic” (Yeo & Hikoyeda, 2000, p. 103). For APIAs prolonging life is desirable over quality of life and they are more likely to desire initiating life support than Caucasians (Yeo & Hikoyeda, 2000). Cultural rituals of the care of the dying person or the body may interfere with the hospital routine.

According to Yeo and Hikoyeda (2000), Filipinos believe that disease is the “will of God” or is affected by “good or evil spirits.”

[They have a] strong reliance on the family as decision-makers in case of illness, strong expectations of care by the family, and a culturally based practice of indirect communication to avoid stressful interpersonal conflicts and confrontations. . . . Their definitions of a dignified death commonly meant a peaceful death free from pain and not being burdensome to others. (p. 112)

Yeo and Hikoyeda (2000) also report that the Japanese culture emphasizes: filial piety; strict self-discipline and self-restraint or stoicism (e.g., not complaining of pain so as not to upset others); obligation toward the family and Japanese community that share a family member’s shame, guilt, or humiliation; quiet forbearance and endurance due to a sense of fatalism; and deferential behavior, modesty, or reticence, particularly in the presence of those in positions of authority (e.g., physicians). (p. 112)

Braun's quantitative survey (1998) among five ethnic groups in Hawai'i in 1998 included 50 Native Hawaiians, 50 Filipinos, 49 Japanese, 48 Caucasians, and 48 Chinese. Overall, 89% agreed that fear of being dependent on others would affect decisions about medical care, and 79% agreed that fear of burdening their families would influence their decisions. There were cultural differences. The majority of both the Japanese and Filipinos (90% each) believe their decisions would be influenced if they were a burden to their families, compared to 60% of Chinese and Hawaiians and 79% of the Caucasians (Braun, 1998). Similarly, approximately 90% of the Filipinos and Japanese believed that being dependent would influence their medical treatment decisions, compared to 56-81% of other groups (Braun, 1998). Native Hawaiians favored a collaborative decision-making model rather than the autonomy model. Even though discussing death is taboo, many Native Hawaiians do make their wishes about after-death care known to their loved ones (Yeo & Hikoyeda, 2000; Nichols & Braun, 1996). Although approximately 92% of the participants knew about living wills, only 42-65% had living wills. Sixty five percent of the Caucasian participants had living wills compared to only 44% of the Native Hawaiians. Although many older Japanese Americans expected that decisions regarding end-of-life care would be made by a family member or their physicians, very few actually expressed their desires to their loved ones or their physicians (Yeo & Hikoyeda, 2000).

While cultural variations in beliefs, expectations in medical care, end-of-life care, and decision making are evident and affect quality of dying, most studies have predominantly included Caucasians, or have been conducted in foreign countries. More studies are needed with other ethnic minority populations in the United States.

Instrument Evaluation

Some studies evaluated instruments that measure quality of dying (Byock & Merriman, 1998; Cheng et al, 2008; Curtis, Patrick, Engelberg, Norris, Asp, & Byock, 2002; Downey, Curtis, Lafferty, Herting, & Engelberg, 2010; Mayland, Williams, & Ellershaw, 2011; Munn et al., 2007; Schwartz, Merriman, Reed, Byock, et al., 2000; Steinhauser, Clipp, & Tulsky, 2002; Teno et al., 1999; van Soest-Poortvliet et al., 2011; Wittkowski, 2001). Many instruments focused on the family's or healthcare providers' perceptions rather than the patient's perspective. Table 1 lists the instruments measuring end of life care or quality of dying from the surrogates' perspectives. Most instruments required completion post-death and the interval from the time of death to the interview was as long as three years. The instruments required recall of the last three days or up to the last 90 days of life. As a result, families had difficulty remembering details and conversations. There were also concerns about concordance between the respondents. Concordance of scores were low between family and healthcare providers in the Quality of Death and Dying and between nurse and physician in EOL in Dementia Comfort Assessment in Dying. Yet, in the study using the Good Death Scale, there was a high concordance between the hospice team and the families in the evaluation of the death.

Table 1. End of Life Instruments: From the Surrogate's Perspective

Instrument	Literature	Population	Timing	Strengths	Weaknesses
EOL in Dementia Comfort Assessment in Dying	van Soest-Poortvliet et al., 2011	<ul style="list-style-type: none"> • Developed for dementia patients in nursing homes, hospitals, and personal homes • Completed by professional caregivers and families 	<ul style="list-style-type: none"> • Post-death 	<ul style="list-style-type: none"> • Good fit with pre-assumed factor structures • Appeared to be most valid and reliable for measuring quality of dying 	<ul style="list-style-type: none"> • Retrospective rating of the nurses were significantly different from the prospective physicians' ratings
EOL in Dementia Satisfaction with Care	van Soest-Poortvliet et al., 2011	<ul style="list-style-type: none"> • After death assessment by families 	<ul style="list-style-type: none"> • Post-death, also used pre-death 	<ul style="list-style-type: none"> • Appeared to be most valid and reliable for measuring quality of care 	<ul style="list-style-type: none"> • Only 10 items measuring satisfaction with care
EOL in Dementia Symptom Management	van Soest-Poortvliet et al., 2011	<ul style="list-style-type: none"> • Developed for dementia patients • Completed by professional caregivers and families 	<ul style="list-style-type: none"> • Post-death, also used pre-death 		<ul style="list-style-type: none"> • Only addressed perceptions of physical and emotional symptoms
Evaluating Care and Health Outcomes – for the Dying	Mayland, et al., 2011	<ul style="list-style-type: none"> • Families evaluated quality of care during the last days of life 	<ul style="list-style-type: none"> • Post-death 	<ul style="list-style-type: none"> • Pilot showed moderate or good stability for 13 out of 17 key questions • Multidimensional instrument 	<ul style="list-style-type: none"> • Tested in hospice and acute care hospital settings • Time lapse of up to 18 months post-death resulting in difficulty remembering certain details or conversations • Tested on an all Caucasian sample
Family Assessment of Treatment at the EOL Short version	van Soest-Poortvliet et al., 2011	<ul style="list-style-type: none"> • Families' perceptions of outcomes of care 	<ul style="list-style-type: none"> • Post-death 	<ul style="list-style-type: none"> • Used in wide variety of settings: nursing homes, private homes, hospitals, intensive care units, inpatient hospice unit 	

Instrument	Literature	Population	Timing	Strengths	Weaknesses
Family Perception of Care Scale	van Soest-Poortvliet et al., 2011	<ul style="list-style-type: none"> Families' perception of care, support, communication, and rooming 	<ul style="list-style-type: none"> Post-death 	<ul style="list-style-type: none"> Appeared to be most valid and reliable for measuring quality of care 	<ul style="list-style-type: none"> Used only in long-term care settings
Family Perception of Physician-Family Caregiver Communication	van Soest-Poortvliet et al., 2011	<ul style="list-style-type: none"> Families' perception of physician communication 	<ul style="list-style-type: none"> Post-death 		<ul style="list-style-type: none"> Used only in nursing homes and assisted living settings
Good Death Scale	Cheng et al., 2008	<ul style="list-style-type: none"> Healthcare providers and families 	<ul style="list-style-type: none"> Post-death 	<ul style="list-style-type: none"> High concordance of the evaluation between hospice care team and families 	<ul style="list-style-type: none"> Surrogate evaluation may not be indicative of the patients' feelings
Mini-suffering State Examination	van Soest-Poortvliet et al., 2011	<ul style="list-style-type: none"> Patients with dementia Completed by healthcare providers and families 	<ul style="list-style-type: none"> Pre-death 	<ul style="list-style-type: none"> Used in a variety of settings: nursing homes, geriatric departments, hospital, and hospice 	<ul style="list-style-type: none"> Consisted of only 10 items, measuring amount of suffering
Minimum Data Set-Palliative Care	van Soest-Poortvliet et al., 2011	<ul style="list-style-type: none"> Assessment by professional caregivers 	<ul style="list-style-type: none"> Pre-death 	<ul style="list-style-type: none"> Variety of settings: nursing homes, residential homes, home care, hospital, and hospice 	
Palliative Care Outcome Scale	van Soest-Poortvliet et al., 2011	<ul style="list-style-type: none"> Developed for cancer patients Completed by professional caregivers and families 	<ul style="list-style-type: none"> Pre-death 	<ul style="list-style-type: none"> Able to use for cognitively impaired patients Measured physical, psychological, and spiritual domains 	<ul style="list-style-type: none"> Used only in nursing homes and palliative care settings
Quality of Death and Dying	Curtis et al., 2002; Downey, et al., 2010; van Soest-Poortvliet et al., 2011	<ul style="list-style-type: none"> Family and friends of the deceased and a few healthcare providers rating QOL in the last seven days of life 	<ul style="list-style-type: none"> Post-death 	<ul style="list-style-type: none"> Respondents' values were addressed and weighted Moderate to high correlation with overall assessments of quality of care and quality of dying 	<ul style="list-style-type: none"> Time lapse between death and family interview was between 8 days to 2.8 years Concerns about reliability and validity due to inability or inaccuracy of recall and

Instrument	Literature	Population	Timing	Strengths	Weaknesses
					effects of bereavement • Low concordance between family and professional scores
Quality of Dying in Long-Term Care	Munn et al., 2007; van Soest-Poortvliet et al., 2011	<ul style="list-style-type: none"> • Developed for cognitively impaired and intact patients in nursing home or assisted living settings • Completed by professional caregivers and families 	• Post-death	• Assessed perspectives on quality of personhood, life closure, and preparatory tasks	• Used only in nursing home, assisted living, and long-term care settings
Toolkit of Instruments to Measure End-of-Life Care	van Soest-Poortvliet et al., 2011	• Families' perception of EOL care in the nursing home	• Post-death	• Used with nursing home residents with dementia, and in hospital and hospice	

The following illustration, Table 2, summarizes the studies that focus on the patient's perspectives, listing the strengths and weaknesses of instruments. Teno (1999) posits that present instruments are inadequate. They were not deemed adequate to measure the changing priorities of the dying person at the end of life, or they measured only one function. The instruments did not address the significant dimensions such as spirituality and transcendence (Teno, 1999). Steinhauser et al. (2002) believed additional subjective measures were necessary.

Table 2. Instruments Measuring Patients' Perspectives

Instrument	Literature	Strengths	Weaknesses
Missoula-VITAS QOL Index	Byock & Merriman, 1998; Munn et al., 2007; Schwartz et al., 2000; Teno et al., 1999	<ul style="list-style-type: none"> • Focused on terminal phase of life. • Addressed spirituality and sense of meaningfulness. • Allowed subjective wording for each dimension of QOL. • Able to measure positive growth during the dying process. • Able to detect change in individuals over time. • Provided a foundation to base discussions with patients about treatment. • Useful clinical assessment tool. 	<ul style="list-style-type: none"> • Complex and difficult to use. • Revised form was not a strong research instrument. • Cannot be used with long-term care patients: validated only in acute settings, where disease trajectories were more predictable.
Multidimensional Orientation toward Dying and Death Inventory	Wittkowski, 2001	<ul style="list-style-type: none"> • Assessed both the fear and the acceptance of dying and death. 	<ul style="list-style-type: none"> • Was tested only on a German non-dying sample. • Only provided information on whether the participant feared or accepted death.
<ul style="list-style-type: none"> • Functional Living Index: Cancer • Functional Assessment of Cancer Therapy • Spitzer Quality of Life Index 	Steinhauser et al. (2002) Teno et al. (1999)	<ul style="list-style-type: none"> • Measured quality at the EOL. • Multidimensional instruments which measured the physical, psychological, and emotional well-being of patients. 	<ul style="list-style-type: none"> • Did not capture experiences unique to the dying process. • Expected the person to return to optimal or normal functioning • Focused heavily on the physical domain and skimmed over the spiritual domain. • Did not look at positive aspects of the dying process or give appropriate weight to patients' emotional and spiritual growth. • Did not assess needs of terminally ill patients.
<ul style="list-style-type: none"> • Schedule of the Evaluation of the Individual QOL at the EOL 	Munn et al. (2007)	<ul style="list-style-type: none"> • Also tested with seriously ill patients in ambulatory settings. 	<ul style="list-style-type: none"> • Validated only in acute settings, where disease trajectories were more predictable.
<ul style="list-style-type: none"> • Hospice QOL Index • McGill QOL Questionnaire 	Munn et al. (2007); Teno et al. (1999)	<ul style="list-style-type: none"> • Addressed spirituality, transcendence, and sense of meaningfulness. • Able to measure positive growth during the dying process. • McGill QOL Questionnaire able to detect change in individuals over time. 	<ul style="list-style-type: none"> • Hospice QOL was specifically designed for hospice or palliative care population. • Validated only in acute settings, where disease trajectories were more predictable.

As shown in Table 2, the quantitative tools measuring patient perspectives are limited in their application, and therefore, very few studies included the patients' perspectives (Black, 2001; Fowler et al., 1999; Hinton, 1999; Kayser-Jones, 2002; Kelner, 1995; Pierson et al., 2002; Porritt, 2001; Reed, 1987; Ringdal & Ringdal, 2000; Singer et al., 1999; Steinhauser et al., 2001; Steinhauser, Clipp, et al., 2000; Sullivan et al., 1998; Tanaka et al., 1999; Yedidia & MacGregor, 2001). In many studies, the patients were only a small percentage of the sample, which also included families and healthcare providers (Black, 2001; Pierson et al., 2002; Porritt, 2001; Ringdal & Ringdal, 2000; Steinhauser, Christakis, et al., 2000; Steinhauser, Clipp, et al., 2000; Yedidia & MacGregor, 2001). Even fewer studies focused on patients in the terminal phase of life. Most studies were done from the family's perspective (Curtis et al., 2002), but little is known about the validity of the family's perspective compared to the patient's perception of the dying experience (Fowler et al., 1999). Past research demonstrated that other people tended to underestimate patient functioning when compared to the perspectives of the patient themselves (Fowler et al., 1999). Jones and colleagues (2000) noted that there was a difference between the nurses' and relatives' perceptions of the quality of death of the patient. Using proxy measures, such as the perceptions of others than the patient, appears to be problematic. The most accurate account is from the primary source, the dying person.

Hawai'i Statistics

According to Vital Statistics Report 2009 (Hawai'i State Department of Health, 2009), there were 507 deaths on the island of Kaua'i, and 9,948 deaths in the State of Hawai'i. The leading diseases causing death in adults in Hawai'i were malignant

neoplasms and diseases of the heart, similar to the federal statistics (National Center for Health Statistics, 2010). Hawai`i's ethnic composition is very different from the rest of the nation. The national census (U.S. Census Bureau, 2011) lists Caucasians as "White persons" and Japanese, Chinese, and Filipinos are combined under the term "Asian."

Table 3. Ethnic Composition of the Population (U.S. Census Bureau, 2011)

	National	State of Hawai`i
White/Caucasian	78.1%	26%
Asian	5%	38.5
Japanese		13.6%
Filipino		11.5%
Chinese		4%
Native Hawaiian and other Pacific Islanders	0.2%	10.1%

Most of the research examining the nature of the dying process has been done in areas other than Hawai`i. Differences in the racial background of the population could make a difference in the results of the study. This demonstrates the need for research to be conducted in Hawai`i, with a focus on our unique cultures.

Summary

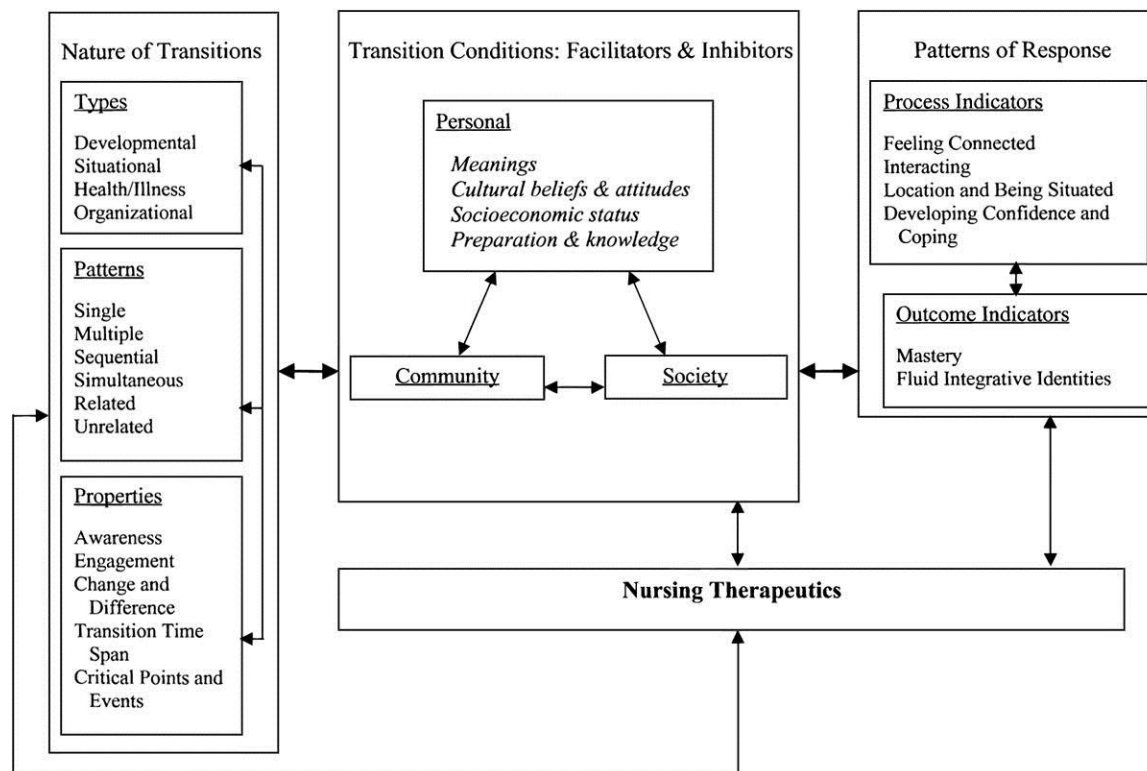
There has been a lack of research done on the dying process, especially on the APIAs (Teno et al., 1999). "Research has not focused on developing conceptual models and measurement tools for examining the quality of care and quality of life of dying patients" (p. 75). The most commonly used instruments to measure the quality of life did not adapt to the changing priorities of the dying and failed to address highly significant

dimensions such as spirituality and transcendence (Teno et al., 1999). Research has shown that spirituality influences the quality of life, but more research is needed to understand how spirituality affects the patients' quality of life (Efficace & Marrone, 2002). Little research has been conducted to explore the patients' perception of the dying experience. The studies that explored the patients' perspectives were done primarily on Caucasians in the continental United States or other countries. Very little research had been conducted with APIAs, which make up 63.5% of Hawai'i's population (U.S. Census Bureau, 2011).

