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Parental Perceptions of Including Children in Family Member's End of Life Care and at the Funeral Services

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Parental Perceptions of Including Children in Family Member's End of Life Care and at the Funeral Services

by

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Abstract

Guided by social cognitive behavioral theory, this study aimed to explore the parental perceptions of including children in family members' end of life care and at the funeral services by examining the potential predicting factors such as anxiety, depressive symptoms, stress, self-efficacy, self-esteem, attitude toward death, children's age, social support, and personal relationships. A total of 120 (58 non-Japanese and 62 Japanese) parents participated in the study by completing either hard copy or online surveys. Data were analyzed by performing t-tests, correlations, and multiple regression. Results indicated that the majority of participants would definitely include their children in the partners' and other children's (if available) end of life care and at their funeral services, regardless of the cultural backgrounds, that social support and parent-child relationships were strongly associated with the parental decision making, and that there were cultural differences in such associations. The findings suggest that strengthening the social support, particularly from family and friends, and enhancing the parent-child relationships might encourage parents to include children in a family member's end of life care and at the funeral service.

Keywords: parental perception, children's grieving, cultural difference

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Parental Perceptions of Including Children in Family Member's End of Life Care and at the Funeral Services

Introduction

Findings from a recent national survey show that one in nine people in America will lose a parent by the time people become twenty years old, and the rate goes up to one in seven if siblings are included (Comfort Zone Camp, 2010). It is expected that 73,000 children will die every year in the U.S., of which 83 percent will leave their siblings behind (Torbic, 2011). Even though most surviving parents felt their relationships with children became stronger after their partners' death, they also noticed that experiencing a loss of a family member for children is overwhelmingly negative, and even infants were affected by the loss (Lehman, Lang, Wortman, & Sorenson, 1989).

The experience of parental death in childhood can be a great traumatic event for the whole family, which places children at risk for a number of negative outcomes. Even though it is not common for grieving children to have clinical levels of medical problems, these children often experience tremendous sadness and despair by often manifesting a wide range of emotional and behavioral symptoms, which may include anxiety, depressive symptoms, fear, angry outbursts, and regression on development milestones (Dowdney, 2000). However, it is important to note that children's responses to and experiences after the death of a family member may differ (Haine et al., 2008), as they perceive and understand the death differently according to their developmental stages (Torbic, 2011). Therefore, at the family level, providing parents with the education and support to enhance parent-child relationships and positive family interactions is critical for children's grieving process (Haine, Ayers, Sandler, & Wolchik, 2008).

For parents and children who are grieving from the loss of a child or sibling, experiencing some difficulties in psychological adjustment may also be inevitable (Morris, Gabert-Quillen, Friebert, Carst, & Delahanty, 2016). Perhaps as a response, prior research has shown that the majority of parents of children with terminal illness may decide not to inform their healthy children of their sibling's terminal aspect of the illness in order to protect them from bearing such emotional burden. As Holland (2004) indicated, considering that it is challenging for those grieving parents in shock to have conversations with their surviving children about the family member's death, and that many adults feel uncomfortable to talk about their own and others' complex emotions at the funeral, grieving parents might try to protect their children from becoming further distressed in such situations. In addition, many parents determined that children would not understand the circumstances (Stehbens & Lascari, 1974). Although for some parents, not informing children of their sibling's terminal status might feel like an advantage, for example, not having to deal with surviving children's immediate emotional reaction to the potential loss, it might result in some long-term adjustment issues after the actual loss (Lauer, Mulhern, Bohne, & Camitta, 1985).

A study conducted by Lauer et al., (1985), for example, showed that children with fewer opportunities to be involved in their siblings' end of life care and activities and present at their death reported that they were inadequately prepared for the sibling's death, felt useless and isolated from parents and the dying sibling, could not get information and support from parents, and felt their family relationships were worse after the sibling's death. In contrast, in the same study, children with more opportunities to be involved felt that they were prepared for the intended death, that their parents provided

enough information and support, that their experiences were very important and helpful for their adjustment in the new life style, and that their relationship with parents became closer after the death. Therefore, the study finding seems to suggest that involving children in sibling's end of life care, even at the death in some cases, and at the later funeral services may be a positive experience for the surviving children and their relationships with other family members throughout this particular life challenging process.

In a similar vein, according to Holland's (2004) study, the majority of children who were not present at their parents' funerals felt being excluded and isolated from their families, in addition to their feelings of sadness from the loss of a parent. Conversely, children who were present at their parents' funerals considered the experience positive and helpful, and no negative effects were observed. As Romanoff (1998) demonstrated, given the nature of death rituals as functions of connection, transformation, and transition, for individuals who experience pain and shock in their grieving process, the experience of attending and being involved in these rituals is beneficial. Furthermore, children who experienced parental death and had less chance to participate in mourning activities, including funeral-related events, were associated with greater risks of depression later in life (Saler & Skolnick, 1992).

As DeSpelder and Strickland (2010) pointed out, "death is a universal human experience, yet our response to it is shaped by our cultural environment" (p. 85). The grieving and death rituals significantly vary across cultures, which are often heavily influenced by religious beliefs (Clements et al., 2003). However, the decision making related to an individual's end of life has typically remained within the realm of each

family and small communities, which is ingrained in the cultural roots of a society (Bowman & Richard, 2003). Furthermore, the culture should not be defined simply as ethnicity, but rather to expect seeing some variations within each ethnic group because individuals adopt and revise the dictates of culture, and reflect on personal circumstances (DeSpelder & Strickland, 2010).

In sum, the experience of losing a family member is significant, and can be very painful and devastating, especially for children. In light of the fact that a great number of children experience or potentially experience the death of a family member, there is a great need to support those surviving children and their families from the loss of loved ones. The experience of being present at a family member's end of life care and attending the funeral services afterwards may have a positive impact on grieving children's well-being, according to prior research (e.g., Lauer et al., 1985). However, research has shown that many children are not given a chance to be included in those emotionally distressing life events, primary due to their surviving parents' attempts to protect them from emotional burden and crisis.

Although there have been some studies on children grieving over parental and sibling losses (Holland, 2004; Lauer et al., 1985; Morris et al., 2016), as well as on surviving parents' grieving experiences with their children (Lauer et al., 1985; Lehman et al., 1989; Stehbens & Lascari, 1974), research remains scant on parental decision making for healthy children who are facing a family member's terminal illness and death. In addition, to the best of my knowledge, there is no research on what predicts parental decision making in terms of involving healthy children in a family member's end of life

care, such as visiting and spending time with the dying family member, or after death rituals, such as attending funeral services. Therefore, such research is warranted.

This knowledge will have implications especially in health care settings to provide another layer of support systems for patients with life threatening illnesses and their entire family. For example, if health care providers as multidisciplinary teams know what predicts the surviving parents' decision making in this regard, interventions assisting in their children's grieving processes would be important to provide surviving parents with needed support in such tough circumstances.

Literature Review

Theories

Social learning theory explains the behaviors and personality development of individuals by theoretically combining social psychology, cognitive psychology, and behaviorism (Crosbie-Burnett & Lewis, 1993). The theory posits that individuals learn from observing others' new behaviors, expectations, and positive or negative consequences of the behavior (Crosbie-Burnett & Lewis, 1993). As individuals gain more opportunities to observe and store these consequences in memory, the increased experience may change how individuals process information which may also change their behaviors (Crick & Dodge, 1994). Individuals cognitively process the expected reinforcement or punishment followed by the behavior, and then perform the learned behavior contingently (Crosbie-Burnett & Lewis, 1993). The theory had been expanded in the last two decades by emphasizing cognitions and emotions, and including the individual's environment of learning. This expansion, especially the inclusion of individuals' learning environment, has made the theory more applicable in understanding

the behaviors of culturally diverse individuals. Considering the cultural contexts, for example, the ways in which individuals cognitively process the information can vary by their ethnicity, at times even leading to contradictory viewpoints (Crosbie-Burnett & Lewis, 1993).

The social cognitive behavioral model (Crosbie-Burnett & Lewis, 1993) suggests that an individual's three domains, specifically behavioral domain, interpersonal domain, and social and physical environmental domain, influence one another, which reflects the interactions among human motivations, thoughts, and actions. The social and physical environment acknowledges the origin of an individual's thoughts and actions. The interpersonal factors recognize the influence of an individual's thought processes regarding social environment, motivation, and action. When individuals process information, their emotions may play a significant role in influencing how they interpret the situation, the motivation of the action, and the choices of the action. Further, the other's emotional response to one's action also affects individual's information processing (Crick & Dodge, 1994). The behavior is the result of social environment with perceptions made through the interpersonal factors (Crosbie-Burnett & Lewis, 1993). Based on the understanding that normally family members create and share social and physical environments, this model explains how each family member relates to one another cognitively and behaviorally in their shared environments (Crosbie-Burnett & Lewis, 1993). Perceptions are affected by how individuals interpret the information, which may vary by each individual because how individuals perceive the information may depend on the degrees of their attention to it and the levels of its importance to them, and can also vary from situation to situation (Huesmann, 1998). Huesmann (1998) also

stated that cognitions and cognitive processing mediate human behaviors as outputs by connecting biological, environmental, and situational inputs.

Relevant Empirical Studies

Personal factors. Prior research found that individuals with high emotional intelligence can cope and deal with negative emotions and make more ethical decisions (Krishnakumar & Rymph, 2012). Specifically, anxiety as a negative emotion may affect an individual's decision making because anxious individuals often greatly take into account risks and uncertainties in their decision making process (Raghunathan & Pham, 1999) by dominantly considering them over the other factors, which possibly leads to their making less ethical decisions. In addition, the individuals under stressful situations are more likely to make decisions without fully considering the alternatives, which could be interpreted as a defense mechanism to prevent themselves from overloading the information (Keinan, 1987). Individuals with higher levels of stress might display more depressive symptoms (Phillips, Carroll, & Der, 2015), which might influence their decision making. Another study also found the relationship between parents' fatigue and their self-efficacy in that higher levels of fatigue were associated with lower self-efficacy (Chau & Giallo, 2014). As fatigue and stress are directly related (Maghout-Juratli, Janisse, Schwartz, & Arnetz, 2010), individuals tend to be more exhausted under stressful circumstances, which may lead to lower self-efficacy and then affect their decision making. Furthermore, when individuals make decisions for themselves, their self-esteem is highly related to their decisions as individuals with higher self-esteem are less likely to make risk taking decisions than those individuals with lower self-esteem. However, those

factors are only related when making decisions for self and not for others (Wray & Stone, 2005).

In addition, human behaviors are influenced by cultures especially the traditions and/or social norms that allow people to interact successfully with the others in the society where there are shared expectations of behaviors in certain situations (Cronk, 2017). Triandis (1989) argued that social behaviors are determined by the concept of self that people perceive as, which is affected by one of the dimensions of cultural variation, individualism-collectivism. In individualism cultures, such as the American mainstream culture, people normally view themselves as independent from others and value their personal goals, uniqueness, and self-expression. In contrast, in collectivism cultures, such as the Japanese culture, people typically view themselves as a part of the whole, give priority to the goals of the group they belong, and behave accordingly in the social context striving to fit in the group (Yates & de Oliveira, 2016).

Furthermore, individuals' attitudes towards death and their behaviors around death may vary depending on their living environments, even though death is inevitable to every human being (DeSpelder & Strickland, 2010). For example, Tanida (2000) suggested that the powerful influences of Shinto and Buddhism strongly support its natural process of and approach to the death of human beings among Japanese people. The Japanese philosophy emphasizes the value of harmony, especially in interpersonal relationships, which includes not only the ones among the living people, but also those between ancestors and descendants (DeSpelder & Strickland, 2010). In the Japanese society, it is believed that there is an eternal relationship between ancestors and their descendants and thus, living people are expected to perform necessary ancestral rites and

dead dispense blessings to their ancestors (DeSpelder & Strickland, 2010). In contrast, people in the western cultures tend to plan for and control major life events including the end of one's life, and there is a growing demand for control over the timing and nature of death by seeking medical solutions (Bowman & Richard, 2003). In the late twentieth century, some people in the western cultures became dissatisfied with communal and fixed answers of death and dying, and they began to seek meaningful ways of death for themselves (DeSpelder & Strickland, 2010). Therefore, there is a great cultural influence on how individuals behave generally, and especially on how individuals perceive death, which might affect the parental decision making process regarding the inclusion of children in a family member's end of life care and funeral services.

Prior research has found that the parental decision making related to their children's health is influenced by their perception of the subject (Austvoll-Dahlgren & Helseth, 2010). Mahon (2009) maintained that when making decisions to include their children in the end of life care and/or funeral services of a family member, parents must consider children's developmental stages, given that their understanding of death is related to their current cognitive capabilities and past experiences of death (Cotton & Range, 1990). As a result, research has shown that many parents of terminally ill children decide not to inform the siblings of the ill children as they do not believe that children will understand the circumstances (Stehbens & Lascari, 1974).

Social/environmental factors. Previous studies have consistently suggested a strong effect of available social support on an individual's psychological well-being, particularly under continuous stress (Åslund, Larm, Starrin, & Nilsson, 2014). Bolger and Amarel (2007) found that individuals with high levels of perceived social support had

less emotional reactions and coped better with stressful situations. For example, knowing that social support is available, parents react less emotionally under stressful circumstances (e.g., a family member is dying), which may allow them to be able to consider others, rather than just themselves, and make decisions for their benefits (Wray & Stone, 2005), such as including the children to be involved in the dying member's end-of-life care and at his or her funeral service.

Furthermore, a study with older adults regarding their end-of-life planning showed that positive relationships, both marital and parent-child relationships, encourage making end-of-life care and after death planning by greater open communication among family members (Carr, Moorman, & Boerner, 2013). Family caregivers are more likely to plan and make decisions for the ill member's end-of-life care and after death, intending to preserve his or her well-being, and ensuring that their wishes and needs are fully met (Kehl, Kirchhoff, Kramer, & Hovland-Scafe, 2009). As positive relationships encourage open communication at a family member's end of life care, the relationships between those who are involved, such as the surviving parent and the dying person (parent or sibling), the surviving parent and the surviving child, and the surviving child and the dying person (parent or sibling), may all determine the openness of the communication, such as whether to share the information about the state of the dying family member's medical condition and his or her preferences of care and/or after death. In general, it is the surviving parent(s) who make the decision as to whether or not to include children at a family member's end of life care and funeral services.

In sum, the social cognitive behavioral theory considers human behaviors as a result of the environment interacting with individuals' perceptions made through their

cognitive factors. The parental decisions of whether or not to include children in a family member's end of life care and funeral services may be the result of the interaction between the social environment and personal factors. Specifically, the factors that potentially predict such a parental decision making may include parents' psychological well-being, perceptions and attitude toward death, perceived social support, personal relationships, and the surviving children's developmental stages. In addition, these personal and environmental factors may individually and/or together influence the parental decision making as a human behavior. Figure 1 presents the conceptual model demonstrating the associations among the personal factors, the social/environmental factors, and the parents' decision making, which this study aimed to examine.

Hypotheses

Guided by the social cognitive behavioral theory, this study tested the following hypotheses in terms of what predicted the parental decision making of including children in a family member's end of life care, such as visiting and spending time with, and at funeral services:

1. The lower levels of anxiety, the fewer depressive symptoms, the lower stress levels, the higher levels of self-efficacy and self-esteem, the less avoidant of the death, the more accepting the death as a nature of human being, or the older the surviving child, the more likely the parents would include the child(ren) in a dying family member's end of life care and at the funeral services.
2. The higher perceived social support, particularly the supports from family and friends, or the more positive personal relationships among family members,

the more likely the parents would include child(ren) in a dying family member's end of life care and at the funeral services.

