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Bereavement Outcomes Associated with Pediatric Chronic Illness: A Systematic Research Review

by

Elizabeth Burgess-Pinto

A Thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Master of Nursing.

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Abstract

A systematic research review was conducted to identify and appraise the literature on bereavement outcomes for families in which a child had died of chronic illness. The review was designed to answer the question "What are the bereavement outcomes for parents and siblings of children who have died of chronic illness?" One hundred and eighty-seven articles were reviewed for possible inclusion. A selection tool, quality assessment tool, and data extraction tool were developed specifically for the group of studies. Of the 187 articles, a heterogeneous sample of 34 met the eligibility criteria of the selection tool. Nine of the 34 studies scored less than 8 out of a total of 17 on the quality assessment tool. Data were extracted from 23 studies. Common themes emerging from the data include: bereavement is not a time-limited process; families experience bereavement as a major transition, a developmental crisis in their lives; after the death families experience an "empty space" in their lives; mothers and fathers grieve in significantly different ways; and adolescents may be more at risk than other age groups of siblings. The review shows that more high quality studies are needed to determine the parameters of normal bereavement.

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Chapter 1

Introduction

The natural order of the universe is that the old predecease the young (DeVries, Dalla Lana & Falck, 1994; Rando, 1986). There is a strong social belief that parents should not outlive their children. The death of a child (at any age) is a violation of this normal life course and exacerbates the grief response. Bereavement researchers have concluded that the phenomenon of parental bereavement is the most difficult form of bereavement (Cieren, 1993; Knapp, 1986; Heiney, Hasan & Price, 1993; Osterweis, Solomon & Green, 1984; Rando, 1986; Saunders (1979-80; Schiff, 1977; Sidmore, 2000; Smart, 1993-94; Talbot, 1986). It has been found that the death of a child produces the highest intensities of bereavement and the widest range of reactions (Braun & Berg, 1994; Parkes, 2002; Pine & Brauer, 1986; Sanders, 1980). Parental bereavement results in more somatic reactions and greater depression, anger, guilt, and despair than does the grief of those who lose a spouse, parent, or sibling (Davies, 1996; Rando, 1985).

There are unique difficulties inherent in the death of a child (Goldman, 1994; Rando, 1986). The relationship between parents and their children is physiologically, psychologically, and socially intense. The closeness of the relationship predisposes the parent to be acutely vulnerable to loss when the child dies (Klass, 1997; Rando, 1985). The normal experience of parental grief closely resembles that commonly accepted as unresolved, pathological, or abnormal (Rando, 1986). An understudied area is the effect of a child's death on siblings (McCown & Davies, 1995). Mahon and Page (1995) note: "Sibling death in childhood often leaves surviving siblings as less recognized grievers (p.20). It has been found that sibling bereavement is a unique and intense loss experience (Robinson & Mahon, 1997). Because grief is most often recognized as the prerogative of the individual, family grief is an under explored concept (Dowd, Poole, Dadhizar, & Giger, 1998). For some time, it has been recognized that there are differences in bereavement outcomes between those who experience sudden death and those who experience death due to prolonged chronic illness (Sanders, 1982-83).

Chronic Illness

In developed countries, childhood cancer remains the most common cause of death after accidents in children aged 1 to 14 years (Stevens & Pollard, 1999). One third of childhood malignancies result in death (Davies & Steele, 1996). Deaths due to cancers and leukemia are followed by the more slowly progressive, more rare disorders, such as muscular dystrophy, mucopolysacharidoses, neurodegenerative conditions, congenital heart disease, and HIV/AIDS (Baum, 1994). Children with life-threatening and terminal illnesses do not represent a homogeneous group of patients (Davies, 1996). The nature and progression of their diseases varies greatly as do their family circumstances. Life-threatening and life-limiting illnesses in childhood are rare and for this reason, the provision of palliative care for children has developed sporadically (Goldman, 1994). Life-limiting illnesses are those such as muscular dystrophy or mucopolysacharidoses, which are likely to progress and terminate life before adulthood. In contrast, life-threatening diseases are those in which medical intervention might be successful but which carry a substantial chance of mortality in childhood. Life threatening diseases include cancer, leukemia, or conditions leading to major organ failure (heart, liver, kidney) (Baum, 1994). Both life-threatening and life-limiting illness are encompassed by the definition of chronic illness outlined by Curtin and Lubkin (1990) as "...a state of unwellness produced by disability or disease requiring medicosocial intervention over an extended interval and affecting many aspects of an individual's life" (p. 18). The impact of chronic illness on the child and on the family is influenced by many factors (Melnyk, Feinstein, Moldenhouer, & Small, 2001; McCubbin, Thompson, Thompson, McCubbin & Kaston, 1993; Newachuk & Taylor, 1992).

