

Death in Middle Adulthood: A Case Study of a Japanese Woman with Terminal Cancer

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Abstract

What is the focus of Death-and-Life Studies? (In Japan, we use the English term “Death-and-Life Studies” rather than “Thanatology,” for the field covers not only “death,” but concerns both “life” and “death”). This broad scientific study still holds many possibilities concerning study and research from “birth to life” and “death.” People can speak of their births through acquired memory. People can experience death as their own but cannot speak of it in the first person; we have not yet resolved a method for people to speak of their own experience of death, nor hear of it. That is, we gaze at life and death standing in between these two momentary but momentous experiences.

Cancer patients face some issues embedded uniquely in their disease, however, they also face issues inseparable from their previous life experiences (including physical, social, psychological, and spiritual pain). This research focuses further on the question of “self-existence” which has much to do with “life” and “death.”

In this research, I interviewed a terminal cancer patient using a phenomenological method. The interview consisted of watching the patient as she went through the process of living her life with her family, and focusing on the things she underwent as she experienced and departed from life. Through interviews with a middle aged female patient, this research attempts to shed some light on “death” and “life” not merely as personal issues, but as coming from relationships centering around family members.

Keywords: relational development, self-existence, bonds

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I. Lifespan Psychology and Death

Introduction

How is “death” understood in lifespan psychology? Death poses the ultimate final developmental task in lifespan psychology, encompassing all the developmental stages from birth to death. As Erik Erikson (1995) suggested, people often consider “death” to be a developmental task limited and specific to later life. However, death may confront anyone at any stage of life, because people may experience death of a family member or even face death themselves at any unexpected time. Since death can occur at any time, “Death” should be considered an important topic in lifespan psychology.

A number of researchers have studied the psychology of patients with terminal cancer and their families. Examples of such studies are: Elizabeth Kübler-Ross’ “five stages” of coping with dying (1969), ways to communicate terminal diagnoses to patients (Buckman 1992), and the psychological process of those who give and receive care (Shneidman 1980; Kishimoto 1980).

Life-span psychologists also have undertaken research on terminal patients’ psychological conditions (e.g., Shimoyama and Tanno 2001). These studies contributed to the literature by clarifying the psychological processes of patients and families facing the patients’ death; such clarification enables doctors to provide the best medical care possible, considering their patients’ psychological conditions.

However, these research studies fail to detail the inner world in which each individual has lived, is living, or will live. The author believes that life span psychology is a field of study that illustrates how people meet and form relationships such as families. Kujiraoka’s (1999) relational development theory was influenced by this philosophy. From this philosophical perspective, it is imperative to examine the factors that cause people to think of death, the significance of death awareness, and the effects of death awareness on human relationships. In contemplating their mortality, many people confront questions of their own personal change and continuity as well as of the change and continuity of their relations with their family and significant others.

The author intended to examine “life span psychology” not as a study bound to the chronology that starts with birth and ends with death, but as a psychological study of life. The psychological study of life pertains to an individual’s daily life as it is filled with

relationships with others. This approach may provide insight into issues related to “death” as well as “life.”

This article explores “life” and “death” through an examination of an individual’s lifecycle and relationships with others. Erikson, who precisely described human life, explained how “identity” was synonymous with “self-existence.” Although identity achievement is typically a developmental task of adolescence, is not limited to adolescence. Identity achievement can continue to be a significant task after adolescence. For example “Self-existence” is an important question to explore throughout human life and in capturing life and death in the last stage of life. What is “self-existence”? In this article, “self-existence is defined as not only an inner self (i.e., “What I am”) but also secure place to “be” (i.e., “I know I can exist here.”), which is achieved through relationships with others, such as family. People in the last stage of life have two aspects of “self-existence.” They are as follows: 1) a change in family/ social roles as physical functions deteriorate (shift in self-existence due to an illness) and 2) self-existence after death.

