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As two become one: The lived experience of a twinless twin

By

Jody Ness

Thesis Advisor, Dr. Tish Smyer

A thesis in partial fulfillment of the requirements for the

Masters of Science

Major in Nursing

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2005

As two become one: The lived experience of a twinless twin

This thesis is approved as a creditable and independent investigation by a candidate for the Master of Science Degree and is acceptable for meeting the thesis requirements for this degree. Acceptance of this thesis does not imply that the conclusions reached by the candidate are necessarily the conclusions of the major department.

Dr. Tish Smyer
Thesis Advisor Date

Dr. Sandra Bunkers
Head Date

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To Gage, my angel in heaven, your spiritual presence guided me on this journey and Skylor will now know that your short stay with her was significant. May God cradle you in his arms like I never could.

Abstract

As two become one: The lived experience of a twinless twin

Jody Ness

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Twins enter life as a pair and are often viewed so in later life. After the death of a co-twin, twins feel like they have lost part of themselves, leaving them alone, often without professional help. No nursing research has provided insight into the experience of a twin who has lost their co-twin.

The purpose of this research was to explore and describe the lived experience of a twin who has lost their co-twin. The aim was to generate an understanding of the unique bond and sense of loss experienced by twinless twins. Phenomenology and Attachment Theory were utilized to guide this study. Colaizzi's seven step method was used to analyze the data. This study of nine subjects identified three themes and nine sub-themes.

This awareness will be beneficial for parents of twins, twins themselves and health care providers. This research contributes to existing literature on twin loss.

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Chapter One: Introduction

Chapter one discusses twin statistics and risk factors before and after birth in comparison to singleton pregnancies. The twin phenomenon is then discussed along with a brief history of how twins have been viewed in society. In addition attachment, identity and grief is reviewed.

Background

In 2003 there were 125,134 live infants of multiple births born in the United States. The ratio is 31.1 twins/ 1,000 live births (National Center, 2003). This number reflects an upward trend in multiple births since the late 1970s. Delayed childbearing is a predominant factor for the increase in multiple births. Physiologically twinning increases until ages 35 to 39 years and then declines with the fall in gonadotrophin secretion. Thirty percent of multiple births are due to childbearing in these women (Bowers, 1997). Also delayed childbearing contributes to infertility. With infertility there is an increase in the use of assisted reproductive technology resulting in multiple gestations (Bowers, 1997 & Withrow & Schwiebert, 2005).

Twins occur in at least two different ways. Monozygotic or identical twins evolve from one egg fertilized by one sperm. The egg splits after fertilization producing twins who share 100% of their genetic material (Stewart, 2000; Withrow & Schwiebert, 2005). Two eggs, each fertilized by a different sperm, produce Dizygotic, or fraternal twins. Dizygotic twins can be of mixed genders and share only about 50% of their genetic material (Stewart, 2000; Withrow & Schwiebert, 2005). Dizygotic twinning occurs more often in families, African American women, increased parity and advanced maternal age

over 35 years. Monozygotic twinning has no association with race, heredity, maternal age or parity. Fertility drugs can increase the occurrence of both monozygotic and dizygotic twins (Lowdermilk & Perry, 2004). In the United States 3% of all live births result in twins, making 6% of all babies born alive, twins (Withrow & Schwiebert, 2005).

Problems are more prevalent in multiple pregnancies than in singleton pregnancies. When compared to singletons, multiple gestation pregnancies have an increased risk for poor outcomes before and after delivery.

The primary factors contributing to perinatal morbidity and mortality in the United States for singletons and multiples are preterm birth and low birth weight. According to Tough et al. (2002) advanced maternal age contributes to this problem. Advanced maternal age is not only associated with an increase in twin gestation, as mentioned earlier, but it is also a risk factor for preterm birth and low birth weight. Advanced maternal age and twin gestation pregnancies when combined pose a risk, but alone, without considering any other risk factors, twin pregnancies pose a significant risk in both preterm deliveries and low birth weight. Preterm deliveries occur 2 to 5 times more often in twin pregnancies than in singleton pregnancies and low birth weight occurs 8 to 10 times more often (Tough et al., 2002).

Twin pregnancies are also two or more times as likely than a singleton pregnancy to have complications in a number of other areas increasing the Neonatal Intensive Care Unit admission to 7 times more likely than a singleton birth. Fetal and perinatal mortality (less than 28 weeks gestation, 6 days after birth) is 3 times higher than singleton births and neonatal mortality (0 to 28 days old) is 3 to 7 times higher than singleton births. After

birth, almost 5% of live-born twins die during the first year of life (Bowers, 1997). The risk of Sudden Infant Death Syndrome is also twice as high for twins (Withrow & Schwiebert, 2005). According to Segal (1999) it is not until after age six and as adults that disease and death rates become similar to singletons.

Demise before birth may be caused by the vanishing twin syndrome, still birth, or fetal transfusion syndrome (Segal, 1999). Vanishing twin syndrome is when one twin early in pregnancy, before 20 weeks gestation, ceases to develop (Segal, 1999). Early in the pregnancy two fetuses are identified by ultrasound but only one fetus consequently develops fully. Often no evidence of twin loss occurs and the assumption is that the twin has been reabsorbed into the placenta (Brisco & Street, 2003). In a study by Briscoe and Street (2003) evidence suggested that 30% of identified twin pregnancies result in a vanishing twin. After 20 weeks gestation the loss is identified as a stillbirth (Brisco & Street, 2003). Stillbirth rates are 3 times higher in twin pregnancies than in singletons (Withrow & Schwiebert, 2005).

Fetal transfusion syndrome or twin to twin transfusion is one of the most serious problems for twin pregnancies. Blood is shunted between placentas causing the recipient twin to be larger and the donor twin to be small, pale, dehydrated, malnourished, and hypovolemic often resulting in death (Lowdermilk & Perry, 2004).

Historical perspective

The birth of twins occurs in all cultures with the incidence being more prevalent in some cultures more than in others. Myths about twins exist in most cultures making “twins themselves a universal phenomenon” (Stewart, 2000). Myths about twins appear

as far back as the Old Testament. Twins were viewed as intense rivals in the Old Testament. The belief was, before birth twins struggled to be born first and after birth they were presented as conflicting halves destroying each other rather than living in harmony (Stewart, 2000).

In Greek mythology twins were worshipped as divine. Greek myth saw one twin being fathered by a human and the other twin being fathered by a god or spirit, therefore creating a divine presence (Stewart, 2000). Aryan mythology also viewed twins in this same manner. Twins have been associated with gods of light, the morning and evening star, or constellations (Stewart, 2000).

The Indo-Europeans believed twins had healing and fertility powers, could aid others in battle, and were sometimes associated with swans or waterfowl. Although, Indo-European twins were mostly associated with horses (Stewart, 2000).

The North American Indians, such as the Mohave, believed twins came from the sky. They descended to earth and were viewed as immortal. Twins were wanted on earth for as long as possible to function as rainmakers, or fertility specialist for the Indians (Stewart, 2000).

In society twinship is viewed in many different ways, both positive and negative. Some populations continue to view twins in the same way as the myths state. Other populations, especially those with advanced technology, view twins within a highly evolved framework. Twins continue to be studied today by researchers because of their unique qualities.

Attachment and twins

Due to the increased use of reproductive technology and delayed childbearing the number of multiple births will continue to increase and society will clearly have to change how twins are viewed as a phenomenon and as individuals. Due to increased morbidity and mortality, healthcare will also encounter surviving twins more often resulting in the need for understanding of the unique bond and grief process for the twinless twin.

Today approximately 3% of the total population are twins. Those who are twins have experienced imbued twin relationships with extreme closeness, magical understanding, private languages, and individual fantasies of having another self (Withrow & Schwiebert, 2005).

Being a twin has both advantages and disadvantages. The closeness can provide some protection against loneliness and ease some of the trials of adolescents (Withrow & Schwiebert, 2005). The twin bond can also have a negative affect on social relationships, increasing the risk of academic delays, inequalities and delayed individuation (Withrow & Schwiebert, 2005).

In this case the individual is part of a twosome. Twins are often referred to by society as a single entity, or given the name “the twins” (Woodward, 1998; Withrow & Schwiebert, 2005). It is difficult for twins to gain a separate identity because of the use of one term for the pair. According to Withrow & Schwiebert (2005) twins tend to form their identity along patterns distinct from singletons. Even when separated or raised apart, monozygotic and dizygotic twins tend to be more alike than when raised together. This

suggests that the presence of the co-twin affects identity formation (Withrow & Schwiebert, 2005).

Leonard (2001) also reports that the concept of being one is complex especially for a bereaved twin making it difficult to create and foster an individual identity. According to Woodward (1998) the development of self begins with proper attachment. Attachment theorists believe attachment develops around six months of age, but Woodward (1998) briefly discusses findings that twins could possibly relate and develop attachment before birth (Woodward, 1998). This early attachment then could affect identity formation.

Because of early attachment and the single identity formation a strong twin bond is developed (Woodward, 1998). When the twin bond is broken or threatened, deep patterns of feelings often arise that threaten a twin's identity and sense of self. These feelings can last a lifetime (Woodward, 1998). According to Segal (1999) and Withrow & Schwiebert (2005) too little is known about twinless twins' reactions to survival after the loss of a co-twin. Some twins may experience guilt, anger, frustration or sadness later in life (Segal, 1999). According to Leonard (2001) multiple birth survivors have reported feeling that something is missing or lost. Endless searching for attachment is pursued, but cannot be found and intense loneliness and guilt arise (Leonard, 2001). It is assumed then that these feelings of loss and inadequate attachment may also threaten identity and sense of self.

Problem and Significance

According to Segal, Wilson, Bouchard, and Gitlin (1995) bereavement researchers have neglected twin loss. Some research has been done on sibling loss, but very little has been done on twin loss because twins are often thought of as the exception or too complicated to study (Withrow & Schwiebert, 2005). The lack of research is mostly due to the lack of awareness about the uniqueness and severity of twin loss (Withrow & Schwiebert, 2005). Leonard (2001) also discusses the need for nursing research to focus on the development and evaluation of strategies designed to foster healthy identity in twinless twins.

The grief process associated with any loss can be unpredictable (Charlton, 2003), but in order to understand the loss from a twin's perspective we must first understand the attachment between the pair and the meaning of the loss for the surviving twin. Understanding the bond and the meaning of the loss will allow professionals to develop interventions for parents and twinless twins. Family members and twinless twins need guidance in order to journey through a healthy grieving process. Twinless twins also need direction to develop a positive sense of self. In order to do this it is important to understand the unique experience of twins.

Purpose

The purpose of this research was to explore and describe the lived experience of twins who have lost their co-twin. The aim was to generate an understanding of the unique bond and sense of loss experienced by twinless twins. This research contributes to

existing literature on twin loss. This study used a qualitative design, phenomenology, to study the lived experience of a twinless twin and answered the question, “What is the lived experience of a twinless twin?”

Chapter Two: Review of Literature

Chapter two discusses the research related to twin behaviors and attachment from 15 weeks gestation to early childhood. The grief process will then be addressed in relation to non-twin loss. Six types of twin identity attachment formation and the separation affects associated with these will then be addressed. In addition, research related to twin attachment and grief in regards to loss will be addressed.

Twin behaviors and attachment (15 weeks gestation to early childhood)

Behavior between twins can be viewed on ultrasound and by 15 weeks gestation activity between twins occurs in all pregnancies (Leonard, 2001). During pregnancy multiples establish a pattern of tactile stimulation among themselves. An important part of the environment during pregnancy is the tactile stimulation received from the co-twin (Leonard, 2001). According to Leonard (2001) ultrasound shows twins approaching each other continuously with their hands, faces or full body. A description of one set of twins observed during ultrasound shows a male twin reaching out to touch the female twin's face. She responded by turning her face toward him and then engaging in a cheek-to-cheek motion of stroking. At age one the twins continued to play a similar game of cheek-to-cheek touch (Leonard, 2001). Behaviors observed during pregnancy can also be observed in infancy and beyond (Leonard, 2001).

Researchers have also found similarities in twins when examining fetal heart rate accelerations, breathing patterns, body movements and sleep wake patterns. Sets of twins' 28-39 weeks gestation were viewed by ultrasound and after birth to identify behavior patterns. Each twin pair was found to be the same 95% of the time regarding the

time spent in sleep wake patterns before and after birth. A notable portion of heart rate accelerations, breathing patterns, body movements and sleep wake patterns was likely due to tactile stimulation between the two (Leonard, 2001). Woodward (1998) also states in a brief description that when observed by ultrasound during pregnancy twins relate to each other and may form some type of attachment prior to and around the time of birth.

