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Parents' Experiences After the Death of an Only Child in the U.S.

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FLORIDA INTERNATIONAL UNIVERSITY

Miami, Florida

PARENTS' EXPERIENCES AFTER THE DEATH OF AN ONLY CHILD
IN THE U.S.

A dissertation submitted in partial fulfillment of

the requirements of the degree of

DOCTOR OF PHILOSOPHY

in

NURSING

by

Juanjuan Li

2021

To: Dean Ora Strickland
College of Nursing and Health Sciences

This dissertation, written by Juanjuan Li, and entitled Parents' Experiences After the Death of an Only Child in the U.S., having been approved in respect to style and intellectual content, is referred to you for judgement.

We have read this dissertation and recommend that it be approved.

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Florida International University, 2021

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I want to thank my parents. Without their supports, I would not succeed.

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ABSTRACT OF THE DISSERTATION
PARENTS' EXPERIENCES AFTER THE DEATH OF AN ONLY CHILD
IN THE U.S.

by

Juanjuan Li

Florida International University, 2021

Miami, Florida

Professor JoAnne Youngblut, Major Professor

There are more than 14,000 parents who lose their only child each year. Following the death of a child, recent studies found bereaved parents experienced a higher level of grief, family dysfunction, more physical and psychological problems. The loss of an only child is one of the risk factors related to parents' poorer outcomes. In the last 20 years, all the studies about the death of an only child were conducted in China under the Chinese only child policy. According to the literature review, parents who lost an only child had more negative outcomes than parents who have surviving child(ren). This study based on the Resiliency Model of Family Stress, Adjustment and Adaptation to describe parents' experiences from 2 weeks to 11 years after their only child's death in the U.S. This study used the conventional content analysis approach to understand the online stories posted by the bereaved parents. The sample included 30 parents who lost their only child in the previous 2 weeks to 11 years and wrote blogs online ranging from 1 day to 6 years. The findings included parents' feelings, family functioning, health problems, coping strategies, and related factors. The bereaved parents who lost their only child used words like "lonely", "empty" and "fear, scared or afraid" to describe their

feelings. Bereaved parents tried to pretend they were functioning normally, and they did not want to move on. They have jealous feelings about other families who have a surviving child or children. Parents also experienced role identity conflict. The bereaved parents did not want to work in jobs handling complaints and their marital relationships suffered negative effects of the child's death. The most common physical problem was sleep disturbances. Some bereaved parents reported psychological problems and suicidal ideation. Also, many parents had problems with daily living activities. Parents' descriptions vary with the child's age/ gender, parent's age/ gender, cause of death, and time since the death. The findings from this study can be beneficial for nursing practice, research, and education; grief management; and better tailoring interventions to help parents bereaved of their only child.

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Chapter 1

Introduction

Background

Nearly 25,000 infants under age 1 and another 45,000 children and young adults between age 1 and 24 die in the United States (U.S.) each year (Xu, Murphy, Kochanek, Bastian, & Arias, 2018). The mortality rate for children under age five is 6.6 per 1,000; for children 5-14 years old is 1.3 in the U.S. Approximately 90% of hospital pediatric deaths happen in the neonatal intensive care unit (NICU) and pediatric intensive care unit (PICU) (Carter, Howenstein, Gilmer, Throop, France & Whitlock, 2004). Causes of child death include illness, natural disasters, traumatic injury, suicide, and child abuse and neglect (Parrish, Schnitzer, Lanier, Shanahan, Daniels & Marshall, 2017).

Illness might be chronic illness (e.g., asthma, cancer and diabetes) or acute illness (e.g., stroke, heart attack, and pulmonary embolism). The most common reason of death for children under age five is preterm conditions in the U.S. (“Child Mortality Estimates,” 2018). The traumatic injury might be car crash as passenger or pedestrian, which is the most common traumatic injury cause of death for children (World Health Organization [WHO], 2018). Unintentional injuries account for about 30% of deaths for young children and suicide/ homicide for about 30% of adolescent deaths in the U.S. (Heron, 2013). Accidents, homicide, and suicide are the most common reasons for death for persons between the ages of 15 and 24 years. Every year, there are about 22,000 young people who lose their lives due to these three reasons (Murphy, Xu, Kochanek, Curtin & Arias, 2017). Natural disasters include earthquakes, floods, snowstorms, hurricanes, and

wildfires, among others. Natural disasters often occur fast and can cause severe problems, such as death, physical injury, damage to properties, and mental illness (Cao et al., 2013).

In the U.S., the child mortality rate is higher among black or African American children than in those of other ethnic origins (Heron, 2013), and lowest among Asian and Pacific Islander children (“Child deaths by race,” 2016). Rostila, Saarela and Kawachi (2012) found that lower socioeconomic families were more likely to experience the death of a child. Child death rate peaks in the first month of life and again during adolescence. During middle childhood, the mortality rate is lower (Fraser et al., 2014). The child mortality rate also has significant disparities between a country’s urban and rural regions (Yi, Wu, Liu, Fang, Hu & Wang, 2011).

Death of a Child

At the end of life, children often suffer from sustaining and painful interventions, such as mechanical ventilation, cardiovascular support, invasive procedures, or cardiopulmonary resuscitation (Kaye et al., 2018). Many children at the end of their lives experienced extensive treatments and related complications. When the curative treatments are no longer effective, and the outcome of the disease is highly uncertain, palliative care involvement is necessary to assist the child and the parents to reconsider the goal of care and encourage maintaining comfort instead of cure (Doorenbos, Lindhorst, Starks, Aisenberg, Curtis & Hays, 2012; Kaye et al., 2018). The parents see their children suffering from pain and treatment, and the children might appear to lack the will to live. The parents may need to give up the curative goals, which are extremely overwhelming (Misko, Santos, Ichikawa, Lima, & Bouso, 2015). Children and families in the PICU setting need to face many different health care professionals every day. Care

may not be well coordinated due to each health care professional being focused on only one part of the child's care, and communication may be disrupted. The purpose of daily rounds in the ICU is to discuss the medical findings and treatments, which include many medical terms the family members may not understand (Doorenbos et al., 2012). The parents may experience extra stress from the fragmented information. Intensive stress can cause physical and psychological problems for parents, such as hypertension, insomnia, depression, and anxiety.

Following the death of a child, recent studies found bereaved parents experienced a higher level of grief in the first six months and parental grief started to improve in the third month after the death (Meert et al., 2011; Youngblut et al., 2017). The character and intensity of grief changed over time. Studies found some parents had difficulties getting back to their daily lives, tried to stay busy, had marital disruption, and increased substance use (Bolton et al., 2014; Roger, Floyd, Seltzer, Greenberg & Hong, 2008; Proulx et al., 2016). Some parents were unable to control their emotions, unable to accept the way other family members grieved (Dias, Docherty & Brandon, 2017). Many of them experienced changes of self-identity and spiritual beliefs and decreased life satisfaction (Gerrish, Neimeyer & Bailey, 2014; Infurna & Luthar, 2017). Parents often keep their child's items, develop connections with the deceased child, and keep in contact with healthcare providers (Gerrish et al., 2014; Harper et al., 2011). Dussel, Bona, Heath, Hilden, Weeks and Wolfe (2011) found that many families reported financial hardships following their child's death due to costs of cancer treatment and work disruptions or terminations. Families with such income loss often dropped below the poverty line.

In addition, family functioning suffered after the child's death (Kaye et al., 2018; Popp, Conway, & Pantaleao, 2015). The family relationships can be strengthened or disrupted before and after the child's death (Cipolletta, Marchesin & Benini, 2015; Joronen, Kaunonen, & Aho, 2016). Studies found that some parents had strengthened their relationship with their spouse and others were struggling in their marital relationship following a child's death (Joronen, Kaunonen, & Aho, 2016; Toller & Braithwaite, 2009). The marital relationship depends, in part, on the acceptance of differences in grief expression (Arnold & Gemma, 2008; Toller & Braithwaite, 2009).

Many studies have found that child loss has significant negative consequences for parents' physical and mental health, such as higher levels of depression and anxiety, higher morbidity of cardiovascular disease and diabetes, and higher risk of marital disturbance (Brooten, Youngblut, Roche, Caicedo & Page, 2018; Murphy, Johnson, Chung, & Beaton, 2003; Rogers, Floyd, Seltzer, Greenberg, & Hong, 2008; Rostila & Ma, 2018; Youngblut, Brooten, Cantwell, del Moral, & Totapally, 2013).

Bereaved parents self-rated their health as only half as good as non-bereaved parents (Wei et al., 2016). Many studies reported that parental physical health declined following the child's death (Brooten et al., 2019; Cacciatore et al., 2013; Infurna et al., 2017; Youngblut et al., 2013). Following the death of a child, parents reported more illnesses, such as colds/ flu, headaches, chest pain, asthma, allergy, shortness of breath, hypertension, arthritis (Bolton et al., 2014; Brooten et al., 2018). Most of the acute illnesses occurred by 6 months (Brooten et al., 2018). Parents' cancer morbidity increased at 2 years and 5 years after the death (Bolton et al., 2014; Huang et al., 2013). Parental mortality increased in the first few years following the child's death (Espinosa &

Evans, 2013; Rostila et al., 2012; Schor et al., 2016). After that, parental mortality dropped to the same level as non-bereaved parents. However, 9 or more years after the death, the mortality of bereaved parents was higher than non-bereaved parents again (Rostila et al., 2012). The common causes of parental death are coronary heart disease, circulatory disease, and suicide (Hendrickson, 2009; Schorr et al., 2016; Zetumer et al., 2015). Bereaved parents experienced a higher mortality rate due to suicide, cardiovascular disease, and cancer (Hendrickson, 2009; Schorr et al., 2016).

Following the child's death, parents experienced a higher level of depression, anxiety, panic reactions, PTSD, somatic symptoms, interpersonal sensitivity, aggression, anger, hostility, substance use, psychotropic medication, and all types of psychosis-like symptoms (Bolton et al., 2014; Devylder, Wang, Oh & Lukens, 2013; Harper et al., 2015; Jind, Elklit & Christiansen, 2010; Koyanagi, Oh, Haro, Hirayama & DeVlyder, 2017; Rogers et al., 2008; Rostila & Ma, 2018). The symptoms of depression decreased after 18 months post-death (Rostila et al., 2018), but some parents had depressive episodes for 3 years (Rogers et al., 2008).

Factors related to poorer outcomes of parents following the child's death include parent and deceased child factors. Mothers experienced poorer outcomes than fathers after the child's death (Koyanagi, Oh, Haro, Hirayama & DeVlyder, 2017). Hispanic mothers reported greater panic than other ethnic groups (Youngblut, Brooten, Glaze, Promise & Yoo, 2017). Younger parents and single parents experienced greater grief and more physical health problems (Floy, Seltzer & Greenberg, 2013; Infurna & Luthar, 2017). Also, parents with less education, low social economic status, and low income experienced poorer physical health status and greater grief (Cacciatore, Killian & Harper,

2016; Infurna & Luthar, 2017; Schor et al., 2016). Witnessing the child's suffering, unexpected death, and dissatisfaction with the treatment triggered greater grief reaction (Gerrish, Neimeyer & Bailey, 2014). Following the child's death, lack of support for post death rituals, isolation, financial difficulties and poor coping strategies often lead to poorer outcomes for parents (Brooten, Youngblut, Charles, Roche, Hidalgo & Malkawi, 2016; Infurna & Luthar, 2017; Snaman, Kaye, Torres, Gibson & Baker, 2016). Factors of deceased children related to poorer parental outcomes include older child age (school age and adolescent), only child; recent death, difficult death, and died by brain death, suicide, violence, car crashes, and long-term illness (Bolton et al., 2013; Cacciatore et al., 2016; Koyanagi et al., 2017; Lichtenthal et al., 2015; Rogers et al., 2008; Youngblut et al., 2017).

Death of an Only Child

Loss of an only child is one of the risk factors related to parent's poorer outcomes. In the last 20 years, all the studies about the death of an only child were conducted in China. China's one-child policy started in 1979 and ended in 2015, which had affected China for 35 years. The policy specified that government officials, workers, and urban residents could only have one child. Some rural provinces allowed a second child and some allowed couples to have a second child when the first child was a girl. However, if the second child was also a girl, they were not allowed to have a third child (Cao, Cumming, & Wang, 2015). There are 150 million one-child families in China today (Feng, Poston, & Wang, 2014). "Shiduer" is a Chinese word, which means parents who lost their only child and cannot have a second one (Zheng et al., 2017). The estimated number is over 1 million families who have experienced the death of their only

child, and this number is increasing by 76,000 per year. These data only included the deceased child aged 15 to 30 years old; parents of a deceased child in this age range have less chance to have a second child. If the child's death age below 15 years old is also considered, the total number of families is 2,412,600 (Song, 2014).

The mortality rate in China for children under age five is 9.3 per 1,000, and for children 5-14 years old, 2.4 per 1,000. The most common reason of death for children under age five is congenital abnormalities and pneumonia (Song et al., 2016). In addition, China's residents are at high risk of contagious diseases, such as hepatitis and tuberculosis. In 2002 and 2003, SARS (severe acute respiratory syndrome) killed around 800 people in China (Travis, 2016). The natural disaster is another common reason for children's death in China. In China, the most common natural disasters are floods and earthquakes. Deaths during floods are normally caused by drowning, injuries, and electrocution (United Nations Disaster Assessment and Coordination Team [UNDAC], 1998). The flood in 1931 killed around 4 million people in China (Travis, 2016). In 1998, a flood led to 3,004 deaths, hundreds of missing and 200,000 injured people with an estimated total cost of \$229 million USD (UNDAC, 1998). The earthquake in 1976 at Tangshan caused about half a million people to lose their lives (Travis, 2016). In 2008, the earthquake killed around 70,000 people in Sichuan, and caused about 20,000 people missing (Xu & Song, 2011), which resulted in 5335 children dead or missing in the disaster-affected regions (Cao et al., 2013).

There are only a few studies focused on the parents' psychological and physical health, and living situations after the only child's death in China (Cao et al., 2013; Liu & Slack, 2014; Pan et al., 2016; Wang et al., 2016; Wand & Xu, 2016; Wei, Jiang & Gietel-

Bsten, 2016; Zheng et al., 2017), and only one study conducted in the U.S. at 23 years ago (Talbot, 1996). These studies identified the parents' responses after the only child's death and analyzed the risk factors for parent's health problems.

Parents who lost an only child are different from parents who lost a child and still have a living child or children (Talbot, 1999). Parents who lost their only child may feel like or may be perceived by others as having lost their parenting role. There is an additional stress of a role change over the stress of bereavement (Harper, O'Connor, Dickson & O'Carroll, 2011). Studies found that parents who lost their only child experience greater grief and role identity conflict (Dias et al., 2017; Gerrish et al., 2014; Zheng & Lawson, 2017). Rogers, Floyd, Seltzer, Greenberg and Hong (2008) found that having additional child(ren) in the family was associated with resilience or recovery from grief and less marital disruption. Gerrish, Neimeyer and Bailey (2014) reported the mothers who lost their only child experienced the highest proportion of complicated grief responses and many were admitted into a psychiatric facility due to high suicide intent. Dias, Docherty and Brandon (2017) reported that parents who lost their only child experienced role identity conflicts. They are still parents but without a child. Zheng and Lawson (2015) noted two themes of identity from their qualitative study: "who I am" and "who we are." One mother who lost her only child in Harper, O'Connor, Dickson and O'Carroll (2011)'s study reported that she keeps her maternal role by visiting and cleaning the grave every day because she was unable to be a childless mother.

Following the death of an only child, majority of the families reported dysfunction, negative family functioning, and parental depression (Cao et al., 2013). Some studies find that death of an only child has negative effects on the marital

relationship, which might lead to divorce (Pan, Liu, Li, & Kwok, 2016; Wei et al., 2016; Zheng & Lawson, 2015). Without a child, the family has lost its wholeness (Zheng & Lawson, 2015). In Zheng's study (2017), all the divorced participants were women because their husbands wanted to remarry with a childbearing age woman to have another child. If the marriage ends, the single parent has to face their old age alone. Those parents also have low self-efficacy, low self-confidence, and less satisfaction with life, especially about the family's economic situation (Wei et al., 2016). They are most likely to worry about their medical fees and housing (Wei et al., 2016). Some parents cannot work due to physical or psychological reasons. Some parents spent too much money on their only child's education, depleting their savings, and the amount of federal subsidy is only US\$22 per parent per month for a family who lost their only child in China (Song, 2014). In addition, most hospitals and nursing homes require consent and signature from the adult child for their parent's admission. Parents who lost their only child could be rejected by hospitals or nursing homes when they need care (Zheng, Lawson, & Head, 2017).

The death of an only child can lead parents to have a high level of depression and anxiety (Wei et al, 2016). Parents who lost their only child often avoid contact with others, especially those who have a child, leading to increased isolation and a small social network (Song, 2014; Zheng & Lawson, 2015). A small social network can lead to less emotional and social support (Wei et al., 2016). In Chinese culture, some people believe if your family tree ended in your generation, it is because you did some "evil things" which brought "bad luck" to you and your family. People don't want to invite those parents to a wedding or birthday party and don't want to talk to them, because they are

“unlucky,” which increases the risk of isolation (Liu & Slack, 2014). There is only one study reported parents’ physical health problems after the death of an only child, which including hypertension, heart disease, cancer, and diabetes (Wei et al., 2016).

The Chinese only-child studies found a higher risk for the parents to develop more physical and psychological health problems when the child they lose is male, older, or died by accident or suicide (Pan, Liu, Li, & Kwok, 2016). A son is the primary farm worker in a family in the underdeveloped areas of China, and the son takes the responsibility to take care of the older parents in traditional Chinese culture, especially in rural areas (Wang & Xu, 2016). Also, in Chinese culture, boys can pass down the family name to the next generation; girls cannot. Failure to pass down the family name is dishonoring to their ancestors. Parents feel more guilt when they lose a boy and end their family name (Wang & Xu, 2016). Parents whose child died from chronic illness may have psychologically prepared for the outcome. They may also be more likely to believe the child has gone to a better place and is no longer suffering (Pan et al., 2016). The parent whose child dies from an accident or suicide may feel more difficulty accepting the death because sudden death doesn’t allow parents to have any emotional preparation (Pan et al., 2016). Parents may have a stronger attachment with an older child, which makes them have more difficulty in accepting the separation from the child (Pan et al., 2016).

Some studies of parental bereavement conducted outside of China found that parents who lost an only child had more negative outcomes than parents who have surviving child(ren), such as higher cancer mortality rate and higher risk of cardiovascular disease (Barrera et al., 2009; Dias et al., Schorr et al., 2017). Studies

showed that surviving children were the major support and purpose of their life (Barrera et al., 2009). However, only a few studies of parental bereavement compared bereaved parents who lost an only child and bereaved parents who have surviving child(ren), even many studies had some participants who lost their only child (Proulx, Martinez, Carnevale, & Legault, 2016; Youngblut, Brooten, Glaze, Promise & Yoo, 2017).

According to census data, there are 14,728,000 (17.78%) families that have only one child under 18 years old in the U.S. (“U.S. families by number of children 2000-2017 | Statistic,” 2017). This number is increasing as the population increases. The mortality rate for children under age five is 6.6 per 1,000 children and for children 5-14 years old, 1.3 per 1,000 children in the U.S. (“Child Mortality Estimates,” 2018). Based on these estimates, there are more than 14,000 parents who lose their only child each year in the U.S. Research is needed to understand U.S. parents’ experiences after the death of their only child, for instance, parents’ health status and family functioning.

Framework

This study used the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1996) to provide perspective on the parents’ perceptions of the death, coping strategies, social support and outcomes following the death of an only child.

