

**“UNCLEAR ACROSS A BARREN LANDSCAPE”:
PARENTS’ EXPERIENCES WITH THE AFTERMATH
OF SUDDEN INFANT DEATH SYNDROME**

by

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Abstract

The sudden and unexplained death of an apparently healthy infant produces a profound and catastrophic sense of loss in parents. This study examines these outcomes in a group of 21 Canadian parents who were each interviewed and asked to tell their story of how they dealt with the aftermath of a death due to sudden infant death syndrome (SIDS). Using a grounded theory approach the results were analyzed using NVivo software and the themes and concepts that arose are described.

The findings describe the grief process and the sub-types of memories these parents articulate, ranging from extremely traumatic to dissociative to pleasant. Issues of coping and resilience are examined, as well as the unique social stressors that these parents encounter. Emerging issues including emotion and grief, the physiology of bereavement, and lactation issues are included. Additionally, unique circumstances relating to the death scene investigation are examined, as well as support mechanisms that these parents used, including online assistance.

It is argued that there is a more nuanced and complex phenomenon at play following a SIDS death. By examining pertinent aspects of grief theory, emotional memory, and post-traumatic stress disorder (PTSD) along with empirical evidence from interviews with parents, a more specific understanding of the unique trajectory that these parents undergo emerges. Grief theory explains

issues including meaning reconstruction and ways in which healing occurs while PTSD and emotional memory add information on the extreme trauma and life-altering changes that parents described in the interviews. Thus the SIDS experience is unique—not the same as other forms of grief, but also not as pathological as PTSD, since some parents do overcome the trauma on their own and do heal in time.

The parents' narratives in this study help to introduce concepts that are emerging in the literature. These include aspects of complicated grief, physiological and anthropological dimensions of grief, and long-term effects relating to grief-related morbidity and mortality.

Keywords: sudden infant death; bereavement; loss (psychology)

Subject Terms: sudden infant death syndrome

This thesis is dedicated to my partner Barry Truax

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Preface: A Note on the Title

For thousands of years cairns have been built in memory of the departed. They are also used to mark the way when it is unclear across a barren landscape. You are invited to join in the building of a cairn in the Cathedral this evening by placing a stone on the cairn in memory of a baby who has died.

On Tuesday, June 24, 2008 a service was held in the Cathedral Church of St. Thomas of Canterbury in Portsmouth, UK with an address by The Very Reverend David Brindley, Dean of Portsmouth. The choral evensong was attended by members of the SIDS 10th International Conference where I presented some of the findings in this thesis. Their program note for the evening included the above quote.

The metaphor seemed apt as a title for a number of reasons. Parents who have experienced SIDS undergo a journey across a very bleak landscape. Throughout history cairns have been used as burial markers as well as markers to show the way forward. They commemorate events, they are used to store food, to hold fires and guide ships, and in the Canadian Arctic take the form of an inukshuk—a representation of a human figure. Cairns are both ancient and modern, universal and local, practical and artistic. They stand in their lonely and barren outposts but unite all travellers as each one leaves a stone just as we did during the service.

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Glossary

Antenatal	Before birth (synonymous with “prenatal”).
Catecholamines	Chemical compounds found in the body that play a role in responses to stress. Examples are epinephrine, norepinephrine, and L-dopa.
Cortisol	A hormone produced by the adrenal gland and implicated in stress response. It increases blood pressure and blood sugar and has many other effects including imprinting memory.
CVA	A cerebrovascular accident or CVA is the clinical term for what lay people call a stroke.
DSM	Diagnostic and Statistical Manual. An American Psychiatric Association publication which classified mental illnesses. It is used primarily in the U.S.; elsewhere, the World Health Organization’s International Classification of Diseases is preferred.
Electrolyte	Any compounds that in solution, conduct electricity. In humans, disruptions and imbalances even in small amounts, can result in cardiac and neurological complications.
Emotional memory	Emotions have a powerful influence on memory. Autobiographical memories which are laden with emotion may be encoded differently from more neutral thoughts. There are two dimensions to this process, the degree of arousal and the range or valence from positive to negative.
Epinephrine	Also known as adrenalin, this hormone and neurotransmitter is secreted during stress to produce the “fight or flight” response.
Etiology	The cause of something. Clinical usage refers to the cause of a disease.

Fetal growth retardation	For many possible reasons a fetus may fail to mature properly which usually results in a baby that is small for its gestational age, something formerly more broadly termed prematurity. These low birth weight infants are at increased risk for SIDS.
Genetic mutation	A change in the chemistry of a gene that is then perpetuated in subsequent divisions. This change may be useful by varying the gene pool, neutral, or harmful causing disorders and disease.
Glucocorticoids	A class of hormones that includes cortisol.
Hormone	A chemical substance formed in one organ or part of the body and carried in the blood to another organ or part. These chemical messengers control, signal, interact, and produce a wide range of effects in the body.
Intrauterine hypoxia	A lack of oxygen in the womb; this may lead to complications, birth defects or even death of the fetus.
In utero	A Latin term referring to “in the uterus”.
MRI	Magnetic resonance imaging is a technique used in radiology to provide high contrast images of body tissues. A specialized form termed functional MRI (fMRI) measures actual neural activity by measuring blood flow. This shows which parts of the brain are active during certain perceptual and cognitive processes.
Morbidity	The prevalence or incidence of a disease in the population at a given time.
Mortality rate	The mortality rate is the measure of the number of deaths due to a condition or disease in a given population.
Neurohormones	Hormones formed by cells in the brain with effects throughout the body.
Norepinephrine	A catecholamine that acts both as a stress hormone and a neurotransmitter; it has a wide range of stress-response functions including the “fight or flight” response (along with epinephrine), increasing heart rate, triggering glucose release and increasing blood flow to muscles.

NVivo 7	A proprietary software package used for the organization and analysis of qualitative data.
Opiates/Opioids	An opiate is any preparation or derivative of opium, e.g. morphine or codeine.
Oxytocin	A hormone used to stimulate labour contractions during childbirth.
Parity	The number of times a woman has given birth; it is used along with gravida which indicates the total number of times a woman has been pregnant, regardless of whether those pregnancies were carried to term, e.g. a woman who has had two normal pregnancies would be referred to in her obstetrical history as gravida 2, para 2.
Pathology	The study and diagnosis of disease through examination of organs, tissues, and fluids, usually through an autopsy. The person doing the autopsy is a pathologist. The specialty is in turn subdivided into a number of sub-specialties such as pediatric or forensic pathology.
Periconceptionally	The period from conception to early pregnancy.
Perinatal	Definitions of the perinatal period vary somewhat by country and jurisdiction but the World Health Organization defines it as the period commencing at 22 weeks gestation (when birth weight is normally 500g) and ending one month after birth. In Canada perinatal mortality is defined as occurring in the period from 20 weeks after conception to 7 days of age. This period is further defined as “fetal mortality early” (20 weeks gestation to 28 weeks), “fetal mortality late” (28 weeks gestation to birth), or “neontatal mortality early” (birth to 7 days).
Prone	The body when lying face downward. The reverse, facing upward is referred to as supine.
Propranolol	A drug in the classification of beta blockers. It has long been used to treat hypertension by blocking the action of epinephrine among other effects. Its use as a treatment for post-traumatic stress disorder is experimental and controversial.
PTSD	Posttraumatic stress disorder is an anxiety disorder that

may develop after exposure to extreme psychological trauma. It is defined in the DSM which gives clear guidelines for its use as a diagnostic category.

Serotonin	A neurotransmitter which modulates a broad range of body functions including mechanisms that regulate breathing.
SIDS	The sudden and unexpected death of an apparently healthy infant under one year of age. The term is only officially used when the event remains unexplained even after a full investigation, review of the history, and complete autopsy.
Thymus	An organ located in the upper part of the chest cavity just behind the sternum. Its interest in relation to SIDS was the theory that swelling of this organ caused breathing irregularities leading to a SIDS death.
Vasopressin	A hormone that causes contraction of smooth muscle including blood vessels among other effects.

Chapter 1: Introduction

1.1 Introducing Sudden Infant Death Syndrome

The loss of a child is an unusual and life changing experience for parents. This in itself makes processes surrounding such a loss an intriguing area of study, and offers a way to examine how people resolve such a complex, deeply traumatic event. It represents a window into issues of grief, sadness, trauma and despair, and also of hope, courage, resiliency and recovery. Sudden infant death syndrome (SIDS) portrays an even more specific and atypical type of loss, incorporating as it does a death scene investigation, an autopsy, and lack of information for parents as to precisely how their child died. In this dissertation I will argue that although in some ways the grief experienced by SIDS parents represents a type of grief that is the same as is generally experienced by people coping with other forms of loss, it is often different qualitatively from experiences people undergo when someone dies at the end of their life trajectory. By that I mean that parents themselves articulate a different process from that of the more usual grief response and they feel it takes far longer to return to a state of functioning and feeling as if things have returned to some form of normalcy. These similarities and differences are the subject of this dissertation.

Elements of traumatic memory and posttraumatic stress disorder (PTSD) also enter into the recovery process along with biological issues that have not yet been incorporated into existing literature. The examination of the SIDS grief

experience in relation to three bodies of knowledge—the grief literature, literature about traumatic memory, and literature about posttraumatic stress disorder (PTSD)—represents a new perspective for examining and better understanding parents' recovery from the death of an infant due to SIDS.

The literature to date about how parents respond to SIDS deaths and how to help them has been largely descriptive, rather than analytical. We know that SIDS represents extreme trauma but we are seldom told why. This under-explored area needs to be developed to fully appreciate the emotional, biological and anthropological components that come into play as SIDS parents recover. Grief literature has evolved considerably in the past three decades, commensurate with the development of qualitative methods that contribute to a more nuanced view of what the grief experience entails. However, this literature is derived largely from palliative and end-of-life adult experiences which leaves many areas unaddressed. For example, spousal grief after a lifetime with a partner is invariably different from that experienced by parents who have known their infant for mere months. These experiential differences often make it difficult to extrapolate from existing grief models in the literature, which have emerged largely from the study of the death of adults to experiences of those concerned with the death of infants. This grief literature offers considerable insight into any form of loss which is a multi-faceted phenomenon. In this exploratory study an attempt is made to further understand the phenomenon by drawing in additional literatures.

Posttraumatic stress disorder and emotional trauma literature have generally evolved independently from the literature on grief. The former (PTSD) literature derives primarily from combat survivors who comprise mostly men and the latter is based in large measure upon accounts of childhood abuse, primarily experienced by women. Once again, there are few points of contact among these literatures, even though all of these areas deal with aspects of loss. Using SIDS parents' narratives, I argue that elements outlined in all three literatures, i.e. grief, PTSD and traumatic memory, exist and that this nexus where elements of each are located represents a starting point for examining the experiences of SIDS parents and their road back to fully functioning adults.

With this in mind, elements that appear different from grief trajectories in the literature are described. The next step is to explore where congruence with the above-mentioned existing literature occurs. There are similarities between SIDS grief and other forms of grief, particularly with respect to newer models that have evolved as a result of qualitative analyses where people have been asked to describe their experiences. Such work contrasts with earlier quantitative approaches where scales and measures were more commonly used to determine grief. The emotional responses and the yearning—the wish to have things the way they were, to restore equilibrium and harmony by having the loved one back—are consistent with experiences common to people who encounter grief. The slow path of recovery among SIDS parents does take place along the lines described by current grief theories. People do get through their loss, demonstrating the resiliency that represents yet another branch of emerging

literature (termed as such). Nevertheless, in spite of these similarities between SIDS grief and other forms of grief there are additional components of SIDS grief which became apparent as people told their stories to me.

In other words, parents recover from a SIDS loss in ways that are similar to other forms of grief but that also include significant differences. These differences have to do with elements of traumatic memory and dissociation and some elements of PTSD. A SIDS loss, sometimes viewed as an extreme and profound reaction, frightening in its intensity, may represent an adaptive way to protect oneself from a grief so overwhelming that it threatens to destabilize these individuals psychologically.

Before addressing the grief literature I begin by explaining what is currently known about SIDS. This includes descriptions of those factors that come into play with SIDS deaths namely the death scene investigation, the coroner's role, the first responders and the autopsy. The descriptions of these situations and roles offer some discussion as to why this is potentially so troublesome. Historical context demonstrates how parents have taken control of the research process and pushed for answers from researchers and clinicians. Data from my 21 interviews and the themes that emerged during my analysis suggest that there is a process that occurs, a trajectory that these parents articulate within the narratives that explain how they make their recovery and how they themselves define that process in a phenomenological way. The incorporation of literature in the discussion of findings is used to support these empirical findings.

1.2 Personal and Professional Context

My personal experience in the health care system dates back over four decades. When I was fifteen, I worked during the summer in a tuberculosis sanatorium in Kitchener, Ontario. It was the end of the era where these patients were hospitalized, sometimes for years at a time. The hospital was being transformed into a long-term care facility. During that summer I encountered young people who had severe debilitating diseases or permanent paralysis following injury, older people who had lived their whole lives unable to help themselves and in constant need of nursing care, and people with chronic progressive diseases such as multiple sclerosis. I returned each summer for four years and came back to find some of these people the same as always, others worse, and some dead. The experience of those summers helped me to decide to become a nurse. At the age of 25 I became Director of Nursing at the Shriners' Hospital in Montreal where I encountered a different type of loss and disability, this time within the context of children and their families. Over the years I did a Master's degree in counselling at the University of British Columbia (UBC) with an emphasis on the psychology of disability. I took a course with a professor visiting UBC from the University of Alberta who was himself a quadriplegic, an experience that was both enlightening and humbling. I realized that I knew a lot less about physical disability than I had previously thought.

As a nurse and a counsellor I have experienced an astonishing range of human experiences, some fascinating, some shocking. When the opportunity came to undertake a doctoral program, I realized this was a chance to interact

and learn from people who had themselves undergone a process well outside the realm of most people's life experiences. It was a journey that I hoped would unravel some questions about grief, loss, mourning and resilience that I had asked myself for many years. I also hoped it might provide some insights for others from parents who are rarely asked to provide their stories in such detail for others to hear.

1.3 Overview of the Thesis

In the remainder of this chapter, after providing an overview of the thesis, I introduce the research question and give a brief overview of what is known about the etiology of SIDS, risk factors associated with it, and the quite recent history of investigation into its causes. The parents with whom I spoke understood much of this, having learned about it following the death of their child, much as a cancer patient becomes expert about their particular form of disease. While not everyone I interviewed was entirely up-to-date on the latest SIDS research, most parents were very well informed, and our discussions were constructed with the understanding that they had all spent considerable time learning and coming to understand as much as they could about SIDS.

In Chapter 2, a review of the multi-disciplinary grief literature places this dissertation in the context of what others have written about grief, followed by those authors who have written about outcomes in this population of parents. (SIDS is defined as a death that occurs between the first month and the first year of life.) I discuss other forms of infant and child loss to situate my work within the

larger field of all forms of child loss since there are similarities and differences among them.

Chapter 3, outlines the methods used for this study including background information about grounded theory and its evolution into the constructivist approach which I adopted. Also included is information about the use of the qualitative research computer program NVivo with which I analyzed the data.

Chapter 4 introduces the death scene investigation, a component of every SIDS death and something that every parent interviewed (except one) encountered. While not overtly problematic for the interviewees, it is a potentially troublesome situation in a number of ways as parents deal with police, first responders including firefighters and paramedics, coroners and medical examiners, and pathologists who will conduct an autopsy.

Chapter 5 introduces findings derived from the analysis of the transcripts of the 21 parents that were interviewed and the themes that emerged from their stories. These themes address five major areas:

1. the grief process with an emphasis on how it is similar but also different from that described in the literature;
2. the memory spectrum to examine the negative and positive reconstructions that these parents described, along with themes relating to mementos, anniversary reactions, and issues of traumatic and emotional memories. Also included in this theme are some thoughts about the dissociative phase that many parents encounter in the immediate aftermath of a SIDS death, and the eventual restoration of positive, integrated reminders of the lost infant;
3. themes of coping, restoration and psychological resilience to explore how people successfully drew on internal and external resources;

4. sources of support, how and why people chose specific people and technological sources such as online activity to help themselves emotionally;
5. social stressors and other incidents that parents encountered in problematic interactions with others.

Chapter 6 serves to elaborate online social support which is a growing area of interest. While many of the parents in my sample experienced their loss many years ago (this is discussed in the Methods chapter 3) they also told me about the fact that they continue to gain knowledge about SIDS and support issues from online activities. This is an important emerging area for information and support for parents experiencing SIDS in future.

In Chapter 7 affective issues which were embedded throughout these five thematic areas are discussed. Some of these such as guilt were expected based on the available literature on SIDS, but other themes such as deep empathy for others in times of crisis were unexpected. Also in chapter 7 I explore physical problems such as lactation suppression which relate to SIDS loss.

Chapter 8 returns to the literature for an overview of the themes that emerged during my interviews with parents, as well as issues surrounding the memory spectrum, coping, restoration and psychological resilience.

Chapter 9 contains a discussion of findings in which I somewhat extend my thoughts about the findings and their implications. A return to the literature suggests ways in which new linkages might be made in terms of the accounts I heard and what has been described in the literatures on grief, PTSD and emotional trauma areas.

In Chapter 10 I conclude by outlining emerging issues which are explored with suggestions for future research directions. These include the lack of a general theory of grief and understudied populations such as men and siblings of children who have died of SIDS.

1.4 Introducing the Research Question

My initial proposal for this doctoral work articulated the following research questions in relation to the aftermath of a death due to Sudden Infant Death Syndrome, which have guided my inquiry and are addressed in this thesis:

- How do families restore meaning during this period of extreme stress?
- How do people reconstruct their lives and resolve issues following an episode of sudden, catastrophic, and irrational loss?
- Do current theories of grief and loss adequately address our understanding of this type of unusual and specific event?
- What methods do parents use to help themselves; what sources of support do they deem most important?

Loss in general is something which everyone must deal with throughout life. Loss can be framed in widely diverse ways, from simple everyday things such as saying goodbye to work colleagues who are moving on, to much more serious losses such as the death of a partner or parent, or in the case of SIDS, an infant child.

It seemed appropriate to develop a better understanding of grief, loss and its resolution by examining and analyzing the narratives of those who have undergone a profound, life-changing, and irrational permanent type of loss. Sudden infant death provides a number of interesting dimensions which make it an unusual experience. Parents undergo a profound and core change as their assumptions about how their lives would unfold are suddenly disrupted. A seemingly healthy infant, with no signs or symptoms whatsoever, and no illness at all, suddenly dies. Following this, there is interaction with the legal system through coroners or medical examiners and police, with the medical system through an autopsy, and long-term interactions with family and friends. The latter may send a profoundly mixed message: children are the most precious beings but after they die you need to get over it. Worse yet, parents may need to endure accusations that they had done something to deliberately cause the death.

Our notions of how people go through grief and mourning have evolved considerably in the past 30 years, consistent with an increase in qualitative research methods. Qualitative investigation has allowed researchers to better understand the complex processes that occur during grief. I entered the doctoral program with a quantitative background (I had spent the past ten years as a medical journalist covering clinical trials) and began learning as much as possible about qualitative approaches. I began with readings in qualitative research and grief theory. This then allowed me to better understand the specific circumstances that these SIDS parents found themselves in and to then situate that framework within a more extended literature of traumatic memory,

posttraumatic stress disorder, and health sequelae, all subjects that emerged from the empirical work I was doing.

Apart from the psychosocial aspects of a SIDS loss, there are wider public health implications. Even though SIDS represents only about 25% of all deaths between one month and one year of age (Hunt & Hauck, 2006), it represents a significant contribution towards infant mortality which is often used as an index of the general state of a country's ability to provide adequate health care services to its population. Infant mortality may be viewed as a type of indicator reflecting the efficacy of public health initiatives. Every society values its children and it is a case of social responsibility for all of us to encourage measures that decrease infants dying and better understand the reasons for that occurring.

1.5 A SIDS Overview

1.5.1 The Current Definition

Sudden infant death syndrome (SIDS) is defined as the sudden death of an infant younger than one year of age that remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the infant's and family's clinical histories (Willinger, James, & Catz, 1991). There is ongoing debate about this definition. For example, if the investigation is not thorough, or if there is no autopsy, it may or may not be considered SIDS. Also, if there are minor pathological findings a final diagnosis may vary. The actual use of this currently used definition varies and remains disputed (Byard, 2004).

1.5.2 SIDS Risk Factors

Parents told me their stories in the context of now knowing some risk factors for SIDS, many of which they had not known during the pregnancy and infancy of their child. Knowing now what they did not know then adds to the considerable burden of guilt they face, although in some cases this has not changed their behaviour. For example, several parents remained smokers even after learning that smoking is a significant risk factor for SIDS.

SIDS risk factors can be grouped under the categories of maternal and antenatal factors.

Table 1.1: Maternal and Infant Risk Factors for SIDS

Maternal and antenatal risk factors	Infant risk factors
Smoking	Age (peak 2-4 months, but peak may be decreasing)
Alcohol use (especially periconceptionally and in first trimester)	Male sex
Illegal drug use (especially opiates)	Race / ethnic background (e.g. black, Native Indian, other indigenous group)
Inadequate prenatal care	No pacifier (“dummy”) used at bed time
Low socioeconomic status	Prematurity
Low age	Prone or side sleeping position
Low level of education	Recent febrile illness
Single marital status	Exposure to tobacco smoke
Increased parity	Soft sleeping surface, soft bedding
Short interval between pregnancies	Thermal stress / overheating
Intrauterine hypoxia	Face covered by bedding
Fetal growth retardation	Sharing bed with parents or siblings
	Sleeping in own room rather than in parents’ room
	Colder season, no central heating

(Hunt & Hauck, 2006, p. 1862)¹

Few parents know about all of these risk factors, some of which have only recently been articulated. Parents in this study who lost infants a decade or more ago did not know at the time of the death of their infants that they may have been increasing the risk for their infants through their practices.

1.5.3 SIDS Causation

The actual causes of SIDS are exceedingly complex. The peculiar enigma of SIDS is that a series of events happens involving a number of variables that come together to produce a final common pathway, i.e. the silent and sudden

¹ Used with permission. This article was published in the Canadian Medical Association Journal, Volume 174 (13), Sudden infant death syndrome, Pages 1861-9, Copyright Canadian Medical Association (1995-2008).

death of an infant. Currently, the most widely accepted model is known as “the triple risk model” (Filiano & Kinney, 1994). In this construct, an infant is (1) vulnerable due to an underlying defect, brain abnormality or genetic mutation. Cardiac defects have also been implicated. The infant then reaches a (2) critical developmental period (the incidence of most SIDS cases peaks between two and four months) during which rapid changes in homeostatic controls occur. These changes manifest in sleep/wake patterns, variations in breathing, heart rate, blood pressure and body temperature regulation all of which have the potential to destabilize an infant’s regulatory system. With these two scenarios in place, the infant now encounters (3) an outside stressor such as second-hand tobacco smoke, overheating, prone sleep position or an upper-respiratory infection. Although none of these factors alone are enough to produce SIDS, a combination of these factors may tip the balance (Filiano & Kinney, 1994).

SIDS is an unusual definition, since as can be seen from the above, it is not really sudden; it does not happen only in infancy (cases over the age of one year are rare but well documented (Byard, 2004; Krous, Chadwick, Crandall, & Nadeau-Manning, 2005)), and it is not really a syndrome which is a group of signs and symptoms used to define a disease. While the typical case occurs late at night and the infant is found early in the morning, babies do die in car seats, while being nursed, while carried by parents, and in child care settings (Moon, Patel, & Shaefer, 2000). There have been cases in twins (Beal, 1989) including at least one case where both died simultaneously (Ladham, Koehler, Shakir, & Wecht, 2001). Child care settings are particularly problematic because not only

are children stressed when they are first placed in an unfamiliar environment but untrained workers may place the child on its stomach adding a significant increased risk for SIDS termed “unaccustomed prone” (Moon, Sprague, & Patel, 2005; Moon et al., 2000).

1.5.4 Historical Context

SIDS has probably existed since the dawn of humankind, but the concept of SIDS is fairly recent, having been constructed in the 1960s. Although it is beyond the scope of this thesis to trace the development of infant mortality throughout Western history, it should be noted that there have always been some changes in views about the value of children in society over time. In the past, children in poor and working class households needed to work as soon as possible to contribute to the household income. To this day, in certain cultures, children are meant to care for and provide for elderly parents. In Western society there has been a near-complete reversal of this value. We now oppose child labour and as a society have a collective notion that it is inappropriate or even morally wrong.

The emotional value of children has also undergone a shift. While it would be presumptuous to assume that in the past parents had less of a bond with their infants because they were so much more likely to die—parents have probably always loved their babies—it took outrageous conditions for social pressure to intervene and make the changes necessary to keep children safe.

On July 22, 1903, Mary Miner, five years old, was playing with some friends across from her father’s restaurant in the Bowery

when she was struck and killed by a Third Avenue electric car. The motorman “had a narrow escape from violence at the hands of a mob estimated by the police...to have been 3,000 strong.” Press accounts describe the girl’s father as “so frenzied with grief that he had to be forced to give up a frantic attempt on the motorman’s life.” Twenty years later, on May Day, 1926—a nationally declared “No Accident Day” for children—memorial services were held at the unveiling of two monuments in New York City. The crowd solemnly honored the memory of the 7,000 boys and girls killed in traffic accidents during the previous year [*sic*] (Zelizer, 1985, pp.22-23).²

It seems hard to imagine in 2008 how people would feel about 7,000 traffic deaths involving children occurring before anyone decided to initiate action.

Similarly, infant death has evolved from a virtual non-issue to an important social concern. Prior to 1877 infant deaths were not reported or recorded in England (Armstrong, 1986). It was even later that death in the first year of life was a social concern, since it happened so frequently. To this day, an infant in the first year of life—the time period for SIDS deaths—is in a type of limbo, born and here but not really a person yet. Perhaps this accounts for the frequent comments made by people to SIDS parents (which I will discuss in my findings) that they can always have more children, that it was never meant to be, and that it’s better the baby died now before the parent really had a chance to get to know it.

SIDS has existed for as long as people have been having babies. It is described in the Bible where it was simply assumed that smothering had taken place, either accidentally or intentionally. But it was not a social problem:

Of interest historically is the attitude people had toward the overlaying and smothering of infants. Sudden unexpected and unexplained infant deaths were not matters in which police and the

² This should read “years” since it refers to the total number of children killed in the previous twenty years.

courts showed much interest until the 17th or 18th century. Before this, overlaying and smothering were matters dealt with by parents and church (rather than civil) officials. Until the early 19th century, these infant deaths were considered a social rather than a medical problem, and as such, were not the subject of anatomical or physiological scrutiny (Savitt, 2003, p.2).

By the 1940s physicians were beginning to question the concept of overlaying or smothering as a reason for the deaths of such large numbers of infants. Doctors Jacob Werne and Irene Garrow of the Queens County, New York Medical Examiner's office, published a series of articles between 1942 and 1953 that drew attention to the problem of sudden infant deaths based on autopsy findings. Attention began to be directed towards the fact that babies invariably find an airway regardless of the position in which they are sleeping or whatever impediments are in their way (Savitt, 1979). Something else must have been responsible for at least some of these deaths.

In the 1950s things had changed dramatically. The church was losing its grip as science and technology provided answers to social questions. Something as mysterious as infants dying for no reason became less and less acceptable. This was particularly the case as medicine made advances in areas such as bacteriology, virology, nutrition and postmortem findings. Societal and family factors were also increasingly being studied by academics. Public interest was aroused in the phenomenon of sudden infant death. Here was a problem that society could tackle with its new-found arsenal of technological tools (Armstrong, 1986).

1.5.5 Sudden Infant Death Syndrome Defined

Savitt (1979) explains that Werne and Garrow's work between 1942 and 1953 demonstrated that infant deaths needed further investigation. In 1962, the American National Institute of Child Health and Human Development (NICHD) sponsored a research conference in Seattle, Washington to exchange ideas and encourage research (Hasselmeyer & Hunter, 1988). There were 10 guest speakers, seven from the United States and three from England. Thirty additional participants attended, all from the U.S. except for Dr. Sydney Segal from Canada (Côté, 2004). Dr. Segal was a medical researcher and teacher from North Vancouver who remained involved with SIDS issues and was deeply influential among SIDS parents until his death in 1997.

This initial conference produced very little in the way of interest or initiatives among the scientific community. A second conference was scheduled in February of 1969, again in Seattle (Hasselmeyer & Hunter, 1988).

Hasselmeyer (1988) who attended the 1969 conference, wrote:

An interesting aspect of the February 1969 conference, and a major factor in the evolution of the sudden infant death syndrome program in the United States, was the attendance at the conference, at their own expense, of parents of SIDS babies seeking answers for why their babies had died. They were disheartened by the lack of research activity on this most tragic medical problem. They organized; they wrote letters to the Congress; they called us; they visited us; they lobbied. Continuing parental pressure on the Congress in the early seventies resulted in NICHD taking a more directed approach toward support of SIDS research. Persistent parental lobbying also led to enactment of the Sudden Infant Death Syndrome Act of 1974 (P.L. 93-270). This act fixed by statute the responsibility of NICHD for the conduct of SIDS research; required the secretary of the Department of Health, Education and Welfare to carry out a program to develop public information and professional educational materials relating to SIDS;

authorized the secretary to make grants and enter into contracts for projects to collect, analyze, and furnish information about the causes of SIDS and to provide information and counseling to families affected by SIDS; and require specific reports to the Congress or its committees concerning SIDS research, information and counseling projects, and internal budgetary requests (p. 2).

Dr. Eileen Hasselmeyer is credited with planning and managing the workshops for this 1969 conference that would kick start the SIDS research process.

Another significant event at the time was the formation of a parent group called the Mark Addison Roe Foundation, founded in 1962 by Jedd and Louise Roe in memory of their son who had died of SIDS. This organization would ultimately merge with a sister group based in Baltimore to form the National SIDS Alliance (Valdes-Dapena, 1995). Thus, parents took control of the agenda, began raising money, continued to press for answers, and they formed important grass roots organizations that were eventually replicated in many Western countries. This process was ongoing for decades and in many respects remains a driving force to this day. Washington State is an epicentre of SIDS-related activities, and Baltimore is the home of First Candle, one of the largest and most influential SIDS organizations in the world.

At this second SIDS (1969) meeting there were 27 guest speakers from four countries: Canada, Czechoslovakia, Northern Ireland, and the United States. Topics were classified along four themes: epidemiology, pathology, virology, and physiology. It was at this meeting that the name Sudden Infant Death Syndrome was adopted and a definition agreed upon (Côté, 2004). The international conferences continued in Cambridge (1970), Toronto (1974), Baltimore (1982),

Brussels (1985), and Lake Como (1987). At the Brussels meeting, a group was formed to promote international co-operation and in Lake Como SIDS International was formed. This organization took on responsibility for subsequent international meetings, the first of which was held in London (1989), followed by Sydney, Australia (1992), Stavanger, Norway (1994), Washington, DC (1996), Rouen, France (1998), Auckland, New Zealand (2000), Florence, Italy (2002), Edmonton, Canada (2004), Yokohama, Japan (2006) and Portsmouth, UK (2008) (Fitzgerald, 2001). The 2006 meeting in Japan was the first conference to be jointly sponsored by both SIDS and the International Stillbirth Alliance. In future, SIDS conferences are likely to be merged within a broader framework of infant deaths from all causes.

The vital role of parents in driving research and increasing an understanding of risk factors is not without its problems. Parents who have lost a child to SIDS have a sense of ownership of the issues and a sense of authority on the subject that can sometimes restrict debate. Some also have unresolved anger issues and have unrealistic expectations of science to answer their questions. Nevertheless, parents have always played a role, attended international conferences, and donated significant amounts of money earmarked for research purposes.

Sudden infant death syndrome now had a name, a definition, and an International Classification of Disease code but the controversy over exactly what SIDS is and what it is not has never subsided. Roger W. Byard and Henry F. Krous, two of the most respected SIDS experts in the world, explain that despite

decades of international research the definition developed by the national Institute of Child Health and Human Development in 1991 is not accepted everywhere, that different jurisdictions and different countries have very different criteria for a diagnosis of SIDS, that autopsies and pathology reports vary widely and in some places are not done at all, and that these discrepancies have led to wide variations in published research findings (Byard & Krous, 2003). It is difficult to develop comparisons of SIDS rates. Even in Canada, there is no national registry and definitions and protocols vary by province and territory, something that is of extreme concern to parents and those providing support for those affected by SIDS.

1.5.6 The Back-to-Sleep Campaign

In spite of these less-than-ideal definitional and jurisdictional issues, the conferences in the late 1960s did lead to a consolidation of sudden, unexplained infant death as an entity that should be examined. It also became apparent that smothering, or “overlying” as it had been termed for centuries, was not always the cause of such deaths. Parents pressed for answers, and researchers began to speculate at first, then form hypotheses, and then conduct rigorous research to rule out initial hunches. Many new theories were proposed including milk hypersensitivity, viral infections, neurological and electrolyte disorders, thymus enlargement, cardiac arrhythmias and many, many more (Guntheroth, 1989). Some of these were later ruled out conclusively while others such as the role of infection, neurological defects in utero and cardiac arrhythmias remain the subject of research.

While these etiological factors were being investigated, risk factors were also being examined. Since all SIDS research is retrospective, it became apparent that fewer SIDS cases were occurring in those infants who were lying on their back (Fleming et al., 1990). While the exact reason for this is not known to this day, the evidence became so overwhelming that in 1992 the American Academy of Pediatrics made nonprone (i.e. side or supine) sleep position the recommended way to place a baby (Task Force on Sudden Infant Death Syndrome, 2000). Canada adopted these practical recommendations shortly thereafter with an active “back to sleep” campaign beginning in 1993 (Côté, Gerez, Brouillette, & Laplante, 2000).

Side sleeping has been found to confer increased risk as well, and thus placing a baby on its back is now considered the optimal way to reduce SIDS risk. There is a large literature on this initiative, considered by some to be one of the biggest public health success stories in the Western world (see for example Alexander & Radisch, 2005; Blair, Sidebotham, Berry, Evans, & Fleming, 2006; Côté et al., 2000; Fitzgerald, 2001; Task Force on Sudden Infant Death Syndrome, 2000; Task Force on Sudden Infant Death Syndrome, 2005). The best evidence is that the supine position (lying face upward) is the single most effective strategy for reducing the risk of SIDS. Ongoing investigations are constantly shedding more light on the reasons for this phenomenon. It appears that babies lying on their backs have less of a tendency to re-breathe their own expired breath which leads to carbon dioxide build-up and lower oxygen levels (Byard, 2004). They are less likely to sleep as deeply, which causes them to

arouse more quickly when they run into problems with breathing. Ironically, this is precisely why parents have historically placed their infants on their stomach, since infants often fall asleep faster, and sleep for longer periods—something tired parents long for.

1.5.7 Current Research Areas

As stated previously, many parents affected by SIDS become intensely interested in research. Currently, investigators are examining specific risk factors and these include socioeconomic status issues. SIDS (like many other health concerns) is an increased problem for families from lower social strata, lower maternal education levels and single marital status (Hunt & Hauck, 2006). There is a vast literature about risks associated with smoking, and more nuanced and specific smoking cessation programs are constantly being developed. An interesting avenue of research is genetic predisposition, particularly now that the genome has been mapped. The relationship between genetic and environmental risk factors and the way one influences the other is being investigated. For example, is it possible to determine which infants are more genetically predisposed to factors such as fever, exposure to cigarette smoke or arousal and cardiovascular irregularities (Hunt & Hauck, 2006)?

There is considerable debate regarding bed sharing. While it is known that an infant sleeping in the same room as parents has a decreased risk of SIDS, it has also been established that co-sleeping with parents confers an increased risk of SIDS (Alexander & Radisch, 2005). Nevertheless, this information does not necessarily change practices, and there has been ongoing debate about how

parents should handle this issue, with many simply opting for co-sleeping in any case. This is particularly true for mothers who breast feed, an increasingly popular option as the benefits of doing so are understood.³ There is no clear way this dilemma can be resolved.

Perhaps the single biggest controversy to date is classification inconsistencies in investigations of SIDS deaths. This is hampering progress and research on multiple fronts. The Scripps Howard News report (Scripps Howard News Service, 2008) is expressing concern regarding exactly what is going on in the United States:

A new look at the records of 40,000 infant deaths casts deep doubt on claims of medical authorities that cases of Sudden Infant Death Syndrome have fallen by more than half since the 1990s. A Scripps Howard News Service investigation of infant deaths going back to 1992 revealed that the quality of infant death investigations, the level of training for coroners, and the amount of oversight and review vary enormously across the country. In many cases, professional bias—both for and against a diagnosis of SIDS—trumps medical evidence. The sloppy investigations and muddled records come with a very high price: the deaths of more babies who might have been saved through medical research (ScrippsNews. (2007). Retrieved June 4, 2007 from <http://scrippsnews.s10113.gridserver.com/>).

The situation is probably not much better in Canada. There are child death review committees in every province but SIDS is only one of the many areas they are mandated to investigate. In the UK, sudden unexpected deaths in infancy are handled through a multiagency approach where a pediatrician and the police are involved immediately, along with social services. They visit the home and follow

³ The Canadian Paediatric Society recommends exclusive breastfeeding for the first six months of a baby's life. Health Canada and the World Health Organization all recommend breast feeding. The slogan "breast is best" has led to steady increases in breast feeding rates in Canada according to the Canadian Perinatal Surveillance System (Health Canada, 2003).

protocols that are well established. These include interviews with family members, a postmortem examination, case discussions, and documentation throughout the process. Parents are notified and involved throughout (Fleming, Blair, Sidebotham, & Hayler, 2004). Child death review committees in Canada, which work under the auspices of a coroner's or a medical examiner's office, are developing better methods for investigating, documenting and classifying sudden infant deaths (T. Ramanzin, personal communication, April 2, 2008).

1.6 The Research Process

I decided to interview parents who had experienced a SIDS death to attempt to understand how they had dealt with these complex issues and explore how their lives had unfolded following the death. I developed a relationship with the executive director of the Canadian Foundation for the Study of Infant Deaths and their program manager arranged contacts with parents of SIDS infants which then led to my interviews. This was consistent with the ethical framework I had proposed in which I suggested an intermediary so that parents would not have to negotiate with me directly until they were comfortable with their decision to be interviewed. The research process is addressed in greater depth in Chapter 3.

As a special arrangements student, I was fortunate to have doctoral committee members who had extensive expertise in women's studies, psychology, health care, communication, criminology and sociology. This multi-disciplinary group was invaluable in shaping and directing my work.

1.7 Summary

This chapter has set the scene for my investigation with an introduction to Sudden Infant Death Syndrome, a personal account that explained my interest in the phenomenon and an introduction to the thesis and a statement of the research question. A high-level overview of what is currently known and understood about the risk factors for SIDS, the current state of knowledge regarding etiology, and a brief historical overview that has led to a definition and the successful “back to sleep” campaign instituted in the early 1990s sets the context for this research. I closed with some comments about the current state of research as it relates to etiology and risk factors, something that is of intense interest to not only the participants in my study but to SIDS parents everywhere.

In the next chapter a more detailed, multi-disciplinary review of the literature offers insights into literature use about grief, which further contextualizes the research undertaken.

Chapter 2: Situating SIDS Grief

2.1 Introduction

In this section I provide a review of the literature that pertains to the work I undertook in preparation for interviews with parents who had experienced SIDS, as well as reviews of literature that I examined during the course of the analysis.

I begin with an examination of aspects of the grief literature. This area is the cornerstone of my work and was the original material which informed my investigations. Following this, I provide an overview of the impact of a SIDS death by reviewing what professionals have written. This section includes contributions by nurses, physicians, allied health professionals and concludes with first person accounts.

The wider literature on child loss is reviewed in the next section. Literature about child loss from the perinatal period through to that of an older child also offers some insights into parents' experiences of grief. The issue of social support and what is deemed useful by parents is discussed. Later (in Chapter 8) I examine aspects of the literature about memory and resilience. Taken together, these areas reflect the starting points for my investigations followed by the foundation for the emerging themes that arose from my interviews with parents and the subsequent analysis of the transcripts.

2.2 The Development of Grief Literature

In my original research proposal I set out to uncover the process by which parents moved through their loss and back towards a state of some form of normalcy in their lives. I found that the narratives did include clear descriptions of that progression. Nevertheless, much more problematic is matching these themes to existing literature.

The emerging interdisciplinary field of thanatology, the study of death and dying, produced over 4,000 scholarly publications between 1984 and 2004 (Neimeyer, 2004). Ongoing research is becoming increasingly specialized and compartmentalized, but the relationship of this body of work to the experiences of SIDS parents is not always a good fit. Specific research projects such as this dissertation have been few and those that have analyzed aspects of parental grief are sometimes dated. To begin, it is helpful to define some common definitions used in this literature.

Many terms are used to describe grief and related phenomena. For example:

The term *bereavement* is understood to refer to the objective situation of having lost someone significant. Across the life span, people have to face the death of parents, siblings, partners, friends, or even their own children. Although most people manage to come to terms with this over the course of time, it is associated with intense distress for most people. This usual reaction to bereavement is termed *grief*, defined as a primarily emotional (affective) reaction to the loss of a loved one through death. It incorporates diverse psychological (cognitive, social-behavioral) and physiological (physiological-somatic) manifestations. Sometimes *mourning* is used interchangeably with *grief*, particularly among those following the psychoanalytic tradition. Our preference is to define mourning as the social expressions or acts expressive

of grief that are shaped by the practices of a given society or cultural group (Stroebe, Hansson, Stroebe, & Schut, 2001b, p.6).