Palliative Care

In 1992, the World Health Organization defined palliative care as

> The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of best quality of life for patients and their families.
>
> (Davies & Steele, 1996, p. 5)

The principles of palliative care include support systems to help the patient's family cope during the period of illness as well as during the period of bereavement (Koop & Strang, 1997).

As early as 1991, the Cancer 2000 Task Force, recommended the development of palliative care centres in Canada and the development of a palliative care curriculum for both nursing and medicine (Mount et al., 1999). It has also been suggested that the terminally ill are a specialized patient population requiring the expanded skills and knowledge of advanced practice nurses (Janssens, Zylicz, & Ten Have, 1999; Weggel, 1997).

While the palliative care options of hospice and home care for adults with terminal illnesses have increased rapidly, these services for children have developed more slowly (Davies, 1996; Lauer, Mulhern, Hoffman & Camitta, 1986; Liben, 1996). In Canada, there are only two centres that focus on care for the terminally ill child, one in Vancouver and one in Toronto (Davies, 1996). Two factors contribute to the lack of pediatric palliative care services. There is reluctance on the part of health care providers to recognize the palliative care phase in children (Liben, 1996). Secondly, only large urban areas are likely to have sufficient numbers of dying children to warrant pediatric palliative care programs. On the other hand, palliative care can be provided in a variety of settings including the home, hospitals, long-term care facilities, and hospices in both rural and urban settings (Critchley et al, 1999). Ideally, the focus of care should be based primarily where the child and family are cared for (Frager, 1996).

Currently, governments have sought ways to reduce health care costs. Because nearly 40% of health care dollars cover hospital costs, many of the attempts to reduce health care costs have been directed to reducing hospital costs (Northcott, 1995). Restructuring of the hospital care system has occurred and there are attempts to shift health care from institutions such as hospitals to the patient's own home. Mount et al. (1994) anticipated that palliative care programs would be a low priority in health restructuring.

There has been a shift in orientation of the chronically ill as recipients of care, to one of active partners within the health care system. Families of the chronically ill undergo multiple and ongoing stressors (Melnyk, Feinstein, Moldenhauer, & Small, 2001; Ray & Ritchie, 1993). The adverse psychological and physical health outcomes associated with bereavement, make intervention with families who have experienced a loss an important health matter (Kato & Manon, 1999). There have also been suggestions that both hospice and home care produce better adjustments to bereavement reactions than does hospital care for the terminally ill (Goldman, Beardsmore, & Hunt; Lauer, 1997; Seale, 1991).

Pediatric Palliative Care and Bereavement Outcomes – The Literature

One way of determining the state of knowledge about a particular subject is to collate and analyze the available evidence in order to make inferences regarding policy and practice (Khan et al, 2000). A preliminary assessment of potentially relevant literature revealed approximately 90 articles on palliative care and bereavement outcomes. This type of search has been referred to as a "scoping search" (Khan, Glanville & Kleijnen (2001). The scoping search included retrieval of previous literature reviews. A sample of the results of the scoping search for articles on palliative care and bereavement outcomes is outlined in Table 1.

Table 1. Scoping Search Outcomes

Author/Year Location	Research Question/Design	Sample	Method	Findings
Birenbaum, L.K Stewart, B.J. Phillips, D.S. 1996 United States	To describe parent's health during the terminal illness of their child and during the first year following their child's death from cancer Quantitative	80 parents 48 families with 49 children 47 mothers 33 fathers	Duke-UNC Health Profile prior to death and at 3 points in time after (2 weeks, 4 months, 12 months	Parents' health is **not** adversely affected by a child's death from cancer

Author/Year Location	Research Question/Design	Sample	Method	Findings
Davies, B. Devau, E. DeVeber, B. Howell, D. Martinson, I. Papadatou, D. Pask, E. Stevens, M. 1998 Canada Greece	The experience of mothers from five different countries who had a child die from cancer in the previous six months Exploratory Descriptive Qualitative	21 mothers	Semi-structured interviews	More similarities than differences. No culturally related differences. Similar reactions to diagnosis, management of end-stage illness, and bereavement.
Dunlop, J. 1984 United States	Case Study Qualitative	2 ½ year old child with tumours and his parents	Narrative	Coordinating referral hospice program fulfills a needed place to connect hospital, home health staff, and family
Hongo, T. Fuji, Y. Yajima, S. Matsushita, T. Ogawan, N. Kinjo, Y. 1995 Japan	To analyze the support of families during terminal care and bereavement Qualitative	25 sets of parents whose children died from cancer. 5 children had received home care.	Interviews	6 of 25 families had not accepted loss of child due to missed opportunity for terminal care. Need support system run by hospital and need to develop home-based terminal care.