Family resilience means successful coping of families when faced with stressful events, such as the death of a parent’s only child (McCubbin & McCubbin, 1988, 1996). The stressor can weaken family functioning and family relationships or strengthen the family through protective factors (Black & Lobo, 2008).

Family resilience, or family regenerative power, describes the capacity of a family to have good outcomes and balance in their life circumstances (Patterson, 2002) and also to grow and develop (Luthar et al., 2000; McCubbin, Balling, Possin, Frierdich, & Bryne, 2002) following significant adversity or crisis.

The assumptions of the family resilience model after a stressful event are that the family will: develop basic and unique strengths, change their traditional functioning to adapt to the crisis, and benefit from social support (McCubbin & McCubbin, 1988). Families who lost their child experience grief and a high level of stress, while trying to achieve or maintain normal family functioning and life balance. The question arises as to why some bereaved families survive when facing the death of a child, while others do not. Surviving bereaved families may search for a view that would give the family meaning, purpose, and shared perspective so the family can move forward as a group. They may benefit from and contribute to the social networks in the community during the period of bereavement (McCubbin et al., 2002).

Masten and Coatsworth (1998) stated that understanding family resilience is needed to understand expected family outcomes, including risk factors and protective mechanisms. Family outcomes are indicated by whether and how they address the family's needs after the child's death (Patterson, 2002) and whether they are able to move forward and cope with stressful events and transitions as a family (Walsh, 2002). The family resilience model includes individual family members' functioning, and family is able to carry out tasks and maintain the relationships with the community (McCubbin, Balling, Possin, Frierdich, & Bryne, 2002). In other words, the outcomes of family resilience include family members' functioning, family well-being, family adaptation and

family adjustment (Lee, Lee, Kim, Park, Song & Park, 2004; McCubbin, Balling, Possin, Frierdich, & Bryne, 2002).

Family resilience is a process of interaction between risk factors and protective factors, which relate to family outcomes (Patterson, 2002). Protective factors can support families against risk factors and bereavement and recovery factors, essential for restoring effective family functioning and promoting adaptation after the crisis event (Black & Lobo, 2008; Greeff, Vansteenwegen & Herbiest, 2011; McCubbin, Baling & Possin, 2002).

Protective and recovery factors include a positive outlook, spirituality, accord among family members, flexibility, communication, financial management, time together, mutual recreational interests, routines and rituals, and social support (Black & Lobo, 2008). Positive emotions that benefit marital satisfaction include affection, humor, offering positive solutions, and accepting suggestions (Bradbury & Karney, 2004). Sharing beliefs and seeking purpose in faith can strengthen family relationships (DeFrain, 1999; Marks, 2004). Family cohesion can increase the family's ability to adjust and reorganize after a stressful event by interacting and supporting each other (Black & Lobo, 2008; McCubbin et al., 2002). Flexibility or the family's ability to rebound and reorganize can be a protective factor for families under stress (McCubbin & McCubbin, 1988). Without flexibility, the family's rules and roles are inflexible and unpredictable, making it difficult to meet the developmental needs of the family and its members (Black & Lobo, 2008). Families need clear and consistent communication, emotional openness, and collaborative problem-solving (Black & Lobo, 2008). Financial difficulties can negatively affect family well-being and relationships (Walsh, 2002). Spending family

time together can create continuity and stability (McCubbin & McCubbin, 1988). In addition, enjoyable family recreation and leisure time can increase family well-being. Clear and consistent family routines and rituals can strengthen family relationships. Community and social supports also can provide a sense of belonging and cohesion for a family (Black & Lobo, 2008).

Research Purpose and Research Questions

The purpose of this qualitative study is to understand the experiences that parents and families have after the death of an only child in the U.S. Bereaved parents and families were likely be in the adaptation phase, establishing new patterns of family functioning, acquiring new or activating old social support resources, and actively engaging in new coping and problem-solving strategies (McCubbin, Balling, Possin, Frierdich & Bryne, 2002). Phenomenology, a qualitative approach to analyze individuals' stories of their experiences for common meanings (Creswell, 2013) are used to discover these parents' perceptions of their only child's death; their family's and their own risk, resilience and functioning following the death of an only child through their statements and conversations on public and open websites. The research questions are:

1. How do parents describe their grief and their family's functioning following the death of an only child?
2. How do these parents describe their physical and psychological experiences and coping strategies?
3. How do parents' descriptions vary with the child's age/ gender, parent's age/ gender, cause of death, and time since the death?

Chapter 2

Literature Review

The death of a child is one of the most difficult and stressful events for a family. After the child's death, bereaved parents experienced multiple health problems, and changes of family functioning. The following section will describe the current studies which focused on family functioning and parent's health problems following the death of a child in multiple children families.

Family Functioning

Cacciatore, Lacasse, Lietz, and McPherson (2013) created an online forum for bereaved parents in 1997, called TEARS: Traumatic Experiences and Resiliency Study. There are 5,955 individual registrations. Of the 972 members they contacted, 503 participated in their study of parents' health status, family functioning, and resiliency. The average years since the death was 4.31 (SD=4.31); among of time ranged from 0.43 to 41.48 years after the death. The measurement tool of family functioning was Family Assessment Device (FAD). Majority of the participants were white mothers in the US. The findings showed that many families have normal family functioning. Most of the families in this study had positive family functioning and positive resilience of coping. Many of the parents engaged in support groups, counseling sessions, and other professional coping activities. The limitation of this study is that all participants are members of the online forum. It is possible that bereaved parents who have better outcomes are more likely to share their stories online. Also, the range of years since the death was large, which may affect the results because a more recent death may lead to

more negative outcomes for the parents. These might be parts of the reasons why the majority of the families in this study were functioning well.

Youngblut, Brooten, and colleagues have conducted separate studies focusing on parents' and grandparents' health and functioning after the death of an infant or child (Youngblut et al., 2013; Youngblut, Brooten, Blais, Kilgore, & Yoo, 2015). The parent study focused on the physical health, mental health and functioning of 176 mothers and 73 fathers at 1, 3, 6 and 13 months after their infant's or child's death in the NICU or PICU. Most of the parents were Hispanic or black non-Hispanic. Most of the children died after limiting treatment or withdrawing life support. The findings show 50% of the mothers and 74% of the fathers returned to work by the end of the first month. However, the majority of the parents in this study were minorities, which might not represent other communities. Their grandparents study indicated 91% of the grandparents returned to the work after the death (Youngblut et al., 2015). Grandparents who had provided childcare had more difficulties focusing on their work than grandparents who did not provide childcare. Grandparents' couple findings were not significantly different by racial/ethnic group and level of childcare.

In conclusion, the studies showed a majority of the families have normal family functioning after the child's death. Most of the bereaved parents returned to work by the end of the first month. Grandparents who provided childcare had more difficulties focusing on their work than the grandparents who did not provide childcare.

Many studies have focused on family relationships after the child's death. The relationships include parents' marital relationship, parent-healthy sibling relationship, and parent-deceased child relationship.

Child death can affect marital relationships and also parents' grief. Many studies have shown the death of a child can strengthen marital relationship through emotional sharing (Joronen, Kaunonen, & Aho, 2016). However, other studies have shown marital relationships can be disrupted by the child's death, due to different grieving strategies (Toller & Braithwaite, 2009). More positive marital relationship was related to better parent bereavement outcomes.

In studies by Alam, Barrera, D'Agostino, Nicholas, and Schneiderman (2012) and Barrera et al. (2009), most of the parents reporting a better relationship with their partners because they no longer needed to take care of the ill child and had more time to spend together. A few parents reported they were struggling in their relationships since the death. Joronen et al. (2016) conducted a study focused on satisfaction with the marital relationship after the child's death in 461 parents from the websites format of three Finnish bereavement organizations. Most of the deceased children were under 1 year old. Most of the parents lost their child less than 3 years ago. Majority of the parents were mothers; 88% had one or more living children (12% lost their only child or all their children). Most of the parents had full-time jobs, college or above education level, and were Christian. The parents were asked to score their marital relationship from 1 "very unsatisfied" to 5 "very satisfied." A majority of the parents were satisfied with their current relationship. Risk factors associated with poorer marital relationship include parents' older age, having health problems, and older age of the deceased child (>2 years old). The limitation of this study and the study by Cacciatore et al. (2013) is lack of comparison of parents on social media with parents who are not on social media. All participants of this study were from one of three organization websites' forums for

bereaved parents. Those parents might already cope well and be willing to share their stories. Also, only 12% of participants were fathers. The findings of this study might not represent fathers' satisfaction with their marital relationship after the child's death.

Many other studies stated there were problems of marital relationships following the child's death. Arnold and Gemma's study (2008) found strain in the marital relationship and reduced communication with the partner. Parents in Barrera et al.'s study stated their partner's grief was too much or too little and they didn't understand their partner's way of grieving. For instance, mothers cried more than fathers and fathers were more likely to maintain routines. Parents often did not tolerate differences in their partner's grief expression and considered divorce. Parents in the Toller and Braithwaite study (2009) stated that although they wanted to grieve together with their partner, accepting their partner's different grieving needs was necessary to keep their relationship. However, parents may need to grieve on their own. Parents have different ways in grieving. Some parents liked to talk about the deceased child; others wanted to move forward quickly with their lives without the child. Some expressed their grief by crying, others by keeping busy at work. In the early grieving process, many parents experienced conflict and believed their partners were not grieving properly, especially if the partners grieved in different ways. Eventually, most parents recognized and accepted the different grieving ways of their partners. They negotiated the differences and tried to meet the grieving needs for both. Some navigated the conflict by seeking help from outside, such as counselors and support groups. These strategies help couples maintain their marital relationship (Toller & Braithwaite, 2009).

In conclusion, studies focused on the marital relationship after the child's death found that some parents had strengthened their relationship with their spouse and others were struggling in their marital relationship (Joronen, Kaunonen, & Aho, 2016; Toller & Braithwaite, 2009). The marital relationship depends on the acceptance of differences in grief expression (Arnold & Gemma, 2008).

Grief & Bereavement

Lichtenthal et al. (2015) conducted a literature review on parental bereavement after a child's death due to cancer. The results showed bereaved parents experienced a high level of depression and anxiety, grief, existential distress, challenges to their sense of identity and meaning-making, guilt, and posttraumatic stress disorder (PTSD). The first 6 months following the death is the most stressful time period for parents (Meert et al., 2011).

Dias, Cocherty and Brandon (2017) conducted a qualitative study on parental bereavement challenges at 1 week, 6 weeks and 6 months after the death of their young child (≤ 24 months old). This study involved 10 parents of children who died from complex chronic conditions. The first theme of the findings was "life without the presence of the child." In the initial period after the death, many parents were distressed by the thought that they would never see their child again. Meanwhile, parents had to get back to their daily lives. Some parents stated they didn't want to get out of bed. They were not used to the new daily activities without child care. Some parents chose to stay busy, such as going back to work or school. Bereaved parents tried to keep the memory of their child alive by keeping the child's belongings and hanging pictures of the child on the walls in their homes. However, they were struggling between "not forgetting" and

“moving on.” The second theme is “emotional turmoil.” Bereaved parents had trouble controlling their emotions, especially in certain situations such as a family member becoming pregnant or anybody’s death. The third theme was “transformed relationship.” Some parents stated their spouse or family grieve differently. A mother mentioned her husband didn’t cry after the death. They have difficulties to emotionally support their spouses. The fourth theme was “relationship with other family member, friends, and community.” Bereaved parents tried to keep connections with other parents of a child with the same diagnosis and maintain the relationship with the healthcare providers they met when their child was alive. The connection with the healthcare professionals is a way to keep connected to their deceased child’s life for the bereaved parents.

Snaman, Kaye, Torres, Gibson and Baker (2016) conducted a qualitative study with 11 bereaved parents whose child died from cancer. The study found parental grief began on the day their child received a life-threatening prognosis; grief journey is never-ending after the death; and the character and intensity of grief changed over time. Many of the qualitative studies focused on mothers, which might be because females are more likely and willing to share their feelings. Another qualitative study by Gerrish, Neimeyer and Bailey (2014) was focused on meaning-making of 13 bereaved mothers whose child died of cancer. The average time since the death was 4.5 years (range 0.80 to 9.3 years). The average age of the deceased child was 14.8 years old (range 2 to 35 years old). Five were adult children. All 13 mothers reported adaptive changes to their self-identity. All the mothers reported changes in how they viewed themselves, other people, and the world, such as increased personal strength and changes in spiritual beliefs. Some mothers reported realizing their own-weaknesses and blaming God. All the mothers reported

developing a connection with their deceased child by visiting the cemetery, speaking to the child aloud, and sensing the child's presence. Harper, O'Connor, Dickson and O'Carroll (2011) interviewed 13 bereaved mothers in the United Kingdom. Most of the participants reported they kept physical remains of the deceased child, such as carrying the child's ashes around with them. Some mothers believed symbolisms represented their deceased child. One mother believed her son became a ladybird, because she saw a ladybird before her son's death.

Only one qualitative study focused on fathers' experiences after the death of their child (Proulx, Martinez, Carnevale, & Legault, 2016). The time since death was 1 to 6 years and the age of their deceased child was 1 to 17 years. Almost half of the fathers lost their only child. The first theme was "needing to push forward in order to avoid breakdown." Caring for other children was the motivation for fathers. Partner support was important too. Some fathers reported that understanding and respecting each other's grief is crucial. Also, keeping busy is an essential strategy. The second theme was "keeping the child present in everyday life." Many fathers mentioned spiritual connection with their deceased child, such as going to the cemetery, cleaning the tombstone, and speaking to their deceased child in their mind. All fathers enjoyed talking about the good times with the deceased child with friends, family or even strangers. The third theme was "finding meaning in their experience of grief." Some fathers enjoyed the present moment, spent more time with the family, gained empathy, and reconsidered their religious beliefs. This study didn't separate the experiences of fathers who lost their only child from those with living child(ren), even though half of the fathers lost their only child. In addition,

Brooten, Youngblut and Roche (2017) mentioned fathers demonstrated emptiness following the death of a child.

A number of quantitative studies on parental grief have been reported. Youngblut, Brooten, Glaze, Promise and Yoo (2017) conducted a longitudinal study on grief of 130 mothers and 52 fathers after their child's ICU death. Grief was measured with the 6 subscales of the Hogan Grief Reaction Checklist (HGRC): despair, panic behaviors, blame and anger, detachment, disorganization, and personal growth. Higher HGRC scores indicate greater grief or personal growth. They found that HGRC scores decreased from 3 to 6 months and from 6 to 13 months after the death. In this study, 30% of parents had lost their only child. However, the study didn't examine the grief of parents who lost an only child and that of parents with surviving children.

Wonch Hill, Cacciatore, Shreffler and Pritchard (2017) found that child death negatively affected mother's self-esteem. Infurna and Luthar (2017) reported parent's life satisfaction declined after the death of a child. Rogers, Floyd, Seltzer, Greenberg and Hong (2008) found that bereaved parents had a lower sense of purpose in life, a higher rate of marital disruption, and a higher rate of religious participation than non-bereaved parents. There were no significant differences in the prestige of their current job and job satisfaction between the bereaved and non-bereaved groups. Bolton et al. (2014) found that bereaved parents experienced a higher risk of marital disruption than non-bereaved parents. Many studies found greater substance use in bereaved than non-bereaved parents (Bolton et al., 2014; Cacciatore, Lacasse, Lietz, & McPherson, 2014). In the study by Cacciatore et al. (2014), about one-quarter of the bereaved parents reported an increase in drug and alcohol use after the death.

In conclusion, recent studies found bereaved parents experienced a higher level of grief in the first 6 months that started to improve in the third month after the death (Meert et al., 2011; Youngblut et al., 2017). The character and intensity of grief changed over time. Studies found some parents had difficulties getting back to their daily lives, chose to stay busy, had marital disruption, and increased substance use (Bolton et al., 2014; Greenberg et al., 2008; Proulx et al., 2016). Some parents were unable to control their emotions or to accept the way other family members grieved (Dias et al., 2017). Many of them experienced changes of self-identity and spiritual beliefs and a decline in life satisfaction. In addition, many parents kept their child's items, maintained their connection with the deceased child, and kept in contact with healthcare providers (Gerrish et al., 2014; Harper et al., 2011).

Physical Health

Most of the studies of parents who experience a child's death focused on mental health with fewer studies focused on parents' physical health. Most of the studies of parents' physical health after the child's death were conducted more than 10 years ago. This section will focus on the studies of parents' physical health conducted since 2008.

Brooten et al. (2018) interviewed 176 mothers and 73 fathers at 1, 3, 6 and 13 months after infant's/child's NICU/PICU death. Most of the parents were Hispanic or black non-Hispanic, high school graduates, and partnered. Most of the deceased children were male and died in PICU. In the first month after the child's death, colds/ flu, headaches, allergic reactions, and other infections were the most frequent illnesses related to the immune system; parents also reported illnesses related to stress, such as chest pain, asthma attacks, shortness of breath, weakness and fainting, gastrointestinal problems,

muscle spasms, kidney problems, and gall stones. Most of the illnesses occurred by 6 months. Very few illnesses occurred between 7 to 10 months. During 11- 13 months, the number of illnesses increased again. Mothers reported more illnesses than fathers of the same child, but with similar monthly illness patterns. During the first month after the child's death, parent hospitalizations were primarily due to anxiety and panic, chest pain, and surgery. Overall, the most frequent hospitalization reasons for both mothers and fathers were infection, chest pain, and gastrointestinal problems. Most of the hospitalizations occurred by 6 months after the death. Many parents reported medication changes, especially medication added or dose increased. This longitudinal study is the most current study which focused on parents' physical health at 1, 3, 6 and 13 months after the child's death. However, there were some limitations. Most of the participants were Hispanic or black non-Hispanic, so the findings may not apply to parents of other races/ ethnicities. Youngblut et al. (2013) showed that parents' self-rated health was lower than 5 on a 10-point scale at 13 months. Newly diagnosed chronic health conditions included angina, hypertension, arthritis, and asthma. Two mothers were diagnosed with cancer.

Cacciatore et al. (2014) conducted an online survey of 503 parents. The average age of parents was 37.7 (SD=8.8) years and the mean time since child's death was 4.3 (SD=4.3) years. Physical health status was measured by asking the parents if and how their physical health had changed since the loss. The findings indicated one-third of parents reported a decline in their health since the loss, half reported no changes, and 13% reported improvement. The most common reported physical health symptoms were weight gain and daytime fatigue. In addition, frequent illness, migraines, panic attacks,

psoriasis, heart palpitations, and hypertension were reported. Infurna et al. (2017) also found that most parents experienced declines in general health and physical functioning after the child's death compared with before the death. Bolton et al. (2014) found parents experienced an increase in the risk of hypertension at 2 years and a decrease in sleep quality after the death.

While most studies stated parent's physical health declined following the death, some other studies found it continues for a long period of time. Rogers et al. (2008) focused on the outcomes of bereaved parents a long time ($M=18.5$, $SD= 10.57$ years) after the child's death. This study measured 856 parents' physical health by asking the question, "How would you rate your health overall." The response scale ranged from 1 "very poor" to 5 "excellent." Parents also reported common physical symptoms on a checklist. Bereaved parents experienced more physical health problems than non-bereaved parents, which included cardiovascular problems such as chest pain, shortness of breath, diagnosed heart trouble, and hypertension. However, the standard deviation is quite large compared with the mean of 18.5 years and a range of 8 to 28 years.