Grief is however not a state; it is a process. Our understanding of how this process unfolds begins with Freud's classic 1917 paper *Mourning and melancholia* which emphasized the 'work' of mourning (Freud, 1917). In this process there is a 'profoundly painful dejection, abrogation of interest in the outside world, loss of the capacity to love, and inhibition of all activity' (p. 125). There is a gradual withdrawal of the libido that was invested in the lost object and this is eventually redirected toward others. When this is accomplished, Freud states that 'the work of mourning is completed' and 'the ego becomes free and uninhibited again' (p. 127). He argued that the process cannot be circumvented and that interference is probably counterproductive. Freud's paper had a lasting influence on later writers because he described an active process which really is 'work'. It takes time and energy, and involves an initial denial of reality followed by a gradual withdrawal of the inward attachment to the lost person (Archer, 1999).

Building on this historic work, the British psychoanalyst John Bowlby developed an influential theory of attachment and loss. His initial interest in this area derived from observations of the extreme distress experienced by infants when their mother is absent. He developed his theories from ethology and control theory and, in perhaps a precursor to stage theories, divided mourning into four phases:

(1) Phase of numbing that usually lasts from a few hours to a week and may be interrupted by outbursts of extremely intense distress and/or anger.

(2) Phase of yearning and searching for the lost figure lasting some months and sometimes for years.

(3) Phase of disorganization and despair.

(4) Phase of greater or less degree of reorganization (Bowlby, 1980, p.85).

Bowlby was quite specific about his stages and extrapolated them in response to the death of a child or to a stillbirth: “numbing, followed by somatic distress, yearning, anger and subsequent irritability and depression, are all common” (p. 122). Bowlby’s work remains highly influential. An interesting avenue of related research implies that grief is adaptive, the price we as social animals pay for the early ingrained and very powerful loss and separation anxiety produced when mother and offspring are physically apart (Archer, 1999).

In 1944, Harvard psychiatrist Erich Lindemann (1944) published another highly influential paper on the symptomatology, course, and management of grief. His clear descriptions, particularly of the somatic features of loss, make for compelling reading even now, over half a century later. Nevertheless, he limits his analysis to the acute phases of loss, stating that acute grief is a definite syndrome with psychological and somatic symptomatology, and this syndrome may appear immediately after a crisis, be delayed, or even apparently absent. His focus then is to modify the extreme reaction into a more ‘normal’ grief reaction, one that the individual can successfully resolve perhaps independently of clinical intervention (Lindemann, 1944). This anticipates the literature on

resilience which developed much later, something I will return to in Chapter 5. Lindemann's paper has been incorporated into the posttraumatic stress disorder (PTSD) literature (Lindemann, 1999) where I would argue it does not necessarily belong. Grief and posttraumatic stress disorder overlap but are not the same. To muddy the waters, SIDS parents appear to experience some—but not all—of the standard criteria for PTSD which is classified as an anxiety disorder. This is a point I will explore in the memory section of the findings in Chapter 5.

More recently, Elizabeth Kübler-Ross (1969), with her book *On Death and Dying* has had enormous influence. Even lay persons can list her famous five stages of denial, anger, bargaining, depression, and acceptance. Her work, derived from interviews with cancer patients who were dying, was controversial and provocative at the time, confronting the taboo that surrounds speaking about death with those who were staring it in the face (Kübler-Ross, 1969). Some aspects of stage theories such as hers have been criticized in recent years (see for example the most recent challenge by Maciejewski et al (Maciejewski, Zhang, Block, & Prigerson, 2007)). However it should be noted that her book, with its warm and compassionate accounts using patients themselves as teachers, remains important. Kübler-Ross revised her thinking in later years and acknowledged that the stages were not always sequential or even really definable: they sometimes overlapped or even occurred simultaneously. In a later work she clarified this:

Patients do not necessarily follow a classical pattern from the stage of denial to the stage of anger, to bargaining, to depression and acceptance. Most of my patients have exhibited two or three stages

simultaneously and these do not always occur in the same order (Kübler-Ross, 1974, pp.25-26).

Much more recent work has challenged stage theory directly. Using a longitudinal cohort study, investigators found that counter to the commonly accepted above model, disbelief was not the initial, dominant grief indicator. It was also established that yearning was a frequent psychological response (Maciejewski et al., 2007), something that I found in my sample as well.

Worden (1991) offers a task model with four stages: accepting the reality of loss; experiencing the pain of grief; adjusting to an environment without the deceased; and 'relocating' the deceased emotionally and moving on with life. All these theories share a stage approach in which the person returns to some semblance of the predeath or preloss state. Resolution and acceptance over time is implied.

While these traditional theorists have had a major impact, a new generation of theorists are re-examining, elaborating and, as was the case with Maciejewski above, challenging dominant models. In an effort to increase comprehension in the field various new models and constructs have been proposed. These have arisen not only from a sense that existing models are not sufficiently comprehensive to understand what is actually occurring, but also in response to a dissatisfaction with a lack of empirical evidence (Bonanno & Kaltman, 1999). These researchers use a variety of approaches to develop different ways of viewing the mourning trajectory. However, some common elements emerge. One is the importance of creating meaning from the loss. A

variation on this theme is Walter's suggestion that the purpose of grief is the "construction of a durable biography that enables the living to integrate the memory of the dead into their ongoing lives" (Walter, 1996, p. 7).

This is a considerable conceptual shift from previous ways of viewing the situation. It also involves meaning reconstruction, the subject of considerable discussion in the literature (Davis & Nolen-Hoeksema, 2001; Davis, Wortman, Lehman, & Silver, 2000; Holland, Currier, & Neimeyer, 2006; Neimeyer, 2001a; Neimeyer, 2001b; Neimeyer, 2005a; Neimeyer, Baldwin, & Gillies, 2007; Neimeyer, 2000; Stroebe & Schut, 2001a; Uren & Wastell, 2002; Wheeler, 2001). One of the chief theorists in the charge towards re-examining traditional models of grief and mourning is Robert A. Neimeyer of the University of Memphis. He is critical of stage theories and the concept that 'working through' the process causes one to end up at some semblance of preloss status (Neimeyer, 1999). His thinking has been influenced by George Kelly (1955), who states that there are numerous ways in which individuals construct their world, that a thoughtful person is "neither the prisoner of his environment nor the victim of his biography," (p. 560) and that in order to understand behaviour one must understand personal constructs. Parents themselves do not arrive at a preloss state at all. They are changed forever, as will be demonstrated in their accounts which follow.

Emerging models of mourning are, according to Neimeyer (1999), characterized by the following elements as outline in Table 2.1.

Table 2.1: Characteristics of Emerging Models of Mourning

Scepticism...	about the universality of a predictable trajectory from disequilibrium to readjustment;
A move away...	from letting go of the one who has died;
Movement towards...	the potentially healthy role of maintaining symbolic bonds with the deceased;
Attention...	to meaning-making processes;
Awareness...	of the implications of major loss for the individual's sense of identity;
The need...	for a possible revision;
Increased awareness...	of growth potential following loss;
A broadened understanding...	of the wider impact on families, not just the individuals.

(Adapted from Neimeyer, 1999, pp. 66-67)

Neimeyer (2001c) provides a new theory of grieving, a reauthoring of life narratives, always with the potential for an emergent new personal construction. These new approaches incorporate a shift toward idiographic approaches and away from stage models, with an emphasis on sense-making, benefit-finding, and identity reconstructions. This expanded view of the process of grief and mourning is one of multiple approaches being taken to expand and consider what is actually happening in the lives of affected individuals.

Bonanno and Kaltman (1999) argue that Freud has been influential for too long and that the concept of "grief work" needs to be reconsidered. In an era that

has seen considerable research conducted on stress, they propose a four-component model that includes

- the context of the loss,
- the continuum of subjective meanings associated with loss,
- the changing representations of the lost relationships,
- the role of coping and emotion-regulation processes (p. 760).

Their influential work is a call to arms for alternative approaches, a challenge to traditional assumptions, and an excellent overview of methodological concerns (their work is quantitative) that they believe have long plagued the field of bereavement research. For example, they suggest that cross-sectional designs have identified phenomenological features but only at certain points in the process, whereas longitudinal studies have been limited by the minimal amount of experimental control they afford (Bonanno & Kaltman, 1999).

Work that expands our understanding of the grief trajectory is also being carried out in Europe. Stroebe and Schut (2001a) have developed a dual process model (DPM) that includes two distinct areas of everyday life experience following loss. The first area is “loss oriented” (p. 59) and consists of grief work with its intrusive elements, a breaking of the bonds and ties to the deceased, and a denial and avoidance of restoration. In the second psychologically distinct process, one finds “restoration oriented” (p. 59) experiences, which include attending to life changes, doing new things, being distracted from grief, and forging new roles, identities, and relationships. In this model, which has

generated wide interest, people move back and forth between the two domains in a continual fashion during their attempts to move through bereavement. Eventually, some form of existential equilibrium is established. Meaning reconstruction is an integral part of this process.

Although there has been considerable development in our understanding of the nature of grief and its effects on people, the majority of authors have addressed the subject in relation to losses occurring at the end of life, primarily amongst the elderly, including widows and widowers. While there was much in the above-mentioned descriptions that resonated and was consistent with the narratives I heard, there were differences as well.

I now turn to the literature that relates more specifically to parents who have lost infants due to SIDS, which offers a different perspective from that described by grief theorists.

2.3 Grief and SIDS

Following the first two International SIDS conferences in 1963 and 1969, the coining of a name and a description for this entity called Sudden Infant Death Syndrome gave researchers a focus and a starting point for research and publications. While the vast majority of these publications dealt with etiology, epidemiology, and risk factors, a psychosocial literature emerged as well.

I began by reviewing these references which allowed me to situate the findings within what has developed historically. At an early stage in the dissertation Medline was searched for all citations for “sudden infant death

syndrome” and almost 6000 citations were downloaded. I then deleted citations which had nothing to do with the research (e.g. animal studies, esoteric causation theories and so on). Issues covered in the literature were noted, according to dates and article titles. This allowed creation of a high level roadmap of the literature and provided insights into the evolution of SIDS as an area of study. For example, the first articles appear in the late 1960s consistent with the emerging interest in the subject as a result of the two Seattle conferences in 1962 and 1969. Although this exercise certainly was not systematic, insights gained from culling these 6000 abstracts left impressions regarding the evolution of SIDS scholarship, all part of the process of situating the research within the numerous and varied studies published about SIDS.

It was informative to see what others have said, particularly in light of how little was known at the time about the causes of SIDS and what had actually happened to these parents. A great deal of understanding has arisen over the past few decades not only in SIDS research but also in grief theory (elaborated more on in the findings section). A SIDS death has been described from multiple perspectives based on the disciplinary context of the author. It is also of interest to examine how specific groups of professionals have approached the care of family members and an understanding of their particular needs following the death of an infant.

I begin with an overview of literature that deals specifically with a SIDS loss, which is followed by a representative sample of literature that deals more

broadly with SIDS as a subcategory of neonatal, perinatal, infant, and child loss, which are often grouped together.

Psychosocial literature which deals specifically with SIDS comes from three fields: (1) nursing, (2) medicine, and (3) allied health care workers including psychologists, social workers, and counsellors. An additional small section (4) of first person accounts adds another perspective. This psychosocial literature is mostly descriptive of what was becoming a much more clearly defined entity. Although I thought it might be useful to familiarize myself with issues that professionals had encountered in their dealings with SIDS parents, in some ways there were many unanswered questions in relation to what this literature was expressing when contrasted with what I heard parents say to me.

2.3.1 Nursing Literature

Nurses have written about the impact and responses of family members to a SIDS death in a beginning attempt to clarify the problem (Carlson, 1993; Nikolaisen, 1981; Picard, 2002; Williams & Nikolaisen, 1982). These articles are descriptive and did not pose research questions. Their purpose was to describe for other nurses what they could expect when having to deal with grieving families. They emphasized the catastrophic nature of the event, and their descriptions were probably useful for nurses particularly in the 1980s as the scope of the problem was emerging. Sally Nikolaisen of Seattle Pacific University, perhaps finding herself at the epicentre of SIDS-related conferences and research activity, gave a comprehensive overview of what was known at the time and touched on differences in grieving between mothers and fathers, the

conspiracy of silence surrounding the family and the special problems faced by children. She also outlined a comprehensive nursing intervention program to help these families (Nikolaisen, 1981). By describing the problem it was assumed that appropriate interventions would follow.

What was missing however was information about how parents construct continuing bonds, problems they encountered with anniversary and cohort reactions (which I will discuss in the findings), and issues of resiliency, a literature that emerged much later. It was assumed that since the grief was more intense, and often devastating, that more intensive intervention would help parents cope.

Picard (2002) incorporated chaos theory into discussions of SIDS grief as she recounted the death of her infant brother almost half a century earlier. While deeply moving, it was anecdotal and constituted a type of individual case study not generalizable to other situations and did not represent a model pursued by anyone else.

Some nurse-authors have described the immediate reactions of parents (Milne, 1989; Smialke, 1978) including the shock and disbelief that parents experienced which they related to the unexpected and irrational nature of the event. Nevertheless, there was no attempt at systematic analysis. Again, there were no research questions and the authors were simply descriptive, in some cases even repetitive, reiterating what was known about SIDS etiology at the time, i.e. far less than is understood now. Unfortunately, this makes for a

distancing between nurses and parents that decades ago was more the norm for health care professionals.

There were some articles that dealt with interventions in the context of current bereavement theories as outlined in the previous section (Gaffney, 1992; Krueger, 2005). Others described specific strategies for dealing with the “survivors”—those family members who were now at risk for psychological problems (Aadalen, 1980; Swoiskin, 1986; Wachowiak, 1978). In my own work (Krueger, 2005) I begin to address meaning reconstruction and place this into the context of newer developments in grief theory. Nevertheless, my work too is descriptive and not analytical.

All of these commentaries provided some context for situating the specific problems that parents face, and recommendations for appropriate care and intervention. Such approaches may have helped nurses better understand and support family members. Swoiskin (1986) in particular outlined an assessment, planning, and implementation process for parents that must have been extremely useful in spite of the fact that all of the hypothesized causes of SIDS which she listed have been supplanted by newer theories. Similarly, Thomas (1992) gave a comprehensive overview of risk factors along with a post-test for continuing education credit. As with any medical condition, the half-life of information is brief and while these articles attempted to educate nurses, some of the earlier articles contain factual information that has long been updated. For example, side sleeping recommended by Thomas (1992) is no longer considered optimal.

The single most comprehensive account of the aftermath of a SIDS death and the book most closely allied with my work was *When a Baby Dies of SIDS: The Parents' Grief and Search for Reason* by Karen Martin (1998) who described in great detail the experiences of 21 mothers and fathers whose trajectories included specific coping strategies at every stage. Her work attempted to answer the question of why traumatic loss appears to devastate some people and strengthen others.

I met several times with Martin to discuss our mutual research interests. We share a common background in nursing. Martin used a grounded theory approach, as did I and which is explained in Chapter 3. Martin found that parents coped with their loss by virtue of three steps:

- searching for a reason;
- searching for logic;
- searching for meaning (Martin, 1998, pp. 203-204).

Of these, the first was identified by Martin as the core experience. She believed that challenges to parents' assumptive world, i.e. the way they made sense of and interpreted their existence, was severely challenged by sudden death. This then created what she termed "cognitive pain" which in turn created emotional, intellectual, and spiritual disruption compounding their emotional pain (p. 218-219). Martin did not however address issues of traumatic or emotional memory responses which are set out in Chapter 5. The great strength of her work remains in the parents' relationship concerns since she only spoke to couples and then

developed models in an attempt to understand how those couples managed marital conflict as a result of the SIDS loss. Although my work was unable to address these relationship issues, I have extended Martin's findings by introducing the spectrum of memory, issues of resilience, a more extended examination of the death scene investigation and its implications, and physical concerns. In addition I add material on the historical development of SIDS as a social concern and ways in which people are using online services for information and support.

Unpublished doctoral theses by nurses included Arnold (1995) who developed a reconceptualization of the concept of grief in relation to SIDS parents as well as more general forms of grief. She argued that grief as conceptualized in the nursing literature did not reflect the unique experiences of most people and that it is a lifelong process (Arnold, 1995). Gudmundsdottir (2000) used a phenomenological approach to describe narratives of loss and healing practices among SIDS parents demonstrating highly individual tactics that helped them restore meaning on a personal level. Sacks (1998) used a content analysis to address gender differences within a broad range of themes pertaining to the loss. She found that while many coping strategies were similar for both parents, there were important differences which she mapped as concepts (Sacks, 1998). Thornburg (1993) used a phenomenological method to examine the meaning of hope for parents who had experienced a SIDS loss.

These writings developed more nuanced analyses dealing with very specific issues. Each explored a fairly narrow aspect of the overall experiences

that parents encounter. My work was much broader and did not involve asking parents specific questions. In addition, none of the above-mentioned works explored the holistic trauma that I heard parents articulate. While authors such as Martin (1998) and Arnold (1995) implied that there was a more profound phenomenon for parents, they did not examine trauma literature in order to make sense of what had happened following a SIDS death.

Nurses both in their journal articles and in doctoral writings introduced the scope of the problem, emphasizing the large number of annual deaths that were occurring at the time and the unique stresses that a SIDS death placed on a family—stresses that can be catastrophic. Bereavement theories which were developed later (as described in the previous section) were clearly unavailable to these authors and the relationship of posttraumatic stress disorder and traumatic memory to grief was also not incorporated into any of their writings. While this literature began to explore the dimensions of the experience of a SIDS loss and its aftermath, none appeared to probe the phenomenon sufficiently. Questions remained in my mind as to what parents had undergone and how they had helped themselves through this crisis.

2.3.2 Physicians' Contributions to Understanding SIDS

Physicians also began writing about SIDS as it emerged as a specific diagnostic category. As with nurses, they began to become aware of the need to help these parents and their families and attempted to share their experiences and suggestions for interventions with other professionals, describing what they were seeing and suggesting what to do and how to do it. As with most of the

nursing literature, none of these articles posed a specific research question and then proceeded to answer it in a systematic manner using either a qualitative or quantitative approach. The writings were often characterized by anecdotal information based on parents that a particular physician had encountered. There was also occasionally a sense of wishful thinking as physicians wrote about how much time should be spent with these parents and families. One physician suggested seeing parents on a daily basis for the first week (Drinkwater, 1988), an almost inconceivable prospect.

Practice guidelines were developed by the Canadian Paediatric Society (Fetus and Newborn Committee, 1983). These are quite comprehensive, but the section on SIDS is cursory and the implication that “family members may at times be less than supportive of the grieving couple” (p. 337) was completely inconsistent with my findings in which family members were completely supportive. Other pediatricians began to examine unique circumstances in which SIDS parents found themselves (Mandell & Belk, 1977; Wright, 1988) reiterating the usual emphasis on reassurance. Wright (1988) focused on the uncertain nature of SIDS and how this was perceived by families and by clinicians. Child psychiatrists also have looked at family responses to SIDS (Cornwell, Nurcombe, & Stevens, 1977) as well as health, fertility, and family dynamic concerns (Bluglass, 1981). These articles began to address some of the complexity of a SIDS death through detailed descriptions of how other family members reacted, but predate more contemporary views of the grief process which had not yet been developed, and hence fail to incorporate these more recent insights.

Nevertheless, in one paper written by a pediatrician (Krein, 1979) the emotional reactions from initial response through to longer range resolution began to be articulated in an effort to help other physicians understand how to help parents during each phase of their recovery.

One study did attempt to address the identification of the re-establishment of family equilibrium by using assessment scales to measure how parents were coping. May and Breme (1982) referred back to Lindemann's (1944) seminal work and developed a Likert-type scale for measuring parameters relating to family adjustment. These were designed to be predictive to identify those people most in need of intervention. In other words, rather than describing the process that parents underwent, there was a more systematic type of evaluation to determine who needed further and more intensive treatment for unresolved grief. While this scale has not become widely used, the authors acknowledged correctly that a SIDS loss has unique aspects and that different models for understanding these differences needed to be developed (May & Breme, 1982).

Guidelines for discussions with parents on the topic of SIDS have been developed by and for physicians to help them in their dealings with affected parents (Cepeda, 1981b; Lindsay, 1999; Mandell & McClain, 1988). Some of these included paternalistic comments that imply poor parenting (Cepeda, 1981b), or highly idiosyncratic and personal reflections (Lindsay, 1999). Additional topics in the literature were the problem of subsequent pregnancies (Drinkwater, 1988), how to support extended family members (Phillips, 1996), how to deal with siblings and the surviving children (Burns, House, &

Ankenbauer, 2004; Mandell, Dirks-Smith, & Smith, 1988) and issues surrounding family relationships and gender differences in response to SIDS. For example, men tended to assume managerial roles in the family, kept busy outside the home, and resisted professional support (Mandell, McAnulty, & Reece, 1980). Helping parents talk to their children about the death was also a subject addressed in the medical literature (Cepeda, 1981a). Many of these articles began with what was then known about SIDS (very little) and then reiterated the problem of guilt and blame that these parents felt, emphasizing the need for support. These were important contributions outside of the scope of my work since I did not speak with children.

As with the nursing literature, physicians emphasized the unique nature of a SIDS loss, its effects on other family members, and the possibility of grief that is more prolonged and profound than that which might be ordinarily expected. There was however no discussion regarding the death scene investigation and its possible effects on families, the role of the autopsy in helping parents recover psychologically, or the mechanisms responsible for the prolonged and devastating grief that appears in these parents. As with the nursing literature, the starting point appeared to be a grief reaction that was somehow more prolonged and more intense, a variation on a theme instead of a different phenomenon altogether. There was also no mention of anniversary reactions, little discussion of the fears of a subsequent pregnancy (and certainly no mention of the

controversies regarding home monitors for infants⁴), the need for more information and educational activities that parents want, all issues that emerged when parents spoke with me regarding their experiences and areas that I explore in the findings from the interviews and the discussion sections to follow.

2.3.3 Literature From Allied Health Professionals

A third category of professionals, psychologists, social workers and counsellors have also addressed SIDS concerns, again with little attempt at analysis of the underlying unique features of the phenomenon, and an emphasis on intervention strategies that might be useful. Some have done so within a context of grief theory (Hawkins, 1980). Many of the same issues addressed in literature written by nurses and physicians appear here as well and once again “parents” are treated as a unit, something that was inconsistent with my findings as men and women pursued different paths of recovery. These authors also emphasize the sudden nature of the event, the need for support, follow-up, and allowing individuals to move at their own pace. These are probably general issues affecting almost anyone in a grief state. Lowman (1979), a psychologist, described an intervention program for SIDS families that was designed to be delivered by visiting nurses in a large rural area of North Carolina. The emphasis was on the irrational nature of the death and the lack of information about how and why their infant died that then related to the profound grief of parents. While

⁴ There is no evidence that home monitoring prevents SIDS deaths but most parents tend to use them with their subsequent children. In some cases they find it reassuring.

this may be true it only partially explains parents' reactions. Again, findings were far more descriptive than analytical.

Social workers also developed counselling strategies meant to be undertaken by health care professionals dealing directly with SIDS parents (Chernus, 1982; Powell, 1991; Woodward, Pope, Robson, & Hagan, 1985). These studies used a questionnaire that was sent to family members or offered counselling services. These articles began to address complex themes of parental grief and also acknowledged that parents themselves can teach health care professionals much about how they themselves were conceptualizing and handling their issues. There was also acknowledgement that people working with parents need to understand their own limitations and emotional involvement. These transference issues remain problematic to this day as professionals—perhaps with infants of their own—cope with a situation where they are expected to act competently and detached when they are themselves overwhelmed and often feeling ineffective. This is an under-researched area which overlaps into other areas in this thesis including first-responders discussed in the death scene investigation Chapter 4, and support, covered in the findings Chapter 5.

Other allied health professionals have described more specific issues faced by SIDS parents including legal system involvement, problems for caregivers, and the role of the funeral director (Markusen, Owen, Fulton, & Bendiksen, 1978). This introduced the concept that a SIDS death is somehow different and that caregivers need to have specialized knowledge to be effective. General psychological effects on family members including the problems of

dealing with the general public that understands little about SIDS were the topic of another questionnaire-based study (DeFrain & Ernst, 1978) which found that SIDS was the most severe crisis these parents had ever experienced, that guilt and psychological difficulties were pervasive, that relationships with other family members were affected, and that the majority of parents (60%) had moved following the SIDS death within two-and-a-half years.

The specific problems of aggression and guilt in grieving parents were examined in one paper from a psychoanalytic perspective (Hasui & Kitamura, 2004). This study had a specific Japanese focus and dealt with cultural issues of aggression suppression and it would be difficult to generalize to a North American population.

Powell, a social worker, has written about the important subject of problems with subsequent children (Powell, 1995). This article built on the above-mentioned findings of responses to a questionnaire sent to Irish families who had experienced a SIDS loss. To this day, this remains an overlooked area of investigation, perhaps because of ethical challenges associated with interviewing children. How parents can learn to help and understand each other has been the subject of one study (Irizarry & Willard, 1999). This quantitative study measured issues of partner response regarding grief reactions after the death, what things helped them (by gender), people from whom help was sought, issues with subsequent pregnancies and sexual activities and attempts to understand one's partner. These areas are briefly described but the authors made no attempt to

analyze motives or behaviours underlying the described activities. They suggested that the data be used as a starting point for counselling intervention.

Long-term social support issues have been addressed by Norwegian psychosocial researchers (Thuen, 1997; Thuen & Schlytter, 1996). Again, these were retrospective questionnaire-based studies in which responses were translated into frequency analyses using quantitative methods. There was a larger-scale study undertaken with 251 parents surveyed and importantly, a break-down by gender. These studies examined some of the gender differences and styles of coping. For instance, women received more emotional support from their friends than did men, but women were affected to a greater extent by the death and for longer periods of time. This provides useful information to help clinicians understand not only how couples both help and support each other, but also how some couples may interfere with and not understand one another's coping strategies. One author admitted that the findings were embedded in Norwegian cultural patterns and may not be comparable with the majority of studies conducted in the United States (Thuen, 1997).

Some authors have focused specifically on the support that they believe parents require (Buschbacher & Delcampo, 1987; Fukui, 1994; Limerick & Downham, 1978; McClain & Shaefer, 1996; Rosenblatt, 2000). These articles all addressed the specific problems faced by SIDS parents. These include the metaphors and rituals associated with the death, anniversary reactions, how to deal with guilt issues, and the role of national support groups such as the UK Foundation for the Study of Infant Deaths.

Another theme was that in some ways only the parents themselves can provide the empathy and understanding to help each other through peer support (usually one parent matched with another parent) and self-help groups (several parents meeting together on a regular basis). The former is an important and ongoing resource, one encouraged and facilitated by the Canadian Foundation for the Study of Infant Deaths through its peer support programs. Unfortunately, none of these authors spoke about gender differences, who attended these meetings, or the perceived usefulness of these groups, once again treating “parents” as a single unit. Support groups are much more frequently used by women; when men attend, they do so for shorter periods of time and for different reasons. Men generally want answers to their questions (and no longer attend when those are answered) whereas women want emotional support in addition to information and participate longer in order to receive this (Martin, 1998).

Vance and colleagues (Vance, Boyle, Najman, & Thearle, 1995) examined gender differences using psychosocial stress response scales and found that women had a longer grief response time period whereas men also had anxiety and depressive reactions sometimes dealt with through heavy alcohol use. Some gender issues overlap with grief theory which I will explore further in the discussion about grief in the findings chapter 5 below.

Two authors who looked specifically at maternal responses to SIDS did so in order to measure state and trait anxiety using a scale (Lewis, 1983) and an examination of the maternal perceptions of the psychosocial sequelae of a SIDS loss have also been addressed (Price, Carter, Shelton, & Bendell, 1985). These

included many symptoms experienced by women but there was also an excellent analysis of the numerous pathways women used to help themselves including support from a wide range of professionals from clergy, physicians and nurses, friends and family. Of interest was that mental health professionals were generally not considered helpful by these respondents.

Community support (Bluglass & Hassall, 1979) and an integrated multiagency approach to supporting SIDS families have also been described (Fleming et al., 2004). Increased public awareness as part of a risk reduction strategy in Japan has been addressed (Sawaguchi, Nishida, Fukui, Horiuchi, & Nelson, 2002). These articles begin a wider discussion of the role of society in helping these parents. In general, allied health professionals add more detail and nuance to the issues of exactly what happens within these families, where specific problems arise, and how these might be addressed.

2.3.4 First-Person Accounts

Because my research consisted of listening to parents describe their own lived experiences I thought it might be useful to read others' published accounts of their SIDS loss. There were two first-person accounts in the literature relating specifically to SIDS (Harman, 1981; Stead, 1998). Both of these intensely personal stories, written by UK mothers (and in the case of Carolyn Stead, a nurse), provide a sense of the raw emotion and unvarnished pain that parents experience, something that is completely lacking in articles written by professionals (where of course it would sound inappropriate). Their power lies in this highly affective delivery. These pieces provide insight into the magnitude of

grief that follows a SIDS death, but fall short of providing insights into the recovery process.

2.4 Literature Based on Fetal-Infant-Child Mortality

There is an expanded literature that covers the spectrum of loss resulting from miscarriage, stillbirth, neonatal loss and even child loss. Some authors have written about SIDS loss from within this larger perspective, i.e. treating SIDS as a subset of any form of parental loss.. In spite of this inclusion of SIDS, these approaches over-generalize from varied sources of child loss in that the literature sources may be inappropriate for SIDS. Nevertheless, it was useful to expand the readings to include this broader category of literature, particularly since this literature included more quantitative and rigorously researched material that posed specific questions about specific aspects of this particular form of grief.

Fetal-infant mortality is classified along a time continuum. Loss of a pregnancy from 20 to 28 weeks is termed *perinatal mortality* (“early”) and from 28 weeks to birth is considered “late.” These are sometimes referred to as stillbirths. Once an infant is born, it may also be stillborn in which case it is considered *early neonatal mortality*. If the newborn dies between seven days and 28 days it is classified as *late neonatal mortality*. Finally, the period from one month (28 days) to one year, is the postneonatal mortality window in which, by definition, all SIDS cases occur (Health Canada, 2003). By including all these standardized categories, as well as earlier stage losses (miscarriage) and later losses (children), there is considerable loss of nuance. Furthermore, there are multiple ways that loss occurs. In addition to miscarriage, stillbirth, neonatal and perinatal

losses, children die from accidents, illnesses, murder and some disappear. All of these categories are included when one talks about parental loss of a child even though such varied circumstances surrounding the loss of a child may result in completely different emotional challenges and consequences for a parent. For example, a parent whose child dies as a result of a rare disease may not experience feelings of shock and disbelief, common amongst SIDS parents. Some authors have even included suicide in discussions of child loss which I believe is a separate problem that cannot be compared to SIDS, occurring as it does later, usually in the teenage years. Suicide is a profound problem for parents, family, and friends but results in differing dynamics.

Increasingly, SIDS is categorized along with miscarriage. National and even international organizations are amalgamating services and research in both areas as the rate of SIDS decreases and awareness of miscarriage and the much large numbers of women involved is increasing. But the two are fundamentally separate, and in my population, I specifically asked mothers who also had miscarriages whether there was any comparison between that experience and the SIDS death and the answer was a resounding no. This is not to say that mothers who suffer miscarriage do not also suffer grief and loss; quantifying grief is a dangerous and presumptuous game. Nevertheless, at the international conference on SIDS in Yokohama, Japan in miscarriage research and support was included in the proceedings. There were thus two separate tracks: SIDS and miscarriage. People attended presentations in one or the other talks reflecting differences in experience and research. This has been a problem

for support organizations such as the Canadian Foundation for the Study of Infant Deaths as well. SIDS parents are very reluctant to donate to and support an organization that also looks after parents who have experienced miscarriage. In Canada parents have asked that their donations directed towards research remain in the SIDS category.

A problem with this area of literature which deals with mortality ranging from fetal to child is that often the issues are discussed in terms of “parents” or even “the family.” It is presumed that all family members share a common experience which may result in inappropriate generalizations. We know that men and women handle things quite differently. Sometimes this is addressed within the findings but to speak of families as a monolithic unit is too broad. Young children, older children, teenagers, and adult children all process, assimilate and recover from a SIDS loss very differently, not only from each other but also in relation to their own parents, i.e. the grandparents.

A seminal book covering parental loss is Therese A. Rando's *Parental Loss of a Child* (1986) which included a specific chapter on SIDS (Taylor, DeFrain, & Ernst, 1986). It remains the single most comprehensive overview of all aspects of infant and child loss to this day. It addresses all types of losses including abortion, miscarriage, newborns, deaths due to SIDS, accidents and suicide and even children who go missing. It falls short however in its incorporation of more contemporary views of grief and mourning developed in the twenty-two years since its publication.

An example of parental bereavement in Anglo-American history was provided in two articles by Smart (Smart, 1993; 2003). Lovell (1997) also examined parental loss, positioning it in a historical and cultural Western context. These writers draw from the much larger historical literature on the changing attitudes and societal values relating to infant and child loss in previous generations where women typically had far more children than is common now. Also, as family structures have changed, so too have views about child death, and arguably, grief and recovery trajectories. Part of the problem that scholars have encountered is the private and even taboo nature of a death in the family. It is only since the 1960s that there has been a closer examination of death and grieving (Smart, 1993). This makes any accounts, including these articles, important for historical purposes.

General issues of parental grief were explored by Arnold and her colleagues (2005). Using a quantitative approach they found that parental grief may last a lifetime in the form of a complex, non-linear, and ongoing process (Arnold, Gemma, & Cushman, 2005). Other authors who have also used quantitative methods have described the comparative differences in bereavement in the death of a spouse, child, and parent (Sanders, 1980), early parental responses to sudden infant death, stillbirth or neonatal death (Dyregrov & Matthiesen, 1987b; Vance et al., 1991), parental response in relation to personal growth following the death of a child (Riley, LaMontagne, Hepworth, & Murphy, 2007; Wijngaards-de Meij et al., 2008), and what can be learned from these families that would be of benefit to therapists (DeFrain, 1991).

Other authors have examined the family unit as a whole. Picard (2002), used a case study approach based on her personal experiences to examine individuals' different approaches towards the death of a child . Davies (1987) looked at memories, mementos and the meaning they created for family members. Her work is valuable because of the large numbers of families she interviewed (n=34) and the length of time she spent with each (over two hours). Unfortunately, sessions were not audiotaped and many responses were not attributed to individuals. Nevertheless, Davies began the process of articulating the memory trajectory, something few other authors address (Davies, 1987). The study was nevertheless limited by including only meanings associated with the deceased child's belongings. My work builds on the idea of a meaning trajectory as well but broadens this perspective considerably.

Meaning creation in narratives of perinatal loss has also been looked at by Willick (2006), again through an account based on her own personal experience. Others have researched the impact of a child's death on family relationships using qualitative descriptive approaches (Brabant, Forsyth, & McFarlain, 1994; Riches & Dawson, 2002) and followed up on families to ascertain the long-term impact of a perinatal death (Rowe et al., 1978). Couple distress following sudden infant or perinatal death has also been studied (Vance, Boyle, Najman, & Thearle, 2002) as well as meaning reconstruction following parental bereavement (Braun & Berg, 1994). In a variation on the role of meaning

reconstruction, attribution adjustment issues have been examined⁵ with the finding that not all parents were concerned with meaning-making and that some parents had a philosophical orientation or worldview that allowed incorporation of this type of tragic event into a previously constructed framework (Downey, Silver, & Wortman, 1990). The same sample was used in a separate study demonstrating the role of social constraints, intrusive thoughts and depressive symptoms among bereaved mothers (Lepore, Silver, Wortman, & Wayment, 1996).

Maternal issues have been the specific focus of a number of authors including Rubin (1985) who studied mother-child attachment disruption and Catlin and her colleagues (2002) who followed up with mothers two years after the loss of their infants to discover issues of ambivalence in their parental role. Both these authors used a qualitative descriptive approach. Others have conducted studies on the mother's experience of social support after a child's death (Laakso & Paunonen-Ilmonen, 2002) and the relationship of personality, coping, and grief intensity (Robinson & Marwit, 2006), the former using a quantitative analysis based on survey data. Unfortunately, the Robinson (2006) study used only children in the sample and about a third of those died due to homicide making the results difficult to extrapolate to my study.

Fathers' experiences of social support have also been examined (Aho, Tarkka, Astedt-Kurki, & Kaunonen, 2007) as have gender differences both in

⁵ Attribution theory deals with people's beliefs in cause and effect and maintains that people believe the world is a controllable and predictable place, something that SIDS parents sometimes call into question.

relation to locus of control (Rubinstein, 2004), and the general long-term trajectory (i.e. ten to thirty years after the loss of the baby) (William, 1995).

Some researchers have examined mental health issues more closely using quantitative methods. These include a study on predictors of psychosocial distress following suicide, SIDS and accidents (Dyregrov, Nordanger, & Dyregrov, 2003); psychological changes—primarily anxiety and depression—eight months post-loss from stillbirth, neonatal death, or SIDS (Vance et al., 1995); anxiety and vulnerability following the death of an infant (Dyregrov & Matthiesen, 1987a); and mental health issues specifically among mothers (Boyle, Vance, Najman, & Thearle, 1996).

A much-overlooked area of parental loss is in the feminist realm, a rich area for discussion. Linda L. Layne who has herself undergone multiple miscarriages, addressed pregnancy loss from this stance and offers insights into maternal guilt that is culturally reinforced (Layne, 2002). She criticized the culture of secrecy that has hurt both women and men as they struggle with their loss (Layne, 1997). In her comprehensive book she used multiple themes including religion, consumerism and technology from multiple disciplinary perspectives (for example, feminism, science and technology studies, ethnography among others) to give a very different perspective on the subject (Layne, 2003). Many of these issues, although situated in the context of miscarriage, are highly relevant to SIDS parents. For example, Layne's concepts of the silent despair and lack of awareness of how parents cope in contemporary society where childbirth is

venerated and the prospect of death is minimized would be consistent with SIDS parents' experiences.

The importance of rituals in relation to perinatal and pediatric death have been examined by several nurse authors in descriptive articles (Capitulo, 2005; Kobler & Kavanaugh, 2007). The role of perinatal bereavement photography has also been studied (Alexander, 2001). Social support from the point of view of unhelpful and avoidant community responses (a major concern for SIDS parents) has been examined by Dyregrov (2003) who has also written about parents' expectations of research participation (Dyregrov, 2004a). Unfortunately, these populations always include parents who have lost children due to suicide, SIDS or accidents, a grouping that is very broad.

The sociobiology of bereavement in relation to the loss of a child has been described in one quantitative study (Littlefield & Rushton, 1986) as has the relation between grief and subsequent pregnancy (Barr, 2006). In an article that turned things around somewhat, bereaved parents themselves offered advice to professionals based on their personal experiences (Janzen, Cadell, & Westhues, 2004).

An example of a case study that explored divergent cultural values including witchcraft in Mexico was offered by Fabrega and Nutini (1994). A South American look at infant loss which was strikingly at odds with North American values was examined by Scheper-Hughes (1992) who found that women in poor Brazilian shantytowns were able to assimilate their infant's death easily in a

culturally adaptive way within an environment where infant death was common. These accounts were strikingly different from my findings.

First person accounts in peer-reviewed literature are very unusual. One such description was a fascinating “auto-ethnographic meditation” by Dr. Penelope Ironstone-Catterall who teaches cultural studies at Wilfrid Laurier University in Ontario (Ironstone-Catterall, 2004). Her startlingly reflexive story, embedded in psychological, social, and cultural models was astonishing to read. As an academic she related her personal experiences to literature, something that few parents are able to do. She writes:

What follows, then, is a patchwork of sorts that contains my many reflections on the loss of my son, on my complicated work of mourning, and on the meanings I have been able to cull from what I can only call “the terrible gift of knowing” the loss of a child. This knowing, however, is not a tidy one. It bears the pain of rupture in a life that assumed to know itself, the challenges this rupture presents to assumptions assumed to be tried and true. It is a knowing that must tolerate contradiction and conflict, the refusal of my thought still to tolerate this thought my thought cannot tolerate (p. 3).

Literature that examines child loss at any age adds a number of dimensions to an understanding of what parents undergo, but it also creates generalities and often moves away from the specific problems and circumstances that SIDS parents encounter.

2.5 Literature About Social Support

About two thirds of the citations in this section have been previously mentioned, but I include them because they also address important aspects of social support, and how parents can be helped by professionals. Nevertheless,

the literature about social support often failed to specifically address the support needs of parents who have experienced a SIDS loss. More often authors dealt with “the loss of a child” which was such a diverse category that it was almost as if one were discussing very separate issues. There was also considerable literature about how professionals should best intervene for parents. Rando (1986) suggested that those who help be realistic in their expectations, treat people as individuals who may all react very differently to the same types of events, to never rush the process, to capitalize on existing coping skills while attempting to minimize self-destructive behaviours such as alcohol abuse, and in many cases, to simply develop strategic and individual approaches. These are familiar interventions that could be used in a variety of life crises, but they provide a useful framework.