After delivery co-bedding has also demonstrated similar patterns, which may contribute to attachment. Co-bedding is when both of the infants are placed in the same bassinet or crib. The advantages to co-bedding are improved heart rate, temperature, respiratory control, fewer apneic periods, lower oxygen requirements, and greater weight gain (Leonard, 2001). Co-bedding has also demonstrated attachment when twins move closer to each other, touch, hug, look at and suck on each other (Leonard, 2001).

A quantitative study demonstrating attachment as children describes the strong bond between twins. Fifteen twin pairs were observed for signs of distress under three different conditions (Gottfried, Seay & Leake, 1994). The subjects were placed in a playroom and three conditions followed. The mother and twins present together, twins together and mother absent, and the subject isolated from both the twin and the mother. Separation from both the twin and the mother produced high levels of distress. Separation from the mother with the co-twin present, however, elicited little distress (Gottfried et al., 1994). Twins are peers with fairly equivalent maturity levels and similar social behaviors. Twins also form a symmetrical relationship where neither partner is dominant (Gottfried et al., 1994). The patterns of distress described support the idea that twins provide

security for their co-twin (Gottfried et al, 1994). A question of concern is, if the security established between twins is broken by loss, can detrimental effects occur?

The grief process

The loss of a loved one to death is a significant experience in one's life. It can affect self-concept, health and socioeconomic circumstances (Steen, 1998). Bereavement is the state of having lost a significant other to death and grief is the personal response to that loss (Steen, 1998). Loss is a unique lived experience, grief is also unique, and is part of healing and health (Solari-Twadell, Bunkers, Wang & Snyder, 1995). To understand the grieving process for a twin we first must understand the grieving process for the general population.

There are many theories on the grieving process and its affects. Grief must be recognized as an individual and dynamic process that has to be worked through by each person (Dunn, 2004). Normal grief is described as uncomplicated and most people are able to cope or work through the process on their own, but a broad range of feelings and reactions may occur. (Dunn, 2004).

Phases of grief may include shock, disbelief, avoidance, mourning, resolution and reorganization (Steen, 1998). Normal grief symptoms vary among individuals, but physiologic, psychological and psychosocial reactions may occur (Steen, 1998). The grief process may last up to 3 years with certain events reviving grief for many years (Steen, 1998). The grieving process can therefore become a health issue. According to Charlton (2003) anything that affects the physical, psychological, emotional and social aspects of a

person's life can lead to an illness through impairment of health. Grief falls into this category.

Loss can occur in many different ways, but the ultimate is the loss of a loved one through death. The response to loss depends on the relationship with the deceased the mode of death, and life crises that occurred prior to the loss (Dunn, 2004). Other factors such as personality, religion, culture and familial factors also influence grief. If a grieving person perceives his or her family or social network as non-supportive in the grief process poor outcomes may occur (Dunn, 2004).

For nurses it is important to understand the concept of grief, it's attributes and consequences (Dunn, 2004). According to Worden (1991) one approach to explain the grief process concentrates on tasks that must be worked through if resolution is to take place (Figure 1).

Task one is to accept the reality of the loss and accept that the loss has occurred. This takes time because it is both an intellectual and an emotional process. The opposite of accepting the loss is not believing it happened. Others may deny the meaning of the loss. It may be seen as less significant. Selective forgetting is also common. If this occurs individuals are stuck in the first task of grieving. Rituals such as funerals and burials may help the bereaved achieve this task (Worden, 1991).

Task two is to work through the pain of grief and recognize that additional pain will emerge during the subsequent tasks of grief. Anything that causes suppression of this pain disrupts task two. The opposite of this task is to not feel. Society can contribute to this by appearing uncomfortable with the individual's feelings. Another problem occurs

when individuals only allow themselves to think pleasant thoughts about the deceased, protecting them from uncomfortable feelings. Alcohol and drugs are often associated with this task. Others may travel from place to place trying to relieve their emotions. Grief counseling is very important if this task is to be achieved (Worden, 1991).

Task three is the adjustment period. Adjusting to the environment in which the deceased is missing is continuous. The individual must find a way to deal with the lost roles of the deceased. Also individuals will have to adjust to their sense of self without the deceased. This task becomes a problem when the individual does not adapt to the loss, withdraws from the world and loses direction in life (Worden, 1991).

Task four is to withdraw emotional energy for the lost one and reinvest it into another relationship. Individuals not have to give up the relationship, but find a place for it in their lives that enable them to function appropriately. This task becomes a problem when the person cannot let go of the past attachment and form new ones. This may be the most difficult task to work through, but with support and time it can be accomplished (Worden, 1991).

Figure 1. Worden's approach to the experience of loss that concentrates on the tasks of grieving.

Worden's tasks

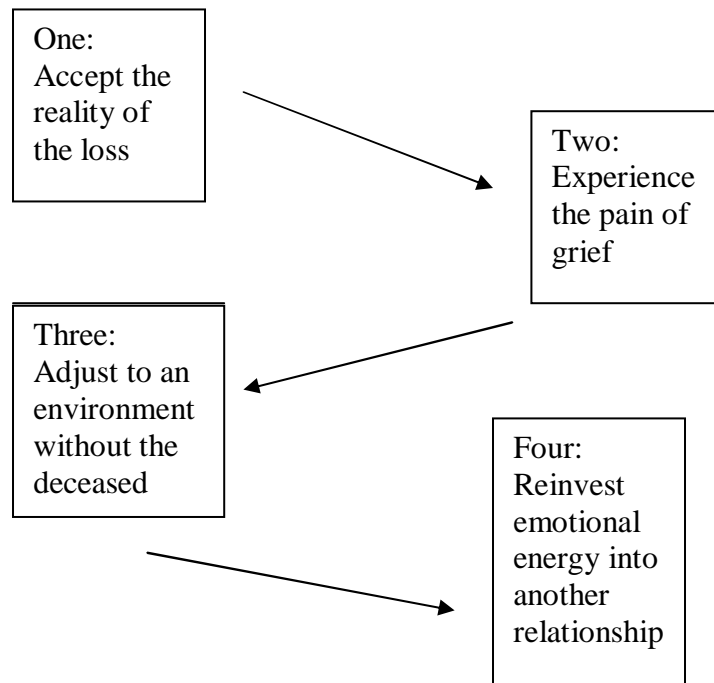


Figure 1: Worden's grief tasks (Worden, 1991).

Grief also has consequences. After loss, the grieving person must give up his or her common view of the world and develop another. A high degree of pain and anxiety occurs as lifestyle changes take place. Some individuals withdraw or restrict themselves socially (Dunn, 2004). According to Dunn (2004) this time of transition is when grieving persons need the most support and assistance in discovering new ways to emerge into the world. Early recognition and intervention is key for nurses to identify those at risk. Information on the grieving process, practical help and advice are often sufficient. Others require in depth support from professional counselors (Dunn, 2004).

Behaviors and attachment in relation to twin loss

Research shows the loss of one twin causes devastation to parents and families, but little is known about the surviving twin's reactions (Leonard, 2001). According to Leonard (2001) after stimulation and some type of attachment has occurred during pregnancy between the twins then a presumption can be made that the surviving twin feels some sense of loss. Although it is unknown if the stimulation between the twins is embedded in the subconscious of the mind of the surviving twin (Leonard, 2001).

According to Segal (1999) little is known about twinless twins' reactions to survival after the loss of a co-twin, but some twins may experience guilt, anger, frustration, or sadness later in life. Woodward's study of multiple-birth survivors (1998) reports a feeling that something is missing or lost (Woodward, 1998). These feelings arise even if the lone twin is unaware of being a twin (Woodward, 1998). Leonard (2001) describes it as endless searching for attachment that cannot be found resulting in intense loneliness and guilt (Leonard, 2001). Some have expressed the sense that part of them is

draining away. Others feel like they are suddenly half, or have lost their identity (Withrow & Schwiebert, 2005).

Behaviors can change for the surviving twin also. After twin loss some twins have tried to develop the talents of their co-twin in order to meet expectations from parents or society. This can lead to identity disturbances and life long patterns of trying to please others (Withrow & Schwiebert, 2005).

Physical identity can also cause problems for surviving twins. Some twins are confused when watching a co-twin die. They are unsure about who is dying or who is dead when they later look in the mirror (Withrow & Schwiebert, 2005). The sight of the surviving twin can often be a painful reminder to the twin's family and being confused for the dead twin can be painful for the survivor (Withrow & Schwiebert, 2005).

The attachment, identity formation and concept of being part of one are complex issues for a grieving twin. Their sense of identity may be challenged and the grief process may be affected (Leonard, 2001). Twins are closer than singletons, depend on each other to form their identities, and concentrate their relationship development on each other. When they lose each other they lose what they have developed. Twins also have little experience being alone so death creates a sense of isolation compounded by feelings that others don't understand what they have lost (Withrow & Schwiebert, 2005). Many twins feel like half a person when a co-twin dies. They have lost the way they identify themselves, as a twin (Withrow & Schwiebert, 2005). According to Leonard (2001) nursing research is needed that focuses on the development and evaluation of strategies designed to foster healthy identity development in twins whose co-twin dies.

Twin Identity Formation

Identity formation is unique for twins and six patterns of identity have been found to develop in twin pairs. Each pattern has different effects on the surviving twin if the twins are separated (Withrow & Schwiebert, 2005).

Unit identity. This is characterized by a merge in identity where one twin thinks of themselves as a half of a whole personality. These twins find separation extremely painful and often live with one another later in life (Withrow & Schwiebert, 2005).

Interdependent identity. Twins in interdependent identity consider each other best friends and look to each other for primary support and develop relationships that mimic the twin bond. They are true friends and depend on each other sharing a healthy relationship (Withrow & Schwiebert, 2005).

Split identity. This is when twins perceive inequalities between themselves and think of themselves as opposites and seldom trust one another. Usually one is considered good and the other bad. The good twin finds relief when separated from the bad twin because the good twin feels like the bad parts of his or her identity are gone. The surviving twin still needs the twinship to highlight the good qualities. The bad twin may experience anxiety and depression because the good parts of his or her identity have been lost. The surviving twin may feel inadequate through life unless an understanding is developed about his or her identity (Withrow & Schwiebert, 2005).

Idealized identity. Twins who find being a twin the most important aspect of their lives and take pride in their unique relationship are in idealized identity. They may not always share thoughts and feelings intimately, but they face the world together.

Separation is not difficult, but they may always think of themselves as a twin (Withrow & Schwiebert, 2005).

Competitive identity. This is characterized by twins sharing a strong empathetic bond for each other, encouraging each other in achievements and they are able to develop close bonds with others. These twins are parallel with each other, but they appreciate the differences that they have. These twins have the most potential outside the twin relationship. They develop intimacy with other people, but are comforted by each other's presence (Withrow & Schwiebert, 2005).

Sibling attachment identity. This is when twins develop separate identities similar to those of very close siblings. Separation from each other is also very similar to non-twin siblings (Withrow & Schwiebert, 2005).

Because of these attachment styles the grief process may appear differently depending on the style of identity attachment. It is also important to remember regardless of the attachment style twins experience a different type of loss than singletons. The age of twin loss may also have an affect on these attachment styles and the degree of loss (Withrow & Schwiebert, 2005).

Sibling loss, in general, can be devastating causing problems with schoolwork, personal relationships, and problems that follow into adult life. The problem for twins is that they have lost a role that can never be regained (Withrow & Schwiebert, 2005).

Strong feelings of guilt also arise, especially for those who have experienced a loss in childhood because of suicide or handicap. The children, especially boys, often engage in risk taking behaviors (Withrow & Schwiebert, 2005).

During adolescence, teens often have difficulty verbalizing feelings. The loss of a sibling during adolescence interferes with identity formation, leaving some feeling different. For a twins, loss means losing part of who they are. They may begin to withdraw and prolong the grief process (Withrow & Schwiebert, 2005).

During adulthood, companionship, rivalry, and loyalty persist. Loss of a sibling may increase awareness of personal mortality, and negatively affect the longevity of surviving siblings. This risk is increased for twins. Surviving twins have to learn to deal with new situations alone without the confirmation they are use to from their co-twin (Withrow & Schwiebert, 2005).

Loss is heightened when the loss is a twin. They are closer, and develop an interdependent identity, which is only known by twins (Withrow & Schwiebert, 2005). The amount of stress experienced by siblings is often correlated with the amount of life space shared. Twinship starts at conception and when death occurs detrimental effects may take place.