3. The Japanese parents would be more likely than the non-Japanese American parents to include the surviving children in the dying family member's end of life care and at the funeral services.

Method

Participants

A total of 120 parents including both non-Japanese and Japanese parents, mostly residing in suburban areas of the state of New Jersey and New York, participated in this study. If they had one child, the child would be designated as Child1, and if they had more than one child, then the oldest one who was under 18 would be Child1 and the next child would be Child2.

Among these 120 participants, 58 (48.3%) participants were non-Japanese and 62 (51.7%) were Japanese. The majority of them were female (80%). Their mean age was 40.29 years (*SD* = 6.38; ranging from 27 to 55). The median of the family income was $100,000 to $149,999 (on a 12-point scale ranging from 1 = *less than $10,000* to 12 = *$150,000 or more*). Most (83; 69.2%) of the participants had a Bachelor's degree or higher, and also most of their partners (83; 69.2%) had a Bachelor's degree or higher. Eighty (66.7%) participants had more than one child under 18 of age, and the mean of each child's age was 8.55 (range = 0 to 17) for Child1 and 5.96 (range = 1 to 16) for Child2. For both Child1 and Child2, gender was equally divided (for Child1, 49.2% girls and 49.2% boys, and for Child2, 46.3% girls and 48.8% boys). For Child1, participants were primarily mothers (80.0%), with 15.8% fathers, and 2.5% step-fathers, and for

Child2, 77.5% of the participants were mothers, 17.5% fathers, and 1.3% step-fathers. The participants' partners were mostly the children's biological parents living together (90.0% for Child1 and 91.3% for Child2). The participants indicated that 9.2% of the Child1 and 7.5% of the Child2 had some kind of developmental delays.

Non-Japanese participants. A total of 58 parents participated in the study. The mean of participants' age was 42.42 (*SD* = 7.22), a range of 27 to 55. Of all the participants, 44 (75.9%) participants indicated themselves as female and 13 (22.4 %) participants as male. As for their ethnicity, 69.0% identified themselves as White, Caucasian, or European, not Hispanic, 19.0% as Asian American, not Japanese, 5.2% as Hispanic or Latino, 1.7% as Black or African American, and 5.2% as other. Among all the participants, 14 (24.1%) participants were born outside of the U.S., and the mean of the length of residing in the U.S. was 24.1 years (*SD* =14.32), with a range of 4 to 47 years. The majority (91.4%) of the participants had at least bachelor's degrees, and 79.6% of their partners had at least bachelor's degrees. The median of the participants' family income was $150,000 or more. The mean age of participants' Child1 was 9.69 (range = 0.5 to 17), with 51.7% boys and 46.6% girls. Most of the participants were mothers (75.9%), 17.2% fathers, and 3.4% step-fathers for their Child1. Eight participants (13.8%) indicated that Child1 has developmental delay such as ADD, born prenatally, speech delay, autism, and dyspraxia. The relationship of the partners to Child1 was 82.8% biological parent living together, 6.9% biological parent not living together, 3.4% step-parent, and 1.7% not a parent but living together. Thirty three (56.9%) participants had more than one child under 18 (i.e., Child2). The mean age of the participants' Child2 was 7.89 (range = 1 to 16), with 51.5% of girls and 48.5% of boys.

For Child2, 72.7% of the participants were mothers, 24.2% fathers, and 3.0% step-fathers. Only one participant indicated that Child2 has developmental delay (i.e., challenge with focusing in school). All who answered the question of the relationship of the partner to Child2 indicated that they were their biological parents living together.

Japanese participants. A total of 62 parents, 52 (83.9%) females and 8 (12.9%) males, completed the survey in Japanese. The mean of their age was 38.34 (*SD* = 4.77), ranging from 31 to 54. The mean of years of staying in the U.S. was 2.2 years (range = 0 to 18), and 45.1% of them were in the U.S. less than a year. About half of the participants (48.4%) had a Bachelor's degree or higher, with their partners 61.3%. The median of participants' family income was $80,000 to $89,999, including 12 (19.4%) participants not indicating their family income. The mean age of the participants' Child1 was 7.48 years (range = 0 to 17), with 51.6% of them being girls and 46.8% boys. Most (83.9%) of the participants were mothers and 14.5% fathers for Child1. Three participants (4.8%) indicated that Child1 has developmental delays, specifically ADHD, born as extremely low birth weight infant, or immature thinking for the child's age. All parents' partners to Child1 were their biological parents, and all but one lived together. Of all, 47 (75.8%) participants had more than one child under 18, Child2. The mean age of the participants' Child2 was 4.60 years (range = 1 to 10), with 48.9% of them being boys and 42.6% girls. For Child2, 61.3% of the participants were mothers and 9.7% fathers, and the participants' partners were all biological parents living together with Child2. Five participants (10.6%) indicated that Child2 has developmental delay, such as speech delay, Pervasive Developmental Disorder, and ADHD.

Procedure

The eligible participants for this study were defined as parents who have one or more children under 18 and have/had a partner who has a relationship with the child(ren). In some cases, both parents in the family participated in the study by completing the surveys separately. The majority of participants were recruited at the following two facilities: A children's center in northern New Jersey which provides care and education for children from birth to five years, and a Japanese school in northern New Jersey which provides care and education for children from three to twelve years. Most of the families in the Japanese school temporally resided in the Unites States for employment and were expected to go back to Japan after finishing their terms in the U.S. To participate in the study, all parents were asked to complete a survey, which assessed their psychological functioning, social support, and relationships with partners and children. Back translation procedures were followed in translating the flyer, consent form, and survey into Japanese for Japanese parents to participate in the study. Online surveys were also made available. The study proposal, including the surveys, was approved by Montclair State University's Institutional Review Board, and all participating parents signed the consent forms before completing the surveys. See Appendix for the flyer, consent form, survey (in both English and Japanese), and the IRB's letter of approval.

Measurements

Dependent variables

Parental perceptions on including children in family members' end of life care and at their funeral services. The participants indicated their likelihood of including children in their partner's and children's sibling's end of life care, such as visiting and spending time with, and at funeral services using 5-point scale (1 = *I would definitely*

include my child, 2 = *I would probably include my child*, 3 = *I might include my child*, 4 = *I would probably not include my child*, and 5 = *I would definitely not include my child*). Sample questions include "how likely is it for you to include child 1 in your partner's end of life care, such was visiting and spending time with, if the child wishes to?" and "how likely is it for you to include child 2 in child 1's funeral service, if the child wishes to?" For analysis, reverse coding was used to increase readability when interpreting the results. Higher scores indicated higher likelihood of including the children.

Predictors: Personal factors

Anxiety and depressive symptoms. The anxiety levels and depressive symptoms of the parents were assessed with the Brief Symptom Inventory-18 (BSI-18; Derogatis, 2001). The BSI-18 is an 18-item self-report measurement for psychological distress and psychiatric disorders. It has three dimensions (6 items each): somatization, depression, and anxiety, along with a global severity index to measure an overall psychological distress level. Only the anxiety and depression dimensions were used in this study. The internal consistency of the scale dimensions of anxiety and depression were both adequate (alphas = .79 for anxiety and .84 for depression). The overall score of the BSI-18 was highly correlated (i.e., $r > .90$) with the score of Symptom Checklist 90-Revised (SCL-90-R; Derogatis, 1994) among a large community population. To measure anxiety level, the participants rated their feelings on each of the respective items using a 5-point scale (1 = *not at all*, 5 = *very much*). Sample items include "suddenly scared for no reason" and "spells of terror or panic." To measure depressive symptoms, the participants rated their feelings on each of the respective items using a 5-point scale (1 = *not at all*, 5 = *very much*). Sample items include "feeling no interest in things" and "feeling lonely."

Stress. The overall stress levels of parents were assessed using the Perceived Stress Scale (PSS-10; Cohen & Williamson, 1988). The PSS-10 is a 10-item self-report measure for generalized perceptions of stress. To determine the feelings and thoughts experienced during the last month, participants were asked to rate how often they felt in certain way on each of the items using a 5-point scale (0 = *never*, 4 = *very often*), with higher scores denoting higher levels of perceived stress. Sample items include "in the last month, how often have you been upset because of something that happened unexpectedly?" and "in the last month, how often have you felt that you were unable to control the important things in your life?" Cohen and Williamson (1988) reported Cronbach alpha coefficient of .78 and the scale's construct validity by its relationship with series of measures of health and health behavior such as failure to quit smoking and vulnerability to stressful life-event-elicited depressive symptoms.

Self-efficacy. The participants' self-efficacy was assessed with the General Self-Efficacy Scale (Schwarzer & Jerusalem, 1995), which is a 10-item self-report measurement of perceived general self-efficacy. A 4-point scale was used in measuring how the participants coped with daily hassles and adapted to stressful life events (1 = *not at all true*, 4 = *exactly true*). Sample items include "I can always manage to solve difficult problems if I try hard enough," and "If I am in trouble, I can usually think of a solution." The total score ranges from 10 to 40 and a higher score means higher levels of self-efficacy. The Cronbach's alpha was .88 for internal consistency of the scale and the test-retest reliability in seven weeks apart was .82 (Leganger, Kraft, & Røysamb, 2000). The constructive validity of the scale was evidenced by its positive correlations with

individuals' past success experiences in vocational (r = .28), educational (r = .27), and military (r = .22) (Sherer et al., 1982).

Self-esteem. The self-esteem levels of the participants were assessed with the Rosenberg Self-Esteem Scale (Rosenberg, 1965), which is a 10-item self-report scale commonly used to measure individuals' global self-worth. The participants rated their positive and negative feelings about themselves using a 4-point scale (1 = *strongly disagree*, 4 = *strongly agree*). Sample items include "I take a positive attitude toward myself," and "I certainly feel useless at times." Negatively stated items were reverse coded before the scores were averaged, with higher scores indicating greater self-esteem. Internal consistencies for this scale ranged from .77 to .88 and test-retest reliabilities ranged from .82 to .85 (Rosenberg, 1965). The scale's construct validity was evidenced by its negative correlations with anxiety, depression, and anomie (Rosenberg, 1965).

Attitude toward death. The parents' general attitude toward death was assessed using two dimensions of the scale, Death Attitude Profile-Revised (DAP-R; Wong, Reker, & Gesser, 1994): death avoidance (5 items) and neutral acceptance (5 items). The participants indicated how well they agreed with the statements related to different attitudes toward death using a 7-point scale (1 = *strongly disagree*, 7 = *strongly agree*). The sample items for death avoidance include "I avoid death thoughts at all costs," and "I always try not to think about death." For neutral acceptance, the items include "death should be viewed as a natural, undeniable, and unavoidable event," and "death is a natural aspect of life." As for the psychometric properties of DAP-R, Wong et al. (1994) reported that the alpha coefficient of internal consistency for the death avoidance dimension was .88, and for the neutral acceptance dimension it was .65. The test-retest

coefficients of stability in a 4-week interval were .61 for death avoidance and .64 for neutral acceptance. The semantic differential (SD) measures of life and death were constructed to evidence the convergent-discriminate validity for the scale, and the results found that the death avoidance dimension to be negatively related to the SD ratings of death (r = -.32, p < .001), and the neutral acceptance dimension to be positively related to the SD ratings of life (r = .20, p < .001) (Wong et al., 1994).

Predictors: Social or Environmental factors

Social support. The parents' social support was assessed using the Multidimensional Scale of Perceived Social Support (MSPSS; Zimet, Dahlem, Zimet, & Farley, 1988), which is a 12 item self-report measurement of how the participants perceived their social support from family, friends, and significant other (four items per subscale). In this study, perceived social supports from family and friends were used. Using a 7-point scale (1 = *strongly disagree*, 7 = *strongly agree*), the participants indicated their degrees of agreement to each of the statements. Sample items include "my family really tires to help me," and "I can count on my friends when things go wrong." Evidence of the scale's psychometric properties was provided in Zimet et al. (1988). Specifically, the Cronbach's alphas for the subscales of family and friends was .87, and .85, respectively, and the test-retest reliabilities with a 2-3-month interval for family and friends subscales were .85, and .75, respectively. The construct validity of the scale was evidenced by its negative correlations with depression and anxiety symptoms measured by the Hopkins Symptom Checklist (Derogatis, Lipman, Rickels, Uhlenhuth, & Covi, 1974).

Parent-Child relationships. The parents' perceptions of their relationships with children were assessed using the Parent-Child Relationship Scale (CPRS; Pianta, 1992). The CPRS is a 15 item self-repot measurement of the parental perceptions of relational conflict (8 items) and closeness (7 items) with their child, using a 5-point scale (1 = *definitely does not apply*, 5 = *definitely applies*). Sample items of the conflict subscale include "My child and I always seem to be struggling with each other," and "my child is uncomfortable with physical affection or touch from me," which represents the parental feelings of having negative relationships with their children. The Cronbach's alphas were both .84 for mothers at the child's age of 54 months and when the child was in the first grade, and .80 and .78 for fathers, respectively. Sample items of the closeness subscale include "I share an affectionate, warm relationship with my child," and "If upset, my child will seek comfort from me," which represents parental feelings of warmth, affection and open communication in their relationships with children. The Cronbach's alphas for mothers were .69 at the child's age at 54 months and .64 when the child was in the first grade, and .72 and .74 for fathers, respectively (Driscoll & Pianta, 2011).

Partner relationships. The participants' relationship with the partner was assessed using the Relationship Assessment Scale (RAS; Hendrick, 1988), which is a 7-item self-report scale to measure their general relationship satisfaction. Using a 5-point scale, the participants indicated their satisfaction levels of the relationship with their partner. Sample items include "How well does your partner meet your needs?" and "In general, how satisfied are you with your relationship?" (1 = *low satisfaction*, 5 = *high satisfaction*). Responses were averaged, and higher scores indicated higher satisfaction of the relationship. The application of the scale is not limited to married couples, but with

any kind of couple relationships such as dating, cohabiting, and engaged couples (Vaughn & Matyastik Baier, 1999). Vaughn and Matyastik Baier (1999) reported a coefficient alpha of .91 for the RAS, and provided evidence of good validity by its positive correlation with relationship quality measured by the Dyadic Adjustment Scale (DAS; Spanier, 1976) ($r = .84, p < .01$).

Sibling relationships. The parental perceptions of their children's sibling relationships were assessed by a single question, "How would you describe the current relationship of your children (surviving child and dying child)?" using a 4-point scale (1 = *the children have many difficulties, and they rarely get along*, 4 = *the children rarely have difficulties, and they get along almost all of the time*).

Analytical Strategy

Correlation, multiple regression, and independent-sample *t*-tests were performed to test the hypotheses. Specifically, correlations were employed to examine hypotheses 1 and 2. When multiple predictors were found to be related to the outcome in a correlation analysis (i.e., $p < .05$), multiple regression was employed to examine if they each was associated with the outcome. In addition, *t*-tests were used to examine hypothesis 3; that is, whether there were differences in parental perceptions of including children in each event between the non-Japanese and the Japanese parents.

Results

Table 1 presents the results of reliability tests for all study variables based on the three different groups of participants (i.e., the whole sample, the non-Japanese participants, and the Japanese participants). The majority of the Cronbach's alphas were above .70, providing evidence of adequate internal reliabilities of the predicting variables.