A brief early paper (Cepeda, 1981b) addressed SIDS parents’ grief directly, but in a context that is now dated both from a grief perspective and what is now known about the syndrome. A later article (Smart, 1993) placed parental bereavement into an American historical context focusing on specific cultural contexts such as the Puritans, the Virginia Gentry and the Victorian era in the United States. Smart’s suggestion that individuals are constrained by thinking they must grieve in a certain manner and that mourning should be completed rapidly with a return to some form of pre-bereavement state did not address what is now known about the complex reactions that parents face.

A number of authors have examined very general aspects of a SIDS loss, usually giving some overall context and then addressing anticipated parental

response and appropriate interventions (Buschbacher & Delcampo, 1987; Irizarry & Willard, 1999; Limerick & Downham, 1978; Smialke, 1978; Thuen & Schlytter, 1996; Wachowiak, 1978). Davies, who has done extensive work with SIDS parents, developed a theme of memory reconstruction, but in a general way for child loss and palliative care (Davies, 1987). My findings presented in Chapter 5 suggest that the way parents reconstruct the memory of their child is an important aspect of recovery from SIDS grief.

Some authors have examined parental loss in general from a more psychological standpoint including locus of control and helplessness in relation to gender differences (Rubinstein, 2004) indicating that mothers had more of a sense of hopelessness. This study examined the loss of adult sons however, a very different context from my work. An examination of the impact of a child's death on family relationships (Riches & Dawson, 2002) examined the issue of marital breakdown following the death of a child, an aspect that deserves wider investigation.

In an article describing the redefinition of the family following the death of a child (Brabant et al., 1994) the authors found that the deceased child continued to be defined as a member of the family, an issue that I describe in my findings and something that is highly consistent with SIDS parents' experiences. In a follow-up of families who experienced a perinatal death in order to determine how they were cared for in the longer term (Rowe et al., 1978) it was determined that giving parents accurate and complete information was therapeutic, but unfortunately this was not done consistently. Lack of information was a common

theme for the SIDS parents with whom I spoke as well. One author examined differences in bereavement behaviours in the case of the death of a spouse, a child, and a parent (Sanders, 1980) showing that the death of a child was the most intense. This is a common finding in the literature but left me questioning the rationale.

Counselling and its benefits in relation to bereaved SIDS parents have also been addressed in a general way by authors who gave some insights into how this might be accomplished by health professionals (Powell, 1991; Woodward et al., 1985), as well as by people within the community (Bluglass & Hassall, 1979). These articles addressed the ambivalent responses that parents have with professionals whom they may blame in some way. This uneasy relationship and even hostility towards physicians and nurses following a SIDS death remains a problem and was something I heard on a number of occasions.

Nevertheless, nurses are sometimes in key positions to help parents, particularly while they are still in hospital in the immediate aftermath of an infant's death. In some cases, practical advice was offered for parents and family members (Capitulo, 2005; Gold, 2007; Swoislin, 1986). One author examined parents' perceptions of helpful interventions and found that nurses can play a key role (Nikolaisen & Williams, 1980). Part of this apparent paradox of nurses being categorized as very helpful or not helpful at all may have to do with the heightened sensitivity that SIDS parents have regarding everything that is said and done in the immediate aftermath of the death. Small, seemingly

inconsequential interactions, either positive or negative, appear to have powerful consequences.

Gender differences are increasingly being examined to better determine interventions that are useful taking into account the fact that men and women operate quite differently given the same set of circumstances. Some authors have specifically looked at maternal points of view showing that non-professional (i.e. family, friends, colleagues) support systems are important sources for women (Laakso & Paunonen-Ilmonen, 2002), that women do not in general develop ongoing mental health issues following infant loss (Boyle et al., 1996) and that information obtained from professionals as well as perceived support was beneficial (Price et al., 1985). These studies also highlighted the fact that women are easier to access in research studies and that far less is understood about men. Sources of tension within a relationship that therapists need to understand have been outlined in a comprehensive manner (Wing & Burge-Callaway, 2001). One author examined sibling reaction (Burns et al., 2004), a very under-represented area in the literature. Unfortunately, this study examined siblings of any age (2 to 16) and grouped them together with the result that findings are too general. One paper examined pregnancy loss from a male perspective in a very comprehensive manner, exploring issues surrounding identity and relationship concerns (McCreight, 2004). McCreight, whom I contacted in Ireland because I found her findings so intriguing and consistent with my findings, found that men have particular problems with self-blame, loss of identity, and the need to appear to be strong and hide feelings of grief and anger.

She acknowledged the difficulty in obtaining men as informants and told me that she spent two years in pregnancy loss support groups to gain the trust of the men she interviewed (McCreight, personal communication, February 20, 2007).

An important area of research which I did not address in interviews is the challenge that couples encounter in relation to grief and sexual functioning. This complex area also involves gender differences as women may experience difficulty in arousal when they are in grief and men wish to engage in sex as a form of tension release (Dyregrov & Dyregrov, 2004). Hagemeister and Rosenblatt (1997) in their study of heterosexual relationships and sexual functioning found that most parents had a break or decline in their sexual relationship but that this was countered by an increase in holding, hugging and touching (defined by some as sexual). Individuals needed to develop new meanings towards sexual relationships including such concepts as doing so for personal pleasure, perhaps creating a new baby, or overcoming the guilt associated with moving forward and looking after oneself. This suggests there is likely a physiological aspect to guilt.

Religion played an important role for some of the parents with whom I spoke. However, the idea that a belief system is comforting and helpful is overly simplistic. While there is evidence that religion can play a part in meaning reconstruction (Matthews & Marwit, 2006) and that those who have strong religious beliefs have better coping mechanisms and less distress (McIntosh, Silver, & Wortman, 1993), one study did not confirm the traditionally held belief that religion necessarily offers solace and comfort (Thearle, Vance, Najman,

Embelton, & Foster, 1995). The study was limited in that it examined church attendance as an indicator. Perhaps parents embrace their faith in a more personal way rather than simply within the institution itself.

A list of professionals who interact with bereaved SIDS parents might include— in addition to the above mentioned nurses, physicians, clergy and therapists—police, coroners, and funeral directors. All of these played important roles with the parents in my study. Very little has been written about these groups in relation to SIDS parents. One study (Janzen et al., 2004) did examine the perceived helpfulness of a long list of professionals from the point of view of parents themselves. The authors examined specific ways that interventions by these professionals are helpful or unhelpful, something I will examine in further detail in the chapter on the death scene investigation.

2.6 Summary

All literatures in any field become refined and more useful as empirical evidence adds to an understanding of the phenomena under review. The literature on grief in general and on professional viewpoints is no exception. Early material reflects what was known at the time and later developments add nuances and perspectives as they become better understood.

Nurses wrote descriptive articles from the point of view that an understanding of SIDS would then translate into other nurses' abilities to intervene effectively with these parents. They often described what they saw in the immediate aftermath of the infant's death and then placed these observations

into the context of what was understood about SIDS at the time. This made some of these early articles historically interesting but did not explain the nature of the phenomenon of a SIDS death. It situated it within a larger, more general body of knowledge about grief in general. For example, few authors spoke of meaning reconstruction, how the death was handled in a way that made sense to parents. Anniversary and cohort reactions were not addressed. For example, other children who would have been the same age as their lost infant beginning school or graduating, trigger emotional responses according to the narratives I heard. These are issues parents must continually confront throughout their lifetime and constitutes a type of reconstruction of grief over and over in new contexts and at different life stages. The repeated message in the nursing literature is that a SIDS loss is worse than other types of losses and that recovery might take longer, which left me wondering why that might be the case. Few authors connected SIDS specifically to grief theory even though this area has been growing rapidly within the past few decades. Martin's work (Martin, 1998) was unique in that she spent considerable time running support groups for parents and developed a different perspective outside of her role as a nurse, and of course also by the fact that she conducted her research on this topic.

Tension between nurses and parents was not addressed in the literature. No parents in my study articulated any particular benefit from interactions with nurses and to this day this group of professionals still does not have an adequate understanding of the problems parents encounter when they lose an infant to SIDS. The Canadian Foundation for the Study of Infant Deaths is developing

course material (a process in which I collaborated) in an effort to address this need.

Physicians formulated their opinions of the aftermath of a SIDS death and the need for intervention often gleaned from questionnaires. As with the nursing literature, specific aspects of SIDS were addressed including the immediate crisis and the weeks following. Long-term follow-up and longitudinal studies were lacking. Physicians are key players in the lives of families with children and as such are often trusted sources in times of crisis. Nevertheless, they can also be seen as representing the system that failed when an infant dies and as such become blamed for the death of an infant. This is not something that physicians themselves have written about.

Allied healthy professionals also largely dealt with an attempt at helping others understand the unusual features of a SIDS death with the objective of appropriate and useful intervention. Paradoxically, some of the findings from this category showed that family, friends and co-workers were more effective at intervention than professionals (e.g. social workers, psychologists) who undertook the studies. This was consistent with my findings in which parents helped each other and when professional help was sought, someone who had also perhaps had a personal loss was considered the most helpful. Grief counsellors and volunteers in hospitals were sometimes dismissed as not being helpful at all. This aspect of “fit” between bereaved parent and therapist is not an issue that anyone has described.

The larger literature based on child loss at any age adds rigour; these studies were characterized by more frequent use of quantitative techniques in which specific issues were examined for statistical significance. Unfortunately though they diffuse the situation considerably, as child loss due to different circumstances and losses occurring at different ages are placed into one single category. I would argue that SIDS is an unusual type of loss that deserves to be studied as such, not as a sub-set of all forms of parental loss of a child.

This was also the case in the literature on support in which generalizations were created because a broad category of loss was used. This was perhaps to be expected since much of the literature I included in this section was repeated from the other professional-specific categories.

The grief literature included many aspects that I found consistent with my findings, for example issues of continuing bonds, incorporating the lost infant into the ongoing daily lives of the remaining family members. Thus, the grief literature is in many important ways a good fit with the findings in my study. Also, issues of resiliency, a much more recently described phenomenon, along with traumatic and emotional memory aspects were not articulated at the time of most of the professionals who were describing a SIDS loss because those concepts had yet to evolve. What was missing were the traumatic aspects, grief as a larger all-encompassing, life altering phenomenon in this instance. Some of these issues are only now beginning to be understood.

In the next chapter I describe how I undertook the task of designing my study, undertaking field work, and analyzing the data.

Chapter 3: Methodology

In this chapter I discuss my rationale for the use of a qualitative approach, specifically grounded theory, and discuss some of the controversy that has surrounded this method. I will provide an overview of the ethics process, the data collection and sampling followed by the analysis using software. I include a section on the software package NVivo 7.

3.1 A Qualitative Approach

In spite of coming to this research with a long history in health care and pediatric settings, I had never encountered anyone who had experienced sudden infant death and I was thus almost completely unfamiliar with the issues surrounding it. I realized that I was not beginning with a hypothesis and that qualitative data collection would largely consist of an inductive process of interviewing parents and determining what themes arose out of their narratives. Because of my lack of background in the area I was nevertheless unsure of what would unfold.

Thus, qualitative research was an option for a number of reasons. Miles and Huberman (1994) suggest that this type of strategy involves the researcher gaining an overview of the context under study from informants who provide an insider's view. The task then becomes one of attempting to understand how these people themselves come to understand and interpret their experiences.

The researcher's task, among others, is to determine which interpretations and themes are the most compelling. Another model that made eminent sense to me was the "cycle of enquiry" (Marshall & Rossman, 1999) which views the research process as a continual and iterative cycle in which one continually collects data, analyzes it, and uses it for developing sensitizing concepts and guiding hypotheses that are then used in subsequent instances of ongoing data collection. This cycle continues until enough work has been undertaken in order to properly answer the research question. In this section I will elaborate on why I chose a qualitative approach and why I deemed grounded theory to be the most suitable method.

Definitional issues for qualitative research are problematic because the landscape of this type of inquiry can contain dimensions of labelling, disciplinary turf issues, post-modern meanings, moral positions and dichotomizing conversations (Schram, 2003). Nevertheless, a good generic starting point is offered by Denzin and Lincoln (2000a):

Qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a series of representations, including field notes, interviews, conversations, photographs, recording, and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them. (p. 3)

This description of qualitative research described my project accurately. I used all the above-mentioned tools. In many cases I went to people's homes to

talk to them about their lives while sitting at their dining room tables, viewed their family photo albums and was shown family pictures on the wall. I treated participants as experts in their own life experiences from whom I would learn. I saw my task as synthesizing and conceptualizing their narratives into theory that could be matched to existing and new data with the objective of better understanding this unusual human phenomenon. These viewpoints are consistent with qualitative (as distinct from quantitative) approaches which are often better at capturing the individual's point of view by getting closer to research participant's personal perspectives, examining their constraints within their everyday social world, and securing rich description by continually writing and reflecting on every aspect of the research process right from the very beginning (Denzin & Lincoln, 2000a). On the suggestion of my supervisors, I kept a research log of all my activities from the first day I began this work.

Qualitative research is often positioned in opposition to quantitative approaches, a dichotomy that I believe has been overstated. This is an argument well developed by Palys (2003) who compares both approaches but also explains that dichotomizing them creates artificial boundaries. Good research begins with a question and the tools used to answer that question should consist of a broad arsenal that includes either a qualitative or a quantitative (or mixed) approach. Morse (1995) states that:

It is important to remember that both qualitative and quantitative methods are merely *tools* for solving research problems. It is the researcher's responsibility to be *wise* enough to recognize when appropriate qualitative or quantitative methods should be used and *smart* enough to do them. Such versatility is the hallmark of a good researcher. (p. 3)

All research positions have controversies, contested philosophical positions and evolutionary issues analogous to where we find ourselves culturally in time and space. The formal, even rigid researcher role of previous generations has evolved into a more fluid and participatory (and hopefully less paternalistic) stance. However, fundamental issues remain, some of them outlined by Lincoln and Guba (2000). Who controls a study? What questions get asked and who gets to ask them? How do we know whether we are telling the “truth” about human experience? What makes our research valid and authentic? Whose voice is captured? Is the researcher properly presented in the context with an appropriate reflexive stance?

Rather than be hamstrung by all these considerations, these questions can introduce healthy debate into the process. One way to work through these areas is to write continually—for oneself, in order to further the research process, to develop ideas, to make notes to oneself and so on. Writing itself can be a method of inquiry (Richardson, 2000).

3.2 Grounded Theory

In my original research proposal prepared in the fall of 2002 I listed the following research objectives:

- To explore how families resolve the issues and restore meaning during this period of extreme stress;
- To explore how human beings reconstruct their lives following an episode of sudden, catastrophic, and irrational loss;
- To explore whether existing stage theories about grief and loss are adequate to address this type of unusual and specific event;

- To explore what methods, and in particular what technologies, families use to achieve those ends.

While my focus has inevitably shifted somewhat as the project evolved, I have attempted to keep these points in mind throughout. Also, in my original proposal I stated that I would be using grounded theory, a method that I later saw frequently misused and which for that reason I almost abandoned. However, after discussions with committee members, I returned to a constructivist grounded theory approach, convinced that it was the best method to answer my specific questions. I will give a brief overview of my understanding of this method, its development, and the controversies that have led to a recent incarnation, Charmaz' constructivist approach (Charmaz, 2006). This is the version I used.

Grounded theory, perhaps the most common and popular of all qualitative approaches, has become controversial and criticized both by those that use it and those who do not. The original incarnation was developed by sociologists Barney Glaser (b. 1930) and Anselm Strauss (1916-1996). Strauss was a student of Herbert Blumer who developed an influential sociological framework that forms the philosophical underpinning of grounded theory (Blumer, 1969). It should be noted that Blumer himself was a student of the extremely influential philosopher, sociologist and psychologist George Herbert Mead (Mead, 1934). Symbolic interactionism, as defined by Blumer (1969) rests on three premises:

- Human beings act toward things on the basis of the meanings that the things have for them;
- The meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows;

- These meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he encounters (p. 2).

Glaser and Strauss originally developed their method to examine issues surrounding death and dying. Their collaboration resulted in a book that captivated researchers and is still in use today four decades later (Glaser & Strauss, 1967). However, Glaser and Strauss parted company in a highly publicized and acrimonious debate. Even this debate has been interpreted and reinterpreted and I will outline only briefly the crux of the argument. Glaser, who has consistently maintained his original position on the philosophy and coding procedures for grounded theory is viewed as somewhat positivist. In his book *Theoretical Sensitivity*, Glaser (1978) defines substantive coding beginning with “open coding” in which the data are “fractured” and questions surrounding what is happening within the data are examined. Then, in selective coding a core category should emerge that addresses the basic processes going on within the data. In his description of theoretical coding, Glaser describes an extremely elaborate way of conceptualizing the many pieces of fracturing data. He describes “coding families” as “the six C’s: Causes, Contexts, Contingencies, Consequences, Covariances and Conditions” (p. 74). This framework, along with Glaser’s coding dimensions, remains useful through the various incarnations and developments of grounded theory, including Charmaz’ constructivist approach (Charmaz, 2006).

Strauss later collaborated with nurse researcher Juliet Corbin to publish a highly influential book, *Grounded Theory in Practice*, the second edition of which

remains in widespread use (Strauss & Corbin, 1998). In it they introduce the concept of axial coding, the purpose of which is “to answer questions about the phenomenon such as when, where, why, who, how and with what consequences, thus giving the concept greater explanatory power” (p. 125). This intermediate category, never used by Glaser, led to a debate often referred to as “emergence versus forcing” (Duchscher & Morgan, 2004). Glaser, remaining true to his more positivistic and quantitative training as a sociologist, insisted that theory emerges from the data whereas using Strauss’ method introduces a forcing model whereby the researcher—according to Glaser—fits the data into conceptual categories in an inappropriate manner. Whether one favours a Glaserian or a Straussian approach depends somewhat on one’s personal views of the role of a researcher as well as beliefs about epistemological and methodological approaches towards grounded theory in general. In examining these aspects, interesting philosophical debates have arisen that go far beyond grounded theory, and touch on fundamental issues pertaining to qualitative research in general (McCann & Clark, 2003a; McCann & Clark, 2003b; McCann & Clark, 2003c).

Ironically, as this debate was going on, increasing numbers of researchers were using grounded theory in a descriptive way. While there is nothing wrong with qualitative description (Sandelowski, 2000) it is *not* grounded theory. Also emerging at this time was a new approach, a type of hybrid model of grounded theory that seemed eminently suitable for my needs, namely a constructivist approach.

Sociologist Kathy Charmaz combines the coding strategies of Glaser and of Strauss and Corbin, never discounting their previous work, but moving forward into more interpretive paradigms where qualitative research has become both artistic and political. She argues that the role of the researcher is critical, and that widely diverse cultural forces, tensions within society, and differing race, class, and gender issues must be considered, never discounted (Denzin & Lincoln, 2000b). Encapsulating a constructivist approach is not easily reduced to a few sentences. Charmaz herself defines it as an one that “places priority on the phenomena of study and sees both data and analysis as created from shared experiences and relationships with participants” (Charmaz, 2006). A constructivist approach thus “necessitates a relationship with respondents in which they can cast their stories in their terms” as well as preserving images of respondents’ experience and attempting to preserve their point of view, their impressions and their response to phenomena (Charmaz, 2000, pp. 525-526). This stance meshed with my understanding of the way the interviews would be constructed, in a collaborative manner.

The other reason I felt strongly that a constructivist approach was necessary was because of the nature of the place and role of data within a research situation. What does the term “data” mean? This issue has recently been discussed (Bryant & Charmaz, 2007) as a problem, namely the fact that data themselves are constructed. For example, I realized that from the outset my interviews would reflect my background as a nurse (including training in pediatrics and obstetrics) as well as a degree in counselling psychology. The

nature of my questions and the results I obtained would in many subtle ways be shaped by this background as well as my age and life stage. A young, beginning researcher or someone trained as a grief counsellor might end up with a very different data set. Previous grounded theorists have spoken about data as a given, but they are not. Some have stressed the researcher's role as an instrument in qualitative data collection (Morse & Richards, 2002).

With this stance in place, I began the actual process of moving forward on the process of obtaining research ethics approval from the Simon Fraser University Research Ethics Board (REB).

3.3 Ethics

On the advice of my senior supervisor I began the process of ethics approval early. Because the standard university ethics forms did not fit my needs well—designed as they are to cover a wide range of research possibilities—I opted to write my own letter of introduction and consent forms. I modelled them on those done by Karen Martin, a researcher at the University of Alberta who has written a book also using SIDS parents as research participants (Martin, 1998). Using Martin's approach, I wrote a letter of introduction which would be passed on to a prospective informant by the program manager at the Canadian Foundation for the Study of Infant Deaths, the national SIDS organization. Once that person agreed to become a participant, I sent them a letter directly explaining in more detail the purpose and nature of the interview process. When we met in person, I read the consent form information aloud and forms were signed. The purpose of the letter of introduction was intended to avoid any sense

of pressure whereby a parent would feel obligated to be interviewed; this buffer insured that they need never contact me if that was their wish.

The ethics approval process was reasonably smooth given that approaching populations that are perceived as vulnerable, as these parents are, causes additional concern for research ethics boards. The Simon Fraser University Office of Research Ethics was no exception. There are very few data about how these families feel about discussing their issues with a researcher. Dyregrov (2004b) has suggested that “too often decision concerning trauma-related protocols in particular, have been made on the basis of this presumed vulnerability rather than empirically based knowledge” (Dyregrov, 2004b, pp. 8-9). In any case, after assurances that I would refer participants to the Canadian Foundation for the Study of Infant Deaths for follow-up counselling in the event of any adverse effects, ethics approval was granted for my project which was deemed minimal risk.

I also made available a copy of the transcript following the interview for any of the participants that requested one; three of the 21 participants did so. I sent them a complete transcript on paper and on CD-ROM as a sound file. I offered all participants a summary of my findings to be sent to them at a later date.

All relevant ethics letters, consent forms and approvals are appended. (See Appendix A). Once ethics approval had been granted I was prepared to meet with parents.

3.4 Data Collection

3.4.1 Sampling

Miles and Huberman (1994) suggest that key features of qualitative sampling include a purposive rather than a random approach, that the samples are usually not wholly prespecified, that boundaries, (i.e. the defined limits of one's case) are established in a frame that will help uncover, confirm, or qualify the basic processes or constructs underlying the study, and finally, that the sampling be theory driven (p. 27). I anticipated from the outset that all my participants would be parents who had experienced the death of an infant due to sudden infant death syndrome and that the interviews with these parents would change focus slightly as my data were analyzed and concepts emerged.

Early in my research process I made contact with the executive director of the Canadian Foundation for the Study of Infant Deaths (CFSID), a national organization that has as its mandate to provide information and resources including support for families affected by perinatal deaths. Shortly after beginning my university work I attended their national meeting in Vancouver, British Columbia where I met affected parents and also the staff who would later make most of the initial contacts for my research participants. As I expected, the gatekeeping process of having the program coordinator for CFSID help me find informants made the task easier for me but also provided a very homogenous sample. Those people who chose and were willing to talk to me were also those who had largely resolved their loss and were able to articulate the process in which they did so. Obviously speaking to newly bereaved and stressed

individuals who were still confused about what had happened, would have been counterproductive, but as a researcher I believe one needs to keep in mind the limitation and the above-mentioned boundaries of the sample, i.e. informants who were more able to discuss their stories with me and thus might be construed as representing a more well-adjusted population.

Initially, I wished to also speak with parents in Germany. I did meet there with a representative from Gemeinsamen Elterninitiative Plötzlicher Säuglingstod (GEPS) Deutschland, the German national SIDS organization. Although this relationship appeared fruitful, there were scheduling difficulties the second time I went to Germany and after careful consideration I abandoned the idea of doing interviews there, a move that was fortuitous since it would have added much more time to the data collection phase. As it was, one of the problems I encountered was that securing, arranging and actually conducting interviews with parents was a time-consuming process. It eventually took me 18 months to secure 21 interviews and involved three trips to Ontario and two to the Edmonton area.

Field relations and gatekeeper issues are important components of the qualitative research process. In spite of my excellent working relationship with the program coordinator for CFSID who was arranging interviews, a number of people who agreed to speak to me after she contacted them to actually arrange a time withdrew. Reasons given to her included: that they were not yet ready to talk about such an emotionally charged topic; when they realized this was more than a cursory series of questions they became worried about their ability to handle

the interview emotionally; and intimidation in meeting a researcher whom they perceived as socially and intellectually threatening. I never insisted or pushed for an interview to materialize realizing that an unwilling informant would be completely counterproductive.⁶ However, the process was far more time consuming than I anticipated. The valuable lesson I learned, however, was the danger of underestimating the time, difficulties and strategies needed to conduct good research, something well understood by experienced qualitative researchers, particularly ethnographers (Hammersley & Atkinson, 1995).

The other logistical challenge I faced was that participants were in geographically diverse locations. I interviewed eight people in and near St. Catharines, Ontario, where the program coordinator for CFSID lived, three people in the Toronto area, seven people in Edmonton and surrounding areas, one person in Surrey, British Columbia, and two people in Burnaby, British Columbia.

Sample size became an issue in a meeting with my committee.

Sandelowski (1995) states that,

An adequate sample size in qualitative research is one that permits—by virtue of not being too large—the deep, case-oriented analysis that is a hallmark of all qualitative enquiry, and that results in—by virtue of not being too small—a new and richly textured understanding of experience (p. 183).

⁶ In total, four participants declined or became unavailable. A husband and his wife did not appear for their scheduled interview; one father changed his mind about being interviewed after he realized that his wife had spent two hours with me, and one mother had scheduling conflicts for the time period that I was available.

I was asked to interview a minimum of 16 participants. I was eventually able to conduct 21 interviews.

3.4.2 Interviews

My counselling background helped with these interviews. However, I refrained from offering any type of intervention or therapy other than factual information about SIDS which I had gleaned. Parents appreciated hearing about the latest research or obtaining a clarification of their understanding of what might have happened. As mentioned earlier, in a qualitative strategy the researcher becomes an instrument. Morse and Field (1995) state that:

In qualitative research, the amount and quality of the data and the depth of the analysis depend on the ability of the researcher. For example, the information elicited from an interview depends on the ability of the interviewer to establish rapport and gain the informants [sic] trust...the depth of the data analysis will depend on the researcher's sensitivity, perceptivity, informed value judgments, insight, and knowledge (pp. 141-142).

I believe that the interviews went well because I asked in-depth questions concerning issues such as obstetrical history, interpersonal relationships with partners and children, in-laws and friends, and in particular, details about the actual death and aftermath of the child. By not avoiding painful aspects of the interview (and it was always difficult for parents) we developed a rapport whereby the experience was somewhat cathartic and genuine. One mother who had lost her son ten years prior said, "Nobody has ever asked me about my hospital experience. Nobody's ever asked me the questions that you have. This is a first for me" (Participant 5). When I asked her how that felt, she said, "It feels good."

In addition to interviews, I also gathered material from newspapers, in particular a large-scale comprehensive overview by Scripps Howard (2008). I also examined online memorial websites, as well as narratives from the CFSID web site, several of which were written by the same people I had interviewed. These are detailed and covered in Chapter 6 dealing with online social support.

3.5 Data Preparation

All interviews were recorded on a Sony Walkman Professional using audiocassette tapes. I transcribed material myself, consistent with the confidentiality clause in the consent form. I did however digitize all material later and created CD ROMs since cassette technology is rapidly becoming obsolete. Cassettes, CD ROMs and interview transcripts (digital and printouts) were never seen or used by anyone other than myself.

Transcriptions are often taken for granted within the research process, but there are considerations that affect quality and the way they are used (Poland, 2002). My tapes were exceptionally clear and there were only perhaps two instances in 650 pages of transcribed notes where I was unable to make out a word accurately. Nevertheless I did have to make decisions regarding the level of detail and whether to incorporate subjective notes regarding an informant's affect. I attempted to be as accurate as possible, capturing every word and pause, interruption and overlap. Although this made the coding more awkward, accurate transcriptions are an important first step in proper data preparation. I made few notes within the transcription, saving that for annotations in the software and for coding considerations. I occasionally noted non-verbal elements

such as tight breathing or crying, mostly brief notes when participants were having difficulty expressing themselves because of the emotionally laden context.

As I mentioned, a project log was kept from the first day I began the PhD program. In it I recorded activities, arrangements with people, meetings and any daily activities that might be relevant to the research process. The issue of reflexivity is an interesting consideration for researchers. Finlay (2002) says:

Researchers have to negotiate the 'swamp' of interminable self analysis and self disclosure. On their journey, they can all too easily fall into the mire of the infinite regress of excessive self analysis and deconstructions at the expense of focusing on the research participants and developing understanding. Reflexive analysis is always problematic (p. 212).

In my notes and my thoughts on the evolving data and analysis I like to think that I kept informant's views foremost, although there is no doubt that research is a balancing act involving considerable contemplation about what is going on, where to move next, when to change tactics, and when to finish.

3.5.1 Coding

A simple definition of coding is "The process of identifying persistent words, phrases, themes, or concepts within the data so that the underlying patterns can be identified and analyzed" (Morse & Field, 1995). The actual process of course is more complicated, with numerous subjective decisions made by the researcher as to what those words, phrases, themes and concepts might be.

Grounded theory does however offer a blueprint. Charmaz' (2006) suggested approach for the coding practices was used. She explains that when

undertaking the initial coding to “remain open; stay close to the data; keep codes simple and precise; compare data with data; move quickly” (p. 49). Although a decision was made, based on my senior supervisor’s recommendation, to use NVivo 7 for my coding, I did however begin with a word-by-word and line-by-line coding analysis by using the comment feature in Microsoft Word, which prepares a call-out for each highlighted portion of the text. I did this for the first eight interviews, prior to beginning the actual coding process within the software. This way I became comfortable with what was in the transcripts without feeling the need to adapt immediately to the software. I knew that once I was familiar with my respondents’ voices, coding would be more fluid and accurate. Marginal notes of this nature are not inconsistent with good practices; there is a long tradition of doing so prior to the widespread use of software—a process of reflection, interpretation, queries to oneself and clarifications, all made with an old-fashioned pencil (Miles & Huberman, 1994).

I analyzed each interview as soon as it was transcribed. Constant comparison is the cornerstone of grounded theory and it was never out of my mind as I worked. Charmaz (2006) says:

At first, you compare data with data to find similarities and differences. For example, compare interview statements and incidents within the same interview and compare statements and incidents in different interviews. Making sequential comparisons helps...What you see in your data relies in part upon your prior perspectives. Rather than seeing your perspectives as truth, try to see them as representing one view among many. That way, you may gain more awareness of the concepts that you employ and might impose on your data (p. 54).

I tried always to keep my research questions in mind as I coded. What are people doing in this instance? How are they helping themselves? What strategies and tools do they use to move out of the painful space they find themselves in following this catastrophic incident? What things do they do immediately, what do they do later on, and how do they interpret these things retrospectively? In other words, what is their trajectory through this process?

I did not analyze all the transcripts in this initial coding procedure. Rather, by the end of coding the initial eight interviews I became more refined and selective in the process, using what Charmaz (2006) and Glaser (1978) refer to as focused coding, “using the most significant and/or frequent earlier codes to sift through large amounts of data. Focused coding requires decisions about which initial codes make the most analytic sense to categorize your data incisively and completely” (Charmaz, 2006, p. 57). For example, I became aware that participants were all talking about various aspects of memories, both positive and negative. I began to define these in a more nuanced way: positive, negative, reconstructed, and fuzzy.

This categorization of concepts began the process of axial coding, the next phase which Charmaz (2006) presents and remains consistent with its first (and controversial) introduction by Strauss and Corbin (Strauss & Corbin, 1997). She describes it as a process that relates “categories to subcategories, specifies the properties and dimensions of a category, and reassembles the data you have fractured during initial coding to give coherence to the emerging analysis” (p. 60). Certainly, by this time codes were becoming logically grouped in a hierarchical

manner in the software which I was using. NVivo 7 is a qualitative research software program that allows for the compilation and comparison of unstructured data.

At this point I was developing codes (placed in “nodes” in the software) that were novel, so I would search previous transcripts for anything that I might have missed or coded incorrectly. I began to organize the codes into the following categories:

Affective constructs which included any type of emotional response, both positive (e.g. personal strength, use of humour, acknowledgement of what had happened) and negative (e.g. guilt, denial, resentment, anger, blaming).

Grief aspects. These were responses that I expected, including the problems associated with the suddenness of the death, the paralysis and the ongoing nature of the grieving process, sometimes over an entire lifetime and anniversary reactions. Nevertheless, there were also unexpected findings in this category such as the distinct nature of this type of loss as opposed to the loss of someone who has died at the end of their life cycle.

The memory spectrum emerged in the form of positive, negative, and unclear or dissociative memories. I also included dreams and mementos in this category, as these had become important through the interviews. This category was unexpected for me and I began to ask parents about their memories as I reflected on how the memory process reconstructed their narrative and also constructed positive and negative remembrances of what had happened. There also appeared to be a trajectory beginning with happy and positive memories of

the birth and life of the infant, through the highly negative events of the death and aftermath, eventually ending up with more positive reconstructions usually accompanied by pictures and mementos. This was not however a trajectory that related clearly to stage theories as articulated by grief theorists.

Negative events included things such as the lack of information about SIDS prior to it happening, a loss of a sense of self, a loss of faith, some relationship concerns and unresolved issues that parents articulated, i.e. ongoing issues that they were still working on.

Physical dimensions of grief included psychosomatic pain that manifested itself in physiological symptoms (feeling like being “punched in the stomach”) and fatigue. Also included in this section were women’s lactation problems.

Restoration issues included aspects of moving forward, new insights, ritual and customs that comforted and helped parents, outreach towards others and a newfound empathy for other parents who had experienced the same types of losses.

Support issues were coded in the following categories: friends, online, religious, spousal, family, and other sources (such as health care professionals). There was also a code for lack of support in this section.

There were a number of items that remained in the free node category, meaning they did not logically fit into the above themes:

- The death scene investigation, which I reviewed separately;
- The birth description, which I used as background;

- The death scene description, the way that parents articulated exactly what happened on the day the infant died;
- Misguided attempts to help, experiences of parents where others tried to assist but did not;
- Hurtful comments by others, phrases such as “you’re young and you can always have more children;”
- A need for privacy, the intrusive nature of other people trying to be helpful;
- Professional competence, times when these people were particularly helpful;
- Relationship concerns, descriptions of what happened with partners as a result of the SIDS death;
- Fear of a SIDS repetition, an almost universal reaction among parents;
- Silence about the SIDS event, the taboo nature of discussing death in our culture;
- Subsequent pregnancies and how they were influenced by parents’ new ways of seeing things including new fears;
- Worried about others, an unexpected finding where parents seemed more concerned about children, spouses and their own parents than themselves, a type of empathy that I found quite striking.

I decided to reorganize these nodes further in a systematic way after every four interviews. The way my interviews were scheduled caused them to come in groups of four and this gave me the opportunity to review and map codes at these points.

The idea of moving backwards to review existing codes and nodes was an iterative process that continued throughout all the interviews. The software makes it quite simple to conduct these types of searches and then either create new codes or refine existing ones. I hyperlinked some material where one

participant said something that was extremely similar to another and I made many annotations for queries to myself, clarifications of clinical information, e.g. a VBAC (vaginal birth after Caesarean), brief reminders as to implied meanings, and even places where I felt I had missed or not listened properly to some material. I also hyperlinked any websites that were relevant in any way so that I could easily revisit them later.

Whenever I added, deleted, merged or split nodes, I made a note of it. In addition, I modelled the nodes after every four interviews. NVivo allows for easy importation of nodes into a graphic display model and then also tracks whether that node is deleted or still active. Models can remain “live”, i.e. linked to nodes and changing as they change, or “static” which is recommended for freezing points in the research process. This creates a visual trail of which nodes were in which category at a given point in the research process.

Examples of codes I merged included “acknowledgement” and “resignation” which while slightly different appeared similar enough to be the same construct. Other nodes such as “grief” became refined through the process into one of the above-mentioned categories. Some nodes were reviewed for consistency, e.g. “relationship concerns” and “spousal support” with items in the former problematic and the latter more positive. The node for “lack of support” was moved into the “negative events” section.

An area that was of interest to me was parental fatigue, but it did not develop into something that people articulated as a problem. Perhaps parents expect to be tired much of the time or perhaps they remember it differently.

However, lactation issues, something I had not anticipated as a problem, emerged as a concern for some women and I became interested in the lack of literature and discussion of this rather common problem (i.e. a problem for all women who lose infants, not just as a result of SIDS).

I maintained detailed and extensive notes about all of my research decisions, consistent with an “audit trail” that some authors have suggested is the best way to maintain validity in the qualitative research process (Chiovitti & Piran, 2003; Giacomini & Cook, 2000; Mays & Pope, 2000; Miles & Huberman, 1994; Morse, Barrett, Mayan, Olson, & Spiers, 2002; Morse & Field, 1995; Richards, 2005). I kept a separate “code note memo” for all of the changes I made to nodes, including why I changed, merged, or eliminated them. I used the program memo function for other purposes as well.

3.5.2 Memos

According to Charmaz (2000):

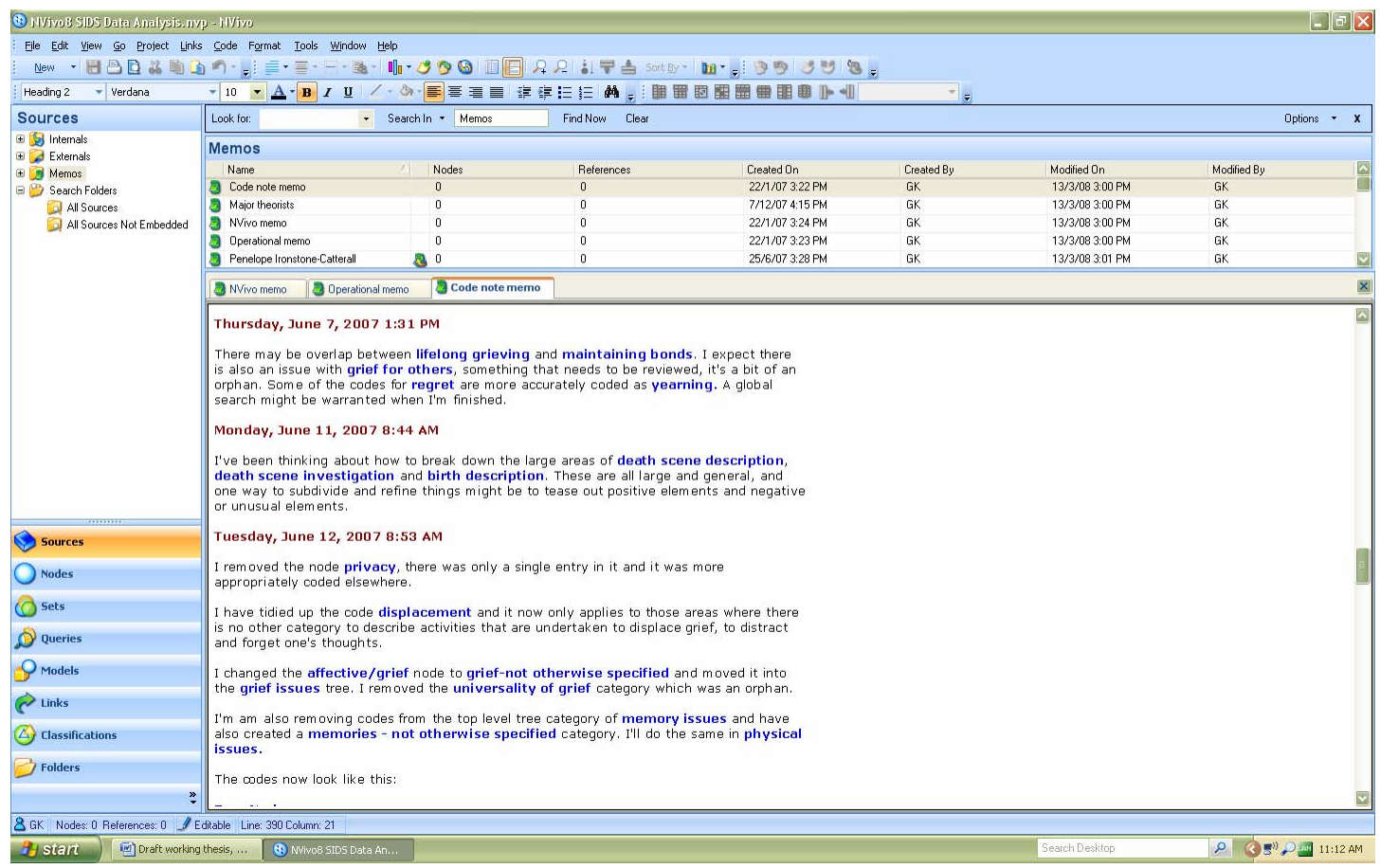
Memo writing is the intermediate step between coding and the first draft of the completed analysis. This step helps to spark our thinking and encourages us to look at our data and codes in new ways. It can help us to define leads for collecting data—both for further initial coding and later theoretical sampling. Through memo writing, we elaborate processes, assumptions, and actions that are subsumed under our codes. Memo writing leads us to explore our codes; we expand upon the processes they identify or suggest. Thus our codes take on substance as well as a structure for sorting data (p. 517).