Author/Year Location	Research Question/Design	Sample	Method	Findings
Lauer, M.E. Mulhern, R.K. Hoffman, R.G. Camitta, B.M. 1986 United States	To examine the national prevalence of hospice/home care in pediatric oncology. Quantitative	103 medical directors of university affiliated pediatric oncology programs	18-item questionnaire	There is a need to increase these programs Institutionally administered programs were superior.
Martinson, I.M. McClowry, S.G. Davies, B. Kuhlenkamp. E. 1994 United States	To report changes over time. An examination of changes in families, 7-9 years following the death of a child with cancer Qualitative	48 families 46 mothers 33 fathers/stepf 71 siblings parents aged 22-58	150 semi-structured interviews questionnaires	Loss of a child required individual reorganization and adjustments within the family system.
Stein, A. Forrest, G.C. Woolley, H. Baum, J.D. 1989 United Kingdom	To assess the impact of chronic life-threatening illness on the family. To examine the family's perception of the care offered by the hospice. Retrospective Qualitative	25 families 26 ill children at Helen House, Oxford, England	Semi-structured questionnaire Self-report questionnaires	Mothers and siblings had higher levels of psychological sympto-Matology. 18 families valued hospice. Others: financial draw-backs, child-minding

The research on which these articles are based is mainly descriptive in nature. Studies on palliative care for children and bereavement outcomes for families are hampered by small sample sizes and the reluctance of professionals and medical personnel to recognize the palliative phase for children (Goldman, Beardsmore, & Hunt, 1990; Frager, 1996; Liben, 1996). Furthermore, as Miles (1985) notes "...it is nearly impossible in grief studies to obtain a large, random, representative sample because of the sensitivity of the subjects under study" (p. 72). The result is that the literature on pediatric palliative care and bereavement outcomes is composed mainly of small, descriptive studies. Despite these weaknesses, the scoping search suggested that there was a sufficient body of literature to review in a systematic manner. Approximately 90 articles related to pediatric deaths and bereavement outcomes were located in the initial scoping search. The reference lists of these articles revealed further studies in the area. It is essential that palliative care services are provided effectively and efficiently and that decisions regarding support for the bereaved and palliative care are based on the best available knowledge. A systematic literature review is an important strategy to identify the current state of knowledge about pediatric palliative care and bereavement outcomes for families. A systematic review has the potential to facilitate research-based practice and to identify the needs for further research.

Purpose of Study

The purpose of this research study was to conduct a systematic research review of the literature on bereavement outcomes for families of children who have died of chronic illness. Objectives of the review included an assessment of the evidence provided by the literature on bereavement outcomes, a description and classification of the research that has been done, and identification of areas where additional research is required. The objective of this synthesis was to extract common themes emerging from the literature rather than conduct an in-depth analysis. The review also includes a consideration of the way in which terms related to bereavement are used.

Research Question

The systematic review was guided by the following question:

1. What are the bereavement outcomes for parents and siblings of children who have died of chronic illness?

Chapter 2

Literature Review

Practitioners and researchers are being encouraged to consider the results of systematic reviews and meta-analyses as part of evidence-based practice (Lemmer, Grellier, & Steven, 1999; Rosswurm & Larrabee, 1999; Yuen, 1999). The systematic review is a useful decision-making tool for health consumers and health providers, since it objectively summarizes large amounts of information, identifies gaps in research, and identifies beneficial or harmful interventions (Bero & Jadad, 1997). In addition, meta-studies, such as systematic reviews are indicated when there have been paradigm shifts in the approach to research in specific areas and also when a discipline fails to progress. (Thorne & Paterson, 1998; Zhao, 1991). In the case of bereavement outcomes for families where children have died from chronic disease, there has been a paradigm shift toward the inclusion of home and hospice care as alternative options to hospitalization of the terminally ill child as well as changes in the approach to research and treatment of chronic illness.

Before undertaking a systematic review, it is important to assess the literature to see if good quality, relevant reviews of the topic have been already completed (Khan, Ter Riet, Glanville, Sowden, & Kleijnen, 2001). According to Khan et al., previous reviews must be critically assessed for quality to ensure that the design, conduct and analysis of the review minimize biases. A checklist must be used to identify flaws in the reviews that might bias results.

Some of the articles described in Table 1 have been included in previous reviews. However, when the explicit criteria (adapted from published guidelines for information synthesis) recommended by Mulrow (1987) and by Oxman et al. (1991) are applied, it is found that many of the authors of these reviews failed to specify systematic methods to identify, assess, and synthesize the information. An assessment of methods used in ten reviews is outlined below in Table 2.

Table 2. Assessment of Methods Used in 10 Reviews

Methodological Criteria	Specified	Unclear	Not Specified
	--------------------------------	n	--------------------------------
Purpose	10	0	0
Data Identification	7	1	2
Data Selection	1	5	4
Validity Assessed	0	2	8
Method for Combining	4	4	2
Qualitative Synthesis	3	2	5
Quantitative Synthesis	1	1	8
Summary	9	0	1
Future Directives	5	3	2

Adapted from: Mulrow, D.C. (1987) and Oxman, A.D. et al. (1991).