Kinship Theory

According to Steen (1998) kinship may play an important role in the grief process. A study by Segal and Bouchard (1993) demonstrates the kinship theory. A study on bereavement experiences of 49 surviving monozygotic and 19 surviving dizygotic twins was performed to identify the intensity of grief experiences. A twin loss survey was completed to assess the intensity of bereavement in response to the death of a twin and other relatives. The age of death was 15 or older. The mean intensity rating for the deceased twin was significantly higher than for mothers, fathers, grandfathers,

grandmothers, spouses and other relatives (Segal & Bouchard, 1993). The project was designed to fill a gap in knowledge about responses to death, bereavement and grieving as well as to furnish a basis for assisting twins who have experienced the loss of their own twin. The findings show that bereavement intensity increases with relatedness to the deceased (Segal & Bouchard, 1993).

A study comparing the nature of grief experienced by bereaved twins and other bereaved individuals was also examined. Two-hundred and seventy-nine bereaved twins and one-hundred and two bereaved non-twins completed the Grief Experience Inventory (GEI). Twins' scores were higher than the non-twins that experienced loss. The non-twin individuals were organized by relationship to the deceased. This study suggests that social relatedness may play a role in bereavement (Segal, Wilson, Bouchard & Gitlin, 1995).

Through witness and support the bereaved can get in touch with the lived experience of loss to death (Solari-Twadell et al., 1995). Screening for high risk bereaved populations is important so that a normal grief process is followed (Steen, 1998). Understanding what the lost loved one meant to the survivors, how they lived together, what their dreams were and the nature of the events surrounding death are important in order to understanding that particular loss (Solari-Twadell et al., 1995).

Based on early attachment findings, identity patterns, feelings of loss, loneliness, guilt, endless searching for attachment, consequences of dysfunctional grief and increased bereavement intensity, twinless twins are a high-risk population that could benefit from support, screening and understanding from the healthcare system. Treatment

can focus on helping the twin find a sense of wholeness. It is important to recognize the uniqueness of the loss and the intensity of the relationship in order to understand the grief process for twins.

The concern lies in the fact that very little research has been conducted so understanding can take place. No nursing research has been done to determine the lived experiences of this grieving population. Through exploration of the lived experience clinicians can better understand the meaning of loss and develop appropriate avenues of care to help twins and their families develop healthy coping strategies. Parents need guidelines to help their surviving twin cope with the loss, but most of all, by researching the lived experience, clinicians can develop plans to help guide surviving co-twins through a healthy grieving process.

Chapter Three: Theoretical Framework and Assumptions

Chapter three discusses the theoretical framework used in this study, which is Bowlby's attachment theory. Assumptions made by this researcher in relation to the bereavement of twinless twins will also be addressed.

Theoretical framework

The theoretical framework for this study is attachment theory. Attachment theory is a way of conceptualizing the tendency of human beings to make strong affectionate bonds with others (Woodward, 1998). The theory arose after Bowlby observed the relationship between babies and children and their mothers (Woodward, 1998). Figure 2 explains Bowlby's Attachment Theory in a schematic form.

Bowlby's work falls within psychoanalytical theory. Attachment theory is built upon Freud's core clinical and developmental insights. Bowlby elaborates on the idea of important early experiences and relationships. He also builds upon the idea of unconscious processes being the key to the power of these early experiences and the role of relationships in reworking these experiences. Early experience is not lost according to Bowlby's theory. For the infant, quality, availability and responsiveness of care are central issues in development. Development proceeds regardless of care, but it continues based on previous patterns of adaptation. Later experience is based on the context of previously formed representations of self and other. Early experience is important because each successive adaptation is a product both of the new situation and of development to that point. Bowlby's theory allows for a basic understanding of the developmental roots of adult disorders, experiences that leave individuals vulnerable to

stressful life circumstances and the ability to find strength from social support (Sroufe, 1986).

According to Sroufe (1986) attachment is an independent system built into human biology to ensure survival. All that is required for attachment is the availability of another for interaction, but the quality of attachment is most important. If responsive care is unavailable, disrupted or insecure, anxiety may be of concern when developing future relationships (Sroufe, 1986).

Separation is a normal part of adaptation and anxiety may occur. If an infant is chronically concerned about care or separation then anxiety becomes pathological. Social expectations by individuals are reflections of their history of availability of care and attachment. Personality also forms from these early experiences of care. Infants who experience responsive care will internalize others as available and themselves as important. Chronic anxiety in relation to care results in a personality that is dependent (Sroufe, 1986).

Mourning the loss of an attachment relationship is normal. Lost relationships must be recovered, if not, an intense emotional reaction may follow. The inability to recover from mourning can be pathological and may lead to depression in adulthood. If a child feels guilty over a loss, is chronically threatened with abandonment, or an attachment relationship has been disrupted they are at risk for pathological mourning and depression. An early unresolved loss leaves an individual vulnerable to a depressive reaction to a loss as an adult (Sroufe, 1986).

According to Woodward (1998) Bowlby's theory is applicable across many different situations. Safe attachment helps children develop a secure and valued sense of self and makes them conscious of their own separate sense of identity. This sense of self allows further bonds to be made with others. According to Woodward (1998) the greatest need for attachment occurs up to the age of three, but the need continues in varying degrees throughout life. The recognition that proper attachment comes from a sense of self gives understanding to why it is difficult for twins to gain a strong sense of identity. Their sense of self is built on the concept of being a pair (Woodward, 1998). The unwilling loss of attachment through death of a twin can lead to a state of separation anxiety (Woodward, 1998). When twin loss occurs an assumption can be made that the twin feels a loss of self and intense reactions may occur. If identity of self is lost or underdeveloped, mourning is unresolved and healthy attachment does not replace the one lost, it is then assumed, based on attachment theory that a pathological condition may occur.

Figure 2 explains Bowlby's Attachment Theory and concepts

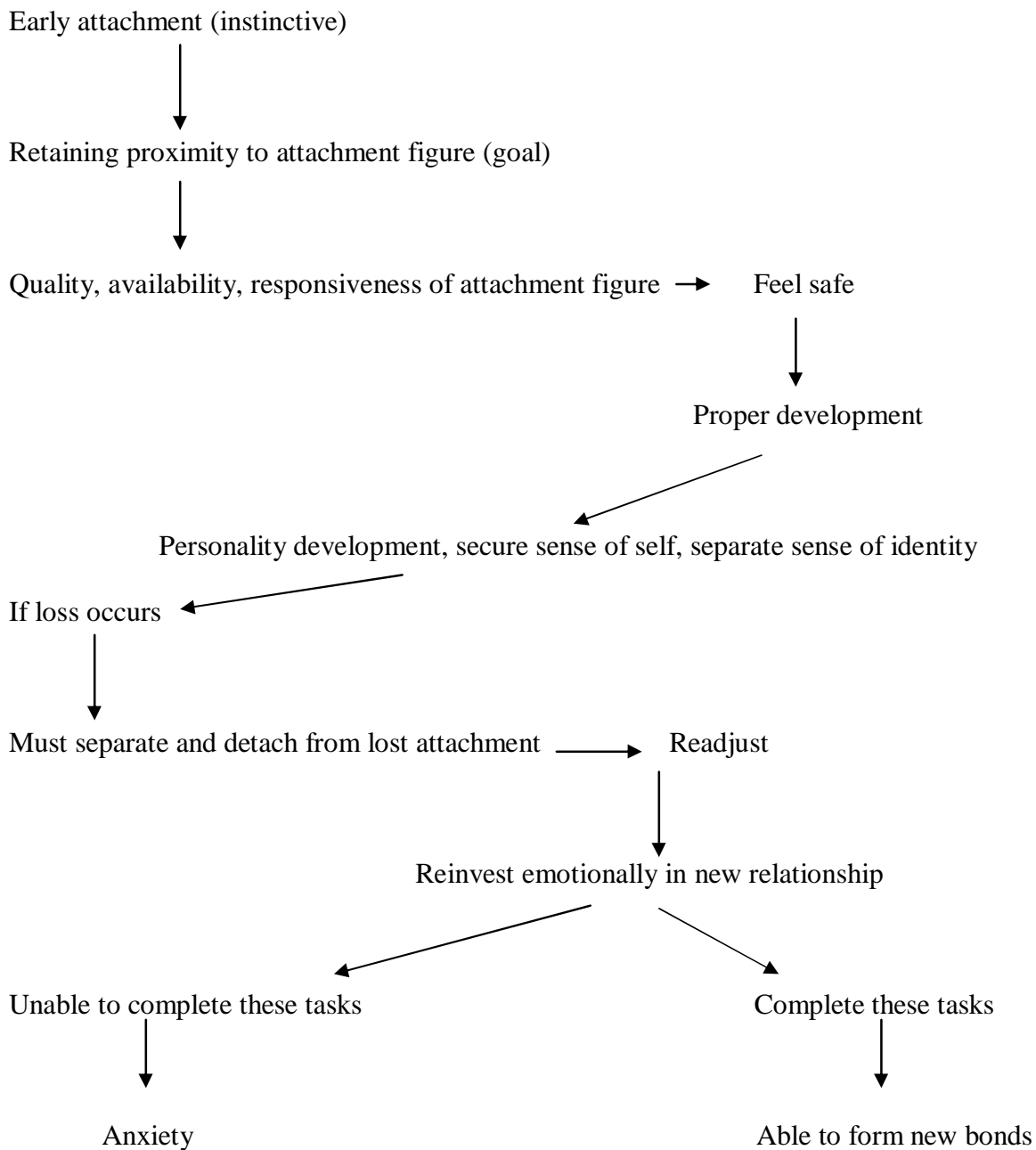


Figure 2: Schematic representation of Bowlby's Attachment Theory.

As stated earlier the loss of a twin can elicit intense bereavement and grief reactions because of the attachment that forms between them. Intense feelings of grief arise from the phenomenon of attachment and the loss of attachment through death. The reality of grief is subjective and the experience is unique to the individual (Burns & Grove, 2001) and phenomenology is an effective way to discover the meaning of the loss experience from a twinless twin's view.

According to Jasper (1994) phenomenology generates theories that will provide descriptive data of a phenomenon, which can be used to guide wider and larger-scale studies from an informed starting point. Attachment theory, and the use of phenomenology, provides a framework to examine the lived experience of twins who have lost their co-twin.

Assumptions

The assumptions being made by this researcher, in relation to twin loss, are guided by the literature, theoretical framework, and research design, past clinical experience as an obstetrics nurse and a personal experience with twin loss as a parent. A twin pregnancy is filled with joy, wonder, and anxiety. As a parent, the loss of a twin is devastating, but the emotional confrontation of dividing joy for the healthy twin and sorrow for the deceased is a task incomparable to any this researcher has known. Studies have been done to explore the experiences of parents who have lost a twin, but no nursing studies have been conducted to shed light on the experience of loss for the lone twin. Through practice and research this researcher has encountered very little information on

the topic and for the sake of my daughter and other lone twins this researcher would like to bring this phenomenon to life.

Through bracketing, this researcher will expound upon the assumptions and preunderstandings made about the twinless twin. Bracketing is the activity of explicating one's own assumptions and preunderstandings about the specific lived experience that is being studied (Munhall, 1994). Munhall (1994) states after becoming attuned to your own beliefs by bracketing then you can wonder how it is for others.

Chapter Four: Method and Procedures

Chapter four discusses the research design, procedures and sample used. The data analyses procedure will be described using Colaizzi's seven-step method.

The purpose of this research was to explore and describe the lived experience of twins who has lost their co-twin. The aim was to generate an understanding of the unique bond and sense of loss experienced by twinless twins. This research contributes to existing literature on twin loss. This study used a qualitative design, phenomenology, to study the lived experience of a twinless twin and answered the question, "What is the lived experience of a twinless twin?"

Research design

Phenomenology is a philosophy, and an approach or perspective to living, learning and doing research (Munhall, 1994). Grounded theory, ethnography, historical research, philosophical inquiry and critical social theory are five other approaches to qualitative research (Burns & Grove, 2001).

Husserl introduced the idea of phenomenology in response to the context-free generalizations of the positivist approach to the natural sciences (Munhall, 1994). Husserl suggested that a phenomenon cannot be separated from the experiences of them, therefore the way to access them is through a description of the phenomenon in the person's own words. "Lived experience" then became the catchphrase for the phenomenological method (Jasper, 1994).