Shift in Self-conception due to Illness

Nishihira (1993) applied Erikson’s developmental theories to his examination of children with muscular dystrophy. He noted that “human development is an effort to live life despite the awareness that people grow up only to die.” Similarly, terminal cancer patients cherish each moment. As long as their pain is under control, they look forward to the next moment, even though the passage of time means getting closer to death. Questions about “life” and “death” are intertwined in such people’s lives.

What do “life” and “death” mean for people who live knowing that they will die in the near future? Physical deterioration and consequent changes in interpersonal relationships largely affect their views on “life” and “death.”

The notion of “self-existence” may provide some insight into this matter. When babies are born, their parents and other family members provide physical and psychological care; babies are accepted just for “being” there. Others do not expect anything from babies; they accept babies despite their temporary inability to contribute to society. As babies grow up into children and adults, societal expectations change. They connect with a wider range of people outside of the family, play new roles in the society,

and acquire new expectations of themselves. For example, when people take on roles in society, such as a worker or a mother, they consider themselves to be someone who “does” things. The sense of “doing” (instead of “being”) assures their place in the society, fosters their sense of self-worth, and helps them come to terms with the meaning of “life” for a moment.

Then what can affirm people’s self-esteem when they are unable to “do” something, due to an illness?

Self-existence after Death

Among many questions regarding death, people often wonder about self-existence after death. For example, some people with terminal illness face a “fear of death” (e.g., Kübler-Ross 1969). This “fear of death” is not only a fear of physical pain before death, but also a fear for self-continuity after death. This fear is often associated with religion and spirituality. How can people overcome this fear? Interpersonal relationships may provide answers to self-existence after death, doubts about religion, and the transition to an unfamiliar afterlife. Questions on self-existence after death include “Where do we go after death?” and “What happens after death?”

“Self-existence” is a concept presented to help understand the process of an individual’s living and dying. A human being is born alone and dies alone; however, he or she connects with others after birth and before death. Therefore, interpersonal relationships are an indispensable part of human life and death. This article discusses “self-existence,” “death,” and the “dying process,” focusing not only on the dying individual, but also on her relationships with others such as her family.

II. Method

1) Interview and Analysis

The author encouraged the participant to share her thoughts about “daily life” and “recent thoughts” instead of using a structured interview script. The author employed an unstructured interview in order to explore the patient’s psychological conditions that varied daily. The author dictated the conversation after the interview with the permission of the participant. The primary care physician, the nurse assigned to her, her family, and

the participant herself all reported the participant's physical and psychological conditions. The participant's discussion of "self-existence" was extracted and analyzed using an "interactive-observational" interview. The context of the conversation was also considered.

2) Ethical Considerations

The Institutional Review Board (IRB) approved this research study. The participant was given both verbal and written explanations of the purpose of the study, handling of the interview materials, and confidentiality. The participant signed the consent forms. The author discussed the participant's conditions with the primary care physician and the nurse assigned to her immediately before each session. The session was conducted considering and adjusting to the participant's reported conditions. The contents of these sessions were shared with the physician and the nurse, with the participant's permission, in order to coordinate the care for the participant.

In the early months of 200Z, the author worked at a palliative care unit in a general hospital in the Middle area of Japan. The palliative care unit had 19 beds in single rooms, and actively collaborated with other departments of the hospital to meet the needs of the patients and their families. The author conducted many 90-minute interviews with terminal patients; the following case study involved 17 such interviews with a 58-year-old patient whom we shall call "Sumire," dying of rectal cancer with sacroiliac metastasis.

Trained in psychology, the author cleared her interview protocols and procedures with Sumire's primary care physician and nurse, as well as the hospital's IRB. Sumire signed consent forms allowing sharing of all interviews with her medical staff. The author discussed the participant's conditions with Sumire's primary care physician and her nurse immediately before each session, and shared the transcribed contents with them afterwards, in order better to coordinate care. The interviewer encouraged Sumire to share her "recent thoughts" about "daily life." Rather than using a structured interview script, the author employed unstructured interviews to explore Sumire's varying psychological condition.

