

Family Caregiving in Japan: The Influence of Cultural Constructs in the Care of Adults with Cancer

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Abstract

Caring culture is a concept embodying the perceptions and caring practices of caregivers, acknowledging the unique role of cultural beliefs in shaping behavior. A qualitative descriptive study with 13 caregivers of adult family members with a cancer diagnosis in Japan was conducted to gain insight into perceptions and experiences surrounding caregiving. Several major categories were identified, representing rarely-reported cultural construct of high cultural value for the Japanese: *On* -repayment for what the patient has given; *Caregiving as performing a socially expected role*; *Enryo/meiwaku* - restraint in asking for help; *Family decision making reflecting strong bonds*; *Omoiyari* - empathizing with the patient's feelings; *Inori* -praying to myriad gods and ancestors. The Japanese cultural construct of *ie* (the strong relationship to family lineage and spiritual connection to past and future generations) is helpful in understanding these categories. Invisible yet powerful cultural construct permeated caregiving practices. Insights from Japanese cultural concepts and beliefs may foster sensitivity and individualized care in diverse settings, cultures, and societies.

Keywords: Family caregiver, cancer, caring culture, cultural beliefs, Japanese

Introduction

Caring for individuals facing cancer is a challenge for family members and for nurses whose goal is providing both client- and family-focused assessment and intervention. Family caregivers are an important resource in health care, and nursing scholars have not only addressed this (Friedemann, 1995, Kaakinen, et al., 2014, Wright, & Bell, 2009, Wright & Leahey, 2013) but have also attempted to examine the impact on patient and caregiver outcomes, including quality of life (QOL) (Chen, Chu, & Chen, 2004; Griva et al., 2016; Raplay, 2008; Shaw et al., 2016; Trudeau-Hern & Deneshpour, 2012; Weitzner, Jacobsen, Wagner, Friedland, & Cox, 1999). The significance of culture to the caregiving process – patterns, interpretation, and impact – has been noted by several researchers attempting to gain insight into both patient and caregiver experiences in chronic illness generally (Sun, Ong, & Burnette, 2012) and along the trajectory of cancer more specifically (Davies, 2000; Koffman, Morgan, Edmonds, Speck, & Higginson, 2008; Mokuau, Braun, & Daniggelis, 2012; Ye, Kellet, Henderson, & Chen, 2015). There are limited studies of Japanese culture and health phenomena (for example, Japanese culture and the concept of the “good death”) (Hattori, McCubbin, & Ishida, 2006; Long, 2004; Sanjyo et al., 2007). Other studies of Japanese caregivers’ behaviours and perceptions have been conducted in the field of gerontology (Asai & Kameoka, 2005; Imaiso, Tsukasaki, & Okoshi, 2012; Long & Harris, 2000; Okabayashi et al., 2008; Tomita, 1994; Yamamoto-Mitani et al., 2004). Only a few researchers have reported

on studies of Japanese family caregivers of people with cancer including palliative and end-of-life situations (Ishii, Miyashita, Sato, & Ozawa, 2012; Misawa et al., 2009; Miyashita et al., 2008; Mori et al., 2012) and there remains a lack of literature concerning research focused on cultural aspects of Japanese cancer caregivers' experiences. The study reported here focuses on the experiences, feelings and thoughts of family members directly engaged in caregiving with cancer patients in various stages of treatment and recovery. Several categories arising from the data reflect core values in Japanese culture that have rarely been reported in the health literature. These values have significance for the provision of culturally appropriate nursing care to families as they navigate the cancer experience.

Family Caregiving in Cancer

The family unit and family context are important considerations in health care. Family assessment models focus on both family structure and function, providing guidance in determining the impact of health-related changes (de Melo & Alarcão, 2011; Svavarsdottir, 2008; Wright & Leahey, 2013). Literature concerning family caregiving experiences documents the interrelatedness between individuals, the family system, and community. Frameworks for family assessment and care acknowledge the effects of an individual's illness on the entire family unit or system, including communication and relationships within the family, and links to larger contexts such as community (Ferrell & Mazanec, 2009; Given,

Given, & Kozachik, 2001; Rodríguez-Sánchez et al., 2011). Studies of the experiences of family caregivers in cancer have revealed difficulties and burdens as reported by caregivers (Given et al., 2005; Weitzner, Haley, & Chen, 2000). Examples documented in the literature include disrupted daily schedules and routines, psychological distress, diminished social relationships, depression, anxiety and financial challenges (Given et al., 1993; Rhee et al., 2008; Schulz & Beach, 1999; Yun et al., 2005). In a similar vein, other studies have linked the incidence of depression and other psychological sequelae (both positive and detrimental) to caregivers' overall quality of life (QOL) (Grant et al., 2013; Grov, Dahl, Moum, & Fossa, 2005; Shaw et al., 2016; Northouse, Katapodi, Schafenacker, & Weiss, 2012).