Many studies focused on cancer morbidity of the parent after a child's death with mixed results. Bolton et al. (2014) found parents at increased risk of cancer 2 years after the death. Huang et al. (2013) noted that the morbidity of pancreatic cancer slightly increased after the first 5 years after the death of a child. Schor et al. (2016) used a population-based birth cohort to analyze the relationship between parental bereavement and mortality and cancer morbidity and survival. This study reported no relationship between the child's death and parents' cancer morbidity or survival an average of 35.6 (SD not provided) years after the death. The difference of findings from these two studies

might be explained by the different time periods after the death. Cancer morbidity increased in the first few years (Bolton et al., 2014; Huang et al., 2013) but not after a long period of time after the death (Schorr et al., 2016). In addition, Huang et al. (2013) did not mention the age of the deceased child. In Bolton et al.'s study (2014), the average age of deceased children was 27 years old and in Schorr et al.'s study (2016), majority of the deceased children were younger than 1 year old. The different ages of deceased children indicated the different level of grief and different age of parents, which might affect parents' health differently.

Fang, Fall, Sparén, Adami, Valdimarsdóttir, Lambe and Valdimarsdóttir (2011) analyzed data of 101,306 parents from Swedish Multi-Generation Register whose child died. This study focused on the relationship between parental bereavement and infection-related cancers. These cancers included the ones related to the Epstein-Barr Virus (EBV), hepatitis B/C virus, human papilloma virus (HPV), and *Helicobacter pylori*. The findings show bereaved parents had a higher risk of infection-related cancer compared with nonbereaved parents, especially cancers related to HPV infection in the first 5 years after the death.

In conclusion, most of the acute illnesses occurred by 6 months (Brooten et al., 2018). Bereaved parents reported more illnesses after the child's death, such as cold/ flu, headaches, chest pain, asthma, allergy, shortness of breath, hypertension, arthritis (Bolton et al., 2014; Brooten et al., 2018). Many of the studies reported parental physical health declined following the death (Cacciatore et al., 2014; Infurna et al., 2017). In the long-term following the death, only cardiovascular problems were significantly higher in the bereaved group than the non-bereaved group (Rogers et al., 2008). The findings of the

relationship between parental cancer morbidity and child death were mixed. The reason might be because each study focused on different time periods since the death and different types of cancer.

Mental Health

Rostila et al. (2018) studied parental use of psychotropic medication after child death in Finland. This study followed 902 bereaved parents for four years after their child's death. The findings showed the use of antidepressants and anxiolytics increased in both mothers and fathers. The first year after the death had the highest percentage of parents using these medications. The use of psychotropic medication gradually decreased after the first year, but was still higher than non-bereaved parents. The symptoms of depression decreased over the first 18 months post death (Floyd, Seltzer, Greenberg, & Song, 2013).

Devylder et al. (2013) reported a higher incidence of psychosis among bereaved parents. Jind et al. (2010) reported bereaved parents experienced a higher level of PTSD. Bolton et al. (2014) found parents experienced a higher level of depression and anxiety following a child's death from a car crash. Rogers et al. (2008) found significantly more depressive symptoms in bereaved parents than non-bereaved parents. The majority of bereaved parents who experienced depression symptoms had depressive episodes for 3 years after the death. Murphy, Shevlin and Elklit (2014) conducted a study on prenatal and postnatal loss. The Trauma Symptom Checklist, used to assess PTSD symptoms after loss of an infant, includes depression, anxiety, dissociation, sleep disturbances, somatization, interpersonal sensitivity, and aggression. The trauma symptoms were similar in both prenatal and postnatal groups. Parents who experienced prenatal loss are

more likely to experience somatic symptoms, such as eating problems, sleeping disturbances, headaches, and dizziness, than postnatal loss. Also, parents who had postnatal loss experienced a high level of interpersonal sensitivity, aggression, anger and hostility. Koyanagi et al. (2017) conducted a study on data from the World Health Survey, which focused on mothers' psychotic symptoms after their child's death in 44 low- and middle-income countries. A total of almost 60,000 women participated in the study. The measure of psychotic symptoms was the Composite International Diagnostic Interview (CIDI). The findings indicated child death was significantly associated with higher odds of depression and all types of psychosis-like experiences (PLEs), for instance, delusional mood, delusion of reference and presentation, delusion of control hallucination. Harper, O'Connor and O'Carroll (2014) reported greater avoidance and alcohol/ substance use associated with a greater depressive symptoms.

Studies have found that using of spiritual coping strategies can improve the bereaved parents' mental health and help in the grief process (Cowchock et al., 2011; Hawthorne, Youngblut, & Brooten, 2016). Burkhardt and Nagi-Jacobson (1989) defined spiritual as interconnectedness to self, others, and the environment. Parents want to keep the good memories of the deceased child, keeping pictures and possessions of the deceased child in the house. They did not believe forgetting the deceased child would relieve their grief (Thompson et al., 2011). Many parents continued to talk to the deceased child, kissing the child's picture every morning and lighting candles in the house (Barrera et al., 2009). Memories are important for them. Some parents reported they had difficulties maintaining the spiritual connection with their deceased child (Barrera et al., 2009).

In conclusion, following the child's death, parents experienced a higher level of depression, anxiety, PTSD, avoidance, somatic symptoms, interpersonal sensitivity, aggression, anger, hostility, substance use, psychotropic medication, and all types of psychosis-like symptoms (Bolton et al., 2014; Devylder et al., 2013; Harper et al., 2014; Jind et al., 2010; Koyanagi et al., 2017; Rogers et al., 2008; Rostila et al., 2018). The symptoms of depression decreased after 18 months post death (Rostila et al., 2018), but some parents had depressive episodes for 3 years (Rogers et al., 2008). Every study used a different type of measure for mental health, which makes it difficult to compare the results across studies. Last, bereaved parents have different ways to keep connection with the deceased child, which is an important coping strategy for the parents (Barrera et al., 2009).

Mortality of Bereaved Parents

Schor et al. (2016) found that death of a child modestly increased mortality of parents. The risk of mortality strongly increased in the first year after the death, with a modest increase throughout the first 9 years, and no increase afterwards. Espinosa et al. (2013) used a large, nationally representative US data source and found bereaved parents had a higher risk of mortality in the first two years after the death of a child. Rostila et al. (2012) studied parents' mortality following the death of a child in Sweden. There were 9,005 mothers and 7,833 fathers who had died after the death of a child out of 584,404 bereaved parents. The deceased child aged from 10 to 49 years old. In the first 4 years after the death of a child, the bereaved parents experienced significantly higher mortality than non-bereaved parents. After the first 4 years, there was no significant difference in mortality between bereaved parents and non-bereaved parents. However, nine or more

years after the death, the mortality of bereaved parents who lost an adult child aged 26-33 years was higher than non-bereaved parents again. This finding is consistent with findings from the Roger et al. (2008) study. Roger et al. (2008) found the morbidity of cardiovascular disease was higher in the bereaved parents' group than the non-bereaved parents' group at 18.5 years following the child's death.

The most common causes of death were coronary heart disease among bereaved mothers and circulatory disease among bereaved parents (Schorr et al., 2016). Hendrickson (2009) found bereaved parents had a higher risk of completed suicide. Zetumer et al. (2015) reported bereaved parents had a higher risk of suicide than bereaved adults who lost other relatives. Parents with a cancer diagnosis before the child's death had a higher risk of rapid demise during a short period after child loss (Schorr et al., 2016).

In conclusion, parental mortality increased in the first few years following the child's death (Espinosa et al., 2013; Rostila et al., 2012; Schor et al., 2016). After that, bereaved parents' mortality dropped to the same level as non-bereaved parents. However, 9 or more years after the death, the mortality of bereaved parents was higher than non-bereaved parents again (Rostila et al., 2012). The common causes of parental death were coronary heart disease, circulatory disease, and suicide (Hendrickson, 2009; Schorr et al., 2016; Zetumer et al., 2015).

Risk Factors Related to Parental Grief

Characteristics of the deceased child. Researchers have investigated the effects of characteristics of the deceased child, including child's age, gender, causes and places of death, and death of an only child on parent grief.

Youngblut et al. (2017) found mothers of deceased adolescents experienced a higher level of grief than mothers of younger children or infants. Meanwhile, many parents in Harper et al. (2011)'s study reported that loss of an adult child might be easier because the parents, perhaps of advanced age, won't live as long with the grief and suffering. Zetumer et al. (2015) conducted a quantitative study of 75 bereaved parents and 275 others who lost a different family member. Only 58 bereaved parents provided enough information on the age of their deceased child. There were 24 parents who lost a younger child (<25 years old) and 34 parents who lost an older child (≥ 25 years old). The results showed bereaved parents had a higher risk of complicated grief and self-blame than adults bereaved of a family member other than a child. Parents who lost a younger child had a higher risk of complicated grief and self-blame than parents who lost an older child.

Youngblut et al. (2017) found that fathers' grief did not differ by the age of the deceased child or the child's mode of death. Mothers whose child died by brain death reported greater despair, panic, blame and anger, and detachment than mothers of a child who died by failed CPR or life support withdrawal. Bolton et al. (2013) reported increased parental marital breakup and alcohol use disorders if the child committed suicide when comparing with non-bereaved parents. Lichtenthal et al. (2015) found poor outcomes in parents whose deceased child had anxiety or sleep disturbances, stem cell transplant, uncontrolled pain or a difficult death.

Parents loss of an only child may be different than those with surviving child(ren). Dias et al. (2017) reported that parents who lost their only child experienced role identity conflicts. They are still parents but without a child. One mother who lost her only child in

a study by Harper et al. (2011) said only parents who lost their only child can understand her feeling. She considered suicide to be reunited with her deceased child, but could not leave her parents alone, because she understands what it is like for the family left behind. She doesn't want her parents to experience what she is experiencing.

In conclusion, one of the factors related to the level of parent grief is the age of the deceased child, which depends on the definition of "older" and "younger." Some studies found parents who lost an adolescent or a child less than 25 years old experienced a higher level of grief; however, another study found that those who lost an adult child had a higher level of grief (Harper et al., 2011; Zetumer et al., 2015). Although the children's mean age is given, the standard deviation is often missing, making it hard to tell the distribution of children's ages. Future studies need to clearly identify the deceased child's age group. There should be a standard way to categorize adult children's ages in groups. For instance, "adult child" needs to identify as "young adult" or "middle age adult." Other factors related to higher level of grief are child died by brain death or suicide or the child experienced a difficult death or was the only child in the family.

Characteristics of parents. The characteristics of parents include parents' age, race, gender, education, income, and social economic status. Youngblut et al. (2017) found mothers had a higher level of grief than fathers of the same child, consistent with other studies (Lichtenthal et al., 2015; Wijngaards-De Meij et al., 2005). Black mothers had greater personal growth than Hispanic mothers post child death. Hispanic mothers reported more panic behaviors at 1 month and greater detachment at 6 months than White mothers and greater detachment at 6 months than Black mothers. Fathers' grief did not differ by race or ethnicity. Wijngaards-De Meij et al. (2005) showed parents with more

education had a less grief and depression following child death. More highly educated parents may be able to find and use better psychosocial supports and coping strategies (Infurna & Luthar, 2017). In addition, a study found married parents are likely to be more resilient than single parents (Infurna & Luthar, 2017).

Many studies focused on relationships between parental grief and factors before and during the death. Gerrish et al. (2014) found factors related to mothers' bereavement after they lost a child due to cancer. Positive factors included having the opportunity to prepare for the child's death and being present when the child died. Negative factors included witnessing the child's suffering from chemotherapy and/or radiation, believing the child's death could have been prevented by earlier diagnosis, and having poor social support. Woodroffe (2013) reviewed studies of factors contributing to parental grief after neonatal death. Before the death, parents may have difficulty understanding withdrawal of life support is necessary, which might increase parental grief. Some parents chose not to get too close to the baby to prevent them from forming an attachment. However, this self-protection strategy may not diminish parental grief. In addition, parents who avoiding an attachment with the child reported feeling guilty after the death of the baby (Woodroffe, 2013). In addition, parents dissatisfied with their child's medical treatment reported a higher level of grief than parents who were satisfied with their child's care (Lichtenthal et al., 2015).

Studies focused on what parents need to know at the dying moments have not been reported. Johnson, Kirchhoff and Endress (1975) found that providing preparatory message about the sensation children will feel during the cast removal reduced children's distress. Other studies also found that providing information before a procedure reduced

patients' stress (Leventhal, Brown, Shacham & Engquist, 1979; Suls & Wan, 1989). If this finding holds with bereaved parents, healthcare providers know what the child's death would be like need to inform the parents what to expect at the dying moment generally, such as peaceful death or massive bleed. Unexpected vision moment (e.g., massive bleeding) can exaggerate grief for many years (Woodroffe, 2013). Also, the future study might need to focus on what parents can do during the dying moment and immediately after the death, for instance, touching the child, singing, talking or praying.

Many studies focused on the short-term factors related to parental grief after the child's death. Woodroffe (2013) believed family death culture, religion, expected death, or palliative care program involvement can have a positive impact on parental grief. However, Youngblut et al. (2017) reported no difference whereas they expected the death, but different expectation of the type of death maybe important. If it is a sudden death, healthcare providers need to tell parents the truth gently. Post death rituals are important for grief too, such as prayer, photographs, washing, dressing, cuddling and touching the child (Woodroffe, 2013). Brooten, Youngblut, Charles, Roche, Hidalgo, and Malkawi (2016) reported parents' need for help with arrangements after their child's death, for instance, decisions of organ donation, autopsy, burial or cremation, and holding wakes. A quiet and private room may allow parents the time to process the news of their child's death. Some parents might choose to leave the hospital as soon as possible after the death. Post-death follow-up appointments in the hospital might trigger emotions and reawaken painful memories (Woodroffe, 2013). Lichtenthal et al. (2015) found parents were willing to participate in the follow-up services from the hospital at which their child was treated, but returning to the place where their child died was too emotionally difficult

for parents. Brooten, Youngblut, Hannan, Caicedo, Roche and Malkawi (2015) reported parents experienced fears and anxiety about subsequent pregnancies after infant deaths. Praying for the subsequent pregnancy can help the parents in coping. The pressure from family members to have another child can increase parents' stress.

Other studies focused on long-term factors related to parental grief following the death. Snaman et al. (2016) found parental grief might be greater and more prolonged when parents are separated from the prior healthcare community and isolated from friends and family. In addition, loss of a parents' caregiver identity and loss of financial or job security can lead to greater grief. Social support resources are helpful to bereaved parents. Lichtenthal et al. (2015) identified poor outcomes related to social network isolation. Better outcomes were related to keeping connections with healthcare providers, feeling connections with the deceased child, and/or being involved in follow-up or formal intervention programs. Harper et al. (2015) found that parents who have higher continuing bonds scores with the deceased child and less frequent visits to the child's grave had poorer grief outcomes in their older age. However, other studies have reported stronger continuing bonds with the deceased child lead to better outcomes (Foster et al., 2011; Seigal, 2017). Harper et al. (2015) noted that the Continuing Bonds Scale they used was developed for bereaved partners, which might be different than of continuing bonds which are typical for bereaved parents. Stroebe et al. (2013) conducted a longitudinal study on the relationship between partner oriented self-regulation and grief. The findings showed parents' avoidance of talking about the death and trying to remain strong can increase their level of grief and their partner's grief. Parents experienced more grief when they and their partner had more Partner Oriented Self-Regulation (POSR). POSR also

lead to misunderstanding of partners' grief. Some parents reported their partner did not grieve as much as they are, because the partner did not show signs of grief. The findings also showed parents who expressed more concern for their partners experienced more grief themselves. Infurna et al. (2017) reported parents' resilience declined following the death of a child. The factors related to resilient were connections with social networks, everyday role functioning and anticipation of support when distressed.

It is not known whether loss of an only child leads to greater grief. Rogers et al. (2008) found that having additional children in the family was associated with resilience or recovery from grief and marital disruption.

In conclusion, the factors related to greater parental grief are being female, Hispanic, younger, low education level, and unmarried. Witnessing the child's suffering, unexpected vision moment at death, dissatisfaction with the treatment, and disarrangement of post death rituals can exaggerate grief (Gerrish et al., 2014; Infurna & Luthar, 2017; Lichtenthal et al., 2015; Wijngaards-De Meij et al., 2005; Woodroffe, 2013; Youngblut et al., 2017). Also, isolation, financial difficulties, great concern about the partner, and loss of an only child are other factors related to higher levels of grief (Roger et al., 2008; Snaman et al., 2016; Stroebe et al., 2013). Majority of the studies had consistent findings, except Woodroff (2013) found that expecting the death was related to lower parental grief, but Youngblut et al. (2017) found no relationship between expected death and parental grief. Harper et al. (2015) reported continuing bonds were related to greater grief, but Foster et al. (2011) and Seigal et al. (2017) reported continuing bonds were related to less grief. These conflicting findings might be due to differences in the age of the deceased child, time since the death and sample size in each study. Woodroff

et al. (2013) only focused on neonates, while Youngblut et al. (2017) focused on children 18 years old and younger; Harper et al. (2015) included deceased child age between 0 to 30 years old, while Foster et al. (2011) did not mention the age range and Seigal et al. (2017) only included a few case analyses.

Risk Factors Related to Physical Health

Many studies focused on parent and deceased child factors that might be related to parent health, such as race, age of the child, child died by suicide, expected death, lost the only child, and social support.

Brooten et al. (2018) found mothers and fathers in white non-Hispanic, black non-Hispanic and Hispanic groups had similar physical health outcomes, including illnesses. Youngblut et al. (2013) found that black mothers reported better self-rated health than Hispanic mothers at 1 and 6 months. Hispanic fathers reported better self-rated health than white fathers at 1 month after the child's death.

Time since death and age of the deceased child also can affect parental physical health. Most illnesses and hospitalizations occurred in the first month after their child's death (Brooten et al., 2018). Huang et al. (2013) found increased morbidity of pancreatic cancer among mothers during the first 5 years after their child committed suicide.

Mothers of deceased adolescent had more chronic conditions (Youngblut et al., 2013).

Many studies focused on parent health after child suicide. Wilcox, Mittendorfer-Rutz, Kjeldgård, Alexanderson and Runeson (2015) studied 1,051,515 parents' sickness absences after an older adolescent and young adult child (16-24 years old) committed suicide in Sweden. Parents of a child who died by suicide had a higher risk of physical sickness absence of work exceeding 30 days. Bolton (2013) found a significant increase

in the number of cancer and diabetes diagnoses for parents whose child died by suicide. Parents after a child's suicide had higher rates of cardiovascular disease, chronic obstructive pulmonary disease, hypertension, diabetes, outpatient physician visits for mental and physical illness, and hospitalizations for physical illness than bereaved parents whose child died as a result of a motor vehicle crash.

Death of an only child is another important factor in parents' health. The cancer survival rate was lower for parents whose only child died (Schorr et al., 2016), suggesting grief might be different for smaller and larger families. The smaller family might lack sufficient social support, which lead to poorer grief outcomes after the death of a child (Schorr et al., 2016). Death of an only child can lead to a higher level of parent grief, which might result in poorer health. Rogers (2008) reported parents who have more purposeful life and surviving child(ren) after the death of a child indicated fewer cardiovascular problems.

Other factors also can affect parents' health after the death of a child. Mothers who expected the death developed fewer chronic conditions (Youngblut et al., 2013). Schor et al. (2016) reported parental greater cancer mortality was associated with low socio-economic status. There was no difference of parents' cancer morbidity if the deceased was an only child or had surviving siblings (Huang, Valdimarsdóttir, Fall, Ye, & Fang, 2013).

In conclusion, research findings identified factors related to poorer parental physical health as being black, a recent death, older child, died by suicide, lost an only child, unexpected death, and low socio-economic status (Brooten et al., 2018; Huang et al., 2013; Rogers, 2008; Schorr et al., 2016; Wilcox, 2015; Youngblut et al., 2013).