Phenomenology is a humanistic study of phenomena conducted in a variety of ways according to the researcher's philosophy (Burns & Groves, 2001). Phenomenon

refers to the objects, events, situations, and circumstances as they appear in the original perception for the participant prior to interpretation (Munhall, 1994). The aim of phenomenology is to describe an experience as it is lived by the study participant and interpreted by the researcher. The experience refers to living through the event, situation, or circumstance from the participants view (Munhall, 1994).

Phenomenology, as a research method, reflects the difference between the natural sciences and human sciences. The natural sciences seek causal explanation, prediction and control, where as the human sciences seek understanding and interpretation (Giorgi, 1970). According to Omery (1983) qualitative studies are meant to compliment quantitative studies not replace them. Omery (1983) states, “to be a scientist does not mean strict adherence to a specific set of methodologies, rather it is to have boundless curiosity surrounded by a discipline” (p. 62). Jasper (1994) states “the purpose of phenomenology, as a research method is to generate concepts and theories’, which can then be tested using other methods” (p.313). Data from phenomenological studies can be used to guide other studies from an informed standpoint (Jasper, 1994). According to Munhall (1994) the intention is not to solve problems, but to lay groundwork to solving problems.

Phenomenology is a way of looking at ordinary human life experiences in their context and then discovering their meaning (Munhall, 1994). With the use of phenomenology we can better understand our being and what it means to be human, “allowing for reflection on the ordinary, which can lead to extraordinary understanding” (Munhall, 1994, p. 4). The dialogue from the participant about the experience and the

researcher's reflections and interpretations constitute the data. According to Burns and Grove (2001) each person has his or her own reality. Reality is considered subjective and the experience is unique. Phenomenology is an effective methodology to discover the meaning of a unique, complex experience as it is lived by the individual.

Phenomenology as a method is an inductive and descriptive way of doing research. The task is to investigate and describe all phenomena in the way they appear in their fullest (Omery, 1983). The first two steps in conducting a phenomenological study are to identify the phenomenon and develop a research question (Burns & Grove, 2001). The third step is to decide on the research method. Next determine if the method of choice is appropriate and defend the choice with a rationale (Maggs-Rapport, 2001). According to Munhall (1994) qualitative methods are best used when there is little known about the phenomena of interest. The phenomenon of interest in this study is "What is the lived experience of a twinless twin?" According to Segal, Wilson, Bouchard, & Gitlin, (1995) twin loss has been neglected by bereavement researchers.

Munhall (1994) states "qualitative studies are needed in current theory formulation and reformulation to access the extent to which biases have influenced worldviews and have established norms and standards that may be inappropriately generalized" (p. 22).

According to Omery (1983) phenomenology has been used to examine areas that traditional forms of research have been unable to study or where attitude toward an experience or the meaning of that experience for the participant has been neglected. "As long as the experience has meaning the potential is there for phenomenology to be utilized" (Omery, 1983, p. 59).

Phenomenology as a research method describes the lived experience of a phenomenon of interest. The lived experiences are what give meaning to each individual perception of these phenomena. The purpose of phenomenological inquiry is to describe exhaustively the structure or essence of lived experiences from a variety of phenomena. The search for unity and meaning of phenomena allows for an accurate description of the everyday lived experience (Munhall, 2001).

After choosing a phenomenon and defending the choice of research method, bracketing is then performed. Bracketing is the activity of explicating one's own assumptions and preunderstandings about the specific lived experience that is being studied (Munhall, 1994). Munhall states (1994) after becoming attuned to your own beliefs by bracketing then you can wonder how it is for others. According to Jasper (1994) bracketing suggests to the reader that the researcher is applying rigorous techniques to decrease preunderstandings from influencing both the collection and interpretation of the data. Bracketing if this study was addressed in Chapter 3.

After bracketing the researcher must seek participants who are willing to describe their lived experience of the phenomenon. Data can be collected through observation, interactive interviews, videotape, and written documentation by the participants (Burns & Grove, 2001). The inclusion of literature, art, film, poetry, and journals may also be used to widen the lens of understanding (Munhall, 1994). If a dialogue is used to research the experience, listening and prompts for the person to continue and requests for examples in order to exhaust the experience from the participants should be used (Munhall, 1994). According to Munhall (1994) we must live in the participant's experience by listening,

feeling the experience, becoming the experience and raising our consciousness so the “ordinary becomes wondrous” (p. 23). Researchers may feel amazed or puzzled during data collection, but will begin to understand the uniqueness of the individual experiences as each becomes real (Munhall, 1994).

According to Colaizzi (1978) the subject does not provide data; the subject is a source of data and a person full of richness. The experiences can be contacted only when the researcher listens to the subject with more than just his ears; he must listen with his total being and entire personality. The researcher must assume the stance of imaginative listening (Colaizzi, 1978). According to Omery (1983) the researcher strives to understand all data in the experience under study from the perspective of the participant. The natural spontaneity of the experience must be preserved while doing this (Jasper, 1994). Jasper (1994) suggests preserving the experience by asking the subjects to describe the phenomena as fully and deeply as possible until they have no more to say.

Procedures

Permission to conduct this study was obtained from the thesis committee and the Human Rights Committee of South Dakota State University (Appendix C). An informed consent and consent to be audiotaped was obtained from all the participants of the study (Appendix A). The consent included the title, purpose and explanation of the research and procedure to be followed, including the use of the findings. An emphasis was made in regards to possible renegotiating of consents if unforeseen conditions arose or second interviews were needed. A statement that the participant had an opportunity to ask questions and that the participant was free to withdraw at any time was included.

The small number of subjects usually used in qualitative research and the depth of detail make it difficult to disguise the subject's identity. It is recommended by Burns and Grove (2001) that a pseudonym be used instead of a subject's name. For this study each participant was given a participant number. Audiotaping took place and this researcher refrained from using names in order to maintain confidentiality. The participants were instructed on this also but often continued to use family names. This researcher refrained from using names within the written document. Protecting the identity of the participants provided confidentiality. Only myself, as the researcher had access to the data. Data was stored in a secure area and will be destroyed after study completion (Munhall, 2001).

The risks and benefits were clearly explained. The risk to participate was minimal, but included bringing back painful memories while discussing thoughts and feelings. No physical harm occurred. A counselor agreed to be a referral if therapy was needed during the study. At this time none of the participants have requested the need for counseling. Allowing the meaning of the lived experience to come to life for these participants was the benefit of this study.

The phenomenon of interest was the lived experience of a twinless twin. Collection of the participant's descriptions was done through an audiotaped interview process taking approximately one hour. Participants were allowed to share experiences through an unstructured interview. The descriptions provided by the participants were read and transcribed so that meaning was significant. Data was reviewed by the researcher and thesis advisor then organized into cluster themes. A written document of these themes was completed providing an exhaustive description of the lived experience.

The participants were then asked to review the written description for validation. No new data was obtained and the participants agreed on the findings.

Sample

The participants were chosen based on a purposeful sampling technique. This method of sampling selects individuals for the study based on their knowledge of the phenomena of study. The criteria for participation included (a) the participants must be a twinless twin (b) male or female, (c) at least 18 years of age and (d) three months past the death of their twin. The deceased twin's age at the time of death was of no significance. The participants were contacted based on replies from newspaper inquiries, and through word of mouth. Qualifications were then determined (Appendix A). At the beginning of the interview an informed consent and permission to audiotape was obtained from all participants. Questions were answered and the process was explained at that time.

Data analysis determined the number of subjects interviewed. Nine participants provided sufficient data about the lived experience of a twinless twin. Seven interviews took place face to face in a chosen setting by the participant. One interview was conducted by phone and mail and another by phone and email. Interview times were scheduled based on the convenience for the participant and researcher. The interview allowed the participants to verbalize feelings in regards to the loss of a twin. Open-ended questions and validation statements were used to facilitate a full view of the experience from the twinless twin. At this time the interviews were audiotaped. At the end of the interviews the participants were allowed to add any additional information that would give insight into the topic. In phenomenology, each individual's interpretation is his or

her own reality of the truth (Munhall, 1994). Direct quotes from the participants were used to answer the research question. The outcome was a description of the phenomenon (Pallikkathayil & Morgan, 1991).

Interview

Interviewing is the most common method of data collection used in qualitative research to provide a forum for exchange of nonverbal and verbal information (Morse, 1994). “The interview involves a process of unveiling personal feelings, beliefs, wishes, problems, experiences, and behaviors” (Morse, 1994 p. 301). Unstructured interactive interviews are used when the researcher has little information on the topic. The goal is to produce a rich description that gives understanding and synthesis leading to theory development (Munhall, 2001).

The first step to the interview process, according to Seidman (1998), is to listen. Listening happens on three levels. First you must listen to what the participant is saying and determine if you understand it and assess whether it is as detailed as it should be. Second, you must listen with an inner voice. Distinguishing surface feelings from in depth personal feelings allows interviewers to listen to the inner voice of participants. The third step is to also keep in mind the process. Be aware of the time and the participants nonverbal and energy cues (Siedman, 1998). According to Streubert Speziale and Carpenter (2003) a first step may also be to develop rapport. This rapport will enable the participant to trust the researcher enough to reveal information.

Asking questions in an interview should be in response to what is heard by the person interviewing (Field & Morse, 1985; Seidman, 1998). The interviewer can come to

an interview with a basic question that establishes the focus, but structured questions are not recommended. Asking clarification questions, seeking concrete details, requesting stories, and exploring are better ways of guiding a participant through the interview process (Seidman, 1998). According to Seidman (1998) “an in-depth interview is not designed to test hypotheses, gather answers to questions or corroborate opinions. Rather, it is designed to ask participants to reconstruct their experiences and to explore their meaning” (p. 76).

The unstructured interview is commonly used in qualitative research (Streubert Speziale & Carpenter, 2003). Open-ended questions are used to guide the interview. The area to be explored is established by the researcher, but the direction taken is up to the participant. No set responses are required in an unstructured open-ended interview. Leading questions should be avoided. A leading question is one that influences the direction that the response will take. Sometimes a lead is in the intonation of the voice or in the framing of the words used. A basic open-ended question to ask is “What was that experience like for you?” This gives the participants the chance to reconstruct the experience according to their own sense of what was important, unguided by the interviewer (Munhall, 2001; Seidman, 1998; Streubert Speziale & Carpenter, 2003). After some of the data has been analyzed and the participant's pattern of ideas is clear then more focused questions may be used (Morse, 1994). Highly structured interviewing techniques occur more often in quantitative studies (Streubert Speziale & Carpenter, 2003).

Another technique is to ask participants to tell a story. This technique can sometimes show how participants dealt with a situation and illuminate it. This technique should be used sparingly (Seidman, 1998). Another variation of this is to ask the participant to reconstruct the experience. This will give the participants the opportunity to describe what they now sense as important about the past experience (Seidman, 1998).

At the end of the interview it is important for the researcher to document what was heard, seen, thought and experienced while conducting the interview. These are called field notes (Field & Morse, 1985; Streubert Speziale & Carpenter, 2003). “This wide-angled view of the situation will provide the opportunity to detail what participants have said and to share what may be implicit in the situation” (Streubert Speziale & Carpenter, 2003 p. 158).

This researcher used an unstructured interview technique with a general open-ended question to start the interview process. After listening to the participant the use of clarification or story telling questions were used. This researcher also documented thoughts, feelings and nonverbals in field notes following each interview.

Analysis

Analysis begins after the first interview and guides the collection of further data. Data analysis should preserve the uniqueness of each experience while permitting understanding of the phenomenon (Jasper, 1994). Colaizzi’s seven step phenomenological method is an appropriate scientific and rigorous method to use to analyze data for the phenomena of interest (Streubert Speziale & Carpenter, 2003). Colaizzi’s seven-step method was used with the steps as follow (Colaizzi, 1978):

1. All of the descriptions are reviewed to acquire a feeling for them.
The researcher and thesis advisor reviewed all interviews.
2. Return to each description and extract phrases or sentences that pertain to the phenomenon. Data was extracted from each interview and reviewed by the thesis advisor.
3. Spell out the meaning of each statement. The researcher discovered and illuminated the hidden meanings.
4. Repeat step three and organize into clusters of themes. Cluster themes were developed and referred back to the original descriptions for validation. Any discrepancies were noted at this time.
5. Develop an exhaustive description of the themes. Three themes were identified and descriptions of each typed using participant quotes.
6. Formulate a statement from the exhaustive description. A statement was formulated from the exhaustive description to identify the fundamental structure of the experience.
7. Return to each subject and discuss the findings. Three participants and one twinless twin that did not participate reviewed the data.