The youngest of eight siblings, Sumire had already lost her parents, but her husband (67) and two daughters (32 and 30) frequently visited her during her hospitalization.

When she entered the palliative care unit, Sumire's personal priority was pain reduction of the sciatica in both legs, while her family was primarily concerned for her psychological state.

Sumire had undergone radiation therapy from April 30, 200X to June 4, 200X, followed by a bowel operation to overcome bowel obstruction on July 7. In 200Y, she was continually hospitalized for inpatient chemotherapy from February 3, 200Y to October 27, 200Y. She was transferred to the palliative care unit on November 24, 200Y, where she remained until her death on May 8, 200Z.

Sumire's Conditions Prior to the Interview Sessions

A primary reason for Sumire's transfer to the palliative care unit was to provide psychological intervention. Nursing notes quote Sumire's husband as asking, "I know that medicine can alleviate her physical pain but not her emotional pain. Please provide psychotherapy to my wife. We came to this palliative care unit because we hoped that someone could listen to her thoughts about death. My wife does not say anything to me, but she sometimes cries holding my hand. I think she is worried about and afraid of death." Clearly, Sumire's family's primary request was for psychological care. Sumire's nurse's report at the time of her admission to the palliative care unit in November, 200Y, painted a completely different picture of Sumire from the calm impression the author had of her at their first meeting in February of 200Z.

Sumire's conditions from the nurse's notes and medical staff's report: Sumire complained of severe chronic pain and sharp prickly sensations at the time of her hospitalization. When her physician was about to examine her legs, she pushed off the physician's hands and screamed, "Please do not touch me!" She would not discuss her emotional pain with the nurse. The primary intervention during the first two weeks was pain management. Pain became manageable only after a palliative care physician and an anesthetist became involved over the first few weeks in the PCU.

Sumire was highly anxious as a result of unexpected pain, and she made many demands of the medical staff. After treatments began to control her pain (December 200Y), a clinical psychologist who worked at the hospital started psychotherapy at Sumire's request. Sumire shared her fear of death and regrets for falling ill. After the New

Year, Sumire stated, “I am afraid this will be my final New Year's. I feel bad that I am a burden to my family. I am resigned, and I don't care if I die.”

Sumire later changed perspectives. She mentioned, “I have to depend on others, so I will just appreciate their help.” The time the author started to visit Sumire coincided with the time when she started to feel appreciative of her family's support. She left the time of death “up to God.” Sumire was perhaps more peaceful and accepting by the time the author met her. Sumire appeared calm at the time because she had started to come to terms with her worries.

III. Interviews with Sumire

During the 17 sessions with Sumire, several core topics emerged, including the “presence of family” and what continues after death. The first impression the author had of Sumire, which was of a quiet person, started to wear off early in their interviews. Her speech was energetic and the author started to identify with Sumire's daughter, rather than with Sumire. The author empathized with her daughter, and felt as though Sumire was asking for an opinion from those who would continue to live after her death. Excerpts and analyses of the interviews follow.

A. Sharing feelings and thoughts and being heard (Restoration of self-esteem)

Sumire: I talk to my older daughter and I have her write down things I tell her. I talk about things to do “after I die.” I tell her, “You don't have to wear a kimono even though your relatives might tell you to do it.” I already gave her clothes to wear for my funeral. But when I tell her such things, she cries and protests, “Why do you say that kind of thing, Mom?”

Author: Of course it would make her cry.

Sumire: I know, but that is reality. I say, “it is you two who would be at a loss when I am gone.”

Author: It is a problem if they need their Mom to do everything. I would be at a loss, too!

Sumire: I know (She laughs). So...

Author: So you want your daughters to listen to you.

Sumire: Yes, I want them to listen to what I have to say.

Aware of her deteriorating physical condition, and knowing that her own death would occur in the near future, Sumire strongly wished to communicate what it is about her that would remain after her death, and as a mother, what she could leave to her daughters.