Table 2 presents the frequencies of the dependent variables indicating how likely the parents would include their children in a family member's end of life care or at the funeral services among the three groups of participants. Overall, the majority of the participants (more than 85%) indicated that they would definitely include their children in the partner's and the sibling's end of life care and at the funeral services. In addition, the parents were more likely to include children in a family member's funeral services than one's end of life care. All of the hypothetical situations were related to one another (r ranging from .08 to .97, all $ps < .01$).

Hypothesis 1

Tables 3 and 4 present the results of the relationships between personal factors, such as the participants' anxiety, depressive symptoms, stress, self-efficacy, self-esteem, attitudes toward death (i.e., death avoidance and natural acceptance), and children's age, and the dependent variables (i.e., parental perceptions on including children in family members' end of life care and funeral services) for the whole sample, the non-Japanese participants only, and the Japanese participants only. The results did not find any associations between the predictors and the dependent variables (all $ps > .05$).

Hypothesis 2

Table 5 presents the results of the relationships between social or environmental factors, particularly participants' perceived social support (from family and friends) and personal relationships (i.e., relationships with children and with partners, and children's siblings' relationships), and parental perceptions on including children in family members' end of life care and funeral services. Among all the participants, social support from friends was positively related to the parent's perception of including Child1 in

Child2's end of life care, $r = .28$, $p = .01$, and including Child2 in the partner's end of life care, $r = .31$, $p = .01$. It suggests that parents who perceive more social support from friends are more likely to include their younger child in the partner's end of life care.

Among the non-Japanese participants (Table 6), perceived social support from family was positively related to the parents' perception on including Child1 in the partner's end of life care, $r = .28$, $p = .04$, and Child1 in Child2's end of life care, $r = .47$, $p = .01$. It suggests that the parents with more support from family were more likely to include their older child in the partner's, as well as the younger sibling's end of life care. Perceived social support from friends was related to most of the dependent variables, r ranging from .44 to .62, all $ps \leq .01$. It suggests that the parents with more social support from friends are more likely to include children in all the situations except Child1 in the partner's end of life care and funeral service. In contrast to the non-Japanese participants, however, no relationships were found in the Japanese participants between either social support and parental perceptions of including children in family members' end of life care and/or funeral services.

Another strong association was found between personal relationships and parental perceptions of whether to include children in family members' end of life care and funeral services (Table 5). Overall, regardless of the samples, it was the parent-/partner-child closeness, not the conflict, that was associated with the dependent variables. Specifically, considering the whole sample, the results showed that parent-Child1 closeness was positively related to most of the dependent variables, r ranging from .21 to .33, all $ps \leq .05$, except including Child1 and Child2 in the partner's end-of-life care, that parent-Child2 closeness was positively related to all of the dependent variables, r ranging

from .24 to .60, all *p*s ≤ .05, and that partner-Child2 closeness was related to including Child1 and Child2 at the partner's funeral service, *r*s = .36 and .23, respectively, both *p*s < .01. It suggests that the closer the parent is to either child, or the partner is to Child2, the more likely the parent would include children in family members' end of life care or at their funeral services.

For the non-Japanese participants (Table 6), among the parent-/partner-child relationship variables, only parent-Child1, parent-Child2, and partner-Child2 closeness were related to at least one dependent variable. Specifically, the results showed that parent-Child1 closeness was related to including Child2 in Child1's end of life care (r = .53, p < .01), that parent-Child2 closeness was related to half of the dependent variables, particularly including Child1 and Child2 at the partner's funeral service, and including Child2 in Child1's end of life care and at the funeral service (*r* ranging from .38 to .71, all *p*s ≤ .05), and that partner-Child2 closeness was related to including Child1 at the partner's funeral service (r = .36, p < .05).

Similar results were found in the Japanese participants (Table 6); that is, parent-Child1, parent-Child2, and partner-Child2 closeness were the only variables that were associated with at least one dependent variable. Specifically, the results showed that parent-Child1 closeness was related to including Child1 and Child2 at the partner's funeral service, and including Child1 in Child2's and Child2 in Child1's funeral services (*r* ranging from .39 to .47, all *p*s < .01), that parent-Child2 closeness was related to all of the dependent variables (*r* ranging from .29 to .54, all *p*s ≤ .05), and that partner-Child2 closeness was related to including Child1 and Child2 at the partner's funeral service (r = .35 and .37, respectively, both *p*s < .05).

The parents' relationships with their partners and the siblings' relationships with each other were also hypothesized as predictors that were related to the parental decision of including children in family members' end-of-life care and at their funeral services. The results showed that the sibling relationship was associated with the parent's inclusion of Child1 in Child2's end-of-life care (r = -.23, p < .05), and the association was only observed when the whole sample was considered. It suggests that the closer the parent perceives the sibling relationship was, the less likely she or he would include the older child in the younger sibling's end-of-life care. In addition, the result also showed that the partner relationship was associated with the parent's inclusion of Child1 in partner's end-of-life care (r = .37, p < .01) and funeral service (r = .34, p < .05), and the association was only observed among non-Japanese participants. It suggests that the closer the parent and her/his partner was, the more likely she or he would include the older child in the partner's end-of-life care and funeral service.

Given that the results from the correlation analyses indicated that there were multiple predictors associated with each of the several dependent variables, further analysis (i.e., multiple regression) was performed to examine the relative contributions that each significant predictor made to the total variances of a dependent variable. Considering the whole sample, given that parent-Child1 closeness, parent-Child2 closeness, and partner-Child2 closeness were all correlated with the parent's inclusion of child1 in the partner's funeral service, results of the multiple regression analysis showed that only parent-Child2 closeness was related to the dependent variable (β = .46, t = 3.51, p = .001, 95% CI [.12, .44]), suggesting that the closer the parents' relationships with Child2, the more likely they were to include child1 in their partners' funeral services.

Given that the social support from friends and the parent-child2 closeness were both correlated with the parents' perceptions of including child2 in the partners' end of life care, the results of multiple regression analysis showed that both social support from friends and parent-child2 closeness were related to the dependent variable (βs = .24 and .26, ts = 2.25 and 2.36, ps = .03 and .02, 95% CIs [.01, .18] and [.04, .43], respectively), suggesting that the more support from friends parents have or the closer the parents' relationships with child2, the more likely they were to include child2 in their partners' end of life care. In the situation of the partners' funeral services, parent-child1 closeness, parent-child2 closeness, and partner-child2 closeness were all correlated with the parents' inclusion of child2 at the event. The result of multiple regression showed that only the parent-child2 closeness was related to the dependent variable (β = .37, t = 2.44, p = .02, 95% CI [.06, .54]), suggesting that the closer the parents' relationships with child2, the more likely they were to include child2 at their partners' funeral services. The social support from friends, parent-child1 closeness, parent-child2 closeness and sibling relationship were all correlated with parents' perceptions of including child1 in child2's end of life care. The result from multiple regression showed that only the sibling relationship was related to the dependent variable (β = -.27, t = -2.40, p = .02, 95% CI [-.34, -.03]), suggesting that the better the relationship between child1 and child2, the less likely the parents were to include child1 in his/her younger sibling's end of life care. The parent-child1 closeness and parent-child2 closeness were both correlated with the parents' inclusion of child1 at child2's funeral service, and child2 in child1's end of life care and the funeral service. Results of the three separate multiple regression analyses showed that only the parent-child2 closeness was related to each of the three dependent

variables (βs = .31, .47, and .38, ts = 2.33, 3.67, and 2.82, ps = .02, < .001, and = .01, 95% CIs [.04, .53], [.15, .52], and [.10, .57], respectively), suggesting that the closer the parents' relationships with child2, the more likely they were to include child1 in his/her younger sibling's funeral services, child2 in his/her older sibling's end of life care or funeral service.

Hypothesis 3

Results from the *t*-tests showed no significant differences between the two groups of participants on their perceptions of including children in the partner's or sibling's end of life care or funeral services. However, there is a marginal difference on the parental perception of including Child2 in Child1's end of life care. Specifically, the non-Japanese parents were more likely to include Child2 in Child1's end of life care (M = 4.94, SD = .24) than the Japanese parents (M = 4.79, SD = .46), $t(78) = 1.91$, p = .06, 95% CI [-.01, .31], representing a small to medium-sized effect, r = .21.

Discussion

Experiencing a family member's death is tough for surviving family members, and how they experience the death would affect the surviving family members' well-being, such as having difficulties in psychological adjustment (Morris et al., 2016) and displaying a wide range of emotional and behavioral symptoms in their later lives (Dowdney, 2000). Children are often greatly influenced by these experiences and often do not have choices in how they deal with such traumatic life events, for example, whether or not they would be involved in various associated activities and rituals, as it often depends on the surviving parent(s)' decisions. Guided by the social cognitive behavioral model (Crosbie-Burnett & Lewis, 1993), the current study aimed to explore

the factors associated with the parent's decision making on including children in a family member's end of life care and at funeral services. The hypothesized predictors included several personal factors, particularly the participant's anxiety, depressive symptoms, stress, self-efficacy, self-esteem, perceptions and views of death, and child's age, and social/environmental factors, including perceived social support and personal relationships.

Overall, the parental perceptions regarding whether to include children in a family member's end of life care and at funeral services were all related to each other in expected directions in 8 different situational scenarios: Child1 in the partner's end of life care, Child1 at the partner's funeral, Child2 in the partner's end of life care, Child2 at the partner's funeral, Child 1 in Child2's end of life care, Child 1 at Child2's funeral, Child2 in Child1's end of life care, and Child 2 at Child1's funeral. The findings suggest that parents in the study sample are more likely to include children, regardless of the hypothetical situations. However, it is not consistent with Mahon's (2009) research, in which many funeral home directors indicated that the surviving parents often acted as negative mediators, as they wanted to shelter their children from death and the funeral. This discrepancy might result from the difference between families' actual experiences of death and their responses to those hypothetical scenarios regarded in the study, which may imply that parents' perceptions on whether to include children in a family member's end of life care and/or at funeral services can be altered when they actually encounter such stressful life circumstances.

On the basis of the social cognitive behavioral model (Crosbie-Burnett & Lewis, 1993) and the relevant empirical studies, the current study hypothesized that several

personal and social environmental factors in parents were associated with their decision making on including children in a family member's end of life care and at funeral services. It is surprising that the results showed that most of the predicting factors were not associated with the parental decision making. Instead, the findings showed that such parental decision making almost solely relies on their personal relationships. Specifically the closeness of parent-child relationships between the surviving parent and children is strongly associated with the parental decision making. Furthermore, the relationship closeness between the surviving parent and the younger child appears to be a stronger predictor of the parental decision making, particularly to the Japanese parents. This finding is partly consistent with previous studies (Carr et al., 2013; Kehl et al., 2009), in that better personal relationships encourage open communications between involved family members in making plans together for the end of life care and after death affairs. However, prior research (Carr et al., 2013; Kehl et al., 2009) has also linked better relationships between surviving and dying individuals to decision making. Findings of the current study showed that in the case of a dying partner, the dying partner's relationships with the participant and the child were both associated with the parental decision making. In the case of a dying child, the relationship between the surviving child and the dying child was associated negatively with parental decision making in the following circumstance: when the siblings have a better relationship with each other, the surviving parent is *less* likely to include the older child in his/her younger sibling's end of life care. It is considerably important to note that this is the only scenario examined in the current study that showed a negative association between a predictor and the parental decision making. This finding might be due to the parents trying to protect healthy

children from bearing such emotional burden (Morris et al., 2016) and from further distressed being present in the stressful situation (Holland, 2004). Given that children's understanding of death is related to their cognitive capabilities (Cotton & Range, 1990), parents might consider that older children may be emotionally affected more than younger children when involved in sibling's end of life. While the closeness of the parent-child relationship has shown to have a strong positive relationship with the parental decision making on whether to include children in a family member's end of life care and funeral services, no relationship was found between the relational conflict of the parent-child relationship and the parental decision making.

In addition, the results showed that children's age was not associated with the parental decision making in any scenarios, but that their birth order appears to matter in the parental decision making. Specifically, the current study suggests that the relationship between the surviving parent and the younger child was greatly associated with parental decision making, in which parents seemed to focus more on their relationship with the younger child regarding all the decision-making situations in a family member's end of life care and funeral services. This finding, however, is not consistent with prior research urging that children's developmental stage must be considered in making decisions regarding whether or not to include children in a family member's funeral service (Mahon, 2009). Nevertheless, findings of the current study support the social cognitive behavioral model (Crosbie-Burnett & Lewis, 1993) by suggesting that some social/environmental dimension factors, especially the closeness of parent-child relationships, greatly affect individual's behaviors.

The current study was also conducted to test the cultural differences on parental perceptions of including children in a family member's end of life care and at funeral services by specifically examining the differences in the decision making between the non-Japanese and the Japanese parents. The results showed that there were no differences between the two groups on such parental perceptions. However, although there were no between-group differences on the parental perceptions, there were some differences in what factors were associated with their perceptions between the two groups.

Perceived social support, for example, is one factor shown to have strong associations with parental perceptions on whether to include children in a family member's end of life care and funeral services among the non-Japanese parents, but not in the Japanese parents. Specifically, among the non-Japanese parents, social support from friends is strongly associated with parental decision making; in that greater perceived friends support appears to encourage the parents to include children in a family member's end of life care and at funeral services.

Personal relationship appears to be another, and the strongest, factor to distinguish the non-Japanese from the Japanese parents in its association with the parental decision making. The current study found that overall, personal relationships as predictors were associated the parental decision making in a greater number of situations in Japanese parents (14 situations) than in non-Japanese parents (8 situations). There were also situational differences in the associations between personal relationships and decision making between the two groups, in that while personal relationships were consistently associated with including children in various funeral services for the Japanese parents, they were not as consistently associated with some specific situations

for the non-Japanese parents. For example, the relationship closeness of the surviving parent and his/her older child was associated with the parental decision making of whether to include children in a family member's funeral service in all the situations for the Japanese parents, however, it was only associated with one parental decision making situation for the non-Japanese parents. Another example can be found in the relationship between the surviving parents and their younger child, as for the Japanese parents, it was associated with their decision making in all the situations, while for the non-Japanese parents, it was associated with only half of the situations. The group difference in the association between personal relationships and parental decision making was also found in partner relationships. For the non-Japanese parents, it mattered in the decision making of whether to include older child in both partner's end of life care and funerals service, but for the Japanese parents, it did not matter. This particular difference is important to note, because overall, personal relationships are associated with parental the decision making for the Japanese parents more than the non-Japanese parents, however, the partner relationship was only associated with non-Japanese parents' decision making. These group differences are consistent with the previous study (Cronk, 2017) in that human behaviors are influenced by the cultures; that is, the expected behaviors in the society shape the human behaviors. Since people may behave accordingly in the social context to fit in the social norms in collectivism cultures (Yates & de Oliveira, 2016), children are expected to be included in a family member's funeral service in the Japanese society. In contrast, the self-expression is an important part of the human behavior for people in individualism cultures (Yates & de Oliveira, 2016), which might provide a

reason for the finding of the current study that the parental decision making differs by individuals and/or situations in the non-Japanese parents.

Findings of the study also support the social cognitive behavioral model (Crosbie-Burnett & Lewis, 1993) by suggesting that the predicting factors may interact with one another in affecting the human behaviors. For example, based on the results of multiple regression, the current study suggests that the closeness of the parent-child2 relationship is more important than that of the parent-child1 relationship in predicting the parental decision making on each of the following scenarios; that is, including child1 at the partner's and child2's funeral services, and including child2 at the partner's funeral service, and child1's end of life care and funeral service. In a similar vein, the result showed that the sibling relationship between child1 and child 2 is more important than the parent's relationship with either child in predicting the parental decision making on including child1 in child2's end of life care. A close sibling relationship would likely prevent the parents from including their older child in his or her younger sibling's end of life care, regardless of how close the parents are to either child of theirs.