Culture in Illness and Caregiving

Consideration of cultural context is valuable in understanding perceptions of wellbeing and illness in everyday life experiences (Farmer et al., 2012; Helman, 2007; Leininger, 1988, 1994; McFarland, Mixer, Webhe-Alamah, & Burk, 2012). The role of cultural conventions, norms, patterns and/or rules in mediating individual and family perceptions of and responses to illness should not be understated (Davies, 2000; Leininger, 1988, 1994). The groundbreaking study by Hall (1980, 1989) examined Japanese patterns of behavior and identified the concepts of 'high-context culture' and 'low-context culture' (Hall, 1989); this anthropological study focused on communication and the ways in which cultural

values affected behaviors and communication patterns. Hall (1989) stated, “Cultures within which people are deeply involved with each other, and information is widely shared through simple messages with deep meanings, are referred to as high-context. Low-context cultures are those highly individualized, somewhat alienated, fragmented cultures such as Swiss and German” (p.39). His findings suggested that Japanese culture was among the high-context cultures that employs indirect verbal expression, as opposed to North American and Western European cultures wherein direct verbal communication is more the norm. Subsequent work by Hall and others (Asai & Kameoka, 2005; Bito et al., 2007; Lebra, 1976; Miike, 2003) identified the concepts *on* (favour and obligation), *omoiyari* (empathy for someone), *enryo* (restraint, being considerate of others), *meiwaku* (bothering others), and *sasshi* (reading the situation and mind) as examples of the unwritten interdependence of social norms and values in Japanese culture. Such core concepts may play a role in caregiving within the family context and, as Kagawa-Singer, Padilla, & Ashing-Giwa (2010) observed, may illustrate the role of culture as a determinant of psychosocial wellbeing and QOL.

Caring Culture

In the study reported here, culture was defined as the core of individuals’ day-to-day practices and views of life, including perceptions and behaviors inherent in caregiving. Culture is a dynamic phenomenon, sometimes transcending time and space - emerging,

flowing, adapting, modifying, and reflecting the shared social context of caregiving. Given this, *caring culture* is a concept embodying the perceptions and caring practices of caregivers, acknowledging the unique role of culture in shaping behavior.

The purpose of this study was to explore Japanese cancer patients' family caregivers' perceptions of and responses to their everyday caregiving practices and experiences. The objectives were to describe caregiving experiences of Japanese cancer caregivers in Japan and to more specifically identify cultural values underpinning their perception of and responses to their day-to-day caregiving lives.

Methods

Design

This was a qualitative descriptive study (Grbich, 2003; Sandelowski, 2000, 2010; Sandelowski & Barroso, 2002) which drew from the general tenets of naturalistic inquiry, with the specific intention of exploring socio-cultural values underpinning Japanese cancer family caregivers' practice and perceptions. According to Sandelowski (2000), qualitative description provides a rich depiction of an experience, event, or process in easily understood language; the interpretation of qualitative data enables the voices of participants to be presented, reflecting the views of the people whose behavior is being studied (Gills & Jackson, 2002; Sandelowski, 2000). As little is known about cultural influences on the

caregiving lives of Japanese primary caregivers of cancer patients – perceptions, attitudes, decision-making, social and familial relationships -- a descriptive qualitative approach was chosen as the most appropriate for this unexplored area (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005; Sandelowski, 2000; Sandelowski & Barroso, 2002; Vaismoradi, Turunen & Bondas, 2013). Use of a qualitative approach allows investigators to focus on areas that are poorly understood within the health care context and/or potentially amenable to intervention. Ultimately, the findings of a qualitative descriptive study have the potential for application to health care situations and can provide direction for improvements to patient and family care (Sullivan-Bolyai, Bova & Harper 2005, p.129).

Participants

Data was collected in 2011-2012, after obtaining ethical approval from the Human Research Ethics Committee of Nagasaki University in Japan and participating hospitals. Participants were recruited from public municipal hospitals and university hospitals in southwestern Japan. Inclusion criteria were as follows: a family member who was key to providing care for a cancer patient; willingness to participate; being fluent in Japanese with Japanese ethnic background. The staff in the institution identified potentially eligible caregivers. Once in contact with potential participants, the first author, as the principal investigator (PI), explained the study purpose and its voluntary and confidential nature, and

obtained written consent.

Characteristics of the Participants

Thirteen family caregivers of Japanese cancer patients ranging in age from their 40s

Table 1. Participant Demographics		
Numbers, <i>n</i>		13
Age group		
	60-70s	7
	40-50s	6
Gender		
	Female	11
	Male	2
Relationship to the patient		
	wife	6
	daughter	3
	daughter-in-law	1
	mother	1
	father	1
	son	1
Performance Status (ECOG) of patient		
	PS 0-1	2
	PS 2	3
	PS 3-4	8
Place of patient		
	Hospital	10
	Home	3
Length of caregiving		
	less than 1 year	8
	1-10 years	2
	over 10 years	3

to 70s were recruited. They had one year to over ten years of caregiving experience both at home and in hospital settings. They were mainly women, and almost half of them were caring for a spouse (Table 1). Eight were caring for patients whose PS was 3 to 4.

Procedure for Data Collection

The first author conducted one semi-structured interview, of about 60 minutes, with each participant (see guide in Figure 1). Interviews were audiotaped and transcribed verbatim. Using an open-ended approach, the interviewer asked family caregivers to talk about their experiences, feelings and thoughts, including reflections on difficulties, life changes, and interactions with the patient and people surrounding them since the diagnosis of

cancer; the effects of being a caregiver on their perceptions and attitudes were explored.