There is a need for more research in exploring Asian American and Pacific Islander patients' perspectives on the dying experience (Nishimoto & Foley, 2001). The current study expanded the literature on the death and dying experiences of APIAs. The purpose of this research was to: (a) understand the meaning of the lived experience of dying as a consequence of serious, progressive illness for APIAs in Hawai'i; (b) identify the values and preferences of those who are dying with regard to care during their illness trajectory and the remainder of their lives; and (c) describe their perspective of "good quality of dying," if this concept exists for them. The research questions were: What is the lived experience of dying for the APIAs? What are their values and preferences for the remainder of their lives with regard to care during their terminal illness trajectory? What is the dying person's perception of "good quality of dying"? Are there cultural differences between the APIAs and Caucasians? In Chapter III, the theoretical framework, transitional theory, will be reviewed.

Chapter III. Theoretical Framework

Transitions are a part of life (Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000). According to Meleis and her colleagues (2000), transition theory focuses on the evolution of an individual (Figure 2). Transitions can be a result of illness; developmental and lifespan transitions such as pregnancy, birth, puberty, menopause, and death; and social and cultural changes such as retirement or migration. Transitions are the consequence of and the antecedent to the alteration in health, lives, relationships, and environment (Meleis et al., 2000). Frequently, the person is not only going through one transition but multiple ones (Meleis et al., 2000), such as pregnancy and motherhood. With each transition, there are properties of the experience, facilitators and inhibitors, process and outcome indicators, and nursing therapeutics. Meleis and her colleagues conceptualize that there are several essential properties of transition experiences: “awareness, engagement, change and difference, time span, and critical points and events” (p. 18). The person in transition is usually aware that changes are occurring. He or she demonstrates engagement in the process by getting information. There is usually an identifiable end point, such as death. Critical points and events such as periods of uncertainty, fluctuation, and disruption are part of the stabilization for this new stage. There are also facilitators and inhibitors to the process (Meleis et al., 2000), including the individuals’ perception and the meaning attached to the situation, and beliefs. The person’s response to the transition is classified as either process or outcome. Process responses indicate how the person is evolving during the transition, e.g., developing confidence and coping. The outcomes are the end results, e.g., mastery.

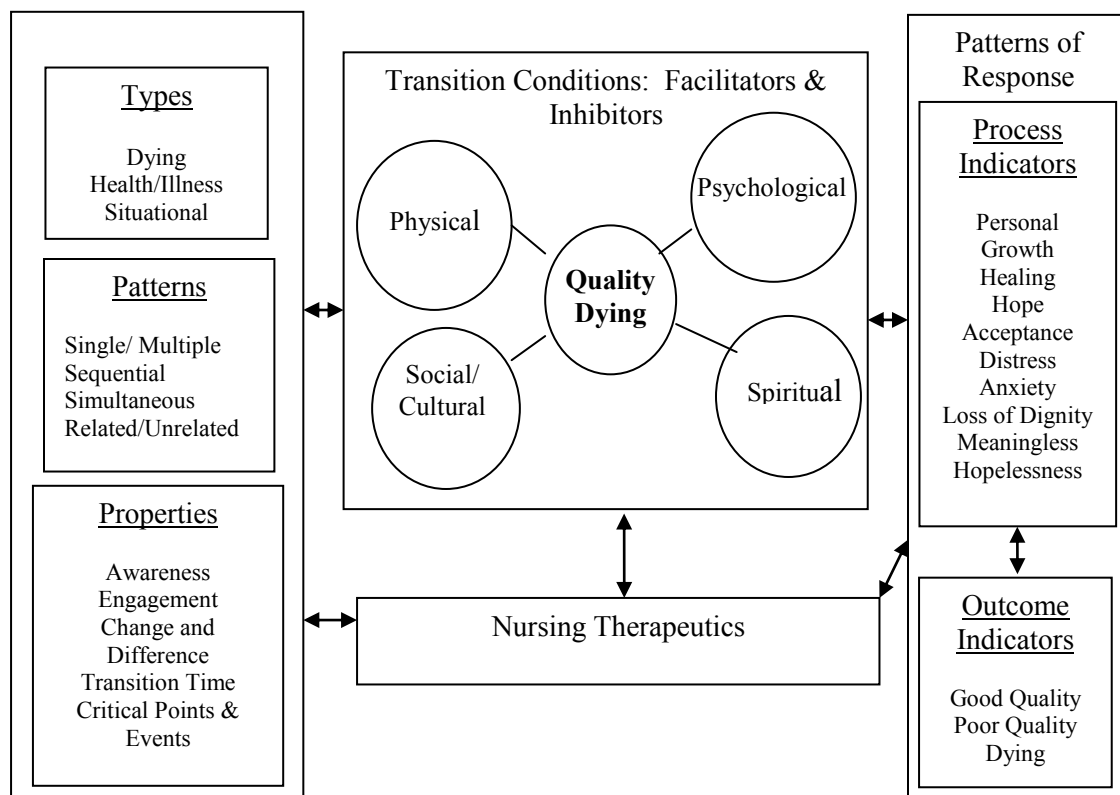
Figure 2. Transitions: A Middle Range Theory

Note. From “Experiencing Transitions: An Emerging Middle-Range Theory” by A. I. Meleis, L. M. Sawyer, E. Im, D. K. Hilfinger Messias, & K. Schumacher, 2000, *Advance Nursing*, 23, p. 17. Copyright 2000 by Aspen Publishers. Reprinted with permission from Wolters Kluwer Health and A. Meleis.

The transition theory (Meleis et al., 2000) is applicable to the dying process. The dying process can be viewed utilizing the transition model, conditions, and indicators. Dying is a transition of life (Figure 3). As a lifespan evolution, dying involves health, illness, and situational modifications. While experiencing dying, the person is also experiencing multiple transitions, e.g., having a life-threatening illness, adjusting to changing roles, losing functions, and altering financial resources. The dying person is usually aware that changes are occurring. The level of awareness affects the level of “engagement.” The dying person is unable to prepare for death and finish end-of-life

closure goals if he or she is unaware that he or she is dying. Transitions occur over time with a terminal point, e.g., death. Throughout the transition, there are critical points and events that require change and adjustment, physically and emotionally. The person's perception of the transition and the meanings attached to the process can affect the course and the quality of dying and death.

Figure 3. Transition: Dying



Note. Adapted from “Experiencing Transitions: An Emerging Middle-Range Theory” by A. I. Meleis, L. M. Sawyer, E. Im, D. K. Hilfinger Messias, & K. Schumacher, 2000, *Advance Nursing*, 23, p. 17. Copyright 2000 by Aspen Publishers. Adapted with permission from Lippincott Williams and Wilkins/Wolters Kluwer Health and A. Meleis.

As illustrated in the literature review, facilitators and inhibitors that shape the person's whole perspective of quality of dying are similar and include the individual's physical, psychological, spiritual, and social/cultural/ethnic values and beliefs.

Outcome indicators of the transition are good quality dying and poor quality dying. A process indicator of quality dying is personal growth of the patient and/or the family (Ersek, 2001; AACN & COH National Medical Center, 2000; Byock, 1996). Both patients and/or families often speak of personal growth that takes place at the end of life even in the midst of struggles to overcome physical, emotional, and spiritual suffering. Some patients and families even describe it as healing (Byock, 1997; AACN & COH National Medical Center, 2000). With acceptance of death and the dying process as part of the circle of life, the patient and the family can learn to "view death as an achievement instead of failure" (AACN & COH National Medical Center, 2000). With a poor quality dying there is distress and anxiety (Hinton, 1999; Jones et al., 2000). This occurs when the dying person's preferences and needs are not met. Other terms used were "loss of dignity" (Madan, T. N., 1992), "hopelessness," and "meaningless" (Fryback & Reinert, 1999).

Although a qualitative methodology was used, this dying transition model informed the research and was useful in explaining the results. The interview questions, although open-ended, were informed by the transition theory. Under the properties of "awareness," "engagement," "change and difference," and "critical points and events," guiding questions were developed (Appendix A). For example, a question under "awareness," was "Tell me how you first became aware that you were dying." The sample included those who currently were going through the transition, those who had

been diagnosed with a terminal illness, and those who were aware of their prognosis of less than six months to live. Interviews were analyzed for themes (patterns of response, process indicators). A description of quality of dying was the intended outcome.

In the role as caregiver, the nurse can “prepare clients for impending transitions and . . . facilitate the process of learning new skills related to clients’ health and illness experiences” (Meleis et al., 2000, p. 13). This research study explored the terminally ill patients’ perception of the experience and the meaning of quality dying and resulted in knowledge that can help nurses better understand, prepare, and support the dying patient through this process.

Summary

This chapter described the theoretical framework, which informed the research and research questions. In the following section, methodology of the research will be delineated.

Chapter IV. Methodology

In this chapter, the research design, including a discussion of qualitative methods, particularly focusing on phenomenology, is discussed. In addition, the population, sample and setting, data collection procedure, informed consent, instruments, assumptions, and the analysis and interpretation of the data are outlined.

Research Design

This research described the lived experience of dying in Hawai'i in the APIA population. The primary question was "What is the lived experience of dying?" Two subquestions were: "What are their values and preferences for the remainder of their lives with regard to care during their terminal illness trajectory?" and "What is the dying person's perception of 'good quality of dying'?" The research design was qualitative, utilizing the phenomenological method.

Certain types of research questions require a specific method. Based on the research question, "What is the live experience of dying?" qualitative research is the best research design best situated to answer that question. The concept of quality of dying needs to be understood, and very little is known, especially from the patient's perspective. "Qualitative research is exploratory and is useful when the researcher does not know the important variables to examine" (Creswell, 2009 p. 18). In qualitative research, the researcher seeks the meaning of the experience by interviewing and using open-ended questions. Interviews are essential to explore what the participant experienced and to understand the phenomenon (Creswell, 2009).

On the other hand, the quantitative method is utilized to test a theory and the data collected supports or refutes the hypothesis. Instruments are used to gather data. These measurements are analyzed using statistical procedures and hypothesis testing (Creswell, 2009). In quantitative research, there are variables, both independent and dependent. In qualitative research, the variables are not known (Creswell, 2009).

Within qualitative research, there are various methods, and one must choose a method based on the research question and purpose of the study. Phenomenology is used to explain the meaning of an experience or to answer the question, “What is the lived experience of . . .?” The purpose of exploring factors surrounding a situation could be answered by the case study strategy. Ethnography would be the best strategy to utilize to study a subculture and grounded theory methodology would have been selected to develop a theory of a concept (Creswell, 2009). Since this research’s question is “What is the lived experience of dying?” the best strategy was the phenomenologic approach.

Phenomenology. The phenomenological method describes, interprets, and reflects the individual’s perception of his or her experience. The lived experience and its meaning are crucial to phenomenology. The intent of this method is not to construct a grand theory, but to understand the lived experiences of the participants. The participants construct meaning as they tell their story. There are two types of phenomenology: descriptive (Husserlian or eidetic) and interpretive (hermeneutic) (Lopez & Willis, 2004). In both, data collection is similar to in-depth interviews. In both, the researcher analyzes the narrative to construct the findings. In the eidetic method, the researcher describes the participants’ experiences. In the hermeneutic method, the researcher interprets the participants’ experiences (Polit, Beck, & Hungler, 2001). A major difference between

the two types is in how the results are analyzed and how the findings are displayed (Lopez & Willis, 2004). Edmund Husserl is considered the father of phenomenology. He believed that by reflecting on human experience, the meaning becomes apparent. He believed what was important in the search for the meaning of human lived experience was the essence of the experience of the participant being described and reported without the biases of the researcher distorting it. He supported the descriptive (Husserlian or eidetic) method.

A major concept in phenomenology is intentionality. It is the orientation of the mind toward some entity, occurrence, or matter. There are two sides of intentionality: noema and noesis. For every noema, there is a noesis and vice versa. The mind breaks down the experience into reality. This cognitive structure is noema. It tells the mind to see the matter and think rationally. It is the “what” that is being studied, the phenomenon. It is the objective knowledge. Noesis, on the other hand, is the way the event is being experienced. It is an act of consciousness, perceiving, thinking, feeling, remembering, judging, hating, imaging . . . things that the mind does (Moustakas, 1994). It is the subjective process. All of these acts are full of meanings that are hidden in the sub-conscious and must be recognized and drawn out.

Husserl believed that research into the lived experience should be directed towards the subjective, pre-conscious, and because of that, he believed that it was necessary for the researcher to allow the essence of the participants’ experiences to be described with integrity. Four basic mechanisms help accomplish this in descriptive phenomenology: bracketing, intuiting, analyzing, and describing. With this method, the researcher must set aside his or her previous knowledge of the topic, bias, attitude, and

values to understand the participant's lived experience. Some researchers suggest that the descriptive phenomenologist should not conduct a detailed literature review prior to the start of the study and should not have any research question other than "what is the lived experience of ..." (Lopez & Willis, 2004). In this method, the researcher needs to assess and reassess any biases or presumptions and counteract them so he can approach the data collection and analysis without preconceptions. This process is called "bracketing" and is an essential component of eidetic methodology. Intuiting occurs when the researcher remains open to the meanings attached to the phenomenon by the participants. Analysis involves extraction of significant statements, categorizing, identifying commonalities, and making sense of the meaning attached to the phenomenon. The descriptive phase is when the researcher can describe and understand the phenomenon.

There are three main methods of data analysis for descriptive phenomenology based on Husserl's philosophy: Colaizzi, Giorgi, and Van Caam. All three describe the meaning of an experience often through identification of themes and common patterns. Commonalities or universal essences are identified, but there are also differences. Colaizzi requires final validation of the results by the participants. Giorgi relies only on the researcher's findings and believes that validation with the participants or using external judges is inappropriate. Van Caam requires intersubjective and external experts' agreement. (Polit et al., 2001)

Martin Heidegger, a student of Husserl, developed the hermeneutic method (Heidegger, 1927/1962). Hermeneutic phenomenology not only describes the essences but also examines the meaning entrenched in the experience. Heidegger believed that

individuals are embedded in a world of cultural, political, and social conditions, which affect the way individuals make meaning of the experience. These meanings may be derived from the narrative, if not from the participants. “The focus of a hermeneutic inquiry is on what humans experience rather than what they consciously know” (Lopez & Willis, 2004, p. 728). The researcher not only asks about the lived experience itself but also asks about the interactions, relations to others, experience of body and time, daily practices, and socialization. These questions could be about a sequential account of a day or the person’s feelings at a certain time. There is freedom in the interpretive inquiry. The belief is that people are free to make choices, but specific aspects of their lives, such as cultural, social, and political influences, affect their choices. The consequences of the decisions are unclear. Nonetheless, a choice is made. The hermeneutic phenomenologist focuses on describing the meaning of the lived experience and how the meaning influences the choices the participants make. There could be more than one interpretation of the narratives.

Interpretive phenomenology has two major differences from descriptive phenomenology. Firstly, in the interpretive study, bracketing is not used. Heidegger (1927/1962) believed that researchers cannot separate themselves from the world. It was impossible for the researcher to be free of biases and previous knowledge and, in fact, he believes that expert knowledge was an essential part of interpreting the meaning that the experience has for the participant. Secondly, in the descriptive phase, the researcher can understand and describe the phenomenon and interpret the meaning attached to the experiences. A concept in the hermeneutic phenomenology is co-constitutionality. The meanings that are extracted from the narratives are reflective of both the participants and

the researcher. As the researcher interprets the meaning of the narrative, the researcher's experiences and empathy are infused into the meaning, thereby resulting in a blend of the participant's and the researcher's meanings.

Munhall (2012) developed a method for interpretive phenomenological inquiry (Table 4). Immersion, step I involves reading, reading, and more reading. Reading as much as you can to understand the method. Immersion is essential to good phenomenological research. Main aspects of step II, coming to the phenomenological aim of the inquiry, are to develop the aim of the research and "decenter" and to "unknow." Through reflection of one's beliefs, preconceptions, and biasness, can the researcher let go and move to "unknow," and be open to what may unfold. In steps III and IV, the researcher listens and reflects, identifies and analyzes emerging concepts, and assesses life worlds. In step V, the meanings are described and interpreted. Steps VI and VII involve writing of the meanings and interpretations and then critiquing the interpretation with implications and recommendations.

Table 4. Munhall's Method for Qualitative Research

Method for Phenomenological Inquiry Broad Outline	
I.	Immersion
II.	Coming to the phenomenological aim of the inquiry
III.	Existential inquiry, expressions*
IV.	Phenomenological contextual and processing*
V.	Analysis of interpretive interaction
VI.	Writing the phenomenological narrative
VII.	Writing a narrative on the meaning of your study
*Concurrent processes.	

Note. Adapted from P. L. Munhall, 2012, *Nursing research: A qualitative perspective* (4th ed.), p. 122. Copyright 2012 by Jones and Bartlett Publishers.

Munhall (2012) emphasized the interconnectedness of the four existential life worlds (spatiality, corporeality, temporality, and relationality). She believed that understanding the life worlds increased the understanding of the person in the world.

Spatiality is the lived space, the environment. It can undertake different meanings for different situations and people. A tent for one person may represent adventure, a family outing, and elicit warm, happy feelings. For another, it may be a reminder of an unhappy time, when he or she was homeless. Spatiality encompasses the feelings, positive or negative, created by the space around us.