To assure rigor while conducting this study dependability, interpretation, validity, ethical rigor, and auditability were used. These approaches to assure rigor were selected from work by Maggs-Rapport (2001), Jasper (1994), Burns and Grove (2000) and Guba and Lincoln (1981).

Dependability was achieved by asking if the methodology chosen was appropriate for the research question studied. Also, a thorough review of the study was done by the researcher and thesis advisor, to assure knowledge could be transferred to others (Maggs-Rapport, 2001). Verbatim transcription and field notes also enhanced dependability.

Interpretation was achieved by bracketing. Limitation of any potential biases was done before and during data collection and analysis. Reflection, clarification, requests for examples and descriptions were used to prevent data contamination and assure conclusions arose from the data and not the researcher (Jasper, 1994).

Validity was achieved by using the last step in Colaizzi's seven-step method. Participants were asked to review and validate the exhaustive description of the lived experience of a twinless twin. This preserved the uniqueness of each individual experience (Jasper, 1994).

Ethical rigor was achieved by protecting the subject's rights through the use of a consent form. Participants were numbered accordingly and the researcher did not use names. Data was kept in a secure place and will be destroyed after study completion (Burns & Grove, 2000).

Auditability was achieved by using Colaizzi's seven-step method as a rigorous data analysis technique. The decision trail for data transformation was clear to the reader and future researchers. The researcher and thesis advisor, to assure accuracy of data interpretation, analyzed data obtained.

According to Munhall (1994) human beings deserve to know all that we can provide through research. When meaning is sought and presented individuals realize that

others share their perceptions. Qualitative perspectives have the potential to discover what precedes specific lived experiences or, if possible, what can prevent them. We can then draw conclusions about what people need to tolerate, manage, or enhance the experience (Munhall, 1994). A phenomenological approach is appropriate because the nursing profession emphasizes a reverence for a client's experiences and is concerned for the quality of life, and the quality of the nurse patient relationship (Munhall, 1994).

To use phenomenology successfully "the best thing to do is be aware of what you are doing and why you are doing it" (Munhall, 1994, p. 28.). Using phenomenology successfully depends on openness to the total phenomenon and the willingness to give credence to the subject's experience (Pallikkathayil & Morgan, 1991).

The recognition of experiences as unique has significance for nursing. "Phenomenology offers an approach, which enables the needs of the client to be identified and to be of foremost importance in the provision and justification of high-quality nursing care" (Jasper, 1994 p. 313).

Chapter Five: Research findings

This chapter presents the lived experience of the twinless twin. A demographic description of each participant and the participant's experience is summarized. The themes of the study are then presented and discussed.

Demographic description

Nine twinless twins were interviewed for this study. One interview lasting approximately 40 minutes to one hour was conducted with each twinless twin. The interviews were audio taped and then transcribed verbatim. Information remained confidential and the audiotapes will be destroyed after the study. Demographic information about each twinless twin is listed in Table 1. Open-ended questions were used to conduct the interview (Appendix B). After the interviews were completed data was organized into themes (Figure 3).

Thoughts and feelings varied, but the majority of the twinless twins that were interviewed described intense feelings and were very distraught, often brought to tears because of the overwhelming feelings associated with the experience of being a twinless twin. For some, the twinless twin experience as described by the participants, was often unexplainable. Many twins felt the experience was unique and could only be described to another twinless twin, if it could be described at all.

Table 1: Demographics of study participants

Category	Number of participants
Age	
40-50	3
50-60	3
60-70	0
70-80	3
Gender of twin	
Male	4
Female	5
Education	
8 th	2
12 th	2
1-2 years if college	4
Masters	1
Ethnicity	
Caucasian	9
Twin type	
Fraternal	5
Identical	3
Unknown	1

Table 1: continued

Category	Number of Participants
Age of loss	
Before 1st year	2
17-19	2
28-31	3
40	1
70	1
Circumstances	
Cancer	3
Car accident	3
Medical reasons	3
Counseling	
Yes	1
No	8

Participant Profiles

Participant one is a 76-year-old Caucasian female. She had a twin sister of fraternal gestation who died at 8 months of age from measles and pneumonia. This participant did not seek counseling for her loss, but was very distraught during the interview, as noted by crying and tears immediately when the interview began. The time she lost with her twin and the constant wondering about what might have been seemed to be the most powerful feelings for her. She stated, “would we have the same likes and dislikes.” “I just wonder what life would be, if it would be different...would we both be married, have kids.” She only knew what her mother and sisters told her and stated she shouldn’t be crying during the interview because she never knew her sister, but always wished she knew more. She also wanted to have twins and often dressed her two daughters alike to fulfill the need to have the twin experience that she missed out on.

Participant two is a 57-year-old Caucasian male. He had an identical twin brother who died at age 40 from bone cancer. This participant did not seek counseling for his loss. He did not cry or show distress, but his comments and concerns were nonetheless powerful. This participant lived with his twin and neither was married so the most difficult times for participant two were special occasions like birthdays and holidays. He also found it very difficult to visit the cemetery after the loss. It took nine months before he could go see the gravesite. Matching head stones were purchased “because we were twins.” On a daily basis this twin described the emptiness at home. “When you sit down at the table, knowing there’s that bare spot.” “We always talked before we went to bed...in the morning we always talked first thing.” This twin also stated he had a higher

grief intensity after the loss of his twin than after the loss of his mother. His most vital comment was “we both got here together...lived a full life.... we were both born together, why can’t we both go together.” He also discussed his concern of developing cancer himself because he was a twin.

Participant three is a 47-year-old Caucasian female. Her twin was a male who died at the age of 28 from leukemia. She did not receive counseling for her loss. She did not become tearful during the interview and stated she had come to terms with the loss. She did discuss missing the constant companionship that the twinship brought to their relationship. She said they spent most of their time together as children and young adults. She states, “if you had to go somewhere you were usually both going... so you weren’t the only one.” When she looks at old family pictures she states, “I don’t think there is just a picture of me or of just him.” After the loss, she found some comfort in a relationship with her older brother, who is also a twin. This participant also found it more difficult to lose her twin than her father. She also is concerned, as participant two was, with developing cancer.

Participant four is an 82-year-old Caucasian male who lost his twin at 2 weeks old from pneumonia. The zygosity is unknown. This twin did not receive counseling for his loss and as he discussed the loss, he did not show signs of distress. His only concern was not knowing what his twin looked like, if they were identical. He expressed “it is something that is in the past.” “I just thought someday I might see him, like in heaven, I guess that is my belief.”

Participant five is a 51-year-old Caucasian female who lost her identical twin at 31 years of age from ovarian cancer. She did not receive counseling for her loss, but during the time of the interview began crying, expressing deep feelings of grief. She states she never really felt like a separate entity because others viewed them as a pair. She also discussed in detail how different their personalities were. Her being the more academic twin and her sister the more athletic. Along with this she discussed her feelings of closeness stating “she was my best friend...we always had friends, but no one that I felt I needed to confide in...it was always her.” She also believes the twin experience is different and unique. Because of always being viewed as a pair, it takes longer for twins to find out who they really are in life. She also found the twin loss to be the most difficult loss for her when compared to other losses. “It was the most comfortable thing ever... it felt like I was more whole, more me when I was with her.” When she died it was very, very difficult.” Her twin had a son at the time also and this participant felt the need to take her twin sister’s son as her own. She confided that she often feels like she let him and her sister down because she couldn’t provide a better life for him. She also finds it difficult to deal with the loss of support that she found with her twin. This twin finds it very difficult to discuss the loss with anyone because of the “hurt and pain” that goes with it. She thought that counseling of some sort would have been beneficial for her, but never was offered counseling or sought out the help herself. Her most profound comment was; “I think she was part of me... it totally was very much a part of me that feels like it is gone.”

Participant six is a 72-year-old Caucasian female who lost her fraternal twin sister at the age of 70 from a heart attack. Her twin had a life long battle with multiple sclerosis also. This participant did not receive counseling for her loss. During the time of the interview she cried with great intensity and found it comforting to rock back and forth in her chair. A detail that was most compelling at the beginning of the interview was the fact that she could not remember the date of her twin sister's death. Towards the end of the interview I found out that her twin did not have a funeral service only a posted memorial on the internet. She expressed deep concern with this and felt that she had not obtained closure. It was not until after our interview that she read the website memorial. She sent me a copy through the mail and thanked me for allowing her to discuss the loss. This participant also found tremendous companionship with the twin bond she experienced. She tells of family pictures with only her and her twin. They were always holding hands. She also discussed the differences in their individual personalities. She felt like the stronger one, but felt "everything about her twin was perfect." She felt like her twin was her strength at times, part of who she was. She also expressed a concern that no one understood the loss of a twin. Only another twin could feel the same thing.

Participant number seven is a 47-year-old Caucasian male who lost his identical twin at the age of 17 due to a car accident. This twin did not receive counseling, but expressed deep feelings of loss during the interview reporting that some type of counseling may have been beneficial at the time, but no one ever encouraged him to seek guidance. This participant, as did others, expressed the uniqueness, closeness and constant companionship of the twin experience. He used phrases like "your closeness is

magnified,” “shadow” or “you can’t see the forest through the trees sometimes you’re that close.” “Your twin is always there...you’re kind of inseparable.” This twin also felt deep regrets because he never got to experience the future with his twin. Many questions are left unanswered for him. “Would we have the same likes and dislikes...would he be batchin’ it now, or would he be married with kids.” He found the unanswered questions to be the most difficult thing to deal with. He also talked about their personality differences growing up. He felt his twin was “following the straight and narrow” more than he was. In regards to this he often wondered why his twin was chosen to die in the accident while he was left to live. His life after the loss was very much in shambles for a period of time. He states “I think I got most of it out of my system in the three years. I was in the army.” “I lost a good chunk of my life for awhile...I just joined the army and ended up with a bunch of hoodlums my age ...it was just excess... rage...just bananas.” “I think I was trying not to think about certain things.”

Participant number eight is a 55-year-old Caucasian male, whose fraternal twin died during the Vietnam War. He stated that the twin experience always made him feel special, especially during birthdays. He states everyone always referred to them as the twins. His twin was killed during the Vietnam War in the line of duty. “It was a special occasion. I was proud of the fact that he volunteered for service.” As a result of his brother’s death this participant joined the Navy and volunteered for submarine service.

Participant number nine is a 47-year-old female who lost her fraternal twin at the age of 31 due to a car accident. She did go to grief counseling after the loss, but also experimented with astrologists and psychics “to find answers.” Growing up as a twin this

participant states, "I never felt alone." "I never felt jealous or competitive, she was always more popular, I was quieter and shy." She also felt they could sense things with each other and knew when to call if they needed each other. She felt the twin experience set them apart from others. After the loss she spent a lot of time with her twin sister's children. Their birthday and her death anniversary are "still melancholy." She states "The first year after she died I went to Mexico for ten days. I spent many hours on the beach listening to the waves, watching the sunrises and sunsets, crying and drinking." She states the "pain never really goes away, but my acceptance is there... our spirits are still one."