Despite not tested as hypothesis in the study, it is worth noting that associations between the circumstances of the parental decision making indicated another differences between the two groups. Specifically, the parental perceptions of including children in a family member's end of life care and at funeral services were all related to each other among the Japanese parents, while only about half of them were related to each other in the non-Japanese parents. One of the dimensions of cultural variation, individualism-collectivism (Triandis, 1989), may provide an explanation for the differences. People in an individualist culture, such as the non-Japanese participants in the study, may see both

the self and others as independent (Triandis, 1989), and thus may consider the circumstances separately when making decisions for their children. In contrast, people in a collectivist culture, such as the Japanese participants in the study, may see the self as a part of the whole (Triandis, 1989), and thus may consider the circumstances as a whole and behave in ways that correspond to the society's expectations. This difference was observed in the findings of the current study, in that none of the Japanese parents had negative perceptions, while a few of the non-Japanese parents indicated negative perceptions on including children in a family member's end of life care or funeral services.

Finally, the attitude toward death was one of the potential predictors for the parental decision making of including children in family members' end of life care and funeral services, and was thought to distinguish the non-Japanese participants from the Japanese participants in its associations with the parental decision making. However, the current study did not show any associations between the participants' attitude toward death and their parental decision making in all the whole sample, or between the non-Japanese and the Japanese participants. The relatively small sizes both in the non-Japanese sample and in the Japanese sample might have reduced the power to detect any hypothesized associations.

Limitations

One of the major limitations is that with the cultural differences in mind, it is likely that the number of participants in each group was not large enough to observe various differences. A greater number of participants in each group, different ethnic groups of participants, equally gendered participants, and equally distributed

relationships of the partners to children are needed to strengthen the current study. Another limitation lies in the reliability of some of the scales used in the study (e.g., neutral acceptance of death), indicated by Cronbach's alpha lower than .70. The issue might attributed to the cultural difference in how the concepts were understood by people in different cultural backgrounds. In addition, the study is built upon parental perceptions on several hypothetical questions. The parents' responses to them might be different from those in real life situations. Future research on parents with real experiences is warranted and may better our understanding. Further, the hypothetical questions including "if the child wishes to" might have confused some participants, as it failed to specify that the parent's preference was the primary focus.

Implications

Despite the limitations, the current study has made great contributions to the field, as it is one of the first studies to explore what predicts such parental decision making. Knowing that personal relationships and social support have great associations with the parental decision making for children's involvement in a family member's end of life care and at funeral services, the relationship between parents and health care professionals can be an additional dimension of personal relationships to be tested, which has the potential to work as another source of social support for surviving parents. The additional personal relationship and social support not only can help the surviving parents maintain their psychological well-being, but also may encourage them to include children in a family member's end of life care and at funeral services. Prior research has shown that children who are not informed regarding a family member's terminal status and potential loss may experience long-term adjustment issues after the family member's

death (Lauer et al., 1985), and that children who have less chance to engage in mourning activities, such as attending funeral services, are associated with greater risks of depression later in their lives (Saler & Skolnick, 1992). Parents who do not include their children in a family member's end of life care and/or at the funeral service therefore, are likely to deal with their adjustment and psychological issues in the grieving process. It is also important for health care professionals to keep in mind that approaching the personal resources that those parents already have, such as family members and friends, may help parents maintain or increase their psychological well-being during such tough times in life. Especially, providing support for parents to enhance positive parent-child relationships at the early point of a family member's terminal illness may promote their children's healthy grieving, as well as psychological well-being.

Conclusion

The parents participating in the study were similar in their decision making, as more than 85% of them indicated that they would definitely include their children in the partner's and the sibling's end of life care and funeral services. However, the current study finds that the parental decision making in terms of whether to include children in a family member's end of life and at funeral service depends primarily on the social environmental factors suggesting that both strong social support and close parent-child relationships promote such parental decisions. The current study also finds that the factors associated with the parental decision making may vary among the parents with different cultural backgrounds. Given that prior research has found that involving children in a family member's end of life care and being present at the funeral services may benefit their well-being and enhance the closeness in parent-child relationships after

the death (Lauer et al., 1985), parents are encouraged to include their children when encountering such traumatic life situations.

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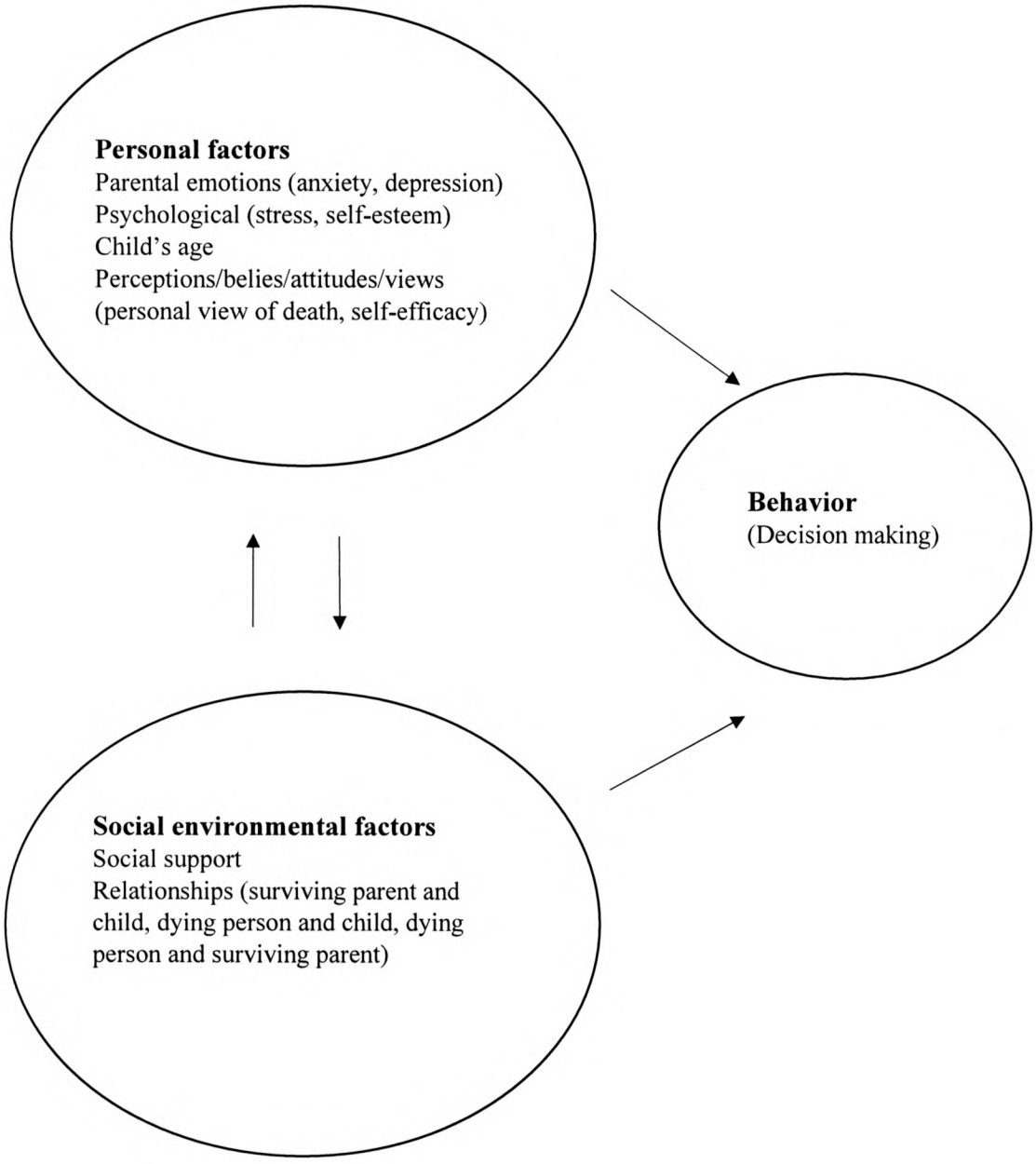


Figure 1: Conceptual model

Table 1. *Results of the Reliability of the Predicting Variables*

	Groups		
Variable	All	Non-Japanese	Japanese
Anxiety	.78	.85	.67
Depressive symptoms	.78	.81	.76
Stress	.80	.88	.64
Self-efficacy	.93	.87	.87
Self-esteem	.92	.86	.88
Death attitude: avoidance	.86	.89	.82
Death attitude: natural acceptance	.62	.51	.66
Social support from family	.85	.77	.88
Social support from friends	.91	.87	.93
Paretn-child1 relational closeness	.78	.84	.76
Parent-child1 relational conflict	.83	.85	.80
Partner-child1 relational closeness	.88	.82	.92
Partner-child1 relational conflict	.80	.83	.78
Parent-child2 relational closeness	.76	.78	.76
Parent-child2 relational conflict	.85	.86	.84
Partner-child2 relational closeness	.87	.88	.87
Partner-child2 relational conflict	.80	.81	.79
Partner relationship	.94	.94	.94

Note: All values denote the Cronbach's alphas.

Table 2. *Participnat's Responces to Whether to Include Children in Family Member's End of Life Care and Funeral Services*

	Would definitely not include			Would probably not include			Might include			Would probably include			Would definitely include		
	T	NJ	J	T	NJ	J	T	NJ	J	T	NJ	J	T	NJ	J
1. Child1 in Partner's EOL	0	0	0	1 (0.9%)	1 (1.9%)	0	3 (2.6%)	2 (3.7%)	1 (1.6%)	11 (9.6%)	2 (3.7%)	9 (14.8%)	100 (87%)	49 (90.7%)	51 (83.6%)
2. Child1 in Partner's Funeral	0	0	0	2 (1.7%)	2 (3.7%)	0	1 (0.9%)	1 (1.9%)	0	7 (6.1%)	1 (1.9%)	6 (9.8%)	105 (91.3%)	50 (92.6%)	55 (90.2%)
3. Child2 in Partne's EOL	0	0	0	1 (1.3%)	1 (3%)	0	0	0	0	11 (13.8%)	2 (6.1%)	9 (19.1%)	68 (85%)	30 (90.9%)	38 (80.9%)
4. Child2 in Partner's Funeral	0	0	0	1 (1.3%)	1 (3%)	0	0	0	0	6 (7.6%)	1 (3%)	5 (10.9%)	72 (91.1%)	31 (93.9%)	41 (89.1%)
5. Child1 in Child2's EOL	0	0	0	1 (1.3%)	1 (3%)	0	1 (1.3%)	1 (3%)	0	10 (12.5%)	2 (6.1%)	8 (17%)	68 (85%)	29 (87.9%)	39 (83%)
6. Child1 in Child2's Funeral	0	0	0	1 (1.3%)	1 (3%)	0	1 (1.3%)	0	1 (2.1%)	7 (8.8%)	2 (6.1%)	5 (10.6%)	71 (88.8%)	30 (90.9%)	41 (87.2%)
7. Child2 in Child1's EOL	0	0	0	0	0	0	1 (1.3%)	0	1 (2.1%)	10 (12.5%)	2 (6.1%)	8 (17%)	69 (86.3%)	31 (93.9%)	38 (80.9%)
8. Child2 in Child1's Funeral	0	0	0	1 (1.3%)	1 (3%)	0	1 (1.3%)	0	1 (2.2%)	6 (7.6%)	1 (3%)	5 (10.9%)	71 (89.9%)	31 (93.9%)	40 (87%)

Note. T = Total participants, NJ = Non-Japanese participants, J = Japanese participants

Table 3. *Means, Standard Deviations (SDs), and Intercorrelations Among the Study Variables*

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1. Child1 in Partner's EOL	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
2. Child1 in partner's Funeral	.63**	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
3. Child2 in partne's EOL	.58**	.48**	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
4. Child2 in Partner's Funeral	.34**	.57**	.86**	—	—	—	—	—	—	—	—	—	—	—	—	—	—
5. Child1 in Child2's EOL	.65**	.44**	.82**	.79**	—	—	—	—	—	—	—	—	—	—	—	—	—
6. Child1 in Child2's Funeral	.53**	.56**	.83**	.92**	.87**	—	—	—	—	—	—	—	—	—	—	—	—
7. Child2 in Child1's EOL	.72**	.69**	.61**	.43**	.56**	.55**	—	—	—	—	—	—	—	—	—	—	—
8. Child2 in Child1's Funeral	.41**	.58**	.08**	.94**	.80**	.97**	.57**	—	—	—	—	—	—	—	—	—	—
9. Anxiety	.05	.09	.08	.04	.00	.01	.02	.04	—	—	—	—	—	—	—	—	—
10. Dypressive Symptoms	-.05	.01	-.03	-.05	-.08	-.04	-.05	-.01	.71**	—	—	—	—	—	—	—	—
11. Stress	.06	.05	-.01	.01	-.06	-.01	-.12	.00	.51**	.56**	—	—	—	—	—	—	—
12. Self-efficacy	-.03	-.04	.02	.04	.02	.06	.19	.07	-.09	-22**	-.43**	—	—	—	—	—	—
13. Self-esteem	.06	.01	.00	-.02	.02	.03	.11	.01	-.21*	-.45**	-.51**	.75**	—	—	—	—	—
14. Death avoidance	-.03	-.01	.06	.13	.10	.12	-.12	.09	.16	.07	.11	-.07	-.01	—	—	—	—
15. Natural acceptance of death	-.01	.05	-.03	-.01	-.01	.04	.18	.06	.03	-.05	-.19*	.38**	.31**	-.16	—	—	—
16. Child1 age	-.02	.08	.02	.03	.01	.04	-.06	.03	.11	.14	-.10	.20*	.11	.00	.05	—	—
17. Child2 age	.12	-.04	.17	.15	.14	.16	.09	.15	.12	.10	-.21	.32**	.26*	.11	-.02	.75**	—
M	4.83	4.90	4.83	4.89	4.81	4.85	4.85	4.86	1.50	1.35	2.44	3.06	3.17	3.44	5.30	8.55	5.96
SD	.50	.49	.47	.42	.51	.48	.39	.47	.52	.44	.53	.53	.55	1.23	.85	4.70	3.94

* $p < .05$. ** $p < .01$.