As she said, “I want them to listen to what I have to say,” she wanted her family to accept her thoughts and feelings. What she felt when she gave her daughters clothes for her own funeral is probably beyond anybody’s imagination. Speaking to her daughter, and having her take notes on her small daily duties after her mother’s death, may have given Sumire a sense that she was successfully playing her motherly role.

Sumire shared her regrets at her inability to help her family due to her physical deterioration. A Japanese mother’s role is traditionally physical labor, such as help with self-care and cooking for her family. Sumire was a homemaker prior to her hospitalization. Now that she was unable to complete “motherly” tasks, she questioned her self-worth. Communicating her motherly role to her daughter helped her appreciate her self-existence. In addition, this conversation was convincing herself as well as her daughter that she was a dying being.

B. Mother’s dignity (Restoration of self-existence II)

Sumire: What’s the date today?

Author: It is the 24th.

Sumire: I will receive my allowance soon. (Sumire smiled and clasped her hands in front of her body.)

Author: Allowance?

Sumire: Yes, my husband gives me some allowance each month.

Author: Good for you! What do you use it for?

Sumire: What do I use it for? When my daughter buys something, like a snack for me, I cannot just take it for free. So I give my daughter money to keep my dignity as a mother.

Author: I see, dignity as a mother.

When the author visited this time, Sumire was watching TV alone. Her husband returned to Sumire’s room and all three chatted for a while. It was surprising to learn that Sumire was receiving an “allowance.” It was hard to imagine Sumire spending money

since she was bed-bound, which led the author to ask questions about her allowance. The author's question exposed the fact that the author had viewed Sumire only as a "patient."

Sumire often reported her regrets at her inability to do things as a mother or a wife. Sumire felt physically dependent on and unhelpful to her family in her motherly role. The moments when she could still act as a mother were indispensable to her self-esteem. She may have felt dignity as a mother when she was helping her daughter financially.

Self-existence after Death

C. Leaving keepsakes

Sumire: I was talking with my husband about things to leave for my daughter. What do you think would be a good gift?

Author: Do you have something in mind?

Sumire: The last thing I bought is a Rolex watch. My older daughter wears it now. It is expensive, as they can confirm if they go to a store. I am hoping that my older daughter will take good care of it.

Author: Uh-huh.

Sumire: The older daughter has mine already, so I am thinking about buying one for my younger daughter. I don't think the older daughter would complain about having my used watch. Do you think?

Author: No, I don't think she would mind. A watch can be used daily, so I think it is a good gift.

Sumire: I think so, too. That's why I am thinking about leaving her a watch.

Sumire stabilized from anemia prior to this second session. At the outset of the session, she said, "I am dizzy from anemia, and I have no appetite whatsoever. I think I am passing away soon." Then she started to discuss keepsakes. She explored the possibility of engraving her and her daughters' names on the back of the watch during the session. Sumire could not help but ask the author's advice in deciding what keepsakes would be appreciated and cherished. Rather than seeking advice, Sumire was perhaps asking for the author to support her desires ("I want my family to cherish my keepsake for a long time. I want them to remember me after my death. I want to secure my connection with others even after my death.").

There are two major reasons for Sumire wished to leave keepsakes. When Sumire lost her mother, her mother only left her family money. Sumire and her sister wished that their mother had left them keepsakes. Sumire understood the sentiment of those who are left behind. She wanted to leave something that signified the wishes and existence of the mother, so that her daughters would not have to suffer the same pain.

Another reason for leaving keepsakes is to leave something of herself behind after she died. Behind her words “I want to leave my daughters keepsakes, and I want them to cherish them,” she strongly wished her family to remember her, to secure her existence after her death. There is no precise answer to the question, “Where do people go after death?” It is understandable that she wished to secure a “place” where she could “exist” after death using something her loved ones could remember her by. Sumire had yet to reach an answer as to how to stay connected with her family, and where she would go after her own death.

D. My existence after I die

Sumire: Do you know the older lady who says, “I love him so much!” and has a picture of her husband by the door?

Author: Picture?

Sumire: Yes, she keeps his picture by the entrance of her room.