Figure 3 Identifies themes and sub-themes of the twinless twin experience

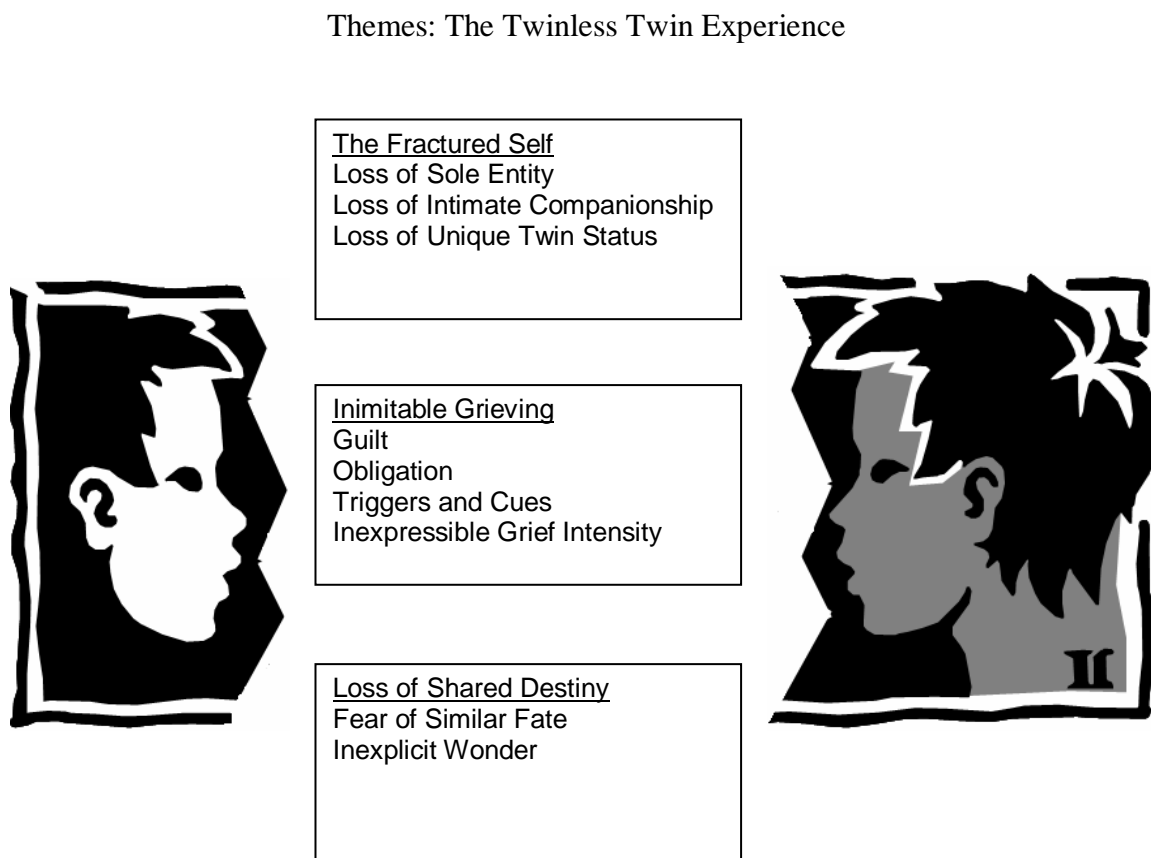


Figure 3: Themes and subthemes of the twinless twin experience.

Theme 1: The fractured self

Loss of sole entity. The loss of sole entity was evident in six out of the nine twinless twin experiences. One twinless twin described the experience like this. “You are never quite a separate entity. I think what happens is people see you as a pair. I think she is part of me. You kind of lose that part. It totally was very much a part of me that feels like it is gone.” Another twinless twin stated, “It’s kind of like losing... you know... where is that other part of you if they are not there, you know. Some of our pictures... I mean it’s always Marge and I. We didn’t take many but it’s always the twins holding... we were holding each others hand. She was my whole life for seventy years.” Another twin had an intense experience and has struggled for years with the twinless twin experience. She describes the single identity in this sentence. “I believe I was blessed with a twin sister and our spirits are still one.”

Loss of intimate companionship. The loss of intimate companionship was also evident in six of the nine twinless twins. A twinless twin who lived with his twin describes the loss of companionship like this. “We always went out, we always done things together, that’s what really hurts the most. We always talked before we went to bed... in the morning we always talked first thing.” Another twin describes her twin as her best friend.

“She was always my best friend. I to this day.... you look back at your high school and your high school class reunion... but I don’t think I had a best friend because she was my best friend. It just kind of took away that need to have the person in your life that you can kind of share everything

with. It was always her. We could talk for hours, we loved being with each other it was the most comfortable thing ever. I felt like I was more whole, more me, I think when I was with her. I went through a divorce about 4 years ago now and I am happily married, but I think next to her death it was the worst time in my life and I wish she had been there for me. I think had that happened with her living it would have been an easier loss for me, much easier, because that part of me would have still been there with her.”

Another twin describes the experience like this. “You’re never alone... you didn’t have to worry about being alone till that happened (death of a twin).” These thoughts and feelings about the loss of companionship tie in directly with the loss of identity. The twinless twins always felt like one with their twin when growing up. They always had a friend and companion. Without their twin they feel they have lost not only their companion, but also part of themselves. Their attachment was unique, and compounded by feeling like one.

Loss of Unique twin status. Seven of the nine twinless twins also felt that the twin experience was unique due to the social perception of identity. After the loss of their twin, some of those things that made them unique disappeared. “Well just that it was always kinda fun to be a twin cuz, you know, not that we were more showered with gifts or anything like that... you were just something different... I mean you weren’t normal.” Another twin felt as a twin she was always admired. Family and friends always asked about the twins and wanted to know the details about their experience. “It’s just put on a pedestal... think it makes you feel different... you know ...kind of a little more special.”

Three of the nine also wanted to have twins of their own just to experience the unique bond that they lose

Theme 2: Inimitable grieving

Guilt. Five out of nine twins described feelings of guilt associated with the loss of their twin. Interview number two even stated, “We were both born together why can’t we both go together.” Others questioned why their twin was chosen over themselves.

“You get all that... why not me instead of him, why not. Here he was doing the right thing or in almost all instances as opposed to me. I go do the other you know. There he was, not all the time, but he was more walking the straight and narrow than I was and then all of a sudden he was the one that’s gone. Those issues are there and will be forever.”

Obligation. Six of nine twins also felt a sense of obligation after the death of their twin. One twin describes intense feelings for her twin sister’s son.

“She had a child he was 5 when she died. I took an instantaneous love of that child because it was hers. I would have loved to have taken him away as my own. I wish I could have made his life a little better. Even to this day I feel like I let him down because he didn’t have a very good life from that point. I kind of feel like I let him down.... maybe her down in a sense.”

Another twin lost his co-twin in the line of duty and joined the military shortly after as a result of his twin brother’s death. “Since my twin was killed in the line of duty

in the United States Army it was a special occasion. As a result of his death I joined the United States Navy and volunteered for submarine service.”

Triggers and cues. Triggers and cues included birthdays and trips to the gravesite. Emotional episodes occurred during these times for many of the twins. One twinless twin states this, “Especially when birthdays come around... really hard every time that rolls around.” Another twin describes this, “I haven’t hardly been able to walk out to the grave stone yet after 30 years.”

Inexpressible grief intensity. Four of the nine twins also described ways in which they coped with the loss and how they often felt like no one understood. Many of them felt alone and could have used more support from the health care system. Two twinless twins thought that counseling would have been beneficial, but they were not encouraged and did not feel like the loss meant enough to others and was not identified as significant. One twinless twin states this.

“Lost a good chunk of my life for awhile. At seventeen years old, how the hell do you deal with it? That was 1976. Whoever heard of counseling what do you do. I just joined the army and ended up with a bunch of hoodlums my age and we just burned the midnight oil for 3-4 years and I just think it was all somewhat just trying to not think about certain things you know.”

This twin also describes intense feelings that were dealt with in an unproductive manner.

“ It wasn’t just excess it was a rage just bananas you know. I think if I would have had counseling or something you probably could have pulled back and looked at things... put some things into perspective and kind of channeled your emotions or your directions in different areas... than just being unproductive.”

Other twinless twins feel only another twinless twin could understand the experience.

“I won’t even discuss anything with my husband because I don’t think he’d understand it’s hard to describe losing a twin. You know your husband, you talk a lot, discuss a lot of things, but it just isn’t something that he wouldn’t know how I felt. Well see there you go... I’m not sure my sister knew how I felt or anyone...how it is to lose your twin and it’s hard to describe how you feel. I think probably cuz it’s kind a like a part of you lost. I just battle it on my own.”

One twinless twin went to astrologists and psychics in the first few years to try and find answers and eventually sought out counseling through her local church. This twinless twin also states this about her loss. “It was the most horrific thing to ever happen in my life. I could not say her name for close to a year, it was to painful to think of her gone.”

The twin’s in this study also described more intense feelings of loss for their twin who died than they did for other siblings or parents who died. Five of the nine interviewed describe feelings like this. “Losing her was bad (mother), but it wasn’t as bad

as losing my brother. I would say to lose him was worse than to lose her.” Another twin who lost her older sister to cancer also describes the twin loss as more intense.

“Not the same hurt that I had with my older sister. I think there is a twinness to it. I do think it is interesting that the loss is so much more for her than for my other sister. Because it should have been a mutual kind of feeling.... it wasn't. There is nothing worse in my life that could happen than losing her.”

The themes that emerged from this study are unique to the twinless twin. The experiences make it difficult for the twinless twin to follow a healthy grieving pattern. Figure 4 identifies Worden's tasks of grief and how the twinless twin experiences grief according to them.

Figure 4 compares Worden's grief process with the lived experience of the twinless twin.

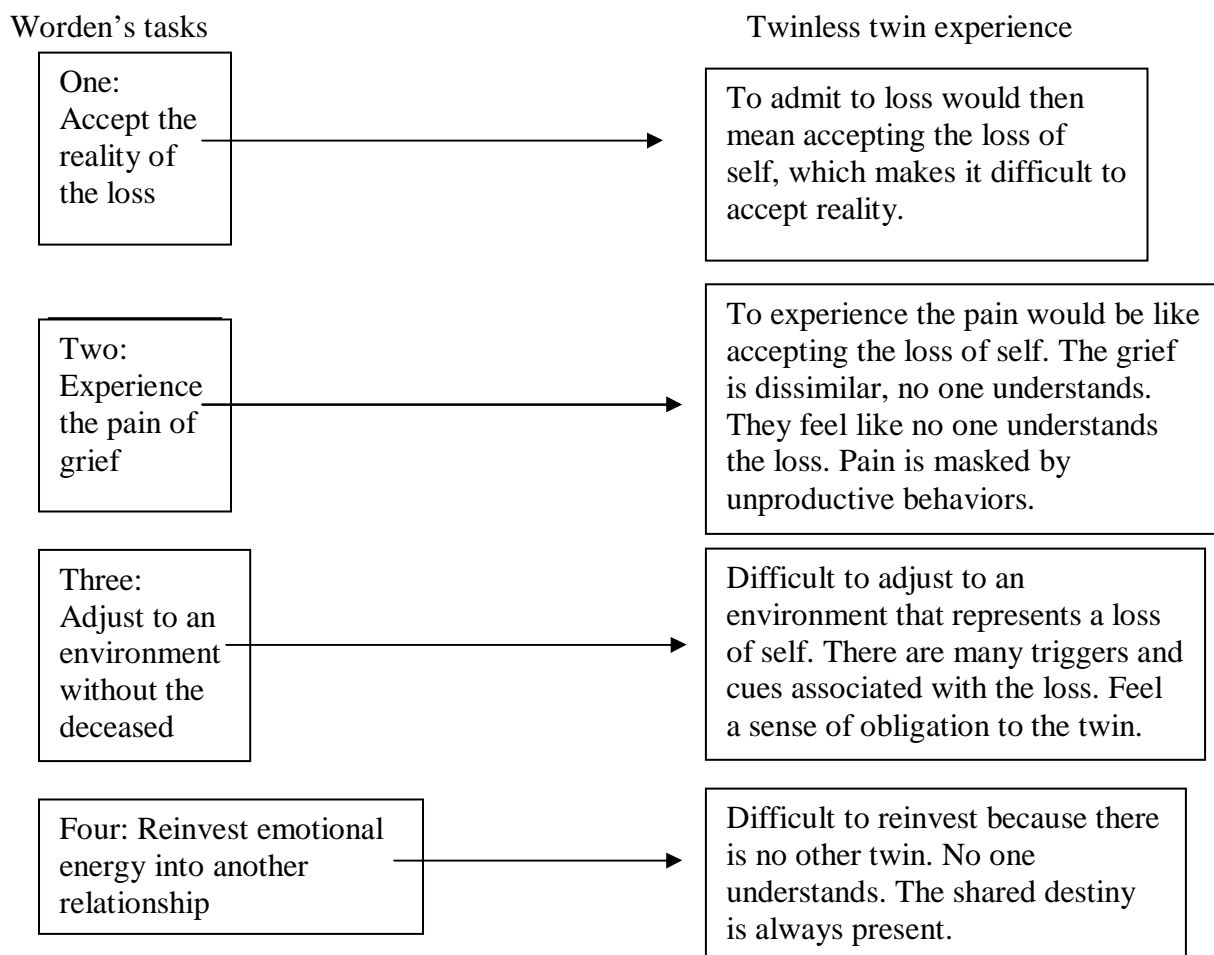


Figure 4: Compares Worden's grief tasks (Worden, 1991) with the experience of twinless twins.

Theme 3: Loss of shared destiny

Fear of similar fate. Three twinless twins lost their co-twin to cancer. They described shared feelings of fear: Will I die too? All three worried about having cancer at some point themselves. The second twinless twin that was interviewed talked in depth about frequent doctor visits and blood testing to make sure nothing was over looked. His statement is “They usually say with twins if one has it the other one will have it” Another twinless twin states she had her ovaries removed shortly after her twin sister died because of the possibility of getting a similar type of cancer.