Table 4. *Means, Standard Deviations (SDs), and Intercorrelations Among the Study Variables*

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	*M*	*SD*
1. Child1 in Partner's EOL	—	.59**	.18	.07	.60**	.32	.55**	.07	.42	-.08	.03	-.13	.06	.05	-.14	-.02	.01	4.83	.57
2. Child1 in partner's Funeral	.77**	—	.27	.29	.22	.27	.70**	.29	.16	.07	.03	-.09	.02	.06	.11	.15	-.25	4.83	.64
3. Child2 in partne's EOL	1.00**	.71**	—	.95**	.85**	.90**	.39*	.95**	.16	.06	-.05	-.05	-.19	.17	-.16	-.00	.15	4.85	.57
4. Child2 in Partner's Funeral	.71**	1.00**	.71**	—	.81**	.96**	.18	1.00**	.17	.10	.03	-.06	-.20	.28	-.05	.08	.18	4.88	.55
5. Child1 in Child2's EOL	.78**	.76**	.79**	.76**	—	.93**	.31	.81**	.04	-.09	-.12	.05	.06	.23	-.16	.07	.23	4.79	.65
6. Child1 in Child2's Funeral	.74**	.88**	.74**	.88**	.80**	—	.16	.95**	.11	.21	-.02	.00	-.07	.32	-.06	.11	.23	4.85	.57
7. Child2 in Child1's EOL	.84**	.74**	.84**	.74**	.90**	.85**	—	.18	.03	-.11	-.24	-.06	-.03	-.19	-.06	-.30	-.22	4.94	.24
8. Child2 in Child1's Funeral	.74**	.88**	.74**	.88**	.80**	1.00**	.85**	—	.17	.10	.03	-.06	-.20	.28	-.05	.08	.18	4.88	.55
9. Anxiety	.06	-.07	-.03	-.20	-.05	-.13	.01	-.14	—	.66**	.59**	-.20	-.24	.26	-.05	.07	.03	1.51	.59
10. Depressve Symptoms	-.01	-.14	-.12	-.26	-.09	-.11	.00	-.12	.79**	—	.65**	-.23	-.43**	.03	.06	.13	.13	1.30	.46
11. Stress	.12	.02	.07	-.04	.00	-.01	.00	-.02	.46**	.46**	—	-.39**	-.49**	.20	-.12	-.10	-.20	2.26	.59
12. Self-efficacy	.01	.21	.01	.23	.09	.19	.12	.18	-.05	-.20	-.17	—	.54**	-.36**	.19	.16	.10	3.44	.37
13. Self-esteem	.07	.18	.11	.22	.08	.15	-.02	.15	-.35**	-.62**	-.31*	.48**	—	-.10	.20	-.02	.12	3.55	.41
14. Death avoidance	-.15	-.16	-.11	-.15	-.16	-.20	-.13	-.20	-.01	.14	.03	.08	-.01	—	-.05	.02	.08	3.52	1.39
15. Natural acceptamce of death	.09	.09	.03	.04	.17	,12	.16	.13	.10	-.08	-.06	.23	.05	-.35**	—	.13	-.14	5.59	.69
16. Child1 age	.03	-.06	.02	-.06	-.08	-.08	-.06	-.09	.20	.25*	.15	-.13	-.16	-.09	-.25	—	.94**	9.69	5.59
17. Child2 age	.22	.16	.22	.16	.04	.11	.17	.10	.26	.20	.09	-.06	-.19	.14	-.40**	.75**	—	7.89	4.74
M	4.82	4.90	4.81	4.90	4.83	4.85	4.79	4.85	1.50	1.39	2.61	2.69	2.81	3.37	5.01	7.48	4.06		
SD	.43	.30	.40	.31	.38	.42	.46	.42	.45	.43	.39	.37	.40	1.06	.90	3.39	2.55		

Note: Correlation coefficients for the non-Japanese participants were listed above the diagonal, whereas those for the Japanese participants were listed below the diagonal.

* $p < .05$. ** $p < .01$.

Table 5. *Means, Standard Deviations (SDs), and Intercorrelations Among the Study Variables*

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
1. Child1 in Partner's EOL	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
2. Child1 in Partner's Funeral	.63**	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
3. Child2 in Partner's EOL	.58**	.48**	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
4. Child2 in Partner's Funeral	.34**	.57**	.86**	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
5. Child1 in Child2's EOL	.65**	.44**	.82**	.79**	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
6. Child1 in Child2's Funeral	.53**	.56**	.83**	.92**	.87**	—	—	—	—	—	—	—	—	—	—	—	—	—	—	—
7. Child2 in Child1's EOL	.72**	.69**	.61**	.43**	.56**	.55**	—	—	—	—	—	—	—	—	—	—	—	—	—	—
8. Child2 in Child1's Funeral	.41**	.58**	.08**	.94**	.80**	.97**	.57**	—	—	—	—	—	—	—	—	—	—	—	—	—
9. Social support from family	.08	-.07	.06	.03	.21	.08	.04	.01	—	—	—	—	—	—	—	—	—	—	—	—
10. Social support from friends	.06	-.02	.31**	.17	.28*	.18	.11	.16	.51**	—	—	—	—	—	—	—	—	—	—	—
11. Parent-Child1 Closeness	.06	.21*	.18	.30**	.23*	.31**	.33**	.30**	.22*	.11	—	—	—	—	—	—	—	—	—	—
12. Parent-Child1 Conflict	.03	-.01	.09	.06	.02	.01	-.12	.02	-.38**	-.07	.01	—	—	—	—	—	—	—	—	—
13. Partner-Child1 Closeness	.10	.01	-.03	.01	.02	.06	.07	.03	.47**	.38**	.05	-.15	—	—	—	—	—	—	—	—
14. Partner-Child1 Conflict	-.01	-.08	.15	.08	.10	.08	.05	.10	-.34**	-.20*	-.02	.69**	-.41**	—	—	—	—	—	—	—
15. Parent-Child2 Closeness	.24*	.60**	.30**	.41**	.26*	.38**	.45**	.42**	.62**	.14	.24*	-.11	.38**	-.09	—	—	—	—	—	—
16. Parent-Child2 Conflict	-.07	-.14	.03	-.04	-.08	-.06	-.08	-.04	-.32**	-.13	.07	.47**	-.20	.43**	-.36**	—	—	—	—	—
17. Partner-Child2 Closeness	.08	.36**	.13	.23**	.07	.18	.18	.22	.38**	.28*	.10	-.12	.78**	-.32**	.56**	-.20	—	—	—	—
18. Partner-Child2 Conflict	-.05	-.10	.02	-.03	-.04	-.05	-.01	-.04	-.28*	-.21	-.05	.38**	-.36**	.60**	-.26*	.73**	-.38**	—	—	—
19. Partner Relationship	.11	.18	-.04	-.02	-.04	-.08	.04	-.06	.14	.16	-.03	-.15	.51**	-.25**	.25*	-.23*	.58**	-.22	—	—
20. Sibling Relationship	-.16	-.01	-.17	-.14	-.23*	-.16	-.06	-.13	-.29	-.09	.25*	-.34**	.19	-.44**	.14	-.49**	.15	-.44**	.24*	—
M	4.82	4.87	4.83	4.89	4.81	4.85	4.85	4.86	4.32	5.64	5.46	2.42	4.15	2.26	4.43	2.29	4.16	2.17	4.03	2.97
SD	.50	.49	.47	.42	.51	.48	.39	.47	.57	.93	1.06	.77	.78	.78	.53	.78	.75	.74	.92	.72

* $p < .05$. ** $p < .01$.

Table 6. *Means, Standard Deviations (SDs), and Intercorrelations Among the Study Variables*

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	*M*	*SD*
1. Child1 in Partner's EOL	—	.59**	.18	.07	.60**	.32	.55**	.07	.28*	.12	.00	.02	.24	-.11	.13	-.23	-.06	-.22	.37**	-.25	4.83	.57
2. Child1 in partner's Funeral	.77**	—	.27	.29	.22	.27	.70**	.29	-.15	.02	.17	.01	.21	-.10	.71**	-.20	.36*	-.21	.34*	.01	4.83	.64
3. Child2 in partne's EOL	1.00**	.71**	—	.95**	.85**	.90**	.39*	.95**	.17	.62**	.20	.18	-.13	.19	.34	.01	.09	-.03	-.01	-.23	4.85	.57
4. Child2 in Partner's Funeral	.71**	1.00**	.71**	—	.81**	.96**	.18	1.00**	.02	.44*	.20	.21	-.10	.18	.38*	-.02	.14	-.05	-.13	-.18	4.88	.55
5. Child1 in Child2's EOL	.78**	.76**	.79**	.76**	—	.93**	.31	.81**	.47**	.59**	.23	.09	.01	.10	.21	-.11	-.02	-.13	-.07	-.31	4.79	.65
6. Child1 in Child2's Funeral	.74**	.88**	.74**	.88**	.80**	—	.16	.95**	.20	.46**	.23	.16	-.03	.14	.32	-.09	.08	-.10	-.16	-.23	4.85	.57
7. Child2 in Child1's EOL	.84**	.74**	.84**	.74**	.90**	.85**	—	.18	.33	.46**	.53**	-.18	.07	-.06	.43*	-.07	.15	-.12	.35	-.13	4.94	.24
8. Child2 in Child1's Funeral	.74**	.88**	.74**	.88**	.80**	1.00**	.85**	—	.02	.44*	.20	.21	-.10	.18	.38*	-.02	.14	-.05	-.13	-.18	4.88	.55
9. Social support from family	-.07	-.04	.02	.04	.01	.01	.03	-.02	—	.30*	.15	-.14	.18	-.18	-.12	-.25	-.21	-.28	.18	.15	5.37	.86
10. Social support from friends	.01	-.10	.11	-.06	.01	-.01	.06	-.02	.58**	—	.14	-.01	-.17	.11	.21	.06	-.09	.01	-.01	-.18	5.27	.58
11. Parent-Child1 Closeness	.12	.39**	.15	.47**	.25	.40**	.28	.41**	.39**	.16	—	-.30*	.48**	-.30*	.47**	-.27	.08	-.21	-.21	.29	4.43	.58
12. Parent-Child1 Conflict	.05	-.11	-.01	-.20	-.10	-.19	-.07	-.20	-.12	-.04	-.42**	—	-.22	.78**	.06	.37*	.01	.17	-.05	-.39*	2.27	.81
13. Partner-Child1 Closeness	-.01	.07	.06	.16	.04	.14	.08	.14	.55**	.19	.46**	-.07	—	.50**	.15	-.15	.59**	-.44*	.15	.15	4.23	.66
14. Partner-Child1 Conflict	.11	-.03	.09	-.09	.11	.00	.09	.00	-.26*	-.14	-.40**	.60**	-.37**	—	.09	.43*	-.28	.48**	-.25	-.58**	2.25	.87
15. Parent-Child2 Closeness	.29*	.54**	.29*	.53**	.39**	.48**	.44**	.47**	.37*	.35*	.71**	-.19	.53**	-.26	—	-.37*	.44**	-.35*	-.03	.10	4.59	.48
16. Parent-Child2 Conflict	.08	-.07	.08	-.08	-.06	-.04	-.02	-.05	-.17	.01	-.32*	.54**	-.25	.47**	-.30*	—	-.07	.76**	-.06	-.50**	2.09	.80
17. Partner-Child2 Closeness	.17	.35*	.17	.37*	.19	.27	.18	.29	.57**	.24	.59**	-.20	.90**	-.37*	.62**	-.26	—	-.45**	.23	.06	4.26	.71
18. Partner-Child2 Conflict	.10	.01	.10	-.01	.06	.00	.06	-.01	-.23	-.13	-.31*	.58**	-.31*	.74**	-.17	.70**	-.32*	—	-.02	-.49**	2.08	.77
19. Partner Relationship	-.16	-,02	-.09	.10	.00	-.02	-.11	-.01	.61**	.16	.44**	-.21	.70**	-.25	.34*	-.30*	.71**	-.32*	—	.02	4.15	.88
20. Sibling Relationship	-.09	-.06	-.09	-.06	-.08	-.06	-.08	-.06	.27	.15	.19	-.24	.24	-.26	.12	-.46**	.23	-.38*	.41**	—	3.09	.84
M	4.82	4.90	4.81	4.90	4.83	4.85	4.79	4.85	5.89	5.63	4.22	2.56	4.08	2.27	4.32	2.42	4.09	2.24	3.92	2.89		
SD	.43	.30	.40	.31	.38	.42	.46	.42	1.02	1.20	.53	.69	.87	.71	.54	.75	.77	.71	.94	.61		

Note: Correlation coefficients for the non-Japanese participants were listed above the diagonal, whereas those for the Japanese participants were listed below the diagonal.

* $p < .05$. ** $p < .01$.

Appendix A: Survey Questions (English)

Please fill in the blank or check an answer that best describes you or your family.

1. How old are you? _____years old

2. What is your gender? _____Male _____Female

3. What is your ethnicity?
   - _____Japanese
   - _____Asian American; not Japanese
   - _____Black or African American
   - _____White, Caucasian, European; not Hispanic
   - _____Hispanic or Latino
   - _____Other (Write in):_____.

4. Were you born in the U.S.? _____Yes _____No

   If not, which country were you born? _____.

   How long have you reside in the U.S.? _____year(s).

5. What is the highest education level you have achieved?
   - _____ Less than high school diploma
   - _____High school diploma or GED
   - _____Some college
   - _____Bachelor's degree
   - _____Graduate degree

6. What is the highest education level your partner has achieved?
   - _____ Less than high school diploma
   - _____High school diploma or GED
   - _____Some college
   - _____Bachelor's degree
   - _____Graduate degree

7. What is your family's total annual income?
   - _____ Less than $10,000
   - _____$10,000 to $19,999
   - _____$20,000 to $29,999
   - _____$30,000 to $39,999
   - _____$40,000 to $49,999
   - _____$50,000 to $59,999
   - _____$60,000 to $69,999
   - _____$70,000 to $79,999
   - _____$80,000 to $89,999
   - _____$90,000 to $99,999
   - _____$100,000 to $149,999
   - _____$150,000 or more

8. What past death experience do you have? (check all apply to you).
   - _____ Parent(s)
   - _____ Grandparent(s)
   - _____ Sibling(s)
   - _____ Child(ren)
   - _____ Relatives(aunts, Uncles, cousins, nephews, nieces, etc.)
   - _____ Friend(s)
   - _____ Pet(s)
   - _____ Other (write in)_____.

A. Please circle an answer for the following statements which are about your perceptions about yourself.

	Strongly disagree	Disagree	Agree	Strongly agree
1. I feel that I am a person of worth, at least on an equal plane with others.	1	2	3	4
2. I feel that I have a number of good qualities.	1	2	3	4
3. All in all, I am inclined to feel that I am a failure.	1	2	3	4
4. I am able to do things as well as most other people.	1	2	3	4
5. I feel I do not have much to be proud of.	1	2	3	4
6. I take a positive attitude toward myself.	1	2	3	4
7. On the whole, I am satisfied with myself.	1	2	3	4
8. I wish I could have more respect for myself.	1	2	3	4
9. I certainly feel useless at times.	1	2	3	4
10. At times I think I am no good at all.	1	2	3	4

B. Please circle an answer that best describes your response to each of the statements.

	Not at all true	Hardly true	Moderately true	Exactly true
1. I can always manage to solve difficult problems if I try hard enough.	1	2	3	4
2. If someone opposes me, I can find means and ways to get what I want.	1	2	3	4
3. It is easy for me to stick to my aims and accomplish my goals.	1	2	3	4
4. I am confident that I could deal efficiently with unexpected events.	1	2	3	4
5. Thanks to my resourcefulness, I know how to handle unforeseen situations.	1	2	3	4
6. I can solve most problems if invest the necessary effort.	1	2	3	4
7. I can remain calm when facing difficulties because I can rely on my coping abilities.	1	2	3	4
8. When I am confronted with a problem, I can usually find several solutions.	1	2	3	4
9. If I am in trouble, I can usually think of a solution.	1	2	3	4
10. I can usually handle whatever comes my way.	1	2	3	4

C. Please indicate the satisfaction level to which each of the following questions about your relationship with your partner.