Corporeality is the lived body and also is known as embodiment. The mind and body are connected. “We are our bodies” (Munhall, 2012, p.159). Our body and mind and the interconnectedness affect the experience. “Meaning and experience cannot exist in isolation” (Munhall, 2012, p. 160).

Temporality refers to lived time. It is subjective time. Passage of time varies with the experience. One’s perception of time is meaningful. History is a part of temporality. It is not only a space in time but also a period in time.

Relationality refers to lived human relation. It is the connection with others, with the world. The connection or the sharing with others can alter the patients’ experience or be altered by the experience. Interactions impact their experience. Healthcare providers and families are usually a part of the patient’s interpersonal environment.

There may be multiple interpretations of the dying experience. To understand the experience of dying, the person who is experiencing the dying process is the best source of information to explain the experience. Interpretive analysis relies on analysis of data

to understand human behavior and meanings. Data include observational notes and interviews. The researcher analyzes the data by asking:

- What is occurring (action or behavior)?
- What is the context of the action or behavior?
- What aspects of the situation are significant from the participants' perspective?
- What meaning do they attach to their lived experience?

The intent for this study is to verify the interpretation with the participants to truly capture their perspective. This may not be possible in this dissertation since dying is unscheduled and unpredictable. Phenomenology is the method best suited for describing the lived experience of the dying people and defining “good” quality of dying. Typically, phenomenologic studies involve a small number of participants, often less than ten. The interpretive method, more specifically, is better for the intention of this study. In conclusion, Munhall’s method will be utilized.

Trustworthiness. In quantitative research the excellence of the research is established by internal validity, external validity, reliability, and objectivity. However, qualitative research cannot be judged by these criteria. It is not possible to establish external validity from a descriptive analysis in the form of statistical confidence limits. Excellence in qualitative research is measured by a different criterion, trustworthiness. Researchers establish trustworthiness of the inquiry and data usually by addressing four questions (Lincoln & Guba, 1985):

1. “Truth value”/Credibility: How can the researcher ensure confidence that the findings are true and credible? Activities that increase credibility are persistent observation over a sufficient period of time and triangulation.
2. Applicability/Transferability: How can the researcher determine the extent that the applicability of the findings in other contexts or with other participants? Providing a rich description enables others to make transferability judgments.
3. Consistency/Dependability: How consistent would the findings be if the analysis were done with similar participants in similar context and analyzed by someone else? The dependability of the inquiry can be addressed by an auditor, who examines the data, findings, interpretations, and recommendations, and confirms that the findings or recommendations are supported by data.
4. Neutrality/Confirmability: How can the researcher ensure that the findings are determined by the participants and not influenced by the researcher’s prejudices, interests, or views? The use of an auditor, as described above, can also establish confirmability.

Role of the researcher. As in most qualitative studies, the primary instrument for data collection in this study is the researcher (Lincoln & Guba, 1985; Merriam, 1998). “The inquiry is value-bound” (Lincoln & Guba, 1985) so care must be taken to avoid biased questions, such as leading or judgmental questions. Other questions that need to be avoided are dichotomous (yes or no) questions, which offer no qualitative information, and multiple questions simultaneously, which may be confusing to the respondents and

they will not know which one(s) to answer and in what order. The participants' stories will guide the interview. How the researcher interviews, communicates, responds, collects, and analyzes the data can affect the responses of the participants or the outcome of the research (Lincoln & Guba, 1985; Merriam, 1998). If a subtle feeling or theme is missed, the findings could be different.

Good communication skills are very important. By leaning forward, sitting eye level, utilizing an open stance, and maintaining eye contact (without staring), the researcher will convey active listening. Silence allows the participant time to reflect and formulate a response. If the researcher is asking one question after another without giving the participant time to respond, the data collected may not be as rich and complete as it could be and this interviewing style may also be a barrier to communication. Being nonjudgmental, respectful, and nonthreatening also promotes communication (Merriam, 1998). Merriam (1998) also believes that being nonjudgmental is crucial to the success of the interview.

Researcher's background and beliefs. The researcher has been a nurse for over 30 years. She has seen people avoid the dying. During this time, the researcher had many opportunities to help her patients during this transition. The researcher feels that sometimes she made a difference and added to the dying persons' quality of dying and allowed them to die with dignity or in the manner they chose. The researcher believes that each person has a right to die with dignity. She also believes that each person's definition of dignity and quality of dying are personal and individual. She believes that in order to be more effective as a healthcare provider and as a caring person, she needs to explore the factors that contribute to the quality of dying or dying with dignity.

The researcher has lived on Kaua`i for more than 30 years in which time she has been active in the community. Kaua`i is a small community where everyone seems to know everyone. Many people know the researcher from her volunteer or educational activities, or know her name through publicity, word of mouth, or her connections to the community.

Assumptions. The researcher holds the following to be true:

1. The subjects are able to verbalize their experiences and process.
2. The subjects respond honestly.
3. The subjects are willing and able to talk about the topic.

Population, Sample, and Setting

The participants were sought through hospices, home health agencies, local hospitals, clinics, and support and church groups. Staff members at many of these sites know the researcher through previous employment, involvement as a volunteer or collaboration on a project, e.g., hospice, and were willing to help recruit participants for the study. Flyers with information about the research and request for participants were circulated. The major method for recruitment was direct recruitment by the staff. Kaua`i Hospice, which had approximately 42 APIA patients in 2009 (L. Miller, personal communication, October 7, 2010) and the oncology infusion center recruited the majority of the participants.

The desired sample size was five to ten participants who met the criteria and were willing to participate. The sample size is based on data saturation. Typically, phenomenologic studies involve a small number of participants, often less than ten.

Research participant inclusion criteria. Creswell (2007) emphasized that it was essential for the participants to be experiencing the phenomenon. The recruited participants had been diagnosed with a terminal illness and were aware of their poor prognosis. Participants were adult (18 years and older) APIAs (self-identification) living in Hawai`i and spoke English.

Research participant exclusion criteria. Participants who changed their minds about being interviewed were excluded.

Protection of human rights. This research was approved by the Institutional Review Board, Committee on Human Studies, at University of Hawai`i at Mānoa. The research was explained to various agencies (Appendix B). Potential participants were invited to participate by various recruiting sites. One of the flyers (Appendix C) was shown to the potential participants. If they agreed to participate in the research, their contact information was shared with the researcher. The researcher then scheduled a meeting with the potential participants.

The “Consent to Participate” (Appendix D), detailing the purpose of the study, the benefits, procedures and risks, voluntary participation and confidentiality, and costs and reimbursement, were explained to the potential participant. They were advised that talking about the lived experience may be upsetting and the interview can be terminated or postponed to another time. They were further advised that their identity would remain confidential unless disclosure was required by law and all identifying personal information would be destroyed after the research was completed. They were then asked to sign the consent form to indicate their agreement to participate, to be audio recorded, and to have excerpts from the audio recording and/or quotes from the interview be used

for educational purposes and publications. Recruitment of people who are interested in sharing their experiences is essential (Munhall, 2012). Two potential participants declined to participate. The family of another declined to even schedule a meeting.

Considering that most people who are dying lack energy and time, participation in a study may be the last thing they would consider doing. As Steinhauser et al. (2002) stated, nonparticipation was a major problem in the dying population. For these reasons, the participants were given \$25 gift certificate as a payment for time, energy, and participation. This research has received support from the John A. Hartford Foundation's Building Academic Geriatric Nursing Capacity Scholarship Program.

Data Collection Procedure

The participant's energy and comfort level were considered in terms of the selection of time and place for the interview. Options of different locations for the interview were offered. If preferred, the meeting took place in their home, the researcher's home or in a classroom at the college. As expected, most (seven) of the participants preferred meeting in the comfort of their place of residence. One interview was done in the researcher's home and another was conducted at the college. A few days prior to the session, the researcher called to remind the participant of the appointment date, place, and time. The chosen setting was conducive for interviewing. The environment was quiet enough so that the participant could be heard; non-distracting so the participant could concentrate on the question or phenomenon at hand; and comfortable (Morse & Richards, 2002). The researcher met with the participant alone to minimize interruptions. Consent was obtained prior to the interview.

Eliciting the participants' feelings, thoughts, and intentions is best obtained through interviews. Through the interviews, the researcher would be able to understand the phenomenon from the participant's perspective and obtain information about events that are not observed or has previously happened (Merriam, 1998). The data was collected through an in-depth, face-to-face, open-ended interview (Merriam, 1998) of approximately 60-90 minutes, which was adjusted according to the participant's energy or comfort level. Each session was audio recorded.

The interview was semi-structured (Merriam, 1998; Morse & Richards, 2002). This type of interview allowed the respondents to take the lead and guide the course of the discussion. The participants were asked open-ended questions with probe questions (Appendix A) adapted primarily from Yedidia & MacGregor (2001) and Meleis et al. (2000). Some of the questions were about the illness, awareness of dying, process questions (the lived experience), meaning (Morse & Richards, 2002) about dying with dignity, and about the "ideal" (Merriam, 1998) quality of dying. The questions (Appendix A) also addressed the essential properties (in italics) of a transition process (Meleis et al., 2000). The aim was to have the participants share their experiences since their diagnosis of a terminal illness.

Their feelings and experiences were explored and the researcher's preconceived attitudes and ideas were not imposed upon them. Clarification and interpretive questions were asked to ensure that the researcher was interpreting the participants' perspective accurately. Observations on setting, tone, and non-verbal behavior were noted by the researcher. Demographic data was collected to enhance understanding of their life world, the meanings of their experiences. This included age, occupation, ethnic background,

religious or spiritual affinity, diagnosis, year of diagnosis, and support groups or services presently being utilized.

The researcher kept track of the time and stopped at the predetermined time or earlier, if necessary, based on the participants' energy level and tolerance. The participants were given a choice to continue, to schedule a second visit, or decline a second interview. Towards the end of the session, the participants were asked if there was anything else that they felt was important to share.

Method of data collection. The data was obtained from four primary sources:

- Verbatim transcripts of the audio-taped interviews.
- Journal notes documented by the researcher during or immediately after the interview, focusing on observations on setting, tone, and non-verbal behavior.
- Notes made during analyzing transcripts.
- Written communication from a participant after the interview.

Data Storage and Management

Although ethical conduct of research is always important, confidentiality and anonymity are particularly critical in Hawai'i where the communities are small and close-knit. The participants were coded with numbers and assigned pseudonyms. The raw data was kept in a secured place in the researcher's office. Only the researcher and the chair of the dissertation committee had access to the raw data. With the consent of the participants, results of the study will be shared with various disciplines, in formal and informal presentations and publications. Participants consented to allow the researcher to use excerpts from the audiotapes or quotes from the interview for educational purposes and publications.

Analysis and Interpretation of Data

The audio recording of the interviews was transcribed verbatim by the researcher. The transcripts were imported into the NVIVO qualitative analysis software program. NVIVO was utilized primarily as an organizational tool for data management. It allowed for organization of text into the four existential life worlds (temporality, relationality, spaciality, and corporeality) and into the four attributes (physical, spiritual, psychological, and social/cultural). The data were examined for themes and concepts (Lincoln & Guba, 1985; Merriam, 1998). Inductive data analysis was utilized (Lincoln & Guba, 1985). It consisted of three major steps: (a) identifying concepts and themes from each of the interviews, using the participant's own words; (b) contrasting the themes, concepts, and patterns from all the participants; and (c) describing the similarities and differences between the participants.

Finally, the themes were re-conceptualized into facilitators and inhibitors that shaped one's whole perspective of quality of dying, the individual's physical, psychological, spiritual, and social/cultural/ethnic values and beliefs.

Summary

In this chapter, the choice of methodology, the researcher's role, background and beliefs, assumptions, research design, population, sample and setting, data collection procedure, informed consent, instruments, and the analysis and interpretation of the data were described. The method that best corresponded with the research questions was phenomenology. Answers to questions about meaning, experiences, and phenomena are best described, analyzed, and interpreted using the phenomenological method. These techniques can help describe the meaning, experiences, and phenomena of quality of

dying. The purpose of the research was to describe the lived experience and interpret the meaning of the experience to the participant. Therefore, the method of design for this research was interpretive phenomenology.

Trustworthiness of research will be determined by four criteria: credibility, applicability/transferability, consistency/dependability, and neutrality/confirmability.

The following chapter will describe each of the participant's lived experience, Living with Dying.

Chapter V. Phenomenological Narrative

Consistent with Munhall's (2007) method of phenomenological inquiry, reflection of each participant's living with dying experience is described. Each case is depicted within the context of the four existential life worlds. The data are then summarized collectively, again within the four life worlds. This chapter culminates with the identification of emerging themes which will be further discussed in the following chapter.

For ease of data management, each participant was labeled one to nine. Furthermore, each participant was given a pseudonym based on his or her number and the corresponding letter of the alphabet. For example, Participant One was given a pseudonym starting with the first letter of the alphabet, A, and for Participant Two, the second letter, B, etc. All spoken grammatical errors were also deliberately left unedited and without adding *[sic]* to each one so as not to distract the reader.

Participant One

"Aaron," a 65-year-old Hawaiian man, lives at home with chronic obstructive pulmonary disease (COPD). He was diagnosed the year prior with end stage COPD and is dependent on oxygen. He has only one lung after a truck accident almost fifty years ago. He actually died and was revived. He also had two other near death experiences: a near drowning and double pneumonia as an infant. Thinking that this may be his mission, he is eager to share his story.

Temporality (lived time). Aaron does not remember when he became ill. “I don’t know. There so much things that I don’t know.” He has lost track of time.

Aaron realizes that he has limited time and that God will take him when He wants and he has to be patient. “It’s almost the end of my journey, but I just gotta be patient, and you know, just go one day at a time now.”

In spite of what he says, he seems to be getting impatient:

I ask Him every day. I ask Him what I have to do with my time. There’s no sign, but I know that one day I going have to do something, and then going be over and I going be happy again. . . . It’s been six months already, and I still going and I get another six months . . . for Him to make up His mind whether He like me or not. See, I committed myself to Him. . . . When He’s ready to take me, He take me. . . . I gotta find what is the thing that is making me keep going on this journey. . . . It’s a difficult road. It’s not a straight road. It is a winding road.

Interestingly, Aaron states that he escaped death, or died and returned to life, several times, perhaps indicating that he believes he may be saved again:

About three times I die. . . . I was on my way to work early in the morning when a truck had run over my car. . . . [My] neck was hanging. . . . When they had dragged me out, they had to hold . . . my head.

His spirit left his body, and he could see what people were doing to him. He continues:

Yeah, I seen my operation. I seen my operation . . . cause my spirit was outside of my body. . . . I can see everybody. . . . I see my uncle. Then this voice from the back of me came. “[Aaron], your time is not up yet.”

He tells other stories indicating that he believes he will live long:

I seen people on the other side, my grandfather and my grandmother. . . . My grandfather told me, . . . “You know what, grandson, you going live to be 150 and still look the same.” I said, “So you telling me I going be dying going all the way up to heaven then?” He says, “Yeah.”

Relationality (lived human relation). Family is important to Aaron:

The most helpful thing was my wife. . . . Without her I think I wouldn’t be here already. But she the one stayed by my side all the time until now. . . . She come check me out, see how I am . . . my brothers and sisters too. They come when I not feeling so good. The whole family come over and give her support . . . and me too.

When he is alone, he gets depressed because he misses his family. He overcomes this feeling by talking with them and giving his wife a hug. One of his sons is in prison, but he feels that he will be able to see him again. “I tell him no hurry. ‘Daddy be home when you come out.’ I going be here when he comes out.”

He also sees his brother and others who have died. They are calling for him to come to them, but he tells them that he is not ready. Aaron now believes his purpose for living longer is to save lives. He states:

[There are] things to do. . . . I ask Him what I have to do with my time. I said, “Okay, I find out what I got to do.” . . . I have to save some lives. I don’t know what kind lives, but I have to save lives. . . . What kind life? Spiritual lives? People who need help? Or people who need advice? . . . I don’t know who I got to help, but I know that is what I got to work on.

When he was hit by a cane haul truck when he was 19 or 20 years old, he was proclaimed dead. He could see everyone crying. He recalls:

Then I hear this voice coming from the back of me. Said, “[Aaron], your time is not yet, so go back to your body.” . . . They had put me inside the ambulance. Just before they had closed the door, my spirit went inside my body again. . . . I think the reincarnation to me is something real great.

He believes his role with healthcare providers is to teach them about listening to patients on how to best treat them. “I gotta teach the doctors and the nurses what kind of medication to give me.” He gave them his opinion on what medications to stop, and after reevaluation, many of his drugs were eliminated. He feels he is doing better.

Spatiality (lived space). In the beginning, Aaron experienced great anxiety manifested through chest pain. He found that thinking of something beautiful helped. Using his prior death experiences as a resource, he shares:

I went through this land of flowers and beauty when I had this reincarnation. . . . Beautiful, beautiful, beautiful. You guys can just stay there. You don’t have nothing to do. Just enjoy the land all to yourself and be happy. . . . Everything is beautiful outside where people no more sickness. . . . The next time I going leave, is going be so beautiful. . . . When time for go, I just going be happy. Smile on my face.

He is not afraid of dying, yet he wonders why he is told that it is not his time and is returned to his “body.” “I don’t see why they would show me the door to eternity . . . then after that they take um away from me. . . . I start wondering what does that mean.”

Occasionally when he is alone at the beach or at the swimming pool at home, he becomes depressed and he sits and cries. “I think I was depressed ‘cause my family.” His emotions are also reflected in his picture frame creations. “Every picture frame is not the same. It’s all different. There’s all different types of feelings that I had that day. . . . So everything I do, there’s . . . something that I really appreciate about the picture frame.” He picks out a frame with sea shells and tells the story of his wife as she looks at the sea.

Corporeality (lived body). Although Aaron openly shares stories of his previous “deaths,” he does not speak much of the progression of his current illness. He talks about how his body, mind, and spirit need to work together. “Your mind, your spirit, and your body, if they no work together they just like crazy. But if your get your brains, your spirit, and your mind working all in one, then you would be yourself.”