Risk Factors Related to Mental Health

Bereaved parents' mental health can be affected by both parent and child characteristics. Mothers have a higher percentage of psychotropic medication use and a higher level of depressive symptoms than fathers (Murphy, Shevlin, & Elklit, 2014; Rostila & Ma, 2018). Cacciatore et al. (2016) conducted a study on the relationship between poverty and psychological distress in 503 bereaved mothers using the Hopkins Symptom Checklist (HSCL-25) to measure both anxiety and depression. The findings showed mothers' greater psychological distress (anxiety, depression, posttraumatic stress symptoms) was associated with lower education and income. Poverty was the strongest predictor of psychological distress. Low income bereaved mothers might have fewer resources to help them with self-care practices, such as eating well, taking time to rest and grieve, and seeking practical help from friends, family and employers. Another study found only financial difficulties to be related to depression symptoms (Harper et al., 2014).

Causes of death significantly influenced parental use of psychotropic medication. Parents whose child died from external reasons (i.e. suicide, homicide or traumatic injuries) had a higher percentage of medication use than parents whose child died from disease (Rostila & Ma, 2018). However, this study didn't state whether the disease was acute or chronic, and didn't clarify the types of diseases. Cacciatore et al. (2016) found higher levels of parent depression after a child's violent death. Wilcox et al. (2015) found a high risk of sickness absence exceeding 30 days due to psychiatric diagnosis among parents whose child died by suicide and traumatic injuries. Risk did not differ between mothers and fathers. Parents' psychiatric impairment after child death did not differ

between suicide or traumatic injury as cause of the child's death. Another study focused on 175 bereaved older parents, mostly in their 50s and 60s, who lost their adult child (Floyd et al., 2013). The average age of the deceased adult children was 34.3 years old. Mothers whose child died of a long-term illness and fathers whose child committed suicide had the highest levels of depression on the Center for Epidemiological Studies Depression Scale (CES-D). Parents with children who died unexpectedly from traumatic injuries or sudden illnesses had a higher level of depression than parents who expected their child's death. Ljung, Sandin, Långström, Runeson, Lichtenstein and Larsson (2014) reported that parents whose child died by suicide had a greater risk of subsequent psychiatric hospitalization. Bolton et al. (2013) showed a significant increase in depression, anxiety, and other mental disorders in parents whose child committed suicide. Also, bereaved parents in the suicide group had a higher level of depression before the death than those in the motor vehicle crash group. The parents in the suicide group were more likely to have lower income and be single.

Rostila and Ma (2018) found a higher percentage of antipsychotic medication use among bereaved parents of a deceased child younger than 15 years old than by parents of a deceased child older than 15 years old. However, Zetumer et al. (2015) reported no significant differences in depression between parents who lost a younger child (<25 years old) and parents who lost an older child (≥ 25 years old). Zetumer defined less than 25 years old as a younger child, which is different than in Rostila and Ma's study. This may explain the conflicting results of the two studies. Cacciatore et al. (2016) found the older age of deceased child and shorter time since the death were related to the mother's greater psychological distress. Floyd et al. (2013) reported that younger parents had a

higher level of depression than older parents. Floyd et al. suggest that losing an adult child might result in fewer disruptions for older parents. For instance, work functioning might be less disrupted if the older parents have retired; older children were not living at home, out on their own and self-sufficient; younger parents have a higher risk of divorce and older parents might have more coping strategies (Floyd et al., 2013). The average age of parents in Floyd's et al. study (2013) was 54 years in the 1994 dataset and 65 years old in the 2004 dataset. However, the authors didn't identify what is "earlier life course" and "older age." Murphy et al. (2014) also found older parents experienced fewer depressive symptoms than younger parents. The authors only stated the mean age of parents was 32.6 (SD=5.1), but did not clarify ages of older and younger parents.

Koyanagi et al. (2017) reported only recent child death (less than 12 months) was associated with higher level of depression, but the number of child(ren) who died (lost one child vs. lost two or more children), time from last child death, and child age at death were not significantly associated with parental depression. Christiansen, Elklit and Olf (2013) focused on chronic PTSD in 634 bereaved parents up to 18 years after the death of their infant and found that PTSD was not significantly related to the age of the deceased child (age ranged 0-11 months), but was more common in mothers than fathers and was related to attachment avoidance, attachment anxiety, emotion-focus coping, rational coping, feeling let down, social support satisfaction and the time since death. Parents with a more recent loss had higher levels of PTSD symptoms. Last, PTSD was not significantly different by the timing of death (prenatal, perinatal and postnatal). Jind et al. (2010) reported the expectation of death and place of death were not associated with PTSD. Mothers were more likely to have greater PTSD than fathers. Rogers et al. (2008)

reported that fathers and parents having a purpose in life had less severe depressive symptoms. Having additional children in the family was associated with resilience or recovery from depressive symptoms, grief, and marital disruption. The causes of death and time since the death were not associated with depressive symptoms.

Cacciatore et al. (2014) reported 15% of the bereaved parents were diagnosed with depressive and anxiety disorders in the first month following the death. A few parents were diagnosed with attention-deficit hyperactivity disorder or bipolar disorder. Some of the parents' mental disorders were diagnosed before the child's death. Ljung et al. (2014) recommended considering genetic factors also.

In conclusion, the parental factors related to poorer outcomes of parents' mental health were being female, lower education, lower income, younger age, poor coping, less purpose of life, and previously diagnosed mental illness (Cacciatore et al., 2016; Harper et al., 2014; Murphy, Shevlin, & Elklit, 2014; Rostila & Ma, 2018). The deceased child's factors related to poorer parents' outcomes are younger child, only child, recent death, died by violence/ suicide and long-term illness (Bolton et al., 2013; Cacciatore et al., 2016; Floyd et al., 2013; Koyanagi et al., 2017; Ljung et al., 2014; Rostila & Ma, 2018). As mentioned before, these studies did not analyze and discuss the death of an only child separately.

Risk Factors Related to Parental Death

Schor et al. (2016) reported mothers have greater mortality associated with bereavement than fathers. In addition, higher mortality was related to lower education level, lower social status, and being Black or white non-Hispanic women (Espinosa & Evans, 2013).

Parents who lost their only child have a greater risk of mortality. Parents with three or more children tend to have the lowest mortality rate among bereaved parents (Espinosa & Evans, 2013; Schorr et al., 2016). Gerrish et al. (2014) reported the mothers who lost their only child experienced the highest proportion of complicated grief responses and many were admitted into a psychiatric facility due to high suicide intent. Schor et al. (2016) also found that parents in a lower socioeconomic status had a lower risk of mortality. This finding may be related to lower socioeconomic status often having bigger families which can provide more social support and other resources. Harper et al. (2011) found that many parents had an ambivalent attitude when talking about their own death. Many parents reported suicidal ideation, but none attempted. These parents said they did not attempt suicide because of their other children. Some mothers reported they might attempt suicide when their surviving child(ren) reach adulthood. As noted earlier, the mother who lost her only child did not attempt suicide, because she did not want her parents to experience bereavement as she did (Harper et al., 2011). Espinosa and Evans reported no relationship between mothers' mortality and the number of children in the family (Espinosa & Evans, 2013). However, all the parents had at least 1 surviving child in this study, which might influence their results. The death of an only child can result in more negative outcomes of bereaved parents (Gerrish et al., 2014; Schorr et al., 2016).

Except loss of an only child, there were some other factors related to parent death, which included age of parents and age of the deceased child. Espinosa and Evans (2013) followed 474 bereaved mothers for 9 years and found the death of a child increased mortality of younger mothers (20-34 years old) more than older mothers (35-50 years old). Rostila et al. (2012) found parents who lost a younger child (10-17 years old) had

higher mortality. Zetumer et al. (2015) also reported that -parents who lost a child younger than 25 years old had a higher risk of suicide than parents who lost a child whose age was 25 or greater. Rostila et al. (2012) found mothers of a younger child (10-17 years old) had 31% increase in mortality, regardless of cause. However, Espinosa and Evans (2013) reported mothers' mortality was not related to the age of the deceased child.

Cause of the child's death was another factor related to parents' mortality. Mothers of children who died at age 10-17 years old from homicide, suicide, criminal activity, drug problems, alcohol abuse or depression had the highest risk of mortality (Rostila, Saarela, & Kawachi, 2012). However, Espinosa and Evans (2013) found no relationship between mothers' mortality and the child's cause of death.

Mothers' mortality had no relationship with the mother's marital status or the gender of the deceased child (Espinosa & Evans, 2013; Werthmann, Smits, & Li, 2010). Werthmann's study was conducted in Denmark, which might be different than in China. In Chinese culture, boys can pass down the family name, continuing their family tree (Zheng, Lawson, & Head, 2017). Many studies have found parents who lost their only son had higher levels of physical and psychological health problems than those who lost their only daughter (Wang & Xu, 2016). It is essential to compare bereaved Asian parents with bereaved parents of other racial/ ethnic groups to investigate cultural differences of the effect of the deceased child's gender on parent mortality.

In conclusion, the parent factors related to parent mortality after the child's death are being female, lower education, lower SES, and being black or white non-Hispanic, and younger (Espinosa & Evans, 2013; Schor et al., 2016). The deceased child's factors

are only child, younger child and child died unnaturally (Espinosa & Evans, 2013; Rostila et al., 2012; Schor et al., 2016). The research gap is the cause and frequency of parent death after the death of an only child.

Death of an Only Child

As indicated previously, death of an only child is one of the risk factors related to some poorer parental outcomes than death of a child in multiple children family, such as higher cancer mortality rate and higher risk of cardiovascular disease. The following section will review the findings about the only child's death and the studies conducted in China under the only child policy.

Following an only child's death, mothers experienced difficulties of being a childless mother. In Harper et al. (2011)'s study, one mother who lost her only child reported she needed to continue to care for her daughter because she was unable to be a childless mother. The only way to keep her maternal role was by visiting and cleaning the grave every day. Alam et al.'s study (2012) found that focusing on healthy siblings is an important coping strategy for mothers. Many parents said the surviving children were the major support and purpose of their lives (Barrera et al., 2009). Parents who lost their only child may feel like having lost their parenting role and purpose of their lives. Some studies had parents who lost their only child, but didn't analyze these parents separately with the parents who lost a child in the multiple children family (Proulx et al., 2016; Youngblut et al., 2017).

Some studies find that death of an only child has more negative effects on marital relationship, which might lead to divorce (Pan, Liu, Li, & Kwok, 2016; Wei et al., 2016; Zheng & Lawson, 2015). However, Joronen et al. (2016) found that parents with no

living children were more satisfied with their marital relationship was surprising and in conflict with the previous studies. Joronen et al. (2016) suggested that couples can spend more time with each other and on their relationship because there is no living child. Last, the findings indicated that parents with one or more living child had a worse marital relationship. However, the ages of those parents were not provided. Parents of childbearing age may be able to have another child, decreasing or eliminating their worry about being childless parents. Parents who are no longer of childbearing age don't have the chance to have a new pregnancy. As Zheng, Lawson, Head and Anderson's studies (2017) showed, Chinese parents who lost the only child and couldn't have another child experienced many difficulties, including divorce. Perhaps this is related to fathers wanting to have another child. In addition, Keim et al.'s study (2017) showed most of the mothers who had another child after an infant's death reported fewer symptoms of grief than the mothers who didn't have a new pregnancy.

There were only a few studies conducted in China under the only child policy, which focused on the death of an only child. Pan et al. (2016) examined the relationship between posttraumatic growth and different factors in 201 bereaved parents age range from 49-80 years old who have lost their only child in China. On average, participants had lost their only child 9 years ($SD=6.26$) earlier. The mean age at death of children was 25 years old ($SD=9.01$). Face to face interviews were conducted in their homes. The measurement of PTSD was Posttraumatic Growth Inventory (PTGI) assessment tool, which is highly correlated with PTSD. The data were analyzed with multiple linear regression. The findings indicated the older the child died, the more PTSD symptoms the parent experienced; parents whose children died by accident or suicide had more PTSD

symptoms than those who died of illness; parents who had lower education and poor health were associated with more PTSD symptoms; the parents who had more community support were associated with less PTSD symptoms. The limitation of this study are data were collected in only one city, which limited the generalizability of the results in other parts of China. Also, the Pan and colleagues think qualitative studies would be helpful for obtaining deeper understanding of this population.

In their cross-sectional study, Cao et al. (2013) examined family functioning of bereaved parents after death of their only child in an earthquake in Sichuan, China in 2008. The earthquake resulted in 5335 children dead or missing. Cao et al.'s study included 83 fathers and 107 mothers at 18 months after the 2008 earthquake in Sichuan province. The average age of these parents was 40.5 (SD=7.20). The properties of more than half of the parents had severe damage during the earthquake; only 18.4% of the parents had another child after the earthquake. Family functioning was measured with the Family APGAR Index. The APGAR Index includes five components: adaptation, partnership, growth, affection and resolution. Depression was measured by Hamilton Depression Rating Scale-17 (HDRS-17). A majority of the families reported individual dysfunction, negative family functioning, and parent depression. Family functioning was a strong predictor of parents' depression, which was associated with parents' being female and divorced or widowed, not having a new pregnancy, above 40 years old, and witnessing the child's death during the earthquake. This study had adequate sample size and significant findings.

Wang and Xu (2016) conducted another study after the Sichuan earthquake to focus on parental PTSD following the death of an only child. There were 176 parents

from heavily damaged counties and 148 parents from moderately damaged counties. Almost half of the participants were fathers (47.7%). Most of the parents were at their 50s ($M=54.60$, $SD=4.75$). All the deceased children were above 18 years old, and most of them were between 18-27 years old. More than half of the deceased children were boys. The data were collected in 2014, which is 6 years after the earthquake. None of the parents had a subsequent child since the study. The PTSD symptoms was measured by PTSD Check-List-Civilian Version (PCL-C), which included 17 psychosocial health problems, such as disturbing memories, loss of interest in things, feeling emotionally numb and difficulty concentrating. Social support was measured by Social Support Rating Scale (SSRS). Protective resilience factors were measured by Resilience Scale for Adults (RSA). The findings shown the parents from heavily damaged counties experienced more PTSD symptoms than parents from moderately damaged counties. There was no significant difference of PTSD between genders. Risk factors related to more PTSD symptoms included losing a child younger than 27 years old, losing a male child, living in the countryside, receiving less social support, and having low income, a low level of education and low resilience. In Chinese culture, boys can pass down the family name to the next generation; girls cannot. Failure to pass down the family name is dishonoring to their ancestors. Parents feel more guilt when they lose a boy and end their family name (Wang & Xu, 2016). Also, in some rural area, adult boys are the main farm workers for each family. Losing a male child means no one can help the parents to work in the farm, which would lead to financial difficulties in the future (Wang & Xu, 2016). In addition, in Chinese culture, it is important for both parents to maintain their family

tree (Wang & Xu, 2016). Therefore, there was no significant difference of PTSD symptoms between mothers and fathers.

Song (2014) conducted a case analysis of 12 cases from Chinese social media. The age of the deceased child ranged from 14 to 38 years. The time since death ranged from 4 to 10 years. Parents worried that nobody would take care of them when they are sick, no nursing home would accept them, and no one would be by their side when they are dying. Most of the nursing homes require adult child's signature in China. Many parents experienced depression, post-traumatic stress disorder, hypertension and abuse alcohol. Some of them considered suicide. One mother attempted suicide but did not succeed. They tried to isolate themselves from their friends, relatives and neighbors. Some of them moved to a place where nobody knew them. Parents who lost their only child in China is a sign of bad luck, because the parents did some evil things, which caused their only child's death. The parents who lost their only child had difficulty being accepted by their community, leading to lack of social support. Divorce is another problem following the death of an only child. The main reason is because the couples lost goals and meanings of their life. One couple in the study stated they did not talk to each other over a year after their only child's death. One mother in the study said her husband wanted to remarry with a younger woman to have another child. Many parents had at least one abortion when their only child was young, because of the Chinese only child policy. Following the death of their only child, the history of abortion added additional guilt and regret to the bereaved parents. Some parents spent too much money on their only child's education, which causes them having no saving, and the amount of federal subsidy is only about \$22-\$100 per person per month for a family who lost their only child (depends on the

locations and the age of parents or age of the deceased child), which is much less than the local minimum living cost. Some parents needed surgery to cure a disease, but they could not afford it.

The second qualitative study was conducted by Zheng and Lawson (2015). This study interviewed 12 bereaved mothers and 2 bereaved fathers who lost their only child in China. Their age ranged from 51-63. The time since the death ranged from 2-12 years. The findings were similar to Song (2014), which included: 1) personal identity changed. They used to be parents with a child, but now they called themselves “Shiduers”, which is a Chinese word means parents lost their only child. Without the only child, the family relationship changed, and the family lost its wholeness. One mother said “without our child, the connection between me and my husband was gone. We ate and slept separately. He didn’t bring home his salary anymore, and he told me he used to do this for the family and now there was no family for us”; 2) Social identity changed. Bereaved parents are isolated from their previous social network, because they do not want to listen to others talk about their living child. One mother who stated “I never wanted to be around my old social life after my child’s death. What do those who are my age talk about? Children, it’s always children. What could I say when I was there?”. Also, people do not want to talk to the bereaved parents because they are an unlucky person. As mentioned before, in Chinese culture, people without a child is unlucky person. People do not want these bereaved parents to attend a wedding or birthday party, because they are unlucky. Bereaved parents only keep contact with another bereaved parents who lost their only child. Peer support is very important for them.

Wei et al. (2016) did a quantitative study to compare well-being of parents who lost their only child with parents who did not have such a loss. There were 194 bereaved parents and 367 non-bereaved parents involved in the study. The findings indicated bereaved parents are more vulnerable and younger, and have lower education, lower income, and chronic disease, which indicated lower well-being. Zheng et al. (2017)'s study also compared bereaved parents and non-bereaved parents (age ranged 50-55 years). The measurements were Instrumental Activities of Daily Living Scale (IADL), Geriatric Depression Scale (GDS), Inventory of Complicated Grief (ICG) and Lubben Social Network Scale (LSNS). The findings indicated bereaved parents have less independence in daily living, higher level of depression, more complicated grief, smaller social networks or fewer social supports than non-bereaved parents. Bereaved mothers have a higher level of complicated grief, higher level of depression, and smaller social support network than fathers. The limitation of Wei et al. (2016)'s and Zheng et al. (2017)'s studies is bereaved parents and non-bereaved parents may not be comparable in other ways.

In conclusion, the death of an only child is related to family dysfunction and parents' physical and mental health problems, changed personal and social identity, and greater anxiety about their life in the older age. Studies in the U.S. have not focused on the death of an only child in the last 20 years. Only a few studies conducted in China under the only child policy. And only two qualitative studies (Song, 2014; Zheng & Lawson, 2015). This study is the first study which focus on the death of an only child in the U.S.

Conclusion

The death of a child is one of the most difficult and stressful events for a family. Following the child's death, parent and family functioning have negative outcomes (Cao et al., 2013); family relationships can be strengthened or disrupted (Joronen, Kaunonen, & Aho, 2016; Toller & Braithwaite, 2009); parents experienced a higher level of grief, morbidity, PTSD, depression, anxiety, somatic symptoms, alcohol/ substance use, and mortality after their child's death (Meert et al., 2011; Youngblut et al., 2017).