Memos in NVivo are easy to create, flexible to organize and useful in ways even beyond traditional grounded theory strategies. I began using them immediately with a section for each participant’s interview context. As soon as the interview

was complete I wrote up notes on what had happened and how the process had unfolded. I did this immediately after every interview no matter where I was located. In some cases this involved handwritten notes later transcribed into the program. I then also kept a memo for each participant, as well as a general one for the overall emerging thoughts I had that pertained to the project as a whole.

Software users have identified creative ways to use memos in NVivo 7. Memos are usually linked (as would be the case with the two examples just mentioned where the linkage is to the transcript). But free-standing memos are also possible. Memos can be grouped, they can even be structured in hierarchies, and of course in software they can be searched and then used to prepare written reports (Lewins & Silver, 2007). Some authors have come up with interesting uses which I replicated (Bringer, Brackenridge, & Johnston, 2006). For example, I created an operational memo in which I made notes on emerging issues to explore in subsequent interviews, which questions might be useful in upcoming interviews, areas of more intense focus, and so on. In a coding memo I tracked which codes I was using, which ones were being strengthened, and which ones were not being supported by subsequent interviews and might have to be discarded. (Refer to Figure 3.1)

Figure 3.1: Screen Shot Showing Code Tracking Changes (Used with permission, QSR International Pty. Ltd.)



In a procedural memo I indicated which software functions worked well, which were problematic, and those that were troublesome. Given my early adoption of NVivo 7, there were continual upgrades to the initial software package that fixed errors; however, there remained some issues which persisted and which I noted as technical problems.

The program allows for extensive linking, some of which I used. Examples might include links to participants' websites and photographs, or a pointer to a newspaper article that they mentioned or that seemed pertinent in some way, or perhaps an email that someone had sent to me. I also created non-linked memos for more peripheral material that I thought might add to my understanding of the work as it evolved. For example, I made notes on the first-person account by Ironstone-Catterall on the death of her toddler (Ironstone-Catterall, 2004) specifically to see what similarities occurred when a mother describes the death of an older child rather than an infant. While this was not a SIDS death there were some similarities including the guilt, flashbacks, the problems with comprehending a meaningless death, difficulty in sense-making, continuing bonds, inconsiderate remarks made by others, and hypervigilance in the subsequent pregnancy.

3.5.3 Demographical Information

From the outset I established some attributes that I wanted to collect. Age and gender of the participant as well as marital status, time since the SIDS event and whether or not the parent had other children seemed logical data points to collect during the interview. After the first interview I realized that other pieces of

information might also be important later on and I decided to collect the following information for everyone:

1. Participant number (to anonymize quotes)
2. Participant age
3. Participant gender
4. Participant age at the SIDS event
5. Time since event
6. Ethnicity⁷
7. Infant age at time of death
8. Infant sex
9. Interview date
10. Interview location
11. Current marital status
12. Marital status at the time of the SIDS event
13. Other children, different partner
14. Other children, current partner

In addition, I collected contact information including email, phone number and postal address. I also included a category indicating whether a transcript and CD ROM had been requested and noted when these had been mailed. All of this

⁷ Ethnicity in this context was broadly defined by place of birth. All but one parent was Caucasian-Canadian.

information was placed into an Excel worksheet and then transposed into the attribute section of NVivo 7. Table 3.1 on page 98 provides an overview of the study participants.

A total of 21 interviews were conducted between March, 2006 and September 2007 (18 months). I interviewed 17 women and four men. There were four couples, i.e. all four men also had their partners interviewed, three of the four at the same time, the fourth within a space of four months. Finding men to agree to be interviewed was problematic. Irish social researcher Dr. Bernadette Susan McCreight, who was mentioned in the literature review section, has explored the issue of a lack of research on male perspectives of grief looking at the impact of miscarriage and stillbirth on male partners (McCreight, 2004). She found that by attending self-help groups over a period of years she was able to gain enough trust to interview men, but admitted that it was time-consuming (B. S. McCreight, personal communication, February 20, 2007). To my knowledge, there has been no published material on men's experiences of loss specifically in relation to sudden infant death syndrome.

Table 3.1: Demographic Information for the Study Population

No	Age	Participant's gender	Age at SIDS event	Time since event (years)	Infant age at death (months)	Infant sex (months)	Number of children, different partner	Number of children, current partner
1	52	Female	16	36	8	Female	1	0
2	34	Female	18	16	4	Male	0	2
3	40	Female	27	13	4	Male	1	2
4	40	Male	40	1	9	Male	1	1
5	36	Female	26	10	9	Male	0	2
6	23	Female	19	4	6	Male	0	1
7	31	Female	25	6	2	Female	0	2
8	34	Female	32	1	9	Male	0	0
9	52	Female	32	20	2	Male	0	3
10	49	Male	37	12	3	Male	0	3
11	48	Female	37	12	3	Male	0	3
12	34	Female	26	8	3	Male	0	2
13	46	Female	19	27	3	Female	0	2
14	49	Female	27	22	2	Male	0	2
15	56	Female	29	27	2	Male	0	4
16	43	Female	29	14	1	Male	0	2
17	24	Female	21	3	2	Male	0	0
18	42	Male	31	11	5	Male	0	2
19	42	Female	31	11	5	Male	0	2
20	38	Male	32	6	1	Female	0	1
21	39	Female	33	6	1	Female	0	1
Total	-	4 male 17 female	-	-	-	5 female 16 male	-	-
Average	41	-	28	12	4	-	-	-

The ages of the participants ranged from 23 to 56 with an average of 41. The average age at the time of the SIDS event was 28. The time since the SIDS death ranged from just under one year to 36 years, with an average of 12.6 years. Twenty participants were Caucasian, one was Pakistani. Consistent with the sex ratio for SIDS deaths, 16 of the infants were male, five were female. The average age at the time of death was four months, again, completely consistent with SIDS averages reported in the literature which indicate two to four months as the peak incidence (Hunt & Hauck, 2006). All participants except one were married at the time of the interview. All but one were currently with the same partner with whom they had been at the time of the death. All but two participants had either one, two or three other children in addition to the one that had died.

The population was thus somewhat homogenous. The demographics were similar to reported data about SIDS parents in terms of the age at the time of the SIDS event and the age of the infants. Ethnicity in relation to SIDS which has not been well addressed. However, as part of good research practice, since this cannot be anticipated, it was my intent to gather more information than might be necessary in order to maximize the chances of testing the data using a combination of attributes and codes, something that NVivo does efficiently and easily. I grouped participants into age ranges (20-24; 25-29; 30-34 and so on). I did the same for time since the SIDS event (10-14 years; 15-19; 20-24 and so on). This made it far more useful to do matrices which are explained in the next section about modelling.

Interviews lasted between one to two hours, with one lasting three hours. The transcripts varied considerably in length, depending on how quickly people spoke. In total 650 pages of single-spaced transcribed material (251,000 words) were coded within NVivo 7.

3.5.4 Modelling and Visual Displays

Visualizing data displays takes two forms. The first category is charts and diagrams, free-form pictograms that take the form of trajectories, clusters of nodes and concepts, relationships among various emerging ideas and similar types of displays. The second category consists of matrices and tables that combine quantitative with qualitative information to make comparisons and projections of the data in order to interpret as widely and broadly as possible. Software makes this task much easier than has previously been the case.

In terms of models, I undertook to try various ways of categorizing, grouping and displaying data after every four interviews. I termed this strategy a phase review; thus, there were five such undertakings for the 21 interviews. For example, after the first four interviews I clustered all codes in NVivo 7. (See Figure 3.2 below). I also created displays in a program called MindManager, visual software that allows for easy and creative ways to manipulate conceptual data. I created visual maps continually, to explore and describe the data. I believe that visual representation of data is an underused way of playing with ideas. Coming from a quantitative background I was initially reluctant to represent material in this way, but after encouragement from my senior

supervisor I became a convert. I was also influenced by Miles and Huberman (1994) who provide extensive and comprehensive templates for undertaking this type of activity. Additionally, Gibbs (2002) provides suggestions including cluster plots (p. 204) as described above; event-state networks in which causal influences and/or temporal flow between items is charted (p. 205); and flow charts and decision-making types of representations (pp. 208-209). Those maps that I created and appeared to transform data into useful structures were preserved.

A type of analysis that I did not undertake until data collection was complete was the matrix coding query. This is described by Bazely (2007) as follows:

A matrix coding query...produces a kind of 'qualitative cross-tabulation' in which coding items (usually a node or multiple nodes) define the rows of the resulting table, and the values of an attribute define the columns. Each cell then references text that results from the combination of a particular node with a value of an attribute—a whole series of coding queries put together. These data are initially presented in tabular form with counts of items in each cell, and with each cell able to be opened to show the text that is referenced there (pp. 143-144).

Figure 3.2: Cluster Model of Codes (Used with permission, QSR International Pty. Ltd.)

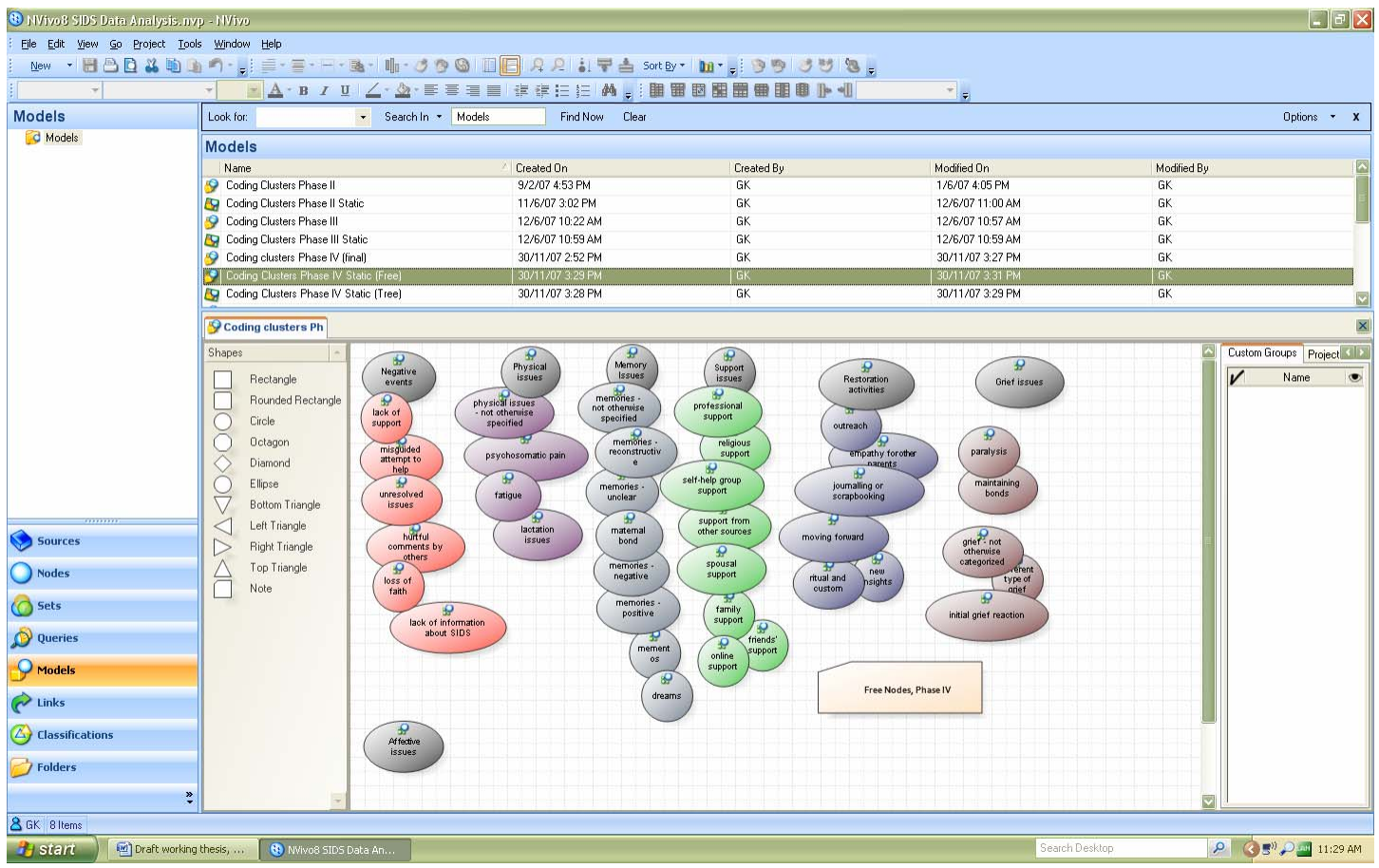
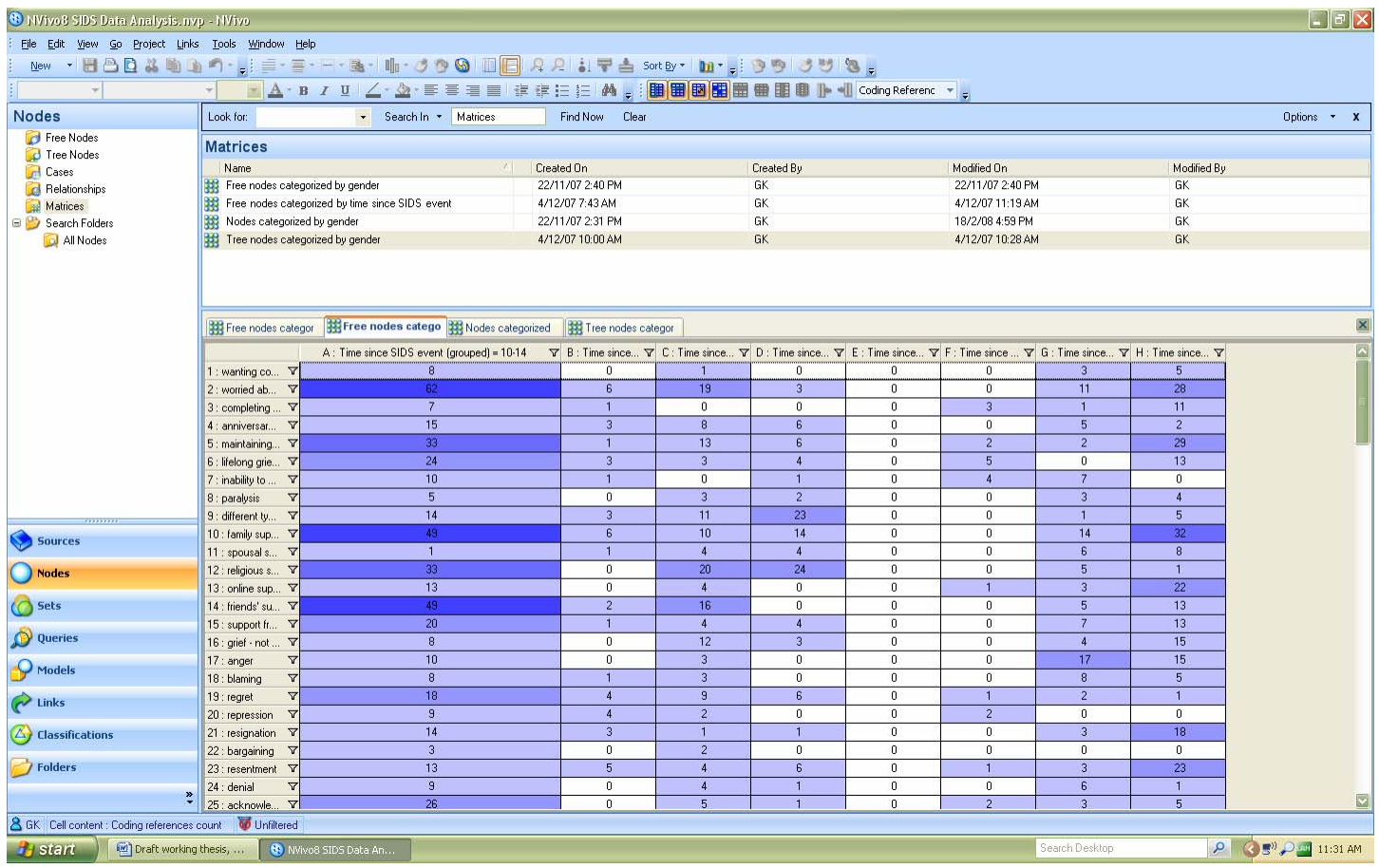


Figure 3.3 provides a graphic view of a matrix code. While this process was fascinating to carry out, the homogenous nature of my population was confirmed in that the findings were consistent with my codes in the ratio of men to women (i.e. 17 women and four men). Perhaps the most useful result was the knowledge that I gained in terms of setting up data, preparing complex queries within NVivo and interpreting results in the numerous visual ways the program affords. The potential for combinations and permutations, filtering, node choices and node groupings is almost limitless. Of course, not all will yield results, but it is so easy to make these types of analyses that following hunches may become a valuable exercise at any point in the analysis, although it is up to the researcher to determine their analytic worth. Those queries that are fruitful can then be saved either in their final output form or as a saved query structure that can be run again and again as the data set grows.

The use of MindManager, which is a stand-alone software package and not part of NVivo, is handled externally to the program. So while it is possible to open the maps from within NVivo itself, the source software must activate for the display. However, NVivo does allow for notes and even coding to be made in a type of “meta commenting” function whereby a separate file opens that then is used for that purpose. In addition to the MindManager mapping tool, I also used the external file functions of NVivo to access the first eight annotated transcripts, and various project, node, source and coding summaries.

Figure 3.3: Free Nodes Categorized by Time Since SIDS Event (Used with permission, QSR International Pty. Ltd.)



Many of these activities were undertaken to introduce rigor into the process. Unlike quantitative approaches, issues of validity and reliability in qualitative methods use different techniques to ensure that that the researcher is getting it right and has some sense of when things are going wrong.

In qualitative research we are not interested in how many or the distribution of predefined variables. Rather, it is important to understand the perspective of those involved, uncover the complexity of human behaviour in context, and present a holistic interpretation of what is happening (Merriam, 2002, p. 25).

As mentioned, I kept a project diary from the beginning of my studies (it ran to 45,000 words), made extensive notes after each interview and kept these in an ongoing manner for each participant in the form of memos, and also developed a project memo in which I noted hunches, ideas to follow up, developing themes, and questions to ask future participants. I was asked to interview at least 16 participants and ended up speaking to 21. These were chosen for their characteristics (i.e. SIDS parents willing to speak with a researcher). This type of purposeful sampling was essential to the success of the process.

The extensive notes and audit trail mentioned above were part of a deliberate strategy of “rich, thick description” which Merriam suggests is “a major strategy for external validity or generalizability in the qualitative sense” (Merriam, 2002). Also related to rigor was the pacing of the project, whereby continual data analysis was undertaken, followed by immediate transcription and coding. This pacing has been described as one in which the researcher is open to incomplete aspects and missed analytic opportunities as well as an awareness of when

saturation has occurred, the sense that no new directions and events are being uncovered (Morse & Richards, 2002). It was an interesting personal experience when, during the twelfth interview I had the sense that clear patterns were emerging in the accounts parents were giving me regarding what had happened to them during and after the death of their infants.⁸

3.6 NVivo 7

Qualitative data analysis using NVivo certainly has its attractions. It is however not without its problems and does influence the research process. Considering the rapidity with which computers have entered the qualitative research field, surprisingly little attention has been paid in the literature to this development as a factor in changing the methodology. Lyn Richards and Tom Richards, developers of NVivo, have perhaps explored these issues more critically than anyone else. They argue that the transformation from manual to computer-aided analyses:

...Has not been accompanied by adequate debate and assessment of methodological implications...There has been little deliberate debate about what that technique does to data, the expectations often exceed reality; increasingly researchers seem to take for granted that the computer can take over analytical tasks. But taking such developments for granted is a serious research hazard (Richards & Richards, 1991).

Richards and Richards (1991) suggest four reasons for this lack of discussion: (1) there seems no need to debate what is obviously an easier, faster, and better way to handle data; (2) users—under time and financial

⁸ Note that my concept of saturation only applies to my population which was not randomly selected.

pressures—take what they are given and use what they can; (3) methodological literature in qualitative research does, in general, not pay much attention to “the processes of handling data”; and (4) programs that work tend to become commercial and “methodological developments through software are by nature resistant to academic debates” (pp. 238-239). I might add that the present incarnation of NVivo 7 (which is a complete overhaul of the previous version) has a seductive appeal based on its look and feel of the ubiquitous Microsoft Outlook.

There are a number of issues that I became aware of as I was working with the software. The first is that coding can easily become an end in itself. Creating, categorizing and naming codes may be the only task that is really done. But coding must at some point translate into concepts. Glaser and Strauss (1967) suggest that:

After coding for a category perhaps three or four times, the analyst will find conflicts in the emphases of his thinking. He will be musing over theoretical notions and, at the same time, trying to concentrate on his study of the next incident, to determine the alternate ways by which it should be coded and compared. At this point, the second rule of the constant comparative method is: *stop coding and record a memo on your ideas*. In doing so, the analyst should take as much time as necessary to reflect and carry his thinking to its most logical (grounded in the data, not speculative) conclusions (p. 107).

Concept development is not done by the software. Nothing is really done by the software other than sorting, categorizing, and searching material that has been input. Just as a word processor does not produce better prose, computer-assisted qualitative research packages (often referred to as CAQDAS, particularly in the UK and Australia) hardly produce better research outcomes. But they might help. Morse (2004) suggests that raising description to a

conceptual level allows for synthesis of material, recognition of patterns within the data, a comparison or perhaps even just a recognition of variation, the recognition of new instances, an expansion of the scope, making it possible to generalize the results, and to apply the concept to new situations (p. 5). These researcher decisions are aided and simplified by the software.

Another problem with NVivo is the quantification of codes, since the number of instances of the same type of thing occurring over and over somehow assumes an aura of importance. But something that happens often is not necessarily important, and something that is found infrequently may be crucially important. Again, it is up to the researcher to determine whether large numbers of instances of something are relevant or if issues mentioned infrequently are important. In my study, only four participants mentioned anything about the difficulty we have as a society talking about death and loss, but it is an important area of concern.

Some software aspects worked very well indeed. These included organizing and planning the projects as well as having everything in one place; making extensive memos and attaching them to the pertinent data; coding, recoding and retrieving coded segments almost instantly, linking the data and hyper linking to web sites; mapping and modelling material; and generating reports to summarize activities. Finally, learning to use NVivo 7 is a useful skill which I am now able to teach to others.

3.7 Summary

This chapter examined my choice of a qualitative approach and grounded theory in particular. A constructivist approach was chosen because that was the best way to answer the research questions in a manner consistent with my personal views. The ethics process and the way these were used in the interviews was described. These interviews were then explained and the data preparation using NVivo software was outlined. Demographic information offers an overview of the somewhat homogenous population and touches on how rigor was considered throughout the process. References about the advantages and disadvantages of using NVivo are included because the literature is lacking in rigorous debate concerning the change to use of software for qualitative analysis from manual methods.

The data collection and analysis were undertaken after completion of the proposal defence. Prior to this I had spent time investigating and writing about the death scene investigation, a unique and potentially problematic aspect of a SIDS death.

The research findings represent an exploratory and descriptive study with the limitation of perhaps too small a sample size for extrapolation. Replication of this work using a larger sample would strengthen reliability and validity. Grounded theory attempts to develop mid-range theory that includes but does not exceed the boundaries of the study population. It is with these caveats that I present my findings and discuss them in subsequent chapters.

In the next chapter an overview of the death scene investigation sets the stage for participants' experiences of a SIDS death and includes findings from interviews with parents about this event which is common to nearly all SIDS deaths.

Chapter 4: The Death Scene Investigation

4.1 Introducing the Death Scene Investigation

In July 2004 I attended the 8th SIDS International Conference in Edmonton, Canada, part of the conference series outlined in the Historical Context section in Chapter 1. As part of that meeting, a workshop in pediatric forensic pathology was organized and I asked to attend. This was a closed session, not open to parents due to the graphic nature of the presentations which included autopsy photographs. This took place almost two years prior to my first interview with a SIDS parent. I became interested in the problems associated with the investigation, a feature of a SIDS death. Typically, child death review teams investigate all child deaths in Canada (not just SIDS) but some are more problematic than others. I formulated some thoughts into a presentation which I subsequently presented in the UK the following year. That presentation dealt with problems associated with the tension that occurs when parents discover their infant dead and are immediately confronted with questioning officials whose purpose is to elicit information about possible wrong-doing.

When I spoke with parents I was familiar with these aspects of a SIDS death and asked them about their experiences with first responders, police, coroners, and pathologists. My purpose in including this section is to situate the SIDS death as not only a chaotic and traumatic event, but one that immediately

involves outside professionals with tremendous potential for additional trauma if the situation is not well handled. Preliminary findings in this section are included to provide first-person context for this area since there is no literature that documents this encounter from parents' point of view. It is an overlooked research area and comments made by respondents warrant further attention.

4.2 The Death Scene Investigation as Problematic

The diagnosis of SIDS cannot be made in the absence of an investigation, autopsy and a review of the circumstances of death and the clinical history⁹ (Krous et al., 2004). There are various professionals who assume the roles associated with these tasks and in some cases there is overlap. At the core of these formal activities are the parents who have lost an infant and may now be traumatized again if there is confusion or incompetence in terms of how the proceedings are undertaken. Certainly, there is always the potential for conflicts between professionals and parents to occur, considering the emotionally charged and chaotic circumstances that unfold in a sudden infant death.

Usually, when someone dies there is some form of illness (or perhaps an accident) that precedes death. The actual process takes place over hours, even days and is marked by stages as the person weakens, loses consciousness and then dies, often with family members present. People comfort each other, phone calls are made, funeral preparations are begun, tasks and responsibilities are

⁹ A clinical history varies by jurisdiction but usually contains information on the pregnancy, reports by witnesses, the infant's medical history, the infant's dietary history, the incidence scene investigation, photographs, diagrams, recreations using a doll and in some cases even religious practices in the home.

divided, families and friend rally to the cause. While there is sadness and grief, there is a certain logical trajectory and orderly progression of events—a rationale.

When an infant dies of SIDS none of these things occur. There is total chaos, confusion, anxiety and even panic, not just for the parents but also for professionals who may be inexperienced in encountering a frightening scene where parents have discovered their seemingly healthy baby now obviously dead. There may be many actors in this scenario. Depending on the jurisdiction, firefighters and/or paramedics may be the first to arrive often with lights blazing and sirens wailing. They may be followed by the police and then later a coroner or a medical examiner. In Canada, both systems are used, depending on the province. Neighbours may walk over to find out what is going on. In cases where parents take their child to hospital, someone else may have to drive them because they are so distraught or engaged in cardiopulmonary resuscitation with their infant.

The research participants in my study encountered all of these first responders in one form or another. How interactions with these players unfold makes a big difference in the ways that parents heal, whether the grief process moves forward constructively or whether residual problems take root. There is clear documentation that how professionals respond to and treat parents has profound consequences (Janzen et al., 2004). It is also crucial that professionals act competently in gathering information about a SIDS death since almost everything that is known about risk factors has been gleaned from retrospective

data coupled with pathology reports from the autopsy and the information they gather might be useful for future research.

4.3 First Responders

When an infant is discovered lifeless, parents or caregivers take one of two steps: either they call 911 and wait for paramedics to arrive (these are also referred to in Canada as Emergency Medical Responders (EMR), Emergency Medical Services (EMS) Primary Care Paramedic (PCP) or other designation depending on the jurisdiction); or they get into their car and take the infant to the nearest hospital emergency room where nurses and physicians initiate cardiopulmonary resuscitation (CPR). In some cases, parents themselves do mouth-to-mouth breathing and there are also instances when parents told me they called 911 to notify the hospital that they were on their way with an unresponsive infant. A potential source of tension develops when parents wish to ride in the ambulance and paramedics refuse. One participant (5) indicated to me that ten years after her son's death she still resents that she was not allowed to accompany him and had to find her own way to the hospital. Family presence during resuscitation is a contentious area with parents wanting the choice of whether or not to be present during these admittedly difficult proceedings and health care providers thinking that this type of presence may hinder, disrupt, or even have harmful sequelae for parents (Boudreaux, Francis, & Loyacano, 2002; Dingeman, Mitchell, Meyer, & Curley, 2007). A further complication for SIDS is that by the time infants are found they are invariably clearly dead; nevertheless, in our culture, CPR is expected even when it is apparently futile.

Police usually arrive on the scene concurrently or shortly after EMS personnel. Parents have extremely vivid recollections of police behaviours at this time. Because it is so unusual to have a police presence in one's home and because parents are in a heightened state of arousal following a SIDS death they remember quite clearly what the police did and whether they were professional, courteous, or incompetent. In some cases police are inexperienced and unable to maintain emotional control themselves. They may even break down during the intensity of the scene. One participant (14) recalled how an RCMP officer began to cry when her other child entered the room. He had assumed the infant who had died was their first and only child and wept with relief when he realized there was another member of the family.

Participants generally accepted that police had to be there and interrogate parents. "They have to ask questions, just in case there's foul play of any sort" (Participant 10). In the shock of the moment, some were confused by what was going on. Participant 11 said, "I remember just looking at him with his hat on thinking you know...what are you doing here?" In some cases, other family members spoke with the police on behalf of the parents. In one case, the mother—whose husband was out of town—seized control of the situation and insisted that the police officer not take her daughter's body "out in a bag" because "she was not a piece of trash" (Participant 7).

In January 2007 I attended a police training seminar conducted by Deborah A. Robinson, an Infant Death Specialist with the SIDS Foundation of Washington. The seminar took place over a three-hour period in Bellingham,

Washington. The program offered to police in Washington State is considered a good model and is emulated by the Child Death Review Unit which operates under the mandate of the British Columbia Coroners Service within the Ministry of Public Safety and Solicitor General.

Police in Washington state are trained using a four-step approach with the acronym C-POD. This consists of *collaboration*, whereby expertise from coroners, law enforcement, emergency first responders, medical specialists, pathologists and child protection and social workers are all potentially used. *Preservation* refers to the maintenance of scene integrity once resuscitation attempts are finished. *Observation* includes being aware and conscious of everything within the environment while suspending assumptions. Finally, *documentation* involves recording everything about the scene, the child, and the witnesses. Police are also taught that their activities, observations, and data collection are invaluable for future researchers doing retrospective reviews to advance understanding of risk factors for not only SIDS but also accidental deaths of infants.

The police have a difficult balancing act. They are trained to investigate criminal activity here but they enter a home where a potentially natural death has occurred. They are taught to be aware of suspicious circumstances, interview parents separately, and may at their discretion ask pointed questions such as “Was this pregnancy planned?” At the same time they are asked not to treat the scene as a potential crime location (by using, for example, yellow crime scene tape) and to do their utmost to maintain sensitivity and tact with distraught

parents and others who may be present (The Canadian Association of Chiefs of Police, 2004).

4.4 Coroner/Medical Examiner

In Canada, the coroner system operates in all provinces except Alberta, Manitoba, Nova Scotia and Newfoundland which use a medical examiner system. Either a coroner or medical examiner is always involved when an infant dies of SIDS. Not all parents have contact with this person and not all of the informants remembered speaking with one in the confusing aftermath of the infant's death. But these officials are normally in attendance fairly quickly. In British Columbia they are on call 24 hours a day and have legal authority to collect information, conduct interviews, inspect and seize documents, and secure the scene.

Increasingly, child death review committees oversee these types of deaths. Modelled on those that have been used for decades in all parts of the United States (except Idaho), these multi-disciplinary teams undertake systematic analyses of child deaths and offer recommendations and formulate policy to help prevent future cases whenever possible. They also identify clusters of cases which may result in further investigations. Their reports are extremely detailed in terms of not only what happened but how and where (Office of the Chief Coroner Child Death Review Unit Annual Report, 2006).

4.5 The Autopsy

In Canada, the coroner or medical examiner has the power to initiate an autopsy (T. Ramanzin, personal communication, September 21, 2007) with or without parental consent. The final diagnosis of SIDS cannot be made in the absence of an autopsy; it is a crucial element in gaining increased understanding of the causes and mechanisms of death relating to SIDS. Properly conducted and professionally handled, the autopsy can reassure parents that they were not at fault. In my research sample all but two cases had an autopsy performed. One mother (1) could not remember whether one had been done and, in a second case, the infant died in Pakistan and was cremated immediately consistent with local custom.

The autopsy is a centuries-old time-honoured medical tradition that has several purposes: establishment of the definitive cause and manner of death; identification of unsuspected associated findings; provision of public health statistics; elucidation of pathogenic mechanisms of death; verification and evaluation of the accuracy of clinical diagnoses; and finally, the education of medical students, clinicians and pathologists. A neonatal autopsy is also of considerable value when counselling families following the death of their infant (Laing, 2004). It has also been a prime source of data on causes of SIDS. Pathologists led the research thrust that has been ongoing since the syndrome was first identified as an entity in the 1960s. Dr. Marie Valdes-Dapena was a pioneer in the field. Working in the Department of Pathology at the University of Miami School of Medicine, she described all aspects of the etiology, pathology,

and epidemiology of SIDS in more than 50 papers (see for example Haust & Gilbert-Barness, 2006; Valdes-Dapena, 1975; Valdes-Dapena, 1988).

The parents in my study were grateful that they were sensitively approached in a discussion of the need for an autopsy. In several cases the coroner contacted them with findings and in other cases these findings were interpreted by a family physician. This pattern is consistent with recent research conducted in Germany that sought to answer the question of whether autopsies are helpful to the parents of SIDS victims (Vennemann, Rentsch, Bajanowski, & Zimmer, 2006). A large-scale follow-up of 373 parents demonstrated that 83% of parents felt that the role of the autopsy was a positive contributing factor in their bereavement process. The authors conclude that:

The high rate of agreement amongst parents regarding the autopsy is also reassuring for criminal investigators and forensic pathologists. A lot of parents fear that they have overlooked an illness in their child and therefore need proof that this was not the case. All major self-help groups in the world approve explicitly of the autopsy in cases of sudden and unexpected child deaths, also because it relieves the parents of their guilt (p. 354).

In a study conducted in North Carolina the autopsy report was used by counsellors who were mostly public health nurses, as a tool for initiating dialogue with parents. The authors found that if nurses were comfortable with discussing the findings and stayed open to questions and reactions from parents, this was a useful tool for removing some of the mystery surrounding the death and helping parents feel less guilty for what had happened (Kotch & Cohen, 1985).

There are however issues surrounding the lack of standards and the variation in availability of adequately trained paediatric pathologists. Ideally, a

SIDS autopsy is carried out by an experienced practitioner using standardized protocols. Unfortunately, world standards and even geographical regions within countries vary widely in the availability of these highly specialized trained individuals. Fortunately, SIDS cases can often be transported to tertiary care centres where these experts work. Nevertheless, there is a consensus that the teaching autopsy is in serious decline. The average medical student now graduates in Canada without having seen one performed and is thus less likely to request one (Byard & Krous, 2004; O'Grady, 2003). Parents continue to press for having autopsies done, particularly since the most recent research in SIDS has uncovered unequivocal pathophysiological pathways derived from tissue studies implicated in the syndrome (Hunt & Hauck, 2006; Moon, Horne, & Hauck, 2007; Paterson et al., 2006). In other words, the most promising areas of research into why SIDS occurs are from the specimens taken during the autopsy

Aspects of autopsy management are critical in ongoing research into the etiology of SIDS. During a special two-hour session devoted to the topic at the 9th SIDS International Conference in Yokohama, Japan (2006), a number of interesting issues emerged. For example, parents can be distraught if the infant is returned to them for burial but with the brain and heart removed and not replaced with filler material. This makes the infant unnaturally light with a strange feel when held, something that is very disturbing for parents. Also, the large central suture line that closes the body cavity needs to be expertly closed so that there is a more natural look to the body. Above all, the parents must have the procedure sensitively and carefully explained and their cultural beliefs and values

must be taken into account (Sawaguchi et al., 2006). Furthermore, when the autopsy is obtained there should be an opportunity for parents to discuss it if they wish. It is unusual for Canadian pathologists to interact with parents directly; the report is usually sent to a family physician or pediatrician. Some parents do not wish to have a copy of the report nor do they wish to discuss it, but others do and this should be their choice.

In summary, properly conducted, there is potential for the autopsy to add to our knowledge of SIDS and to provide comfort and solace to bereaved parents, proving to them that theirs was actually a SIDS death and that nothing they could have done would have prevented their loss. When an autopsy is not performed, there is the potential for a permanent question mark to linger.

4.6 Untangling the Issues—An Ongoing Debate

Issues of first responders, police interactions, discussions with pathologists and coroners all involve a larger framework within which parents deal with professionals, often people they do not know, in a manner not of their choosing. One lens that might be used to view these multiple interpretations might be through surveillance as boundaries of information systems. (This is different from surveillance as a matter of social control although this occurs in a SIDS death as well). Marx (2003) suggests that surveillance “is a property of any social system—from two friends to a workplace to government” (p. 816). He suggests that:

Information boundaries and contests are found in all societies
...Humans are curious and also seek to protect their informational

borders. To survive, individuals and groups engage in, and guard against, surveillance. Seeking information about others (whether within or beyond one's group) is characteristic of all societies (p. 816).

Surveillance enters into the spectrum of a SIDS death in multiple ways. The concept implies close inspection, particularly when something suspicious is at play or the possibility exists for something unwanted or unwarranted to happen. It could even be broadened to form a component of the entire trajectory of sudden infant death, from conception to aftermath, from the intensely personal to the very public. The following aspects might be considered contested areas in informational boundaries in relation to a SIDS death:

- Death scene investigation, as photographs and aspects of the scene are recorded systematically;
- Autopsy, a surveillance of the body itself, with samples of fluids and tissues removed for further analysis, and toxicity studies done to rule out wrong-doing;
- Neighbours, relatives, as questions arise and people speculate about what the parents might have done;
- Day care settings, as liability issues arise when a SIDS death occurs;
- Media, the investigative point of view as well as implied blame and finger-pointing.

Death in our society is a strange mixture of bereavement and bureaucracy. It consists of a blurring of the boundaries of the personal and the public. There is government and legal involvement when one thinks of estates, wills, inheritances, and taxes, but a SIDS death incorporates more controversy.

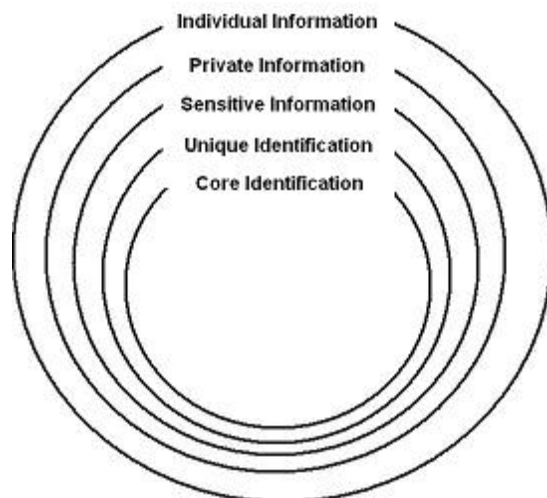
There are additional reasons why there is potential for volatility in a SIDS death. Marx (2003) suggests that there are a number of concentric circles of

information that involve the private and the personal in increasing penetration. Starting with the outermost and least innocuous circle and moving inward toward the most contentious, he suggests the following structure:

- Individual information: any data category that can be attached to a person, e.g. type of car one owns, an address, a name
- Private information: that which is not automatically available, e.g. social insurance number, search warrant, or a credit card number
- Intimate or sensitive information: much more personal attitudes, conditions, and behaviours including sexual activity, health issues, ethnicity
- Unique and core identity: the fundamental information that makes us unique (p. 7).

The latter might include for example, genetic information. Figure 4.1 represents this graphically.

Figure 4.1: Marx's Concentric Circles of Information



(Marx, 2003, used with permission)

It is precisely because the death scene investigation moves so rapidly into these core areas that the potential for conflict arises. Parents in their home in our society have clear expectations of privacy. We are protective of, and vigilant about, what occurs in our private spaces. SIDS is something that occurs at the very core of human activity. A child dies within the sanctified space which has suddenly become a very public space as police and various allied personnel intrude. In some instances, the infant's body has been removed without parental consent. The trajectory of events moves rapidly from the relatively innocuous outer sphere to the intensely personal and sensitive core. According to Marx (2003):

In the West we place particular emphasis on the sanctity of the borders around the person, the body, the family and the home, and on the protection of information gathered in certain professional relationships such as those involving religion, health and law (p. 2).

These factors all come into play. Even religious practices are investigated as part of standardized procedures in the U.S. (The Centers for Disease Control and Prevention (CDC), 1996). The surveillance model is one way that a model of conflict might be viewed. As one mother said, describing the "body man" coming to remove her deceased son:

But I looked out and there was his car and it was this ugly maroon station wagon. And this man was ugly. And I remember seeing him for years after. Any time there was a death ... he was the one taking the body out. And isn't it funny, I still think of...I know he wasn't an ugly man or a bad man but I still think of him as very ugly. And he came to the door and the police and the medical examiner were at the door and I remember going out, we had this porch attached to our house. I remember him going out and I stood right here at the door [jumps up to demonstrate] Guenther and he went to walk in

and I stood right here and he backed off and he said “Mrs. _____ , I’m so very, very sorry for your loss “(Participant 14).

He never set foot inside the house. In this case the boundaries were clearly established by the mother in question.