There was a time he was fearful of dying, and he realized that his anxiety caused his high blood pressure and chest pain, and he needed medications to control it. “Then . . . I heard something say get rid of your anxiety. That is the one that’s making your blood pressure or whatever come up that you need help of medication.” He found that thinking about the beautiful place he saw in his “reincarnation” alleviated his fear. “My body like be happy.”

At one point when he was “completely sick,” he was on many medications and injections. He started to learn about his medications and how it affected him. “I started investigating. I said, ‘Okay, spirit, I going investigate my body. What kine chemicals get down there?’” When he understood how the drugs affected him, he told his healthcare providers which medications he was stopping. “This one cannot, this one cannot. . . .”

Participant Two

“Brianne,” a 61-year-old Japanese woman, is diagnosed with pancreatic cancer with metastasis. She has decided against any treatment. She wants to live the rest of her life at home to the best of her ability and with the people she loves.

Temporality (lived time). The initial shock when she got her diagnosis did not last long. She was somewhat prepared for it since she had other relatives who died young. She says:

[I felt] at peace and that feeling came right away because I think there is that initial shock when the doctor gives you the diagnosis, but I think in my mind I feel I've already practiced it, the shock, or the impact because I have other relatives die at an early age.

Brianne does not believe in the afterlife but believes there is a purpose for her life. She continues:

You're put on this earth, you live that life, and you do it in the best way you can . . . and for all the righteous reasons and . . . when you go, you just go. . . . I know death is the final and it just a matter of when. I was given six months or less to live, but it's given me time to prepare so that's the good thing. . . . I'm not afraid of dying. . . . I know when you are terminal, you realize your time is limited too, so you want to be as productive as you can. It's just my nature. . . . I don't like to sit around.

Relationality (lived human relation). What has been the most helpful to Brianne is her circle of friends. “I think that the overwhelming emotion is the support of

friends. Even people that you don't realize you've had an impact on. They come out to support you. So that I think is the most overwhelming feeling.”

She is preparing for her death by visiting loved ones far away to say goodbye. She says:

[I want] to see people that's been meaningful in my life and have impacted my [life]. . . . So I made a trip to California, oh, probably a month and a half after I was diagnosed and everything was stabilized, and still my goal is to do it one more time, probably in July, and just live . . . to also spend the last few good months I have with people that are meaningful . . . just having the time with people that I don't see often.

One of the most difficult things is leaving her husband behind. She spent most of her time supporting their son's activities and thought that she would be the one to take care of her husband in his later years. She has been preparing for the inevitable. She has been “spring cleaning,” cleaning out closets so that her husband would not have to do it. She thinks that he would worry about being disrespectful towards her if he had to make decisions on whether to keep or discard her things. She states:

I did all my closet cleaning because I want to make sure just knowing the kind of person he [is], if I left things behind, he would be overwhelmed. . . . So given the diagnoses early enough, gave me time to accomplish those goals, like clean closet, clean papers, update our will, and that kind of stuff. So the paperwork is all completed.

Brianne has many friends who are medical doctors who have provided her with advice.

I have a cousin who's an oncologist, hematologist in Virginia so he's. . . . He and his group of 35 doctors been my second opinion. So I'm real lucky I can sit here in Hawai'i. I don't have to go to the mainland and I get great support. My friends, being well-meaning, will drop off brochures, never push any one kind of therapy, but they want to keep me alive and keep me healthy, so they drop brochures and just say, "If you have time, this is something you may want to look at." So, support in that way and I think support is one, one of probably the most important key when you're ill. I'm really lucky where I feel, you know, I get that support.

Brianne and her husband are exploring hospice philosophy and services, but it was important to her to keep her regular physician. It was reassuring that hospice would work in conjunction with her physician.

When asked what "good death" means to her, she explains:

[It means] saying what you need to say to the people . . . that you love and are meaningful in your life. . . . To me, it doesn't mean they have to be at my deathbed because I've all told my really good family and friends and the kids that I don't feel they should be here [at] my deathbed . . . that they should remember me the way they remember me, healthy, vibrant.

She also has worked on a book of her favorite recipes and many pictures of family and friends. She had been asked for her recipes and thought what better way for them to remember her.

Spatiality (lived space). Brianne describes her lived experience since her diagnosis:

Overall, peace . . . I just feel this real calm-like Zen type of feeling like . . . you're put on this earth, you live that life, and you do it in the best way you can . . . and for all the righteous reasons and... when you go, you just go.

One of her most difficult problems is deciding where she wants to die. Although she wants to die at home, a place of happiness for her, she does not want her death to leave a negative memory for her family. She clarifies:

It has become much more popular for patients to die at home. For me, I think of our home as being a happy place, so [I] don't want to leave some sadness in the home. . . . So that is a struggle, where will I go during the final days. We'll probably be here, but there's that side of [me] that feels [I] don't want to leave that heavy feeling when people walk in the home that the first impression will be “this is where [Brianne] died.”

Corporeality (lived body). Once she got her diagnosis of pancreatic cancer with metastasis, Brianne decided against any treatment and opted for quality of life instead of quantity. “Mine had metastasized to the colon and bowel and I already had ulcerations in my stomach. . . . So I decided . . . the odds weren't in my favor so I just elected to do quality of life.”

One of her hopes for the end of her life is to be comfortable, but there is still fear of the unknown. She explains:

You know, you get all the drug therapy you need to be comfortable. So on one level you feel at peace with that, but on another level, you know, we're afraid of

the unknown. So that is the part, maybe, there is some ambivalence. But, you know, I have strong hope that I will be comfortable. . . . Not being able to predict, I think that's the hardest.

Recently, the pain has been getting worse causing nausea. She is attempting to find the correct medication dosage:

The pain is triggering the nausea. . . . But [the doctor] thinks I just have a high tolerance [for] pain. . . . So now if I have any form of, even slight, discomfort, he doesn't want to leave it up to guessing. So, I'll start taking MS . . . at night. From tonight I'll take 15 mg slow-release, so I'll sleep through the night and when I get up . . . it will still be in my system, so I'll be functional. . . . My big problem, that I keep fighting them is that I don't want to be put down. . . . At this level, I'm okay. I'm functional, but when I went to 30, boom, I was out cold.

She does not dwell on the progression of her illness:

I take things as they come so I don't anticipate what may come. . . . Just pickup and do the best you can out of the day. . . . The other hard thing is I'm the kind of person who likes to be in motion, so when the days that I'm not feeling well, that's real hard. . . . It's been a little more difficult . . . because you realize you are beginning to see some limitations take over your life. . . . The hardest part of being ill is having to lay in bed or having to sit down and you can't do anything. To me, then I feel [like] a prisoner of my illness. That is why I really shy away from drugs that are going to make me groggy because that is like giving up my freedom.

Brianne is truthful about her condition to her family who are on the mainland. “I’ll say, it’s been a rougher week or a rougher day. And so when they do come, they’re not going to be surprised . . . you know, if your appearance changes.” Her weight is a sensitive matter for her and indicates her health status. “For me, weight is a huge barometer of my health and so that is a sensitive issue.”

Participant Three

“Charles” is a 55-year-old Japanese man with a diagnosis of end-stage emphysema in 1999. He had a third of his lung removed in 2004. His health really deteriorated in 2007 after his beloved dog died. He is now dependent on oxygen. He is living at home with his parents and has been anxiously waiting for death to come.

Temporality (lived time). Charles has been looking forward to dying. He wants to die to get relief. He explains:

When hospice came, I told them there’s no relief. I am not going to get any relief, now is to die. . . . I have been basically waiting to die because death is the only relief I’m going to get. . . . At first I didn’t want pain. , , , After two years, I don’t care. I don’t care how painful it is, I don’t care. I just want to go. . . . I don’t need the last thing, the last meal, last this. . . . I just want to go. . . . So if [euthanasia] was an option here, I’d take it. I’d take it. I’d take it in a heartbeat, cause I’m tired. I’m real . . . I mean [really] . . . I’m tired.

His biggest fear is “hanging on.” “The fear is I’m going to keep hanging in there and keep hanging on. I don’t want to be alive next year.”

He is not considering ending his life himself, but if death happens as a result of a treatment plan, he can accept it. He was told that turning his oxygen off during the night

may help with his sinus, throat, mouth, teeth, and eye pain, but his oxygen may get too low and he may not wake up. He states:

I take the risk. At night because the oxygen dries my sinuses and my throat and my mouth and even my eyes to the point it burns. I take it off and I take an extra lorazepam for sleep, and the nurse said that if [I] do that, [I] might go to sleep and not wake up. . . . You basically die in your sleep. . . . [It] helps because now when I take it off at night before I go to sleep, I don't wake up with sore teeth. The teeth aren't as in pain. That helps. Besides right now, if that happens, it happens. That's a plus for me. I want to go.

He realizes he has no control over time. With his increasing dependence on oxygen, he cannot drive nor do things independently:

That's really frustrating because that means I have to depend on somebody. I cannot go very far because on 10 liters, the tank doesn't last. . . . I'm out for an hour and I'm exhausted. I got to come home. So that limits where I can go and things that I can do. We go to Kahala Mall and he pushes me in a wheelchair because I cannot walk around the mall. I mean, that's depressing. I live like that for the past two years, pretty much.

Relationality (lived human relation). Charles, 55, lives with his parents and depends on them to take him places and care for him. Despite his dependency on them, there seems to be little interaction among them.

I think they accepted it. Friday, she's going to Diamond Head mortuary to make the arrangements. It's not like she's making the arrangements in tears. I mean she kinda has the attitude of "everybody dies." . . . I don't know about my dad. I don't

know how he's going to take it. My sister and my nieces and nephews, they got their own lives. They'll feel sad, they'll feel a loss. . . . It is no big deal.

When asked if he talked to his parents about any of his feelings or what he wants, he mentions, "The only thing I wanted was to be put in an urn between my two dogs [who died earlier]."

His mother walked the researcher out after the interview and talked about her feelings, at which point she was encouraged to talk with Charles. Charles later wrote to the researcher and expressed his gratitude. His mother had returned to his room after the researcher left and they had a heart-to-heart talk:

She told me that while they will miss me, her and my dad will be alright. That took a lot of stress off me and lifted me out of my depression. I didn't realize it, but that was exactly what I needed. [It] meant a lot and makes my passing that much easier and less painful.

Charles has other people willing to help him and provide stimulation and enjoyment. He finds mental stimulation in talking with hospice. Hospice has been helpful trying to find the right medication for his pain control. He especially enjoys talking with the nurse:

[I] think the most helpful has been [the nurse] because she'd come, we'd sit and we'll talk. I can talk to her about stuff. . . . That is one thing I miss about being in school. I go to school, my ideas, my opinions had weight. People respected me. . . . When they took me off [hospice] last year, she came on her own time. She couldn't come every week, but she made time to come and see me.

His neighbors were willing to take him surfing when he expressed he wanted to surf one last time. He declined because it would be too much of an imposition on them:

I wanted to catch one last wave. There's a couple that we know up here. He works in the Coast Guard. The wife just got a new job at Hawaiian Airlines. They are going to help me do it. Handi-Van going down somewhere. . . . That meant I had to be off the oxygen. The imposition, as busy as he is, he is with the Coast Guard, APEC is coming, the Coast Guard is really busy. She just starting her new job at Hawaiian Airlines, so she's really busy. So it will be a major imposition. It would be just too much work for everybody including me . . . so I just told them to forget it.

He describes a negative interaction with a healthcare provider. The dentist refused to fix his teeth, even though his teeth cause him a lot of pain and fixing them would improve his quality of life. "Once [hospice] tell him I am on hospice care, [he] figuring you going to die. You got six months or less to live and why work on it. So [the doctor doesn't] want to do it."

Spatiality (lived space). To Charles, his life is of no value. He has to depend on his oxygen tanks almost 24 hours a day. His condition makes even a simple task such as walking very tiresome and he gets short of breath very easily. He cannot do much for himself, and he has to rely on others to take him to the doctors or do things for him.

I'm basically "bedbound." I can still walk around the house and whatnot. I spend twenty-three hours a day in bed. And so basically, TV is my life. That's about it. I eat. I sleep. It is just a useless existence.

Death would mean relief. “Nothing is as important to me as dying. Nothing. . . . [It] means relief, and end. . . . I’m gonna be done. I’ll be finished. There will be no pain, no fear, no doubt. It would be over. I’ll be finished.” He views that after death, he would be happier being with his dogs he loved. “I’m not a religious person, and my vision is I’m gonna die and I’m gonna be reunited with my two dogs.”

Corporeality (lived body). Twelve years ago, Charles was diagnosed with emphysema. His condition has deteriorated to the point where he is dependent upon oxygen. He can no longer do things that he had enjoyed such as surfing, going to school, and driving. Even walking is difficult. “I . . . get shortness of breath just doing little things. . . . They put me back on hospice, and I have been on it ever since. And I have been on max oxygen for the last six months [and] max medications.” Hospice has been adjusting his medications for pain control and to ease his breathing. Eating is difficult for him because his teeth are in ill repair. He has lost three crowns and has a cracked tooth. He cannot find a dentist who will fix his teeth because of his breathing difficulty and the need to be on oxygen and the type of insurance he has. Hospice is assisting him in finding a dentist but without any luck.

Charles feels he has no joy in his life. He has lost his independence:

The quality of life is pretty much gone because I can't really do anything. I cannot go to the movies. I cannot go to a restaurant. I cannot go to the beach. I cannot go. I'm basically “bedbound.” . . . It is just a useless existence.

He views death as relief:

I have been basically waiting to die because death is the only relief I'm going to get. . . . At first, I didn't want pain. That was my main concern. I don't want to

die painfully. . . . Hospice assured me they get medications that make the transition as painless as possible. After two years, I don't care. I don't care how painful it is. I don't care. I just want to go.

Participant Four

“Duke” is a 59-year-old Hawaiian man diagnosed with pancreatic cancer. He first started having problems with his pancreas in 2001 and was hospitalized again in 2006, 2009, and 2011. During the 2011 hospitalization, the physician asked Duke if anyone told him that he had pancreatic cancer. Hearing the answer “no,” the physicians finally told him he had pancreatic cancer. He is now living in a hospice home. He has one sister with whom he is close and who is doing the preparations for when he dies. She lives on the other side of the island.

Temporality (lived time). By the time he was diagnosed, the cancer had metastasized. The doctors told him that chemotherapy would not make any difference, so he decided against it. “I decided not to take chemotherapy because it doesn't make sense. Control pain and whatnot. . . . [If] chemotherapy sort of going to last for a while, it does make sense.” He decided against chemotherapy, requested palliative care, and asked not to be resuscitated should his heart stop beating. He shares:

I told my doctor that when it gets worse . . . [if] they can put me at ease. He said [he] would let me sleep easy instead of letting me lay there and watch me suffer. . . . I can't predict the future. I can't predict what's going to happen to me. . . . The future, I leave it in God's hands. . . . They gave me six months and if I can go another month of living, another month of living. It depends. It depends on my body and it depends on the Person above.

He wants more time but also realizes, “When it's time to go, it's time to go. There's nothing you can do about it.”

Relationality (lived human relation). Duke prays to God. “I always pray and thank God and Jesus. I always pray to Them and tell Them, ‘Thank You for everything,’ for what They have given me and what They created for us.” He asks for forgiveness for his sins, thanks God, and prays for himself and others:

[I] ask God to help me to sleep through the night peacefully and may I see the next day, and I always thank him for the bread of life. . . . I always ask Him to . . . bless the people who's involved with me and bless the people here. Bless the people outside too. . . . When the time comes and if I don't get up one day, it's okay. That was a good time to go. I always thank God . . . and I always thank the people that helps me out. . . . I can't predict the future. The future, I leave it in God's hands.

He has a close relationship with his sister. She calls him often:

She's my right hand. She's going to be the one. When I'm gone, she's the one that's taking care of what she needs to do with my body. I asked to be cremated. They asked me, “Where you want to be scattered?” I told them, “You guys choose. It doesn't matter where. What you want to do is just be at peace.”

He states that leaving his family and friends behind will be the most difficult task for him. He also realizes that it will also be hard on them:

All I can say is that dying is . . . a better relief for me. Better off for me. That way, I don't have to suffer the rest of my life. Doesn't make my family suffer too

long and my friends. That's why when it's time to go, it's time to go. There's nothing you can do about it.

He finds the healthcare providers at the hospice home most helpful:

They're always there when you need them or you call for them, they're always there. . . . They really, really do the best to help me out. They make me comfortable. They make me happy. Keep me as happy as I can.

He has advice for others including healthcare providers. “You got to ask the patient what he or she wants because that's their body and let them make the decision.”

Spatiality (lived space). Nature makes him happy. Duke loves his hospice home because he can look out of his window and enjoy nature. Even though his sister wants him to move to a home closer to town so it would be easier for her to visit him, he turned her down because he enjoys the view:

I like the scenery I got over here by my window, the swimming pool by the canal.

It makes me happy. I love the birds and all the geckos. Got plenty geckos running around here. I like the doves. They always come by my windows, the doves. I like the plants and everything.

He said it is important for him to live the best he can each day and that includes enjoying “each scenery . . . each sunrise, sundown, and . . . enjoy what I have. . . . Enjoy the people. Enjoy that I can see out. . . . I am happy where I am.”

Corporeality (lived body). The problems with his pancreas started in 2001. They told him that it was inflamed, so he changed his diet. For the next 10 years, Duke was hospitalized several times for the same problem: his pancreas. Not until 2011, when he was hospitalized for generalized swelling, red urine, and breathing difficulty, was he

finally diagnosed with pancreatic cancer with metastasis. He believed that his unhealthy eating and drinking were causes of his cancer.

I was eating a lot of high cholesterol foods like fatty foods and a lot of greasy foods and lot of soda and chips and high [sugar] candy and a lot of saimin. And that's what inflamed my pancreas. . . . I could have listened to my mom. . . . She's always telling me stop drinking, stop smoking. Stop drinking. Stop smoking. You aren't going to make it in life. Stop drinking, stop smoking. "Yeah, yeah, yeah, yeah, yeah." I wish I had listened to her.