Figure 1. Abbreviated interview guide

Would you tell me about your experiences of being a caregiver of your family member with cancer (patient)? - When was the cancer discovered? How did you feel and react when it was diagnosed? - How have things changed in your life since becoming a caregiver? - What does it mean to you to be a caregiver? - How would you like to care for and what would you like to do for your patient? - What is the most important value (to keep in mind) for you to be a caregiver? - How does being a caregiver affect the activities that are most important (or of interest) to you? - When you are caregiving, what makes you feel good or bad?

Since caregiver depression and QOL have been correlated with the patient's functional status (Northouse et al., 2012; Rhee et al., 2008; Weitzner et al., 1999), the Eastern Cooperative Oncology Group's (ECOG) Performance Status (PS) indicator (Oken et al., 1982; The Eastern Cooperative Oncology Group, 2006) was used to describe the patient's functional status. This instrument was completed by the staff nurse who introduced the participants to the principal investigator (PI) as part of the recruitment process (PS 0-1: normal to some symptoms, but nearly or fully ambulatory, PS 2: less than 50% of daytime in bed, PS 3-4: more than 50% of daytime in bed to completely bedridden).

Data Analysis and Interpretation

Qualitative transcript-based content analysis was selected as the inductive approach to

reviewing and analyzing interview data. This allowed extraction of sub-categories and categories, an important approach when investigating a phenomenon which is novel and not previously studied (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005; Sandelowski, 2000; Sandelowski & Barroso, 2002; Vaismoradi et al., 2013). Transcripts were read several times in order to gain a sense of the interview as a whole (Grbich, 2003; Morse & Field, 1995; Polit & Beck, 2003). Then colored tabs and underlining were used to identify key ideas and expressions thought to be significant for the participants. Open coding, an early step in conceptualization of the data, was used (Elo & Kyngäs, 2008; Morgan, 1993). This process led to the derivation of sub-categories, which were given concept labels that were descriptive of participants' own terms for their thoughts, feelings/emotions, and experiences. The sub-categories had commonalities or similarities that enabled the researcher to group them under broader conceptual labels and, as a result, major categories were identified. Categories represented areas or focal points where there was consistency across participants and where common language and descriptive terminology for experiences and emotions were noted (Elo & Kyngäs, 2008; Graneheim & Lundman, 2004; Hsieh & Shannon, 2005; Sullivan-Bolyai et al., 2005). Six categories are reported and elaborated upon here because they are reflective of cultural values and mores that may be uniquely Japanese and extend beyond what earlier literature has reported concerning a strong relationship between cultural values and family caregivers' experiences (Bito et al., 2007; Helman, 2007; Tomita, 1994; Yamamoto -Mitani et

al., 2004; Yuhara, 2011). Categories and sub-categories not only offered a rich description of experiences, but provided insight into the cultural meaning and significance attached to caregiving. Alignment of categories with cultural concepts and/or general social values in Japan, including hidden and implicit meanings, was part of the analytic and interpretive process. When it was appropriate, cultural conceptual labels were given to major categories, since labeling them with native descriptive language helped to capture the underlying values or nuances.

Throughout the analytic process, the PI attempted to “remain true to” the feelings and emotions described by participants and thus labels attached to categories and sub-categories reflected their actual words or the larger context of their experiences. Trustworthiness was strengthened through repeated review of the transcripts and member check between PI and the first co-investigator (CI) after the initial phase of data analysis. Peer debriefing was conducted with one CI, especially concerning analysis of the Japanese text. Finally, a discussion of categories and sub-categories and their interpretations occurred between the PI, the first CI and the second CI, a Canadian experimental psychologist with expertise in palliative care in Canada; this discussion allowed for the analytic process to be multidimensional and interdisciplinary, as well as comparative from Eastern and Western perspectives.

Results

Japanese Cancer Family Caregivers' Caregiving Experiences and Their Realities

Fifteen major categories (see Figure 2) with 93 sub-categories were extracted from analysis of the data. Although all fifteen major categories are of importance in elucidating the caregiving experience, and were not experienced in isolation from one another, this report focuses on the six most representative of Japanese culture because of their overriding significance in understanding the notion of caring culture and because they are concepts rarely or unreported in the literature to date. Of these six categories, four reflect relevant Japanese socio-cultural concepts and therefore are titled *on*, *enryo/meiwaku*, *omoiyari*, *inori*. The other two categories, *caring as performing a socially expected role*, and *family decision making reflecting strong bonds*, are named using descriptive phrases derived from caregivers' elaboration of the realities of their experiences.