In one case the parents prayed together while the police did their investigation:

So they did their thing and we were, we were downstairs in, you know, mourning, and...praying, and they were...uh....doing their job. And they took a number of things with them, they took the mattress, the blankets, to the police station, they took a number of articles from his crib and then....because I recall, several days or weeks later, going to the police station and picking them up, getting them back (Participant 10).

Suspicion can arise from the smallest detail:

I remember he had a pair of overalls that I had for [my son] that he wore the day before. And one of the buttons had broken off, so actually I put a safety pin in it. But it wasn’t just a regular safety pin it was a protective safety pin. And so I remember he showed me that and he said, “Is there a button missing here?” And I said, “No that’s been gone a long time.” I says, “I put that on.” So maybe thinking that [he] choked on...on the button or whatever. So he just ...asked me what happened (Participant 11).

One mother, whose son died while in the care of her own mother did not even hear about the investigation until much later:

They took everything, they went through everything and...it wasn’t until I got a phone call and they said there is no concern and the investigation has been closed. I said investigation? Investigation of what? I had no clue. And they said well whenever there is the death of an infant we have to investigate and make sure there was no foul play (Participant 4).

There were many different accounts of the circumstances in which the police arrived. For the most part, parents understood the necessity for the

questions and were treated with respect. Nevertheless, it is a tense, even harrowing experience for parents.

4.7 Summary of the Death Scene Investigation

In this chapter I have introduced the death scene investigation as a feature that could add to the anguish that SIDS parents encounter. In all the literature reviewed previously this aspect was never mentioned and to date it has been poorly described. It is important because first responders, coroners or medical examiners, the police, and pathologists all play a role in how events unfold once the infant has died. There are multiple nodes where issues can resolve smoothly or become troublesome for parents. How people behave, what is seen, and what perceptions take place all play a role. An autopsy is performed, a medical function that also carries considerable symbolic meanings. The relationship among parents and all the various groups associated with these tasks might be viewed within a surveillance model which I discuss as one way of understanding the inherent tensions surrounding the procedures including the autopsy and the police investigations.

The death scene investigation is one of the processes that SIDS parents must go through en route to having their loss identified legally as a SIDS death. Memories of the death scene investigation are often a part of the memory spectrum, which is discussed at length in the next chapter. The death scene investigation—seldom addressed in psychosocial literature about SIDS—can become part of the negative events surrounding a SIDS death, and is worthy of

greater research attention. In the next chapter, I outline additional aspects of parents' grief after SIDS.

Chapter 5: SIDS Grief

5.1 Introducing Interview Findings

In Chapter 3 I outlined both the rationale for using a qualitative approach and also provided details about how data were coded and analyzed. Later in this chapter I will introduce the concepts of affective constructs and grief aspects, as well as the memory spectrum, all of which emerged from my data. In this chapter, I review my findings that show how I arrived at these concepts. Five major thematic areas emerged from my analysis of the data. I will introduce these briefly before returning for a more detailed view.

Not unexpectedly, parents went through the trajectory of *the grieving process* in their narratives. Nevertheless, grief for an infant who has died of SIDS takes on a somewhat different shape from the grief experienced when someone dies at the end of the life span and there appeared little relationship to existing stage theories as described in the grief literature. There is the sense that one is robbed of the future that something profoundly, unfair and even unfathomable has occurred, when a child dies ahead of its parents. It is a powerful disruption in the narrative that people script for themselves and their lives. It is also a grief that resurfaces continually on anniversary occasions, throughout the parents' lifetime.

A second major theme which I introduce is the *spectrum of memory*. This unanticipated finding emerged as people remembered and described either

highly negative or very positive events. For example, the death scene was uniformly recalled as horrific, frightening, even gruesome, but always negative.

It can't be happening. So then I picked him up again and...and then I just felt...it was like picking up a doll. There was no life, no movement, no...and I knew he was gone, it just...you know, so I put him back down and then I was like hysterical (Participant 11).

[My wife] was yelling and screaming, I ran up the stairs to see what she was yelling and screaming about and she was running towards me and she was holding [our son] and he was all limp and his face was all blue (Participant 4).

Then there would be positive memories, the way the baby laughed and acted, the interaction, the smell, the nursing experiences and so on. I became interested in how these memories were part and parcel of the same experience, two sides of the same coin, positive and negative wrapped up in the same chain of events. The memories also formed part of a trajectory that I will explore in two dimensions: the traumatic aspect which moves from the powerful imprint of the discovery, through to dissociation and resolution, and also the slow change as dominant negative thoughts shift into more comforting and reassuring recollections.

Somewhat linked to the first theme is the third major theme, of *coping, restoration and psychological resilience*. Moving forward and onward with one's life does occur. People do this in individual ways. Parents care for their other children, and they establish a certain sanity and rhythm in their lives when almost everything appears to have spun out of control. They move out of their homes where they feel safe but suffocated by sadness, back into society where they interact with others. They redefine their relationships with their partners, their

family, they find out how to comfort each other and also try to understand why their partner is grieving differently. They demonstrate that humans are resilient in the face of overwhelming loss.

The fourth theme that emerged involves *sources of psychological, social, and emotional support*. Social support is a key area and I was expecting to find a variety of ways in which people obtained help. This type of help came from obvious sources such as family, friends, self-help groups, professionals such as counsellors, and in some cases from religious people such as clergy. Online sources were also used, a phenomenon discussed in a separate chapter (6) since this type of interaction is novel and emerging. While the support sources were varied and often useful, they did not fit the pattern consistent with other types of death in the family.

The fifth major theme comprises *social stressors, personal losses, and permanent change*. This area is not as circumscribed as the others but is an important source of frustration and deviation on the road back to recovery. These constitute the incidents and difficulties that hinder the process, some of them unique to parents who have lost children and very different from obstacles encountered by those who are grieving other types of more usual losses. In this section I include the comments made by others that range from insensitive and unhelpful through to negative and damaging. Also in this category is the resentment of never having been told anything about SIDS, the shock of something happening that one did not even realize existed as a possibility. Some people spoke about the loss of self and the loss of faith. SIDS parents always

understood what I meant when they were asked whether people had made thoughtless or insensitive remarks indicating it is a common experience. The replacement child was perhaps the most frequent: "Don't worry, you can always have more children." Other awkward scenarios involved answering the question of how many children one has. This took parents time to think through in order to settle on an answer that was personally satisfying without being overly confrontational, i.e. does one admit to having a child that died or does one leave it out of the total number? Variations on this theme included the many ways others simply avoided talking about the event and in some cases avoided the parents altogether, thereby placing parents in the uncomfortable situation of having to reassure others that they were not going to fall apart at the mere mention of the SIDS event.

Running through these five major thematic areas were the various affective issues expressed in the narratives. Some of these were negative and expected, e.g. guilt, denial, regret, resentment and fear; others were more positive and perhaps less expected, with feelings of hope and acknowledgement, and even humour.

Finally, there were a few physical themes associated with the grief process. Losing an infant and having one's world shattered results in physical manifestations, some consistent with the literature, others poorly described. An example of the latter is the lactation problems that some mothers experience after SIDS as their milk continues to flow and their breasts engorge. Other more general affective issues and the physical concerns are discussed as findings

warranting further research and are taken up in the Discussion section, Chapter 9.

5.2 The Grieving Process

All of a sudden I could feel this something coming from the very pit of me, the very core of me. I went running into my mother-in-law's room and I stuck my face in her pillow and this noise started coming out of me and I was wailing. It was a wail, but it came from the very core. And I can't tell you the power it had, and it just—and my mouth opened and it started and I could not stop it. And it just—I can still hear it in my mind and it was like this: Ohhhhhhhh. I can't even describe it and it just kept coming and coming (Participant 14).

The study parents experienced grief in a manner consistent with many aspects of the grief literature, with some notable exceptions. These exceptions included the fact that the initial grief reaction is overwhelming in its intensity, that it is somewhat different from the grief that they experienced for other types of losses, and that anniversary and cohort situations exacerbate and re-invent the trauma even years later.

Parental bereavement is intense, as parents grieve for the lost future with their child (Rando, 1986). One participant (18) said, "You give up your whole being for this one child." Somehow there seems to be much more of the self incorporated into the grief, a personal loss that is different from the loss of the other that occurs when a relative or close friend dies. When asked how this type of grief response is different, participants explained to me that the baby was something they had created, a part of them, a symbol of their love, one aspect of the commitment that two people have to each other in a relationship, and

something that is shared. All of this is threatened and potentially destroyed following a SIDS death. Others define it simply as the ultimate type of loss humans can experience:

I don't think there's a greater loss. I will—I was thinking about that when I was driving in today. I really do not believe there is a greater loss than a child (Participant 14).

The experience is described by this same participant as “primal...love I can't even describe...it just comes right from everything you have.” Another participant (16) made a clear distinction between her grandmother dying and the SIDS death:

My grandmother passed away a year ago. She was 99 years old. I look at it and she lived a long, happy life. I know my parents are going to die, I know I'm going to die. I've had a life, I've experienced things...I want my children to grow up and outlive me and have a good life and be happy and stuff, but I mean as far as like if I die tomorrow, I've done things (Participant 16).

It is the infant that has never “done things.” Living and experiencing a long and fulfilled life and then dying peacefully is the normal trajectory, what everyone hopes for, and what we all attempt to achieve. Dying suddenly in infancy, having experienced very little, is the exact opposite, a frightening and disturbing twist in the story of a human life. All grief is painful, even overwhelming, but these parents appeared to indicate that their loss was also somewhat different.

There are also differences in the intensity and perhaps even the quality of the grief itself when an infant dies. There is certainly a disruption in the life narrative, as expressed by participant 20 who said “We're supposed to bury our parents; I'm not supposed to bury my six month old daughter.” This aspect of

children predeceasing parents has been widely described (Arnold & Gemma, 1991; Braun & Berg, 1994; De Vries, Lana, & Falck, 1994; Lovell, 1997; Martin, 1998). Taylor, DeFrain and Ernst (1986) suggest that:

For the vast majority of us a baby is the very antithesis of death. A new life, it represents hopes, dreams, and new beginnings. It embodies the future, while providing an extension of the parent in the present and symbolizing the parents' continuity and immortality. A baby represents the potential for fulfilling dreams, starting over, rectifying past mistakes, putting into practice new insights (p. 162).

Many parents maintain bonds with the infant who has died, a well-researched area of the literature (Klass, 1988; Klass, 2006; Klass, 2007). Some opt for cremation so that the ashes can stay close to the family even if they move. Others have memorials in their gardens in their homes, or purchase plots where they too will be buried alongside their child. One mother (Participant 14) said that she discussed interring the infant's ashes with the parent that dies first. This reunification in the afterlife was expressed by several people. One father described looking at the open night sky in the rural area where he lived and saying a few words to his lost daughter while finding the stars he associates with her.

Unexpected loss can initiate an intense grief reaction for anyone in any situation, but it is the norm for SIDS parents. It is difficult and time consuming to initiate recovery. One participant (14) stated, "I don't think your mind really allows you to start feeling other things for a full year." Another mother said, "We were just on auto-pilot." Others are paralyzed:

I didn't get dressed for a good eight months. I betcha if I went out ten times in eight months it was amazing. I would get up, I'd take a

shower, change my 'jamas and that's how I'd spend my day (Participant 13).

Others are confused, knowing that things will never be the same, or they are consumed and overwhelmed by what happened, thinking about nothing else night and day. Women in particular may perseverate with their thoughts, the same images repeating over and over in their mind. It appears men are better at thought stopping (Dyregrov & Dyregrov, 2004), a process by which they are able to switch off at least temporarily, intrusive and painful thoughts. In general, people are paralyzed, disbelieving, no longer able to function normally, numb and disoriented. In some cases this takes the form of establishing boundaries. Several told me that they were unable to visit the cemetery assuming that they would be overcome once again. Several expressed the idea that thinking about their infant under the ground was too overwhelming to conceptualize.

Anniversary reactions are well known for parents who lose infants. They remember not only the day the infant died, but their birthdays as well. Holidays, particularly Christmas, can be difficult and parents learn coping mechanisms such as special ornaments or prayers that include the infant. What is not described in the literature is the unexpected cohort type loss that parents experience. One mother describes going to her daughter's Christmas concert:

The curtain opens and there's all these kindergarten kids standing on the stage and you know how they're supposed to stand together, but there's this one little gap. And did that hit me. Oh my God, I'm looking at these kids and they're all the kids that [my son] would have been in kindergarten with. And they're all the kids that were born the same year, and there's that little gap...He should have been in that gap (Participant 14).

Some parents develop rituals which may—or may not—involve the rest of the family. One mother described how she always makes a cake on his birthday but no longer mentions the reason to the rest of the family. It has become her private ritual, the special cake simply appears as dessert.

Several mothers indicated that they had also had miscarriages but did not describe these losses as comparable to the SIDS loss. Unfortunately, researchers often include neonatal losses such as miscarriage and stillbirth with perinatal losses such as SIDS but they can be quite different. Two mothers described their miscarriage as possibly resulting from the stress of unresolved grief following the SIDS death, occurring as it did quite closely afterwards. Subsequent pregnancies are a significant problem for parents, something I will discuss later.

In summary, some grief reactions experienced by SIDS parents are similar to other types of losses that also produce a grief response and are very consistent with the grief literature, but others are different. In particular, the length of time taken—years in some cases—to establish some type of equilibrium, appears to be longer although again, the length of time any person grieves for any loss varies widely. For SIDS parents, the initial grief reaction, sickening in its intensity, may be different from a more anticipated loss as they themselves expressed this. The anniversary reactions and unexpected situations that parents encounter when they realize their child should have been present catches people off guard and in a sense re-invents the grief over and over again, sometimes for

decades. The role issues of no longer being a parent and the unrealized potential of a lifetime of activities and dreams unfulfilled can be overwhelming.

5.3 The Spectrum of Memory

In this section I present the memory spectrum beginning with the initial negative impact followed by the later more positive reconstructions. These phases were quite consistent through the interviews and there did seem to be an overall arc to the process, although the time frame probably varied among individuals, i.e. for some the resolution and ability to speak comfortably about the pleasant aspects of their child took much longer than for others. I did not map a chronological time span for each parent, something that would be interesting to develop in follow-up interviews which in my study I was unable to do. Of interest was the fact that these phases did not appear to correlate very much with the traditional stage theories that grief theorists develop.¹⁰

5.3.1 Initial Negative Memories

Perhaps the single most traumatic memory described by SIDS parents is that of discovering their infant son or daughter dead. It is a scene so wrenching that few described it in great detail although their recall of the event was clear.

One parent who did elaborate describes it this way:

My daughter was eight months old. My husband woke me up and said, "Take this" and handed me a Valium. And I said "Why?" He said, "Just take it, don't ask any questions." And I did and he says, "I have to show you something," and he took me into the room where she was cold. Still...umm....my memory of that particular

¹⁰ The trajectory that I describe for the subjects in this work is not comparable in any way to traditional stage theories and my intent is not to compare the two.

event was that she had a little bit of milk on her mouth as if she had—you know—had a slight burp as a last event. And—that event has haunted me the rest of my life (Participant 1).

Others, who were in a hospital setting at the time, remember details with astonishing clarity, even a decade later:

That's another sound that I hear is the tape ripping off the door. When they ripped the tape off the door and they threw the doors open and it was like having tunnel vision, I could see in this room a baby laying on a gurney (Participant 15).

Others remember more general negative events, such as the house being “cursed” (Participant 16) or dressing the infant and then laying him in his casket which was described as “really hard” (Participant 18). A father remembers the jacket he wore when his infant died (he was carrying her in a snuggly over the jacket at the time of her death) saying:

I had the jacket downstairs that I wore that night and I could never wear it again. And it sat kind of on a coathook forever and I finally got rid of it ...it got to be just a bad jacket (Participant 20).

Some parents described continuing on immediately after the death as if their baby was still alive, something that might be interpreted as denial. One mother rocked the deceased baby even though her sister asked her not to, and another mother changed the diaper describing her actions fairly matter-of-factly:

Like he's cold, he's stiff, he's not—and I looked at him and I said, I remember saying this, “No I think I like this little sleeper, I think he looks so nice in it” (Participant 14).

While few spoke at length about these disturbing events, they were consistently clear, sometimes decades later:

I remember the phone call as if it were five minutes ago, from my wife. I remember, you know, them laying him on the stretcher...on a bed in the emergency room. Vividly. (Participant 10).

Following the initial time period, usually several days later, parents describe events as becoming “a blur” (Participant 1). Over and over they told me they couldn’t remember, that things were a blur, that they were in a fog or a haze.

My memory at that time—like my friends would phone me and say oh you know we were going to take you out for lunch and I would completely forget. My memory was just a (makes a whooshing sound like it was just absent, then laughs). It was terrible (Participant 16).

She then added later, “I just remember a lot of gray...I just remember gray, the colour gray, like everyone was gray.”

Others described feeling like “a zombie” (Participant 16) or thinking that their recollection of events at that time were out of sequence. Others felt they lost periods of time, even entire days:

It’s just really a—difficult and yet—over the days—and that whole day too, your whole mind is—is floating and the day just flew by. You know before I knew it somebody was putting some food in front of me. And I don’t even know who it came from or where it came from. You go into shock sort of (Participant 11).

Another mother actually described a dissociative experience during the funeral of her son:

I remember just sort of feeling like being up in a corner watching it all. And, stupid little things. Like I didn’t want to buy a dress because—or go out and get shoes or anything—‘cause I would never wear this outfit again, so I had a dress that I wore, and I wore these cowboy boots that were beige in colour, this navy dress, walked into the church in this, and I’m thinking—I must have looked like a real sight, like. I can remember being up here and thinking what the hell is with those cowboy boots? Like I’m in this body

wearing them and now I'm up here going what the hell is with these cowboy boots? (Participant 14).

Some parents worried that they were going crazy, that things “didn't seem real” or being “on autopilot” (Participant 15). One parent simply established an emotional boundary:

I only allow myself to go so far with that, because it's just—I knew it would drive me crazy. I never let myself go too far into that. Anything that I felt was going too far I kind of put a stop to it in my head (Participant 19).

These negative memories are primarily in the immediate aftermath of the SIDS death, but they are temporary, and were, for the participants interviewed, largely replaced by more positive memories later.

5.3.2 Later Positive Memories, Mementos and Reconstructions

Pictures are such an important part of mementos and positive memories. Each parent showed me some mementos. Either they were on the wall (some parents had a special wall devoted for this purpose) or they were in an album, sometimes lovingly crafted in a scrapbook with captions. Others had created websites which I will discuss later. The memories and mementos represented a clear transition, from the above-mentioned pain towards a reconciliation:

It was painful for me to look at the pictures for the first while, but now I love to look at his picture. You know, I think—Oh!—he was such a cutie. Cutie petutie you know, you look at it differently than you did at the beginning (Participant 11).

Others described their memories now as “wonderful” (Participant 13) or precious because they are so few in number. One participant (2) told me, “I remember every outfit he ever wore.” Others treasured the physical space where the baby

had existed and visited it repeatedly (in contrast to PTSD symptoms where people avoid the scene):

I left things up in her room and spent a lot of time—I had a little rocker in her room. We spent a lot of time just, you know, on the rocking chair. And I spent a lot of time in there with her...with our little nursing pillow and some of her little outfits and it was just very comforting for me (Participant 21).

A pervasive theme was the use of mementos such as scrapbooks and pictures. Some people kept boxes with things, others had videos that they had done, one mother showed me a composite photograph in which the infant had been included to make the family “complete.” In some cases parents placed things in the casket—an angel pin, a cross necklace, even a pocketknife—so that a physical treasure would stay with the child forever. These were comforting gestures for parents, as were visits to the gravesite where parents would go to leave flowers and toys. This is common for all families and on several visits to local cemeteries I have always been impressed by the number of trains, dolls, stuffed animals and other types of toys placed on graves in those areas devoted to infants and small children.

Other mementos included locks of hair, a ceramic footprint and of course clothing. One participant (5) told me that when she first came home “I slept with his blanket.” Not only were there reminders in the households I visited of the infants, they were often placed in a prominent place, perhaps not a shrine, but in a public place, on the television, in the hallway, somewhere where parents could show others their family, a grouping that always included the infant that had died.

Parents remember their children in certain ways. I specifically asked parents how they reconstruct the image of the lost child now when they think of him or her. Often, the infant is remembered as exactly the way he or she was at the time of death, frozen in time. Others viewed the child growing older, now doing certain age-appropriate things such as beginning school or for those who lost their children long ago perhaps finishing high school or even getting married. Still others imagine their children based on their other children's characteristics, an interesting way to develop a composite. However, one mother who had the opportunity to have a computer generated image developed based on other family members and that infant's age in the present time declined, saying she just couldn't do it. So there are boundaries that are established in some cases.

These reconstructions in the minds of parents are not mutually exclusive. Some parents did both, remembering their infants as babies but also imagining them in the here and now, grown up. When asked how she pictures her lost daughter now, one mother (Participant 13) said:

A young lady—but still a baby—it's kind of a—this is what was and this is what might have been.

This same mother was overcome when she saw a doll that had a likeness of her husband's eyes, her son's mouth, sitting in a pile of leaves perhaps in October, the same month her daughter was born. She purchased it on the spot.

Parents also described mementos such as photographs. It was an area that emerged in the first few interviews and I asked subsequent parents to describe these aspects for me. All parents spoke about their current image and

view of the infant, usually in a positive way indicating acceptance of the role and place of this child in their family. In numerous ways, a lasting relationship had been built and the place of the child was established in the family.

In summary, the initial intense shock that parents experience is frequently described in the literature but not explained. It appears to trigger not only an emotional but also a biological response in a manner I describe in the Discussion chapter 9. The literature that describes this type of emotional memory is found in the trauma, stress, and PTSD literature which does not describe grief. It is my belief that there is overlap and that by comparing models of grief and incorporating what is understood about the physiological responses known to occur in other instances of trauma that a new understanding of what happens to SIDS parents might be possible. This might be viewed as an extension or elaboration of grief theory.

The same holds for the dissociative phase. This is the next phase following the initial reaction and has perhaps been confused at times in the literature with denial, a different type of process. In denial, parents would simply not believe that something had happened, and I did not find any evidence for this construct in the stories I heard. In dissociation, there is a fuzziness, a lack of clarity as to one's surroundings and what is going on, and this was often articulated. Both denial and dissociation are defence mechanisms, but I believe it is dissociation, a type of compartmentalization where one places something into a compartment to be retrieved later, which was present for most SIDS parents.

These are issues to which I return in Chapter 9 in Recommendations for Future Research.

5.4 Coping, Restoration and Psychological Resilience

Parents spoke of the many ways that they learned to move forward in their lives, reaching out to others, gaining new insights, and using rituals and culturally symbolic actions in order to help not only themselves but also those close to them. In some cases, these new insights were also indicative of the new meanings that people had created for themselves. One father spoke of the death of his infant son as a precursor to the death of his father:

When he did die...ten years later, I said that prepared me. Going through that partially prepared me, that—you know what? He's fallible and he's gonna go and you know that, but it's gonna happen. And so it was still brutally difficult, but it helped to have gone through that experience (Participant 10).

This same participant set up a Centre where he and his wife meet with other couples to discuss and help them through their bereavement process. This was where I met with them and the room, adjacent to their house in the country, had an extraordinarily peaceful and soothing feel to it. Both parents were deeply religious and felt that God had called them to help others as a way of living their lives. For them, this calling gave meaning to the death of their son.

Some parents felt that their values had shifted, that they learned to appreciate their partners more, and they felt closer to their children. One mother learned to accept the inevitable forward flow of life:

Made me realize that life is going to go on whether I want it to or not. Nothing's going to change what happened. I can either learn to

live with it, or crawl under a rock and choose not to exist
(Participant 13).

Several parents spoke of developing a different appreciation of their own parents. In some cases when the thought of suicide crossed their minds (it is an issue for some SIDS parents) they remembered their own parents, thought about how they themselves felt, and realized that they would put their own parents into exactly the same position and pain. This type of empathy appeared to be powerful and healing.

One mother (Participant 13) described how she believed that her daughter who had died of SIDS had arrived to strengthen her relationship with her husband, which had been clearly the case—decades later they are still happily married. Not only did this explain to her why her daughter arrived in her life, but it even gave some meaning for the short duration of her life:

Her purpose was to bring [us] together and that's why she was only here for four months, 'cause her job was done. And I felt the most incredible...it was like that [snaps fingers]...it was like her purpose was served here, boom this is why, I knew it in an instant [snaps fingers again] as fast as I could snap my fingers and I had such peace.

Many parents went to support groups where they received warm comfort and heard stories that made them feel less lonely in their personal journey. However, some parents also saw behaviours in others that made them uncomfortable, people unable to move forward. For those determined to put the pieces of their shattered lives back together this was an interesting insight, seeing someone else stuck in their grief. They became determined not to go that same route themselves.

Generally, however, there was tremendous empathy for other parents. This extended to other types of losses—parents who had had children die of leukaemia or mothers who had experienced miscarriages:

When you experience loss, the loss of a child and others experience the loss of a child then you have...somehow...a bond together (Participant 10).

This bond extends to understanding the tremendous variation that people have in expressing their grief. Referring to the group process one father said:

They're all different. The one doesn't want to talk about it, the next one does want to talk about it. The one's gotta blame, they gotta put a blame somewhere, the next one doesn't, they're just intensely sad or lonely. See they're all different so you need to really get to know a little bit in where they're at, what's their belief system (Participant 10).

Gender also plays a role. One mother suggested that:

I think the biggest support came from my girlfriend, I had a girlfriend who lost two children to a rare blood disease...we had a lot of talks and I found as a woman that women need to do that. You know men don't need to do that as much, but women need to talk about it (Participant 11).

Because SIDS parents undergo unusual circumstances with the police, the coroner and perhaps others who carry out the death scene investigation, they are particularly able to empathize with this aspect as well:

I had parents here tell me that they were kept out of their own home for two weeks while police had their investigation, that they were treated as if they were murderers (Participant 15).

Parents also know how important it is to acknowledge the infant's name. They ask for the name and they use it in conversation. This type of outreach and empathy can be satisfying, a reciprocal exchange where both parties benefit:

You can see people come into the meeting and it would be like there was a black cloud hanging over them. You can see in their body language, they're burdened. And you can see them walk out with a lighter step and standing taller and you know you've done some good for them (Participant 15).

SIDS parents learn from other SIDS parents. There is a unique power in hearing the phrase that yes, each day can get slightly better from someone who knows exactly what is going on.

Grief and mourning have deep cultural and spiritual rituals associated with them. Parents described these for me, again demonstrating a range of activities influenced by their beliefs, their families and their traditions. Some parents opted for an open casket and viewing as is often the case in Canadian funerals. However this then created a new dilemma, namely whether young siblings should see the body:

My one son, yeah I gotta see him and wanted to see him a number of times whereas I think my daughter, my older son saw him once and then they didn't want to see it anymore. So we did not have our three-year old see him and that's another regret. I think it would have been wise...if it were to happen today with what I know I would have him see him for sure (Participant 10).

In cases where there was a traditional burial parents would have to decide whether to have the interment in the "baby land" section that most cemeteries have. Some found this appropriate, while others did not. Some parents opted to have a family plot so that they could later join their infant in the afterlife. Others found the traditional closing of the casket overwhelming in its metaphor of finality. Several parents were overcome as they described this process. One mother said that she refused to watch the process.

Several parents spoke of cremation. This has the important benefit of allowing parents to stay physically close to the remains. One mother (Participant 12) laughed as she said to me “He’s up in my bedroom, he always will be.”

Other parents went through the ancient ritual of dressing their infants. One mother said:

We went through the ritual of dressing, and put him in overalls and a t-shirt and a baseball cap, kind of the way we like to remember him (Participant 19).

For some this was a final shared experience, the entire family together in a sad last rite. One father described it for me:

My wife asked the funeral director if she could participate in the dressing of the child...and they allowed that. So my wife was dressing [our son]...and she was talking to him the whole time. And she enjoyed that. And then I picked him up and I put him in the casket. I had a chain and a crucifix that I had my whole life since I was a young boy and I put it around his neck and let him take it with him. And then, that was it (Participant 4).

Another mother told me that during the visitation she was holding her hands together and the ring that had a birthstone for each of her children suddenly popped a stone out. To this day she hasn’t been able to repair the ring which to her is a metaphor for one child missing.

Physical locations become important to family members. One mother (Participant 8) described how she went into the nursery and continued reading long after the baby had died. Another mother (Participant 16) went to the gravesite with a book and spent time reading. I asked her whether she did so out loud and she laughed a little and said, “No, no, inside my head.”

As was mentioned, many parents showed me scrapbooks, something that not only gave them a focus and something to do but also to create permanent reminders of a brief life lived. Others created online memorial sites which I will discuss separately in Chapter 6.

To summarize this section, issues of coping and resilience were common. These are not specific to SIDS parents, all those who grieve and mourn participate in rituals and help themselves in their own manner. What is of interest is that we have not paid enough attention to the overall process by which people help themselves get better. The literature is dominated by problems associated with grief. There are descriptions of depression, despair, hopelessness, sadness, even shame and guilt. Nevertheless, these aspects are counterbalanced by personal growth, new insights, different forms of strength and new understandings of other people who have experienced their own loss.

Understanding resilience provides us with mechanisms for reinforcing individuals' personal resources, mobilizing those forces which are analogous to supportive physical measures that assist in helping broken bodies heal themselves. Resilience is nevertheless not always an individual process. It is reinforced and aided by others, those who provide the many different ways in which people seek, obtain, and benefit from support. I return to these issues in Chapter 9.

5.5 Sources of Psychological, Social, and Emotional Support

5.5.1 The Context of Support

Social, psychological and emotional support is an extremely diffuse category. I use the term to indicate instances where mature people (parents) seek help from others to deal with feelings of sadness, depression, anxiety and in order to obtain practical advice about how to deal with other children. It is also a space where parents can be comforted, reassured, and above all perhaps, given hope that life will change and they will be able to eventually move forward, based on experiences that others who are further in the trajectory have undergone. For those who seek professional help it might take the form of an outsider providing a different framework for them to consider, or an atmosphere of trust where they can share those aspects of their grief that they are unable to speak with their partner about. One participant told her partner that she wanted to see someone to deal specifically with her concerns as a mother.

I expected to encounter support issues in the stories parents told me, and as it turned out it was an important part of their narratives. Parents relied on partners and family members for help, including their own parents and in some cases even grandparents. They turned to friends for help, they used a variety of professionals such as counsellors and therapists, and they used self-help groups, particularly those organized through the Canadian Foundation for the Study of Infant Deaths. Other sources included religious means and a few unexpected sources, such as funeral home directors. Online support as was

mentioned is covered in a separate chapter. Cases where support was notably lacking or absent or problematic in some way are discussed in the next section.

As was outlined in Chapter 2, authors often refer to “the loss of a child” which is probably too broad to be meaningful. A SIDS loss is different from miscarriage and stillbirth and very different from the loss of a child due to suicide or homicide which in some instances may be even more shattering. Thus placing them all in a similar category, implying that parents choose means to help themselves by seeking out others in every case of child loss is to describe a process that is overgeneralized. Not only do SIDS parents want to speak with other SIDS parents, they would prefer to deal with people their own age, and if they have other children, speak to parents who are also in that situation, since dealing with their other children is something for which they seek help. Even when professional help is sought, it seemed to be advantageous if that person had had some type of loss themselves and was able to identify with the problem. One mother described how her therapist shared her own miscarriage experience with her, something she appreciated.

Some of the material discussed in the literature review was developed by and for other professionals such as nurses. Unfortunately, in Canada today there are few resources for public health nurses to spend a lot of time with parents following up and helping them through the grief process and none of the parents spoke of discussions with nurses. There is also a problem with obtaining professional counselling, something that is not covered by provincial health plans. The study parents highlighted help from other parents as their primary

source of support, and in those cases where professionals were involved, they spoke of counsellors as useful, often in the context of fairly brief interventions of perhaps a few months.

Support for parents was not articulated specifically as an unmet need. What appears to be far more important is that people who interact—however briefly—with bereaved parents, is that they do so respectfully, with tact, and with empathy for their situation.

5.5.2 Parents' Voices

One of the major differences that I found in my analysis and the findings in the literature is that “parents” are rarely, if ever, a single unit who respond and behave as a unit. They are individuals who differ in the way they react to bereavement, how they cope, and how they use support in its many forms. It seems that one parent will develop a certain coping strategy, e.g. seeing a therapist, and the other parent will develop an independent strategy, e.g. returning to work and developing a closer relationship with another co-worker who is a bereaved parent or simply becoming heavily involved in their career once more. Having individual coping strategies in place then allows this same couple to support each other in ways that are more intimate and more appropriate within that type of relationship. Even when one parent’s coping skills appear dysfunctional or inappropriate, the ability of the other person in the relationship to allow that person to work through things in their own manner appears key to long-term success. In other words, giving one’s partner

permission to engage in any type of activity that was deemed helpful, often strengthened the couple's ability to cope together.

In most cases friends and family rally the moment they hear about the loss of an infant. This shocking, unexpected and often catastrophic event is always taken seriously and as is often the case in a family crisis, people move rapidly to be physically nearby. Parents of these parents travelled overnight to arrive, others began making telephone calls, anyone who was available arrived and began to help. In some cases, family is a crucial support:

If it weren't for my family I wouldn't be here. I really wanted to be with them at whatever cost, I just wanted to be with them
(Participant 17).

Family members undertake the supportive tasks necessary when parents are paralyzed by grief. They answer the phone, plan the funeral, arrange flowers. They deal with the endless bureaucracy that a death in our culture (as anyone who has ever been an executor knows) necessitates. In some cases they protect parents in dealings with the police and the coroners. Other family members may even take care of the children:

I think she took my kids to my mom and dad's so they can be in a sane environment, 'cause she didn't want them around the crib because the police were there (Participant 15).

Food appears to be an important part of almost every culture's mourning practices. Perhaps we eat to remind ourselves that we are still alive and require sustenance and nourishment. Bereaved parents have little interest in cooking, and so the task is taken over by family members:

Both moms were really good, they were cooking and you know making coffee for everybody and I thought well that's good because I'm in no shape to be doing that (Participant 21).

In some cases bereaved parents suddenly became the children again, being comforted by their own parents:

I had the opportunity to go to my dad's...for two days and be babied a little (Participant 5).

Over and over again I heard stories of support from the parents of the SIDS parents, even though they too were in personal crisis. Parents of parents occasionally reached into themselves to provide wisdom for their grieving children:

I was sitting on the footstool by the chair he was in, he had his foot up and I said, "Dad how do I know, how do I know that there's really a heaven?" I was raised that way but how do I know? And he said to me, "Who do you think you are?" I said, "What do you mean?" And he said, "You're a human being, you and [your husband] can create—just like we create automobiles—we create the interiors, we create the exteriors, we create the wheels, you can create the body, you can create the bone, you can create the blood, you can create that physical...but she was the smiles, and the giggles and the laughter, you can't make that. It's got to come from somewhere, you can't tell me it's not going back somewhere" (Participant 13).

Some parents redefined their relationship with their parents as a result of their SIDS loss. The intensity and the need for comfort at a very deep and personal level helped both generations learn something new about each other.

Parents themselves however did have to deal with their other children. Those children, astute as children usually are, sense problems. Parents struggle with the best way to handle this:

So that night we told her. And we used to call his bedroom the shiny bedroom...it was bright yellow and it had little farm animals all over it. After he died she started calling it the shiny bedroom. And I said to her, we're going to make the shiny bedroom into your playroom. Oh mommy, I don't want to do that, she said, what if [he] wants it back? And I said he's not going to want it back. So we made it into her playroom, but she never—her toys were in there and she'd go in and get them but she never played in the shiny bedroom (Participant 14).

While it is perhaps expected that family, particularly parents (and in at least one case, grandparents, since many of these affected parents were quite young), would rally to the cause, an extremely important source of support turned out to be friends. Our friends tend to have a different relationship with us, a source of a different kind of support that is not as encumbered by the family history and the underlying dynamics. In some cases friendships emerged when parents met other parents who had also lost an infant or a child:

When you experience loss, the loss of a child and others experience the loss of a child then you have—you have somehow—you can have a bond together. You walk the same road if you will (Participant 10).

One mother told me that “the biggest support came from my girlfriend” (Participant 11), adding that she would bare her soul to her friend and that she felt that women needed to talk far more than men did. One mother, whom I was interviewing during breakfast in a restaurant (we had managed to find a private corner), spoke easily about her experiences as a SIDS mother until she described one of her most important sources of support:

I had one girlfriend who was pregnant with the first child who came every day. And just sat on the couch...that was pretty special (Participant 12).

With that, she suddenly began to cry as she recalled the powerful and unconditional support that was provided by someone who did nothing but offer herself which is sometimes the most important contribution of all.

Another mother spoke of a similar experience:

I had a girlfriend who just started showing up and let me cry. And she would cry with me, and she'd talk with me. Every Tuesday, she would arrive, and you know what? Long after [my son] was gone, and long after [my daughter] was born, we continued. And we continued those Tuesday morning rituals for I'll bet you ten years (Participant 14).

Not all friends are comfortable in the role of being supportive. Parents quickly learned who was emotionally available and who didn't want to become involved. Sometimes friendships ended as a result of what was perceived to be a failure at providing emotional support at a crucial time. Those who helped clearly made a lasting impact.

Parents spoke of their own parents' support and that of friends more often than they referred to their partners as sources of support. Either this latter aspect was implied and a given, or it was too personal to describe in detail with an interviewer that they had met for the first time. But I refer back to my sense that parents as individuals are knocked off balance initially, grieving independently and in the context of their individual lives, searching for a solution that fits them specifically. Only when this is accomplished do they return back into the relationship for mutual support.

About half of the respondents spoke about receiving professional help or advice in one form or another. One participant (1) had received eye movement

desensitization and reprocessing (EMDR) treatment for posttraumatic stress disorder, something she found helpful. Those who saw counsellors described the experiences as positive, something that offers a different perspective from friends and family. Another mother (Participant 21) told her husband that she wanted to see a woman therapist to talk about “mom things” that she felt he wouldn’t understand. She also realized that she did not have sufficient personal resources to undergo this crisis on her own. She found two sessions a week for about a month very helpful, demonstrating that even brief intervention can be incredibly useful. This particular therapist had lost a baby herself which this mother described as adding to her ability to empathize with her situation:

So basically I went in there and she was very—she was just a good listener and I went in there and pretty much just bawled for a whole hour. And she sort of interjected a few thoughts now and again, and it was things that someone had said or something that—something that family had done, you know that I would sort of spew to her and she would just sort of put it in perspective for me (Participant 21).

Trusted physicians also became important allies. In one case the pediatrician arrived at the hospital to confirm that yes, everything that could have been done to resuscitate her son, had actually been carried out:

I was so glad he was there. Because I trusted him. I didn’t trust the doctors and I said...did they do everything? (Participant 5).

His reassurance that they had done all they could meant a great deal to her and relieved her at this time of great anxiety. Other parents described interactions with coroners and medical examiners who showed courtesy and respect in their dealings, something parents appreciated. One mother described how their family

doctor helped them tell her four-year old son that his sister had died, something she and her husband simply didn't know how to do.

Many parents found their way into self-help groups. These are sponsored across the country by the national SIDS organization, CFSID. Since all my participants were obtained through this organization I knew that they would be familiar with its structure and the programs that were offered. Nevertheless, they uniformly found the self-help groups useful, sometimes in surprising ways. One mother describes her first visit:

One of the first things that gave us hope was walking into that room, but before we walked into the room we heard laughing. And we stopped. And we thought we can't be in the right place, there's laughter coming out of that room. So we walked past a couple more times, more laughter, more laughter. And then L. saw us and she said, "Hello, are you here for the SIDS group?" And we said, "Yes." And she said, "You're in the right place." So we went in. And I remember...it was the first thread of hope that we were going to be normal again. It was like—they're laughing, they look normal! You know...it was like somebody threw me a lifeline (Participant 14).

Not all parents found the meetings easy to deal with, describing them as draining. It was also a long journey for some to drive to locations where the meetings were being held. Another development that was unexpected and interesting for me was that some parents began to see other parents whom they perceived as not moving forward in their lives, remaining "stuck" in their grief, unable to resolve it. Seeing this was for some a motivating factor in addressing their own issues, not succumbing to the same kind of despair, perhaps getting on with their lives because of the fear of staying forever in that sad lonely space where they saw others stalled.

A number of parents spoke to me about their religious faith. About half (seven women and three men) spoke in some way about a belief in God that helped them through their grief. Very few authors have addressed the implications of child loss and Christian or other faiths and related values in a scholarly manner. Linda Layne, who has done extensive work on narratives of pregnancy loss from a feminist standpoint, writes that both the Old Testament story of Abraham who is ready to sacrifice his son to prove his faith, and the entire story of the New Testament—where Mary’s suffering at having lost her son and not having much to say about it is sometimes overlooked—deals with the parental loss of a child (Layne, 1997).

One father said to me:

We’re Christian people and our faith has certainly not made us exempt from grief or mourning, but we have a comfort in where we believe [our son] to be (Participant 10).

Later during our discussion he added:

Now what happened, I know what happened...he just stopped breathing and he died. Why? I can’t answer that question so I’m not going to go there. I do know that he was—we’re Christian people and therefore he would be a child of God’s as well as us and then I believe that he will go to be in heaven and that’s good enough for me (Participant 10).