	Low				High
1. How well does your partner meet your needs?	1	2	3	4	5
2. In general, how satisfied are you with your relationship?	1	2	3	4	5
3. How good is your relationship compared to most?	1	2	3	4	5
4. How often do you wish you hadn't gotten into this relationship?	1	2	3	4	5
5. To what extent has your relationship met your original expectations?	1	2	3	4	5
6. How much do you love your partner?	1	2	3	4	5
7. How many problems are there in your relationship?	1	2	3	4	5

D. During the past 7 days including today, how much were you distressed or bothered by each of the following problems?

	Not at all	A little bit	Moderately	Quite a bit	Extremely
1. Nervousness or shakiness inside	1	2	3	4	5
2. Feeling no interest in things	1	2	3	4	5
3. Feeling tense or keyed up	1	2	3	4	5
4. Feeling lonely	1	2	3	4	5
5. Suddenly scared for no reason	1	2	3	4	5
6. Feeling blue	1	2	3	4	5
7. Spells of terror or panic	1	2	3	4	5
8. Feelings of worthlessness	1	2	3	4	5
9. Feeling so restless you couldn't sit still	1	2	3	4	5
10. Feeling hopeless about the future	1	2	3	4	5
11. Feeling fearful	1	2	3	4	5
12. Thoughts of ending your life	1	2	3	4	5

E. Followings are statements people use to describe relationships with family and friends. Please circle an answer that best describes your response to each of the statements.

	strongly disagree	Disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Agree	Strongly agree
1. My family really tries to help me.	1	2	3	4	5	6	7
2. I get the emotional help and support I need from my family.	1	2	3	4	5	6	7
3. My friends really try to help me.	1	2	3	4	5	6	7
4. I can count on my friends when things go wrong.	1	2	3	4	5	6	7
5. I can talk about my problems with my family.	1	2	3	4	5	6	7
6. I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
7. My family is willing to help me make decisions.	1	2	3	4	5	6	7
8. I can talk about my problems with my friends.	1	2	3	4	5	6	7

F. The following questions ask you about your feelings and thoughts during the last month. In each case, you will be asked to indicate how often you felt or thought a certain way.

	Never	Almost Never	Sometimes	Fairly Often	Very Often
1. In the last month, how often have you been upset because of something that happened unexpectedly?	1	2	3	4	5
2. In the last month, how often have you felt that you were unable to control the important things in your life?	1	2	3	4	5
3. In the last month, how often have you felt nervous and "stressed"?	1	2	3	4	5
4. In the last month, how often have you felt confident about your ability to handle your personal problems?	1	2	3	4	5
5. In the last month, how often have you felt that things were going your way?	1	2	3	4	5
6. In the last month, how often have you found that you could not cope with all the things that you had to do?	1	2	3	4	5
7. In the last month, how often have you been able to control irritations in your life?	1	2	3	4	5
8. In the last month, how often have you felt that you were on top of things?	1	2	3	4	5
9. In the last month, how often have you been angered because of things that were outside of your control?	1	2	3	4	5
10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?	1	2	3	4	5

G. Following are statements related to different attitudes toward death. Please circle an answer that best describes your response to each of the statements.

	strongly disagree	Disagree	Moderately disagree	Undecided	Moderately agree	Agree	Strongly agree
1. I avoid death thoughts at all costs.	1	2	3	4	5	6	7
2. Death should be viewed as a natural, undeniable, and unavoidable event.	1	2	3	4	5	6	7
3. Whenever the thought of death enters my mind, I try to push it away.	1	2	3	4	5	6	7
4. I always try not to think about death.	1	2	3	4	5	6	7
5. Death is a natural aspect of life.	1	2	3	4	5	6	7
6. I would neither fear death nor welcome it.	1	2	3	4	5	6	7
7. I avoid thinking about death altogether.	1	2	3	4	5	6	7
8. Death is simply a part of the process of life.	1	2	3	4	5	6	7
9. I try to have nothing to do with the subject of death.	1	2	3	4	5	6	7
10. Death is neither good nor bad.	1	2	3	4	5	6	7

If you have one child, that child will be Child 1.
If you have more than one child, the oldest child under 18 will be Child 1, and the next child will be your Child 2.

Please fill in the blank or check an answer that best describes Child 1.

1. How old is Child 1?_____years old

2. What is the gender of Child 1? _____Male _____Female

3. What is your relationship to Child1?
   _____ Father _____ Mother
   _____ Other (write in):_____.

4. Does your Child 1 have any known developmental delay?
   _____No
   _____Yes (write in):_____.

5. What is the relationship between Child 1 and your partner?
   _____Biological parent: living together
   _____Biological parent: not living together
   _____Step-parent
   _____Not a parent but living together
   _____Other (write in):_____.

6. What past death experience does Child 1 have? (check all apply to child 1).
   _____ Parent _____ Grandparent(s)
   _____ Sibling(s) _____ Great grandparents
   _____ Relatives(aunts, Uncles, cousins, etc.)
   _____ Friend(s) _____ Pet(s)
   _____ Other (write in)_____.

H. Please reflect on the degree to which each of the following statements currently applies to **your** relationship with Child 1.

	Definitely does not apply	Not really	Neutral, not sure	Applies somewhat	Definitely applies
1. I share an affectionate, warm relationship with my child.	1	2	3	4	5
2. My child and I always seem to be struggling with each other.	1	2	3	4	5
3. If upset, my child will seek comfort from me.	1	2	3	4	5
4. My child is uncomfortable with physical affection or touch from me.	1	2	3	4	5
5. My child values his/her relationship with me.	1	2	3	4	5
6. When I praise my child, he/she beams with pride.	1	2	3	4	5
7. My child spontaneously shares information about himself/herself.	1	2	3	4	5
8. My child easily becomes angry at me.	1	2	3	4	5
9. It is easy to be in tune with what my child is feeling.	1	2	3	4	5
10. My child remains angry or is resistant after being disciplined.	1	2	3	4	5
11. Dealing with my child drains my energy.	1	2	3	4	5
12. When my child is in a bad mood, I know we're in for a long and difficult day.	1	2	3	4	5
13. My child's feelings toward me can be unpredictable or can change suddenly.	1	2	3	4	5
14. My child is sneaky or manipulative with me.	1	2	3	4	5
15. My child openly shares his/her feelings and experiences with me.	1	2	3	4	5

I. Please reflect on the degree to which each of the following statements currently applies to your perception of **your partner's** relationship with Child 1.

	Definitely does not apply	Not really	Neutral, not sure	Applies somewhat	Definitely applies
1. The partner shares an affectionate, warm relationship with my child.	1	2	3	4	5
2. My child and the partner always seem to be struggling with each other.	1	2	3	4	5
3. If upset, my child will seek comfort from the partner.	1	2	3	4	5
4. My child is uncomfortable with physical affection or touch from the partner.	1	2	3	4	5
5. My child values his/her relationship with the partner.	1	2	3	4	5
6. When the partner praises my child, he/she beams with pride.	1	2	3	4	5
7. My child spontaneously shares information about himself/herself.	1	2	3	4	5
8. My child easily becomes angry at the partner.	1	2	3	4	5
9. It is easy for the partner to be in tune with what my child is feeling.	1	2	3	4	5
10. My child remains angry or is resistant after being disciplined.	1	2	3	4	5
11. Dealing with my child drains the partner's energy.	1	2	3	4	5
12. When my child is in a bad mood, the partner knows they're in for a long and difficult day.	1	2	3	4	5
13. My child's feelings toward the partner can be unpredictable or can change suddenly.	1	2	3	4	5
14. My child is sneaky or manipulative with the partner.	1	2	3	4	5
15. My child openly shares his/her feelings and experiences with the partner.	1	2	3	4	5

J. The following 2 questions are hypothetical questions. Please circle an answer that best describes your response to the questions.

J-1. How likely is it for you to include Child 1 in your partner's end of life care such as visiting and spending time with, if the child wishes to?

1 I would definitely include my child.

2 I would probably include my child.

3 I might include my child.

4 I would probably not include my child.

5 I would definitely not include my child.

J-2. How likely is it for you to include Child 1 in your partner's funeral service, if the child wishes to?

1 I would definitely include my child.

2 I would probably include my child.

3 I might include my child.

4 I would probably not include my child.

5 I would definitely not include my child.

**** If Child 1 is your only child, stop here and thank you again for your participation. If there is Child 2 available based on the earlier description (page 7), please continue.

Please fill in the blank or check an answer that best describes Child 2.

1. How old is Child 2?_____years old

2. What is the gender of Child 2? _____Male _____Female

3. What is your relationship to Child 2?

   _____ Father _____ Mother Other (write in): .

4. Does your Child 2 have any known developmental delay?
   _____No
   _____Yes (write in):_____.

5. What is the relationship between Child 2 and your partner?
   _____Biological parent: living together
   _____Biological parent: not living together
   _____Step-parent
   _____Not a parent but living together
   _____Other (write in):_____.

5. What past death experience does Child 2 have? (check all apply to child 2).
   _____ Parent _____ Grandparent(s)
   _____ Sibling(s) _____ Great grandparents
   _____ Relatives(aunts, Uncles, cousins, etc.)
   _____ Friend(s) _____ Pet(s)
   _____ Other (write in)_____.

6. Please circle an answer that best describes your response to the question.
   How would you describe the current relationship between Child 2 and Child 1?

1	The two have many difficulties. They rarely get along.
2	The two have many difficulties. They get along some of the time.
3	The two have some difficulties. They get along most of the time.
4	The two rarely have difficulties. They get along almost all of the time.

K. Please reflect on the degree to which each of the following statements currently applies to **your** relationship with Child 2.

	Definitely does not apply	Not really	Neutral, not sure	Applies somewhat	Definitely applies
1. I share an affectionate, warm relationship with my child.	1	2	3	4	5
2. My child and I always seem to be struggling with each other.	1	2	3	4	5
3. If upset, my child will seek comfort from me.	1	2	3	4	5
4. My child is uncomfortable with physical affection or touch from me.	1	2	3	4	5
5. My child values his/her relationship with me.	1	2	3	4	5
6. When I praise my child, he/she beams with pride.	1	2	3	4	5
7. My child spontaneously shares information about himself/herself.	1	2	3	4	5
8. My child easily becomes angry at me.	1	2	3	4	5
9. It is easy to be in tune with what my child is feeling.	1	2	3	4	5
10. My child remains angry or is resistant after being disciplined.	1	2	3	4	5
11. Dealing with my child drains my energy.	1	2	3	4	5
12. When my child is in a bad mood, I know we're in for a long and difficult day.	1	2	3	4	5
13. My child's feelings toward me can be unpredictable or can change suddenly.	1	2	3	4	5
14. My child is sneaky or manipulative with me.	1	2	3	4	5
15. My child openly shares his/her feelings and experiences with me.	1	2	3	4	5

L. Please reflect on the degree to which each of the following statements currently applies to your perception of **your partner's** relationship with Child 2.

	Definitely does not apply	Not really	Neutral, not sure	Applies somewhat	Definitely applies
1. The partner shares an affectionate, warm relationship with my child.	1	2	3	4	5
2. My child and the partner always seem to be struggling with each other.	1	2	3	4	5
3. If upset, my child will seek comfort from the partner.	1	2	3	4	5
4. My child is uncomfortable with physical affection or touch from the partner.	1	2	3	4	5
5. My child values his/her relationship with the partner.	1	2	3	4	5
6. When the partner praises my child, he/she beams with pride.	1	2	3	4	5
7. My child spontaneously shares information about himself/herself.	1	2	3	4	5
8. My child easily becomes angry at the partner.	1	2	3	4	5
9. It is easy for the partner to be in tune with what my child is feeling.	1	2	3	4	5
10. My child remains angry or is resistant after being disciplined.	1	2	3	4	5
11. Dealing with my child drains the partner's energy.	1	2	3	4	5
12. When my child is in a bad mood, the partner knows they're in for a long and difficult day.	1	2	3	4	5
13. My child's feelings toward the partner can be unpredictable or can change suddenly.	1	2	3	4	5
14. My child is sneaky or manipulative with the partner.	1	2	3	4	5
15. My child openly shares his/her feelings and experiences with the partner.	1	2	3	4	5

M. The following 6 questions are hypotheticals questions. Please circle an answer that best describes your response to the questions.

M-1. How likely is it for you to include Child 2 in your partner's end of life care such as visiting and spending time with, if the child wishes to?

1 I would definitely include my child.

2 I would probably include my child.

3 I might include my child.

4 I would probably not include my child.

5 I would definitely not include my child.

M-2. How likely is it for you to include Child 2 in your partner's funeral service, if the child wishes to?

1 I would definitely include my child.

2 I would probably include my child.

3 I might include my child.

4 I would probably not include my child.

5 I would definitely not include my child

M-3. How likely is it for you to include your Child 1 in Child 2's end of life care such as visiting and spending time with, if the Child 1 wishes to?

1 I would definitely include my child.

2 I would probably include my child.

3 I might include my child.

4 I would probably not include my child.

5 I would definitely not include my child.

M-4. How likely is it for you to include your Child 1 in Child 2's funeral service, if the Child 1 wishes to?

1 I would definitely include my child.

2 I would probably include my child.

3 I might include my child.

4 I would probably not include my child.

5 I would definitely not include my child.

M-5. How likely is it for you to include your Child 2 in Child 1's end of life care such as visiting and spending time with, if the Child 2 wishes to?

1 I would definitely include my child.

2 I would probably include my child.

3 I might include my child.

4 I would probably not include my child.

5 I would definitely not include my child.

M-6. How likely is it for you to include your Child 2 in Child 1's funeral service, if the Child 2 wishes to?

1 I would definitely include my child.

2 I would probably include my child.

3 I might include my child.

4 I would probably not include my child.

5 I would definitely not include my child.

Thank you for your time and participation.

Appendix B: Survey Questions (Japanese)

以下の質問に、あなたまたはあなたの家族について最も近い回答で空白を埋めるかチェックをして下さい。

1. あなたの年齢は? _____歳

2. あなたの性別は？ _____男性_____女性

3. あなたは何の民族に属しますか?
   _____日本人
   _____アジアンアメリカン; 日本人以外
   _____黒人又はアフリカンアメリカン
   _____白人又はヨーロッパ人; ヒスパニック系以外
   _____スパニック系又はラテン系
   _____その他(詳細を書いてください):_____.

4. アメリカには何年程滞在していますか？ _____年

5. あなたの最終学歴は何ですか?
   _____ 高校中退以下
   _____高校卒業又は大学検定
   _____短大又は大学中退
   _____大学卒業
   _____大学院卒業以上

6. あなたのパートナーの最終学歴は何ですか?
   _____ 高校中退以下
   _____高校卒業又は大学検定
   _____短大又は大学中退
   _____大学卒業
   _____大学院卒業以上

7. あなたの家族全体での年収は?
   _____$10,000 未満　　_____$10,000 ～ $19,999
   _____$20,000 ～ $29,999　　_____$30,000 ～ $39,999
   _____$40,000 ～ $49,999　　_____$50,000 ～ $59,999
   _____$60,000 ～ $69,999　　_____$70,000 ～ $79,999
   _____$80,000 ～ $89,999　　_____$90,000 ～ $99,999
   _____$100,000 ～ $149,999　　_____$150,000 以上

8. 過去に誰の死去を経験していますか？
   _____ 親　　_____ 祖父母
   _____ 兄弟　　_____ 子供
   _____ 親戚（叔父、叔母、いとこ、甥、姪、など）
   _____ 友人　　_____ ペット
   _____ その他（詳細を書いて下さい）_____.