Figure 2. Categories relating to the *Caring culture* of Japanese cancer caregivers

- | | |
|-----|---|
| 1. | <i>On</i> : Caring is repayment for what the patient has given the caregiver and includes sharing memories of the past with the patient |
| 2. | Caregiving as performing a socially expected role |
| 3. | <i>Enryo/meiwaku</i> : Restraint in asking for help |
| 4. | Family decision making reflecting strong bonds |
| 5. | <i>Omoiyari</i> : Empathizing with the patient's feeling and thoughts |
| 6. | <i>Inori</i> : Praying to myriad gods and ancestors |
| 7. | Positive mindset and respite |
| 8. | Financial state and problems |
| 9. | Patient state |
| 10. | Anxiety about an unforeseeable future and burden |
| 11. | Relationship with the patient |
| 12. | Evaluation of caregiving |
| 13. | Social support and resources |
| 14. | Caregiver's own health state |
| 15. | Social activities and life patterns |

Findings are described by category beginning with an overview of the nature of the category followed by quotes that illustrate the substance of the category. Supporting quotes are freely translated from Japanese, but not rigorously edited for English in order to maintain the structure of participants' thoughts and words, and to preserve original meanings as much as possible. Also note that the letters of the alphabet indicate the participant and the numbers were used to code their actual statements in supporting quotes.

On: Caring is repayment for what the patient has given the caregiver and includes sharing memories of the past with the patient

Family caregivers' world views regarding their roles with family members with cancer were multifaceted. What the caregivers saw through providing care for a loved one seemed to reflect what they had received from and shared with the patient. Caring was described as love and repayment for what the caregiver had received from the patient, including memories shared with the patient beyond the present time and space.

B-3: My mother has worked so hard to raise us- 4 children, we can't repay...so I wish for her to live as long as she can. For a doctor, she is one of many old women, but she is the only mother for me and for us. She used to work really hard...I have never seen my mother resting. She kept herself so busy and even on the rainy days she did needle work at home. When my father got tuberculosis, she really had to work hard for us [in tears].

F-3: I observe my father and I think hard and wonder about what he might be able to eat. Then I bring some food for him and leave it there in his room quietly [without mentioning it]. When I see him eating what I have brought him, I feel good. I think I can never provide enough care [to repay him]...

Caring and affection were portrayed as never ending, extending both into the past and the future shared with the patient and other family members. The Japanese term *on* and repayment for *on* (a circular process) represent values rooted in and modified by Confucian philosophy and manifested in Japanese religions and folk beliefs; in the context

of the Japanese family, these values are highly influential (Lebra, 1976). A typical example of this circle is found in the related and well-known concept of filial piety, which embodies repayment to parents from their children. Within the history of the samurai period, *on* became part of the code of conduct and an assurance of a vassal's loyalty. There is an unspoken social contract between *on* givers and receivers (Hane, 1992; Kagawa-Singer et al., 2010).

Caregiving as performing a socially expected role

Data indicate that Japanese family caregivers were caring for the patient not simply because they were a family member or because they voluntarily wanted to assume a caring role. Although they wished to care for their loved one, unspoken social expectations and norms urged or even forced them to do so, as an individual who had received *on* (thus owing a social debt to repay) and as one who was expected to assume social roles related to social status and gender. This was particularly felt by women.

A-4: I think the wife of a first-born son is expected to look after her parents-in-law.

When I thought of bringing my father-in-law back to his home and caring for him at home, my sisters-in-law told me that they do not mind taking him back to his home, but I was the one who was the primary caregiver and it would be a hard task. I was really shocked by what they said...then I could not decide to bring him back to his

home. This is a regret...he worked so hard to build that house but he could not stay during last stage of his life.

G-11: I do not want to regret at the end, and as I am the eldest daughter, I strongly feel that I am responsible for supporting my father [patient]. I feel that my father is expecting that from me too and I wish to meet his expectations as much as I can. I think, in that way, he feels relieved.

Family caregivers and patients formed a team, as in a three-legged race, working together to cope with the difficult journey. The family caregivers suffered from anticipatory loss and grief, sharing the challenging experience with the patient and other significant family members. The socially expected role performance (as daughter-in-law, eldest daughter, or father, for example) was an overriding force governing the caregiving role. Family caregivers were sometimes clearly told that they were in the position to be a primary caregiver due to their social footing, as evidenced in the statement above, and this was reported as often being accepted without question.

Enryo/ meiwaku: Restraint in asking for help

The Japanese caregivers in this study frequently expressed both apprehension and feelings of reserve when they needed or received help and support from others. “Social self-restraint, termed *enryo*, is a product of the suppression of individuality under the pressure of

group solidarity and conformity” (Lebra 1976, p.252), and includes a fear of bothering others (*meiwaku*). These two influential concepts have been previously described in the general literature on caregiving and health-related decision-making (Asai & Kameoka, 2005; Bito et al., 2007; Miike, 2003). Although family caregivers were aware of their strong needs for support and assistance in maintaining both their own and the patient’s everyday lives, they were, as primary caregivers, reluctant to ask for help from others, including other family members.

J-10: There are relatives and nephews of my husband [patient], but they all have their own family and work to do and are busy, so I can’t rely on them [to help me and the patient]. So I have decided to hire people to provide care – a helper, by using the elderly care insurance. I do not want to cause trouble.

A-3: I considered and wondered how the nurses think and feel about me bathing or feeding my mother-in-law when she was hospitalized. Although I wanted to take care of her by myself, at the same time, I did not want to interfere with the nurses’ job and make them feel uncomfortable. I certainly did enryo [restraint in asking for help] to them.