These reviews address the topics of: bereavement (Demi & Miles, 1986; DeVries, Dalla Lana & Falck, 1994; Koop & Strang, 1997; Kato & Mann, 1999; Klass & Marwit, 1988-89; Schulz, Newsom, Decamp & Mieboer, 1997); sibling bereavement (Walker, 1993); pediatric chronic illness (Williams, 1997); pediatric hospice nursing (Martinson, 1995); and family care in late stage pediatric cancer (Bakke & Pomietto (1986). No review was found which focussed exclusively on bereavement outcomes for parents and/or siblings of children who died of a chronic illness.

Purposes were generally broadly stated (Bakke & Pomietto, 1986; Demi & Miles, 1986; DeVries, Dalla Lana & Falck, 1994; Koop & Strang, 1997; Kato & Mann, 1998; Klass & Marwit, 1988; Martinson, 1986; Schulz, Newsom, Fleissner, Decamp & Nieboehr, 1997; Walker, 1993; Williams, 1997). The sources of information were clearly identified in seven of the reviews (Demi & Miles, 1986; Kato & Mann, 1999; Koop & Strang, 1997; Martinson, 1986; Schulz et al, 1997; Walker, 1993; Williams, 1997). Selection methods of reviewed data were described in only one review (Williams, 1997). Clear criteria for selection were not outlined in any of these reviews. Standardized methodological criteria for assessing the validity of data were not identified in any of these reviews. The author of one review (Walker, 1993) specified that there were no methodological or theoretical restrictions for a review of sibling bereavement. More than half of the reviewers neglected to identify specific future directives. Oxman et al. (1991) suggest that it is difficult for a reader of a review to know what was done or make a reasonable evaluation, when the decision rules are not specified. "If an overview does not report how something was done, it is reasonable to assume that it was not done properly" (Oxman et al., p. 97).

A further observation on the sample of articles and of the review articles is that there is a lack of consistency in use of terms. Few authors defined the terms used. A concept analysis of grief by Jacob (1998) shows that the terms grief, mourning, and bereavement are used interchangeably, sometimes within the same article or study. Karen Martin (1999) confirms this finding in her studies of deaths due to Sudden Infant Death Syndrome (SIDS).

Systematic Reviews

The combination of results of research for generalization began with Karl Pearson's work in 1904 regarding inoculation effects on enteric fever in India and Africa (Beard, Curry, Edwards & Adams, 1997). One of the earliest fields to use meta-analysis was agriculture. The early work focused on the combination of p-values. Later emphasis was on estimation of effect sizes. The method flourished in the social sciences and rapidly escalated to other fields. The term meta-analysis was coined by Glass (1976) to refer to quantitative summaries of individual studies. However, Glass used the term to refer to a philosophy rather than a statistical technique (Bangert-Drowns, Rudner & Lawrence, 1999). Glass specified that a literature review should be as systematic as primary research and should interpret the results of individual studies in the context of distributions of findings, partially determined by study characteristics and partially random. Cooper (1982) introduced the term "integrative review" to describe the application of the research process to a collection of studies. More recently, the term "systematic review" has been used to describe the scientific process of reviewing research. The term "overview" is sometimes used to denote a systematic review whether quantitative or qualitative (Cook, Mulrow & Haynes, 1997). The most recent term found is "disciplined literature review" a term used in the Information System literature (Clarke, 2001). Other terms include "literature review", "research review", "research synthesis", and "integrative research review" (Cooper, 1998). Cooper notes that some of these terms are interchangeable with "literature review" being the broadest term. He notes that "research syntheses" focus on empirical studies and that they are the most frequent type of review.

The systematic review has become a scientific investigation with pre-planned methods and a collection of original studies as the subjects (Cook, Mulrow & Haynes, 1997). Scientific strategies that limit bias are applied to the systematic retrieval, critical appraisal, and synthesis of all relevant primary studies on a specific topic (Ohlsson, 1994). Cook, Mulrow et al. state:

> All reviews, narrative and systematic alike, are retrospective, observational research studies and are therefore subject to systematic and random error. Accordingly, the quality of a review – and thus its worth – depends on the extent to which scientific review methods have been used to minimize errorand bias (p. 377).

The results of multiple studies are synthesized using strategies that best limit bias and error. When the results are summarized, but not statistically combined, the review is called a qualitative systematic review (Cook, Mulrow et al., 1997; Badgett, O'Keefe & Henderson, 1997). The term "meta-analysis" is usually used to refer to quantitative systematic reviews, reviews in which the results of individual studies are combined and statistically analyzed. (Haselkorn, Turner, Diehr, Ciol & Deyo,1994; Zhao, 1991). Light and Pillemer (1982) state that the most valuable syntheses make use of both qualitative and quantitative information. Reviews are termed systematic when the account of the search appraisal and synthesis methods would, in theory, permit the replication of the review by others (Nottingham, 1998).