He decided against chemotherapy because they told him that it would not make much difference and gave him six months to live. He wants to be kept comfortable:

When I walk, I get short of breath. When I eat, I get short of breath. When I drink, I get short of breath. When I walk to the bathroom, I get short of breath. When I use the bathroom, I get short of breath.

The hospice nurses are managing his shortness of breath and pain. Between the analgesics and the sleeping pill, his pain is managed. He is very appreciative that they are always there. "They really, really do the best to help me out. They make me comfortable. They make me happy."

Participant Five

"Edward," a 68-year-old Korean man is diagnosed with lung cancer. He lives at home with his wife. He wanted to be interviewed outside the home because he did not want to upset his wife.

Temporality (lived time). He went to see a doctor after he suddenly experienced shortness of breath while carrying his great-granddaughter, and then again the next day

while walking to the plane. He could not breathe. He was diagnosed with lung cancer and was given a life expectancy of six months to one year. That was three years ago.

The doctor is surprised that he is still alive. He is happy and continues with his life, not dwelling on dying:

[The doctor is] . . . surprised that I'm still here. . . . I don't know what's going on in her mind, but I think that I am outliving what people thought initially, and I have no problem with that. . . . The doctor says, “. . . I cannot say whether you have one year or five years. We just don't know.” So, I don't live thinking that I am going to die next year. I live. I know I'm going to die. I don't know when.

Relationality (lived human relation). Edward believes in God and life after death. The world after death is a better place where one will live with God. However, he is unsure whether he is worthy to enter heaven. He wishes he paid more attention in church and lived his life more like a good Christian.

I've been going to church all my life. . . . I believe. Whether I deserve to go is something else. I haven't been a very good person all my life. . . . If you believe, all you have to do is ask for forgiveness and you're forgiven.

He plans to be cremated and his wife will take his ashes to their house. When she dies, his children will cremate her and mix their ashes together and then scatter their ashes. They would be together again. However, he is open to the idea that she may meet someone else. He is concerned about his wife. She is worried about how she will take care of everything.

I don't think too much about dying . . . although I think my wife does, and she's concerned about what's going to happen when I do die, how she's going to take

care of everything, and how her life is going to be without me. . . . She accepts it, too, although sometimes she gets upset. She knows it is inevitable . . . [but] she doesn't want to think about it.

To prepare her, Edward is teaching her things that need to be done.

He appreciates what his wife has done for him and wants to tell her so before he dies. He says that although he was articulate in his profession as a lawyer, he finds talking about his feelings very difficult:

Before I die, I want to talk to my wife and make sure she understands that I appreciate what she has done for me . . . sticking with me in spite of the illness. . . . I get hard time just speaking to another person and letting them know how I feel. I don't have an easy time with that. I get easy time talking, but to let them know how I feel, that's a little bit more difficult.

He gets angry with himself because he takes out his frustration on her instead of talking with her. If he had the resources, he wants to take his wife to places she has not seen: the big sequoia trees in California, Spain, and to Germany to visit her brother, whom she had not seen since 2005.

He says he is not afraid of dying but is sad that he is. He will miss seeing his wife, children, and grandchildren accomplish things, for example, graduation:

I feel sad. To me, I feel sad that I'm going to go. I don't think I'm afraid of dying. I just don't want to die. So I feel sad that I'm going to because I got a lot of grandkids. I got my wife, my children. Not being able to see them do certain things, that's what makes it sad. But dying, I think, is so final.

He has an estranged relationship with his brother. As he talked about his relationship with his brother, his anger surfaced. They have not talked for many years, and even when his brother found out that Edward is dying, he did not contact him. Edward told his wife not to let his brother come to the funeral.

Spatiality (lived space). Edward wants to die on Kauai. Kauai is home. He does not want to die on Oahu. He wants to die on Kauai in the hospital where he can get pain medication quickly if he needs it. After he dies and is cremated, he wants his ashes to be placed in his home. When his wife dies and is cremated, their combined ashes will be scattered.

Corporeality (lived body). He knew something was wrong when he could not breathe as he carried his great-granddaughter to the car. He had to give the child to her father so he would not drop her. After several tests and visits with doctors, he was diagnosed with lung cancer. He started chemotherapy, and, initially, he was “sicker than a dog,” but is now handling it very well. “In dealing with this illness, the treatments are the most difficult.”

His family is no stranger to lung cancer. His father, uncle, and cousin died from lung cancer. His cousin was about the same age as Edward. When Edward asked what his prognosis was, the doctor said, “Well, you going to have a lot of pain, and then you're going to die.” That is what concerns him the most, the pain. “The only thing I'm concerned about is the pain, that I cannot stand pain. I tell all the doctors I see that I have an allergy to pain.” He has been reassured by his other doctors that they can control the pain. His definition of a “good death” is “one that is painless. One where you just fall asleep. Where everything stops.”

Participant Six

“Frank” is a 57-year-old Filipino man with Stage IV lung cancer. He lives at home with his wife and son. He shares the timeline and events leading to his diagnosis. Everything is written on a calendar.

Temporality (lived time). Frank was diagnosed with Stage IV lung cancer in 2009. He had gone to the emergency room because he could not lift his arm. He remembers that two years prior to that incident, he had rib pain, which the doctors told him was bruised ribs and did not run any diagnostic tests. When he was diagnosed, the oncologist told him to get a second opinion. The second physician told him he had lung cancer. He knew it was serious and he lost hope. He felt that there was nothing anyone could do. With chemotherapy and radiation therapy, the cancer became smaller, giving him hope. In fall of 2011, he received word that the cancer had spread to his bone and spine. He restarted his “anti-cancer” diet.

Since 2011, his chemotherapy regime has changed. He is hoping for more time. “I could outlive my cancer. Maybe I could live five years more or maybe, ah, if it is going to shrink, I might live another 10 years more.” He hopes he has time to finish transforming his basement into an apartment, so his wife can rent it out for income.

Relationality (lived human relation). Frank prays to God every day. He had a difficult time coping with his first chemotherapy and prayed for assistance. He prays for the cancer to stop growing and prays to be healed. Contradictorily, he says that he is ready to die. “I had already surrendered to God that any time that He likes me to go to Him, I'm ready. But in my mind, I am fighting it, fighting my sickness.”

He thinks that death is a happy ending because God is waiting for him, and it is a better place, but he is sad for his family:

I think it's a happy ending. I'm happy to die. . . . I'm prepared. I know God is waiting for me. . . . Since dying is going to another place better than what I am now, it is not really hard, but the loss of me in the family . . . there is an emptiness in their hearts.

His family is very important to him. Since he is unable to work, his wife is now working two jobs. He is trying to renovate their basement, so they can rent it out. “At least my wife could have extra money and she can quit the other job.”

His son returned home after he graduated from college and is helping them. Frank worries about how he can help his children with their education and become successful, so they can help his wife in the future:

The most difficult thing for me [is] trying to sort out how to help my kids be successful in their studies, and then hoping that my kids are going to help their mom when they're done, or when they're already working for the mortgage.

He hopes that his family is with him when he dies:

I wish that my kids are with me, my wife, when I get bedridden . . . or at least . . . come for my burial. I had the experience that it is much easier for those who have lost you, accept you when you are cremated.

Since Frank does not work now and stays mostly at home, he misses his friends. “Socially, I am disconnected to friends. Because I'm just right here, and I just cannot go out and talk to friends.” When he does spend time with his friends, he does not feel ill.

He describes a very negative interaction with one of his early physicians which affected him deeply. When the doctor declared, "You are in Stage IV cancer, lung cancer, and I'm sorry. You're going to die," Frank sank into depression. The physician had shown no compassion. He was the "angel of death."

He has some suggestions for the medical profession. He thinks each patient should have a panel of doctors instead of being referred to another physician:

If you have a panel of doctors, they could try to formulate an idea that is best for you so that it will be easier for your treatment. Not only one doctor . . . but if it's a panel of doctors, then it might be easier to analyze one problem.

He also feels that medicines should be available to everyone with a particular disease or disorder. He had seen a new drug on television for lung cancer, but it was not offered to him. He believes that it should be available to all who are afflicted with cancer, and not only to those who can afford it, who are in the continental United States, or who has insurance.

Spatiality (lived space). Death to Frank is a "happy ending" because God is waiting for him in a "better" place. On the other hand, he is sad knowing how his family will be affected. He wants them at his bedside when the time comes or, at least, at the burial, and he wishes to be cremated. He feels that both of those requests will help the family accept his death. There is love and caring, but not complete openness. He has not discussed his dying and what he wants with his family because of fear that it would make them depressed. "If I start talking about that topic, their positive attitude towards me becomes into a negative . . . and the morale will go down." It is as if he has built a

bubble around his family, trying to be positive, and not bringing up anything that would create depression.

Corporeality (lived body). Frank is very specific about the details of his condition, referring to a calendar for dates and sequence of events. After multiple tests when he went to the emergency room because he could not lift his arm to change a light bulb at work and was in pain, he was given the probable diagnosis of cancer. A biopsy confirmed the diagnosis, Stage IV lung cancer. He wonders if the pain he felt in his rib two years prior was indicative that he had cancer then. He was told by one of the physicians that smoking caused the cancer, but he only sporadically smoked cigarettes given to him, and he never bought a pack himself.

Chemotherapy was terrible. Smells affected him; he could not eat. He was always nauseous that he had to keep a bucket by his bedside. He felt so weak that he was unable to do anything. He lost weight, “going down little by little.” He prayed to God:

It is only on the mercy of God if I still could go through [it]. . . . So with the help of God, the chemo and my prayers, I am surviving little by little. . . . The only problem now . . . in September last year 2011, they said my cancer had moved into my bone and to my back.”

He started to eat healthily and cut back on meat and sugars. “Sugar is the food for the tumor. . . . So mostly I was having a vegetable diet that are high in alkalinity.” He stopped the diet for a while, but is restarting it now that the cancer is spreading.

He is trying to live “in a positive way” and ignore the fact that he is terminal. When he does think about his condition, he becomes depressed and more anxious. “When I think about it, the more I slump myself into the couch and the more anxiety I

become.” So he tries to keep busy. He is busily working on the basement renovation. Recently, as he was working, pain in his side increased. He rested for three days. Now that it has subsided, he is resuming work on the room.

Participant Seven

“Gina” is a 58-year-old Filipino woman with breast cancer with bone metastasis. She was originally diagnosed 11 years earlier and was believed to have been cured. She lives at home with her husband.

Temporality (lived time). Gina was first diagnosed with cancer in her right breast in 1994 and chose to have a radical mastectomy, even though it was very small. Believing that they removed all the cancer cells due to the extensive surgery, she did not need any chemotherapy or radiation. She thought she was “cured,” but 11 years later in 2005, she was diagnosed again with breast cancer with bone metastasis. “So essentially it has spread after 11 years, when I thought. . . . They usually say that after a certain amount [of time], . . . ‘you’re safe.’”

When she was diagnosed with metastasis, she tried naturopathic remedies. She did not want radiation or chemotherapy, so she spent a year trying many different remedies without much success. In looking back, she has no regrets in trying alternative healing methods before resorting to chemotherapy or radiation. She needed the time to accept radiation and chemotherapy and to prepare her body for it.

She views cancer as a gift. It made her examine her life and realized that life was precious. “So knowing that life is precious, what you want to do with it?” She was busy “doing, doing, doing, doing, and not really paying attention to what my needs, my

personal needs were.” She examined how she wanted to spend her life and took time for herself. When she was diagnosed with metastasis, she asked:

So why did the cancer come back again? . . . You know how they say that the universe sometimes keeps sending you messages, or God or universe or whoever you want to say, keeps sending you messages. If you don't get it the first time, the next time it comes a little bit harder with more force. . . . So I think at this point . . . it's calling me to get back to my spiritual journey.

She is not afraid of dying:

What is the saying, “Today's a good day to die”? I don't dread it. Dying is not an issue for me, I guess. I think that I lived my life pretty well. I have had a wonderful life so far. I have no regrets. So if it happens to be, that's good.

She wants to enjoy life as much as she can. She keeps a positive outlook and believes that is why she is doing well.

Relationality (lived human relation). She believes one of the purposes of her cancer is for her to continue on her “spiritual journey.” So she meditates and has joined a centering prayer group. She sits in silence for 20 to 30 minutes and focuses on God’s presence within her:

At some point, then you're totally open for whatever presence that’s supposed to be there. It is like an intensive listening and being in a receptive state for whatever is to come to you. . . . We read part of the Scripture . . . and there is moments of silence, three or four moments of different silence where we contemplate on the Scripture and try to see what comes up spiritually for us, and then afterwards, we talk about our experience of that Scripture.

She advocates for open communication with family and friends, so they can provide support. "I think it really is helpful . . . just so that you, as the patient, don't feel like you are bearing the burden alone. It lightens the load. And it may even offer you a new outlook." She does not want people to feel sorry for her and takes offense to them asking, "Oh, how are you doing?" She sees it as a "'poor me' kind of attitude." At one point she finally told her friends:

When you see me, [do] not think of me as "Oh, look at poor [Gina] with cancer.

Oh, we feel so sorry for her." I want you to look at me and think, "Wow, look at [her]. She is doing so great today. Look at all the stuff that she can [do]."

She wants to be seen as more than a "diseased sick person because that's not who I am. I am more than that. I am way more than that."

She describes her husband as phenomenal. When she was very weak and ill, he did everything from cooking to cleaning house to washing her clothes. "I didn't feel like he felt sorry for me. I didn't . . . feel like it was really burdensome." She is very appreciative that he kept a positive attitude when he was in her presence. What is important to her now is being with family. She has three grandchildren and one on the way. "It's priceless to have the young ones around and to see them especially at this time when they're growing and changing." She is planning a trip to Missouri for a family wedding in June. She and her husband will continue on to New York to see Broadway shows and will be staying with a friend.

She is very grateful to the infusion center and the staff, especially her oncologist. "You really get that she cares about you and that's really important that you believe in your doctors and the people that are taking care of you." The physician knows that

performing is important to Gina and she has considered this quality in developing her treatment plan:

[The doctor has] been sensitive to me maintaining a quality of life that I want for myself, and that's being able to perform because she is a musician herself also. So she understands perfectly. . . . The treatments that she's developed is so that I can still go for treatments and still have the ability to perform and not be so debilitated from the treatment that I can't participate and perform.

Spatiality (lived space). Since Gina views cancer as a gift, she prioritized and started doing things for herself, doing things she likes and eating more healthily. When she was diagnosed with cancer the second time, she re-examined her life and believed she needed to continue her spiritual journey. The cancer also reaffirmed how she wanted to live, with a positive outlook:

The positive outlook is very, very helpful. Sometimes, you know, you get into feeling sorry for yourself, sometimes, but I try not to dwell there. And just being appreciative and thankful for everything that I do have and that I can do helps keep me going. . . . I think that is why I am I doing so well for so long. . . . You have a choice in how you live your life and how you experience your life. You can experience it negatively and be sad, be mad, be angry, or you can experience it positively, and be appreciative and thankful and excited. It is a simple choice that we make each day and each moment. So I go for the positive and the happy part. Who wants to be sad and angry? And I think some people don't realize that it is a choice that we can make and no matter how much pain we might be in, or how tired we may be, if we don't focus on that and focus on "I have a very caring

family and I have so many friends who love me and care about me.” If you focus on that, you can't go wrong.

The cancer gives her an opportunity to be an example, a role model, for other people. It allows her to demonstrate to others how to deal with a devastating condition. “You can deal with it well and you can still live your life, you can still enjoy your life, and I think that's part of my purpose and the purpose of dealing with cancer.”

She wants to enjoy life on Kauai. “This is a paradise. . . . I think a lot of times we forget to appreciate how fortunate we are, as people living here, especially on Kauai, in this country, and everything that we have.” When asked about how to improve her quality of life, she replied:

Well, the quality of life I have here on Kauai is really top-notch. We have clean air, we have clean water. We do have access to fresh vegetables that aren't filled with pesticides and stuff. We do have to rely on a lot of foods that are brought in from the mainland and that is a consideration, but . . . How could I improve my quality of life any more than it is?

Corporeality (lived body). Gina was first diagnosed in 1994 with breast cancer and opted for a radical mastectomy. Since the lump was very small, the physicians believed that she did not need any subsequent chemotherapy or radiation. She started to eat more healthily and started to do things she wanted and to enjoy life more. Eleven years later in 2005, she experienced pain in her chest while she was doing yard work. It was a sternum fracture; the cause was bone metastasis. Later she fractured her hip. The pain made her rely on a cane for walking.

Not wanting to submit her body to radiation or chemotherapy, she tried many alternative nonconventional therapies. “I didn't want any chemicals. I didn't want radiation. I didn't want chemo. I kind of was making things a little difficult for my oncologist.” Gina tried homeopathy to build resistance to the cancer cells, kinesiology testing to various substances, decreasing heavy metal poisoning by changing all her teeth fillings to enamel, and even sought the advice of a few psychics. These treatments, not covered by insurance because they are considered as unconventional and unnecessary, were expensive. “But I felt that it was important.”

When she consulted the psychics, she prepared to ask them questions. “One of the questions I asked, and I talked to two different people, was: ‘Is chemotherapy or radiation beneficial for me?’ . . . The answer was ‘yes,’ which was not the answer that I wanted to hear.” She ignored it for a while until another person confirmed it.

A personal friend of mine, who I know and I respect as someone who is connected with spirits, he did kinesiology on me and it also confirmed that chemotherapy would be beneficial for me. I burst out into tears, and I said, “But I don't want to hear that.”

Later she realized that she gave a year for the naturopathic way to work and decided to give radiation and chemotherapy a chance. She had no regrets taking the time to try the naturopathic treatments:

I believe that all I did naturopathically in the very beginning was actually [what] I needed to do because it helped my body prepare, to be able to take the chemo and radiation. I think if I hadn't done that first, I really would have been down for the count in doing the chemo and radiation. So taking the fillings out, detoxifying . . .

it was a detoxifying thing too. So I think that was important for me to go through that first. . . . I was not ready for chemo or radiation. . . . I have to feel like I had done everything possible naturally before going to the chemical thing.”