Author: Hmm, I don’t know.

Sumire: I wonder what has happened to her. She always says, “I just love him so much.”

Author: Her husband is a lucky guy.

Sumire: I am not sure if I said she loved him while he was alive. Her husband is long gone.

Author: Really?

Sumire: But I am not sure if she said she loved him while he was alive.

Author: I am sure he heard her say it sometime when he was still alive.

Sumire: True. I am sure he did.

Sumire enjoyed having tea with her family in the afternoon. This author’s visit coincided with her teatime. Sumire, her daughter, and the author had tea together. In casual conversation out of the blue, Sumire brought up the subject of the lady who kept her husband’s picture. Prior to this, Sumire had been discussing a completely different

issue. She was recounting a story about her daughter eating a sandwich in secret, and then she asked the author coyly, “Prepare tea for me, would you?” Initially, the author was at a loss about what triggered Sumire to talk about the lady with her husband’s picture.

Why did Sumire fixate on this topic? When Sumire and the author started to get used to discussing death (at least when the author was not scared to discuss death), Sumire’s question shifted from keepsakes to her existence after death. (Of course, anxiety about existence after death was directly related to death anxiety.)

Sumire not only discussed keepsakes for her daughters but also for her husband. She considered buying a new ring, wearing it until her death, and then giving it to her husband after her death. The purpose of the shared ring was to secure a connected place for the couple, a place where Sumire would exist for him after death. She discussed this tentative plan with her husband. Sumire also commented that her husband would go for a drive with her picture in the passenger seat.

Sumire’s pursuit of “family connection after death” left a significant impression on the author. Sumire noted that her husband and her daughter took turns sleeping over with her, and they were able to spend quality time with Sumire in her hospital room. Sumire’s decision to move to the palliative care unit allowed her to spend ample time with and communicate with her family. Sumire also stated that the hospital room had a similar ambience to her bedroom in the family home. Her family provided significant support to Sumire. The thought of not being able to spend time like this with her family after death may have been more difficult for Sumire than the thought of death itself.

IV. General Discussion

This section will deepen the previous analysis.

The Role of Family in Restoring Self after Illness

The central existence for Sumire was her family. When Sumire went into palliative care, her eldest daughter resigned from her job and dedicated herself to caregiving, because she “did not want to have regrets later.” Her daughter’s resignation made Sumire realize that her family was ready to accept her imminent death.

Ever since learning her own terminal diagnosis, Sumire was actively involved in her

own care, instead of her family making decisions without her. Her family was on “her side,” supportively processing imminent death together. Processing the death together “on the same side” is different from some families who process feelings as those who will be “left behind” are on “the other side” of the dying patient. For example, Sumire and her family communicated that they had quality time with each other (sometimes including the author), and she has “no regrets” even though she had limited time left. Though sometimes shedding tears as they listened to Sumire, her family prioritized her wishes over their own during the hospitalization. This family support helped Sumire feel more secure and assured.

Sumire’s connection to her family both helped and challenged her self-esteem. Physical deterioration due to illness prevented Sumire from playing a role of “a wife and a mother.” She used to feel like she was dependent, useless, and a burden on her family. She gained a different perspective when she witnessed her family accepting her feelings and dedicating themselves to daily caregiving. She was able to find a new task as a mother, which is to share wisdom and knowledge with her family.

People need places to “be” and things to “do.” Primary caregivers provide security to the infants of this world who cannot do anything on their own. Erikson (1950) noted that primary caregivers give security to “be” when infants struggle with “trust” and “mistrust.” Subsequent physical growth leads to expectations of self and to expectations that others “do” something for the community. Sumire and her family expected her to “do” something for her family as a mother and a wife. She was “doing” something in the community so she had “a place to be.” She gained “a place to be” internally (within self) and externally (with others) by “doing” things. Her life evolved around “doing” things until she fell ill and was no longer able to “do” anything physically. She felt uncomfortable living in a “place” where she used to “be.” This change necessitated reconstruction of her “place to be.” This change was a struggle for her and her loved ones.