Parent and deceased child factors related to parents experiencing greater grief, higher level of depression and anxiety, more problems of physical and mental health following the child's death. Mothers experienced more physical and mental health problems than fathers after the child's death (Murphy, Shevlin, & Elklit, 2014; Rostila & Ma, 2018; Youngblut et al., 2017). Hispanic mothers reported greater panic than mothers from other ethnic groups (Brooten et al., 2018). Younger parents, unmarried single parents and parents with less education experience greater grief and more physical health problems (Infurna & Luthar, 2017; Wijngaards-De Meij et al., 2005). Also, parents with low socio-economic status and low income experience a lower level of physical health and greater grief (Bolton et al., 2013; Cacciatore et al., 2016; Schor et al., 2016).

Witnessing the child's suffering, unexpected child death and dissatisfaction with the child's treatment often increases parents' grief reaction (Gerrish et al., 2014; Lichtenthal et al., 2015; Woodroffe, 2013; Youngblut et al., 2013; Youngblut et al., 2017). Following the child's death, lack of support for the post death rituals, isolation, financial difficulties and poor coping strategies lead to poorer outcomes for parents (Brooten et al., 2016; Harper et al., 2014; Infurna & Luthar, 2017; Lichtenthal et al., 2015; Snaman et al., 2016;

Youngblut et al., 2017). Factors of the deceased child related to poorer parent outcomes include age of child, only child, recent death and/ or difficult death, and died by brain death, suicide, violence, unintentional injury, and long-term illness (Bolton et al., 2013; Cacciatore et al., 2016; Dias et al., 2017; Floyd et al., 2013; Harper et al., 2011; Huang et al., 2013; Li et al., 2004; Parrish et al., 2017; Schorr et al., 2016; Youngblut et al., 2017; Zetumer et al., 2015). It is essential to know the high risk factors related to poorer parent outcomes to be able to intervene with the parents' bereavement, physical and mental health, and mortality after the death of a child.

Many studies had conflicting findings of child's age related to parent outcomes (Floyd et al., 2013; Harper et al., 2011; Youngblut et al., 2017; Zetumer et al., 2015). The main reason is that there is no standard definition of "younger child" or "older child." Most of the studies identified children as older or younger in relation to the other participants in the study. Future studies need to identify the child's age in a standard way, such as newborn, infant, toddlers, school age, adolescent, young adult and middle age adult.

Following the death of an only child, parents had difficulties of being childless parents and needing to maintain their parental role (Dias et al., 2017; Harper et al., 2011; Zheng & Lawson, 2015). Family functioning declined after the only child's death (Cao et al., 2013). Marital relationship might be weakened, because parents lost the goal of their life and father want to have another baby with a younger woman (Song, 2014). Childless parents worried that no one would take care of them when they are old, sick, and dying (Song, 2014). In China, without the sponsor of adult child, it is difficult for childless parents to be accepted by any nursing home (Song, 2014). In addition, financial

difficulties added more stress (Song, 2014). Isolation is another problem for the parents who lost their only child in China, because they do not want contact with people who have a child, and the social identity label bereaved parents as an unlucky people (Song, 2014). Peer support is very important, because bereaved parents only want to get together with other bereaved parents who lost their only child (Zheng & Lawson, 2015). Parents who lost their only child have a greater risk of mortality and higher level of grief than parents lost a child in multiple children families (Espinosa et al., 2013; Gerrish et al., 2014; Schorr et al., 2016). In addition, the cancer survival rate was lower for parents whose only child died (Schorr et al., 2016). Some parents experienced suicidal ideation and attempts following the death of an only child (Song, 2014).

The risk factors related to parents' poorer outcomes following the death of an only child are similar to the child's death in a multiple children family, which included deceased child died by accident or suicide, parents had low education and poor health status, lack of social support and more recent death (Pan et al., 2016; Wang & Xu, 2016). However, in the multiple children family, younger bereaved parents experienced greater grief than older parents (Murphy et al., 2014), while in the only child family, bereaved parents above 40 years old experienced greater grief than younger parents (Cao et al., 2013). The reason is because older parents have less chance to have subsequent pregnancy, which means they will be childless parents in the rest of their life. The younger parents have more chances to have another baby(ies), which can help parents cope (Brooten et al., 2015). In addition, losing an only boy lead to more PTSD symptoms than losing an only girl in China (Wang & Xu, 2016), because boys can pass down the family name, which is very important for parents.

This study is innovative because there is no study on parent's experience following the death of an only child in the U.S. in the last 20 years. To understand parents' experiences after the death of an only child in the U.S., a qualitative study is needed. This qualitative study described bereaved parents' experiences following the death of an only child in the U.S. by using online content analysis method. The knowledge of this study can help the researchers and clinical providers understand the parents' difficulties after they lost their only child, which are different from a child's death in families with multiple children. This knowledge is important for health professionals and social workers to prevent parents' poor outcomes after the death of an only child. In addition, this study is the background research to inform future studies.

Chapter 3

Design and Methods

Research Design

The purpose of this qualitative study is to understand the experiences that parents and families have after the death of an only child in the U.S. The research questions are: How do parents describe their grief and their family's functioning following the death of an only child? How do these parents describe their physical and psychological experiences and coping strategies? How do parents' descriptions vary with the child's age/ gender, parent's age/ gender, cause of death, and time since the death? This study used the phenomenological qualitative approach which analyzes the stories of experiences of individuals to describe the common meaning for the group of people (Creswell, 2013).

This study is one of the first to use conventional content analysis approach to understand the online stories posted by bereaved parents. More and more people share personal narratives on the Internet (Mazanderani & Powell, 2013; Morison, Gibson, Wigginton, & Crabb, 2015). Using research methodology to understand online posted content has increased (Barratt & Maddox, 2016; Pink, Horst, Postill, Hjorth, Lewis & Tacchi, 2016; Wilson, Kenny & Dickson-Swift, 2015). Conducting a qualitative research study using internet data collection is a feasible and cost-effective approach. The data for a longitudinal study can be collected from the existing online content by following bereaved parents' posts over time. This data provided a picture of how bereaved parents felt and what they did at specific times after the death that can be identified and gathered in a short period of time with minimal effect of recall on the health. Changes that parents

described over a period of 1 to 10 years can be gathered from the internet over several months, rather than following bereaved parents prospectively over a period of 10 years (Hokby et al., 2016). Blogs provide qualitative data already in electronic format. There is no need to record and transcribe from a voice record or synchronization of time between researcher and participants (Jones & Alony, 2008). Writing a blog is self-motivated, which might better reflect parents' valuable insight than in-person interviews (Jones & Alony, 2008). Internet content is not influenced by the researcher's presence and is free from the interaction bias (Hawthorne Effect) that can occur when participants know they are being studied (Bryman & Bell, 2016; Hookway, 2008; McKee, 2013). Through analyzing the internet content, qualitative researchers can get the first insight of individual behaviors and experiences. It is a good way to explore new knowledge about subjective experiences, which might not be asked during the interview (Seale, Charteris-Black, MacFarlane & McPherson, 2010). Some hard to reach groups and sensitive topics (e.g., health conditions, politics and religions) are more likely to be reached through the internet (Mazanderani & Powell, 2013; Morison et al., 2015). In addition, using the internet content that the parents have posted avoids retraumatizing them by asking them questions and recalling difficult experiences during an interview (Stevens, Lord, Proctor, Nagy, & O'Riordan, 2010), which might trigger a panic attack in bereaved parents.

This qualitative study analyzed parents' personal narratives following the death of an only child, using conventional content analysis for themes and subthemes. The NVivo 11 software was used to assist with and support the analysis process. The researcher always maintains control of the analysis process. The themes and subthemes described parents' experiences following the death of their only child.

Setting

This study used public internet search engines, including Google[®], Yahoo[®], Bing[®] and DuckDuckGo[®]. The data are public and no password, membership, or reading permission is needed. Data were collected from blogs and forums. Data in Facebook was not included because it is a content host website which requires a user account, and most of the Facebook groups require permission to join. The accessible information might be limited on Facebook. The majority of the parents in this study are mothers because women are more likely to share their feelings than men. Most studies of parents' bereavement are of mothers. Race and ethnicity were unknown. Although many parents did not mention their age in their profile pages, some mentioned their age when the child died. Based on the time since the death, it was possible to calculate how old the parents were when they wrote the blogs.

Sample

The sample included 30 parents who lost their only child. Sample size was based on the number needed to reach data saturation. In qualitative studies, sample size is determined by occurrence of data saturation. Other studies of bereaved parents have reported data saturation with about 30 participants or less (Brooten, Youngblut, & Roche, 2017; Cipolletta, Marchesin, & Benini, 2015; Mäkelä, Axelin, Feeley, & Niela-Vilén, 2018;). Inclusion criteria for the study were: parents who lost an only child or all of their children in the U.S and whose posts are in English. There was no limitation of the parent's gender, deceased child's age, child's gender, the years since the child's death or whether the parents have a subsequent pregnancy. About half of the sample included bereaved parents of deceased boys and 13% of fathers. The age of the deceased child

ranged from newborn to 30+ years old, which is the youngest and oldest age found. The time since the death ranged from a couple of months to decades, depending on when the parent chose to post their comments, independent of this project. The causes of death included acute and chronic illnesses, suicide, drug overdose and traumatic injury. The exclusion criteria included parents who have surviving children, blogs written about someone else's story, and the writings are hard to understand (e.g., poem). Parents who did not provide any background information (location and age) were included as long as their writing was in English. This study did not need to consider retention strategies because all of the data consisted of existing stories/posts on public websites.

Procedures

Following IRB approval from Florida International University, the PI generated searches on Google, Yahoo, Bing and DuckDuckGo, using keywords found in the literature, such as "death of an only child." DuckDuckGo is a search engine that does not optimize the results based on searching history (Kurtz et al., 2017), which may find more results. Words noted frequently in the blogs/posts were added to the keywords for additional searches in Google, Yahoo, Bing and DuckDuckGo, such as "lost only child."

While collecting the posts/blogs, the PI went through each users' profile to identify their background information as much as possible, including parent gender, age, race/ ethnicity and location; deceased child gender, age, cause of death, and time since the death. Gender of the parents and deceased children were expected to be readily available, but parent age was hard to establish (Kurtz et al., 2017). Blogs or posts by users' accounts that meet the inclusion criteria were included, looking at the posting history for each user and downloading all their posts which relate to the death of their

only child. In addition, more users can be found from the comments of the posts. The sample size is based on the number needed to reach data saturation. Initial searching stopped when the PI started to read the same information again and again, which is about 30 parents.

The measures in this qualitative study included parents' age/ gender, deceased child's age/ gender, causes of death and time since death. Based on the study of Kurtz et al. (2017), parents' ages were hard to find, resulting in missing data. The information of the child's age, child's gender, parents' gender, causes of the death and time since the death were easier to access based on the content.

Data Management

A unique study-generated identification number was assigned to each user's account and stored in a separate password protected file. All of the online personal narratives were organized in chronological order and time since death under each user's ID. Users' demographic information was tagged with their study ID and stored in a password-protected file on a password-protected Dropbox.

Data Analysis

Data were analyzed using conventional content analysis for themes and subthemes. Conventional content analysis is used to describe a phenomenon (Hsieh & Shannon, 2005). In this study parents' experiences after the death of an only child is the phenomenon. Conventional content analysis allows themes and categories to emerge from the content, instead of using pre-conceived categories (Kondracki & Wellman, 2002). After data collection, the PI and another nursing researcher individually read five randomly chosen users' narratives and make notes on potential initial codes. Then, the

two coders came together to discuss and compare the codes they had developed. When the coders agree on codes and the operational definitions, the PI input all the data into NVivo 11. The NVivo program was used to code and manage the data and explore the file. The PI and the other nursing researcher individually went through all the coded data using the codes and operational definitions that had been agreed upon and edited them. The coding method is by highlighting the words or phrases which capture the key concepts and placing the words or phrases into emerging different categories based on their relationships (Hsieh & Shannon, 2005). When a new code was suggested by either coder, the two met, discussed, and decided on whether to include the new code and its definition.

Analyzing the content of personal narratives can answer the following research questions: How do parents describe their grief and their family's functioning following the death of an only child? How do these parents describe their physical and psychological experiences and coping strategies? How do parents' descriptions vary with the child's age/gender, parent's age/gender, and cause of death? Analyzing the longitudinal personal narratives can answer the research question of how parents' experiences differ by the time since the death.

Human Subjects Protections

This study aims to describe parents' physical and mental problems after the death of an only child in the U.S., and if parents' problems differ by the deceased child's age, mode of death, and time since the death. The sample size is 30 parents who have lost their only child. There was no limitation of the parent's age and gender or years since the child's death. Data were collected using internet searches, including Google, Yahoo,

Bing, and DuckDuckGo. The potential risk was breach of confidentiality regarding parent's user ID.

The data were collected from public Internet websites. This study did not need to consider the issue of recruitment and obtaining informed consent because all of the data were collected from posts on public websites. There was no interaction with the users. Direct quotations from personal narratives were used sparingly to decrease the possibility of someone else tracing the source of the data and exposing the users' accounts. All the data were stored in a password locked file folder in a password protected Dropbox. Also, the list that links the user's account name with the user's study ID was stored in a separate, password protected file.

There was no direct benefit of the study to the individuals who have posted on the websites. The potential societal benefit was the knowledge of parents' experiences after the only child's death, data important for healthcare professionals and ultimately for parents themselves who have lost their child.

The importance of the knowledge to be gained includes identifying the parents' physical and psychological problems after the death of an only child and the risk factors. This is the only study with parents who lost their only child in the U.S. reported in the last 22 years. The method was identification and collection of online blogs/posts and analyzed with conventional content analysis; other parental bereavement studies used interviews and surveys. This study focused on an understudied and vulnerable population with little risk to the parents.

Ensuring Trustworthiness

Ensuring trustworthiness is important in qualitative studies. To establish trustworthiness, four criteria need to be addressed: credibility, dependability, transferability and confirmability (Shenton, 2004). This study used the following strategies to ensure trustworthiness.

Credibility is also called internal validity. The question of how congruent the findings are with reality needs to be addressed (Shenton, 2004). This study used online data, which has the risk of fictitious blogs (Jones & Alony, 2008). Carefully checking the content of the blog may increase the identification of fictitious stories and the user's account, such as looking at the user's number of posts, number of followers, the details of the data and the other topics about which the user had written. If a user had frequently posted on different topics with only one or two posts about bereaved parents and had a large number of followers, the user might be trying to attract followers and that user's data were excluded. The PI of this study consulted with the chair and committee members about the data collection and analysis to maintain credibility. Establishing familiarity with the culture of bereaved parents through the literature review and consultation with the committee was another strategy. Also, NVivo was used only to facilitate data management and codes. Data analysis was conducted by the PI. Feedback of peers, the chair, and other committee members were essential during the study. Their questions and perceptions guided the PI to refine the method and develop greater findings. Dependability is also called reliability (Shenton, 2004). This study collected data from blogs, which did not need to consider the interview and transcription process. However, errors might happen during the data organization process. The PI needed to

carefully and effectively organize blogs under each users' account. If a user had written blogs on the different social media platforms, the PI grouped all the blogs together under one of the user's accounts. Transferability, or external validity, means the findings can be applied to a greater population (Shenton, 2004), although this is not usually an aim of qualitative methods. This study collected data from the internet, which could only represent bereaved parents who wrote on the internet. The findings of this study provided valuable information and insights for future studies to better understand this phenomenon. Confirmability is an issue of representation (Shenton, 2004) of bereaved parents' experiences, rather than the preconceived notions of the PI. The PI consulted with the chair to review the data and discuss the emerging themes.

Chapter 4

Results

The purpose of this qualitative study is to understand the experiences that parents and families have after the death of an only child in the U.S. The research questions are: How do parents describe their grief and their family's functioning following the death of an only child? How do these parents describe their physical and psychological experiences and coping strategies? How do parents' descriptions vary with the child's age/ gender, parent's age/ gender, cause of death, and time since the death? This study used the conventional content analysis approach to understand the online stories posted by bereaved parents who lost their only child in the U.S.

This study included mothers (n=26) and fathers (n=4), with no mother-father couples. The majority of the parents (n=25) were located in the U.S.; 5 parents' locations were unknown. Of the 11 parents who provided information on their age, the youngest was 23 years old, and the oldest was 69 years old. This study included 3 parents who lost all of their children. Most of the parents (n=21) had religion and believed in God. About half of the parents (n=16) were employed before the death and 14 parents were employed after the death. Marital status of the parents included 15 who were married or partnered, 6 who were single, and 9 whose marital status was unknown. The time since the death ranged from 10 days to 11 years. Most of the parents (n=24) provided longitudinal data, which ranged from 2 days to 6 years. The number of posts for each parent ranged from 1 to 323 (See Table 1).

Table 1 Description of Parents (N=30)

Characteristic		Mothers (n=26)	Fathers (n=4)	All (N=30)
Age	M (SD)	48.8 (11.17)	64	50.1 (11.49)
	Missing	15	3	18
Time since death (month)	M (SD)	34.1 (42.45)	8.8 (10.79)	30.9 (40.53)
	Missing	0	0	0
Number of posts	M (SD)	43.9 (77.59)	5 (3.08)	38 (73.44)
Time period of the posts (month)	M (SD)	17.5 (24.14)	3.2 (3.96)	15.7 (22.98)
Marital status after the death	Married	11	4	15
	Single	6	0	6
	Unknown	9	0	9
Religion	Catholic	1	0	1
	Christian	2	0	2
	Believe god	19	2	21
	Unknown	7	2	9
Employment status after the death	Employed	14	0	14
	Unemployed	2	0	2
	Unknown	10	4	14

The 30 parents lost 34 children: 19 boys, 13 girls; 18 adult children, 6 adolescents, 2 school-age children, 3 toddlers, and 1 newborn. There were 6 children's age and 2 children's gender were unknown. The causes of death varied. The most common causes of death were car crashes (n=9), cancer (n=4), and other accidents (n=5) (See Table 2).

Table 2 Description of Deceased Children (N=34)

Sex of deceased child	Boys	19 (55.88%)
	Girls	13 (38.24%)
	Missing data	2 (5.88%)
Deceased's age group	Young adult	18 (52.94%)
	Adolescent	6 (17.65%)
	School age	2 (5.88%)
	Toddler	3 (8.82%)
	Newborn (term unknown)	1 (2.94%)
	Missing data	6 (17.65%)
	Missing data	6 (17.65%)
Mode of death	Car crash	9 (26.47%)
	Accidental overdose	3 (8.82%)
	Suicide	1 (2.94%)
	Acute illness	2 (5.88%)
	Cancer	4 (11.76%)
	Murdered	2 (5.88%)
	Other accidents	5 (14.71%)
	Missing data	8 (23.53%)

Question 1: How Do Parents Describe Their Grief and Their Family's Functioning Following the Death of an Only Child?

Common themes for research question #1 include parents' perceptions of losing an only child, factors related to parents' grief and parents' functioning. The subthemes included holidays, people hurt the parents' feelings, no surviving child, and other factors.

Parents' perceptions of losing an only child. The bereaved parents described their feeling as pain, lonely, hurt, depressed, panic, empty, and sad, regardless of the time since the death. They wanted a private place and "*curl up.*" They believed no one could understand their feelings, except other bereaved parents. Six parents felt scared, fearful, and afraid because they did not know how to survive without their only child. This feeling appeared most frequently during the first two months after the death. Four parents found it hard to believe their only child has gone forever. They were still in the denial stage, even after seven years following the death. Eight parents felt angry, hate, and unfair, especially during the first two years following the death. Two mothers stated they often felt jealous of other families who have a child or children. They thought their jealousy was an envious feeling. They thought they needed to change their perspective and feel happy for the families who have children. Two bereaved parents described their feeling as a roller coaster over time, with some days being "*ok*" and other days being not "*ok.*" As time went on, they stated the pain is not easier, but different. The parents might have more "*ok*" days after many years following the death than the parents lost their only child recently. Seven bereaved parents tried to hide their grief by figuratively "*wearing a mask.*" They tried to pretend they were doing well and were normal, which was difficult and they stated they hate that feeling.