The traditional approach to literature review is the narrative review, a summary of research that lacks explicit descriptions of systematic methods (Cook, Mulrow et al., 1997). Table 3 compares the salient features of narrative and systematic review. The narrative review is considered appropriate for describing the history or development of a problem and its management when research is scant or preliminary, or if studies are limited by flawed design. If a review is prepared according to the criteria outlined by Cook, Mulrow et al, it is more likely to be systematic and to provide unbiased conclusions. If review methods reflect those found in the middle column of Table 3, the article is more likely to be a narrative review, and the conclusions are less likely to be based on an unbiased summary of all relevant evidence.

Table 3. Narrative vs. Systematic Reviews

Feature	Narrative Review	Systematic Review
Question	Often broad in scope	Often a focused clinical question
Sources and Search	Not usually specified, potentially biased	Comprehensive sources and explicit search strategy
Selection	Not usually specified, Potentially biased	Criterion-based selection, uniformly applied
Appraisal	Variable	Rigorous critical appraisal
Synthesis	Often a qualitative summary	*Often a quantitative summary; can be a qualitative summary
Inferences	Sometimes evidence-based	Usually evidence-based

*A systematic review that does not include a statistical analysis can be just as valuable as a meta-analysis (Mulrow & Oxman, 1997).
Table 3 is adapted from: Cook, D.J., Mulrow, C.D. & Haynes, R.B. (1997).

The systematic review method of quantitative research is well developed. However, despite the growth in qualitative research and the importance attributed to its usefulness for health services research in particular, little attention has been paid to outlining a rationale or developing standards for the systematic review of qualitative research (Popay, Rogers & Williams, 1998). One issue is that qualitative research is inductive in nature, while the process of a systematic review is considered to be deductive (Morse, 1997). Nevertheless, Murphy et al.(1998) suggest that when qualitative research is conducted properly, and data analyzed thoroughly, valuable information can be obtained on the implementation and impact of health services.

Increasingly, it is recognized that findings from qualitative and descriptive research have an important role to play in increasing the effectiveness and appropriateness of health care interventions (DeVries, Weijts, Dijkstra & Kok, 1992; Lemmer, Grellier & Steven, 1999; Mays & Pope, 2002; Popay, Rogers, & Williams, 1995; Popay, Rogers & Williams, 1998; Secker, Wimbush, Watson, & Milburn, 1995). Suri (2002) notes that the purpose of a meta-analysis is to accept or reject a hypothesis, while the purpose of a qualitative research synthesis is to promote an understanding of the phenomenon at hand. Slavin (1986) proposed the method of "best-evidence synthesis" in which a meta-analysis of quantitative findings is followed by a narrative review of qualitative data. Slavin specified well-described inclusion criteria for empirical studies, but did not provide guidelines for systematic and rigorous synthesis of qualitative research.

There is much information on methods for systematic review of quantitative research. There are very few guidelines for systematic review of qualitative research. Lemmer, Grellier and Steven (1999) modified the Cochrane Center review protocol in order to study qualitative literature on characteristics of health visiting. Sandelowski, Docherty and Emden (1997) comment that the aim of qualitative metasynthesis is to account for all important similarities and differences in language, concepts and images around a specific experience. Suri (2002) notes that qualitative synthesis is best suited to understanding the phenomenon at hand. Apart from Slavin (1986), no literature was found that addressed the method of combining qualitative and quantitative literature in one research review. Dixon-Woods, Fitzpatrick and Roberts (2001) write that qualitative and quantitative research are usually only found in conjunction with each other in the context of single studies, either where the study employs a multi-method design, or where qualitative research is used as a precursor to a quantitative research question. They argue that the use of qualitative research in a review helps to challenge the tendency of systematic reviews to reflect the perspectives of clinicians rather than of recipients of care. Dixon-Woods et al. state, "Reviews which rely exclusively on qualitative primary research tend not to be called 'systematic reviews' and systematic review which do use mixed method studies usually prioritize the quantitative data." (p. 127).

Theory of The Process of Systematic Research Synthesis

The underlying principles of systematic research reviews are comprehensiveness, objectivity, and accurate data analysis (Hayward, 1997). There are three critical components of a review: the literature search, the retrieval of information from research reports, and the procedures for combining results of studies (Cooper & Dorr, 1995). Accordingly, the process for conducting a good systematic review involves the five stages outlined by Cooper (1998) and Smith, Smith, and Stullenbarger (1991):

(1) problem formulation, (2) data collection, (3) data evaluation, (4) analysis and interpretation, and (5) presentation of results. First, a well-formulated, answerable research question is posed. Second, using multiple sources, all potentially relevant articles are identified and retrieved. Then, all of these articles are assessed for relevance using predetermined selection criteria. Fourth, the validity or methodological quality of all the relevant articles is assessed. Fifth, data are extracted and abstracted using explicit data collection tools. Lastly, the abstracted data are analyzed and synthesized as conclusions are drawn (Counsell, 1997; Hayward, (1997); Pinch, 1995; Smith, Smith, & Stullenbarger, 1991; Van Tulder et al, 1997).