People with religious conviction sometimes look outside of themselves; they see the world as being guided and controlled by a higher power which alleviates some of their concern in attempting to find out exactly what happened and why. They may also believe that the people they meet are sent by God to help them. One mother who received a telephone call from another SIDS mother

whose son had the same name and even the same middle name as her son told me:

To me that was a direct message from the Good Lord that you know, you need---and she left her phone number and said that I should connect with her. And so then she called about a month later, and we had a chat on the phone and then we got together...that was a real big support for me...to talk about it (Participant 11).

Rituals were important to parents. One mother cried when she saw a baby being baptized, but was also comforted by the process. Others found the friends that they knew through their church a strong source of support. In some cases (but not always) the minister or priest was very helpful. Others believed that they became better people as a result of their loss. Framed in Christian principles obstacles in life are to be overcome, to strengthen one, develop sound moral character, and to develop empathy and compassion for others, as well as to learn about ourselves here and now in preparation for the afterlife, at which point the family will be reunited. One mother also described how she learned humility after her minister said during a service:

God has given us everything, we have such freedom...but we are not perfect. And with that being not perfect, things happen (Participant 19).

Sometimes support came from unexpected places. A store clerk stayed late to give one mother pictures that she had had taken prior to her daughter's death. Not only did this clerk spend time with the mother looking through them, but she gave them all to her free of charge once she had heard that her daughter had died. Another father (Participant 18) described how a prominent public figure

telephoned him after reading the memorial in the town newspaper. Others described support from co-workers, from their employers, and from people they barely knew. Parents found great comfort in knowing that the death of their infant had touched so many people, like a stone thrown into a still pond that created ever widening rippling circles.

In a few cases animals became important. One woman went riding:

I spent lots of time on my horse, that seemed to be a solace kind of place for me (Participant 21).

Others looked after their dogs, grateful for the distraction and comfort that pets can provide.

Support was a crucial part of recovery for parents. This was an expected finding and various means of using others to help oneself is an important potential source of self-help for anyone undergoing grief and mourning. In summary, parents found many ways to help themselves through discussions with others, but always in individual ways. Unfortunately, because I did not interview parents more than once, I was unable to delve more deeply into the relationship concerns that would help in an understanding of how couples navigate the process together. This is an area that deserves more attention.

In spite of the many sources of support there were also cases where it was notably absent and it is these areas to which I now turn.

5.6 Social Stressors, Personal Losses, Permanent Change

This major thematic area dealt with diffuse negative events, interactions with others that were recalled as unhelpful and hurtful, personal losses and resentments about what had transpired, all with a common theme of roadblocks on the way to recovery. These were interactions, events and a lack of information that parents described as problematic. There is no clear body of literature in this area in which parents themselves identified problems that they encountered. Gold (2007) has identified a series of criticisms that bereaved parents have identified in their encounters with health care personnel. These included a lack of emotional support, insensitivity, administrative rigidity, and a lack of information among other complaints. One might argue that these issues are hardly unique to bereaved parents—clashes with health care personnel sometimes seem to be the norm for anyone needing health care. Nevertheless SIDS parents identified specific problems that pertained to their situation.

Grief can be a strange and isolating emotional space wherein people struggle with their circumstances but must also interact socially with others who do not understand, lack empathy, and in some cases are completely insensitive to what has transpired. Death of any kind brings about a mixture of emotions coupled with inevitable clashes with administrative, legal, and bureaucratic systems. Lovell (1997) worked in a pathology laboratory where she encountered the low priority placed on stillbirth post mortem reports waiting to be typed. She writes:

I noticed that childbirth and child-death—two distinct life events—were in temporal collision. One effect of this collision was that they

often became bracketed together by health professionals, by lay people and even by the parents themselves creating a setting where acknowledgement that something significant had taken place was not fully accorded. The contradictory events of life and death were not simply conflated into one traumatic event but were treated *as if one cancelled out the other* (p. 38).

As a culture, we are often ambivalent towards parents, families and children. As was mentioned earlier, the message may be that children are priceless but the equally powerful message that we sometimes send when that priceless child dies is to imply that people get over it. We begin to worry when people are stuck in their grief too long. We expect grieving parents to conform to certain social norms. This is a particular problem when an infant dies of SIDS. Very few people actually know very much about the etiology and risk factors associated with SIDS but they may be quick to offer an opinion on what happened and why. The lack of knowledge among professionals and lay people may lead to the implication that parents did something wrong. It most certainly seems to elicit thoughtless comments which most SIDS parents have heard at one time or another. These include the “replacement child” concept:

I was told I was young, that I could have more kids, not to worry, that what was meant to be was meant to be (Participant 12).

Other parents encountered religious conflict :

I have a cousin who is Jehovah’s Witness that tried to tell me, oh you know she doesn’t go to heaven...only 144,000 are...And then I had an aunt [who asked] well was she baptized?...Well how can you bury her inside the cemetery, don’t you feel guilty? [Since she was not.](Participant 13).

Some people tell parents they should feel fortunate that the infant wasn’t older. This, like the replacement child reassurance, is so incongruent with how

parents feel that they learn to dismiss these types of comments as coming from people who are ignorant of the transformation they are undergoing. There is a general sense in our society that a relationship with children increases in value as they age, that interpersonal connections deepen and strengthen over time, but this is not a concept that makes any sense to parents who love their children right after they are born and then even more once they begin to interact and respond to parents.

It is particularly difficult for parents when professionals are callous. One mother described how concerned she was with the birth of a subsequent child after her previous infant had died of SIDS:

At one point, I had had him in my room and I took him back to the nursery and I looked in the window at him and I couldn't see him breathing so I went back in to check on him. And the nurse sort of said what are you doing. And I said oh I couldn't see him breathing. And she said...well maybe you need to put a piece of paper in front of his nose so you can see it flap in the breeze (Participant 15).

Another mother went to the library to read about SIDS, something she had never really known anything about:

I asked them for books on cot death or SIDS and I remember the librarian turning around to me and saying, "Oh, did you hear that the cause of death was because parents smoked during pregnancy?" And I smoked during my pregnancy. And that was when I left the library bawling my eyes out (Participant 16).

The problem appears to be that parents remember the slightest hint of blame and accusation, no matter how innocuous the context. One mother, ten years after the death of her daughter, recalls clearly the hospital physician speaking on the telephone with a colleague saying "The parents deny that that

ever happened.” The implication was that the parents were somehow responsible. Just as support from various sources is important, a lack of it may be perceived as wounding:

I was never asked if I wanted to hold her one last time, I was never asked if I wanted to say good-bye, I was never offered any counselling. Nothing. Zip. Nada (Participant 1).

Other parents described clashes with in-laws. While familial tension is common in any family, it somehow becomes exacerbated and comments are magnified and intensified, in some cases causing damage that can last a long time.

5.6.1 Misguided Attempts to Help

Several parents described people trying to be helpful which they interpreted as not helpful at all. Hospital staff are often concerned about parents who wait in the typical small rooms while their infants are being resuscitated unsuccessfully. In an attempt to help, chaplains are sent in, older hospice volunteers, or perhaps a counsellor—all not wanted or needed. Parents are almost never in any type of emotional space where they can sit and speak with a stranger, no matter how qualified or competent. I consistently heard that parents wanted a family member, a trusted physician, or their minister or pastor to come, but never someone that they had not met before.

Family members may project their own coping strategies on to parents:

My dad’s an alcoholic, the first thing he said to me was when the doctor gets there get him to give you and [your husband] something to get through this. Get him to—and I’m like what? Like this is

minutes after my son's died, I'm phoning my parents and my dad's telling me to get on something (Participant 14).

At times, medication was sometimes seen as the solution:

The doctors tried to give you pills, you know, relax, don't go off the deep end (Participant 2).

Other people become worried that the parent will become suicidal. Sometimes, parents just want to be left alone. A constant stream of visitors brings new issues, particularly for women who feel pressured to provide social amenities in a clean home:

I didn't want to have to deal with all the people. In my mind I thought I have enough to deal with, I don't want to have to worry about cooking and cleaning and I just didn't want to have any of that to worry about (Participant 21).

There are special issues that SIDS parents face, particularly when they move back into the community. When asked how the baby is doing by those who have not heard the news, they are forced into a discussion, reliving the events and recounting them for someone else who may be suddenly shocked and saddened, reinforcing the feelings for the parents. More insidious is the simple "How are you?" so commonly the first thing that is said to anyone and everyone. Answering "fine" is a lie and telling the truth is more than people want to hear. Thus a simple greeting becomes a trap. Other seemingly straightforward social conversations are troublesome for SIDS parents:

You go to the grocery store and you'd see someone and they want to come up and talk to you but I don't think they really know what to say. And part of you, I mean you want to say Hi, and you want to—but that's really the topic of choice, right? You can't really avoid it and—and I thought, oh I don't want to have to either repeat the

story or I just—I don't feel emotionally strong enough to have to say it over and over and over (Participant 21).

Sometimes family members clean up the infant's room as soon as possible. Others make sure all traces of baby paraphernalia are whisked away, as if by not having any reminders present the pain will somehow be lessened. For some parents this process has completely the opposite effect. The child's clothing, which can be so important for parents, should be kept and given back to them:

When we got back from the funeral I called the hospital and I asked about the clothes she was wearing and they said, "Oh they would have gone to the incinerator by now" (Participant 13).

Parents also have problems answering the question of how many children they have. Some include the child, saying I have four, three still living, one that passed away. Others talked about answers that varied depending on how well they knew the person. Others simply omitted the SIDS infant, but that might cause them additional guilt as they omit saying anything. It was never a straightforward issue for any parent. All had thought about this as a problem.

Some parents expressed dismay at never having learned anything about SIDS. Mothers receive a package of information when they come home from hospital, but as any new parent knows, there are few times during the day when sitting down and reading is an option. The lack of knowledge seemed to somehow increase the shock—something that they had never even thought as a possibility suddenly became very real.

5.6.2 Personal Losses, Permanent Change

In some cases parents were simply unable to resolve certain aspects of their grief. Some wounds stayed open, perhaps permanently. Parents spoke of a loss of part of themselves. The abrupt change, being alone in the house, was at times shattering:

I had all this alone time that I'd been wanting and I thought what am I going to do with myself? I mean, she occupied my entire day. And now I have all day, but nothing that I really think is important enough to do...Lots to do but nothing to do (Participant 21).

Other parents spoke about a loss of faith, anger at God. Some spoke in terms of a diffuse, life-altering experience:

You're grieving so much more than just the person. You're grieving the family, you're grieving the dreams, the loss of dreams (Participant 10).

Other parents had accepted the fact that they would always sink back into sadness at recounting the death of their son or daughter. It is a type of loss that re-emerges when others in the family die, particularly parents and grandparents who were involved in the life of the infant and perhaps present and helpful when the death occurred. Parents make these connections and grieve all over again in some cases for multiple people. There are also anniversary reactions and cohort situations where everything surfaces again. Other parents continually question why it had to happen. A few parents had never visited the grave site again. In one instance, even the marker had never been placed on the site. It was a task waiting to be completed.

5.7 Summary of the Major Findings

In this section I have outlined the five major themes that emerged from the interviews with the parents: the grieving process, the spectrum of memory, themes of coping and resilience, sources of psychological and social support, and social stressors and personal losses. Each of these areas add to the literature I provided that was introduced previously. The empirical evidence from the narratives themselves help in a better understanding of the concepts described.

While aspects of the grief experience were similar to those described in the literature, the intensity and duration were much more striking. This has been described in the literature, particularly that authored by professionals as described in section 2.3. As was mentioned in that section, the process has often been defined but not analyzed, and it was this reason that I attempted to go further in an understanding of what was happening for these SIDS parents. I thought I was hearing material from the study parents that I had not read about in the literature. This led into a more careful examination of the role of memory and how it relates to the grief experience.

The memory spectrum described by parents was different from that which any authors have articulated, particularly the way in which initial traumatic recollections move through towards positive lasting thoughts. In my analysis I began to examine memories as parents recounted them, categorizing them as positive, negative, unclear and also those memories where parents could not

remember what happened because they seemed to be in a dissociative phase. These are elements that I return to in the literature in Chapter 8.

Coping and resilience, a new area of study which I will examine in more detail in the Discussion Chapter 9, was demonstrated by these parents as they healed. It is an area in which I found considerable consistency with the relatively limited literature on the subject and the narratives from the informants. Parents were able to help themselves heal and demonstrated multiple ways of helping themselves, often through their support networks.

Support, as might be expected, came from myriad sources and was welcomed and often used. More specific to a SIDS death were the sources of stress and misguided attempts at helping these parents who must struggle with some of the unique social consequences of losing an infant. Support did not usually come from professional sources, but rather from family and friends. Parents used different ways of support services, i.e. men did different things than women and described the process differently.

Social stressors are an almost universal problem for SIDS parents all of whom can recount thoughtless and insensitive comments made by others intentionally or unintentionally. These are alluded to in the literature, but SIDS parents discuss them in a more concrete manner, giving specific examples of situations in which they find themselves in their dealings in public and with other people they know. It is perhaps an aspect of SIDS that underlines the profound experience of loss, i.e. that no one, not even professionals, know what to say and how to say it in the face of this type of human catastrophe.

Chapter 6: Online Support

6.1 Introducing Online Activities

During that past two decades the Internet has transformed the way many people inform themselves, stay in touch, share messages and photographs, and develop relationships. For example, the website CaringBridge used by 20 million families allows people to support and comfort each other through a range of events from chronic illness and recovery through to life-changing events such as organ transplant or military deployment. There are large numbers of other sites that provide specific and helpful ways for people to benefit from others' experiences and use of online technology.

Online social support represents an important emerging way for parents to obtain information about SIDS, meet and interact with others through forums and chat rooms, publicize their experiences through memorial sites, raise awareness of the problem of SIDS as a public health issue, raise funds for the cause, and provide resources such as research information. This area is set in a separate chapter because it is a specialized and multifaceted topic that is constantly changing and it is likely to increasingly evolve into an important tool for everyone connected with SIDS, parents and professionals alike. All SIDS organizations at the local, national and international level in every Western country use the Internet as their primary communication portal. Some of these sites include information for new and expectant parents, support and assistance for those who

are bereaved, research news and initiatives, advocacy to help build public awareness about SIDS and its consequences, specific information for professionals and the media, and ways to donate to non-profit organizations.

Parents receive much-needed face-to-face support from their family, including extended family, their friends, professionals (including health-care workers, therapists, and counsellors), clergy, support groups and others. Increasingly, though, they are also going online. While the former modalities represent a more private and personal network of help, use of the Internet and related technologies is a new way of building and using community services. Even when people meet with others, they often follow up or interact with someone through email or a website after an initial encounter. In this way online activities supplement and add, but do not displace, real life ways of working through bereavement. Organizations such as the Canadian Foundation for the Study of Infant Deaths are increasingly using their websites as their primary portals for a wide variety of activities including all of those mentioned above.

Parents in this study used the Internet in a number of different ways. Although in most cases the loss had occurred in a pre-Internet era, everyone eventually went online for various purposes. There are three ways in which online services were used by my study participants.

- Some used chat groups to discuss their losses with others or perhaps “tell their story”—something that is encouraged in these types of groups;

- many obtained information about SIDS from sites such as the one run by the Canadian Foundation for the Study of Infant Deaths (CFSID) as well as numerous others particularly in the United States (for example, First Candle);
- a few created memorial pages for their lost infant, either on a general web site such as the one offered by CFSID, or on an individual web page.

Staying in touch and creating memorial sites are ways of community building as parents describe their experiences for others and invite other SIDS parents to contact them through the page. Information seeking is a more individual activity that can decrease anxiety as parents better understand what happened.

Since the precise causes of SIDS remains unknown, the Internet also provides a forum for those interested in unsubstantiated and peripheral etiology, for example vaccines as a cause (Zimmerman et al., 2005). Some parents and health care professionals consider this type of misinformation problematic, misleading, and worrisome but, as with many types of information available through the Internet, it is up to the user to determine accuracy and credibility of information.

6.2 Context and Literature

Although the study parents did not speak extensively about the Internet and did not give any indication that it had always been an important source of information and support at the time their infant died, they did use it to a certain

extent and implied that they currently used email for SIDS-related activities just as they would for other types of communication. Every parent with whom I spoke had Internet access. Email is widely used now, but it will presumably be an increasingly important way for parents and other concerned people including grandparents, caregivers, aunts, uncles, to obtain information and perhaps connect with others, particularly those in remote or rural areas. A summary of other ways parents are using online services is included at the end of this chapter.

Computer-mediated communication has become an extremely broad area and might be thought of simply as “human-to-human communication via computer networks” (Herring, 2001). Several authors (Fernback, 1997; Norris, 2004; Thurlow, Lengel, & Tomic, 2004) have drawn on the German sociologist Ferdinand Tönnies’ *Gemeinschaft* and *Gesellschaft* concepts to better understand the nature of community. The former term (which has a slightly different feeling in German and is difficult to capture entirely accurately in English) is usually translated as community, groups based on a feeling of togetherness, something that is personal; the latter is translated as society, groups sustained by an instrumental goal, less personal. Both are emerging in online situations as they have in real life.

One problem with evaluating online social networks and communities is the assumption that this activity is best compared to face-to-face or “real” activity. This might not be an appropriate model. All the participants had ready access to other people in a physical sense, but it would be easy to imagine a marginalized

mother with highly specific concerns and needs going online to find others who share her needs and interests. The recent ScrippsNews series online (Scripps Howard News Service, 2008) which provided forums for parents to share their experience revealed considerable frustration, resentment, and a lack of local face-to-face resources for parents to obtain information and social support. This indicates that there are wide-ranging unmet needs at the individual and the social level.

Internet communities are constantly in flux both in terms of participants, who tend to come and go (as they do in real-life groups) and in terms of their structure. Earlier, free-for-all settings such as those offered by Yahoo or Google have long since been replaced with more closed types of settings such as CaringBridge and those offered by CFSID where registration is required and people get to know one another in more private settings. The larger commercial groups, while well-intentioned, have been infiltrated with far too many commercial interests as well as the inevitable bizarre, sexual, and otherwise offensive postings that permeate almost every open newsgroup. Most of these have been abandoned by the SIDS parents' community in favour of sites requiring registration and which are often moderated to deal with inappropriate visitors.

Information seeking is a common activity for SIDS parents and many sites provide excellent resources. A SIDS death has a number of elements: it is unexpected, parents are frequently uninformed (as noted earlier), parents feel guilty, angry, perhaps victimized and look for answers to alleviate those feelings, and there is a police response, as well as a coroner's investigation. There may

even be confused responses from relatives and friends. Parents are looking for specific information including etiology, risk factors, current research, approaches to subsequent pregnancy, relationship concerns, dealing with other children, family members, co-workers and friends. They may also become involved in fund-raising, teaching, increased public awareness initiatives and peer support. Others are interested in raising awareness of SIDS and safe sleep arrangements. Still others (like myself) become directly involved in the organization by becoming board members and creating educational materials. Many of these activities are increasingly being carried out online, not just for people in large urban areas, but everywhere, as people tend to email even those geographically close to them. Virtual support and information communities for SIDS parents are here to stay.

Most articles that address issues of grief online do so in a general context, i.e. they do not deal specifically with parental loss of a child or infant (De Vries & Rutherford, 2004; Geser, 1998; Moss, 2004; Roberts, 2004a; Roberts, 2004b; Roberts & Vidal, 1999; Veale, 2004). SIDS parents are looking for much more specific information. Web-based resources for women following pregnancy loss (miscarriage) have been examined by researchers (Geller, Psaros, & Kerns, 2006) but again, parents experiencing a SIDS loss do not always relate to information about stillbirth and miscarriage which they interpret as both causing and creating different problems. An ethnographic study of perinatal grief online found that women created a tightly-knit community even though they had never met in person (Capitulo, 2005). An examination of parental loss of a child in

relation to a web-based community has been undertaken (Hastings, Musambira, & Hoover, 2007) which demonstrated that discussion of crucial topics enabled parents to reconstruct meaning in a shared environment where cooperative group was created.

6.3 Grief Moves Online

Online memorial sites are a more complex phenomenon, one that I have examined with my colleague Christopher Finlay who is at the Annenberg School for Communication at the University of Pennsylvania. In a presentation we gave at the SIDS International Conference in Yokohama (Krueger & Finlay, 2006) we described qualitative analysis techniques informed by ethnography to examine the role that these virtual spaces assume for parents.

Finlay and I (Krueger & Finlay, 2006) became interested in why someone would want to post pictures and private thoughts regarding the death of their infant on a website and designed a study to address this question of motivation and whether it was a useful process in helping mothers through their grief. All of the 20 sites we examined were managed by mothers except for two. One had been done by a grandmother, and another by a father.

After an extensive content analysis of the 20 online memorial websites created by these individuals, we developed 45 separate categories for each site regarding authorship, textual and visual analysis, community building and the role in the grieving process (Krueger & Finlay, 2006). The sites were rich in imagery, metaphor, and provided insights into how people were coping with their

loss. It appeared to us that the bricolage aspect of putting together these sites from a diverse range of available choices, a sort of electronic scrapbook or quilt, was in itself a therapeutic activity, something that parents could do that would connect them to their infant, allow them to mull over pictures and poetry, letters and notes to the deceased, while distracting them from their pain. In other words, learning the tools to build and develop a website using the infant's artefacts as raw material, appeared initially therapeutic. We think perhaps that not only was this an activity that displaced sitting in a rocking chair and crying, but also an activity that built community. It is the digital version of creating a scrapbook, something that pre-Internet parents (including those in my study) carried out. One father (Participant 18) described how his partner "buried herself in her scrap-booking...it was just something that she needed to do and she'd stay up until four o'clock in the morning and scrapbook, just to have some focus." The implication was that by undertaking this activity she was finding solace as well as creating a legacy for the future.

In the study sample, one mother created an individual online memorial site, several others placed pictures and comments on the CFSID site, and one participant created a blog that was not related to her SIDS experience but indicated to me that she was clearly, even exuberantly moving forward with her life, having recently completed a European tour on a motorcycle.

Geser has suggested that "death is an event taking place at the interface between public and private spheres, so that it profits highly from any technologies which—like the Internet—increase the permeability between private

and public worlds” (Geser, 1998, np). By creating a website—in effect an electronic scrapbook—mothers can serve both solitary and social needs. The ability to reach potentially thousands of visitors may be reassuring, as a SIDS death may be an isolating experience. Certainly, these SIDS memorial sites are often confessional in nature. As was discussed in the findings, parents encounter social situations that are difficult for them to navigate, for example, answering the question of how many children they have. These parents understand these problems intimately and immediately and empathize with each other in ways that would be difficult if they were to speak with people who had not been placed in that situation. SIDS parents often refer to each other as “parents” in settings such as conferences where they might ask “Are you a parent yourself?” An affirmative answer implies that one is a SIDS parent.

We found that the websites created by parents had a home-made quality to them that were in stark contrast not only to a corporate or business site on the Internet, but also very different from funeral industry standards (which also increasingly use the Internet). Funerals, funeral homes, traditional grave markers and memorials of any type conform to a more formal, traditional, and even conservative format. These memorial web sites did not. They are filled with pictures and poems, toys and angels, music and thoughts that are extremely informal and usually very busy. It is as if every aspect of web site development has been incorporated much as someone learning to paint might use every colour available. It would appear that building the site is more important than a

finished process, and that part of that practice of construction is what provides comfort.

In addition to being an individual activity, the memorial website also creates and builds community. Parents include guest books which are often not signed by other SIDS parents but by people who read and view the site with the intent of reassuring themselves that they are fortunate in not having this type of tragedy strike their own family. Emails are exchanged, notes are left, and in this way the parents who created the site are able to read acknowledgements by others in a way that would be impossible in a physical cemetery. In the latter, it is impossible to determine who has seen the marker and the act of visiting it is a solitary experience. In a digital mourning space it is now possible to connect with those who have dropped by and it is even possible to contact them.

In some cases, the guest books were used by families themselves. They would leave notes to each other promising to stay in touch. There are even awards for sites, a more unusual type of activity where people may vote for a site. These votes are tabulated by moderators who present sites with certificates of merit which are then proudly displayed on the web site itself. It appears to be a type of affirmation that not only are people visiting, reading, and looking at the pictures, but that they approve of the way the site is laid out and organized.

Fourteen of the 21 parents in my sample (which included three of the four couples interviewed) had placed a memorial on the CFSID web site (eleven infants in total). This gallery allows parents to include a picture and a caption and music plays in the background. The names are never removed and the site is

updated regularly. There did not appear to be any relationship between the time since the SIDS death and the memorial placement. Once this web page was established by CFSID even parents whose loss had occurred many years earlier placed a memorial on it.

There was one participant in my study (7) who created a web site (and by complete coincidence was captured in the sample chosen for the previously described study). She identifies herself as “the mother of twinless twins” and writes on that page:

On October 16, 1999, my whole world crashed, I was home alone with my three children (Josh who is 4, and the twins), my husband was away on business. I woke up to find my daughter had died. I called 911, and started CPR, (in my heart I knew it was to [sic] late) with Nick in the swing and Josh watching I couldn't stop. I sent Josh to the back door to wait for the police so he wasn't watching me do CPR on his baby sister. The police arrived, then the ambulance, then detectives, it happened so fast I didn't know what to do first. The EMT tried to talk to me as I was being lead [sic] out of the room with my two sons, away from my daughter. I told her (the EMT) "I know," at least twice. I didn't want her to say those words (she's DEAD) with my sons in hearing distance. I just didn't want to hear what she was going to say, and I didn't want Josh to hear either. She didn't, I think she knew, that I knew my daughter was gone. I had to call someone to come over so I called my sister, my father, and just as I hung up my mother-in-law called to see how we were doing I told the ambulance was here, she hung up and they were here within minutes (SIDS Families, 1999).

As online communication becomes more widespread parents will probably continue to use this technology more and more. Expanded uses that are currently being developed include:

- Information for new parents about SIDS for issues such as risk reduction strategies and safe sleep arrangements;

- Dissemination of research findings to share what is currently known about SIDS and what is emerging as new areas of investigation;
- Educational literature that can be printed out on many different aspects of SIDS including information and also misinformation, which abounds in this area;
- Education and support for those in specific circumstances, such as loss of twins or triplets;
- Literature in multiple languages to address minority groups who are often overlooked in general educational strategies;
- Advocacy, including how parents themselves can be involved in fund-raising activities, peer support, group leaders and public awareness campaigns;
- Pressure on policy makers to keep SIDS in the public health arena and preventing it from disappearing as a concern for all;
- Co-ordination of international activities including learning from those countries that are doing things well, such as Norway;
- Social networking sites (e.g. Facebook, MySpace, CaringBridge) where parents place pictures, share stories, and provide information and support for each other;
- Expanded online memorial services including professionally designed memorial services, DVDs of services, tribute possibilities

such as flowers and candles and other commercial online services derived from the funeral industry which is rapidly providing these types of products and services;

- Email, chat groups, instant messaging, video chat and virtual reality sites where people can encounter each other in real time using either their computer cameras or avatars such as those used in Second Life, a three-dimensional virtual world increasingly being used by non-profit agencies and self-help groups;
- Hybrid sites such as Scripps Howard (2008) that combine parents' stories, videos and pictures, along with the ability to interact with the designers and providers of the service, a database of SIDS deaths throughout the US in order to uncover trends and clusters, and a social policy initiative to influence decision makers;
- Professional development; online courses, educational material for health care workers, distance education.

Parents in my study indicated that they prefer support and encounters with other parents who have also lost infants and are their own age. This makes online support preferable since it would appear that the type of person they interact with is more important than whether the interaction is face-to-face or online. Some parents in my study began with an online encounter and then later met the person. Even when this is not possible, the Internet allows people to connect without constraints of time and geography. Thus, a mother who is unable to sleep is able to send messages to people knowing that in the morning a

response will be waiting. Virtual chat rooms that are moderated are comforting for parents because they feel safe in being able to discuss intimate and personal aspects of their lives related to their SIDS grief with people that they have come to know in this environment. Virtual spaces such as online memorial sites can also fulfil other roles that are important to parents, including showing that the infant was beautiful, lived a short but healthy and happy life and was loved by all who had contact with her or him. There is often a sense of acknowledgement in these online spaces that however brief the life was it was valued. Family members can also access these pages, an important consideration as people become geographically more dispersed.

How technology will impact and affect SIDS parents in the future is as uncertain as the world wide web itself. Online chat rooms are already evolving into social networking sites and blogs and future online modalities will continue to change.

Chapter 7: Emotional Trajectory

There were two areas within the analysis that were not as striking as the previous sections in terms of the frequency with which participants included them in their narratives, but are nonetheless worthy of discussion. I did not have sufficient empirical data to extend concepts in the way I was able to develop themes in the previous group of findings, yet they are of sufficient interest to warrant further research.

In some cases these were intriguing comments that I heard from only a handful of participants, and in the case of lactation suppression, something that was described in only four of the seventeen female cases. Partly this was because I learned about parents' experiences as I underwent the process of interviewing them. Had I been able to return to the first participants after having interviewed perhaps a dozen, I would have asked different questions and probed more specific areas.

The first of these two areas involves affective issues that form a trajectory throughout the parents' stories; the second includes some of the physical issues surrounding grief, an emerging area of research.

7.1 Introducing an Emotional Trajectory Perspective

Throughout the coding and analysis of the narratives I extracted passages where informants spoke about emotional and behavioural issues that related to

their grief process. These affective codes fell along a trajectory, some occurring immediately, others in the intermediate time span, i.e. several weeks or several months following the death of the infant, and others many years after the fact. The immediate emotional response following a SIDS death was shock and paralysis. However, an unexpected finding was the number of times parents were worried about others in their immediate family. They expressed concern for their surviving children, their partners, their parents, even for caregivers and in one case the RCMP officer. Along with their own reactions I heard repeatedly how parents at the time of their most extreme distress, expressed concern about what was happening to others around them.

Later, in the intermediate stage several weeks or months after the SIDS death, some parents developed resentment towards others with children, the injustice of a world where even “bad” people are allowed their children while they have lost theirs. This resentment sometimes moved towards resignation, an acceptance of the way things are, a fatalistic stance that life is not always fair, just, or comprehensible. Also at this time, parents consistently worried about subsequent children. The parents’ fear that the SIDS event could repeat itself cannot be underestimated. Reactions ranged from a pervasive anxiety through to genuine panic and terror. Some parents I interviewed who had lost their first and only child to SIDS were unsure that they wanted to conceive again, so great was their fear of a repeat SIDS event.

Prior to returning to the physical issues section, I return to the literature to review what has been described regarding emotional responses and grief, two

separate areas that are sometimes conflated. I then outline what parents themselves articulated in the context of these emotional responses within the grief process.

Finally, often years later, parents expressed hope, gave examples of where they found personal strength and courage, acknowledged what had happened, but also expressed regret at how things had unfolded and what they would have done differently at the time.

7.1.1 Literature and Context

Returning for a moment to Stroebe and her colleagues' definitions of bereavement, grief, and mourning (2001b), grief consists of an emotional or affective reaction while incorporating cognitive, social and behavioural components. (Physiological and somatic issues will be discussed in the following section although there is some overlap). Grief is sometimes thought of as synonymous with possible emotional responses. Rando (1986) gives a very long list of possible affective and behavioural responses under the categories of vegetative symptoms. These include:

- anorexia,
- anhedonia,
- decreased energy, initiative, motivation and sexual desire,
- sleep difficulties, withdrawal,

- cognitive disruptions such as feelings of losing control, going crazy, being overwhelmed,
- inability to concentrate or make decisions,
- a combination of anger and depression which may manifest itself in anxiety, irritability, restlessness, and tension,
- a long list of subjective feelings including fear, guilt, helplessness, hopelessness, insecurity, yearning, sadness, and worry (Rando, 1986, p. 18).

More recently authors have examined the specific role of emotion within grief. According to Bonanno (2001a) there are four distinctions: first, emotions are ephemeral, lasting from a few seconds to several hours while grief is an enduring state that lasts for months to years. Secondly, many different types of emotions, in some cases very wide ranging, occur within a single grief process. These may be negative emotions such as sadness, anger, hostility, fear and guilt. Or they might be positive, e.g. amusement, happiness and pride. Thirdly, emotions are linked to meaning structures including danger or benefit, coping, or just getting through the moment; grief is associated with a larger scale type of evaluation and meaning reconstruction that encompasses the individual world. Finally, emotions elicit short-term responses aimed at changing or maintaining the immediate psychological or physical state, i.e. coping. Grieving typically evokes longer-term efforts aimed at ameliorating changes in social roles, one's economic status or family circumstances (Bonanno, 2001a).

It has been speculated that there is a temporal course to grieving in which certain emotions predominate. This was the case in my data. This model also appears to support some aspects of stage theories and perhaps even common sense:

Surely it is the case, on average, that bereaved individuals become less intensely emotional and less preoccupied with their loss over time. To the extent that a bereaved individual moves from an initial conviction that the lost individual is indispensable and therefore must be recovered to an acknowledgment that the person is—at least in the ordinary, everyday sense—gone, then there is likely to be a general progression from protest (anxiety, anger, searching), to intense sadness, to less intense and less frequent sadness (Shaver & Tancredy, 2001, pp. 72-73).

The emotional dimensions of bereavement also fit into the dual process model described earlier (Stroebe & Schut, 2001a) wherein there is a trajectory from loss-oriented everyday life experiences towards more restoration-oriented constructions and reconstructions. This is though a very unclear path that varies considerably from individual to individual. All of the behavioural descriptions and states inherent in this model involve an emotional context.

The literature differentiating emotions within a grief context is limited, it appears to be an emerging concern that has not yet been well developed. Then within that, the examination of emotions and grief in the context of infant loss is even more limited. Some authors have attempted to unravel the existential complexities that plague parents sometimes all their lives (Arnold & Gemma, 1994). Aggression and guilt following infant loss have been examined in relation to pathological processes (Hasui & Kitamura, 2004) and the psychological effects of stillbirth and neonatal death on fathers have been studied. Badenhorst, et al.

(2006) demonstrated that shock, anger, emptiness, helplessness and loneliness are common among fathers, but that guilt is perhaps not as common. I did not encounter any evidence that fathers felt less guilty than mothers, but once again, this study used a different population. One study that did specifically examine long-term adaptation in relation to differences in men and women and was related to SIDS did not examine emotions per se but rather looked at symptomatology (Thuen & Schlytter, 1996).

Some authors are descriptive, listing only the emotions themselves (Buschbacher & Delcampo, 1987; Krein, 1979; Smialke, 1978) or incorporate them into a specific model. Rubin (1982) showed that even years after the death of an infant due to SIDS mothers never relinquished their attachment, had not completed the mourning process but rather demonstrated less intensity and frequency of feelings (p. 281).

Archer (1999), a psychologist who approaches grief from an evolutionary point of view, talks about intrusive thoughts or rumination which may be an attempt to psychologically undo events (and would explain the guilt that so many SIDS parents endure). Suppression and distraction are strategies for coping with these unwanted thoughts. He also discusses what he terms “counterfactuals”, i.e. “if only” types of thoughts where the past could be undone. This leads to the intriguing question “of whether distress causes the person to examine the event and to seek to change it in thought, or whether the undoing thoughts generate the distress” (p. 135). Rumination and perseveration are certainly issues for SIDS parents as I examined in the memory section above. Archer (1999) also

considers blaming and self-blaming (or simply guilt), along with attempts at control, the concept of hardiness, and meaning construction as important mental processes.

Finally, recent literature has uncovered the sense of yearning as a frequently encountered psychological grief response more so than depression (Maciejewski et al., 2007). I specifically questioned parents about this construct and found consistency in their responses. They all felt a sense of loss and longing along with an implicit desire to have the infant back.

7.1.2 Parents' Voices: Shock, Bewilderment, and Concern for Others

When parents describe events as they unfold, they often told me that they were in a state of shock following the SIDS death. Fourteen actually used that word:

After the hospital thing was done, of course shock had set in. I was in complete shock (Participant 12)

And everybody through I was just going to be a mess and what I was—was just in shock (Participant 19)

The term shock originates as a physiological clinical term referring to insufficient blood flow to vital organs with potentially life threatening consequences. It has since been extrapolated into a psychological context but maintains some of the physiological overtones (I will discuss other physical responses later). It is an imprecise term and as such not really used in the literature, but the implication when used by SIDS parents probably refers to a profound, overwhelming, all-consuming and uncontrollable negative psychic response. One of the few

authors who describes it in relation to grief does so in the context of the accidental death of a child, suggesting that shock acts as a buffer from a perception that otherwise threatens to engulf the person (Sanders, 1986).

Associated with this sense of shock is bewilderment:

You don't know what you're allowed to do or not and I said can we pick him up? You know we're standing there kind of like looking down at him and—and afraid to touch him or anything (Participant 15).

One mother went so far as to describe her reaction as panic (Participant 12).

There is also a sense of confusion. Parents describe not knowing what to do next, realizing that their life was upside down, wanting to be suddenly left alone, but unsure of almost everything. This initial shock reaction might also be interpreted as denial, something that Kübler-Ross first described (1969) in her stage theory:

I said don't cover her face, that means she's dead. Don't cover her face (Participant 13).

One mother took the pamphlet that was given to them by their family doctor thinking naively that they would get through this easily:

I remember looking at that pamphlet after they all left and said, you know I don't think we're going to need that, you know. If we call this group it might be to help other people, because we're doing so well. You know we thought we were just doing so wonderful, you know 'cause we'd handled that couple of hours with all those people in our house just fine. Little did I know that the dam would burst (Participant 14).

One mother needed to confirm that her son was actually dead:

And they asked me did I want to see his body and I thought about it. Well, I'm not going to believe it unless I do see him (Participant 15).

One mother was aware that allowing herself to fully realize everything would be psychically too much to bear:

I surely think your body will only let you go so much. I think I would have lost my mind if I didn't let it come in at—you know slowly ease it in (Participant 19).

I thought it was just so overwhelming at that point, my brain was almost in shut-down mode (Participant 21).

During this time parents also attempted to regain control of a chaotic situation. SIDS deaths can involve a large number of outside people: firefighters, paramedics, police, coroners or medical examiners to name just a few.

While shock, paralysis and fighting for control were not unexpected (see Martin, 1998)), what was unusual and interesting to me was the extent to which parents became concerned about others around them. The degree of empathy and protection that people afforded close family members was a consistent theme in the narratives. Nineteen gave specific examples of this type of behaviour.

Parents were very concerned about their children, who in a few cases found the infant. In some cases there was an instant protective decision to remove young children from the scene:

It was not good to be around these crying adults, it would have scared them...they haven't dealt with death yet (Participant 12).

My thought was to get the children downstairs into the dining—the living room, away from the room [where the dead infant lay] (Participant 16).

Parents also had to tell their other children what happened. One mother described how they approached this in conjunction with her husband:

We both knew that she knew something horrible had happened that day and she was not ready to hear about it. So that night we told her (Participant 14).

Others worried about their partners. One father said:

I just think she was more crippled than I was and I just knew I had to be strong (Participant 18).

Another mother described how difficult it was to know that her husband was in pain but she herself was powerless to do anything about it:

This obviously shook him to the core, but he never wanted to talk about it. And the first night when we were there, when we were in bed...it was dark, I'm lying there...well I was crying and I stopped crying and I was trying to get to sleep because I knew it was going to be a long day the next day and I was trying to get to sleep so he thought I was asleep and I heard him start to cry. And I don't know whether I should have but at the time I said "Are you OK?" and he said, "I miss him" (Participant 3).

Sometimes the empathy took on a bitter edge:

My wife cries every morning, my wife cries every night when she goes to bed. My wife cries a few times a day, she misses him so much, she just felt like she's been ripped off (Participant 4).

One mother (Participant 5) broke down as she described her husband's initial reaction as "a mess...he was so bad."

Several mothers described how they did not sleep the subsequent night, watching over their children in a type of primal protection scene where some

unknown force has stolen one child and they must stay alert and awake to prevent a recurrence.

Parents also expressed dismay at seeing their own parents unravel—sometimes for the first time in their lives:

My dad held him. And it's really, really hard to see my dad cry. 'Cause I—before that I probably had seen him cry twice in my life. And—so that was hard. And he held his little hand (Participant 17).

I am really close to my mom, but part of me said you know she's dealing with a lot of this too...she's dealing with the grief of losing a grandchild but she's dealing with not knowing how to help me (Participant 21).

My dad was just inconsolable and so right then and there I lost it...I've never seen my father cry before, ever, ever. And to this day only one other time (Participant 3).

Even baby-sitters were consoled. In one case the woman who was caring for the infant at the time of the death was immediately reassured by the mother:

She sat down with me and I'm hugging her and she's like you're not supposed to be doing this, I should be doing this to you and I'm like no, no, It's OK. You know I'm OK (Participant 3).

7.1.3 Parents' Anger and Other Emotional Responses

In some cases the initial shock and concern for others develops into certain types of anger. This was particularly the case for men. One father (Participant 4) described feeling “ripped off” and angry with himself. Another father (Participant 21) described his frustration at a vengeful God who took his daughter. Parents sometimes expressed dismay that others had their children when they had lost theirs. One mother found it difficult to assimilate the fact that her sister-in-law had considered an abortion when she herself had wanted her

now-lost daughter “from the minute we found out” (Participant 13). Others expressed their sense of injustice:

What bothered [my husband] and I so much is the homeless, the drug-addicted, the alcohol, anybody—sounds so harsh but—our thought pattern, I’ll be honest with you, our thought pattern was why the hell do they get to keep their baby and look at the conditions that they’re putting their baby through, addicted to drugs...why do they get to keep their baby but we don’t? (Participant 5).