Primary family caregivers perceived themselves as the last stronghold of caregiving for the patients. The strong sense of responsibility as primary caregiver, together with hesitation to ask for help from others (*enryo*), imposed desperate feelings of helplessness,

driving caregivers “to the wall”. They often stated that they did not want to cause trouble (did not want to be *meiwaku*) for others. Such hesitation and apprehension were described within their relationships with other family members and health professionals. The sense of *enryo/meiwaku* also played a role in caregivers’ recognition of the need to access formal resources that would mitigate their sense of burden.

Family decision making reflecting strong bonds.

The family support system often strengthens family bonds and brings positive input for caregivers in continuing the provision of care. Being understood by family and having a common goal within the family were reported as being particularly important for caregivers. At the same time, such family ties added another dimension to family decision making. A particularly significant experience of family decision making was reported in instances where prognosis or end-of-life decisions (“do not resuscitate”, for example) needed to be made. Some family caregivers reported that they were reluctant to tell the patients that they were at the end stage of cancer.

B-2: *All family members know about it [that my mother has cancer and is at the terminal stage], but we have not told her so. I do not want to tell my mother... she is old, and I do not want her to suffer...it is a pity [to know such bad news at her age].*

D-3: *We have not told my husband [patient] that he is almost at the end stage of his*

life. He developed stroke and has had a chronic condition for many years. It is just recent that he was diagnosed with esophageal cancer and he is getting weaker and weaker. Pain is controlled very well so that is good. I do not want him to know that he has incurable cancer. We try hard for him not to know it. We decided not to make a gastric fistula. We [family but excluding the patient] have discussed it and decided not to do much medical intervention for him. We do not want him to suffer.

This approach not only limited patients' access to information concerning their health status but it also extended to family members the right or responsibility for making decisions on behalf of patients. This might be construed as depriving patients of their rights; however, families reported doing this as a way of protecting their loved ones from potential psychological suffering and pain. Having a family group which could share bad news, for example a prognosis including death, seemed to strengthen family relationships and encouraged caregivers to face and deal with their day-to-day caregiving practices. Sharing in family decision making reduced the obstacles for and difficulties of caregivers.

Omoiyari: Empathizing with the patient's feelings and thoughts.

Often caregivers could understand the patient's feelings and were able to provide what their family member wished for and needed. These practices were often the result of repeated careful observation and reading of the situation, and actions were taken without validating

(verbally confirming or denying). Understanding each other without speaking is one characteristic of communication norms in Japanese culture. This specific communication feature is a part of Japanese norms called *omoiyari* (reading and having empathy for others' feelings), commonly found in high-context cultural societies such as Japan (Asai & Kameoka, 2005; Bito et al., 2007; Lebra, 1976; Miike, 2003). For example, taking the patient back home seemed to be particularly important for both the patient and the caregiver, but this too was not clearly spoken of between them. The way in which caregivers dealt with their reality of providing care also highly reflected their view of life and life experiences. Often this was seen and understood as an important lesson from past experiences, encompassing regret and personal values underpinned by such *omoiyari*.

A-9: I wish my father-in-law died at home because he built that house by working so hard, but I could not...there was a lack of family support plus I missed the right timing. When his condition deteriorated, it was so quick and I missed the time to bring him back to his home. It was too late. I do not want to have a repeat this time [her mother-in-law is now the patient].

B-11: My mother says nothing, but I feel for her...she does not want to be alone and she wants someone to stay next to her.

Inori: Praying to myriad gods and ancestors

Inori is translated as praying. Praying for and clinging to something beyond human power was described as a natural response from caregivers facing difficulties and helplessness in their lives. Some participants characterized this as follows:

C-13: I pray to a neighbor who has passed away. We used to be very close like sisters. I feel that she says “Hold on” to me and encourages me. I often talk to her [while she is not here any longer] and ask her “Why do I have to be in this [bad and suffering] situation. I have done nothing wrong”. She says nothing but I feel that she encourages me...

E-6: I pray to Buddha [at home] and also pray “please protect us” to the Koubou Daishi [the grand master who propagated the Buddhist teaching] along the way home. It soothes my mind and I am helped by doing so.

M-7: I lost my daughter when she was elementary school and I have a family Buddhist altar at home. I pray to both the ancestors of mine and the ancestors of my husband [patient] every morning. That’s all I do.

Ancestors, deceased close friends, gods and Buddha are symbols of power above humanity and help caregivers to cope with and manage their difficult times and emotional burdens. For their spiritual and emotional tranquility and balance, Japanese caregivers seemed to pray or talk to a number of gods and ancestors. Interestingly, some prayer took the

form of conversation between caregivers and gods, acknowledging the power of nature or spirits represented as ancestors and deceased loved ones.

Discussion

The preceding section summarizing the results has focused on six primary categories arising from the data, and excluded ancillary categories that, while relevant, did not add new insights to the same degree as the cultural concepts described in participants' accounts.

Insights gained from the six major categories, and their cultural significance, add to the body of knowledge concerning family caregiving in cancer and embody the concept of caring culture as reflected in participants' descriptions of perceptions and caring practices. The ensuing discussion will elaborate on the primary categories, their relationship to caring culture, and the nursing implications that may be derived.