These steps are usually outlined consecutively (see example in Appendix A). However, in reality, the process is iterative. The chronology of the process can vary during the review (Khan, Ter Riet, Glanville, Sowden & Kleijinen, 2001). It is not always possible to complete one phase before another has started, and sometimes it is more efficient to work on several phases simultaneously. Cooper (1998) notes that while compiling a synthesis of literature, a researcher might encounter unanticipated elements of the topic under scrutiny that might lead to amendments of conceptual definitions or inclusion criteria.

Problem Formulation

According to Counsell (1979), a well-formulated research question includes a specific population and setting, condition of interest and exposure, and one or more outcomes. A clearly formulated question helps define the criteria that studies must meet to be included in the review. Cooper (1982) states "reviewers who employ broad conceptual definitions can potentially reach more definitive and robust conclusions than reviewers using narrow definitions" (page 794). Cooper (1998) notes that reviewers do not need to be as conceptually precise as primary researchers when developing operational definitions. The concepts and associated operations can become more precise as the reviewer becomes more familiar with the body of research. In other words, the process is iterative and the synthesist can determine parameters since it is possible for unanticipated elements to arise. In Cooper's words, "research syntheses involve many empirical realizations" (1998, p. 4). As the literature search proceeds, the reviewer constantly reevaluates and refines the concepts of concern.

Mulrow and Oxman (1997) suggest that review questions should address outcomes that are meaningful to people making decisions about health care. In other words, questions should address the choices or practical options people face when making decisions about health care

Data Collection

Search Strategies. Traditionally, the sample frame for a systematic review includes all studies the researcher/synthesist is able to obtain (Cooper, 1998). To identify as many studies as possible and to reduce the risk for bias, multiple overlapping research strategies that relate to the research questions and are based on the inclusion criteria of the review (i.e. study design, participants, interventions, outcomes, and language) are used (Van Tulder, 1997). Typically, the search strategy includes electronic databases, nursing journals, other health care journals, theses and dissertations. The aim of the search strategy is to minimize non-retrieval of relevant studies and retrieval of irrelevant material, and to maximize retrieval of relevant studies (SCHARR, 2002).

Published studies can be identified from a variety of sources using the following strategies: (1) searching on-line computer databases (Medline, CINAHL, HealthStar, PsycInfo, ERIC, and others; (2) using abstracting services (Dissertation Abstracts International and Cambridge Scientific Abstracts; (3) checking study registries and indexes (Cochrane Collaboration Agency for Health Care Policy and Research, Government Publication Office Monthly, Canadian Research Index; (4) hand-searching table of contents of key journals; and (5) checking reference lists of all retrieved studies to locate studies not previously identified through other sources; and (6) through informal methods such as contacting key informants (Cooper, 1998).

It is often suggested that the review process should include searching for unpublished articles and grey literature (literature that has not been formally published in peer-reviewed journals) such as conference proceedings, unpublished dissertations, policy documents and local project research reports as well as contacting key informants (Cooper, 1998; McManus, et al. 1998). It is important for synthesists to consider carefully the inclusion of unpublished sources of material in order to avoid publication bias towards positive results (Cook, Guyatt, et al.1993). However, Cook, Finlay, et al. (2001) found that grey literature searching is not a useful tool in the area of palliative care and represented an unwarranted use of resources. Personal contacts who have included these strategies state that there is no advantage to using them for a Master's level thesis (C. Berry; V. Strang, personal communication, March, 2001). Such searches are time-consuming and expensive. In addition, samples of studies found through personal contacts, web pages, etc., are more likely to contain flawed methodology (Cooper, 1998). Cook, Finlay et al. suggest that since palliative care is an emerging field the material in databases is likely of variable quality and therefore could include material that would be considered grey literature. Furthermore, Cooper (1998) notes that the bias of published literature probably does not extend beyond the primary hypothesis or research question of a particular study. Based on this information, it seems that it would be reasonable at this point in time to omit grey literature from systematic reviews that focus on bereavement outcomes and palliative care. However, in the future it may be more feasible to include grey literature in reviews on these topics since new tools for searching grey literature are being developed (Cook, Finlay, et al. 2001).

It has been found that published research is biased toward significant findings and that English language bias can be introduced if a systematic review includes only articles printed in English (Egger et al. 1994; Sterne, Egger & Smith, 2001). Non-English language studies are under-represented in most databases (Mosteller & Colditz, 1996). The inclusion of articles published in other languages is likely to increase precision and may reduce systematic errors (Khan & Kleijnen, 2001; Moher et al. (1996). However, the inclusion of articles published in languages other than English is limited by the researcher's facility with languages and the budget required to translate such articles into English.