How dare you have your baby, where’s mine? Where’s my daughter? It was...totally irrational (Participant 1).

Pervasive through the narratives was the expected guilt that parents expressed. Almost everyone (n = 19) spoke about it to some extent. Parents blame themselves—sometimes for the rest of their lives—for not arriving earlier in the morning when the baby is quiet, for placing the baby on its side, for having invited friends over the night before for a drink, for smoking—in fact for as many reasons as there are circumstances. Some parents went so far as to describe it as the most fundamental failing a parent can experience—failure to protect their offspring. Others constructed the death as God’s punishment.

Not only did parents feel guilty initially, but they felt guilty when they started to resolve their grief. Beginning to laugh again made them feel guilty, having sex again made them feel guilty. But mostly it was blaming not only one’s self but others:

It’s a struggle all the time, you blame yourself, you don’t blame yourself, my wife blames me, I blame her, we blame each other, we blame the doctor...(Participant 4).

Some parents achieved some measure of relief from their guilt when they received the autopsy report:

I wanted to see that word at the bottom of it, to prove that I didn't do anything wrong. Because I was afraid that I had done something wrong (Participant 7).

A diagnosis of SIDS gave this mother that reassurance: no known cause was found.

Later in the grief trajectory, regret sometimes emerged, the sense that things could have been done differently. There were also hopeful affective statements and acknowledgement of personal strength. Growth through suffering does occur (Tedeschi & Calhoun, 1995) and parents were able to achieve meaning for the events that had so changed their lives:

He was a part of our lives, he was meant to be here, his life's journey was very short but I thank God for him in spite of that (Participant 10).

I need to acknowledge my son so when people ask me how many children I have I say I'm the mother of three, we have two girls at home, our son died at two-and-a-half months old, that's what I say. And they say Oh—we're so sorry, and I say...thank you but don't worry...we've coped with it...we're OK (Participant 14).

It was nobody's fault. It just happened (Participant 5).

Occasionally parents described themselves as stronger now, others described a depth of resources that they didn't know they had. One problem that was frequently encountered however was the fear of a SIDS repetition with a subsequent pregnancy. This is not an entirely irrational belief. The risk for

subsequent children is slightly higher (Smith, Wood, Pell, & Dobbie, 2005).¹¹ One author who describes the subsequent child following a SIDS death does so from the perspective of the previously mentioned “replacement child” model (Powell, 1995).

Mothers are frightened that they will become pregnant again and in two cases they miscarried after they conceived. Some parents used monitors to check the baby’s breathing; however, these give parents a false sense of reassurance, as they are not known to prevent SIDS, and sometimes go off so frequently due to movement or artefacts that parents abandon them. Some parents described themselves as overly protective and in some cases where the SIDS death had been the first child they described to me their fear of becoming pregnant again:

I don’t really know. I could never go through it again. I would never go through it again. If that were ever to happen again, I wouldn’t—I wouldn’t stay here (Participant 17).

Others developed a fatalistic attitude:

You want to believe it’s like a shot in the dark, and it’s like getting struck by lightning. That you’re never going to have this happen to you again (Participant 19).

Not all parents viewed this as negative. One father described “cuddling” his surviving son more often, perhaps something all parents should do more often.

¹¹ It has been suggested that the subsequent siblings of a previous SIDS victim may be approximately five times more likely to die of SIDS since the genetic and environmental risk factors may replicate (Hunt & Hauck, 2004).

These issues of shock mixed with empathetic responses emphasize the catastrophic nature of a sudden SIDS death. Anger, guilt and blaming may also be exacerbated in this type of loss. Fear of a subsequent pregnancy is a consistent problem for SIDS parents. Nevertheless, some parents develop a healthy protective and caring affect towards their other children.

7.2 Physical Issues

In my analysis of the transcripts there were few references to physical effects secondary to the grief process, but they did arise. In this section I describe some of the psychosomatic pain descriptions that parents articulated. This is followed by a discussion of an unanticipated finding poorly described in the literature, the problem of sudden lactation cessation and how it affects SIDS mothers.

Physical symptoms have received less attention in the grief literature than the psychological aspects. Biological responses to grief were described early on by Lindemann (1944):

Sensations of somatic distress occurring in waves lasting from twenty minutes to an hour at a time, a feeling of tightness in the throat, choking with shortness of breath, need for sighing, and an empty feeling in the abdomen, lack of muscular power, and an intense subjective distress described as tension or mental pain (p. 155).

These early descriptions were of historical interest because grief had mostly been viewed as an emotional problem. There are however physiological processes as grief is a holistic phenomenon that affects physical as well as

emotional states. The physical aspects have only more recently been described and investigated in the literature.

Authors have become more specific about issues such as neuroendocrine correlates of bereavement including cortisol level suppression, impaired immunological functioning, and sleep disorders (Hall & Irwin, 2001) issues to which I return in the Discussion Chapter 9. Current researchers are examining health outcomes of bereavement, demonstrating the physiological relationship between known increased mortality associated with bereavement, and specific physiological parameters, thus demonstrating the complex interplay between situational, intrapersonal, interpersonal and coping factors (Stroebe, Schut, & Stroebe, 2007).

Participants did give some physical descriptions of their grief, stating for example:

I often describe grief as someone punching you in the stomach, really hard (Participant 11).

It's almost like something sharp...much bigger than a needle, more like a blade (Participant 1).

One participant (3) who worked as a courier said to me:

I was always on the road and probably for about three months every time I saw an ambulance or a fire I started shaking so bad I would have to pull over.

This reaction might be construed as consistent with a PTSD type of response, a physical response to an emotional stimulus.

One mother described a generalized, total-body reaction:

When I found out what had happened...my whole body wanted to expel. I wanted to puke, I wanted to pee, I wanted to, you know number two...just everything just wanted to come. Like my whole body just like completely shut down pretty much (Participant 17).

Another mother (Participant 19) spoke of “empty arms” which apparently is common among SIDS mothers.

The issue of health outcomes of bereavement is not one I address in this thesis as I have no empirical evidence that anyone was physically adversely affected other than the few indications described above. Nevertheless, there is an emerging body of literature describing the wide-ranging and diverse effects of bereavement on morbidity and mortality which also includes suicide. These data derive largely from widows and widowers who are followed and compared to population norms in order to determine increased problems. Since these samples of mostly older people may not be comparable to SIDS parents, we are left with little evidence, and more questions as to the actual effects of bereavement on health.

In a review article on this subject, Stroebe and her colleagues (Stroebe et al., 2007) found data to support not only an overall increase in mortality as a result of bereavement, but also more nuanced reasons including an increase in alcoholism, which itself increases the risk of higher morbidity and mortality; increased anxiety and stress, again a precursor to physical problems; and other related problems including memory impairment, work and relationship difficulties, and social isolation, all of which increase health care costs.

Results of a large longitudinal study in Denmark where 21,062 parents who had lost a child were followed from 1980 to 1996 did show an overall increased mortality from both natural and unnatural causes in mothers and increased mortality from unnatural causes in fathers (Li, Precht, Mortensen, & Olsen, 2003). A slightly smaller but similar Danish cohort was also used which determined that the death of a child was associated with an increased risk of myocardial infarction in parents, and that this risk was especially high for parents who had lost their infant due to sudden infant death syndrome (Li, Hansen, Mortensen, & Olsen, 2002).

The health effects of bereavement is an area of concern that warrants considerable further investigation.

7.2.1 Lactation Suppression

Of the study participants, four mothers described lactation issues following the death of their nursing infants. I attempted to find more information regarding this phenomenon in the literature.

Women who suddenly lose their nursing infants encounter serious problems with lactation suppression (Kochenour, 1980). In the past, the dopamine receptor agonist bromocriptine mesylate (Parlodel) was used to artificially induce lactation cessation, but concerns about increased risk for cardiovascular and cerebrovascular accidents prompted the manufacturer to remove the drug from the market for this purpose leaving no other pharmaceutical options for women (Rayburn, 1996). There is almost no literature

on the issue of SIDS and lactation suppression, perhaps because there is no longer any pharmaceutical intervention. It is however a widespread problem deserving more investigation.

Spitz and her colleagues (Spitz, Lee, & Peterson, 1998) are quite critical of the lack of awareness and research in this area, as reflected in the subtitle of their article *Little progress in one hundred years*. She writes:

In the United States 2 million women are delivered of live infants each year and do not breast-feed. Our review suggests that despite current nonpharmacologic treatment for lactation suppression up to one third of women may experience severe breast pain post partum. Thus each year hundreds of thousands of women may experience moderate or severe symptoms associated with lactation cessation (pp. 1487-1488).

The problem for SIDS mothers is that the physical pain intensifies the grieving process:

So you have to bind yourself and it hurts, you've got your physical pain, you've got—Oh my God I just want to feed my baby. My arms hurt, my arms hurt and my breasts hurt terrible (Participant 13).

Women help each other with this problem:

I was glad that she was here to kind of help but I do remember being so sore when I came home and thinking oh, OK I don't know what to do now, what do I do with all this milk? And so she was...very helpful and said OK go ahead and pump now but that'll be the last time and let's get you wrapped up and heating pads and stuff. And it took about four days until things sort of levelled off a little. One of those very abrupt things that was...pretty hard (Participant 21).

There are protocols and suggestions for mothers that can be followed which will alleviate some of the physiological and psychological effects. Lactation expert Debra Busta Moore has written about best practices for this group of

women with a clear, one-week overview of what can be done to help phase out milk production efficiently and safely. These measure include a regime of breast pumping, warm showers, ice packs or cabbage leaves and use of ibuprofen for pain relief (Moore & Catlin, 2003).

7.3 Summary of the Findings and Recommendations for Further Research

In this chapter I have outlined the diffuse emotional and behavioural issues that parents experienced and related them to their journey through the process of recovery. These findings pertain to the emerging area of traumatic and emotional memory and how parents are affected by the interplay among these elements. These issues relate to my argument that emotional memory and PTSD include a physical component that extends what is described in the grief literature.

In terms of physical issues I included descriptions given by parents for some of the ways they experienced grief in a somatic manner. There were two components to this. The first includes the distress that parents feel physically which has been under-reported in the literature, usually just with descriptions of the various types of sensations that people have rather than any attempt to articulate why they occur. The second aspect is the relationship between grief and increased morbidity and mortality, something about which even less is known, since only long-term longitudinal studies will give us answers to those types of questions. Somewhere in between these immediate concerns and those

that occur much later we also need a better understanding of the myriad effects of post-traumatic stress disorder and the physical aspects of emotional memory.

These issues are related in a holistic way. Grief impacts humans in multiple ways that we do not yet understand. In the conclusion there is a description of a very under-investigated area of the problem of sudden lactation suppression for women who lose their infants. I have suggested that along with the memory spectrum, there are physiological and physical symptoms which occur during SIDS grief which to date been largely omitted from discussions in the literature.

Chapter 8: Situating Parents' Narratives – Overview of the Literature

As was explained in the Methods Chapter 3 the qualitative approach used consisted of an iterative process whereby research questions were formulated and data collection began. This was not a linear process. During the formulation of my research questions I read widely in the areas covered in the previous chapter. Then, during analysis of my data themes arose which required reading in topics that I had not foreseen but that merged during these interviews that constituted the data collection process. These included memory and issues of resilience as well as strategies parents used to return to a type of normal life again. Reading in these areas helped make sense of some of the themes in these accounts and helped to better understand the research questions that had formulated. These topic areas in the literature are now described.

8.1 The Memory Spectrum, Literature and Context

Through interviews it became apparent that parents were reconstructing events as the narrators of their lives and that they were doing so not only from their personal standpoint as a mother or father of an infant who died, but also at a certain point in time. Those who were middle-aged or elderly spoke more easily about the death than those for whom it had been more recent. The most difficult and wrenching interview occurred with a father who had lost his son just nine

months ago. Along with reconstructing events, memories and narratives were also distinctly positive and negative and I became interested in the separation of the two, the balancing of different types of reconstructed memories, and how that process might change over time.

The death scene was a very difficult area to discuss. Most parents broke down even speaking about this aspect of their child's death, finding their infant cold, blue and lifeless. However, other reconstructions emerged; the way the baby had laughed and acted, the smell, the satisfaction of feeding time and so on. I became interested in how these things were aspects of the same experience, two memory constructions recreated by one individual and somehow intertwined.

I also included dreams, mementos, and reconstructive memories in this category, the latter describing how parents think of their children now. Some described them as always remaining an infant, others developed images of them as older, and a few reconstructed how they might look based on their other children's physical attributes. While it is possible that many parents have dreams about their infants, this was not a category that developed well and I abandoned it. But positive and negative memories became more and more defined as the interviews progressed. As I thought about what was happening and patterns emerged or became evident in my data it appeared that as in the preceding grief process, there was a trajectory emerging. Having a baby is a mostly positive experience, so the descriptions of the infant were warm, happy, satisfying. The SIDS death on the other hand was a highly negative memory. After that, the

memories become fuzzy, unclear, distorted in time, and even lost. I termed this phase dissociative, although that term means different things in different disciplines. I use it to describe a phenomenon whereby people move into a protective phase in order to guard against emotional trauma that cannot be contained. Again, this area was difficult to match to literature, a partial fit. Nevertheless, there are some areas of traumatic stress, memory, dissociation and posttraumatic stress disorder which help organize and make sense of the stories these parents told. The literature is hampered by the difficulty in categorizing trauma and bereavement. For example, posttraumatic stress disorder is present in the Diagnostic and Statistical Manual of the American Psychiatric Association (American Psychiatric Association, 1994) but grief is not mentioned at all. It has been argued that this relationship warrants closer examination and that the fields of trauma and bereavement and the implications for examining where overlap might occur are long overdue (Simpson, 1997).

Parents went through a clear trajectory in the process of having their child die of SIDS. During the interviews the death scene would be described in great detail with astonishing clarity and focus. For example, even decades after the event people describe what was said and who did what with striking recall.

Following this, there was usually some type of inability to recall details, a dissociative phase that involved a sense of loss of time and space. Some parents apologized for their inability to remember events within this time period. Over the course of years in some cases, parents moved back into more normal functioning, appropriate memory recall, and normal interpersonal relationships. I

will describe examples of these later, but to establish some context I offer some explanations from the literature, keeping in mind that in almost all cases the descriptions between what is described in the research literature and the experiences I heard are only a partial fit.

Both traumatic memory and posttraumatic stress disorder involve complicated psychological processes that are highly contested. Traumatic memories are the result of traumatic events and may cause a different type of encoding than more neutral thoughts. When these memories persist over time and involve ongoing problems they can lead to posttraumatic stress disorder, an anxiety disorder with specific diagnostic criteria. The literature is dominated by accounts of abuse in girls and women and combat trauma in (mostly) men resulting in impaired psychological functioning that can be quite serious. One of the problems is that most of the literature is based on repeated trauma, not a single event as is the case here. To further confound any comparisons, the trauma may occur in childhood (abuse) or early adulthood (emotional trauma in combat situations) which manifests itself later, perhaps much later. Again, this is not the case with SIDS parents, who experience trauma as a single event at a particular point in their life.

PTSD descriptions often begin with Freud who referred to repression of traumatic memories as a basic defence (Harre & Lamb, 1983). While this may have led to immediate equilibrium it prevents integration of the problem and a recovery of normal functioning, something that has been termed “shock mastery” (Horowitz, 1999b). Horowitz has this to say:

In PTSD, a cardinal set of symptoms involves intrusive, unbidden repetitions of memory. Such memories can be experienced as re-enactments with pangs of strong negative emotions, and images that have an intensity bordering on perception. Some people react to such intrusions with secondary anxiety to their sense of loss of control (p. 3).

Horowitz (1999) provides an extremely useful model of the phases of response to trauma that appears consistent with my data. He describes it as *usual equilibrium* in which conscious experiences and action patterns feel ordinary. Then, once a stressor event occurs, there is an *outcry* which is a state high in racing ideas and intense emotions, followed by *denial* in which emotions may be numbed, some memories and ideational implications of the stressor event are avoided and coping actions may be blunted, followed by *intrusion* in which intrusive ideas, unbidden images and pangs of intense feeling arise. Later, in a phase he terms *working through*, there is oscillation with both intrusive and omissive experiences with gradual reduction in degree of overmodulated and undermodulated states, ending with *completion* in which conscious experiences and action patterns once again feel ordinary (Horowitz, 1999b).

This does not however entirely explain the intense initial imprint of the negative memory, the recreation of the highly stressful death scene. Recent work by Brunet and his team (Brunet et al., 2008) at McGill University suggests a biological model, a translational model of PTSD based on hormonal modulation which overstimulates hormones. According to Van der Kolk (2007):

Intense stress is accompanied by the release of endogenous, stress-responsive neurohormones, such as the catecholamines (e.g., epinephrine and norepinephrine), serotonin, hormones of the hypothalamic-pituitary-adrenal axis (e.g., cortisol and other

glucocorticoids, vasopressin, oxytocin), and endogenous opioids (p. 222).

While this describes repeated exposure which is not the case here, it does explain the extreme hyperarousal present at the discovery of the SIDS infant and also explains in part parents' ability to recall every detail of this part of their narrative with such clarity. The shock of the event triggers high hormonal output which may result in a strongly imprinted memory.

One participant informed me of work being done using a beta-blocker to diminish the effects of traumatic memory (Participant 15, personal communication, June 20, 2007) which supports this hypothesis (Brunet et al., 2008). This would be a fascinating area for future research, i.e. would SIDS parents benefit from an injection of propranolol which has been shown to diminish the long term effects of trauma? This possibility has caused considerable ethical debate including the area of informed consent, since people in traumatic stress are probably not able to make clear decisions for themselves (Tenenbaum & Reese, 2007). There are also discussions of the morality of helping people forget (Hurley, 2007), in a sense taking the "sting" out of their traumatic memories (Henry, Fishman, & Youngner, 2007). An intriguing question arises about whether or not people must endure the trauma in order to successfully recover or can they revert to Horowitz's "experiences and action patterns that feel ordinary" (Horowitz, 1999b) or perhaps even Freud's notion of suppression, by receiving a pharmacological agent. It is perhaps a question that cannot be answered.

SIDS parents themselves sometimes refer to “flashbulb” memories to describe these horrific and intrusive thoughts. The actual description of the way this term is used tends to refer more towards events where the majority of people remember an event collectively—the example used in the original description was the fact that most people (of my age at least) remember what they were doing when the news of President Kennedy’s assassination was announced (Brown & Kulik, 1977). While this has provided interesting fodder for research on traumatic amnesias, it is not a good fit for the searing intensity of SIDS parents’ recollections of the death incident.

Traumatic memory plays a role. A variation on the dual nature of memories comes from Waites (1997) who describes “two common but seemingly paradoxical posttraumatic symptoms: being unable to remember and being unable to forget” (p. 106). Waites describes a biphasic pattern in PTSD with high levels of anxiety and agitation coupled with emotional constriction and avoidance behaviour (p. 112). Functional magnetic resonance imaging (fMRI) studies show that grief is mediated by a distributed neural network that affects affect processing as well as episodic memory retrieval (Gundel, O’Connor, Littrell, Fort, & Lane, 2003). It may also be the case that anxiety, which might lead to enhanced memory, along with depression, which might lead to an inability to remember, are present simultaneously even though they are processed in separate regions of the brain. In my data, however, the memory issues were sequential, i.e. intense clarity followed by a period of hazy and indistinct recall eventually emerging into a type of normality.

PTSD, traumatic memory, and grief are described in the literature but not as a concurrent state perhaps because it is not a good fit. In other words, where these concepts overlap is seldom explored. There do however seem to be elements of all three present in the reactions experienced by SIDS parents. Key criteria for PTSD as defined by the Diagnostic and Statistical Manual of the American Psychiatric Association, including recurrent distressing dreams, sense of a foreshortened future, and significant impairment in social and occupational areas of functioning (American Psychiatric Association, 1994), were not really present according to my informants. When I asked about dreams, they were in some cases pleasant. Some writers appear to take it for granted that grief and PTSD overlap. Lindemann's seminal paper (Lindemann, 1944) as described earlier, has been included in Mardi J. Horowitz' book *Essential Papers on Posttraumatic Stress Disorder* (Horowitz, 1999a). He justifies its inclusion as an example of "anger turned against the self" (p. 20) but it is not at all clear from the general literature on PTSD that grief should automatically be included and his choice of this article is selective and subjective.

DeVries (1996) described the intersection of traumatic memory and grief does so in a cultural context:

At the death of an important person in one's life, one generally experiences strong emotions and marked changes in behavior patterns. Among these emotions may be feelings labeled as sadness, anger, fear, anxiety, guilt, loneliness, and numbness. Behavior changes may include loss of appetite and weight loss, disruption of work activities, loss of interest, decrease in sociability, disrupted sleep, and disturbing dreams. These feelings and dispositional changes may result from many things, including uncertainty about what to do, loss of gratification, and disruption of familiar living patterns. The problems are greater when the loss is

unexpected, is traumatic, or occurs at times of uncertainty, each of which aggravates the disruption of familiar patterns (p. 404).

Most of these findings (with the exception of disturbing dreams) were consistent with my findings.

Dissociative functions and bereavement have also been examined by Kauffman (1993) who writes:

Contemporary bereavement theory understands that the mourning process is not simply a sequential series of distinct moments. The process is understood to move from denial to affirmation of the fact of a death through intermediate stages, even indefinite intermediate stages, by *combinations* of affirmation and denial. We partially accept and partially deny a death *at the same time*. The stages or phases of the process overlap, so that denial runs into and through the movement toward acceptance or assimilation (p. 32).

Kauffman (1993) suggests that dissociation may be adaptive. Depression may be an affective link to loss which remains intact while the cognitive awareness of the loss is dissociated. People alternate between a dissociative state and an integrative state and also deal with the intrusive memory flashes that produce such anxiety. Certainly in the study sample people seemed to have been in a protective phase after the initial shock of the discovery of their infant.

How grief and PTSD literature will develop will in part depend on when and how complicated grief is introduced into the next version of the Diagnostic and Statistical Manual (DSM) (American Psychiatric Association, 1994). This new and controversial category will encompass (1) a sense of disbelief regarding the death; (2) anger and bitterness over the death; (3) recurrent pangs of painful emotions, with intense yearning and longing for the deceased; and (4) preoccupation with thoughts of the loved one, often including distressing intrusive

thoughts related to the death (Shear, Frank, Houck, & Reynolds, 2005). I return to this in Chapter 9 with a discussion of a case for complicated grief.

This complex debate introduces the idea of grief as pathology, something explored by Stroebe (Stroebe, 2001) who believes that much more input is required by authors in multiple fields to sort out the differences between a difficult but normal trajectory and one that veers into problems requiring treatment. This same theme of waiting for a DSM category to be introduced in order to stimulate research is also explored by Hyer and Brandsma (1999) demonstrating yet again the enormous difficulty in classification of complex human behavioural pathways and the often fine line between what is considered normal coping and what would be termed a pathological complication.

The memories that parents spoke of were not all negative and frightening. Much later in the trajectory, parents told warm stories about their infants, they showed me pictures, and they even laughed about some of the activities they had shared with their now lost children. Framing this positive reconstruction could probably be done in many ways, including a natural resolution and outcome based on resilience. Another reason for describing positive memories is the meaning-making process already described. One way to understand why people eventually speak in positive ways about highly negative events is to understand the process as a re-authoring of life narratives. If, as previously stated, a SIDS death is a disruption in the life narrative, it is also one that parents can repair. This is also something that is done in a social context, so people share these memories (e.g. a book of photographs which several parents showed me) in

ways that intertwine their personal histories with those of others (Barclay & Smith, 1992). Narrative provides a way for adults to tell their stories in ways that are contextual, with coherence and plot; interpretive, not just a collection of facts but rather an embodied account of events with values and purpose; retrospective, a history of what has gone on before; and temporal, since we are always “within time” (Rossiter, 1999). These types of activities are similar to those undertaken by virtually all grieving adults, i.e. the eventual resolution of a loss into a framework where sadness and anguish gives way to a softening of the pain and recall of the pleasant and satisfying memories.

8.2 Coping, Restoration and Psychological Resilience: Literature and Context

The dual-process model mentioned earlier covers two major areas through which people cycle continuously, namely (1) a loss-oriented and a (2) restoration-oriented series of everyday life experiences (Stroebe & Schut, 2001b). As was explained in Chapter 2.2, loss-oriented experiences include grief work, breaking of bonds and ties of the deceased, and issues of denial and avoidance. Restoration activities which comprise doing new things, being distracted from grief and forging new roles and relationships, add a more nuanced and expanded view of the recovery process which has traditionally focused on grief as a highly negative state, perhaps even pathological. The people in my study, having experienced one of the most devastating losses imaginable, did actually recover. They told me so and they also explained to me how they accomplished this. Of course, one might argue that those people that

ended up agreeing to be interviewed were also those who were able to explain how they had dealt with things. Those people who had not dealt with their loss would not come forward and thus this study could be criticized as having a sampling bias. This may be the case. Nevertheless, restoration activities and in particular the nature of resilience, became pertinent as an emerging area of inquiry. The experiences of those who had accomplished this restoration provided an excellent opportunity to study the resilience and restoration processes. The area was also of interest because I had found so little in the literature that alluded to this aspect of recovery, i.e. the studies in my review from professionals including nurses, physicians and allied health care workers never mentioned this area. It would appear to me that if one were to plan intervention programs for SIDS parents that an important strategy would be to build on this resiliency that parents have.

Restoration activities consisted of things like developing new empathy for other parents, particularly those who had also lost children. Parents learned to share their experiences and reach out towards others in ways that helped them to cope and to mature. Other parents learned to write journals, to create scrapbooks, or build websites as another form of social communication. In this way they helped themselves and others at the same time. Parents thus did not stay in one place over time; they learned how to move forward, move back into relationships with partners, children, family and friends, colleagues, co-workers. They returned to society and interacted with the general public. They gained new insights into themselves using rituals and social customs to reassure themselves

and come to terms with their new lives. Before describing some of these areas, it is appropriate to speak briefly about new research in the area of resilience.

Bonanno (2001b) states that despite the ubiquitous nature of grief, theorists have focused on a very narrow range of loss experiences, primarily psychiatric and clinical perspectives. This emphasis on grief as chronic or pathological has been overgeneralized to all individuals. This has then led others to examine a much broader range of issues inherent in the process with many challenges to traditional assumptions.

Bonanno argues that traditional “grief work” is far from a clear trajectory through a painful, difficult time towards some type of resolution. There is simply no empirical evidence that humans fit within this over-simplified model. Emotional dissociation may be adaptive (and common and normal), positive interactions can and do occur, laughter happens and has interpersonal benefits (Bonanno, 2001a). In other words, the news is not all grim.

How might one conceptualize these somewhat good news sounding stories with our general view of grief as a pervasively sad state of affairs? Again, Bonanno (2004) gives some insights. He argues that resilience is different from recovery:

The term *recovery* connotes a trajectory in which normal functioning temporarily gives way to threshold or subthreshold psychopathology (e.g., symptoms of depression or posttraumatic stress disorder [PTSD]), usually for a period of at least several months, and then gradually returns to pre-event levels...By contrast, *resilience* reflects the ability to maintain a stable equilibrium (p. 20).

It could be argued that the parents I spoke with hardly maintained a “stable equilibrium” particularly in the early period following the SIDS event, but neither did most of them drift into pathological functioning (there was at least one exception which I mentioned in the findings, the mother who stayed in bed for eight months). The problem perhaps has been that the grief literature is dominated by pathological models and in particular references that overlap with PTSD. As I argued earlier, there is a *partial* fit with some aspects and while it may provide a useful model for *some* aspects of the behaviours, it does not give a complete picture. Bonanno (2004) argues that the assumption of the grief process frequently overlapping into PTSD is simply untrue. In reality, resilience is common. It must be kept in mind that Bonanno is speaking about grief in general and I am arguing that SIDS represents a different type of grief with a different type of process.

The issue is that those experiencing a relatively smooth transition back towards normalcy have been labelled as suffering from “absent,” “prolonged,” or “delayed” grief. The reality, according to Bonanno, is that there are “multiple and sometimes unexpected pathways to resilience” (Bonanno, 2004, p. 25) and that many people show traits of hardiness, self-enhancement, and benefit and use positive emotions including laughter. He states:

Different aspects of a person’s worldview may be more or less functional in relation to the painful reality of the loss. In other words, some people may hold worldviews that would be more easily shattered by the death of a loved one which thereby predisposes them to grieve more severely. Others may hold more resilient worldviews that could more readily assimilate the death of a loved one, thereby obviating the need for more elaborate cognitive

restructuring of different aspects of the self (Bonanno, Papa, & O'Neill, 2002, p.193).

There was actually tremendous variation in the way parents spoke to me about their loss. While some were clearly pained and cried during portions of the interview, others were more matter-of-fact and showed little or no distress when recounting all the details. It should be noted, however, that in cases where the infant had died in the care of someone else, parents were sometimes more comfortable and less overtly emotional about telling their story. This is consistent with my thoughts on the hormonal and hyper-aroused state that is initiated with parents finding their infant dead. Those who did not themselves find their child dead may not have undergone this phase.

Personality characteristics are also a factor in successful coping. Some people learn early in life to be more self-reliant, to take charge of themselves in times of crisis, to benefit from ingrained hardiness and resilience, and to stay optimistic throughout any life event. Others may show versatility and creativity in the face of even extreme adverse events (Tedeschi & Calhoun, 1995).

8.3 Summary

This section offers a review of literature in two broad areas—memory and emotional resilience—that emerged as the interviews were being transcribed and coded. The first area deals with the spectrum of memory, those reconstructions that parents used to tell their stories. These were not areas that I read in the literature from professionals as outlined in the literature review on grief and SIDS.

It was however an area that I heard distinctly in the narratives as I spoke with parents. As such it represented a departure from what has been written.

The second area is the newly emerging field of emotional resilience which offers insights into how people reconstruct their lives after traumatic loss and how they help themselves heal, again an area that I had not seen in writings by and for health care professionals. Since so much of that professional literature attempts to understand the processes of the SIDS experience in an effort to design appropriate interventions, I believe that this component is an important building block in helping parents to help themselves by using their natural and innate resources.

The following discussion returns to the findings with references back to the various literatures.

Chapter 9: Discussion

In this section I will extend and discuss the findings, offering additional information about the constructs, referring both to the literature and to the empirical findings to further my arguments. Included are sections on the grieving process, memory issues, the newer concepts of coping and resilience, sources of support and stressors that parents experienced. I include briefly a case for the emerging category of complicated grief and close with a discussion of those areas that appear to warrant further research.

9.1 The Grieving Process

The extensive literature on grief that has evolved in the past few decades tells us much about this complex human phenomenon, but it fails to address all of the specific issues faced by SIDS parents. As I have argued, there appears to be a somewhat different process going on, something more than what is told us in the literature. SIDS grief is not simply more profound and longer-lasting than that experienced when for example an aging parent dies. It is in some ways a different phenomenon. Authors who have written specifically about SIDS and/or infant or child loss begin the process of addressing some of these phenomena, but do not complete the picture. The accounts from the study parents appeared to go beyond what has been described in the literature.

The death of a child does seem to lead to more intense loss than that of a spouse or parent. Additionally, parents are more anxious when this type of loss occurs, as they make more of an attempt to maintain connections with the lost child, and the length of time for placing the death into perspective takes longer, at least three to four years (Genevro, Marshall, & Miller, 2004). These findings are consistent with what I heard in the narratives from the parents I interviewed. It does not however address the issue of why this might be the case and we are left to continue to speculate.

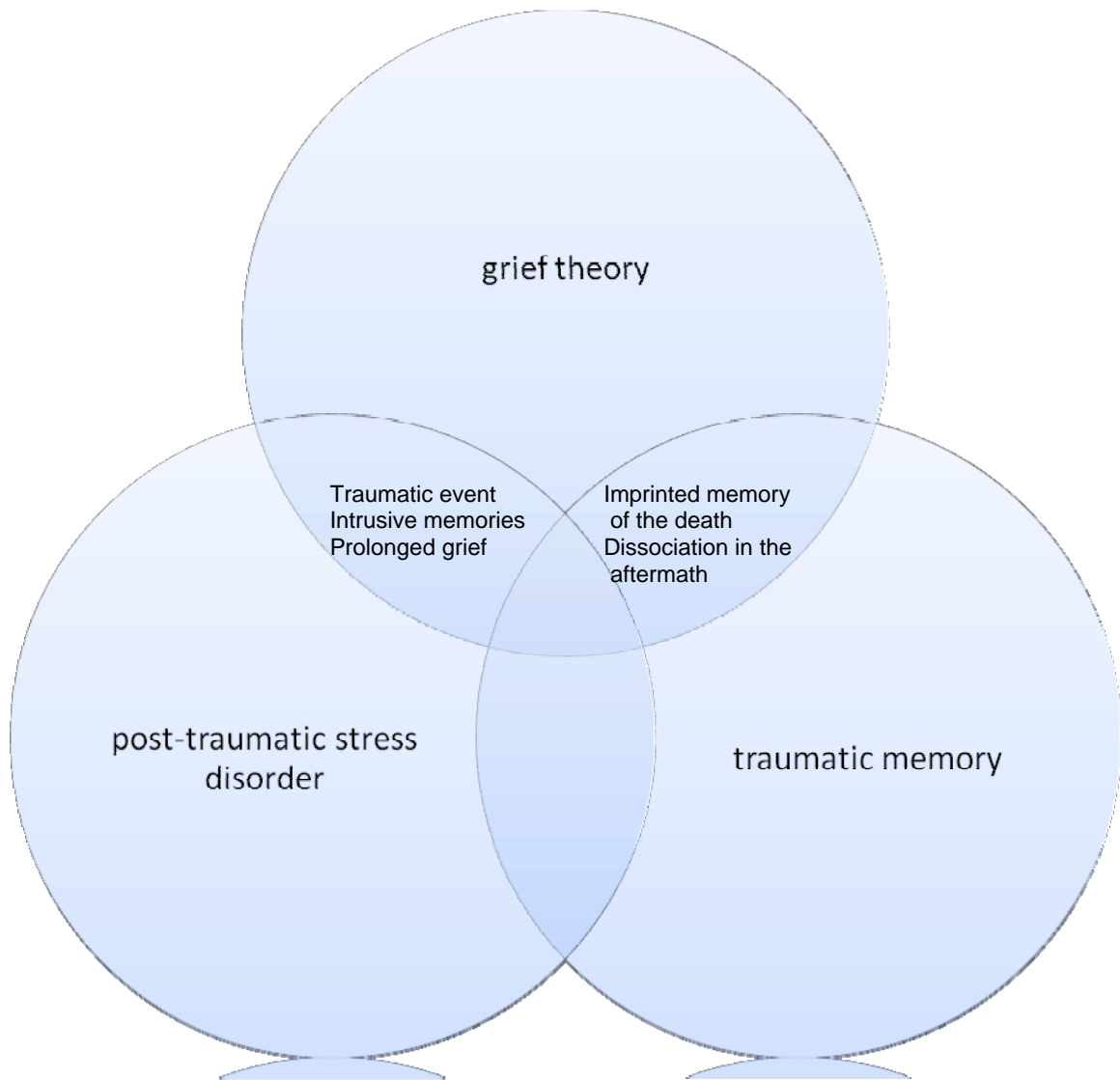
Parents themselves confirmed that their infant's death was not in the same category as the loss of someone who had lived their natural life and had died in old age. When asked whether this was a different type of grief reaction, parents said yes, this was a different experience. Part of it seemed to be the natural order of things (people become old and eventually we all die) and part of it appeared to be that even when someone dies an earlier death, there is usually a rationale, e.g. someone lived a lifestyle that predisposed him to early disease and death or drove unsafely which led to an accident. Once again we have the disruptive and irrational nature of a SIDS death.

Grief, loss and mourning are usually framed as an emotional construct with behaviours that lead to recovery. There is also a psychobiological component that may be important in the case of these parents. Furthermore, there is no biological continuation as parents understand they will have no replication of themselves either in the form of a child growing up or of eventually becoming grandparents through that child. This is not simply painful but may be

disorganizing and confusing (Rando, 1986). This may be the case for any parent losing a child at any age.

What was striking in my narratives was that there seemed to be no complete resolution of this disruption even many years later. Parents were able to conjure up the relationship with all of its emotional components, the sadness and despair, the cherished intimate details of the relationship with the baby, decades after the death had occurred. They did so within the space of the interview, moving into that private relationship and sharing it with me, and then moving out of it again once the interview was completed. There appears to be something that becomes triggered, even decades later, that initiates an emotional and even physical response whereby parents return to their grief-stricken state. Many of the issues of grief, memory, and trauma are thus interrelated. One way to examine this triad is through my initial argument, that elements of grief, PTSD, and traumatic memory all play a role (see Figure 9.1).

Figure 9.1: Areas of Influence in a SIDS Death



The three thematic areas may converge, coming together to form part of the entire range of experience for these parents. It is at the convergence of these concepts that parents' experiences are best understood.

If one assumes that what parents undergo in a SIDS loss is a normal grieving process for them under the circumstances, and not a prolonged variation on what happens to people in other circumstances of loss, then the starting point for understanding the process shifts. Future researchers might consider the fact that these parents are not undergoing a variation on a theme (i.e. grief that is more intense and lasts longer than usual), but a somewhat different process. This would explain why the research appears lacking and inconsistent with what parents themselves are articulating, and why they sometimes appeared confused when I suggested how this was different from other types of losses they had encountered. For the study parents it was a different phenomenon.

Also not described in the literature but apparent during the interviews was the way in which parents moved into a deeper state of grief and sadness during descriptions of the loss of their infant even though this had occurred a decade or more previously. It appears that some form of emotional memory is reactivated much in the same way that a scent or sound elicits a remembrance of something past. How this reactivation occurs and what processes underlie the phenomenon remain areas for investigation.

When one considers the traumatic nature of the event and the relationship to PTSD and emotional trauma and perhaps stress, some aspects of the trajectory these parents described become clearer. It is to this discussion of memory that I now turn.

9.2 The Spectrum of Memory

The trajectory that was described in relation to parents' memories, both positive and negative, is a partial fit with the literature, partly because that body of work is itself still being developed in relation to grief. As mentioned, the literature on posttraumatic stress disorder derives from what used to be termed "shell shock" and now is more commonly known as combat or war neurosis or a variation thereof. This origin in the battlefield, describing primarily male responses with trauma repeated over time in a foreign geographical and cultural landscape is the first part of the problem, as concepts are transferred into a grief literature where the event is close to home and happens once only. Furthermore, the entire concept of PTSD remains contested in spite of its inclusion into the Diagnostic and Statistical Manual of the American Psychiatric Association (American Psychiatric Association, 1994). Brewin (2003) questions whether PTSD is a "discovery" or an "invention" and alludes to the paradoxical problem, discussed earlier, of memory that is more intense and also repressed. Researchers are attempting to unravel this issue. It does appear that actual physical responses occur in the brain, and perhaps even structural physical changes within subsections such as the amygdala. It is known for example that trauma results in a re-experiencing of events, as well as emotional numbing, and persistent hyperarousal (Bower & Silvers, 1998).

Analogous to PTSD, traumatic memory has developed as a literature that is based primarily on the experiences of women who were sexually abused as children. Again this represents a population that suffered repeated trauma, early

on in life and occurs primarily in women. This too is a problematic base from which to make comparisons with adults who suffer the loss of their child.

Nevertheless, there are some places where literature fits the data. Both bodies of work (PTSD and traumatic memory) have expanded considerably to include areas well beyond their original focus of combat and incest and sexual abuse survivors. There are however still issues with extrapolations made from studies done with end-of-life deaths and the resulting grief.

When PTSD and grief overlap in the literature it is often in discussions of prolonged or complicated grief and the justifications for creating a new category for the next version of the DSM (Lichtenthal, Cruess, & Prigerson, 2004). The problem then becomes that SIDS parents become categorized as pathological based on a normal grief trajectory, rather than having their own unique path through the process, one that difficult though it may be, is surmountable and not abnormal.

For SIDS parents there do seem to be elements of grief, PTSD, and emotional memory, with perhaps a common denominator of emotion playing an important role. As was previously discussed, emotion can be distinguished from grief, but is also intertwined. This does not make SIDS grief unique, but does add elements from these other literatures to it.

The complex puzzle that involves the relationship of emotional memory and PTSD has been described more than theorized. But of interest is the aspect of reliving the experience and moving back into that emotional space during the time that one is describing events which may or may not occur. There are two

scenarios that have been described in this context, both of which I encountered during the interviews. In the first case, the event is relived; in the second, it is recounted (Brewin, 2003). I found that parents told the most painful parts of their stories in one of these two ways. In the first, they entered the emotional space of the time and event, they began to cry, their faces contorted with pain, their voices cracked with emotion. In the second scenario, parents went through the details of the death in a much more matter-of-fact way and in one case recited it as if from a script, rapidly moving through the events with little emotion at all. In the former, the event became alive with emotion during the retelling of it (and then dissipated when that portion of the story was complete); in the second, the events were told as if the narrator was a dispassionate third-party observer commenting on her own life story, an actor recreating the role, entering into it, but not losing emotional control. One mother said in a very quiet voice:

I walked in the room and immediately knew there was something wrong. It just was quiet...deathly quiet...There was no life in that room. I just knew right away that there was something wrong. So then I remember going up to [my son] and...picking him up...and then...I froze, you kind of freeze. And actually what I did is I...is I laid him back down thinking in my head sort of....let's try this again (Participant 11).