A. あなたが会得しているあなた自身についての申告に対しての答えに丸をしてください。

	強く同意しない	同意しない	同意する	強く同意する
1.少なくとも他の人と同等に、自分は価値のある人だと感じる。	1	2	3	4
2. 自分には数々の良質な部分があると感じる。	1	2	3	4
3. 概して、自分は不成功だと感じる傾向にある。	1	2	3	4
4. 自分は他の人達と同様のことができる。	1	2	3	4
5. 自分にはあまり誇れるものがないと感じる。	1	2	3	4
6. 自分に対してポジティブな姿勢をとっている。	1	2	3	4
7. 全体的に自分自身に満足している。	1	2	3	4
8. 自分自身をもっと尊敬できたらいいのにと思う。	1	2	3	4
9. 時に自分は無用だと切実に感じる。	1	2	3	4
10. 時に自分には全く価値がないと思う。	1	2	3	4

B. 各申告への答えを一番良く説明している回答に丸をしてください。

	全く真実ではない	ほぼ真実ではない	程々に真実である	確実に真実である
1. 自分が十分に努力すれば必ず難しい問題を解決できる。	1	2	3	4
2. もし誰かが私に反対したとして、自分はその意味と自分が欲しいものを手にする手段を見つけられる。	1	2	3	4
3. 自分にとって、目標を見失わずに成し遂げることは簡単である。	1	2	3	4
4. 予期しない出来事に効率的に対処できる自信がある。	1	2	3	4
5. 自分には甲斐性があるので、不測の事態に対処できる。	1	2	3	4
6. 必要な労力を注げば問題はほぼ自分で解決できる。	1	2	3	4
7. 自分の対処能力に頼れるので、難しい問題に直面しても自分は冷静なままでいられる。	1	2	3	4
8. 問題に直面した時、大抵の場合幾つかの解決策を見いだせる。	1	2	3	4
9. もし困難な場面にあっても、大抵の場合解決策を考えつくことができる。	1	2	3	4
10. 大抵の場合何にでも対応できる。	1	2	3	4

C. あなたとパートナーとの関係に関する以下の質問に対して、あなたの満足度を示してください。

	低い				高い
1. あなたのパートナーはどれくらいあなたの要求を満たしてくれますか？	1	2	3	4	5
2. 一般的に、パートナーとの関係にどれくらい満足していますか？	1	2	3	4	5
3. 他の関係と比べて、あなた達の関係はどれくらい良いものですか？	1	2	3	4	5
4. どれくらいの頻度でこの関係を始めなければ良かったと思うことがありますか？	1	2	3	4	5
5. 望んでいた関係に比べてどれくらい今の関係に満足していますか？	1	2	3	4	5
6. どれくらいパートナーのことを愛していますか？	1	2	3	4	5
7. あなた方の関係の中でどれくらい問題がありますか？	1	2	3	4	5

D. 今日を含めた７日の間に、以下のことで苦痛だったり悩まされたりしたことがどれくらいありますか？

	全くない	少々	程々に	かなり	ものすごく
1. 神経質、または内面の震え	1	2	3	4	5
2. 何事も無関心に感じる	1	2	3	4	5
3. 緊張感	1	2	3	4	5
4. 寂しい気分	1	2	3	4	5
5. 理由のない急な恐怖心	1	2	3	4	5
6. 陰鬱な感覚	1	2	3	4	5
7. テロやパニックの呪縛	1	2	3	4	5
8. 無価値だと感じる	1	2	3	4	5
9. そわそわしてじっと座っていられない	1	2	3	4	5
10. 未来に希望がないという気分	1	2	3	4	5
11. 怯える感情	1	2	3	4	5
12. 命を絶とうという気分	1	2	3	4	5

E. 以下は、人々が家族や友達との関係性を表現する時に用いられるものです。各申告への答えを一番良く説明している回答に丸をしてください。

	強く同意しない	同意しない	あまり同意しない	同意もしないし異論もない	わずかに同意する	同意する	強く同意する
1. 自分の家族は自分を助けようと努力する。	1	2	3	4	5	6	7
2. 自分が必要な感情面での助けやサポートは家族から得る。	1	2	3	4	5	6	7
3. 自分の友達は自分を助けようと努力する。	1	2	3	4	5	6	7
4. 何か上手くいかない時、友達に頼ることができる。	1	2	3	4	5	6	7
5. 自分の抱える問題を家族に話すことができる。	1	2	3	4	5	6	7
6. 喜びも悲しみも分かち合える友達がいる。	1	2	3	4	5	6	7
7. 家族は喜んで私の決断の手助けをしてくれる。	1	2	3	4	5	6	7
8. 自分の抱える問題を友達に話すことができる。	1	2	3	4	5	6	7

F. 以下の質問はあなたの過去一ヶ月間の感情や思いについてです。各々について、どれくらいの頻度であなたがそのように感じたのか、そのように思ったのかを記してください。

	一度もない	ほぼ一度もない	時々ある	頻繁にある	かなり頻繁にある
1. この一か月の間に、どれくらいの頻度で何か予期しない出来事が原因で動揺したことがありますか？	1	2	3	4	5
2. この一か月の間に、どれくらいの頻度で自分が人生の中で何か大事ことを制御できないと感じたことがありますか？	1	2	3	4	5
3. この一か月の間に、どれくらいの頻度で神経質になったりストレスを感じたことがありますか？	1	2	3	4	5
4. この一か月の間に、どれくらいの頻度で自分の個人的な問題を解決できると自信を持つことができましたか？	1	2	3	4	5
5. この一か月の間に、どれくらいの頻度で自分の思い通りに事が進んでいると感じましたか？	1	2	3	4	5
6. この一か月の間に、自分がすべき全ての事のうち対応できなかったことがどれくらいの頻度でありましたか？	1	2	3	4	5
7. この一か月の間に、どれくらいの頻度で生活の中での苛立ちを制御することができましたか？	1	2	3	4	5
8. この一か月の間に、どれくらいの頻度で自分が物事を管理出来ていると感じたことがありますか？	1	2	3	4	5
9. この一か月の間に、何か自分がコントロールできないことが原因で腹立たせられたことがどれくらいの頻度でありましたか？	1	2	3	4	5
10. この一か月の間に、どれくらいの頻度で困難なことが積み重なり過ぎて乗り切ることができないと感じたことがありますか？	1	2	3	4	5

G. 以下は死に対しての様々な態度についてです。各申告へのあなたの答えを一番良く説明している回答に丸をしてください。

	強く同意しない	同意しない	あまり同意しない	未定	わずかに同意する	同意する	強く同意する
1. 死については完全に考えないようにしている。	1	2	3	4	5	6	7
2. 死は自然なこと、避けられないこと、拒否できないこととして捉えられるべきである。	1	2	3	4	5	6	7
3. 頭に死についての考えが浮かんだとき、自分はそれを押し出そうとする。	1	2	3	4	5	6	7
4. 死についてはいつでも考えないようにしている。	1	2	3	4	5	6	7
5. 死は人生の中の自然な一面である。	1	2	3	4	5	6	7
6. 自分は死を恐れも歓迎もしない。	1	2	3	4	5	6	7
7. 私は死そのものについて考えることを避ける。	1	2	3	4	5	6	7
8. 死は単純に人生の過程の一部である。	1	2	3	4	5	6	7
9. 死という話題と何の関係も持たないように努めている。	1	2	3	4	5	6	7
10. 死は良いものでも悪いものでもない。	1	2	3	4	5	6	7

子供が一人いる場合、ここからの質問の中ではその子供を子供１とします。
子供が二人以上いる場合、ここからの質問の中では１８歳未満で一番年上の子供を子供１とし、その次の子供を子供２とします。

以下の質問に、子供１について最も近い回答で空白を埋めるかチェックをして下さい。

1. 子供１の年齢は?_____歳

2. 子供１の性別は？ _____男性 _____女性

3. あなたと子供１の続柄は?
   _____ 父親 _____母親
   _____その他（詳細を書いてくださ
   い）:_____.

4. 子供１には何か発達の遅れがありますか?
   _____いいえ
   _____はい (詳細を書いてください):_____.

5. 子供１とあなたのパートナーの関係性は何ですか?
   _____親: 一緒に住んでいる
   _____親: 一緒に住んでいない
   _____義理の親
   _____親ではないが一緒に住んでいる
   _____その他 (詳細を書いて下さい):_____.

6. 子供１は過去に誰の死去を経験していますか？
   _____ 親 _____ 祖父母
   _____ 兄弟 _____ 曾祖父母
   _____ 親戚（叔父、叔母、いとこ、など）
   _____ 友人 _____ ペット
   _____ その他（詳細を書いて下さい）_____.

H. 以下の今**現**在の**あなた**と子供１との関係についての**申**告に対して、どの程度当てはまるかを回答してください。

	全く当てはまらない	あまり当てはまらない	普通	少々当てはまる	確実に当てはまる
1. 私は子供と愛情やあたたかい関係を分かち合います。	1	2	3	4	5
2. 私と子供はお互いにいつも苦戦しているように感じる。	1	2	3	4	5
3. 動揺した時、子供は私からの慰めを**求**める。	1	2	3	4	5
4. 子供は私からの愛情表**現**やスキンシップを心地よく思わない。	1	2	3	4	5
5. 子供は私との関係を大切に思っている。	1	2	3	4	5
6. 私が褒めると、子供は誇りに満ちる。	1	2	3	4	5
7. 子供自ら、自分のことについて私に話す。	1	2	3	4	5
8. 子供は私に対して怒りやすい。	1	2	3	4	5
9. 簡単に自分の調子を子供の感情に合わせることができる。	1	2	3	4	5
10. 叱られると、子供は怒ったままだったり抵抗したりする。	1	2	3	4	5
11. 子供に対処していると、自分の気力を吸い取らる。	1	2	3	4	5
12. 子供の機嫌が悪いと、その日は困難で長い一日である。	1	2	3	4	5
13. 子供の私に対する感情は予測がつかなかったり、急に変わったりすることがある。	1	2	3	4	5
14. 子供はコソコソしたり私を操ったりする。	1	2	3	4	5
15. 子供は自分の感情や体験をオープンに私に話す。	1	2	3	4	5

I. あなたが思う今**現**在の**パートナー**と子供１との関係についての以下の**申**告に対して、どの程度当てはまるかを回答してください。

	全く当てはまらない	あまり当てはまらない	普通	少々当てはまる	確実に当てはまる
1. パートナーは子供と愛情やあたたかい関係を分かち合います。	1	2	3	4	5
2. パートナーと子供はお互いにいつも苦戦しているように感じる。	1	2	3	4	5
3. 動揺した時、子供はパートナーからの慰めを**求**める。	1	2	3	4	5
4. 子供はパートナーからの愛情表**現**やスキンシップを心地よく思わない。	1	2	3	4	5
5. 子供はパートナーとの関係を大切に思っている。	1	2	3	4	5
6. パートナーが褒めると、子供は誇りに満ちる。	1	2	3	4	5
7. 子供自ら、自分のことについてパートナーに話す。	1	2	3	4	5
8. 子供はパートナーに対して怒りやすい。	1	2	3	4	5
9. パートナーは簡単に自分の調子を子供の感情に合わせることができる。	1	2	3	4	5
10. パートナーに叱られると、子供は怒ったままだったり抵抗したりする。	1	2	3	4	5
11. パートナーは、子供に対処していると気力を吸い取らているようだ。	1	2	3	4	5
12. 子供の機嫌が悪いと、パートナーにとってその日は困難で長い一日である。	1	2	3	4	5
13. 子供のパートナーに対する感情は予測がつかなかったり、急に変わったりすることがある。	1	2	3	4	5
14. 子供はコソコソしたりパートナーを操ったりする。	1	2	3	4	5
15. 子供は自分の感情や体験をオープンにパートナーに対して話す。	1	2	3	4	5

J. 以下の仮設的質問に対して最もあなたの回答に近いものに丸をしてください。

J-1. 子供１**が望むなら、お見舞いや一緒の時間を過ごすなどのあなたのパートナーの終末期ケアに参加させることをどの程度容認しますか？**

1 確実に参加させるでしょう。

2 たぶん参加させるでしょう。

3 もしかすると参加させるでしょう。

4 たぶん参加させないでしょう。

5 絶対に参加させないでしょう。

J-2. 子供１**が望むなら、あなたのパートナーのお葬式に参加させることをどの程度容認しますか？**

1 確実に参加させるでしょう。

2 たぶん参加させるでしょう。

3 もしかすると参加させるでしょう。

4 たぶん参加させないでしょう。

5 絶対に参加させないでしょう。

****** お子さんが一人の場合はここで終わりになります。この記入済みのアンケートと、署名済みの許可書１部（もう１部は家庭保管）を封筒に入れ、学園にお戻し下さい。ご協力、誠にありがとうございました。**

7ページの質問で子供２に各当するお子さんがいらっしゃる場合は続けて下さい。

以下の質問に、子供２について最も近い回答で空白を埋めるかチェックをして下さい。

1. 子供２の年齢は?_____歳

2. 子供２の性別は？ _____男性 _____女性

3. あなたと子供２の続柄は?
   _____ 父親 _____母親
   _____その他（詳細を書いてください）:_____.

4. 子供２には何か発達の遅れがありますか?
   _____いいえ
   _____はい (詳細を書いてください):_____.

5. 子供２とあなたのパートナーの関係性は何ですか?
   _____親: 一緒に住んでいる
   _____親: 一緒に住んでいない
   _____義理の親
   _____親ではないが一緒に住んでいる
   _____その他 (詳細を書いて下さい):_____.

5. 子供２は過去に誰の死去を経験していますか？
   ____ 親 ____ 祖父母
   ____ 兄弟 ____ 曾祖父母
   ____ 親戚（叔父、叔母、いとこ、など)
   ____ 友人 ____ ペット
   ____ その他（詳細を書いて下さい）_____.