Eight parents mentioned their self-identity changed during the first three years following the death of their only child. Five believed they are still parents, but childless parents. Generally, these parents lost their child less than 2 years ago or more than 6 years ago. They missed being parents. One mother adopted two teenage girls to keep her mothering role. Three parents thought they were not parents anymore, especially for the parents who lost their only child one to three years ago. No one will call them mom or dad again. They thought the idea of “*still [being] parents*” was not helpful, because they believed other people would not think they were still parents. One mother stated she cannot talk with other mothers about mothering because no one wants her advice since she lost her only child. Two felt confused with their role, especially during the first year after the death. They asked themselves “*who [am] I really*”. They did not know what to do with their parenting role. They knew they were still parents, but they did not feel like it. The changes in self-identity can affect their grief process. Eight parents reported no distractions from the death and no goals for their future, which was a negative factor in their bereavement process.

Factors related to parents’ grief.

Holidays. Holidays are difficult for bereaved parents. Most parents (n=18) stated they did not like holidays, such as weekends, child’s birthday, Mother’s Day, Memorial Day, date of child’s death, Thanksgiving, Christmas and Halloween. Bereaved parents described their feelings about holidays as hard, dread, difficult, scary, sad, heartbroken, heartache, miserable, rough, anxious, and painful. Holidays brought the memory of their child back, especially when looking at the presents the child gave to them before the death and remembered how holidays used to be when their child was alive. Also,

bereaved parents felt sad when people said “happy holidays” to them. Although not happy they felt they still needed to smile and say “thank you”. One mother mentioned it was difficult to receive a Christmas card from someone who did not know the child had died and addressed the deceased child in the card. During holidays, bereaved parents stayed at home most of the time without any distractions, which likely may have increased the level of their grief. Mother’s Day is one of the hardest holidays for bereaved mothers. They were still mothers but did not have a living child to celebrate Mother’s Day with them. Some bereaved parents did not celebrate any holidays because they felt guilty celebrating after their child’s death and some spouses did not want to celebrate. Having surviving child[ren] might change their feelings about celebrating holidays.

People hurt the parents’ feelings. Bereaved parents thought they were sensitive and easy to hurt. Some parents stated it hurt when people talked about their own child or grandchild in front of the bereaved parents. Watching other families with their children around the town or on campus was hurtful. People did not want to talk to the bereaved parents and did not know how to talk to them. Parents complained that people saw them as invisible, believed bereaved parents are “contagious,” and avoided communicating with them. The bereaved parents thought other people do not want to know their feelings, as they do not ask how the bereaved parents are doing, avoid mentioning the deceased child and apologize for asking questions about the child. These behaviors always hurt bereaved parents’ feelings. Three bereaved parents shared their experiences when asked difficult questions like “do you have kids” or “how many kids do you have.” These

parents thought the best answer was telling people the truth, that their only child passed away.

Two bereaved parents reported feeling hurt when people compared the death of their only child with the death of a 90-year-old father or other family members, implying they are the same kinds of death. They felt people would judge them as not doing their best to save the child's life. Being asked why they did not have more children was extremely hurtful. A mother was told by a Christian that she should not grieve too much because she has faith. Many parents reported the most painful situation is people think they need to move on, forget the pain, go out to have fun. They did not like people saying *"things will get easier"*, *"do not be upset"*, *"do not shut away from everyone"*, *"need to get busy"*, *"I don't think I could make it what you are going through"*, *"I know it must be hard"*, and *"I know how you feel."* They hoped people could just pray for them, give them a hug, and say *"my thoughts and prayers are with you."*

No surviving child and no grandchild. A couple of parents stated that having more children might have been helpful. Most parents in this study were no longer of childbearing age and did not have the chance to have a subsequent pregnancy. Three parents wrote that they did not have any hope of having another child, which made them feel sad and hopeless. Some younger parents tried to have a new pregnancy after their only child's death. One mother had a miscarriage after the child's death, and another mother was worried that being perimenopausal would not allow another pregnancy. Nine parents felt sad when thinking about never having a grandchild and never being a grandparent. They were looking forward to having a grandchild and saving their child's

toys for the grandchild. They felt sad about not having a grandchild who could use their child's toys. One mother wished her child's girlfriend was pregnant.

Other factors. After the child's death, parents may have opportunities to talk about their deceased child in an event or in front of someone, which was difficult for them. For instance, they might meet a friend on the street who did not know the child had died and asked how the child was doing. It was difficult for the bereaved parents to explain their only child had passed away. Two parents reported having difficulty cleaning their child's room and going through the child's things, deciding how to organize things and how to give the child's things to someone who may need them. Next, four parents described feeling sad when their child's friends or other family members got married, graduated, or had children. Some of them felt unfair and angry to think their child would never reach the next milestone, and they would never have a grandchild. Some parents shared stories about seeing a child on the street or the TV, who looked like their child, which was a bitter-sweet experience. Some tried to take a picture of the child who looked like their deceased child and cried a lot afterward.

In addition, 10 parents lost other family members, such as parents, siblings, cousins, and pets after their child's death. Death of family members can add more grief to the bereaved parents. Some parents refused to go to the funeral(s) which were too difficult and stressful for them. Some parents did not know what to do with the child's ashes - where and how to store the ashes, should the child's ashes be divided or not; whether to give a small portion to a loved one or carry the ashes around with them all the time.

In addition, five parents mentioned being afraid that their child would be forgotten by others, such as family members and friends. They wanted the child to be remembered forever. It was difficult to see other people forgetting their child's name and never mentioning their child anymore. This stress usually appeared after the first year since the death.

Parents' functioning. There were 16 parents employed before the death; two of them quit or lost their jobs after the death. Parents who returned to work after the child's death stated they were very emotional at work, cried a lot, and were unable to concentrate. They did not want to go to work in the morning and counted the hours at work until they could go back home. One mother reported she misses work time frequently, due to sadness, crying, and being unable to get out of bed in the morning. Some parents did not want to go to work or quit their job because they did not want to smile and talk to people at work, especially in customer service positions. Some parents felt too tired to explain to people what was wrong with them at work. One mother chose to quit her job to move to another city. They reported losing their motivation. They lost their only child, and there is no other child who needs to be fed. They lost their goal of working. One mother lost her job due to broken arms. After her arms healed, she had difficulties finding a new job, because she was in her 50s and was not fully functioning emotionally after her child's death.

Of the 18 parents who had partners before the child's death, 13 stated they still wanted to be together and were still in love. Five parents had separated or were going to separate after the child's death. One mother was asked for a divorce because her husband was too sad to cope. Another mother was told by her husband that she had changed too

much after the child's death, so he wanted to divorce. However, she found out later it was because he had someone else. A mother was divorced because of her manic episode after the child's death. One father was asked for a divorce because his wife thought his pain consumed her. One housewife complained she had to find a job after the divorce. She had been a housewife for decades, so it was hard for her to go back to work at an older age and after losing her only child. Four of the divorces happened in the first 3 years after the child's death. Four divorced parents had lost an adolescent or adult child. These findings answered the research question of how parents describe their family's functioning following the death of an only child.

Seven parents reported that their spouse was grieving differently, which had a negative impact on their marital relationships. One father complained a lot that his wife only wanted to focus on herself, became very mean and angry and did not allow him to talk about his grief. This father felt he could not fit into his wife's life. Some mothers mentioned their husbands do not want to talk and share the pain, and they could not comfort each other. One mother complained her husband was not emotionally ready to find a job at 10 months after the child's death. Another mother complained her husband did not help her go through their child's things. She had to do it all by herself, which was overwhelming. Many mothers stated they understood that females and males grieve differently. One mother worried about her husband who coped by riding his motorcycle. When he left home, she was afraid that she would lose her husband after she lost her only child. One mother stated her husband understood why she cries all day. Another mother hoped her husband could understand why she was not functioning as well as he was. Two

mothers stated they tried to help their husbands cope, such as taking him to counseling and sharing coping strategies with him. Neither husband was able to use this type of help.

Some parents mentioned their old friends were not as close as they had been. Bereaved parents felt there are not many topics they can talk with their old friends, because their friends are interested in children and grandchildren. After the death of an only child, these childless parents had difficulties participating in any communication which was about the child or grandchild. Nevertheless, bereaved parents started to make new friends with other bereaved parents. They believed only bereaved parents could understand their feelings.

Question 2: How Do These Parents Describe Their Physical and Psychological Experiences and Coping Strategies?

Common themes for research question #2 include parents' physical and psychological experiences, coping strategies, and factors that stressed parents or affected their coping.

Parents' physical and psychological experiences. The most common physical problem was sleep disturbances. Some parents had insomnia, and others woke up many times at night. The sleep problems were reported by parents immediately after the death and by parents a decade after the death. In addition, some parents stated they feel short of breath, heart attack feelings, and chest pain. A few mothers complained about overeating and gaining weight. Stomachache, back pain, acid reflux, hair-thinning, arm or shoulder pain, nausea, broken arms, and flu also were reported.

There were 11 parents who reported they have psychological problems, which included anxiety disorder, PTSD, depression, Bipolar II, manic, and panic attacks. A

couple of parents mentioned taking Alprazolam, Sertraline, and Hydroxyzine as needed. Some parents diagnosed with a psychological illness after the child's death had pre-existing psychological problems before the death. The psychological problems were reported by parents after a few months and by others a decade after the death.

Thirteen parents stated they wanted to die because they wanted to meet with their children in the other world. Some wanted to die in their sleep; one mother wanted to jump from Niagara Falls. Two mothers wanted to be diagnosed with an illness and then refuse the treatment. A couple mothers stated they had made suicidal attempts. Only one mother described the detail of the suicidal attempt, which was holding a metal umbrella in a lightning storm. Seven stated they would never attempt suicide, which was against God's word and no eternal life. They would go to hell if they committed suicide and would never see their children who are in heaven. One mother did not believe that. Based on the data, suicidal ideation was most common during the first six years after the death especially for those who lost an adolescent or adult child. None of the parents of the younger child reported suicidal ideation.

Nine parents reported living problems because they felt too tired to do any daily living activities. For instance, some parents found it difficult to take a shower, go to the gas station, clean the house, maintain the lawn, and garden. They just wanted to curl up on the couch the whole day. Several parents reported not taking as good care of themselves as before the death. One mother forgot to pay her water bill, and the water company cut off her water supply. One mother stated she drinks too much alcohol. Another mother had difficulties going to the grocery store because she would remember

when she was shopping for her child. Most of the living problems happened during the first year after the death of the only child, which may severely affect parents' health.

Factors related to parents' health. There are many things that can stress the bereaved parents. Three parents were worried about their own parents' health, because of heart surgery, Alzheimers, and stroke. One mother's sibling could no longer take care of their parents and she moved to her parents' city to take care of them, which was extremely stressful for her. Except worrying about their parents' health, these bereaved parents also did not want their parents to worry about them. A mother described she was always hiding her grief when she stayed with her parents because she did not want her parents to see her cry. She tried to pretend she already "*got over*" the death, which was difficult for her. After the death of an only child, parents were more likely to worry about who would take care of them when they are old. Also, they were afraid if their spouses die, they would be alone in the world. Parents worried about how to survive if they lost their spouse. Three parents felt it difficult to remodel, repair, or move out of the house where their child grew up, because they wanted to keep the house the same as before the child's death. They believed that changing the environment was erasing the memory of their child.

Except for these common stresses the parents may have after the death, there were many other stressful events mentioned by some other parents, which included getting a letter from the cemetery, reading autopsy reports, financial difficulties due to their child's high treatment costs and the husband being unemployed, a car crash, and broken arms. One mother worried about her husband a lot because he was coping by riding a motorcycle. The mother was afraid to lose her husband. One mother was worried that the

tree planted for the child after the death was not doing well. These stresses may affect parents' physical and psychological health.

Coping strategies. Most of the bereaved parents (n=23) shared their experiences of coping. There were three types of coping: someone, something, and professionals, which can help parents manage bereavement. These findings answered the research question of how the bereaved parents described their coping strategies.

Someone. One father reported he had a new baby two years after the death, and one mother adopted two teenage girls. Both of them stopped writing posts after this occurred. Another young mother stopped writing blogs a year after the child's death. Three bereaved parents had a grandchild. One mother reported she could not go through the grief process without her grandson. Another mother enjoyed spending time with her grandson. One mother never met her grandchild, because the child's mother took the child away.

Three parents shared that they liked people to ask about their deceased child, acknowledge the child, and mention the child's name. They reported that the most helpful friends never tried to tell them how to handle the grief. They wanted a friend who is a good listener, and who would sit with them, let them cry, hold their hands, and not say anything. They wanted to talk to other bereaved parents who really knew their feelings. They liked talking with other family members about the child's happy stories. Some parents enjoyed the younger generation visiting them, such as their niece, nephew, and child's friends. Some parents said they liked hearing their child's friends tell them how much the child loved them and how much the child affected their friends' lives. One mother loved seeing her nephew wearing her child's clothes. The mother who adopted

two girls believed it was a good way to cope, which made her feel happy and practice mothering skills again. A few parents mentioned their parents are supportive. In addition, family members helping the parents handle the child's funeral was helpful. A couple of parents mentioned the health professionals at the hospital. One mother stated that the child's nurse was compassionate. She told the parents "*it is hurt*", sided with them, and prayed with them.

Something. There were many things that can help the bereaved parents cope. Several parents mentioned that crying as much as they wanted would let them feel better. A few parents cited moving to a new place where nobody knows them or traveling were helpful. Sometimes, going outside the house lets them feel better. Some parents felt talking to strangers about the child's death or sharing their feeling online were helpful. Also, reading books, listening to music, punching bag, lighting candles, walking, yoga, exercising, bike riding, and hiking were mentioned by several parents. One mother was a singer. She believed singing established a connection with her child, and she wrote a song for her child. Another mother liked to use Photoshop to recreate her child's pictures. Some parents reported meditation as helpful. One mother reported going to different geographic areas was helpful, such as mountains, desert, and beach. Another mother complained that she could not go anywhere during the cold winters, which was stressful. Also, gardening and looking at beautiful things were good ideas. Internet shopping was mentioned by one mother. A few parents found that pets were very supportive.

Six parents liked to talk and write letters to the child. Some parents wrote in journals. Many parents reported going to the cemetery or accident site and talking to the child or leaving flowers as helpful. A mother took the child's ashes to his favorite place.

Some parents preferred to wear child's clothing and bracelets and smell the child's shoes and drawers. They liked to go into the child's room over and over again or stay in the child's room all day. One mother moved into her child's apartment. A few parents stated they enjoy listening to the child's voice mail, voice records and watching the child's videos. Some parents liked to log into child's Facebook, Email, and Obit accounts. Several mothers mentioned making a quilt and blanket from the child's clothing. Some parents decorated their house with the child's memories, such as the child's pictures, paintings, and toys. Establishing a scholarship at the child's school was mentioned by two parents. A few parents sent the child's pictures to friends and gave the child's things to someone who was in need. Having or getting a tattoo which represented their child was helpful for some. Some parents stated taking good care of themselves and thought of doing things for the child are helpful. Avoiding triggers was important to diminish their pain.

Four parents continued to celebrate their child's birthday by making a cake, having a small dinner with family, receiving presents from other family members, going to the cemetery and leaving flowers, traveling, and making their child's T-shirt blanket. Some special birthday events mentioned in the posts included a drum circle and sound circle, balloon release, getting on child's Facebook and waiting for the child's friends to send messages to the child, singing, and having a tattoo. Thanksgiving, Christmas, and New Year's Day are the hardest holidays for bereaved parents. Seven parents reported they did nothing on Christmas except stay at home and cry. Four other parents celebrated the holidays by going to the child's favorite restaurant and having the child's favorite dish, having and decorating a Christmas tree, taking a pumpkin to the cemetery, doing all

“*the usual*” celebrations, hosting Thanksgiving party for a lot of people, traveling and singing a song. Other parents tried to cope during the holidays by staying with friends and families who knew their grief, working and staying busy, reading, staying at home with pets and foster children. Some parents refused to call the death date as an anniversary. At the death date, some bereaved parents went to the cemetery, lit candles, celebrated child’s life with family, listened to the child’s voice message, released balloons, purchased a gift for the child and traveled.

Ten parents reported that keeping busy is important. There were 14 parents who were employed after the child’s death. Although they stated they do not want to work, they thought working kept them busy, providing a good distraction. Some parents did not have a job, but they were doing volunteer work to keep themselves busy, such as working in animal shelters. One mother was helping with the local Compassionate Friends chapter, an organization of and for bereaved parents. Some parents believed helping others was a good coping strategy. One mother handmade afghans and baby blankets to donate to the local hospitals. Some mothers suggested doing some simple tasks as helpful, such as crocheting, knitting, and crosswords. Some mothers shared taking care of pets and husband are good distractions. As mentioned before, a foster child was a great distraction. Also, going back to school was another option.

A few parents believed socializing was helpful, although they did not like it. One mother thought participating in the child’s social groups was helpful, while some parents avoided attending any such events.

Professionals. Several parents (n=13) mentioned seeking help from professionals, which included counselor, support group, daily email, Compassionate Friends, behavioral

therapist, AliveAlone, meditation teacher, and spiritual healer. Some parents preferred the support group, but other parents liked the counselor. Parents who preferred support groups wanted to make new friends with other bereaved parents. As mentioned before, they believed other bereaved parents can understand their feelings. Also, they wanted to know what the grief process would be like in the future. It was necessary to hear other bereaved parents sharing their experiences who lost their only child a long time ago. One mother's son died of suicide. She wanted to meet with other parents of children who died by suicide. However, some parents did not like the support group. One mother felt uncomfortable filling out a workbook before the meeting. One mother was the only one showing up in the group meeting, which made her feel disappointed. Another mother complained there was too much silence during the meeting.

Some parents liked counselors who told them the pain would not be less and taught them how to manage the pain. One mother said her therapist understands her feelings because she also lost the only child. Some parents did not like the counselor, because the counselor tried to get them past the death, to move on. As mentioned before, bereaved parents believed they would never get over the pain.

Some parents did not like professional help at all. One mother spent most of her time in bed, which did not allow her to go out of her house. Another mother did not trust professionals. Someone reported it was weird to talk and cry in front of strangers and painful to talk about the child's death repeatedly. One mother thought the daily small prayer email from an organization is helpful.

Factors that affect parents coping.

Dreams and signs of the child. Many parents (n=10) shared they were happy to dream about the child, wanted to dream about the child, and prayed to dream about the child. They always felt happy the next day if they dreamed of the child. Some tried to find out how to dream about the child at night by reading books about dreams. Usually, they were more likely to dream about the child smiling and hugging them. Not being able to see the child's face in the dream made them feel sad the next day. Parents reported dreaming about the child two months after the child's death and others at a decade after the death.

Except dreaming about the child, many bereaved parents (n=7) liked to see a sign, which they believed represented their child. For instance, a mother reported her cat was acting weird and she believed it was because her son came back. Some other signs included light(s) and/or phone screens turning on automatically, hearing a song at a store which was played at child's funeral, doors opening by themselves, and some plants, flowers, butterflies, or birds. Some parents shared every time when the phone rings, they felt it was their child calling them, which made them feel sad. Also, a few parents mentioned seeing a child on the street or on TV who looked like their child, which was an emotional moment.

Religion. The keywords of religion in this study included pray, god, and church. Most of the bereaved parents (n=22) addressed their perceptions of religions after the death of their only child. None of them were fathers. Overall, religions helped the bereaved parents to cope. Many parents reported that praying a lot made them feel better. They thought they needed to have beliefs. They believed they would meet with the child

in heaven. Only one mother stated she did not believe she would go to hell if she commits suicide. Some believed the child existed in other forms with them, such as spirit. They were more likely to read books about faith and the afterlife.