She flew over to Oahu for radiation treatments and returned the same day and reported to work. Sometimes, she could not go to work because of the side effects of the therapy. Once radiation was completed, she started on chemotherapy and has been on it ever since. Regimens change and the side effects vary with dosage and medication. She has had many infections:

So [the doctors] felt that by making the dosage smaller, spread over a longer period of time, will be easier on my system. So that seems to have worked because I don't have all of those infections recurring each time.

She lost her long hula hair, “which in the beginning was a very big deal for me because [my] hair was part of my identity and now I don't care anymore.” She uses wigs and has a whole collection of hats and berets. “The wigs are fun and I have wonderful hats and berets which people have complimented me on my berets. So not having hair doesn't bother me anymore and I'm able to deal with it.”

One of the side effects she had recently was myositis where her thigh muscles were inflamed and causing pain. Changing the chemotherapy agent stopped the pain, and the inflammation is slowly improving. Gina feels better and is happy that she can walk and still perform on stage:

I perform nightly at South Pacific, a musical in the dinner theater, and even when I was walking with a cane, was able to perform on stage. The character that I played is an older woman, so . . . having a cane added to it actually.

For her, the most difficult part has been

Realizing that you can't do everything you want to do. . . and . . . when you're in so much pain, you can't do anything else but just lie there. But I guess it is mostly just knowing that . . . there are limitations in your life.

When asked what her vision of a “good death” is, she replies:

A painless death. I believe, I think my uncle died this way. He just died in his sleep. . . . But another more romantic view would be . . . going together with a loved one . . . like the movie, *The Notebook*, where the couple were in bed together, and they just both died. That would be the ultimate.

Participant Eight

“Hana,” a 60-year-old part-Hawaiian, Japanese, Caucasian, and Chinese female, lives at home with her husband. She has been diagnosed with breast cancer with bone metastasis.

Temporality (lived time). Hana was first diagnosed with breast cancer in 1998. She underwent chemotherapy and radiation from 1998 to 1999. Later in 2009, she went to the emergency room for what she thought was a heart problem. It turned out to be a fractured rib. The cancer had metastasized to her bones. She at times wonders if it was because she did not remain on chemotherapy for five years as the physician had prescribed. “It is what it is now and that is all there is to it. So, I don't dwell on it a lot.”

She has restarted her chemotherapy which she finds an inconvenience. Although she considers herself to be an “on the spur of the moment” type of person, she must now schedule her life around her treatment regimen. She has managed to go to Las Vegas and Atlantic City a few times and is planning future trips.

There is so much she wants to do. Besides trips to Las Vegas and visiting family in Ottawa, Ontario, she wants to see her granddaughter graduate from college. "I want to be able to hang around for that. That would be so satisfying to me. I want to see our grandson graduate from high school. He's got two more years." She asked her physician if she would be around next Christmas. She was told, "You got to talk to God. Only He knows." So she has been praying to God. "Because I have goals. I have things I want to do, but if I can't, so be it. I'll be disappointed, probably, but it is what it is."

She views the time she has had as a gift. "However, being a cancer warrior from 1998 . . . and I wasn't just like in the . . . early stage. . . . I was like Stage Level II [or] III, back then. So everything I have today was like a long gift of time." She realizes that her life has a time limit, and she wants to prepare her family and loved ones:

[I want to] make sure that the people closest to me, my family, my husband, that they would understand that my time is limited. . . . My illness have a definite timetable. . . . I want to make sure all the people that truly love me, that they will be prepared, or I can help prepare them. . . . I've been doing that, preparing them, showing them that when this happens, the best thing to do is to live. Live as normal as you can.

She has a bucket list, things she wants to do before she dies. One of her unfinished affairs is completing her parents' estate:

I think I pretty much [took] care of a lot of it. And after I say something like that, I would always say, "P. S. God, that doesn't mean that I'm saying that I'm ready, okay?" . . . I still got things to do.

Relationality (lived human relation). Hana considers herself very lucky because she is loved by her family and friends. “I had the love of family and friends that I could not even measure, that I cannot even begin to explain or express.” She is so grateful for having such a supportive husband. He took the trouble to read up on her cancer. “From that first diagnosis in dealing with my cancer . . . he was so supportive of every aspect of my care.” He carries her purse because she now has a tumor on her shoulder. He drives her to chemotherapy, accompanies her to all her appointments, and is there for her around the clock. “That’s priceless. I don’t know what else one can expect, and that overwhelming love and support is amazing.” Hana also realizes that “it’s tough being a caregiver” and encourages him to go on a three-week break to their granddaughter’s graduation in Canada. “He’s been so supportive to me towards our life here . . . living. I’m lucky. I’m really, really, really, really blessed.”

Friends even come from far away, to see how she is doing. Family and friends are very important to Hana, and she wants to prepare them for the inevitable. She is concerned about her siblings. She and her siblings had lost their two parents in 2010, and it has been really tough for them. She has three sisters and one brother. She is the oldest of the girls, and although her brother is a year older than Hana, she assumed the parent role. She was always the “leader of the pack.” She is doing all she can to prepare them. She instructs:

Don’t you dare put me in a coffin! I don’t want to be in a coffin. I given them explicit instructions, just to the point, all of the directions: what funeral, what mortuary to use, what I want done, how I want [them] to cremate me. I want this.

I want that. Don't you dare do this! Don't you dare do that! I know I talk like that in front of my family to prepare them, and so they wouldn't be afraid.

Her siblings jokingly ask her if she wrote everything down. She also has gotten her other affairs in order. She has given away her valuables, such as jewelry, gold, designer bags. She does not want her husband to have to deal with it. Furthermore, it was important to her to do this:

I just wanted them to know that I wanted them to have these treasures. . . . My husband was happy because it took the burden off of him. There's still a lot of things in the house that he will have to contend with.

She is also creating memories for her siblings:

I don't want my siblings, especially, to suffer. I'd like to think that they going to have this great void. So, in the last year I've been doing more, more to be with them. . . . We [her sister and two nieces] were up in Kokee this past weekend, and I wanted to dance naked underneath the stars, and oh, my God, they got out there with me. And it's that kind of thing that they'll draw on . . . because I was so [nutty].

That was one item on her bucket list. It was liberating. "It was just to know you could express yourself, and you could live your life and do the things that you truly wanted to do without judgment. It's a wonderful thing!"

She had originally asked her husband to dance with her under the stars for her birthday present. He declined:

He just said, "You're crazy," but anyway it's a lot easier to do that with a bunch of women than in mixed company, and it was so precious to me that [I got to do it

with] my sister and my nieces. There was no hesitancy on their part, and one of my cousins who jumped in and joyfully said, “Oh, my goodness! I love this! We are creating memories.” And that’s precious. I have the most wonderful things to take with me or that I’ve given. I hope my niece will remember that. . . . There are a couple of other things [on my bucket list] that I’m not allowed to share yet.

She believes in and is devoted to God and prays to Him for herself and others. She prays so she has time to meet her goals, if possible. She prays that her family is prepared and has asked God to help a friend who was suffering. He assists her in her decision making. “I know God, and there is a definite love and devotion to the God that I believe. Otherwise I couldn’t make the kinds of decisions that I made in my life.”

She appreciates her oncologist, believing that the physician enriches her life:

[The doctor] could touch parts of your mind, your heart, your soul, as well as care for you. . . . I have the most wonderful doctor here. You know, part of the cure is the belief, not the cure. . . . Part of the cure is the patients’ belief in their doctor, and I completely, without any hesitation, believe that she would do the best she can for me, and what more can anybody else want in this world? . . . I think part of having that quality of life, as we call it, is having that doctor, that doctor and being close to your family, and your friends. Because the amount of support, love, and energy that you going to get from that, you cannot measure.

At one point, Hana was feeling very low. Her oncologist, knowing Hana loves music, sang to her a spiritual hymn. “It was amazing.” The physician had touched Hana’s soul, heart, and spirit. Another time, feeling Hana’s pain over the loss of her mother, the oncologist prayed with her. “[The doctor] has an incredible ability to

recognize her patients, their particular needs or their characters. . . . She also understands me, you know. She knows how to treat me.”

Another reason Hana appreciates her physician is that the oncologist orders many bone scans and tests to “have the most information that she can get to make the best decision.” On the other hand, her physician in Honolulu “was just overwhelmed, worrying about insurance and what it’s going to cost. . . . As a business person, I can appreciate all of that.”

Spatiality (lived space). What is important to Hana now is “to continue in this peacefulness that I have. I want my family to be comfortable with the inevitable. I speak about it. I talk about it. I remind them.”

Hana shares another memory she has created for her friends and family. She loves to dance, and after a rough year of broken bones, she decided she needed a dance party. She turned her driveway into a dance hall and had about 70 people dance the night away:

Music is [such a] wonderful place to get away. You listen to music, and you’re swaying and just enjoying it . . . and if you don’t dance and laugh and listen to the music, oh, Lordy, I don’t know what one would do!

Hana had a friend who was also diagnosed with cancer and he was so afraid of cancer and what it meant. “From the time he was diagnosed, he lived in fear of it. I used to always say to him, ‘[Friend], . . . don’t let it rule your life. Don’t let it dictate how you live your life.” She later saw him again and talked to him:

He said, “Well, I called hospice because the doctor said there’s nothing more that can be done. I just want hospice help keep me, to help me stay numb . . . so [I]

can go through it more easily.” [I told him] I want to be living. I want to be participating, doing lots of things. I don't want to be in hospice care until they have to help me, help me with medications or something. So he said to me, “You're just as sick as I am. . . . I just don't know how you do it.”

She did not know what to say to her friend. She continues:

I wish I could've said something profound to him, to help him, but I can't show [him] how to live. I can't teach [him] how to live, how to look at life. There's so much, there's so much [beauty]. . . . You sit out here. There's all these birds. They're beautiful. There's so many things that are so beautiful. I truly don't know how to, what to say.

She has thought about her death but does not dwell on it:

Well, if I was to say I've never been afraid, that would be a lie. Because everybody thinks about their mortality at some point in time and it's a little bit unsettling. . . . [I] could say, “Oh, if I only had taken my [medication].” But I'm not like that. It is what it is now, and that is all there is to it. So, I don't dwell on it a lot.”

She does not live with regret. Instead, she wants to live, to do the things on her bucket list and to enjoy life. She hopes to lie down one night and go to sleep and not wake up. She also voiced her concern that, like her mother, she may have extreme pain near the end:

I said to [my mother,] “Mama, just close your eyes and let our love carry you away.” So I said to my husband, “I want you to, if you see me suffering like that, I want you to hop up there onto my bed and tell me and remind me that . . . ‘Just

let our love carry you away.’” And, hopefully, I’ll just slip away nicely like that. . . . I said that to my mom and I watched her slip away, just like that.

Corporeality (lived body). Hana was first diagnosed with breast cancer in 1998 and underwent chemotherapy and radiation from 1998 to 1999. She was supposed to continue with the chemotherapeutic agent for five years, but she stopped. In 2009, she suffered a rib fracture which was diagnosed as bone metastasis from her breast cancer. She restarted chemotherapy. Tumors are still appearing. One is on her shoulder, which she calls her “noble emblem.” Even with nodules appearing, she generally does not feel ill. Other than the time of her broken bones, she is not in constant pain. So, she is trying to live her life as normally “as it should be and as it can be.” Yet, she is fearful. She is worried that doing the normal things that she loves to do would cause a broken bone or fracture. “Because it appears, unknowingly I could easily fracture my bones.”

She gets nauseated from the radiation, but she is able to control it by meditation and music:

I [am] able to sit in a chair or on the sofa, listen to the music, and just think the nausea away. Just imagine all that pain and my achy bones, just take it away through thinking. You know, I can usually do that. . . . I’m finding that is getting harder to do that. That frequency of the nausea is quite, quite frustrating. But in spite of all of that nausea, I’m alive.”

She is hoping that they will find a cure or a medication that will “hold the line,” so she can see her granddaughter graduate and other events.

She is afraid that she will have excruciating pain as her mom, who died of pancreatic cancer, did. She describes how she wants her last days to be:

[I hope my husband will say:] “Okay, close your eyes. Be comfortable” or “Just close your eyes and let our love carry you away.” And if I can keep hold of that thought in my mind, I am hopeful I will be spared, all that pain and hardships. . . . I hope that would numb my senses. But I also . . . want to be lucid. I want to know what's happening. . . . So I always thought I would swoon about and collapse away, knowing myself, the love for the melodrama.

The above quote was her description of a “good death.”

Participant Nine

“Iris” is a 42-year-old Filipino woman with breast cancer. She lives at home with her husband, spending most of her time praying and crying.

Temporality (lived time). Iris was diagnosed with cancer in her right breast in 2006. She had a mastectomy and completed radiation therapy and continues with chemotherapy. She feels angry and sad because she is so young. “I spend my days on my treatment instead of being happy, go to the mall, shop, exercise. . . . My life all stopped when I heard . . . that the cyst was cancer.” She still cannot accept the fact that she has cancer, and even has difficulty saying the word:

They just told me that I had the word “C.” Cancer was really hard for me to accept until now. It's been six years, but I'm still . . . cannot accept this. Why me? In all of the people, why me? Why at this point in my life? I am so young and all. But slowly, I'm beginning to accept.

She wonders if it was related to a condition she had when she was younger, about age 12. Her period was not normal, and the doctors in the Philippines said it was a hormonal imbalance. She recalls:

So [I] went to see another doctor who told me he wanted to examine me, and they will insert something, but I didn't want because I was so young that time. I was afraid. I was like if I had that, I would not be able to marry. I felt that doing that, I would not be a virgin anymore.

At age 18, she had cysts in her breasts, which were removed in the Philippines, but she failed to have check-ups when she moved to the United States. "Since I was so young, I didn't see doctors here. I just work, work, and work, and I didn't follow-up on my cysts." She regrets it because the cancer may have been caught earlier.

When she went to the Philippines, she noticed a dimpling on her breast. She waited until she returned here to see a physician. "That's when they found the 'C.' If I went to the doctor earlier, then . . ."

Cancer is like a death sentence to her:

When I heard the word "C" . . . the word "C" is life threatening. . . . I was afraid that . . . I have only little time while I wanted to grow old with my husband.

That's why it's hard when you want to do things like normally, like you go to the mall, shopping, picnic. . . . But when I learned about this, I just stayed home, in my room for how many years. Until now, I don't go out. . . . But for me, my happiness . . . it all stopped already. . . . My happiness . . . my hobbies all stopped.

Now she stays home, only going out primarily for her treatments. She does not find any joys in her life.

Relationality (lived human relation). Iris prays to God daily asking for His forgiveness. "Forgive me, for when I was young. When you're young, I guess . . . I tend

to answer my parents back when they scold me. I answer them back. I think all that stuff maybe . . .”

She prays that He will heal her. “I’m praying to God that He will heal me . . . bless all my medicines . . . all my doctors and nurses and all my medicines. He will bless them and He will heal me . . . through them. . . . I know He is beside me.” She believes that God hears her prayers. “He’s hearing our prayers, my family, my siblings’ prayers. People are praying for me, and He’s hearing us. That’s my consolation.”

When asked about what she thinks is going to happen to her in the future, she replies, “I don’t know. Only God can tell.”

Iris is close to her family. What is important to her now is “to be with my family and to continue with my treatment and being with the people I love.” Her sister recently came from the island of Hawai’i for a visit. Iris was so happy to see her and her family. She wants to visit her mother in the Philippines after her bout with chemotherapy:

I’m clinging to God and my family. They’re taking care of me, my husband, my sisters. They love me. So, that is a good feeling. But I have to feel good about myself, too, instead of crying all the time. I have to think about my family. They love me so much. I wanted to do all my treatment because I want to live. I want to be with them.

She knows that she cannot always be crying, but she cannot change. She says that her family has accepted her diagnosis and prognosis, and although she claims that she also has accepted her fate, she still cries, does not go out, and prays for a cure:

I always cry because it’s so hard for me to accept that I have this illness. . . . I only live one day at a time. If God heals me, then I would be very grateful. If He will

take away my cancer, I would be praising Him forever like I do now. . . . The rest, they all accept. They can easily accept. Only now, only this year, only this month, I can accept that I have this. . . . It was so hard for me. Like what I said, all my hobbies had stopped. I don't go out. I don't shop anymore.

She wants to return to work after her treatment. "That way I would be busy, and I won't stay in my room and cry." She is looking forward to seeing her coworkers.

She appreciates her doctors and the nurses. "When I go to the infusion, they take care of [me]."

Spatiality (lived space). Cancer is a death sentence to Iris; her world is shattered. She refuses to accept that she has cancer and will die as the result. She prays for God to heal her. She cannot think about the future and spends her time, praying and believing that God will heal her, and she will be well. When asked about what the end of her journey would be like, she replies, "I don't want to think [about] that. I just want to think that I will be well. I still want to believe that He will heal me. I will be well. I will do my treatment, and He will heal me."

Corporeality (lived body). Iris was diagnosed with breast cancer in 2006. Since her mastectomy she has been on chemotherapy and radiation. She has a history of hormonal imbalance when she was younger. She found multiple cysts in her breasts when she was 17 or 18 years old, and had them excised. She wonders if they were precursors to her breast cancer.

Cumulative Analysis

In this section, the data will be analyzed collectively. Comparisons and contrasts of the four existential life worlds between the nine participants will be highlighted. The

section will conclude with the identification of emerging themes. The themes will be further developed in the final chapter.

Temporality (lived time). All participants realize that their time is limited and beyond their control. “I [Frank] know I'm going to die. I don't know when.” “I [Duke] can't predict the future. I can't predict what's going to happen to me.” “If it happens, it happens and if it doesn't happen, it doesn't happen [Gina].” “When you go, you just go [Brianne].”

Five out of nine participants believe that death is determined by a Higher Being. Most of them believe that God has the power. “When He's ready to take me, He take me [Aaron].” Hana has been praying for more time “because I have goals. I have things I want to do.” Iris has been praying to be cured.