6. 以下の質問に対して最もあなたの回答に近いものに丸をしてください。
   子供２と子供１の今現在の関係についてのあなたの見解はどうですか？

   1 子供達がぶつかることは多くある。子供達が仲良しなのは珍しい。

   2 子供達がぶつかることは多くある。時々子供達は仲良しである。

   3 子供達はたまにぶつかることがある。子供達は大抵仲良しである。

   4 子供達がぶつかることは珍しい。子供達はほぼいつも仲良しである。

K. 以下の今**現**在の**あなた**と子供２との関係についての**申**告に対して、どの程度当てはまるかを回答してください。

	全く当てはまらない	あまり当てはまらない	普通	少々当てはまる	確実に当てはまる
1. 私は子供と愛情やあたたかい関係を分かち合います。	1	2	3	4	5
2. 私と子供はお互いにいつも苦戦しているように感じる。	1	2	3	4	5
3. 動揺した時、子供は私からの慰めを**求**める。	1	2	3	4	5
4. 子供は私からの愛情**表現**やスキンシップを心地よく思わない。	1	2	3	4	5
5. 子供は私との関係を大切に思っている。	1	2	3	4	5
6. 私が褒めると、子供は誇りに満ちる。	1	2	3	4	5
7. 子供自ら、自分のことについて私に話す。	1	2	3	4	5
8. 子供は私に対して怒りやすい。	1	2	3	4	5
9. 簡単に自分の調子を子供の感情に合わせることができる。	1	2	3	4	5
10. 叱られると、子供は怒ったままだったり抵抗したりする。	1	2	3	4	5
11. 子供に対処していると、自分の気力を吸い取らる。	1	2	3	4	5
12. 子供の機嫌が悪いと、その日は困難で長い一日である。	1	2	3	4	5
13. 子供の私に対する感情は予測がつかなかったり、急に変わったりすることがある。	1	2	3	4	5
14. 子供はコソコソしたり私を操ったりする。	1	2	3	4	5
15. 子供は自分の感情や体験をオープンに私に話す。	1	2	3	4	5

L. あなたが思う今**現**在の**パートナー**と子供２との関係についての以下の**申**告に対して、どの程度当てはまるかを回答してください。

	全く当てはまらない	あまり当てはまらない	普通	少々当てはまる	確実に当てはまる
1. パートナーは子供と愛情やあたたかい関係を分かち合います。	1	2	3	4	5
2. パートナーと子供はお互いにいつも苦戦しているように感じる。	1	2	3	4	5
3. 動揺した時、子供はパートナーからの慰めを**求**める。	1	2	3	4	5
4. 子供はパートナーからの愛情表**現**やスキンシップを心地よく思わない。	1	2	3	4	5
5. 子供はパートナーとの関係を大切に思っている。	1	2	3	4	5
6. パートナーが褒めると、子供は誇りに満ちる。	1	2	3	4	5
7. 子供自ら、自分のことについてパートナーに話す。	1	2	3	4	5
8. 子供はパートナーに対して怒りやすい。	1	2	3	4	5
9. パートナーは簡単に自分の調子を子供の感情に合わせることができる。	1	2	3	4	5
10. パートナーに叱られると、子供は怒ったままだったり抵抗したりする。	1	2	3	4	5
11. パートナーは、子供に対処していると気力を吸い取らているようだ。	1	2	3	4	5
12. 子供の機嫌が悪いと、パートナーにとってその日は困難で長い一日である。	1	2	3	4	5
13. 子供のパートナーに対する感情は予測がつかなかったり、急に変わったりすることがある。	1	2	3	4	5
14. 子供はコソコソしたりパートナーを操ったりする。	1	2	3	4	5
15. 子供は自分の感情や体験をオープンにパートナーに対して話す。	1	2	3	4	5

M. 以下の仮説的質問に対して最もあなたの回答に近いものに丸をしてください。

M-1. 子供２が望むなら、お見舞いや一緒の時間を過ごすなどのあなたのパートナーの終末期ケアに参加させることをどの程度容認しますか？

1 確実に参加させるでしょう。

2 たぶん参加させるでしょう。

3 参加させるかもしれません。

4 たぶん参加させないでしょう。

5 絶対に参加させないでしょう。

M-2. 子供２が望むなら、あなたのパートナーのお葬式に参加させることをどの程度容認しますか？

1 確実に参加させるでしょう。

2 たぶん参加させるでしょう。

3 参加させるかもしれません。

4 たぶん参加させないでしょう。

5 絶対に参加させないでしょう。

M-3. 子供１が望むなら、お見舞いや一緒の時間を過ごすなどの子供２の終末期ケアに参加させることをどの程度容認しますか？

1 確実に参加させるでしょう。

2 たぶん参加させるでしょう。

3 参加させるかもしれません。

4 たぶん参加させないでしょう。

5 絶対に参加させないでしょう。

M-4. 子供１が望むなら、子供２のお葬式に参加させることをどの程度容認しますか？

1 確実に参加させるでしょう。

2 たぶん参加させるでしょう。

3 参加させるかもしれません。

4 たぶん参加させないでしょう。

5 絶対に参加させないでしょう。

M-5. 子供２が望むなら、お見舞いや一緒の時間を過ごすなどの子供１の終末期ケアに参加させることをどの程度容認しますか？

1 確実に参加させるでしょう。

2 たぶん参加させるでしょう。

3 参加させるかもしれません。

4 たぶん参加させないでしょう。

5 絶対に参加させないでしょう。

M-6. 子供２が望むなら、子供１のお葬式に参加させることをどの程度容認しますか？

1 確実に参加させるでしょう。

2 たぶん参加させるでしょう。

3 参加させるかもしれません。

4 たぶん参加させないでしょう。

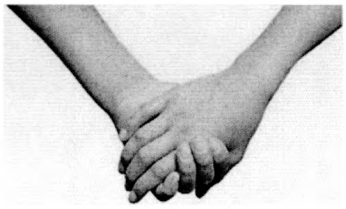
5 絶対に参加させないでしょう。

質問は以上になります。この記入済みのアンケートと、署名済みの許可書１部（もう１部は家庭保管）を封筒に入れ、学園にお戻し下さい。ご協力、誠にありがとうございました。

Appendix C: Flyer (English)

Are you a parent?

Research Participants Wanted!!



- I am looking at what predicts parental decision making of whether or not to include children in family member's end-of life care, such as visiting and spending time together, and at the funeral services.
- If you are a parent of a child/children age under 18, and currently have a partner, or previously had a partner, who has a relationship with your child/children, you are eligible to participate.
- This survey will take 10-15 minutes.

Yuki Takahashi, Master's Student in the Department of Family and Child Studies, is conducting this study. If you are interested in participating using hard copy of survey or have questions, please contact at takahashiy1@mail.montclair.edu

Online survey is available at

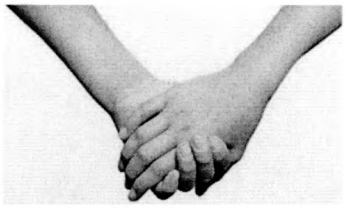
https://msusurveys.montclair.edu/index.php/191592

This study has been approved by the Montclair State University's Institutional Review Board.

MONTCLAIR STATE UNIVERSITY

Appendix D: Flyer (Japanese)

研究へのご協力のお願い



- 親が子供を家族のお見舞いや一緒に最後の時間を過ごすなどの終末期ケア、またお葬式に参加させるか否かの決断をするのにどのような要因が関係しているのかについての研究をしています。
- １８歳未満のお子さんをお持ちで、今現在、または過去にあなたのお子さんと関係のあるパートナー（ご結婚されている方、ご結婚されていなくてもお子さんを一緒に養育されている方、またはお子さんの親）がいる方が対象です。
- このアンケートは１０－１５分程かかります。

オンラインのアンケートはこちらの URL からアクセスできます。

https://msusurveys.montclair.edu/index.php/561152

この研究は Family and Child Studies 学部の修士課程に在学中である髙橋有希（タカハシユウキ）が行っております。質問がある方はＥメールにて本人に連絡してください。

Ｅメールアドレス：takahashiy1@mail.montclair.edu

この研究は州立モントクレア大学の治験審査委員会の承認を受けております。

MONTCLAIR STATE UNIVERSITY

Appendix E: Consent Form (English)

MONTCLAIR STATE UNIVERSITY

College of Education and Human Services
Department of Family and Child Studies
Voice: 973-655-4171
Fax: 973-655-6795

CONSENT FORM FOR ADULTS

Please read below with care. You can ask questions at any time, now or later. You can talk to other people before you sign this form.

Study's Title: Parental Perceptions of Including Children in Family Member's End of Life Care and at Funeral Services

Why is this study being done?
With increasing number of children experiencing loss a family member, and given its impact on the well-being of surviving members, knowing what predicts parents' decision making in including children in the dying family member's end of life care such as visiting and spending time with and/or at the funeral service would help support the family's grieving process.

What will happen while you are in the study?
Should you agree to participate in the study, you would be asked to fill out a survey, consisting of questions about your personal attributes, social support, psychological functioning, attitude about death, and relationships with family members, and the data would be used in reporting results for the study.

Time: This study will take about 10 to 15 minutes.

Risks: The risks are no greater than those in ordinary life. You may feel some psychological discomfort when answering some of the questions.

Benefits: There are no benefits to you being in this study. However, others may benefit from this study because the results of this study will help increase our understanding of parents' decision making while grieving.

Who will know that you are in this study? You will not be linked to any presentations. We will keep who you are confidential.

You should know that New Jersey requires that any person having reasonable cause to believe that a child has been subjected to child abuse or acts of child abuse shall report the same immediately to the Division of Youth and Family Services.

Do you have to be in the study?
You do not have to be in this study. You are a volunteer! It is okay if you want to stop at any time and not be in the study. You do not have to answer any questions you do not want to answer. Nothing will happen to you.

Do you have any questions about this study?
Yuki Takahashi: takahashiy1@mail.montclair.edu, and/or
Dr. Steven Lee: leech@mail.montclair.edu

Do you have any questions about your rights as a research participant? Phone or email the IRB Chair, Dr. Katrina Bulkley, at 973-655-5189 or reviewboard@mail.montclair.edu.

MONTCLAIR STATE UNIVERSITY

College of Education and Human Services
Department of Family and Child Studies
Voice: 973-655-4171
Fax: 973-655-6795

One copy of this consent form is for you to keep.

Statement of Consent
I have read this form and decided that I will participate in the project described above. Its general purposes, the particulars of involvement, and possible risks and inconveniences have been explained to my satisfaction. I understand that I can withdraw at any time. My signature also indicates that I am 18 years of age or older and have received a copy of this consent form.

Print your name here	Sign your name here	Date
Name of Principal Investigator	Signature	Date
Name of Faculty Sponsor	Signature	Date

Appendix F: Consent Form (Japanese)

MONTCLAIR STATE UNIVERSITY

College of Education and Human Services
Department of Family and Child Studies
Voice: 973-655-4171
Fax: 973-655-6795

許可書（大人用）

以下の文章を注意深く読んで下さい。いつでも質問できますし、このフォームにサインする前に誰か他の人と話し合っても構いません。

研究のタイトル: Parental Perceptions of Including Children in Family Member's End of Life Care and at Funeral Service
（子供を家族の終末期ケアやお葬式に参加させるか否かについての親の見解）

なぜこの研究は行われるのか?
子供が家族を失う経験をすることが増えている状況と、その経験が家族全体に及ぼす影響を考えた時、親が子供を家族のお見舞いや一緒に最後の時間を過ごすなどの終末期ケア、またお葬式に参加させるか否かの決断をするのにどのような要因が関係しているのかを知ることは、その後の家族の悲しみを乗り越える過程を手助けするのに役立つ。

この研究にどのように参加するか?
この研究の参加に合意された場合、あなたの個人的な性格の属性、身近な人からのサポート、心理的機能、死に対する考え、家族間の関係などの質問に筆記で答えてもらいます。そしてこのデータはこの研究の結果をまとめるのに使われます。

時間: １０分から１５分程度かかります。

リスク: 普段の生活以上のリスクはありませんが、質問によっては不快に感じることがあるかもしれません。

利益: この研究に参加することでのあなたへの直接的な利益はありません。しかしこの研究結果は、悲しみを乗り越える過程での親の決断に対しての理解を高めることを手助けをするので、他の誰かの為になります。

あなたがこの研究に参加することは誰が知りえますか? あなたが何かのプレゼンに関係づけられることはありません。あなたの個人情報は機密に守られます。

何か子供が虐待の対象になっている、または虐待的行動が疑われることがあれば、それを察した人はニュージャージー州の規定により直ちに青少年と家族サービス事業部に報告しなければならないことをご理解下さい。

MONTCLAIR STATE UNIVERSITY

College of Education and Human Services
Department of Family and Child Studies
Voice: 973-655-4171
Fax: 973-655-6795

この研究に参加しなければならないか?
強制ではありません。あくまでもボランティアです。いつでも止められますし、答えたくない質問には答えなくても結構です。参加しないことでのあなたへの代償はありません。

何か質問がある場合は下記まで
Yuki Takahashi（髙橋有希）：takahashiy1@mail.montclair.edu　日本語可
Dr. Steven Lee: leech@mail.montclair.edu

上記のこの研究への参加者としての権利について質問がある場合は下記まで
The IRB Chair, Dr. Katrina Bulkley, at 973-655-5189 or reviewboard@mail.montclair.edu.

二部同封されている許可書の一部はあなたが保管してください。

コンセントの申告
私はこの文章を読み、上記されているプロジェクトに参加することを決めました。この目的、内容、考えられるリスクや不都合などについて納得できる説明がありました。私はいつでも止めることができるということも理解しています。それから、私の署名は私が１８歳以上であること、そしてこの許可書のコピーを受け取ったことも明示します。

あなたの名前を活字体で	あなたの署名	日付
Name of Principal Investigator	Signature	Date
Name of Faculty Sponsor	Signature	Date

Appendix G: Approval Letters from recruiting sites

BEN SAMUELS
CHILDREN'S CENTER
MONTCLAIR STATE UNIVERSITY

December 15, 2016

Attn: Institutional Review Board
Montclair State University
1 Normal Avenue
College Hall, Room 248
Montclair, NJ 07043

Re: Parental Perceptions of Including Children in Family Member's End of Life Care and at Funeral Services by Yuki Takahashi

Dear Review Board,

This letter serves to give permission to Yuki Takahashi to complete her research project, Parental Perceptions of Including Children in Family Member's End of Life Care and at Funeral Services during Spring Semester 2017 at our facility.
Yuki Takahashi will have access to parents of children who attend our center to conduct her research project. The research project has been described to me to my satisfaction.

Sincerely,

Tara Evenson

Tara Evenson
Director and Principal
Ben Samuels Children's Center

Mailing:
1 NORMAL AVENUE
MONTCLAIR, NJ 07043

Location:
80 CLOVE ROAD
LITTLE FALLS, NJ 07424

T 973 655 7177
F 973 665 5155

(201)947-4832 • phone
(201)944-3680 • fax

www.japaneseschool.org

JAPANESE CHILDREN'S SOCIETY, INC.
8 West Bayview Ave., Englewood Cliffs, NJ 07632

December 20, 2016

Attn: Institutional Review Board
Montclair State University
1 Normal Avenue
College Hall, Room 248
Montclair, NJ 07043

Re: Parental Perceptions of Including Children in Family Member's End of Life Care and at Funeral Services by Yuki Takahashi

Dear Review Board,

This letter serves to give permission to Yuki Takahashi to complete her research project, Parental Perceptions of Including Children in Family Member's End of Life Care and at Funeral Services during Spring Semester 2017 at our facility.

Yuki Takahashi will have access to parents of children who attend our center to conduct her research project. The research project has been described to me to my satisfaction.

Sincerely,

Toru Okamoto
Principal
Japanese Children's Society, Inc.

APPENDIX H: IRB approval letter

MONTCLAIR STATE UNIVERSITY

Institutional Review Board
College Hall, Room 248
Office: 973-655-3021
Fax: 973-655-3022

Jan 4, 2017 1:14 PM EST

Ms. Yuki Takahashi
Dr. Chih-Yuan Lee
Montclair State University
Department of Family and Child Studies
1 Normal Ave.
Montclair, NJ 07043

Re: IRB Number: **IRB-FY16-17-482**
Project Title: **SS Parental Perceptions of Including Children in Family Member's End of Life Care and at Funeral Services**

Dear Ms. Takahashi:

After an expedited review:

- Category 7. Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Montclair State University's Institutional Review Board (IRB) approved this protocol on **Jan 3, 2017.** The study is valid for one year and will expire on **Jan 3, 2018.**

Should you wish to make changes to the IRB-approved procedures, prior to the expiration of your approval, submit your requests via a Study Modification in Cayuse IRB.

Please note, as the principal investigator, you are required to maintain a file of approved human subjects research documents, for each IRB application, to comply with federal and institutional policies on record retention.

After your study is completed, submit your Project Closure submission.

If you have any questions regarding the IRB requirements, please contact me at 973-655-5189, cayuseIRB@mail.montclair.edu, or the Institutional Review Board.

Sincerely yours,

Dr. Katrina Bulkley
IRB Chair

cc: Ms. Deborah Reynoso, Graduate School, Academic Services Coordinator