Family Caregivers, *On* and repayment for *On*, and Caring as Performing a Socially

Expected Role

On indicates debts owed by individuals who have previously received favors given by superiors, whether human or above or beyond the human (Lebra, 1976). Hane (1992) explains, "a person owed *on* to his feudal lord, parents, teachers, emperor, society, and so on" (p.28). Interestingly, for the family caregivers in this study, caring was seen both as

repayment of a debt and as gratitude for love given by the patient. In addition, caregiving was seen as the performance of a socially expected role. *On* emerges within many aspects of social activities and human relationships including larger social systems in Japan. Individuals may owe several *on*, social debts or duties, and may have roles to assume, including a ‘social role’ as the ‘primary caregiver’. On the other hand, participants in this study reported that caring was seen as a great opportunity to return debts owed to care recipients and to act on their socially expected roles, performing as a good wife, daughter-in-law, primary caregiver, and so on, if the tasks were manageable. Thus, caring as repayment of the debt of and gratitude for love received from a cancer patient did not mean it is always negatively perceived, or construed as an obligation forced upon caregivers. A sense of the ‘right balance’ between receiving *on* and repayment for *on* through caregiving was reported to be central to whether the caregiver was motivated to continue providing care, or was dissatisfied and feeling burdened, with potential future regret for being a caregiver. Regardless of the family caregiver’s view of caregiving as a chore or an opportunity to repay for what had been received from the patient, a circular process of *on* and repayment for *on* seemed to be a significant but implicit cultural norm affecting behaviors and perceptions of the family caregivers. Nurses should observe and carefully assess for this invisible cycle in order to provide supportive care or additional resources when necessary.

Family Caregivers, *enryo/meiwaku*, *ie* and the *uchi-soto* Dichotomy

Family caregivers did not wish to disturb others' feelings, time, resources, and everyday life patterns, and they avoided becoming a "trouble for others" as seen in the category of *enryo/meiwaku*. These complicated feelings experienced by participants often led to them holding in their problems and difficulties, making them invisible (Saito et al, 2015). Considering the categories of *enryo/meiwaku* with the two dichotomous Japanese concepts *ie* and *uchi-soto* assists in understanding Japanese family functioning. The *ie* is related to but also different from the concept of 'household' or 'family' in English. Nakane (1970) explains its wholeness and perpetuity by pointing out that *ie* exists within the time continuum from the past to the future, as it includes not only living family members but also deceased members (ancestors) and even projections to the unborn. Saito (2000) explains that, with the Japanese *ie* concept, it is crucially important to identify who are immediate members of the *ie* and who are not. Thus, resource and information-sharing inherent in the provision of mutual support and shared decision making are done in an *ie*.

Additionally, the Japanese distinguish one situation from another according to the dichotomy of *uchi* and *soto*. Lebra (1976) states, "*Uchi* means 'in, inside, internal, private,' whereas *soto* means its opposite, 'out, outside, external, public'" (p.112). *Uchi* may force family members to solve problems and issues internally, and avoid speaking about those problems to the public (including health professionals) as this would be shameful and bring

disgrace to the family name. In other words, an individual always carries *ie* and family honor on his shoulder. This may be seen in other cultures or societies, but the Japanese are particularly known for this as a 'closed' culture (Lebra, 1976). This characteristic was evident in family caregivers' perceptions and actions as they expressed their hesitation about speaking openly about their concerns and asking for help from others, particularly from someone from *soto* (outside the *ie*). This is an important consideration for nurses, who are at *soto* from the *ie*; assessing patients and their families and effectively intervening could be influenced by these cultural concepts. Notably, while it may seem paradoxical, for some caregivers, or on some occasions, *soto* and *enryo* facilitated a caregiver's request for help, as seen in the example of the participant who hired professional care workers rather than ask for help from other family members. In this case, with the presence of financial resources, there was less *enryo* in hiring professional care workers. Thus, *enryo* and not wanting to disturb (*meiwaku*) others' work was reported as being dependent on the situation and on how the caregivers saw and felt about the situation. The highly subjective nature implicit in *enryo* creates a certain ambiguity for nurses who try to provide efficient assessment and care for their patients and families. However, such cultural and invisible actions are always in the caregivers' minds, and thus nurses should be aware of the cultural norms and concepts underpinning caregivers' behavior, carefully observing and assessing their perceptions of the situation and whether they are struggling to maintain their everyday care for both the patient

and themselves.

Family Decision Making Reflecting Strong Bonds: *omoiyari*, *ie* and *sasshi*

The concepts of Japanese *enryo-sasshi* communication (restraint-inference) and *omoiyari* (empathy) provide insight and understanding into the experiences of Japanese caregivers and their decision-making practices. Japan is well known for its collective and high-context culture; Japanese communication relies a great deal on nonverbal mutual understanding (Adair & Brett, 2005; Bito et al., 2007; Hall, 1989; Miike 2003). According to Miike (2003), *enryo-sasshi* communication is characterized by the message sender's silence and ambiguity and the receiver's sensitivity; this communication functions smoothly in Japanese society.