Bereaved parents had different perceptions of religion. Two parents stated they are Christian or Catholic. Most (n=21) said they believe in god or pray. None of the parents reported going to church every week. Many of them had questions like “*does God understand my feelings?*” and “*does God want me anymore because I don’t respect my life?*” Many parents felt angry with God, questioning “*why did God take my child?*” Some parents understood why God took their child. Others thought humans should not try to understand God. Several parents thought God abandoned them and did not love them. One mother stated she does not believe in a vengeful God. One mother stopped going to church after the death, because she did not like people “*act[ing] as a judge and threaten[ing] eternal damnation*”. Another mother reported she started to form a new relationship with God outside of the church walls. Several parents shared they thank God for the years they spent with the child.

Online forums. Many bereaved parents (n=11) shared their perceptions of online forums or blogs. They thought the internet sharing is helpful, loved, welcomed, supportive, caring, compassion, peace, comfort and feel at home. Many parents liked online sharing believing that people in the forum understand them. Many parents stated they logged in every day to read the posts, but they did not post because other people’s words were what they felt. They found hope when other bereaved parents said they would survive. They felt they were not alone, and their grief was normal. Some parents were seeking help on the internet because they did not know how to handle the grief.

However, one mother's counselor told her not to use the forum and read other people's posts, because it is not good to know other parents do not get better a long time after the child's death.

Question 3: How Do Parents' Descriptions Vary with the Child's Age/ Gender, Parent's Age/ Gender, Cause of Death, and Time Since the Death?

Common themes for research question #3 include Child's and parent's age/ gender, cause of death, and time since the death.

Child's and parent's age/ gender. Parents who lost a boy wrote much more than parents who lost a girl. The four parents who lost a boy wrote more than 100 posts, and all the parents who lost a girl wrote less than 70 posts. Seven parents who lost a boy wrote for more than 1 year, and only two parents who lost a girl wrote for more than 1 year. The 4 parents who wrote for more than 6 years had all lost a boy.

Most of the divorced parents (n=4) lost an adolescent or adult child. All the parents (n=13) who had suicidal ideation were parents of a deceased adolescent or adult child. None of the parents of deceased school age or younger child posted about suicidal ideation.

The mothers (M=43.88) wrote more posts than fathers (M=5). Younger parents and parents of younger deceased children often had a subsequent pregnancy and stopped writing posts soon afterwards.

Causes of the death. The causes of the child's death can be positive or negative factors that affected parents' grief. Parents felt better when thinking that the child passed away in their sleep, did not suffer, and died instantly. One child who liked to ride a motorcycle died after hitting a deer. His mom stated her son died doing something he

loves to do, which made her feel better. Also, they had had a prior conversation that if he had an accident, he did not want to live with a life support system, which let the mother feel better about removing life support after the accident.

Five parents talked about causes of their child's death that negatively affected their grief, such as unexpected death, unknown cause of death, and not knowing exactly what happened. Parents whose child died as expected from their chronic illness had less than 10 posts, which is much fewer posts than parents of a child whose death was unexpected. It was stressful when people did not help the bereaved parents to find out the truth of the death, they believed someone was lying about the truth, or the parents did not believe what was officially reported. If the child had married, the bereaved parents needed to get the death report from their child's spouse, which may be difficult. Also, the time waiting for the death report and the autopsy report was stressful.

In addition, a couple of parents whose child died in a car crash as passengers reported the legal judgment was unfair, which made them feel anger and sadness. For instance, a driver only got five years' probation for taking a life. This was especially true when their only child was the only one who died in the car crash and the driver had no injury. One boy died of a car crash as the passenger, and his friend was the driver who made a wrong decision to hit a wall. The bereaved parents asked the judge to reduce the driver's felony charge to a misdemeanor because they tried to forgive him and did not want him to go to jail. However, they regretted and were angry about their decision later.

The causes of death can make parents feel guilty. One mother thought the child's death was her fault because she let the physician administer several vaccinations which caused the child's seizures leading to the death. Another mother reported her son did not

take care of himself and died of a chronic illness. She believed that if she had done more to help her son to take care of himself, he might not have died. A father reported his children died in a house fire because he did not pick them up from the house as he was supposed to. Some parents shared their feelings about removing life support. It was a difficult decision, especially hearing a friend's child recovered from the "life support". The bereaved parents felt stressed when thinking about whether removing life support was the right decision.

Time since the death. The 12 parents who lost their only child in the previous three months posted most frequently and had several posts. Parents (n=10) who lost their only child more than 3 months but less than two years ago posted differently. Four only posted a couple of times, but four others wrote a lot. The eight parents who lost their only child more than two years ago wrote a smaller number of posts, and six of them only wrote a few posts.

The psychological and sleep problems occurred regardless of the time since the death. The first two months after the death, parents were more likely to feel scared without their only child. The parents may have more "ok" days after many years following the death than the parents who lost their only child recently. The denial stage could continue for seven years after the death. The parents who lost their child less than 2 years ago or more than six years ago were more likely to believe they are still parents. Some parents thought they were not parents anymore, especially those who lost their only child one to three years ago. In the first year after the child's death, parents did not know who they really were. Many parents' self-identity changed during the first three years following the death of their only child. Most of the bereaved parents' suicidal ideations

were in the first six years following the death. Most of the living problems happened during the first year after the death of the only child. Four of the divorces happened in the first 3 years after the child's death. After the first year since the death, the bereaved parents were more likely to worry their child would be forgotten by others. Some parents started to dream about the child two months after the child's death, and some continued until a decade after the death.

Chapter 5

Discussion

The purpose of this qualitative study was to understand the experiences that parents and families have after the death of an only child in the U.S. The research questions were: How do parents describe their grief and their family's functioning following the death of an only child? How do these parents describe their physical and psychological experiences and coping strategies? How do parents' descriptions vary with the child's age/ gender, parent's age/ gender, cause of death, and time since the death? This study used the conventional content analysis approach to understand the online stories posted by bereaved parents who lost their only child in the U.S.

Common themes for research question #1 include parents' perceptions of losing an only child and factors related to parents' grief and functioning. The subthemes of factors related to parents' grief included holidays, people hurting the parents' feelings, and lack of a surviving child, among others. Common themes for research question #2 included parents' physical and psychological experiences and factors affecting parents' health, coping strategies, and coping. Common themes for research question #3 included the child's and parent's age/ gender, cause of death, and time since the death.

The present study adds to the knowledge on parents' experiences after the death of an only child in the U.S. by collecting data from online blogs written by parents at 2 weeks to 11 years after the child's death. Most other studies focused on families of multiple children (Barrera et al., 2009; Harper et al., 2011; Joronen et al., 2016; Youngblut & Brooten, 2013) or under the Chinese only child policy (Song, 2014; Wang & Xu, 2016; Zheng, Lawson, & Head, 2017). The present study is the first study which

focused on the death of an only child in the U.S. In addition, while the majority of researchers in this area started collecting data at least 1 month or several months after the child's death (Brooten et al., 2018; Cacciatore et al., 2014; Gerrish, Neimeyer & Bailey, 2014; Proulx et al., 2016; Schor et al., 2016; Youngblut et al., 2017), the present study included 5 (16.7%) parents who lost their only child less than 1 month ago. In addition, many other longitudinal qualitative studies only followed the participants 1 to 2 years or less (Brooten et al., 2018; Dias et al., 2017; Stroebe et al., 2013). In the present study, 10 (33.3%) parents provided data over 1 year, and 4 (13.3%) parents provided data over 6 years. Many studies only focus on a single cause of death (Dias et al., 2017; Gerrish, Neimeyer & Bailey, 2014; Lichtenthal et al., 2015; Snaman et al., 2016), while the present study had 7 different causes of death. Also, many qualitative studies had small samples of 10 or fewer bereaved parents (Dias et al., 2017; Harper et al., 2011; Gerrish, Neimeyer & Bailey, 2014; Snaman et al., 2016), while the present study involved 30 bereaved parents. This study is the first to use an online data collection method in this research area. While other longitudinal research only interviewed participants a few times during the study (Dias et al., 2017; Stroebe et al., 2013; Youngblut et al., 2013), the present study involved 13 parents (43.3%) who wrote more than 10 blogs and 4 parents (13.3%) who wrote more than 100 blogs over a long period of time (up to 6 years). The data of this study are sufficient to explore the research questions.

Question 1: How Do Parents Describe Their Grief and Their Family's Functioning Following the Death of an Only Child?

Parents' perceptions of losing an only child. In the present study, the bereaved parents described their feeling as pain, lonely, hurt, depressed, panic, empty, sad, angry,

fear and hate, regardless of the time since the death. Some other studies described parents' feeling depressed, distressed, aggression, anger and hostility, which are similar to the finding of the present study (Lichtenthal et al., 2015; Murphy, Shevlin, & Elklit, 2014). In addition, bereaved parents who lost their only child frequently used words like "lonely", "empty" and "fear, scared or afraid" to describe their feelings. Bereaved parents who have a surviving child or children may not feel lonely or empty. The only child is the center of the family. After the death of an only child, parents feel lonely, even if they have a partner. The bereaved parents who have a surviving child or children may not have these feelings.

The parents in the present study reported that, as time went on, the pain was not easier, but different. Snaman et al., (2016) found that the character and intensity of grief changed over time. Some bereaved parents in the present study described their feeling as being on a roller coaster over time, which is consistent with the findings of Dias et al. (2017).

Some parents in the present study stated they had no goals for their future after the death of their only child. Some other studies also found that bereaved parents had a lower sense of purpose in life and lost the meaning of their life (Lichtenthal et al., 2015; Rogers et al., 2008; Song, 2015). However, none of the studies compared the sense of purpose between parents who lost their only child and parents with a surviving child or children. Perhaps parents who lost their only child have a lower sense of purpose in life, because they had no child to take care.

In the present study, some bereaved parents believed they were still parents after the death of an only child; some parents did not think they were parents anymore; and

some felt confused with their role. Dias et al. (2017) reported that parents who lost their only child experienced role identity conflicts. They are still parents but without a child. In the Chinese study, bereaved parents called themselves “Shiduers”, which is a Chinese word that describes parents who lost their only child (Zheng & Lawson, 2015). There is no such English word to describe this population group. The present study found that the parents who lost their only child less than 2 years or more than 6 years ago often believed they were still parents. Most of the role identity changes were reported during the first 3 years following the child’s death. Perhaps the limited number of participants in this qualitative study may not explain the pattern of role conflict changes over time after the death. The role identity changes over time have not been reported by other studies. Future study is needed to explore the parents’ role conflict and changes over time after the child’s death.

Many new findings in the present study have not been mentioned in any other studies. This study is the first study where parents equated their jealous feelings about other families who have a child or children. This conflict feeling may add more stress to the bereaved parents. The bereaved parents may only share this thought in their blog but not with an interviewer. This may help to explain why other qualitative studies did not have this finding. In addition, this study found that the bereaved parents tried to pretend they were “normal people” who are doing well. Other qualitative studies did not mention it, which may be because the interview questions did not address, or participants did not want to share this feeling with the interviewer. Parents stated it is hard to believe their only child has gone forever. They were still in the denial stage, even after seven years following the death. The denial stage is the first stage of grief (Kübler-Ross, 1969). In

other studies of bereaved parents, the denial stage appears in the first 6 months after the child's death (O'Connor & Barrera, 2014). However, the bereaved parents who lost their only child experience a much longer denial stage than after other family members' death. Future study is needed to focus on the differences of grief stages between parents who lost their only child and parents who have a surviving child or children.

Factors related to parents' grief.

Holidays. The present study found that holidays are difficult for bereaved parents, which is consistent with other study (Dias, Docherty & Brandon, 2017). However, none of the studies described parents' feelings, difficulties, and what bereaved parents do during the holidays following the death of an only child. The present study found that bereaved parents described their feelings of holidays as hard, dread, difficult, scary, sad, heartbroken, heartache, miserable, rough, anxious, and painful. The difficulties are remembering the child, responding to "happy holidays" greetings, and lack of distraction. Some parents refused to recognize the death date as an anniversary. Mother's Day is one of the hardest holidays for bereaved mothers after the death of their only child, because of changes in their role identity. The memory of the child and lack of distractions would likely bring more distress and anxiety to the bereaved parents. Future study is needed on parents' difficulties and needs during holidays.

People hurt the parents' feelings. The present study reported the bereaved parents were sensitive and easily hurt, consistent with another study (Murphy, Shevlin & Elklit, 2014). The present study found that the bereaved parents who lost their only child did not want to move on, and they do not like people trying to help them move on. Dias, et al. (2017) concluded that the bereaved parents who lost a child and still have a

surviving child or children were struggling between “not forgetting” and “moving on”. None of the parents in the present study stated they wanted to move on or struggled between “not forgetting” and “moving on” following the death of an only child. Bereaved parents who have a surviving child or children may need to move on to be able to take care of their living child. The bereaved parents in the present study lost the purpose of “moving on”. Many parents reported the most painful situation is people thinking they need to move on, forget the pain, and go out to have fun. They hoped people could just pray for them, give them a hug, and say “*my thoughts and prayers are with you*”.

The present study found that people do not want to talk to the parents who lost their only child, which is consistent with the Chinese study of Zheng and Lawson (2015). In the U.S., people do not know how to talk to bereaved parents. In China, people do not want to talk to the bereaved parents who lost their only child because they are considered unlucky people in Chinese culture. Although the culture is different between these two countries, the bereaved parents faced the same difficulty. These behaviors always hurt bereaved parents’ feelings and increased the risk of social isolation.

Also, parents in this study found it difficult to answer the question about how many children they had. The best answer is telling people the truth, which is that their only child passed away. Parents who lost a child but still have a surviving child or children may have the same difficulty associated with whether to count the deceased child when answering this question.

Some parents in the present study reported how other people hurt them by asking why they did not have more children, comparing the death of their only child with other family members’ death, judging the bereaved parents for not saving the child, talking

about their own child or grandchild in front of the bereaved parents. Future study needs to focus on how to cope with these situations. Also, educating people on how to communicate with bereaved parents is essential.

No surviving child and no grandchild. The present study found out parents had no distraction after the death, parents lost their parenting role, and self-identity changed after the death of an only child. Several studies reported caring for other children provided motivation and purpose for the bereaved parents (Barrera et al., 2009; Proulx et al., 2016; Rogers et al., 2008). Rogers et al. (2008) found that having additional children in the family was associated with resilience or recovery from grief and marital disruption. In the present study, younger parents tried to have subsequent pregnancy after the only child's death. One father reported he had a baby two years after the death. And one mother adopted two teenage girls. Both of them stopped writing posts afterward. After these parents have more children, they may not have time to write blogs. Also, taking care of children is a distraction and a good coping strategy for bereaved parents. However, most of the parents in this study were no longer of childbearing age and were not able to have a subsequent pregnancy. There is very little literature on the older bereaved parents who lost their only child.

Other factors. The present study found that telling people about the child's death, cleaning out the child's room, and issues about storing ashes are difficult for the bereaved parents. Having friends or family members who marry, graduate or have newborns can cause parents distress, which is consistent with Dias et al.'s (2017) study. This study found that parents felt unfair and angry to think about their child never reaching the next milestone, which has not been reported by any other studies.

Parents' Functioning. The present study found that bereaved parents did not want to go back to work and had a hard time getting out of bed in the morning, which is consistent with the study of Snaman et al. (2016). The present study reported that bereaved parents found it difficult to work in customer service after their child's death, which requires smiling and talking to people at work. Future studies need to identify what the parents do at work when discussing job satisfaction after the child's death. Bereaved parents stated they had no motivation to work, as there are no longer child needs to be met. It is well documented that surviving children were the major purpose of parents' lives (Barrera et al., 2009). The bereaved parents' job satisfaction and motivation after the death of an only child has not been reported.

Child death can affect marital relationships. Many parents (n=13) in the present study stated they still wanted to be together and were still in love. However, some parents' (n=5) marital relationships were disrupted by the child's death, which is consistent with other studies (Bolton et al., 2014; Rogers et al., 2008). The present study found couples grieved differently, which is consistent with that reported by Barrera et al. (2009) and Stroebe et al. (2013). Arnold and Gemma (2008) found reduced communication between partners after the child's death. Some mothers in the present study mentioned their husbands did not talk and could not share the pain and comfort with each other. In the present study, factors contributing to marital relationship disruption included failing to cope, having an extramarital affair, ignoring their partner's grief, manic episode, and death of a teenage or adult child. Joronen et al. (2016) found that older age of the deceased child (>2 years old) was associated with poorer marital relationship. There is very little research on marital relationship disruption after the death

of an only child. A few studies conducted under Chinese only child policy concluded that the death of an only child may lead to divorce due to lost family goals; husbands also wanted to marry a younger woman to have a child (Pan, Liu, Li, & Kwok, 2016; Wei et al., 2016; Zheng & Lawson, 2015). Future studies are needed to identify the reason for the marital relationship disruption after the only child's death in the U.S.

The present study found that some bereaved parents' old friends kept their distance from the parents because of having fewer common interests not involving childrearing. These bereaved parents preferred to make new friends with other bereaved parents who lost their only child. This finding is similar to other studies conducted in China under the only child policy (Song, 2014; Zheng & Lawson, 2015). As mentioned before, people without a child are unlucky people in China (Zheng & Lawson, 2015). People do not want to talk to them. In the U.S., research in this area has not been reported. Based on this study, people do not know how to talk to the bereaved parents and hurt parents' feelings unintentionally. Future study is needed to describe the reasons for parents' social isolation after the death of an only child.

Question 2: How Do These Parents Describe Their Physical and Psychological Experiences and Coping Strategies?

Parents' physical and psychological experiences. The most common physical problem was sleep disturbances in this study, which is consistent with Bolton et al. (2014). This study found that the bereaved parents experienced shortness of breath, heart attack feelings, chest pain, and fatigue, findings consistent with that reported by other studies (Brooten et al., 2018; Cacciatore et al., 2014; Rogers et al., 2008). A few mothers reported overeating and gaining weight, which is consistent with the research of

Cacciatore et al. (2014). Many studies found greater substance use in bereaved parents (Bolton et al., 2014; Cacciatore, Lacasse, Lietz, & McPherson, 2014; Harper, O'Connor & O'Carroll, 2014). In the study by Cacciatore et al. (2014), about one-quarter of the bereaved parents reported an increase in drug and alcohol use after the child's death. In the present study, only one mother stated she drinks too much alcohol while some others reported drinking only a glass of wine in the evening. Perhaps bereaved parents with alcohol problems were less likely to write blogs online. Parents in this study also reported stomachache, back pain, acid reflux, hair-thinning, arm and shoulder pain, nausea, and broken bones, which were rarely discovered by other researchers. The present study found that none of the fathers reported any physical problems. Brooten et al. (2018) found mothers reported more illnesses than fathers.

Some bereaved parents (n=11) in the present study reported psychological problems, consistent with many other studies (Bolton et al., 2014; Cacciatore et al., 2014; Devylder et al., 2013; Jind et al., 2010; Koyanagi et al., 2017; Murphy, Shevlin & Elklit, 2014, Pan et al., 2016; Rogers et al., 2008). Parents reported psychological symptoms as early as 1 month and as late as 10 years after the death. None of the fathers reported any psychological symptoms. Also, some parents in this study diagnosed with a psychological illness after the child's death had pre-existing psychological problems before the death, which is consistent with the research of Brooten et al. (2018) and Cacciatore et al. (2014).