Life-closure activities are important. Since life is time-limited, four participants want to put it to good use. Hana views “everything I have today was like a long gift of time.” She is spending her time preparing her loved ones, living “as normal as you can,” and creating memories for them. She also has a bucket list of things she wants to do before she dies. Edward continues with his life, not dwelling on dying. Cancer has made Gina examine her priorities and what she wants to do with her life. She takes time for herself, does things that are important to her, and enjoys life. Brianne continues to be “productive,” preparing her loved ones, spending time with people who are “meaningful,” and creating a cookbook of her favorite recipes for her friends.

Time for preparation is important to four participants. For Brianne, Hana, and Edward, preparing their loved ones for the inevitable is important. Brianne not only has taken the time to ensure that the wills and other paperwork have been completed, but she

has cleared out her closets so her husband would not be overwhelmed with the task.

Hana has prepared her family by giving them lists of their responsibilities. She even has given away her valuables. Edward has been preparing his wife to manage their financial matters. Gina believes that she needed time to try nonconventional methods to combat cancer, which prepared her body for chemotherapy and radiation.

Four participants want more time. Duke wants more time, but also realizes “when it's time to go, it's time to go.” Similarly, Hana wants more time since she has goals and things to do. “I have things I want to do, but if I can't, so be it.” Iris wants to be cured so she can grow old with her husband, shop, and resume her hobbies. Frank wants more time to finish transforming his basement into an apartment.

Time has come to a standstill for three participants. Aaron does not know what to do and is asking God. “I ask Him every day. I ask Him what I have to do with my time. There's no sign, but I know that one day I going have to do something, and then going be over and I going be happy again.” For Iris, “My life all stopped when I heard that the cyst was cancer.” Charles wants to die to get relief, but time is passing slowly. “After two years, I don't care . . . I just want to go. . . . I don't want to be alive next year.”

The recurrence of cancer after more than 10 years after the initial diagnosis and treatment has similar reactions on two participants. Gina thought that she was “safe” after 11 years, only to find out that the cancer had spread. She searched for meaning in the recurrence. For Hana, when the cancer resurfaced in the bones, she wondered if it was a result of stopping the medication prescribed after the first bout of cancer, but she does not dwell on it. Instead of feeling cheated or unfairly punished, she too searched for meaning in the recurrence. Later, both women are living their lives to the fullest. Three

other participants had symptoms long before they were finally diagnosed. Duke had problems with his pancreas since 2001, and he was hospitalized several times before being diagnosed 11 years later. Iris had cysts removed from her breasts when she was 17 or 18 years old. She wonders if it was a precursor to her breast cancer diagnosis at age 36. Frank was told that the pain in his side was a bruised rib two years before being diagnosed with lung cancer, Stage IV, on the same side.

Relationality (lived human relation). Family is important to all the participants. As Hana puts it, “I had the love of family and friends that I could not even measure, that I cannot even begin to explain or express. . . . I don't know what else one can expect, and that overwhelming love and support is amazing.” Gina feels her husband’s support and positive attitude are the most helpful factors in her journey. “I didn’t feel like he felt sorry for me. I didn’t . . . feel like it was really burdensome.” To Charles, his dogs are his family. They are important to him, so important, that he wants his urn to be placed between the urns of his two dogs. Only Edward does not want anything to do with his brother. They had not talked for many years and he forbids his wife from allowing his brother to attend his funeral.

Many of the participants are very appreciative of their support, including Edward who yells at his wife and is having difficulty expressing his appreciation to her.

Approximately half of the participants are concerned about their loved ones and are assisting them in different ways. Edward’s wife did not know how to take care of financial matters, so he is preparing her, teaching what needs to be done. Hana has given away her “treasures” to lift the burden off her husband. She is creating special memories now and is preparing her siblings by assigning them duties to complete after she dies.

Frank is busy renovating his basement into an apartment for extra income to allow his wife to quit her second job. Brianne has cleaned out her closets so that her husband would not be left with that chore.

Nearly all participants (eight) have a special relationship with their doctors or nurses. Hana describes how her oncologist touched her soul, heart, and spirit by singing a spiritual hymn when Hana was feeling very depressed. Gina's oncologist adjusted her treatment plan to enable Gina to continue to perform, an important aspect of her quality of life. Many participants discussed how the medical team met their needs, whether it was for pain control, a sounding board, or mental stimulation. However, Frank described a cold encounter with the physician who diagnosed him with cancer. "You're going to die." He felt no compassion. Frank also thought that having a "panel of doctors" to determine the treatment of care would be ideal. Charles also had an unpleasant relationship with a dentist who refused to help him with the pain in his teeth since Charles was on hospice care.

Seven participants seek solace in God, or life after death, a "better place." Six of them pray to God, thanking him and asking for assistance. Iris prays for forgiveness and healing.

Friends are also very important to six participants. Three took the time and effort to visit friends who live out of state. Two participants describe feeling isolated or disconnected from their friends.

Three participants describe the importance of good communication. Frank felt no compassion from the physician who told him, "You're going to die." Gina believes that patients need to be open with their family and friends so they can provide the patient with

support. She describes how some words, however well-meant, could be perceived negatively. “How are you doing?” was perceived as a “‘poor me’ kind of attitude.”

Edward has difficulty expressing his appreciation to his wife and hopes he can do so before he dies.

Spatiality (lived space). Living with dying has both positive and negative meanings for four participants, and mostly positive for four other participants. For one participant, Iris, it is purely negative. To her, cancer is the death sentence, and her life stopped at the point of diagnosis.

Living with dying caused some participants negative feelings, such as depression over loss or anticipatory loss. Charles has lost his independence because of his physical deterioration. He feels that his life has no value. “It’s just a useless existence.”

The themes that promoted positive experiences or feelings include: the spiritual journey, going to a better place, or being reunited with loved ones (four participants); enjoying life and being positive (three participants); being home (three); enjoying nature (three); and pain control or relief (two).

Corporeality (lived body). The most common theme (eight participants) is symptom control. Most have or are anticipating pain and desiring pain control when the time comes. Brianne wants to ensure that the pain management does not alter her ability to function.

Six participants describe their treatment and the associated side effects. Most had nausea. Each interviewee handles their symptoms in different ways, including medications, meditation, music, and changing the dosage of the chemotherapeutic

medications. Gina describes the need to seek alternative therapies before accepting the conventional radiation and chemotherapy.

Five participants describe the connection between the body and mind. Aaron describes how his anxiety caused his high blood pressure and chest pain, requiring medication until he found a way to decrease his anxiety. He found that visualizing the paradise he saw when he had “died,” alleviated his fear. Losing her hair was akin to losing her identity for Gina. She now has fun using wigs, hats, and berets. Frank tries not to dwell on his condition because he becomes depressed and more anxious. For Brianne, she does not dwell on thinking about the progression of her illness. Days when she is not feeling well are especially hard for her. She does not want to be a prisoner of her illness. Hana controls her nausea with meditation and music. She calls the tumors which are popping out of her skin her “noble emblems” and describes herself as a cancer warrior. She hopes that at the end when she has excruciating pain, her husband will tell her, “Let our love carry you away,” and his words will ease her transition. Gina consulted psychics to see if they sensed whether chemotherapy or radiation was beneficial for her. She also asked a friend who is connected with spirits and kinesiology. He, too, confirmed that chemotherapy would be beneficial.

The cancer diagnosis motivated four participants to take better care of themselves, including changing their diet and eating more healthily. Four participants describe physical indicators of their illness: external tumors, loss of hair, and loss of weight.

Maintaining function, control, and independence are important to three participants. The ability to work and perform is important to Gina. Brianne is steadfast that the medications do not alter her ability to function because she does not want to feel

“like a prisoner of my illness.” Conversely, because Charles has deteriorated to the point that he is dependent upon others, especially his parents, he feels his life has no value.

Two participants chose quality of life over quantity. Brianne and Duke chose no treatment since the cancer had metastasized. They believe that treatment at this late stage probably would not make a difference, and they wanted to enjoy what they had. On the other hand, Charles and Duke view death as a welcomed relief. For Charles, there is no joy or quality in his life now.

Four participants question why they are ill. Brianne’s father was also diagnosed with pancreatic cancer. Is it hereditary? Duke questions if his drinking caused his pancreatic cancer. Frank wonders why he has lung cancer when he only smoked sporadically. Iris wonders, “Could the cancer have been detected earlier if she had followed up with her physician after the removal of breast cysts?”

Emerging Themes

After interviewing and analyzing the participant accounts of the lived experiences of dying, four distinct themes emerged. These themes can be classified in the physical, psychological, spiritual, and social realms. They are identified as: Higher Being and spirituality, family and healthcare provider support, symptom management, and mission and attitude. These themes, as well as cultural considerations, will be discussed further in the next chapter.

Chapter VI. Thematic Discussion, Summary, and Conclusion

This chapter commences with a discussion of the themes that emerged from the individual interviews. This discussion includes a comparison of these themes with those that emerged from the literature review. Subsequently, consistent with Munhall's (2007) methodology, an examination of the possible implications for nursing practice, study limitations, and recommendations for further research is addressed.

Thematic Discussion with Current Literature Review

The purpose of this research was to: (a) understand the meaning of the lived experience of APIAs in Hawai'i who are dying as a consequence of serious, progressive illness; (b) identify the values and preferences of those who are dying with regard to care during their illness trajectory and the remainder of their lives; and (c) describe their ideas and beliefs of "good quality of dying." As addressed in the previous chapter, the examination of the individual experiences led to four recurring themes: Higher Being or spirituality; family and healthcare provider support; symptom management; and mission and attitude. These themes can be classified in the physical, psychological, spiritual, and social realms, similar to those found in the literature review. These themes, along with certain cultural aspects, will be further addressed in this section.

Higher Being or spirituality. The phenomenon of spirituality was discussed repeatedly during the interviews. It represented hope. Many of the participants relied on their faith and a "Higher Being" to help them through their transition. Many even looked forward to an afterlife. Brianne, who didn't believe in the afterlife, talked about "this real calm-like Zen type of feeling." The majority of the others believed in an afterlife. They

thought of being reunited with loved ones, family, God, or, for Charles, his two dogs. They believed it will be a better place, beautiful place, a place of no suffering. The literature review described where several studies have shown that spirituality enhances the quality of life (Fryback & Reinert, 1999; Georgesen & Dungan, 1996; Steinhäuser, Clipp, et al., 2000). Reed's (1987) study of 300 adults demonstrated that terminally ill hospitalized adults had a greater spiritual perspective than non-terminally ill hospitalized or healthy non-hospitalized clients. The spiritual perspective was positively related to well-being (Reed).

Frank prayed and thanked God every day and was waiting for the day God says, "Oh, you're done, (Frank)." Frank adds, "It is only on the mercy of God. . . . I had already surrendered to God that any time that He likes me to go to Him, I'm ready."

Gina believed that there was a reason for the cancer to return, a lesson to be learned:

It came back again saying, 'I'm still here. I want you to get this.' . . . It's calling me to get back to my spiritual journey. . . . We talk about our experience of that Scripture. Sometimes there will be huge revelations and sometimes you'll find a lot of us think similarly. Sometimes someone will come up with a totally different perspective. Oh wow, I never thought of it that way. And that's the part of being in the group that I like, is sharing the different perspectives."

AACN & COH National Medical Center (2000) reported that many participants in their research found meaning and growth as they examined their relationship with others and God.

Iris experienced spiritual distress. She wondered, “Why me? Why at this point in my life? I am so young and all.” She prayed for God to heal her every day:

I am praying and I’m clinging to God and my family. . . . All I have to do is my treatment and pray. . . . I don't think about all those parties anymore. I don't think of all those shopping, dress. Not anymore. It all stopped. My happiness, my hobbies all stopped, for me.

This is consistent with the Georgesen and Dungan (1996) finding that when spiritual dimension is disturbed, the wholeness and harmony of the individual are affected. If spiritual distress is managed, hope and quality of life increased. The “dynamic integration” of an individual’s body, mind, and spirit is needed to maintain harmony and balance and could contribute to personal growth and optimal functioning. Ersek (2001) found that with the acceptance of being terminally ill, hope shifts from that of cure to one in which individuals aim to completing their life-closure goals. However, Iris still prayed for a cure and could do nothing else.

Family and healthcare provider support. Relationships are both great sources of support and concern. Support from loved ones and healthcare providers have been identified as the most helpful to the participants in their lived experiences. Hana expressed:

I think part of having that quality of life, as we call it, is having that doctor and being close to your family, and your friends. Because the amount of support, love and energy that you gonna get from that, you cannot measure.

Good communication is essential. It can convey either caring or coldness. Communication can be more than just verbal. As Hana puts it, actions and

communication “could touch parts of your mind, your heart, your soul.” For Frank, the doctor was “the angel of death. He never care. The doctor told [me], ‘You’re going to die.’ So I asked him, ‘Is that the only words that you could find for me?’”

Importance of relationships is supported by Ryan’s (2005) phenomenological research which concluded that the genuine caring and honesty from the healthcare providers, involvement in life activities, and positive interactions with loved ones and the healthcare system were essential. Communication and connecting with someone, including the healthcare provider, to talk to and who would listen and know them, were important to the dying patients (Johnston & Smith, 2006; Steinhauser et al., 2001; Steinhauser, Clipp, et al., 2000).

Edward noticed a change in the relationship that he had with his wife. “Knowing that you’re going to die should make you change and not be such a dingbat.” Although he denied wanting to reconcile with his brother, his statements implied otherwise:

I’m the one that’s sick. You should call me. What the heck, what’s matter with you? Anyway, that is one guy that not going to miss me when I go. I am not going to miss him either. . . . Yeah, I’m sad. Before he and I were really, really close.

Strengthening or repairing relationships is important for the dying (Cohen & Leis, 2002; Fowler et al., 1999; Pierson et al., 2002; Singer et al., 1999; Tanaka et al., 1999).

Even the supportive relationships were of great concern. Most wanted to make things easier for their loved ones, such as, cleaning out the closets, finishing the renovation of the basement so the wife could rent it out for extra money, and preparing

loved ones. Frank did not discuss what he wanted done when he died in an effort to prevent his loved ones from getting depressed:

I feel fine as though it is not yet time for me to be talking about that. Because if I start talking about that topic, their positive attitude towards me will become into a negative side and then, their prayers or their thinking about me will lessen up my morale and everything else in the house. The morale will go down. And then a house with very low morale, what do you think will happen? Everything else is going to fail.

Symptom management. Pain control was a concern for all participants except Iris who could not think beyond praying to be healed. They were concerned of the pain being manageable at the end. They also wanted other symptoms to be controlled so they could continue to function independently and as normally as possible. Gina incorporated her cane into her role in the play. Brianne described it the simplest. If she had to remain in bed, she would “feel [like] a prisoner of my illness. . . . I think that is the hardest, being disabled.” Charles’ and Duke’s activities were already limited due to their illness, and Charles hated that he needed to rely on others for things. Duke was grateful that he was in a hospice home where he could easily get assistance. Both looked forward to the end of their lives to get “relief,” but Charles’ pain was not well controlled, and he stated, “I want to die so bad. I could taste it.”

This finding was consistent with other research. The dying patients’ need for control over pain and symptom management was a common theme (Cohen & Leis, 2002; Johnston & Smith, 2006; Pierson et al., 2002; Singer et al., 1999; Steinhauser, Clipp, et al., 2000; Tanaka, Iwamoto, Kaneyasu & Petrini, 1999). The three “physical”

determinants to quality of life which were identified in Cohen's and Leis' (2002) research (patient's physical and cognitive functioning, quality of palliative care, and the physical environment) were also addressed by the participants in this study. Maintaining independence was also important to the preservation of dignity (Madan, 1992).

Mission or attitude. Acceptance may be the key to living life to the fullest. Gina took stock of her life and chose activities that were important, thus increasing her quality of life. Duke continued to appreciate nature. Three participants insisted on creating memories for their loved ones. Aaron crafted picture frames from shells based on his memories. Brianne published a book of her favorite recipes with pictures and stories of her life. Hana created memories such as dancing under the stars naked and holding a large dance party in her driveway. Others were working on completing other projects in preparation for their deaths. Edward was teaching his wife how to budget and do the taxes so she can do them when he is gone. Frank was completing the basement so that it can provide additional income for his wife and family.

Sadly, Iris was unable to accept her prognosis, and as she described it, her life and joys "all stopped" when she got the diagnosis of "C." Life closure affects all dimensions of quality of life (AACN & COH National Medical Center, 2000; Byock, 1996; Pierson et al., 2002; Steinhauser et al., 2001; Steinhauser, Clipp, et al., 2000). It involves self-examination, reflection of meaning about one's life, and experience of love of self and others. It also includes a sense of completion in relationships with family and friends and the acceptance of the finality of life. Acceptance was described in terms of inevitability, faith and spiritual values, life's diminishing rewards, completing life, final benefits, humor, and sharing (Hinton, 1999). Many dying people search for a meaning to their life

(Yedidia & MacGregor, 2001), which can be obtained through life review and working toward the accomplishment of personal goals. Fryback and Reinert (1999) found that people who found meaning in their disease thought they had a better quality of life because of it.

Preparation for death and the dying process for most of the participants was evident, except for Iris. She was distressed which related to denial and the fears of death and dying. She could not “live” or take joy in any activity because she spent her time praying for healing and crying. Sullivan, Ormel, Kempen, and Tymstra (1998) determined that distress from death and dying affected the person’s health status, especially mental health status.

Cultural aspects. Although “talking about death . . . is taboo” (Yeo & Hikoyeda, 2000, p. 103), many Native Hawaiians do make their wishes known to their loved ones (Yeo & Hikoyeda, 2000; Nichols & Braun, 1996). The findings of this research did not yield similar results. Initially, there were four Native Hawaiians who volunteered to be part of the research. Three of them, Aaron, Duke, and Hana had no difficulty talking about their illness, thoughts, and feelings. The fourth volunteer could never be contacted. Family members would answer the phone, give various excuses, and finally said that the volunteer was not interested. It could not be determined if the decision was that of the volunteer or the family members. There was much difficulty recruiting Native Hawaiians for this study. Even the clinic for Native Hawaiians declined to participate in this research. Difficulty in recruiting Native Hawaiians could be interpreted as in support of the literature review finding that Native Hawaiians believe discussing about death was taboo.