Similarly, the concept of *omoiyari* is also very common within Japanese society. Lebra (1976) states, “*Omoiyari* refers to the ability and willingness to feel what others are feeling, to vicariously experience the pleasure or pain that they are undergoing, and to help them satisfy their wishes” (p.38). Kindness and benevolence become *omoiyari* only if they are derived from sensitivities to the communication recipient's feelings. Consideration for others, as *omoiyari*, is a sense of attentiveness and an indispensable cultural sense of living in society (Fukushima, 2011; Lebra, 1976), thus an element of caring culture. Significantly, examples of thoughts and caring practices shared by participants in this study were the result

of caregivers' careful and deep observations and good intentions to protect their loved ones. Because caregivers had known the patients for many years by sharing their lives, they knew what the patients were like and what they would like to do without needing to speak about or confirm those things. This invisible and implicit caring communication was like the process of knitting, with the delicate yarn of observation structured between caregivers and patients over a long period of time. Sensitivity and observation were also reported to be very important elements of the caring culture of Japanese caregivers. These were extended to caregiving work in affirming and respecting the patients and their preferred ways of spending their limited everyday lives. Sensitive and caring social values were evident in the context of caregiver/care recipient interaction; it was seen that the caregivers in the study *omoiyari* for the feelings of their family members with cancer, putting themselves in their shoes. As a result, caregivers and family members sometimes decided not to share information such as diagnosis and prognosis with the patient; similarly, they might leave something that the patient wanted to eat and enjoy without speaking about or confirming it directly with the patient. Such findings illustrate the power of nonverbal communication used in a way to protect from harm and ease the pain of patients, thus expressing love and affection. It can be seen as the presence of strong family ties and *ie*. Because Japanese culture is highly dependent on context, the ability to 'guess' by understanding a given context requires individuals' ability of *sasshi* (inference).

While contextual and non-verbal behavior is very important in other societies, the Japanese might be more likely to behave in a silent manner. *Sasshi* functions only if such sophisticated guesses are accurate between individuals. However, when *enryo-sasshi* communication does not work, an individual might be reluctant to send a message or insist on his need being fulfilled because of the sense of *enryo* (restraint in asking for help and being reserved). In this study, for example, it was frequently reported that caregivers were reluctant to ask for help from others, even from other family members. Caregivers stated that they would rather not disturb others, and did not voice their needs and feelings or ask for help. Reading the situation and the other person's feelings were felt to be socially required by caregivers, once more illustrating a closed cultural practice. If family members did not ask for help or share their challenges outside of *ie* they might have been at risk of social and emotional isolation, increasing their psychological burden and stress.

Previous research on caregiving has reported that caregivers' depression, fatigue, and financial burden are detrimental to their coping. There exist the parallel issues of suicide, double suicide, murder/suicide or abuse, all of which have been reported (Hane, 2006; Yuhara, 2011) in both the East and West, but particularly in Japan: 1% of suicides in Japan (317/31,690) were attributed to caregiving fatigue in 2010 (National Police Agency, 2011). However, this is said to be only the tip of the iceberg (Hane, 2006, Yuhara, 2011). Japan's rapidly aging population has the highest proportion of people over 65 worldwide as 23.1% in

2010 (Statistics Japan, 2011), leading to increased incidence of elderly caregivers taking care of elderly patients. This, together with Japanese caregivers' cultural and behavioral characteristics, creates potential risk for caregivers in terms of burden and related health effects. Given Japanese family caregivers' *enryo* behavior and practices, in which caregivers sometimes face hesitation and restraint in asking for help from others, it might be beneficial and useful, as well as culturally appropriate, for nurses to approach them about the possibility of visiting nurses and other health care personnel such as established social services.

One aspect of family decision making that reflects the strong bonds inherent in family relationships is the generally accepted and common practice for physicians to consult with the family of the patient first (i.e. prior to consulting the patient). It is rare for the patient to request that the physician discuss his/her case directly, prior to involving the family. A relatively new pattern of informed consent in Japanese society is to ask a patient, prior to any clinical procedure, if s/he wishes to know all information about his/her illness and health or if s/he wishes to share information with his/her family (or any other preferences). Otherwise, doctors will commonly speak with the patient's family first, particularly if the illness is serious and will involve surgery and other interventions. The notion of autonomy might differ in Japanese society when compared with Western society. Nurses unfamiliar with Japanese culture might be surprised to find that family members would decline to disclose the nature and details of the illness and the seriousness of the situation to the patient. Doctors and nurses

document these decisions, and the entire health team will adhere to the family's decision as well as patient's decision if that has been made clear. If the family has decided not to disclose the true health status of the patient to him/her, it is often observed that there is a balance of merged *omoiyari* and *sasshi* elements working between family members (who do not wish to make the patient suffer and hurt and, at the same time, hope to protect a patient). Bito et al. (2007) studied and compared Japanese attitudes toward end-of-life decision making among Japanese Americans and Japanese in Japan, and found that all groups preferred group-oriented decision making with family. In addition, fear of being *meiwaku* and being a burden to caregivers were reported in his study. Nurses should be sensitive to these variations in the cultural connotations of "consent" and shared decision making.