Sumire’s suffering, anxiety, and support are related to her family relationships and developmental stage (middle adulthood). One of the developmental tasks of middle adulthood is re-questioning one's identity. This process is different from identity issues of adolescence. Individuals in middle adulthood look back on their lives, explore their own lives, and consider the ends of their lives. General populations who typically live longer gradually experience changes in physical functions and roles when they are in middle

adulthood. They usually have adequate time and psychological capacity to ponder these questions. Sumire, on the other hand, had to explore the general task of middle adulthood and end of life issues simultaneously. Though this was a difficult process for her, her family supported her for “being” there rather than “doing” something and thus helped to restore her “a place to be.”

Self-existence cannot be discussed without others. Others sometimes confirm and at other times deny self-existence. Merleau-Ponty (1964) described the relationship of an infant to his or her mother as “mirroring each other indefinitely like two mirrors facing each other.” This metaphor is not only applicable to infant-mother relationships but also to more general relationships among people. Self-existence constantly changes, depending on how the individual reflects in others' “mirrors.” Family members and medical professionals made it possible for Sumire to achieve a peaceful life in the palliative care unit.

Another fear pertains to self-existence after death. Sumire was not certain about afterlife because she subscribed to no specific religion. For Sumire, the afterlife that nobody has confirmed was daunting. Though she was frightened to think of death as the end of everything, she was unable to simply believe in heaven. Though religion can be helpful for uncertain matters such as afterlife for some people, Sumire wanted to find and believe in an answer that would satisfy her, borrowing the insight of others. Sumire worried more about her connection to and her being remembered by her family than about the security of a particular afterlife.

After decades of mirroring each other, how can others' mirrors reflect each other after Sumire's death, i.e., losing one of the reflecting mirrors? There is no simple answer to this question. Finding a way and a place to mirror the existence of both the dying and those left behind, even in a different format than before death, may help reduce death anxiety.

V. Conclusion

Cancer patients suffer physical, social, psychological, and spiritual suffering both related to the illness and to general life concerns apart from the illness. Though people often discuss “life” and “death” as opposites, questions of “life” may be similar to that of

“death.” This article explored “self-existence” that is deeply related to “life” and “death.” The living and dying process cannot be generalized or discussed lightly. This article intended to consider some questions of “death” and “life” by analyzing interpersonal relationships (instead of focusing just on the patient) through interview sessions with a terminal female patient in late middle adulthood. The author reflected on one cancer patient’s journey of life with her family and described the process of living and dying through her wisdom.

The author would like to conclude this article by expressing much gratitude to Sumire and her family. They helped the author explore the most fundamental questions of human life, a topic about which we all have much to learn.

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中年期と死 ——中年期後期を生きる日本人女性の事例から

要旨

人のその一生の流れを包含する生涯発達心理学では、死はどのような意味を持つものとして語られてきたのだろうか。例えば、人の生きる過程を年齢段階という軸に沿って捉える視点からは、死は「老いることの意味」として中年期以降に着目され、人は自分の死を自覚することによって喪失感や焦りを感じ、その一方で死を自覚するからこそ、残された生への思いが強くなるという生への渴望として死の意味が説かれる（やまだ 2002）。

このような死を生終わりとどう理解し受容するのかという視点からは、自分が死ぬ存在であることをその内に抱えながら生きることや、死を見送る者の生と逝く者の生が重なりながら並走し、互いの生の中に死という出来事があるという死生の意味の動的な部分をみつめる視点を欠いている、年齢に沿った発達という人前の死生の普遍性だけではなく、個々人が持つ死生の意味をも包含する変様性にも着目する必要があるといえる。

そこで本稿では、自らの死を考えながら生きることを余議なくされている末期癌患者との対話を取り上げ、死から照らし出された生の意味、死に逝く当事者にとっての死生の意味について、死生の固有性を含めた新たな生涯発達論について論じた。

キーワード：生涯発達、自己形成、自己存在、死