On the other hand, another mother spoke rapidly and in a flat voice with no emotion:

And when I went in the room, he was on his stomach which was normal because he was five and a half months so he was rolling. So I wasn't surprised to see him on his stomach, I thought that was normal, but when I touched him he didn't respond and when I flipped him over, his face was completely blue and all around the lips and he wasn't breathing (Participant 6).

Both of these possibilities were surprising to me at times. In some cases I was taken aback by the intensity of the parental response, problematic at times because as a counsellor I wanted to intervene but as a researcher could not do so. At other times, I was curious about the objective nature of the storytelling, as if the parent was speaking of someone else's child. This is not to say that these parents did not at one time relive the experience with the same emotional intensity. What is much more likely is that their story has shifted focus.

Brewin (2003) writes:

Each time they are recalled, people automatically create a new memory for that act of remembering to add to the original memory. If during each act of remembering certain parts of the memory receive a lot of attention and other parts are ignored, the ignored parts will become harder and harder to retrieve and the contents of the available memories will gradually change (p. 99).

I speculate that perhaps those parents who had attended self-help groups where they recounted their story over and over were able to speak more easily about it to me, but this was not the case. The reality is more complex. Some people appear to relive the event each and every time it is recalled, complete with emotional context. This is an area that deserves much more investigation.

The areas of PTSD, emotional and traumatic memory, and grief theory represent literatures that all contribute to an understanding of the experience of SIDS parents. It is beyond the scope of this thesis, and well beyond my own training and competence, to explore the emotional and biological factors. These include concepts of neural plasticity, stress-induced neurochemical responses,

and biological and even molecular activities that lead to behavioural responses that can be measured or imaged. I believe that future directions will implicate biological processes and clarify their role in inducing and modulating emotional responses both immediately after a death, and in the long term as parents recover. This will assist not only in better understanding but also hopefully, will help in determining who requires professional intervention and what form that might take.

An area for further research involves the stages through which parents move, stages that are different from those described in the grief literature. In my work I began by sifting through the various types of memory reconstructions that I heard. These ranged from highly traumatic to unclear, something I termed dissociative. Additionally, there were pleasant memories both before and after the death, and reconstructed elements, how the infant or child might be now in the present. In reconstructing these elements a trajectory emerged. Parents were happy and busy with the baby and then shocked and traumatized by the death. Following this there was a long, slow recovery period and eventually an incorporation of the infant into the family structure, obviously with a role that was different from living children. How people move through these various stages and what happens to them at each point in time is a topic that would make an interesting longitudinal research initiative. Also still poorly understood is how people move from something so profoundly horrific into a normally functioning—albeit forever altered—state once again, indicating that resiliency may be more common than was previously assumed.

9.3 Coping and Resilience

In my original research questions I wished to examine areas of loss and decided to choose a population that had undergone an extreme instance. I asked how families restore meaning during this period of extreme stress and how they reconstruct their lives and resolve issues following this sudden, catastrophic and irrational loss. What was in some ways surprising was that in most cases, people had successfully worked through this personal catastrophe and come out whole, functioning well, and apparently even happy once again. They were altered and different, but their lives were on track again. Of course this statement requires the caveat that I mentioned earlier, namely that those people who chose to speak with me were also the ones who realized they could do so and were by definition more resolved in the issues than others who were unable to speak with me at all. For example, as I mentioned in the Methods Chapter 3, two participants agreed to meet with me and then did not show up, perhaps because they felt unable to follow through on a discussion of what had happened to them.

The literature on resilience grows out of a physical analogue. Just as people who are diseased, traumatized, or even chronically ill tend to get better on their own or with minimal medical assistance, so too those who are psychologically scarred often gravitate towards more stable, healthy functioning. This literature is optimistic and even reassuring. It implies that humans can grow through trauma, that hardiness, self-control, and coping can be achieved. People are able to draw on others, on their personal resources, their beliefs, and the

meaning they ascribe to life events to resolve this most difficult of life's challenges.

The concept of how people cope, what sources of support they choose and how they do so, which meaning constructions they create, and how religion plays a part in their lives are all things that are poorly understood. It would be helpful if we could undertake an objective assessment of SIDS parents based on all these factors and then plan for an appropriate intervention (or conversely, when to leave people alone) but humans are far too complex for that and our understanding of grief is still too limited.

Perhaps the large literature on grief that has emerged in the past decades is too clinical, too focused on the problems that people have, the areas where they become stuck, the negative encounters of dealing with death and dying. It should also be remembered that seminal theorists in the field were physicians—psychoanalysts and psychiatrists—but since then research has been produced by psychologists, nurses, and social workers. These people all wear a clinical hat and may bring a certain pathological perspective to what may after all be a normal human process—difficult, painful, time-consuming, but essentially resolvable. Part of the problem of examining a SIDS death is that we ourselves may view it as overwhelmingly tragic, something that should not have happened, a permanent and ongoing life issue. Bonnano (2001b) who argues in favour of resiliency, suggests that:

A shift in perspective from the pathological to the normal patterns of grieving raises myriad important research questions: If grief is a normal process, why do we grieve? How do people naturally get

over their grief? What happens when people grieve? Do people actually resolve a loss? Or are we transformed by the process? If so, what changes when we mourn a loss? Why do some people show little or no grief? Why do some people show extreme forms of grief? How can these people be helped (p. 720)?

Not only did SIDS parents get over the loss of their child, but in some instances they even made sense of it. They incorporated meaning into the process, they developed new insights into themselves, a newfound admiration and love for their other children and remaining family members. They even appreciated that they had incorporated the lost child into the existing family, an “angel” that was always present, whose birthday and death anniversary was remembered and celebrated, and who occupied a special role, sometimes even as guardian.

Issues of resilience mean that the research question and the approach to it might be inverted. Rather than seeing SIDS as a catastrophic loss requiring Herculean effort to overcome, perhaps ordinary people rise to the difficult task of whatever is placed in their path and move on with their lives and moving across a “barren landscape.” Furthermore, they do so in individual and creative ways. Rather than view these parents as heroes (I am frequently told by other parents that they don’t think they could handle this type of death if it were to happen to them) perhaps it is more of a case of ordinary people rising to an extraordinary, harrowing challenge. It is a process that once begun, must of necessity unfold. Bonnano (2002) writes:

The traditional emphasis in bereavement theory on the working through of the pain of loss in the service of severing the attachment bond with the deceased suggests a view of the self as a functional

but static entity. The loss of an important person in one's life creates a dysfunctional, fragmented self that must be revised and updated before normal functioning can resume (p. 196).

Some parents did think of themselves as different people now, living a "new normal" type of life, to use a term that SIDS parents sometimes articulate.

The issue of resilience does not diminish the pain or difficulty of the grieving process. According to Bonanno (2004) people may struggle to maintain normal functioning but they are generally able to continue their lives; secondly, most people will overcome their problems associated with loss; and finally, and perhaps most importantly, there are several ways for resilience to manifest itself.

Resilience ties in with the many ways people choose to help themselves, find support, and manage their lives. It was also the case in the way people rejected those avenues that they perceived as unhelpful. So for example, parents were very specific in telling me who they wanted nearby for help and comfort and when they wanted to be alone. They rarely appeared confused or uncertain about what helped them in this regard and how. Additional research is needed in this area in order to determine how and why some (most?) people overcome problems by themselves or with minimal intervention, for example a brief therapy series of 10 sessions. Bonanno (2004) writes:

It is imperative that future investigations of loss and trauma include more detailed study of the full range of possible outcomes; simply put, dysfunction cannot be fully understood without a deeper understanding of health and resilience. By viewing resilient functioning through the same empirical lens as chronic forms of dysfunction and more time-limited recovery patterns, researchers will be able to examine and contrast each of these patterns (p. 27).

An interesting avenue of research would be a much more holistic approach. Just as I have argued that grief and mourning have an important physiological component, similarly becoming healthy and whole again also involves processes that incorporate both physical and psychological components. Lindemann (1944) was very clear in his early descriptions of the immediate physical symptomatology of grief, something that has been well described in the later literature as well (see for example Rando, 1986). What is much less clear are the long-term health effects and the processes by which people help themselves in ways that affect them in every sphere. I believe research will continue to uncover the multi-faceted relationships of healing which are currently artificially divided into psychological and physiological dimensions. We also need to better understand how others help in this process through emotional support, something that was important to everyone with whom I spoke.

9.4 The Support Spectrum

The literature on grief has undergone considerable theoretical diversification with no one discipline or theoretical paradigm currently dominant (Genevro et al., 2004). This range of theory with multiple points of view also influences approaches and intervention, the broad subject umbrella for psychosocial support. There are numerous issues in the area, i.e. what works for whom, under what circumstances, at what point in the grief trajectory, and so on. Intervention for parents bereaved by SIDS could have been a separate study and the literature on provision of care by health care professionals is also developing rapidly, sometimes separately, and sometimes integrated with theory. As was

mentioned in the literature review, articles on how to help parents written by health professionals usually reiterate what is currently known and understood about SIDS, parental and family member reactions, and possible complications. This then forms the basis for suggested interventions and ways to help these family members through the process. Unfortunately, there are many redundancies in such an approach and an oversimplification that gives professionals the message that the grief is more severe and the intervention must be more intense.

As was noted earlier, parents relied on many ways to help themselves, using family, friends, professionals, and even pets as sources of comfort and psychosocial support. They spoke with people either individually or in groups such as those sponsored by SIDS organizations. They went online to contact others, they made scrapbooks, they built memorial web sites. In some cases they prayed, looked up at the night sky and imagined their son or daughter as an angel, spoke with their lost infants, and in one case even continued the bed-time story ritual, at least temporarily. Some became peer support workers, helping others which in turn helped them as they learned that they had skills and strengths that could be mobilized in this type of volunteer effort. Others taught professionals, for example nursing students, giving a first person account and providing a real flesh and blood perspective.

Not all strategies were positive. A few parents spoke of spouses drinking heavily, others withdrew into themselves (and as was mentioned in one case even into her bedroom for eight months), and one contemplated legal action

against a medical system that he perceived had failed him and his son. Others decided they had had enough with God, whom they perceived as unjust and vengeful.

There was no single source that worked for everyone; people made their own choices about what they thought would work. What was striking however was that the choices were individual. To reiterate my earlier criticism of literature that deals with “parents” as a single entity, I found no evidence that husband and wife acted as a unit, doing the same thing at the same time with the same results. What was far more likely was that individual parents did individual things in their own sphere, in their own time frame and that this then allowed them to rejoin each other within the relationship in a more positive and forward-looking manner. When asked what worked for them, parents gave decisive answers. While multiple sources of support were the norm, there was always one person in their lives who pulled them through and offered some type of relationship framework that helped.

In Canada, one of the most effective means for helping parents is provided through the Canadian Foundation for the Study of Infant Deaths with its peer support program. Parents can make an initial contact, receive verbal and written information about SIDS, and be placed in touch with a local SIDS parent who offers help and support. They may also be able to join a local group where those are available. Whenever possible, parents are matched by age, something that parents have indicated is important to them. Once parents have gone through the process of working with a peer support worker they sometimes

choose to become one themselves. As was mentioned in the findings, parents develop a new empathy for other SIDS parents through the process of becoming a peer support worker themselves. Some find it helpful to then reach out and help others which gives them a sense of purpose and usefulness as well as staying in touch with a community that has SIDS as its common denominator. Parents who choose to become SIDS peer support workers are also given training and provided with resources by CFSID. These programs have been in place for several decades and are cost-effective as well as useful. Many areas throughout the world offer similar models.

One area that was striking in my findings and somewhat overlooked in the professional literature is the role of friends as support. While it may seem obvious—after all we turn to friends for multiple problems in life—for SIDS parents this may represent a very important type of help. Parents of parents are themselves grieving, not only for their lost grandchild but also for their children. SIDS parents are highly conscious of this and while support from one's parents is available it also appears to be a burden to reach for it. Coupled with this are the many inherent difficulties in a parent-child relationship which may complicate matters. In-laws add yet another layer of potential tension. Children require care which may be therapeutic but not an appropriate source of comfort through dialogue. Friends, outside of these dynamics, might be a crucial way to talk about what has happened, or as was pointed out in the narratives of some parents, an important ally who did nothing more than offer herself and her presence as comfort. This “being with” someone is an important component of psychotherapy

whereby one pays someone to devote their entire attention to one's own problems and concerns. How friends do something similar for SIDS parents warrants further attention.

Issues of resilience and support represent a more positive and healthy trajectory through grief. Nevertheless, SIDS parents experience important stressors as well.

9.5 Social Stressors

The literature on specific problems that SIDS parents encounter in relation to their type of loss is fleeting and cursory. Parents themselves not only spoke of these types of problematic interactions but smiled ironically when I mentioned them. It was as if SIDS parents themselves have experienced many of these trite, pat and thoughtless comments such as "it was meant to be" but researchers have not quite known how to incorporate or conceptualize them as problems. We know that people say thoughtless things, but the underlying motivations are elusive. SIDS parents take these interactions very seriously and in some cases develop a cynical attitude towards people's inability to empathize properly. For whatever reason, there is no discussion of the role of these comments in the literature in spite of the fact that SIDS parents can produce a list of them. Conversely, little has been said about the positive and empathetic community response that the death of an infant can elicit. This is gratifying for parents, as is the display of emotions they sometimes saw in health care professionals. Parents never viewed these episodes of physicians, nurses, social workers, and even police officers crying as unprofessional, but were moved by the human

display of empathy. Once again, parents told me stories that I had not read in any of the literature.

The death of one's child is a personal experience that must eventually be resolved at a personal level. But it quickly moves into a relationship issue where sources of support as well as sources of tension must be negotiated with one's partner and also with one's other children. There are also extended family members that invariably come into the mix, particularly parents and in-laws. Finally, social situations must be negotiated as people move into the community, go back to work, and resume their roles in society.

Parents were consistently surprised and gratified by the number of people who showed up at the memorial service and the way people supported them during this initial bereavement period. Then they encountered problems afterwards. There appears to be an ambivalent message sent about what the experience of losing a child is like. Klass (1996) writes:

A mother whose child was born with a defective heart and died a few weeks later wrote in a newsletter about how differently her community responded to the news of her pregnancy than to the news of her child's death. When she was expecting, everyone told her that this was the most blessed of life's events and that her baby was a new person, a unique individual, different from anyone else. She was told that this new person would change her life forever.

And yet when this most blessed and unique person dies, everybody acts like it's nothing: "Oh well, better luck next time"; "It's better he died before you got to know him", "You'll have more babies."...So parents who lose a baby will generally try to hide their feelings of grief from others for fear of ridicule, disapproval, or stern lectures about how lucky they are—to have other children or the ability to have new (and obviously improved) babies (p. 203).

Public concern for the welfare of children is a fairly recent phenomenon. For centuries, children were little adults, not treated in any special way and not necessarily considered precious lives, at least not by society. But according to Zelizer (1985), in the late nineteenth and early twentieth century children became sacred, their death a sacrifice worthy not only of private but of public sorrow.

Zelizer writes:

What explains the surge of private and public concern with child life and child death? What inspired the nineteenth-century cult of child mourning and the twentieth-century campaign for child life? Based on a "rational investment" hypothesis, some historians suggest that demography regulates sentiment. According to this view, traditional indifference or resignation to child death was a logical psychological response to high mortality rates. David Stannard estimates that in seventeenth- and early eighteenth-century New England, a young married couple could anticipate the probable death of two or three of their children before they reached the age of ten. He suggests that the emotional restraint of Puritan parents may have been "an intuitive response to this possibility, a means of insulating themselves...against the shock that the death of a child might bring." From this perspective, children were mourned more deeply only after they became safer emotional investments by living longer (p. 30).

It is possible that we have still not moved beyond this societal sense that infants are not yet real people, that their untimely death represents some kind of mistake, a birth that should never have happened, a call back to wherever they came from. Parents do not hold this view at all. Their experience is completely at variance with this social perspective. They value the brief period that the infant was with them, they treasure the life that existed, no matter how momentarily, and they develop a new respect for the fine, mysterious line between life and death that is usually underestimated by most people.

Implicit in many of the comments people received and the way others avoided dealing with the death of the infant was a sense of fear. People are frightened by sudden death:

In daily existence there is an expectation that the world we inhabit is regulated, controllable, that we have responsibilities and choices, that life is ordered and framed by birth, and death, the latter coming at the end of a long life and by 'natural' means. In contradiction to these expectations, sudden death strikes in various guises and, like the Grim Reaper of the medieval woodcuts, randomly claims young and old, male and female, wealthy and poor (Howarth, 2007, pp. 155-156).

Ironically, parents sometimes tended to overcome these awkward social interactions by guiding others through the process, helping them to understand that it was all right to talk about the death of the infant, explaining perhaps that they were still having tremendous problems but were seeking help for them, or perhaps reassuring others that they were ready and able to discuss even painful aspects of the infant's death.

The complex healing trajectory and the place of society in the process is a microcosm of the relationship society has always had towards children. Moreover, the role and place of children at different ages and stages from helpless infant to productive young adult is also something that has varied through time and place and will continue to evolve and change. What is perhaps unclear even now is our ambivalence towards infants. They promise potential as humans but are still totally dependent. They are born to young families who can continue to have more children. There remains however a tension between societal views and expectations of an infant's development and the meaning that

that same infant has for parents. The nature of that disparity could be explored within the context of changes in family structures, the changing nature of parenthood, and the role that children play in an ever-changing social landscape.

9.6 A Case for Complicated Grief

The major themes in this thesis are interrelated and represent my own attempt at summarizing areas that are as interlocked as pieces of a puzzle. One way in which some of these issues are being categorized, described and researched is the emerging area of complicated grief. This is not an area I examined but one that may synthesize some aspects in ways I proposed earlier.

Complicated grief is a diagnostic category proposed for the next version of *The Diagnostic and Statistical Manual of the American Psychiatric Association* (American Psychiatric Association, 1994). There is a large literature dealing with contested issues of grief in which it is argued that some forms are quantitatively and qualitatively different, more pathological (specifically more traumatic), more difficult for the person to resolve independently, and representing models that are substantively different from that of PTSD (Boelen, van der Hout, & van den Bout, 2006; Lichtenthal et al., 2004; Neimeyer, 2005a; Neimeyer, 2005b; Neimeyer, 2006). This debate is being supported with empirical evidence showing statistically significant differences from symptoms of anxiety and depression, although findings are preliminary (Bonanno et al., 2007).

Related to my work are the similarities and differences between complicated grief and PTSD. Shear and her colleagues (2005) found that both

are triggered by a traumatic event with subsequent feelings of shock, helplessness, intrusive images, and avoidance behaviours. On the other hand there are differences in that PTSD is triggered by a physical threat and leads to fear as the primary emotion, whereas complicated grief is triggered by loss and has sadness as its primary emotion. Nightmares are common in PTSD and uncommon in complicated grief. In PTSD there are painful reminders linked to the traumatic event whereas in complicated grief the painful reminders are more pervasive and unexpected and there is yearning and longing for the person who died along with pleasurable reveries (p. 2602).

As I have argued throughout this thesis, the evidence for problems associated with grief comes largely from widows and widowers, a population that is different from SIDS parents. People who are older and have spent a lifetime together encounter problems that may be somewhat different from SIDS parents who are younger and lose an infant that they have known only a short time. The trauma, grief and potential for long-term grief may exist for everyone, but the populations are different. Some of this preliminary work in determining complicated grief as a diagnostic category might help in an understanding of what SIDS parents experience. Of interest to me and the findings I present here is that this ongoing discussion will help synthesize some areas that have not been brought together. Although parents will not automatically fall into the diagnostic category of complicated grief, by examining those people whose experience is different—including SIDS parents—a better understanding of their responses and personal journey will emerge.

9.7 Summary of the Findings

This section has outlined the five major thematic areas: the grieving process, the spectrum of memory which parents drew on in order to reconstruct their narratives, the coping and resilience features of their experiences, the ways in which they sought and found sources of psychological and emotional support, and the social stressors and personal losses they encountered as they interacted with society. I closed with some thoughts on the emerging category of complicated grief. The literature on this topic may help provide some insights into the experience that SIDS parents undergo. I conclude the discussion section with thoughts on those areas that I felt warranted further research.

9.8 Discussion of the Findings and Recommendations for Further Research

Two themes addressed here—the emotional trajectory and the physical issues surrounding grief—warrant further research. I include also a brief overview of the problem of lactation suppression which has implications far beyond the experience of SIDS mothers.

9.8.1 Emotion and Grief

It might be argued that this entire dissertation is about emotion and it is certainly a pervasive construct flowing through the entire work. Nevertheless there are some aspects that are distinct for SIDS parents. No category in my analysis produced as large a number of constructs with as much variability as the affect section. I recorded negative emotions including guilt, resentment, anger, shock, denial, yearning and panic along with more positive feelings of personal

strength, hope and even humour. As mentioned earlier, emotion is different from grief. Emotions are ephemeral, grief is enduring; emotions constitute multiple forms throughout an ongoing and prolonged period of grief; emotions are linked to simple and proximal appraisals of danger or coping potential whereas grieving produces more profound meaning understandings; and emotion and grief elicit different types of coping responses, the former more short term (Bonanno, 2001a).

Part of the problem of separating grief from emotion is that few authors do this and the two concepts are rarely completely separate. Even categorizing them is difficult. Thus, I found striking examples of empathy in SIDS parents as they protected their children and were overwhelmed by the suffering of partners and their own parents. Empathy is more of an ability to enter into someone else's emotional experience which then in turn triggers an emotional response of its own. So for example, seeing one's own father break down for the first time might elicit an unusually powerful feeling of sadness secondary to the empathetic response.

Similarly, guilt, usually considered a straightforward emotion, can also be construed as something much more complicated for SIDS parents. There might be a sense of shame, personal anger at having failed as a parent, perhaps a type of blaming that is directed inward when there is no external focus available. It is even cultural in that we live in a society where parents are expected to care for their children. A failure to do so brings severe censure and social sanctions, not just in terms of public opinion but even in a legal and authoritative sense. In

Canada we maintain mechanisms for reporting mistreatment and abuse of children for this reason. We believe that their proper care is everyone's responsibility.

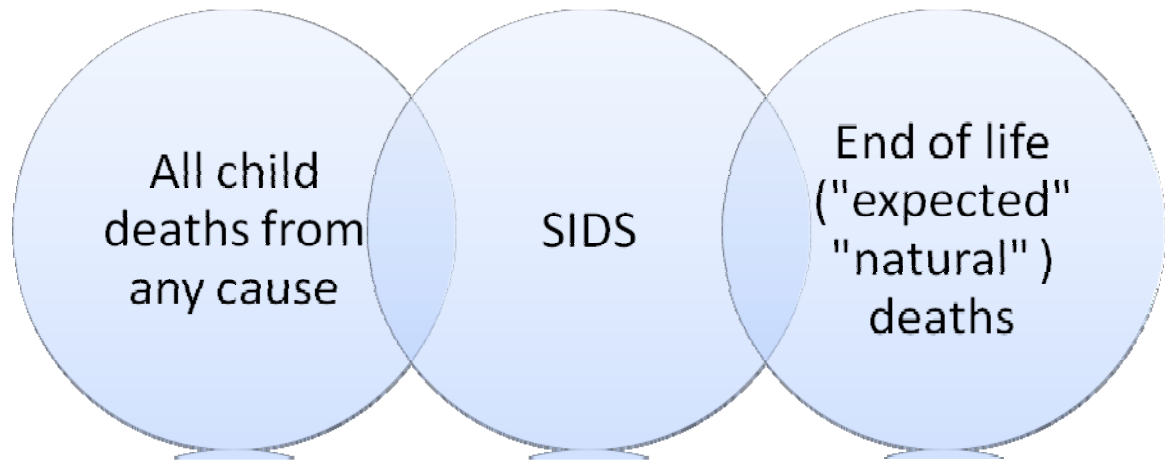
The fear of a SIDS repetition, which is common for all parents who have experienced it once, goes beyond the mere fact that it might happen again. I believe that the real fear that these parents face is that having gone through the experience once they simply will not survive it a second time. Having used all their resources to pull themselves through the most terrible ordeal of their lives once, they cannot even consider the prospect twice. Fear is a primal and important component of survival, but exactly how that fits in with these parents is unclear. What was apparent though was their increased vigilance and protectiveness towards subsequent children. Parents used monitors, cared for their infants with a strong sense of protection, and they educated themselves about all the risk factors associated with SIDS.

Issues of yearning and regret in the way that I defined it are closely related. Both have to do with a need to rewrite one's personal story, recreate the narrative so that the outcome is slightly different, revisit the scene and replay things so that some things are done differently. Parents regretted not holding their infants after they had died, they wished their children had participated in things differently, and in many small ways thought back to what they might have done differently. This also tied in with guilt in which something not done makes one feel that one could have done something else.

In a general sense, parents underwent a profound change in their emotional lives following the death of their infants. They experienced extremely powerful emotions such as shock and even panic, which was later followed by a suppression of all emotion leading to numbness and memory loss for some events that followed. This was then followed by a long slow recovery in which more normal emotional functioning emerged. Nevertheless, some parents re-enter a state of mourning and bereavement when they talk about the death of their infants as they did during my interviews. Time does not seem to play a role in this case and whether the death occurred ten, twenty or even thirty years before, the emotional space opens up and parents move into a mournful phase, however briefly.

Grief has sometimes been viewed as an emotional response to loss when it is actually a multi-faceted phenomenon that incorporates a number of processes. As researchers unravel the relationship between the over-arching trajectory of grief and examines the subset of emotional response inherent in this longer arc it would be worthwhile to examine the role of specific emotional responses, both positive and negative that SIDS parents encounter. By understanding for example how guilt and anger is different in this population (I believe it is) one might further help and comprehend their reactions. But what is also needed is a more nuanced approach that attempts to understand differences in the types of grief people experience based on the type of loss. One way of visualizing this is in Figure 9.2.

Figure 9.2: Different Types of Deaths Leading to Different Outcomes



9.8.2 Physiology and Bereavement

Typically when people are in grief they suffer short-term physical consequences including loss of appetite, sleep disturbances, fatigue, and a whole host of somatic complaints ranging from muscle tension, to SIDS mothers' feelings of their arms aching. These issues have been well described in the literature (less so perhaps for SIDS experiences), but once again there has been little attempt at explaining possible reasons. For example, is there an adaptive reason for a loss of appetite or sleep disturbances typically found in grief? Or are these the by-products and inverse of bonding and loving others? These are the short term physical concerns, but there are also outcomes that cover a longer period.

While I have no empirical evidence for long-term effects of adverse health outcomes relating to bereavement based on this study, these are being investigated. Increased morbidity and mortality as a result of loss has been extensively investigated although almost always using widows and widowers who are usually older and have lost their life partner. As was mentioned previously, these circumstances are quite different from younger SIDS parents who have lost a child and thus there may be little correlation between the research literature for the former and the grief of the latter.

Some issues in my narrative did emerge. There was talk of suicide from one participant and there was a reference to excessive drinking by another. Stroebe and her colleagues (2007) have reviewed the literature and found that suicide was a risk for widows and widowers, and that a broad range of factors came into play that resulted in negative health outcomes. But again, these populations are different. Nevertheless, consistent with my argument that these parents undergo elements of grief, PTSD and traumatic memory, these are all stressors and the relationship between stress from any source and negative health outcomes is very well known.

Morbidity and mortality are discrete variables often used to measure health outcomes. But the health effects of bereavement are more subtle and in many ways not differentiated from emotional consequences, psychological coping or social context at all. Everything comes together to form part of a whole. One such holistic model is offered by Hall and Irwin (2001) who argue that bereavement can translate into adverse health outcomes in the following

manner: bereavement takes place in a social context which includes ethnicity, socioeconomic status, role function and network characteristics, as well as in an individual context which includes genetic predisposition, age, sex, and psychiatric history. The stress is perceived by the individual who then uses self-concept constructs such as mastery and self-efficacy but may also cope using substance abuse or other self-damaging behaviours. This then leads to affective and sleep disturbances which in turn leads to biological responses in three domains: the autonomic nervous system, the neuroendocrine system, and immunological functioning. Any or all of these then may lead to disease progression (p. 474).

These are not well-developed theories and much more research needs to be undertaken. Health effects of bereavement also add to the controversy of whether grief is a pathology or even a disease. There is a strong case being made for a DSM category of complicated (or prolonged) grief which would categorize it as a mental illness. A demonstration of negative health sequelae might lead some to conclude that grief is a disease. I would argue that what is more important is to keep in mind that for the majority of individuals, grief is a process through which they work themselves, without significant intervention. People know what they must do in order to move through the grief trajectory themselves and they also know what resources they can use that will effectively help them in their journey. In spite of this, there will always be people who require more help in order to prevent long-lasting adverse outcomes both psychological and physical. Part of the future research task will be to differentiate those people at risk and those who will be able to navigate the process independently.

Additionally, as long-term longitudinal data become available, we may be able to determine who is more at risk for increased morbidity and mortality, but these types of studies will always be limited by the lack of an adequate control group. Eventually, everyone faces some form of grief experience, no one is spared, and the research task remains that of determining who needs what type of help and at what stage.

9.8.3 Lactation Suppression

Mothers who are bereaved need assistance with the problem of lactation suppression. This is an overlooked area in the literature. Because there are thousands of infants that die from all causes each year in North America the specific steps that need to be taken should be well understood by nurses and other health care workers who deal with this population. Even women who experience miscarriage may have problems. Milk production may commence even if the infant was lost as early as 16 weeks' gestation (Pugmire, 1999).

Lactation specialists are generally familiar with the best way to proceed, but someone may not be available. The person counselling or offering support for the mother may not be familiar either with what to do. Many women, even those who have breastfed children, may be completely unaware of the specific and best means to stop milk flow in a safe and efficient manner using techniques that are effective and that minimize the pain and potential for inflammation that can occur. A promising source of this type of useful information is the Internet although conflicting information can be a problem. There are also long cycles in the overall history of breastfeeding (e.g. wet nurses for the wealthy). When I was

a junior nursing student (1970) it was unusual for women to breast feed as hospitals were inundated with free samples of formula which most women continued when they went home. The pendulum has now swung in the opposite direction with most women at least attempting to breast feed, as the benefits for the infant once again become known. As breastfeeding becomes increasingly widespread, the potential number of women affected by issues if and when their infant dies also increases.

Future research in this area should include evidence-based advice for women rather than the sometimes confusing anecdotal help that abounds in discussions of this topic, e.g. the use of cabbage leaves to reduce swelling and discomfort. Although sometimes useful methods evolve out of old fashioned and time-honoured traditions, proper clinical trials provide more objective results and might be more widely used.

Chapter 10: Conclusion

He's very much a part of our lives...not the way we want him to be, but he's very much a part of our lives (Participant 19).

I didn't want it to rule my life and I didn't want people to feel sorry for me...when I talk about my kids I include [my son] because he was one of my children (Participant 3).

We had lots of experiences with this and you know I think that's what's helped me to be the person I am today (Participant 13).

My original intent in undertaking this research was to explore how parents resolved the extraordinary experience of losing an infant to sudden infant death syndrome. The question arose out of my nursing and counselling background in which I became increasingly interested in how people handled loss. Some preliminary explorations also convinced me that the experience that SIDS parents undergo following the death of their infant was an under-explored area of concern. The vast majority of publications dealing with SIDS examine risk factors, causation theories, and many varying aspects of etiology. There is a paucity of research literature on what happens to families after that. Even those researchers who do address these issues do so under the umbrella of child loss in general, something that is sometimes too broad to encompass what occurs in this population. Nevertheless, there is literature that pertains to the experiences of SIDS parents and child loss in general, which I reviewed. Later, as findings emerged I continued to read the areas related to the thesis that emerged from the empirical evidence, namely post-traumatic stress disorder, emotional and

traumatic memory, resiliency and physiological processes. This literature context developed concurrently with my data analysis. Something that was apparent when parents spoke to me was that the stories they were telling me differed from what had been written. In some cases they themselves formed a different perspective, at variance with the grief literature and incorporating problems that were highly specific to their situation.

I spent considerable time determining the best qualitative approach towards data collection and data analysis. Although initially reluctant to use a grounded theory approach because I believed this is a method that has become increasingly misused and even inappropriately used, these considerations were balanced with an overview of how grounded theory has evolved, some of the controversies, and specifically how my work is situated within that tradition. Included are some thoughts on the use of the software package NVivo which influences the research process even while it aids the researcher's tasks.

The parents' narratives were analyzed using the software and a series of themes emerged. These included the grieving process, the memory trajectory, issues of coping and resilience, sources of support, and those social stressors that in many ways are peculiar to SIDS parents. In addition, there were findings for which I found less evidence but which warranted more study and I categorized these as such. They included specific emotional concerns as well as physical concerns. Included in this category were specific problems of lactation suppression encountered by mothers.

Many of the findings appear in the words of parents themselves. I quoted extensively in order to have the narrators themselves explain concepts, situations, problems and even solutions and outcomes in their own words, which are more powerful than any paraphrasing I might have attempted. Also, by using their voices I attempted to articulate some of the unique circumstances they encountered which have to date not been well described.

In the discussion section I returned to my researcher role and attempted to synthesize the literature, the empirical evidence, and my own thoughts about the topic in order to more clearly identify what we know and what questions remain. I also included some thoughts about directions for future research in this area which is ripe with possibilities.

We need a more holistic and multi-disciplinary approach towards the study of grief. It has been traditionally treated as a psychological concern but there are also lessons to be learned from physiology and even neuroanatomy as functional magnetic resonance imaging has shown. This blending of psychological and physiological concerns is beginning in areas such as PTSD and emotional memory and should be extended into the study of specialized forms of grief such as the experiences that SIDS parents undergo. Once the process is better understood, better interventions can be developed and improved strategies for helping people recover using their own resources as well as determining which people will need professional help.

In spite of decades of research and thousands of published articles and books, there is still a great deal we do not understand about grief and in

particular the processes that specific subgroups such as SIDS parents encounter. We have described things much better than we have analyzed them or provided theoretical frameworks for the underlying processes. Stroebe and her colleagues (Stroebe, Hansson, Stroebe, & Schut, 2001a) reflect on this lack of theory in grief and state:

We lack a general theory of grief that explains a number of basic questions: Why does it happen in response to only certain losses? What is the role of security and attachment? What are the links between symptoms of grieving and affective or cognitive systems? How and why does it abate? Is it indeed functional, as other emotions are? What is the nature and explanation of individual differences in grief experience? Can others really help, and if so, how (p. 746)?

We need even further refinement for the specialized trauma of experiences such as sudden infant death syndrome, which create an even more complicated type of grief process.

SIDS parents undergo a form of grief that is best understood in the context of elements of grief theory, emotional and traumatic memory, and posttraumatic stress disorder. Some of the work being done on complicated grief as a distinct type of experience may explain some of the processes that amalgamate elements from the three literatures and perspectives, but it is more likely that it will describe a subset of all people suffering all types of grief. This effectively means we still need further understanding of the special problems that SIDS parents encounter. The other issue which I have repeatedly stated is that our understanding of grief has derived almost exclusively from experiences undergone by those who lose partners at the end of a lifetime. Extrapolating from

this understanding towards the very different scenario of an infant dying may not be the best way to build a theory of grief for these parents. They told a different story.

The study was limited in that I used a sample of participants that all came through the CFSID network. These were people who identified themselves, registered with the organization, received preliminary counselling and in some cases peer support, and had participated in group activities. This is a very self-selected group. Further work with a much broader population of parents would be valuable, perhaps drawing on First Nations participants, those from differing cultural backgrounds, or those from lower socioeconomic groups. By incorporating a broader range of parents, reliability and validity could be strengthened as my findings are replicated and outliers and variances incorporated. This exploratory and descriptive study does not allow for the nuanced comparisons that might help us further understand differences in men and women, differences at varying times in the lifespan, religious affiliation or ethnicity. These are areas that are all important but cannot be determined from my limited sample.

Also of interest is the fact that parents are having children at a later age on average. Does this mean that grieving and mourning is more or less problematic? Are people who are more mature also more or less resilient? These are not answerable questions at this point.

Siblings of SIDS infants and those children that are born later in the family also constitute a group about whom little is known. Growing up in the shadow of

the forever-perfect infant that became an angel in heaven creates problems in some families. It's difficult to compete with someone who has died and some parents alluded to issues with their teen-age children. Of course it is extremely difficult to factor out the SIDS death as the cause of behavioural problems since all adolescents have issues of one kind or another. Nevertheless it would be a research topic that might yield interesting results, if ethics approval could be obtained.

Some of the issues of intervention have been addressed in this study. It was noted that this is a highly individual process, that sometimes friends are as effective as professionals, and that by helping themselves individually, family members are then able to in turn help each other. This two-stage process is yet another area worthy of investigation.

SIDS parents have long been telling their stories. Those of us who research this area have listened carefully but have not always heard exactly what they are saying and have not fully analyzed the processes described. Just as the literature is becoming more and more nuanced in terms of describing what exactly is happening in which population, similarly we need to continue to examine how these parents who have suffered such a profound loss, manage to restore their lives and achieve normal functioning once again.

Appendices

Appendix A: Letter of Invitation

Letter of invitation for SIDS research

[Date]

My name is Guenther Krueger and I am completing a PhD at Simon Fraser University in Burnaby. The subject of my research is how parents cope with the loss of a child to Sudden Infant Death Syndrome (SIDS).

My background is in nursing, including time spent in pediatrics. I also have a counselling degree and have worked in many health care settings. For the past 14 years I have worked as a medical writer. I have a long-standing interest in family issues and interpersonal relationships.

I am interested in learning how your child's SIDS death affected you and what strategies you used to help yourself through the aftermath of this event. My plan is to listen to your story and then develop a comprehensive picture of how people cope with sudden and unexpected catastrophic loss.

Meetings may be held wherever you choose, either in your home or at any location that you prefer. All interviews will be audio-taped although I am the only person who will listen and transcribe them. Your name will not be used and I will make every effort to maintain your confidentiality.

The results of this research will be published as a PhD dissertation and available to the public. This project has been approved by the Simon Fraser University ethics approval board. My supervisor is Dr Ellen Balka of the School of Communication.

I do hope that you will consider participating in this research. I know that losing a child is a devastating experience. However, sharing information may provide valuable lessons for many others. I hope you will consider participating and I look forward to hearing from you.

Guenther Krueger
PhD Candidate
Simon Fraser University
Burnaby, British Columbia

Appendix B: Participant Consent Form

Project Title: Sudden Infant Death Outcome Studies
Researcher: Guenther Krueger, Simon Fraser University
Supervisor: Dr Ellen Balka, Simon Fraser University

The purpose of this doctoral thesis project is to explore how the loss of an infant due to Sudden Infant Death Syndrome might affect all areas of life. Those who are interviewed might benefit others by sharing their story and may also contribute to a better understanding of how people resolve this loss, something that is not as fully understood as other areas of human behaviour. Although theories of grief, loss, and mourning have long been used, they are being updated as a result of research such as this.

I will be interviewing you for one to two hours, with one possible follow-up interview. These interviews will take place at your convenience and in a location where you feel comfortable. During each interview, you will be asked to tell about your feelings and experiences as they relate to the death of your infant. I will be recording these interviews on audiotapes. Only an identification number will be used on the tapes and transcripts so that your identity will be protected. I will be the only person listening to and transcribing the interview. In addition, any other names or places on the tapes that will identify you will be altered and not transcribed. Nothing you say during the interviews will be shared with your partner or any other participant in this project.

There is no payment for your participation in this project.

Following the interview, you may request a copy of the transcript for review and clarification. I will also make the results of my research available to you if that is your wish. You may contact me at any time regarding your participation in this project.

The University and those conducting this research study subscribe to the ethical conduct of research and to the protection at all times of the interests, comfort, and safety of participants. This research is being conducted under permission of the Simon Fraser Research Ethics Board. The chief concern of the Board is for the health, safety and psychological well-being of research participants.

Should you wish to obtain information about your rights as a participant in research, or about the responsibilities of researchers, or if you have any questions, concerns or complaints about the manner in which you were treated in this study, please contact the Director, Office of Research Ethics by email at hal_weinberg@sfu.ca or phone at 778-782-6593.

Your signature on this form will signify that you have received a document which describes the procedures, possible risks, and benefits of this research study, that you have received an adequate opportunity to consider the information in the documents describing the study, and that you voluntarily agree to participate in the study.

This is to certify that

I _____ hereby agree to participate as a volunteer in the above-named project.

I understand that the interviews may be difficult and painful and that I may stop the interview or my participation if I feel unable to continue.

I give permission to be interviewed and for those interviews to be recorded on audio-tape. I understand that these tapes may be used for educational purposes, that they will only be reviewed by the researcher and that all attempts will be made to protect my identity. Transcripts of the tapes will not have my name on them nor anything that might identify me. All tapes and transcripts will be kept in a locked drawer and only the researcher will have the key.

I understand that the results of the study will be published but that my name and specific information that might identify me will not be used.

I understand that I am free to deny any answer to specific questions. I also understand that I am free to withdraw my consent and terminate participation at any time without penalty merely by saying that I no longer wish to be a participant in the study.

I have been given the opportunity to ask whatever questions I wish, and all such questions have been answered to my satisfaction. I have also been given a copy of this consent form.

[Signatures]

Participant

Witness

Researcher

Date

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