Family Caregivers, *ie*, and *inori*

Japanese family caregivers prayed to myriad gods and to their family roots for their spiritual and psychological peace. Praying for and clinging to something beyond human power was described as a natural response from caregivers facing difficulties in the course of their caregiving experiences. Participants reported a strong link with *ie* members, particularly their ancestors, but also including gods and Buddha. Smith (1974) explains the ancestor worship of the Japanese by explaining the *bon* festival. Bon is known in English as the Festival of the Dead, and the feast of souls runs in midsummer between August 13-15 in

Japan. It is one of the biggest Buddhist holidays (dating from the seventeenth century) focusing on ancestor worship; it continues to be seen in the modern cultural tradition. Welcoming their ancestors' spirits every midsummer to their *ie*, together with praying to myriad gods, Buddha and ancestors, is indicative of the strong spiritual bonds of family members (caregivers and patients alike) and their ties to ancestors and cultural roots. The concept of time is reported as another component related to caring culture. Caring practices described by participants in this study included past times and memories shared with patients, *on*, and spiritual bonds with ancestors. These practices comprised caregivers' coping or preparation processes in anticipating loss and grief, and should be understood and supported by nurses as they work with both patients and families to provide individualized care.

Strengths and limitations

A strength of this study of the experience of Japanese caregivers is that the team included both cultural insiders of Japan and West. This allowed for discussions as to what was fundamentally different between the two cultures and what was likely to be more of a difference in expression, thereby enhancing the interpretation of the data.

The small sample size, governed by geographic realities, is a limitation of this study. A larger sample may have uncovered additional cultural practices that shape family caregiving in Japan. We also do not know the extent to which the findings are relevant to

Japanese caregivers of people with illnesses other than cancer. As noted above, because the study was conducted in Japan, we do not know the extent to which the constructs explicated are relevant to caregivers of Japanese origin living in other countries, where some non-traditional cultural constructs may be partially or wholly adopted. Even within Japan, individual caregivers may adhere more or less strongly to traditional culture. However, because the Japanese culture is traditionally 'closed,' Japanese caregivers whose experience is shaped by the constructs described here are unlikely to volunteer them on their own, wherever they live. Therefore, the extent to which they are important to individual family caregivers of Japanese heritage needs to be specifically assessed in order to best support them.

Implications for family nursing practice and research

The findings of this study provide insight into cultural constructs and their significance to the experience of Japanese caregivers. This research underscores the importance of accounting for cultural beliefs and practices in family-focused nursing care. This adds to evidence that indicating that supportive nursing interventions cannot be designed without attending to and validating the underlying meaning of care and caregiving (Davies, 2000; Leininger, 1988, 1994). However, this study goes beyond this general conclusion to elucidate rarely reported cultural constructs, how they influence family caregiving, and how

they often interact, and includes suggestions for how to ensure culturally sensitive nursing care for those who adhere to this caring culture. Further research into the cultural constructs relevant to Japanese family caregiving caring for people with different illnesses is warranted. Future research might develop and evaluate ways of integrating these findings into family nursing care, both in Japan and in other societies, and evaluate the impact of this on family caregivers, other family members (including the patient), and nurses.

Conclusion

This study sought to explore family caregiving for people with cancer within the Japanese cultural context. The findings of this study suggest a complex and important interplay between cultural norms and practices and the everyday realities of caregiving. The cultural concepts inherent in caregivers' descriptions of their experiences - *social debt (on)*; *caregiving as performing a socially expected role*; *restraint in asking for help (enryo/meiwaku)*; *family decision making reflecting strong bonds*; *empathy (omoiyari)*; *praying (inori)* - were reported to permeate almost all aspects of caregiving, both practical and spiritual, and had an impact on processes of decision making, family communication and resource access and utilization. It is critical for nurses to understand the cultural values and social expectations at the core of individual and family practices in the course of cancer care. The findings of this study suggest that it is important for nurses to provide culturally-relevant

family assessment, which may be called ‘*ie* assessment’ for Japanese families, as well as culturally-tailored interventions for both patients and their family members. This assessment should, however, include consideration of the degree to which Japanese patients and caregivers adhere to specific beliefs and cultural practices; nurses should be aware of the possibility that families, despite having Japanese cultural heritage, may have become distant from cultural traditions or may have assimilated to a large extent into another society. Nurses working with families in cancer care need to understand caring culture in order to better meet patient and family needs in any society. Insights from Japanese cultural concepts may also foster sensitivity and individualized care in diverse settings and cultures within other societies. Family nursing has always espoused the notion of family-relevant and family-sensitive care, and much research has been devoted to expanding our understanding of the precise meaning of these terms. Illness-specific and cultural contexts add more complexity to family nursing care; in this study, the interplay of the family cancer experience with Japanese cultural concepts was evident and participants reported this in cultural terms, articulating their experiences in language not previously captured in the caregiving literature. The findings reported here add to family nursing knowledge and provide a foundation for future research and theory development that incorporate consideration of culture-specific beliefs and practices—not in a formulaic manner, but in inductive approaches to family care.

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