Yeo and Hikoyeda (2000) also concluded that prolonging life was desirable over quality of life; however, that finding was not fully supported in this research. Hana was the only Native Hawaiian continuing her chemotherapy to prolong her life. She was doing it to be able to enjoy her quality of life. The other two, Aaron and Duke, chose palliative care and were waiting to die.

Yeo and Hikoyeda (2000) described the Filipino's definition of a "dignified death commonly meant a peaceful death free from pain and not being burdensome to others" (p. 112). However, this research demonstrated that this definition was not limited to the Filipinos. Brianne (Japanese), Hana (Native Hawaiian), and Edward (Korean) worried about pain management and loss of their independence. Filipinos believe in the "will of God" (Yeo & Hikoyeda, 2000). Frank surrendered to God and "any time that He likes me to go to Him, I'm ready." Gina believed God was sending a message to her when her cancer returned. He wanted her to learn something.

Yeo and Hikoyeda (2000) also found in their research that the Filipinos tend to "avoid stressful interpersonal conflicts and confrontations" (p.112). Frank avoided talking to his family because of fear that it would make them depressed, and he did not want to deal with a "very low morale." There is love and caring, but not complete openness.

Usually a family member or healthcare provider is expected to make the end-of-life care decisions for many Japanese Americans, but many patients have not shared their desires with their loved ones or their physicians (Yeo & Hikoyeda, 2000). The Japanese culture also emphasizes self-restraint or stoicism. Charles had difficulty talking with his family about his feelings of his illness and his wishes, except that he wanted his ashes

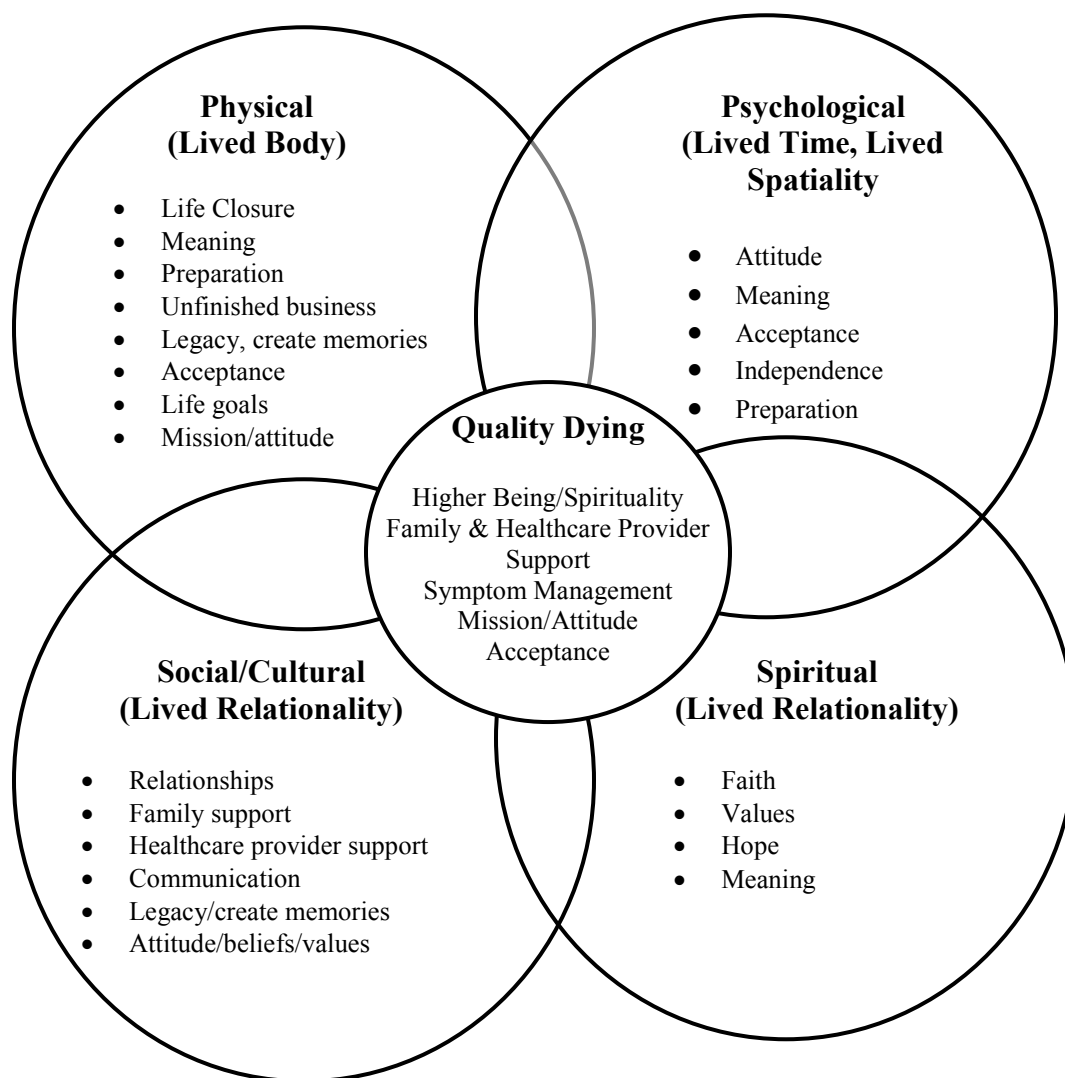
buried between those of his beloved dogs. He was able to discuss his pain with his healthcare providers but not his family. Brianne, on the other hand, had no difficulty expressing her wishes and feelings to her physician and family and was directing her own care.

Transition Theory: Facilitators and Inhibitors

Dying is a transition of life. Based on Meleis' transition theory (Meleis et al., 2000), the outcome of quality dying is shaped by facilitators and inhibitors, including the individual's physical, psychological, spiritual, and social/cultural/ethnic values.

The biggest inhibitor in this research is denial. Iris could not accept her diagnosis and spent her time praying. She could not get on with her life. The other participants accepted their diagnosis, facilitating them to: prepare for their future; complete their unfinished business; strengthen relations with their family, friends, and God; and examine their life and goals.

The initial concept of quality dying (Figure 1 in Chapter II) illustrated four distinct realms: psychological, social/cultural, spiritual, and physical, when in reality all realms are interconnected. Psychological aspects, such as attitude can impact the physical being or vice versa. Socio-cultural aspects such as personal connection can alter the patient's experience. These realms also overlapped the life worlds. The psychological realm had similar attributes as temporality and spatiality and vice versa. Physical and corporeality attributes were identical. Social/cultural and the spiritual realms included relationality. Subsequently, the concept illustration was revised (Figure 4).

Figure 4. Revised Concept of Quality Dying

Summary

The nine participants described many of the themes identified in the literature to varying degrees. The themes assessed through examining life worlds could also fit the physical, psychological, spiritual, and social/cultural realms. These realms as well as the life worlds were not distinct from each other but interconnected. The major themes that

emerged in this research are considered facilitators to quality dying. The initial concept of dying was revised (Figure 4).

Study Limitations

The limitations of the study must be considered when interpreting the results of the study

Sample size. The sample size may be too small to generalize to other populations. The respondents may have been more motivated or frustrated among the population and, therefore, not representative. However, there was data saturation and since there are many similarities among the themes of the participants, this group may more likely have results that are transferable. This study was done in Hawai'i, geographically isolated from the continental U.S.A. Therefore, the results may be transferable to smaller communities within other states.

Limited participant demographics. The original intent of this research was to explore the meaning of quality dying and the values and preferences toward the end of life of Native Hawaiians. However, due to the difficulty of recruiting Native Hawaiians into the study, the inclusion criteria were expanded to include APIAs. As a result, the nine participants came from different ethnic and religious groups. The participants included three Native Hawaiians, three Filipinos, two Japanese, and one Korean. Eight participants identified themselves as Christians and one as a Buddhist.

Volunteers. The Native Hawaiians who were willing to discuss their experience with dying volunteered. As a result, their participation may not be the usual Native Hawaiian belief that talking about death is taboo.

Implications for Nursing

Although this phenomenology research has described the lived experience of people who are dying, it only represents nine people who were interviewed at a particular point in time. Still, it provides valuable knowledge and leads to the question: “What are the nursing implications?” Several implications were identified by the author and should be explored by healthcare providers and researchers in the future.

- Good pain control and symptom management are essential for quality of life and dying. Poor symptom control affects their function and enjoyment of family and life and leads to desiring death for relief.
- Connecting with patients, listening to their wants and needs and good communication, enable healthcare providers to support their patients through the final transition. Feeling that the healthcare providers truly care about them and support them adds quality to the patients’ lives.
- Patients seem open to discussion about their condition. Empower and facilitate the patient to talk with his or her family and physician about pain and palliative care and advance care planning.
- Incorporation of this information into the patient care plan will help achieve the patient’s goal and maximize quality of life.
- Cultural characteristics should be considered only as guidelines. This research illustrated some differences from what was gleaned from the literature. There could be many reasons for this. Many people are of multiple ethnicities. Those who are purely one ethnic group are generally third or fourth generation and well acculturated into the general population. Lastly,

Hawai'i is a melting pot of different ethnicities, where people live, play, marry, and work with different ethnicities and constantly adopt each other's customs, traditions, and values.

- Dissemination of research findings to participants, communities, and professionals and lay people groups is the researcher's ethical responsibility.
- Provision of quality end-of-life care is an ethical duty for healthcare providers.

When contemplating the meaning of quality dying, this researcher could not help but hypothesize that unless a person accepted that he or she was dying, that person could not define quality dying and subsequently live it. It would be important to explore this concept with further research.

Most studies conducted on the dying patient's perspective in the literature review did not include any APIAs or included very few APIAs (Cohen & Leis, 2002; Hinton, 1999; Holcomb et al., 1993; Pierson et al., 2002; Steinhauser, Christakis, et al., 2000; Steinhauser, Clipp, et al., 2000; Yedidia & MacGregor, 2001), or those that did were done outside of the United States (Ringdal & Ringdal, 2000; Singer et al., 1999; Tanaka et al., 1999; Wilson, 2000). This research contributed to the knowledge, but additional deeper research is recommended.

Conclusion

The purpose of this research was to describe: (a) the meaning of the lived experience of APIAs who are dying in Hawaii; (b) their values and preferences regarding their care; and (c) their ideas and beliefs of "good quality of dying." In order for healthcare providers to provide quality care, especially towards the end of life, a deep

understanding of the quality dying phenomenon, from those who are experiencing it, is necessary.

Nine terminally ill participants were recruited from hospice and a chemotherapy infusion clinic. Their interviews were recorded and transcribed verbatim. Meanings and themes were extracted from the recorded conversations. These meanings were examined individually and then in the aggregate. This research resulted in the emergence of four major themes: a Higher Being or spirituality; family and healthcare provider support; symptom management; and mission and attitude.

A review of the literature was compared to the themes that emerged from this study. As discussed earlier, the manifested themes were supported by previous research, although there were some deviations in the cultural realm: relatively open discussions of dying and death with the Native Hawaiian and Japanese participants and fear of pain, especially at the end was a universal concern, irrespective of ethnicity.

General recommendations for future research were identified. Additional research is needed to study the cultural needs of the APIAs living with a terminal illness. Nishimoto and Foley (2001) illustrated that meeting the cultural needs of the terminally ill patients made a positive impact on their quality of life. Another future study could include those who have not accepted their terminal status and their ability to define quality dying and to live a quality life.

Appendix A. Guide Questions for the Interview

Topics	Sample Questions
<i>Illness Experience</i>	
Initial Question	Tell me about your illness: When did you first become ill? What treatments have you undergone?
	Tell me what it has been like for you since you have been diagnosed?
Probes	How are you feeling in your body, your mind, and spirit?
<i>Awareness of Dying & Change/Difference</i>	
Initial Question	Tell me how you first became aware that you were dying. Tell me about what you think is going to happen to you in the future. What has your doctor or nurse told you about your illness?
Probes	What do you think will be the eventual outcome for you of your present illness?
	How do you see your life now, and where do you see it going?
<i>Prospect of Dying Engagement</i>	
Initial Question	What does it feel like to think you might die?
Probes	
	How do you feel about staying here in this life, in this world?
	Tell me a little bit about how this experience has been for you?
	What has been the most difficult? What has been most helpful?
	What kinds of things have you wanted to talk about but couldn't?
	What is important to you now?
<i>Process of Dying Critical Points/Events</i>	
Initial	Could you tell me what you're thinking about... what dying might be like?
Probe	What does being close to death feel like? Can you say?
<i>Meaning/Ideal</i>	
Initial	What is important to you now? What do you want?
Probes	What kind of things do you think could improve the quality of your dying process? What does a "good death" mean?

Note. Adapted from "Confronting the Prospect of Dying: Reports of Terminally Ill Patients" by M. J. Yedidia & B. MacGregor, 2001, *Journal of Pain and Symptom Management*, 22, p.810.

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Appendix B. Living with Dying

The purpose of this proposal is to understand how terminally ill APIAs in Hawai'i describe their feelings and thoughts about their experience of dying so that others can understand their experience. Dying is one of the few things all humans will experience. Still, society is uncomfortable and unwilling to discuss it openly. Dying persons have opportunities for positive experiences and personal growth and to share their knowledge. These events are difficult for the dying persons and their families.

Since society is uncomfortable about discussing the dying process, there are few descriptive studies on the experience of the dying. With limited data, it is difficult for healthcare providers to support the dying patient and his family through this potentially positive experience. Sharing their experience can help the healthcare providers improve the quality of dying or dying with dignity.

To participate in this study, the participant must:

- Be 18 years or older
- Asian/Pacific Islander American living in Hawai'i
- Have a prognosis of six months or less.

Interviews will be conducted in private, be audio recorded and last about 60-90 minutes. Privacy and confidentiality will be protected using a number, not names, and keeping all information in a locked file or password protected computer. The participants will receive \$25 gift certificate for compensation for their time. If you have someone

qualified and interested in sharing their story/experience or would like to obtain more information, please contact me, with their permission:

.

Charlene K. Ono, APRN, MS, Doctoral Student

822-1696 or onoc@hawaii.edu

Appendix C. Living with Dying

Aloha, my name is Char Ono. I am a nurse and a doctoral student at University of Hawai'i, Mānoa. I have lived on Kaua'i for over 30 years and teach nursing at Kaua'i Community College. I am interested in improving quality of life at the end of life. My research study is exploring what it is like to live with a life-threatening disease. I am looking for people who are interested in talking with me about their experiences as they come close to the end of their lives. To participate in this study, you must:

- be 18 years or older
- be an Asian or Pacific Islander who live in Hawai'i
- have a terminal illness

Interviews will be conducted in private and will be audio recorded. The session will last about 60-90 minutes. The participant will receive \$25 gift certificate to compensate for their time. If you are or someone else is qualified and interested in participating in this study or would like to obtain more information, please contact me:

Charlene K. Ono, APRN, MS, Doctoral Student

822-1696 or onoc@hawaii.edu

Appendix D. Consent to Participate

Agreement to Participate in
LIVING WITH DYING STUDY

Charlene K. Ono, APRN, MS, Doctoral Student

University of Hawai'i, School of Nursing

Webster Hall 301

2528 The Mall

Honolulu, Hawai'i 96822

(808) 822-1696 Home

(808) 651-5122 Cellular

Purpose

I want to talk story with you and to understand what you are going through as you come close to the end of your life. I will be asking questions about your feelings and beliefs. Although this research project is part of my requirements for a doctoral degree, I am doing this to better understand your experience with hopes to improve the quality of dying by making healthcare providers aware of and address components which affect quality dying.

Benefits

Participating in this research may be of no direct benefit to you. It will allow you to tell me your story, experience, with a terminal illness. This may provide you with an opportunity to share feelings that you may not have shared with anyone else before. It is

believed the information you share will improve the knowledge of what it is like to be dying and will help nurses and other healthcare providers improve the services to people who are dying. By publishing the study results, other healthcare providers who care for those with terminal illnesses can be reached.

Procedures and Risks

If you choose to participate in this study, you will be interviewed. The interview will last approximately an hour and will be audio recorded. During the interview, the researcher may take notes. You may ask any questions about this study. For some, talking about death may be upsetting. The interview can be stopped at any time, for example if you get tired or upset. If you get upset while we are talking or even days later, please call your hospice nurse or social worker who is specially trained to deal with these issues or the local mental health department at 274-3190.

Voluntary Participation and Confidentiality

Your participation is voluntary. You may withdraw from the study or we can stop the interview at any time without any problem. The audio recording will be transcribed word for word. The interview data will be coded with a number, not your name, so it will be confidential. The data will be kept in a locked file or password protected computer. I will use this information to educate others but at no time will I use your real name or if the presentation is on your home island of Kaua'i, Maui, Hawai'i, or Molokai, I will not use your real voice. In the process of evaluating this study, your data may be examined by my dissertation committee, or the University of Hawai'i Committee on Human Studies, or recruiting agency's Institutional Review Board (IRB). Your identity will remain confidential unless disclosure is required by law. All identifying personal

information will be destroyed after my dissertation is completed. The audio recording will be kept so that excerpts from it can be used in educational presentations.

Costs and Compensation

There are no financial costs associated with your participation. You will receive a \$25 gift certificate the first time we talk to compensate you for your time. The findings of the study will be shared with you and your family, if you wish.

If you cannot obtain satisfactory answers to your questions or have any comments or complaints about your participation in this study, contact: Committee on Human Studies, University of Hawai'i, 2540 Maile Way, Spalding 253, Honolulu, Hawai'i 96822. Phone: (808) 956-5007. Email: uhirb@hawaii.edu.

I ask for your Kokua and participation in my study.

Read and explained to the potential participant by:

Charlene K. Ono, APRN, MS, Doctoral Student, UHM

Date

Please check the following to which you agree:

- ☐ I agree to participate.
- ☐ I agree to be audio recorded.
- ☐ I agree that excerpts from the audio recording in my voice can be used for educational purposes and publications.
- ☐ I agree that quotes from the interview be used for educational purposes and publications.

Participant's Signature

Date

Printed Name

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