Inexplicit wonder “what would have been and what will be. Six out of nine twins also felt like their future was suspended, unknown. They wondered what would have been and there were unfulfilled possibilities. Two of the nine lost their twins in infancy; their loss is described like this.

It makes me sad... because I didn't know her. Would we share the same likes, dislikes... if we were identical, not looking, but our likes and dislikes? When I was young I would sit by myself... you would wonder... what if we would have been look alike or have the same taste... you just wonder what life would be... if it would be different. You know if you would be married and have kids.... married and have twins. It's just a sad feeling, I didn't know her. Well you wonder what life would be like, if we would be together or if we would fight or not talk to each other.... if she would go one way and I would go the other or if we would have been really close. It's always in the back of your mind. What could have been?

Would she like my husband? Would I like her husband? Would she have as many babies as I had? I think the worst thing is ... is I don't know what life would have been like."

The other twin who lost his co-twin in infancy wondered what his co-twin would look like. He was concerned with physical appearance the most because their zygosity was unknown.

The many unanswered questions make it very difficult for twins who lost their co-twin early in childhood. These twinless twins were 72 and 80. The difficulty of the experience is long and often challenging without support and guidance for the twinless twin.

The inexplicit wonder occurs later in life also. This twinless twin, who lost his co-twin at seventeen, states this about his future.

"Ya think back, did I ever really know my twin. Would he live here or somewhere else or what life path would he have taken. That's the main thing, once you're over the loss a little bit then it's like.... what could have been. Would he have had a family or would he been batchin' it right now. Would he have had family, kids, it's more how things would have been now."

Chapter Six: Conclusions, Implications and Recommendations

This chapter presents a summary of the research, major findings, and relationship to Attachment Theory, conclusions, implications, limitations and strengths of the study. Additionally, recommendations for future studies are identified.

Summary of the research

These interviews conducted with twinless twins revealed that the experience of twin loss is a real and often unexplainable experience that can result in intense feelings lasting for long periods of time. Twinless twins are often left to deal with this loss on their own because far too few health care workers know the intensity of the experience. As one twin stated “ I just battle it on my own.” Many of the participants felt a deep sense of loss for what they had or in some cases what they were not given the chance to experience, if the twin loss occurred early in life.

The twinless twin phenomenon has been neglected by health care leaving a void in the emotional well being for many twinless twins. Twins enter life as a pair and are often viewed so in later life. After the loss, twins feel like a part of them is lost and deep grief experiences emerge leaving the twin alone without professional help. Twinless twins need someone to guide them and help them make sense out of the loss that they have experienced. Currently tools to identify intense feelings of loss for twinless twins are not available. Screening tools need to be created to identify twins who are experiencing intense feelings or who may have an altered state of grieving. The themes that emerged from this study can be a starting point in the development of appropriate grief intensity tools.

Major findings

Three major themes and nine sub-themes emerged from this study. The three major themes were (a) The fractured self, (b) Inimitable grieving, (c) Loss of shared destiny.

The four sub-themes under theme one are (a) Loss of sole entity (b) Loss of intimate companionship, and (b) Loss of unique twin status. The four sub-themes under theme two are (a) Guilt, (b) Obligation, (c) Triggers and cues (d) Inexpressible grief intensity. The two sub-themes under theme three are (a) Fear of similar fate and (b) Inexplicit wonder.

Under theme one: The fractured self, six of nine twinless twins felt a loss of sole entity and loss of intimate companionship. Seven of nine felt a loss of unique twin status.

Under theme two: Inimitable grieving, five of nine expressed some type of survivor guilt. Six of nine also felt a sense of obligation after the loss of their co-twin. Triggers and cues were identified in most of the interviews with birthdays and gravesite visits being the most difficult. Four of the nine felt inexpressible grief and intensity. These twins often coped with the loss in unproductive ways. Seven of the nine also described magnified grief incomparable to anything they have every known.

Under theme three: Loss of shared destiny, three twinless twins who lost their co-twin to cancer described feelings of fear. They expressed concerns about developing cancer and dying too. Six of nine felt inexplicit wonder about “what would have been and what will be.”

These themes were reviewed with the nine participants and one twinless twin who was not interviewed due to the recent loss of her twin. This review of themes is the last step in Colaizzi's research process. This process ensures trustworthiness of the data analysis.

Relationship to Attachment Theory

The impact of twin loss is unique, as identified often through the interviews conducted in this study. In relationship to Bowlby's Attachment theory, these interviews bring to life the unique experience of attachment, identity and loss for the twinless twin. Losing part of who you are is, for a twin, a very devastating experience. The lack of research regarding the loss of a twin reveals a limited understanding of this unique experience in health care. The experience has come to life during these interviews describing the loss as significant, different and worthy of attention by health care workers.

The findings relate to Bowlby's attachment theory in various ways. Although Bowlby studied attachment between infants and their mother's, it has been noted that his findings are applicable across many different arenas.

The first part of Bowlby's Attachment theory describes the development of self. The instinctive behavior of humans to create bonds to ensure survival correlates with the development of a sense of self. This sense of self allows the child to grow and experience bonds later in life. With twins this process is different because of two babies. Attachment differs because of the strong bond, and single sense of self that occurs between the twins. A self-contained unit often forms leaving the co- twin as the attachment figure, not the

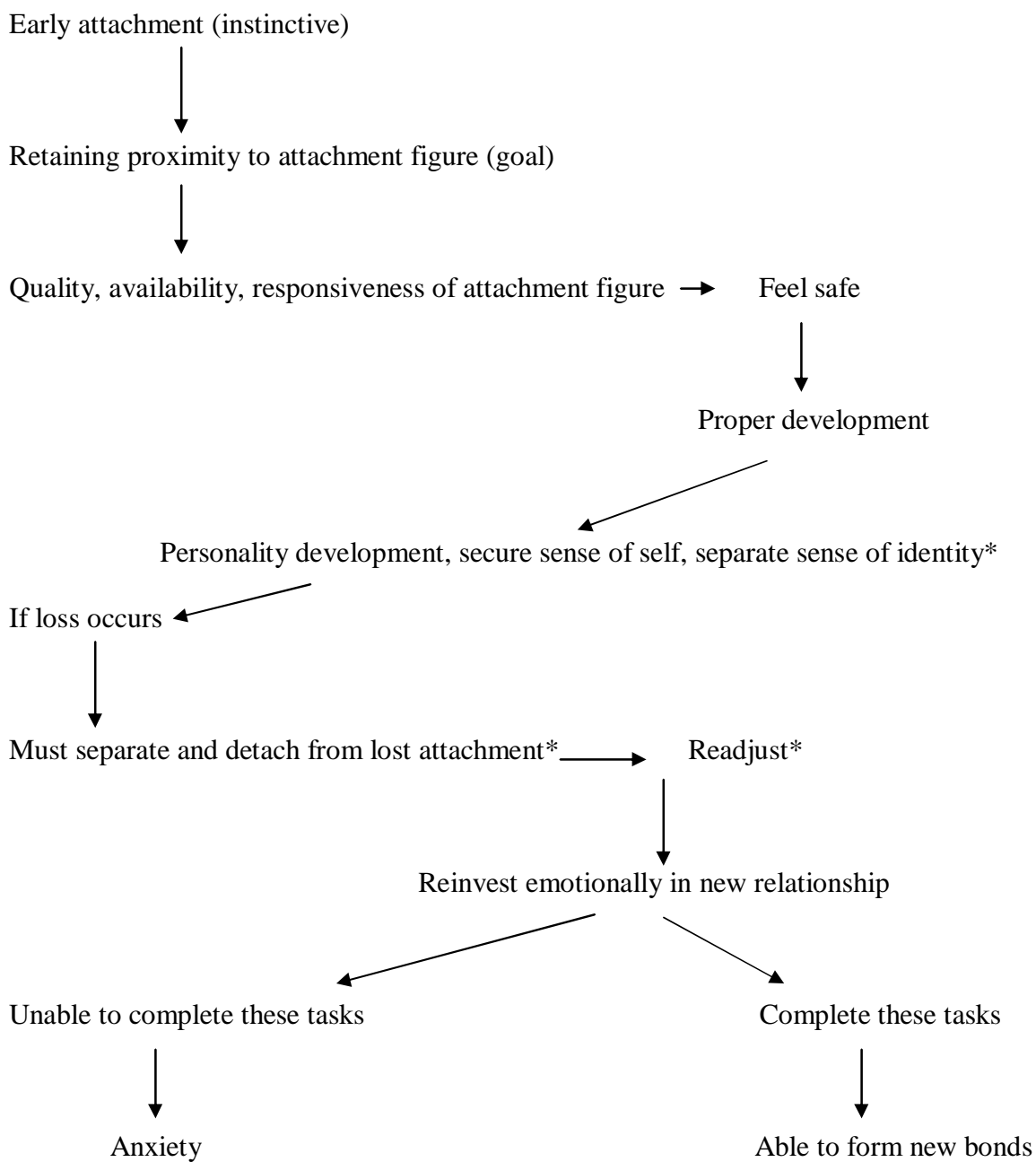
mother. This self-contained unit was mentioned numerous times during several of the interviews conducted and led to identification of “The fractured self” theme. The issue of being a “single entity” as one twinless stated was challenging, but “never wanting to be pushed away” as another twin stated. Although the bond is unique, it can cause problems when twins try to develop that individualized sense of self. As one twinless twin stated, “it is difficult to see the forest through the trees at times, that’s how close we were.” The problem for health care workers lies in the fact that parents of twins need to become aware of this phenomenon. Families with twins need to support twins in a way that allows them to develop equal attachment with others as they grow. Examples of this, as mentioned by several twinless twins, are separating twins during the school years and as adolescents and encouraging participation in different activities.

From Bowlby’s work, proper attachment lies at the heart of the development of a sense of self. For twins it is difficult to do this because of the single identity. The concept of single identity changes for twins. To the twin this means being without your twin because the only identity they know is as a pair. Separating their identity would require them to lose the uniqueness they cherish, their twinship.

The second part of attachment theory is the loss of the bond that is cherished. When attachment is unwillingly broken it changes the lone twin’s sense of self and changes the way they look at themselves because they have always been one with their co-twin. One twinless twin interviewed felt like she had lost part of who she was. Another felt she was more whole, more herself, when she was with her twin. The reason twin loss is so unique is that twin’s do not know what it is like not to be a twin until the

loss occurs. This sense of loss, which may be more intense, needs to be addressed more in the research arena. Through Bowlby's observations, he found that when bonds that are made are threatened or broken, deep patterns of feelings and behaviors arise that undermine a sense of self (Woodward, 1998). One twinless twin describes the mayhem he experienced after the loss of his twin. He joined the army and reported unproductive behaviors that were a result of suppressing feelings of his loss. One other twinless twin reported going through a divorce, for which she sought counseling. Her counselor thought some of her feelings of loss were in relation to the loss of her twin. Twin loss is unique and unlike other losses. The single identity and close bond create a foundation for unhealthy grief. Figure 5 depicts Bowlby's Attachment Theory and identifies those areas that are of concern for a twinless twin.

Figure 5 outlines Bowlby's Attachment Theory and addresses those areas that are of concern for the twinless twin.



*Signifies the steps that twinless twins have difficulty completing.

Conclusions

Although many forms of grief and loss have been researched, the loss of a twin remains open for investigation. The loss of a twin leaves the remaining twin uniquely classified as a twinless twin. This unique loss and classification deserves investigation by health care professionals. Screening must also occur for those who have lost their co-twin so a single self-concept can develop and healthy grieving can take place.

At this time there is no phenomenological research available on the lived experience of twinless twins. One study by Woodward is similar, but not described as phenomenological, although the lived experience is brought to life in this study.

Woodward (1998) conducted a study entitled *The lone twin: Understanding twin bereavement and loss*. The purpose was to explore, from over 200 twinless twins, the actual experience of the loss and to have twins categorize the severity of the loss themselves. Woodward (1998) conducted interviews with each twinless twin and used Bowlby's attachment theory as a framework to understand the twin loss experience.

Woodward found that the loss of a twin is very profound, with 81% of the twinless twins interviewed describing the loss as severe or marked. Woodward's study revealed eight themes. The effect on parental attitude, guilt, negative aspects of being a twin, closeness, polarisation, the worst aspects of loss, the effect of the loss on relating to others and ameliorating factors (Table 2). A comparison of Woodward's' themes and this researcher's themes can be found in Table 2.