In the present study, some of the bereaved parents (n=13) had suicidal ideation, which is consistent with other studies (Harper et al., 2011; Hendrickson, 2009; Zetumer et al., 2015). Harper et al. (2011) reported that a mother who lost her only child did not

attempt suicide because she did not want her parents to experience bereavement as she did. In the present study, many of the bereaved parents (n=7) stated they would never attempt suicide, which was against God's word and prevented eternal life. They would go to hell if they committed suicide and would not see their children in heaven again. This finding was not reported by other studies of bereaved parents. Zetumer et al. (2015) reported that parents who lost a child younger than 25 years old had a higher risk of suicide than parents who lost a child whose age was 25 or greater. However, the present study found that parents of an adult deceased only child had more suicidal ideation, perhaps due to the lack of possibility of having subsequent pregnancy after the only child's death.

Except for physical and psychological problems, the present study found that many parents (n=9) reported some living problems because they felt too tired to do any daily living activities. For instance, some parents had difficulties in taking a shower, going to the gas station, cleaning the house, maintaining the lawn and garden, taking good care of themselves, and forgetting financial obligations. Most of the living problems happened during the first year after the death of their only child. Research in this area was rarely reported by other studies. The living problems may lead to more health problems in the future.

Factors related to parents' health. Few studies have focused on factors related to parents' health after the only child's death. The present study found that bereaved parents worried about their parents' health, the death of their pets, and remodeling, repairing, or moving out of their old house. After the death of an only child, parents were worried about who would take care of them when they are old, a finding consistent with

the Chinese study (Song, 2014). Also, they were afraid of being alone in the world if/when their spouses die. Many other stressful moments were mentioned in the present study, for instance, grocery shopping, getting a letter from the cemetery, financial difficulties, and the tree planted in memory of their child dying. Many of the parents' stress factors in the present study have not been reported in other research. Future study is needed to focus on the factors that may affect parents' physical and psychological health.

Coping strategies. The present study described the coping methods of bereaved parents following the death of an only child, which included staying busy, keeping the memories of their child alive, and wanting to meet other parents whose child died from the same cause. These findings are consistent with other studies (Proulx et al., 2016; Snaman et al., 2016; Thompson et al., 2011). Both the Harper et al. (2011) study and the present study mentioned the bereaved parents carrying the child's ashes around with them. A few parents in the present study mentioned they like to stay with families and talk about the child's happy stories, which is consistent with the findings of Proulx et al. (2016). Both the present study and Song (2014)'s study found that some parents want to move to a new place where nobody knows them. The present study also found that traveling, crying, sharing online, reading, writing, music, exercising, meditation, gardening, pets, and going out of the house were very helpful. Several studies concluded that bereaved parents' connections with healthcare professionals lead to better outcomes (Dias, et al., 2017; Lichtenthal et al., 2015). However, none of the parents in the present study reported maintaining a connection with the healthcare providers. Perhaps it was because most of the child deaths were sudden in this study. There was no opportunity for

parents to build a relationship with health providers. Only one mother mentioned the child's nurse as being compassionate and supportive.

Spiritual connection with the deceased child is one of the important coping strategies. Burkhardt and Nagi-Jacobson (1989) defined spiritual as interconnectedness to self, others, and the environment. The present study found that parents developed a connection with their deceased child by visiting the cemetery, lighting candles, writing letters and speaking to the child aloud, which consistent with the findings of other studies (Barrera et al., 2009; Harper et al., 2011; Proulx et al., 2016). The present study reported the bereaved parents liked to smell child's clothing, shoes and drawers, which was not reported by other studies. Also, some bereaved parents made a quilt and blanket from the child's clothing, as in other studies (Barrera et al., 2009; O'Connor & Barrera, 2014). The bereaved parents in the present study found that simple tasks were helpful, such as crocheting, knitting, and crosswords. In the Harper et al. (2011) study, one mother who lost her only child reported keeping her maternal role by visiting and cleaning the child's grave every day. One mother in the present study adopted two girls to continue her mothering skills. Also, the present study found that taking good care of themselves and thoughts of doing things for the child were helpful. The child was their purpose for life. Doing things for the deceased child was a way to keep the goal.

Youngblut et al. (2016) reported parents' need for help with arrangements after their child's death, such as decisions about organ donation, autopsy, burial or cremation, and holding wakes. The present study found that family members helping the parents handle the child's funeral was helpful. In addition, this study's bereaved parents enjoyed the younger generation visiting them, such as their niece, nephew, and child's friends.

Since the parents lost their only child, they missed the feeling of raising a child. This finding has not been reported by other studies. Some studies of children's deaths reported that parents' poor outcomes were related to social network isolation (Lichtenthal et al., 2015; Snaman et al., 2016). In Song's study (2014), bereaved parents who lost their only child wanted to stay away from people who knew them while their child was alive. In the present study, some parents believed socializing was helpful, but other parents avoided attending any such events. It is important to identify the type of socializing in future studies when discussing coping strategies. Bereaved parents wanted to share their feelings with good friends or family members, but do not want to participate in a public event about their deceased child.

None of the studies mentioned what parents prefer to do during holidays. In the present study, some parents did not want to celebrate or do anything during the holiday, because of not having a surviving child. They prefer to stay at home. Some parents made a cake, had dinner with family, went to the cemetery, traveled, sang songs, worked, released balloons, read a book, lighted candles and purchased a gift for the deceased child. Without the living child, the childless parents lost the motivation of celebrating holidays.

Some parents in the present study reported that seeking help from professionals was helpful, which is consistent with other studies (Cacciatore et al., 2013; Toller & Braithwaite, 2009). The present study found more details about effective support groups and counselors. Bereaved parents participated in support groups to make new friends and learn from others. However, it depended on the number of people participating and talking in the meeting. The present study also reported a good counselor needs to

understand parents' pain and know they likely would not get over their pain. Parents stopped going to a counselor who tried to get them past the death, to move forward. Some other parents did not feel comfortable to cry in front of strangers and talk about the child's death repeatedly. Future study needs to focus on designing different types of support groups or counseling sessions, such as different group sizes, face-to-face, or teleconference.

Factors to affect parents coping.

Dreams and signs of the child. The present study reported the bereaved parents can sense the child's presence and believe some signs represent their child's presence, which is consistent with the findings of other qualitative studies (Gerrish, Neimeyer & Bailey, 2014, Harper et al., 2011). The present study also reported that dreaming is an important coping method for the bereaved parents. They want to dream about the child. They tried to find out how to dream about the child at night. There is very little literature on dreams in bereavement study.

Religion. Religious practices are important coping strategies for the bereaved parents. Schneiders (2003) defined religion is a set of rules to guide individuals' lives during grief process. Religion can include spiritual, but spiritual do not need to include religious practices (Schneiders, 2003). Many parents in the present study stated they prayed a lot, a finding consistent with that reported by Rogers et al. (2008). Hawthorne, Youngblut and Brooten (2017) found that mothers reported greater use of religious coping practices than fathers. None of the fathers in the present study reported using religious coping practices. The present study also reported many parents were angry with God, which is consistent with other studies (Gerrish, Neimeyer & Bailey, 2014; Proulx et

al., 2016). The parents in Proulx et al. (2016)'s study reported that the death of their child challenged their belief in God. The present study reported the bereaved parents thought God had abandoned them.

In the present study, none of the parents went to church weekly or regularly. One mother avoided church because she felt people were judging her and threatening her with eternal damnation. This behavior also contributed to bereaved parents' keeping a distance from their old friends in the church. Many parents in the present study believed they would meet with their child in heaven, if they do not commit suicide. Overall, religious practices were helpful factors that can help the bereaved parents to cope. The bereaved parents may need to practice religion together, instead of going to church with other families who have children.

Online forums. One study (Cacciatore et al., 2013) of bereaved parents focused on using an online forum to recruit participants and collect data. The present study is the first study to use an online content analysis method. The present study reported parents like to share feelings online because they can find hope, seek help, know they are not alone, and have other people understand their feelings. The present study included 30 parents and their independent online posts. Future study can use computer data crawler method to collect a larger sample, which systematically browses the World Wide Web (Amudha & Phil, 2017). Also, future studies need to explore how internet sharing helps parents cope.

Question 3: How Do Parents' Descriptions Vary with the Child's Age/ Gender, Parent's Age/ Gender, Cause of Death, and Time Since the Death?

Child's and parent's age/ gender. Several studies found that mothers experienced more physical and psychological problems than fathers after the child's death (Murphy, Shevlin & Elklit, 2014; Rostila & Ma, 2018; Lichtenthal et al., 2015; Schor et al., 2016; Wang & Xu, 2016; Wijngaards-De Meij et al., 2005; Youngblut et al. 2017). The present study reported that mothers wrote more posts than fathers. Perhaps the mothers were more willing to share their feelings and/or experienced more symptoms. However, none of the fathers reported any physical and psychological problems. The studies conducted in China under the only child policy found that parents who lost their only son had more physical and psychological health problems than those who lost their only daughter (Wang & Xu, 2016; Zheng, Lawson, & Head, 2017). In the present study, parents who lost a boy wrote more posts than parents who lost a girl. Research about the difference between the death of the only son and the only daughter in the U.S. has not been reported. The present study found that the parents of an older deceased child (teens or adult) were more likely to experience marital disruption. Youngblut et al. (2017) found mothers of deceased adolescents experienced a higher level of grief than mothers of younger children or infants. The present study reported younger parents were more likely to stop writing the posts a couple of years after the child's death. The younger parents had more time to have a subsequent pregnancy, and subsequent pregnancy can help the parents in coping (Brooten et al., 2015). It may help to explore why younger parents in the present study were more likely to stop writing the posts.

Causes of death. This study found that parents felt better when they believed their child passed away in their sleep, did not suffer, and died instantly, which is consistent with that reported by Gerrish et al. (2014). The present study found that the parents who expected the child's death wrote fewer posts than the parents who did not expect the child's death. Several other studies reported the bereaved parents who expected the death developed fewer chronic conditions and lower level of depression (Floyd et al., 2013; Youngblut et al., 2013). The parents who experienced fewer physical and psychological symptoms may be less likely to write and share online.

Some parents blamed themselves for their child's death. This finding is consistent with other studies (Lichtenthal et al., 2015; Woodroffe, 2013). Some parents found it difficult to make the decision of removing life support, which is consistent with the study of Woodroffe (2013).

In addition, the present study found that bereaved parents were more stressed if the truth of the child's death was unknown, if they believed someone was lying about the truth, or if they did not believe what was officially reported. Helping the parents find out the truth and providing more details about the child's death are important. Also, this study reported parents whose child died as a passenger in a car crash reported the legal judgment was unfair, which made them feel anger and sadness. It is important to help the parents understand the "facts" of their child's death and the legal process and judgment. Research in these areas has not been reported.

Time since the death. In the present study, bereaved parents described their feelings regardless of the time since the death. Bereaved parents stated they might have more "ok" days after many years following the death than parents who lost their only

child recently. Other studies found that the recency of the child's death was related to the parents' greater psychological distress, higher level of depression and more PTSD symptoms (Cacciatore et al., 2016; Christiansen, Elklit & Olf, 2013; Koyanagi et al., 2017). The present study reported the parents who lost their only child less than 3 months ago wrote posts most frequently. The parents who experienced more physical and psychological problems may be more likely to share their feelings and seek help from others.

In conclusion, the present study adds to the knowledge on parents' experiences after the death of an only child in the U.S. with data collected from online blogs written by parents at 2 weeks to 11 years after the child's death. The present study found that parents described their feelings of grief following the death of an only child as pain, lonely, hurt, depressed, panic, empty, sad, angry, fear and hate, which is consistent with other studies (Lichtenthal et al., 2015; Murphy, Shevlin, & Elklit, 2014). Bereaved parents who lost their only child frequently used words like "lonely", "empty" and "fear, scared or afraid" to describe their feelings. Bereaved parents did not want to "move on". The present study is the first to report that parents may pretend they are functioning normally and doing well and they have jealous feelings about other families who have a surviving child or children. Parents' role identity conflict needs further study to understand parents' role conflict changes over time after the child's death. Lastly, the present study found that some bereaved parents were still having trouble believing their child died at 7 years following the death. Future study is needed to focus on the differences in grief between parents who lost their only child and parents who have a

surviving child or children. Factors that may exacerbate parents' grief included activities at holidays, having people hurt their feelings, and having no surviving child.

The present study found that the bereaved parents did not want to work in jobs handling complaints, such as customer service, after their child's death. Future studies need to identify which types of positions are most stressful after the child's death. A few parents' marital relationships suffered negative effects of the child's death in the present study. There is very little literature on marital relationship disruption after the death of an only child. Future studies are needed to identify the prevalence and reasons for the marital discord after an only child's death in the U.S. Also, the present study is the first study to report that people avoided talking to the bereaved parents in the U.S.

In the present study, the most common physical problem parents reported was sleep disturbances, which is consistent with Bolton et al. (2014). Many bereaved parents in the present study reported psychological problems, consistent with many other studies (Bolton et al., 2014; Cacciatore et al., 2014; Devylder et al., 2013; Jind et al., 2010; Koyanagi et al., 2017; Murphy, Shevlin & Elklit, 2014, Pan et al., 2016; Rogers et al., 2008; Youngblut et al., 2013). Some parents had suicidal ideation, as in other studies (Harper et al., 2011; Hendrickson, 2009; Zetumer et al., 2015). Also, the present study found that many parents had problems with daily living activities, which were rarely reported by other studies. Future study is needed to focus on factors which may affect parents' physical and psychological health.

The present study described the coping methods for bereaved parents following the death of an only child, findings consistent with many other studies (Brooten, Youngblut, Caicedo & Dankanich, 2019; Caicedo, Brooten, Youngblut & Dankanich,

2019; Proulx et al., 2016; Snaman et al., 2016; Thompson et al., 2011). The present study found that parents maintained their connection with their deceased child, which is consistent with the findings of other studies (Barrera et al., 2009; Harper et al., 2011; Proulx et al., 2016). In the present study, some parents believed socializing was helpful, but others preferred avoiding attending any such events. Many studies report that holidays, birthdays, and anniversaries of the death are difficult for parents (Dias, Docherty & Brandon, 2017; Parker & Dunn, 2011), but this is the first study to report what parents actually did during these difficult events. The present study had conflicting findings about seeking help from support groups and counselors, as in other studies (Cacciatore et al., 2013; Endo, Yonemoto & Yamada, 2015; Toller & Braithwaite, 2009). Future study focused on ways to improve support groups or counseling sessions to meet the parents' needs is needed. Factors affected parents' coping included dreams and signs, religion, and online forums. Some bereaved parents could sense their child's presence and interpreted some signs as coming from their child, which is consistent with the findings of other qualitative studies (Gerrish, Neimeyer & Bailey, 2014; Harper et al., 2011; Youngblut et al., 2017). There is very little literature on dreams in bereavement studies. Many parents avoided suicide so they could be reunited with their child in heaven. None of the parents reported going to church weekly or regularly in the present study. There is very little literature on the details of bereaved parents' religious changes after the child's death (Hawthorne et al, 2017). In the present study parents reported that sharing their feelings online helped them find hope, seek help, know they are not alone, and communicate with other parents who lost a child. Future study can use a computer

data crawler method to build a larger sample and explore how internet sharing helps parents to cope.

The present study found that mothers wrote more posts than fathers. None of the fathers reported any physical and psychological problems. Parents who lost a son wrote more posts than parents who lost a daughter. Younger parents were likely to stop writing posts a couple of years after the child's death. Parents whose deceased child was teenaged or older were more likely to have suicidal ideation and experience marital disruption. Parents who expected the child's death wrote fewer posts than parents who did not expect the child's death. Parents described a roller coaster of "ok" and "not ok" days, although they had more "ok" days after many years following the death than parents who lost their only child recently.

Conclusion

This study found that the bereaved parents' experiences after the death of their only child in the U.S., which were description of grief, family's functioning, physical and psychological problems, coping strategies, and factors related to parents' grief. Future studies are needed to focus on the differences in grief between parents who lost their only child and parents who have surviving child(ren) and identify which types of job positions are most stressful after the child's death. Also, the future studies need to identify the prevalence and reasons for the marital discord after an only child's death in the U.S. The factors which may affect parents' health and the ways to improve support groups or counseling sessions to meet the parents' needs are essential to be discussed in the future study. The future study also can use the computer data crawler method to build a larger sample and explore how the internet sharing help parents to cope.

This study has offered valuable information and insights which described bereaved parents' experiences after the death of an only child in the U.S. There are a few limitations with this study. First, all the bereaved parents in this study were recruited from the internet. The parents who wrote on the internet may grieve differently and use different coping strategies than parents who did not write online. Second, most of the deceased children in this study were adolescents or young adults. The older bereaved parents may grieve differently than the younger parents following the death of an only child. Third, fewer fathers were recruited than mothers, which is a common finding in these studies.

The findings from this study can be beneficial for nursing practice, research, and education; grief management; and better tailoring interventions to help parents bereaved of their only child. The findings of this study can help nurses to better understand parents' feelings after the death of their only child and provide better care to avoid any panic triggers. Understanding bereaved parents' difficulties and health problems can help nurses to provide prophylactic healthcare and patient education. This may prevent the bereaved parents from the consequential negative outcomes after the death of their only child. In addition, appropriate and effective interventions can be developed based on the findings of this study. A next step in research in this area may be a quantitative on the effects of internet posting or blogging for bereaved parents.

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PUBLICATIONS

- 1, Hidalgo, I., Brooten, D., Youngblut, J., Roche, R., Li, J., & Hinds, A. (2021). Practices Following the Death of a Loved One Reported by Adults from 14 Countries or Cultural/Ethnic Group. *Nursing Open*, 8(1), 453-462.
- 2, Youngblut, J.M., & Li, J. (2019). Editorial: parent, grandparent, and sibling responses to the death of an infant or child in intensive care. *Pacific Rim International Journal of Nursing Research*, 23(1), 1-5.
- 3, Brown, E. L., Ruggiano, N., Li, J., Clarke, P. J., Kay, E. S., & Hristidis, V. (2019). Smartphone-based health technologies for dementia care: opportunities, challenges, and current practices. *Journal of Applied Gerontology*, 38(1), 73-91
- 4, Ruggiano, N., Brown, E., Li, J., & Scaccianoce, M. (2018). Rural demential caregivers and technology: what is the evidence? *Research in Gerontological Nursing*. 11(4), 216-224
- 5, Li, J., Brown, E., Ruggiano, N., and Olenick, M. (2017, May). *Smart phone technologies for dementia care: a systematic review*. Poster presented at Miami Veterans Affairs Nursing Day, Miami, FL.
- 6, Li, J., and Caicedo, C. (2017, February). *Family health outcomes and use of leisure activities in families with medically complex children*. Poster presented at the 31th Southern Nursing Research Society Annual Conference, Addison, TX.

7, H. Jiang, J. Li, and Dr. VanderMeer; “Exploring the workload balance effects of including continuity-based factors in nurse-patient assignments.” DESRIST 2016 Conference. St. John’s, Canada.

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9, Youngblut, JM., Brooten, D., Caicedo, C., Li, J., & Hidalgo, I., Parents’ stress, concerns, and mental health within 24 hours of their preschoolers’ hospital discharge for traumatic brain injury. *Journal of Developmental and Behavioral Pediatrics*. (Major revision)

10, Caicedo, C., Sampedro, AD., Li, J. Families with medically complex children with special health care needs in 3 care settings: effects of leisure activities on parent health and family functioning. (in progress)

11, Brooten, D., Youngblut, JM., Hannan, J., Caicedo, C., Li, J., & Dankanich, J. Child ICU Death: Parent Health and Functioning 1, 3, 6, 13 months and 2-6 years after the child’s death. (in progress)