Study Selection. Search results are reviewed for relevance and titles and abstracts are assessed to determine whether each article might be eligible for inclusion in the study. This search is guided by the research questions (Petitti, 1994). In order to minimize bias, the selection criteria must be well defined (Cooper, 1998). Mulrow and Oxman (1997) state: "It is important to err on the side of over-inclusion because once a trial has been excluded from the selection process, it is unlikely to be reconsidered" (p. 26). Questionable articles, which are included at one stage, can be excluded at a later stage when more information on the study is available. Cochrane reviews employ an excluded studies table to list studies that appear to meet the inclusion criteria and which might at first seem relevant, but upon closer inspection must be excluded (Petitti, 1994). According to Meade and Richardson (1997), the use of a selection protocol helps reviewers by providing a document that outlines the parameters of the review question and the selection criteria, thus making the process accountable. Reviewers can use the protocol for guidance in resolving disagreements about article selection. If there is a large sample of studies from which to select, the task is simplified by reviewing all of the titles, then the abstracts, and then the full articles excluding studies that do not meet one or more of the selection criteria at each step (Pettiti, 1994)

Even with specific selection criteria, decisions about which studies to include involve judgment. To ensure these judgments are reproducible, there should be more than one reviewer to apply independently the inclusion criteria to all potentially relevant articles. The criteria should be pilot tested by two independent reviewers (Hayward, 1997). The purpose of pilot testing is to refine and clarify the inclusion criteria and to ensure that the criteria can be applied consistently by more than one person (Mulrow & Oxman, 1997). There are a number of ways to quantify reliability between reviewers. Cohen (1998) states that two methods appear most often in research syntheses. The first is that the reviewers report their agreement rate; this is the number of agreed-on codes divided by the total number (Cohen, 1998). The second is Cohen's Kappa, defined as the improvement over chance reached by the reviewers. Percent agreement and agreement beyond chance (Kappa) can be calculated using Cohen's Kappa correlational statistic (Gordis, 1996; Hayward, 1997; Hunt & McKibbon, 1997). If Kappa is greater than or equal to 0.8, the reviewers can independently rate subsequent studies. If Kappa is less than 0.8, the rating of all studies is done by two or more reviewers, and when disagreement occurs, reviewers will meet to discuss discrepancies and issues are resolved by consensus (Hayward, 1997). Cohen (1998) states that high reliability is reached if reviewers resolve differences by consultation with each other or with a third reviewer. If there is poor agreement between reviewers, the selection criteria are revised, as necessary, to facilitate a mutual understanding of them .To facilitate the synthesis process, each study should be assigned a unique identifying number as it is selected for possible inclusion in the review (Petitti, 1994).

Study Quality Assessment. There is a great deal of controversy regarding the assessment of quality of studies for systematic reviews (Broome, 2000). It has been shown that the results of systematic reviews are influenced by the quality of the primary studies included (Khan, Daya, & Jada, 1996). Quality assessment of studies is used at various stages in the review process from study selection to formulation of recommendations for practice and research, for example the specification of inclusion/exclusion criteria at the study selection stage is a form of quality assessment (Khan et al 2001). Similarly, a decision regarding minimum quality of study design is usually applied at the selection stage (Khan, Ter Riet, Popay, Nixon, & Kleijnen 2001).

The purpose of applying a quality checklist is to provide a profile of each study alerting the reviewer to particular methodological strengths and weaknesses. The quality profile can be used to assess the quality of reporting as well as the methodological quality of the particular study (Downs & Black, 1997). A profile of quality of reporting assesses whether the information provided is sufficient to allow the reader to make an unbiased assessment of the study findings. In assessing quality of each review article, it is important to make the process as rigorous and well defined as possible, while maintaining a practical perspective (Brown, 1991). The measurement of research quality should focus on the critical aspects of the study that, if seriously flawed, would bias outcomes and/or generalizability as a result of variation in quality.

There are at least 25 published scales or checklists for assessing the quality of randomized studies (Downs & Black, 1997; Khan, ter Riet, Popay, et al, 2001; Ohlsson, 1994). However, Downs and Black and Ohlsson state there is some controversy over the efficacy of these scales and there are no validated checklists for non-randomized studies. The existing instruments tend to lack sub-scales that provide profiles of the strengths and weaknesses of each methodological area and also often exclude a consideration of external validity (Downs & Black, 1997). There are a number of checklists available for checking both quantitative and qualitative studies (Rychetnik, Hawe, Shiell & Frommer, 2002), but it is not known if these have been used for previous reviews. Downs and Black have shown that it is possible to employ one checklist to assess randomized and non-randomized studies.

Beck (1997) states that the criteria for a quality checklist must be rated in the context of the research questions and the substantive area of concern. Problems can arise if some research articles are missing information; sometimes reports contain insufficient detail about statistical procedures or about sample selection or composition (Cooper, 1998). Cooper recommends contacting the researcher who did the study but notes that if the study is old, it is best to either exclude it from the review or include only certain information from the study in the synthesis.