 Table 2: Comparison of Woodward's themes and current study themes

Woodward's themes	Current study themes and sub-themes
The affect of parental attitude	
Guilt	Guilt
Negative aspects of being a twin	Fear of similar fate
Closeness	Loss of intimate companionship
	Loss of unique twin status
Polarization	The fractured self
	Loss of sole entity
	Obligation
The worst aspects of loss	
The effect of loss on relating to others	Inimitable grief
	Inexpressible grief intensity
	Triggers and cues
Ameliorating factors	Implicit wonder "what would
	have been and what will be

Implications

The implications of twin loss for healthcare will inevitably become a problem due to the increasing number of twin pregnancies. There are measures that can be taken to increase awareness for parents, health care workers and twinless twins themselves. Parents can be counseled prior to delivery and possibly throughout the vital years of attachment about developing a single sense of self for each twin. Twinless twins can also be screened using bereavement tools based on the common themes found through this and future qualitative or quantitative research. Counseling can be offered focusing on accepting the reality of the loss, identifying impediments that are hindering the grief process and offering support as the twinless twin reinvests back into life.

Twinless twins also need comfort in knowing that their loss is identified as unique and other twinless twins themselves often express what they are feeling. Support groups like the *Lone Twin Network* are growing. Twins need to be aware of these resources to aid in a healthy grieving process.

Limitations

The small number of participants involved in the study (9) is a limitation itself. All 9 of the participants were Caucasian. The interviews were conducted with twinless twin from the Midwest only. Only one interview was conducted with each person. Also, with a qualitative study, there is not the ability to generalize to a larger population.

Strengths

Broad open questions were used to allow the participant to take a path of their own and express the twinless twin experience in their own words. These open-ended

questions provide in-depth information that cannot be obtained through quantitative research. All of the participants were eager to tell their story.

Recommendations for future study

Further research in this area is needed to bring the experience to life. A larger sample that replicates this study would increase the validity and add to the literature available on the twin loss. The sample could come from different areas of the country to broaden the findings on the experience of twin loss. As technology leads to an increase in twin pregnancies, there may also be an increase in the unique twin loss experience. Heightened awareness of the loss would be beneficial for parents of twins, twins themselves and health care providers. Further research should be conducted to validate the identified themes for appropriateness and completeness when describing the lived experience of a twinless twin.

One way to do this could be through quantitative studies conducted in hospital or clinic settings. Surveys or screening tools could be developed in regards to the identified themes. These surveys could be mailed out to twinless twins. The screening tools could be used in the clinic setting to identify those in need of professional counseling. This population of grieving individuals has been overlooked by healthcare and it is time to recognize twin loss as unique and individual from other losses in society.

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Appendix A: Demographic Data

1. Age_____
2. Gender_____
3. Ethnicity_____
4. Education level_____
5. Religion_____
6. What was the gender of your twin?_____
7. Are you identical or fraternal twins?_____
5. How long has it been since your twin died?_____
6. How old were you when your twin died?_____
7. What were the circumstances of your twin's death?_____
8. Have you received counseling due to the loss of your twin?_____If yes, describe

Appendix B: Interview Questions

The interview included open-ended questions to allow the participants to describe their thoughts and experiences in detail. The subjects were instructed prior to the start of the interview not to use proper names in the effort to maintain confidentiality.

General research question

1. Tell me what it is like being a twinless twin?

Examples of prompts or cues

1. Tell me your feelings and experiences associated with the loss of your twin?
2. Tell me about the death of your twin?
3. Tell me how this has affected your general attitude toward life?
4. How does being a twinless twin make you feel about yourself?
5. Tell me how the death of your twin has affected how you feel about others?
6. Do you have anything else you would like to share with me?

Appendix C: Cover Letter

Dear twinless twin:

I am conducting a study entitled “As two become one: The lived experience of a twinless twin” for the thesis requirement at South Dakota State University.

The purpose of this research is to explore the meaning of loss for the twin who has lost their co-twin. The aim is to generate an understanding of the unique bond and sense of loss related to death of a co-twin. This will provide a framework for nursing interventions for the twinless twin as well as parents of the twin. It will also answer my research question “What is the lived experience of a twinless twin?”

The review board at South Dakota State University has approved the study and procedure. You, as a twinless twin are invited to participate. Your participation is voluntary and you are under no obligation to participate.

To participate in the study you must be at least 18 years of age, a twinless twin and three months past the death of your twin. A scheduled interview will be conducted based on convenience for the participant and the researcher. To accurately obtain the spontaneity of the experience, the interview will be unstructured and audio-taped taking approximately 1 hour. A follow- up interview may be necessary if further information is needed.

Risks to your participation may include emotional responses due to questions, at times, of a sensitive nature. You have the right to withdraw at any time. Referrals to counseling can be made if needed. The cost of this is born by the participant.

The interview and responses are strictly confidential. All study data will be collected by the researcher, stored in a locked safe and will not be shared without your permission. The data will be presented in a written report; names and circumstances will be changed to safeguard identity. Thank you for your time and assistance.

If you have questions you may contact Dr. Tish Smyer, thesis advisor, or myself at the numbers below.

Sincerely,

Jody Ness, RN
Graduate student
(605) 692-1610 or troyness@brookings.net

Dr. Smyer, RN, DNSc
Thesis Advisor 1-605-688-6567

Appendix D: Consent Form

This is an invitation for you as a twinless twin to participate in a research project titled “As two become one: The lived experience of a twinless twin.” Under the direction of Dr. Tish Smyer, thesis advisor and the Graduate Nursing department of South Dakota State University this topic will be researched. My name is Jody Ness; I am doing this thesis as part of the requirements for a Master’s of Science degree in Nursing. The purpose of this study is to understand what it is like to be a twinless twin through the experiences of twinless twins themselves.

Please read or listen to the following information:

The nature of the research project has been explained to me and I understand the purpose of the study. I understand that my participation is voluntary, involving an interview that will be audio-taped and take approximately 1 hour. I realize all information will remain confidential and my identity will be safeguarded. Audio-tapes will be kept in a locked safe during the study and destroyed after completion of the study. I understand the results of the study will not identify me. I understand that I have the right to withdraw from the study at any time without penalty. I also understand that the researcher may withdraw me as the participant from the study at any time if so deemed necessary.

The risk to my participation is minimal, but may include bringing back painful memories, talking about uncomfortable thoughts or feelings, but no physical harm is expected. I am aware that a counselor has agreed to be used as a referral if therapy or counseling is needed while participating in this study. I understand cost of therapy will be my responsibility.

Benefits of my participation may include knowing you are not alone and being able to put feelings into words for another person to hear.

Upon completion of the study I understand that the results may be made available to me. I understand a summary may be requested at the time of the interview, but an address must be provided to the researcher.

I understand that I am to rely on the researcher for information regarding the nature and purpose of the research study, and the risks involved. I may also contact the thesis advisor if questions arise. I have been given the opportunity to discuss all of the above with the researcher.

I understand that ethical standards of nursing will be strictly adhered to. I understand mandatory reporting will be done if I disclose information about harming or having harmed a child. The researcher as a registered nurse in South Dakota is obligated to report these findings to authorities.

I will receive a copy of the signed consent form and I fully understand that my signature signifies that I give my consent to participate and I have in no way been coerced. I have read the consent form and hereby voluntarily consent to participate in this study.

Subject's Signature Date

I have explained this study to the above subject and have sought his/her understanding for informed consent.

Researcher's Signature Date

Contact information:

Jody Ness, RN, graduate student 1-605-692-1610

Dr. Tish Smyer, RN, DNSc 1-605-688-6567

Dr. Debra Spear, Chairperson Human Subjects Committee, Psychology Dept., SDSU 1-
605-688-6578

Appendix E: Newspaper Inquiry

Are you a twin, at least 18 years of age or older, who lost their co-twin to death?

Research subjects needed for a study of twinless twins. Study being conducted as part of the thesis requirements at South Dakota State University. Please contact Jody Ness, SDSU College of Nursing graduate student at (605) 692-1610.

Appendix F: Human Subjects Form

Human Subjects Committee
Human Subjects Approval Request
South Dakota State University

Exempt Expedited Review Committee Review

1. Principal Investigator Jody Ness, Graduate Nursing Student

Phone No. (605) 692-1610

Email Address of Principal Investigator troyness@brookings.net

College/School South Dakota State University Department Nursing

If student, faculty advisor Tish Smyer Graduate Undergraduate

(Please use an additional sheet to list others involved with the project).

2. Project Title As two become one: The lived experience of twinless twins

3. Sponsoring Agency None

4. Project Period (contact with subjects): From 11 / 18 / 04 To 11 / 18 / 05

5. Location for Conduction of Study South Dakota

6. Number of human subjects to be selected minimum of 8 possibly more depending on the data received, not to exceed 15

7. Types of subjects to be selected (see instructions on long form)

Normal Adults Pregnant Women Prisoners

Minors Fetuses Mentally Disabled or Retarded

8. Exemption from Committee Review Requested? Yes No

If "yes", indicated basis for exemption:

Common Educational Setting Educational Tests Study of Existing Data

Survey/Interview Research Observational Research

9. Are any drug or chemical or biological agents to be administered to human subjects?

Yes No

10. Are specimens or samples of tissues, body fluids, or other substances to be collected from participants?

Yes No

11. Has each investigator involved in the study completed the NIH on-line training and filed the copy of the certificate with

Carolyn in the Graduate School? Yes No

12. **Research Protocol:** Complete a description of the proposed study following instructions.

13. **Informed Consent:** Attach copies of all forms which will be used to obtain the legally effective informed consent of human subjects or their legal representatives, or jurisdiction why informed consent should be altered or waived.

Authorized Signatures:

Principal Investigator _____ Date _____

I do do not wish to appear before the committee

Advisor (If student project) _____ Date _____

Department Head or Dean _____ Date _____

Research Protocol

South Dakota State University

A. Objectives: The purpose of this research is to explore the lived experience of twins who have lost their co-twin. The aim is to generate an understanding of the unique bond and sense of loss related to death of a co-twin. This will provide a framework for nursing interventions for the twinless twin as well as parents of the twin. This study will use a qualitative design, phenomenology, to study the lived experience of a twinless twin and answer the question, What is the lived experience of a twinless twin?

B. Participants: Participants will be selected based on a purposeful sampling technique. An information letter will be posted on support group websites for twinless twins and in local newspapers. Participants must be a twinless twin, at least 18 years of age and three months past the death of their twin.

C. Time Required for Individual Participants: Each participant will be interviewed and audio-taped. The interviews will take approximately 1 hour. Participants will be asked at the end of the research analysis to review the phenomenological description for accuracy. This review can be done through e-mail or regular mail.

D. Compensation to Participants: No compensation will be given for participation in the study.

E. Benefits to Participants: The participant may feel that they are not alone and they are

given the opportunity to put feelings into words and discuss their experience with another individual.

F. Methods: Phenomenology will be the qualitative method used to study this phenomenon. Phenomenology is a research method that describes the lived experience of a phenomenon of interest. The phenomenon of interest is the lived experience of twinless twins. Participants will be recruited through websites for twinless twins and local newspapers. After criteria to participate is evaluated, participants will be asked to sign a consent form. Data will be obtained through an audio-taped interview process taking approximately 1 hour. Confidentiality will be maintained by using numbers instead of names to individualize the participants. All data will be kept in a locked safe and destroyed after study completion. Colaizzi's seven-step method will be used to analyze the data obtained. Dr. Tish Smyer, thesis advisor, will also analyze data for accuracy. To assure methodological rigor the techniques of dependability, interpretation, validity, ethical rigor and auditability will be used.

G. Risks to Participants: There will be minimal risks, however, discomforts to the participant may include bringing back painful memories while talking about uncomfortable thoughts or feelings.

H. Risk Reduction: A counselor will be available to use as a referral if needed. The cost of therapy is the participant's responsibility.

I. Confidentiality (include location of storage for confidential information): All participants will be asked to sign a consent form. Information in the consent form is based on the criteria from the Human subjects committee. All information obtained will remain confidential by using numbers instead of names to represent participants. All data will remain in a locked safe during the study. The data will be destroyed after the study is completed.

J. Recruitment (include a copy of any advertisements, flyers, or posters to be used): See attached cover letter. A purposeful sampling technique will be used to recruit participants.

1. Websites: A copy of the attached cover letter will be posted on twinless twin websites.

2. Brookings Register, Sioux Falls Argus Leader and regional newspaper publications: A copy of the attached add will be submitted.