Data Extraction. It is generally agreed that the study characteristics and results should be abstracted onto structured forms that have been pre-tested and that an explicit plan to ensure reliability should be in place (Petitti, 1994). The use of these forms simplifies the selection process, increases reliability, and provides a record of the judgments made about each study (Meade & Richardson, 1997). The information to be extracted should be based directly on the questions to be answered in the review since detailed forms can be tedious and waste time while forms that are too brief can omit important data (Khan & Kleijnen, 2001).

Data Analysis and Synthesis. Analysis of the review data involves the reduction of the separate pieces of information collected by the reviewer into a unified statement (Cooper, 1998). Systematic reviews appraise critically, summarize, and attempt to reconcile the published evidence concerning a particular problem. They have gained prominence as useful tools for evidence-based decision-making (Lemmer, Grellier & Steven, 1999). Harlen and Schlapp (2000) state that the greatest challenge in conducting a review is to reconcile the different findings from different studies.

The method of analysis and synthesis used depends on the type of literature reviewed. In a quantitative review, or meta-analysis, the results of two or more primary studies evaluated are statistically combined to produce an overall estimate of the treatment effect (Harlen & Schlapp, 2000). When the results of primary studies are summarized, but not statistically combined, the article is considered a qualitative review (Van Tulder et al, 1997).

The guidelines for quantitative analysis are well developed. However, according to Mulrow and Oxman (1997), there are three circumstances in which the use of statistical analysis in a review is inappropriate. The first is lack of relevant, valid data.

When reviewers focus on meta-analysis, they can include marginally relevant or poor quality studies with questionable data. It can be important to know that there is no reliable data on which decisions can be based so that researchers can undertake studies to produce the needed data. The second circumstance is when data are statistically and clinically too heterogeneous; for example, it is inappropriate to combine effect sizes and t-tests. The third circumstance is that it sometimes does not make sense to do a statistical analysis; for example, if the methodology of the collected papers is phenomenology. Some studies use statistical analysis inappropriately, for example studies are pooled without accounting for variations in quality, or the studies are heterogeneous (Petticrew (2001). Cooper (1998) notes that the basic premise behind the use of statistics to analyze review data is that a series of studies focus on an identical conceptual hypothesis. If this is not so, then he states there is no need for the application of cumulative statistics. As Petticrew states, "Systematic reviews should not...be seen as automatically involving statistical pooling as narrative synthesis of included studies is often more appropriate and sometimes all that is possible" (p. 100).

The first step of analysis is to specify the comparisons that are to be made. An issue for many researchers is whether differing types of research should be compared. Lemmer, Grellier, and Steven (1999) recommend that it is important to distinguish between comparing results of comparable studies to combining results from variable studies on the same topic. They state the latter is justified when there is little information on a topic. Once the areas of comparison have been delineated, they are grouped in a table (Mulrow & Oxman, 1997).

Guidelines for non-statistical analysis of both quantitative and qualitative literature are almost non-existent. Jensen and Allen (1996) and Thorne and Paterson (1998) recommend the use of constant comparative analysis to critically appraise qualitative literature. This is a procedure described by Noblit and Hare (1988). It is a method of meta-data-analysis (meta-ethnography) that is appropriate to the synthesis of interpretive qualitative research reports. Unlike meta-analysis of quantitative research, meta-ethnography is interpretive rather than aggregative (Lemmier, Grellier & Steven, 1999). The researchers compare and analyze texts, then develop new interpretations in the process. The seven-stage meta-ethnographical approach is an interpretive content analysis. The findings of individual studies are combined in the same way as data from individual participants in primary studies. Lemmer et al (1999) find that this method is onerous for large numbers of qualitative studies.

Cooper (1998) states that it is important the reviewer uses appropriate rules of inference when analyzing data. He states that "synthesis generated evidence is always purely associational" (as opposed to causal) (pg 155). Whichever approach is used, the synthesis requires two steps: to exclude or downgrade studies that are of insufficient quality to contribute to a synthesis of evidence, and to determine a method to obtain a summary of the evidence (Dixon-Woods, Fitzpatrick & Roberts, 2001). The method for obtaining the summary will vary according to the characteristics of the data. Suri (2002) notes that the coding process for synthesizing qualitative research is eclectic, while the process for quantitative data is sequential.

Chapter 3

Methods

The methods used to review the literature on bereavement outcomes are described in this chapter. A working definition of systematic research review is provided followed by an outline of the objectives and procedures of each phase of the review process.

A systematic research review is defined as an overview of research studies that uses explicit, systematic, and therefore reproducible methods to locate, select, critically appraise and synthesize relevant and reliable evidence on a specific topic (Goodwin et al. 1994). Cook, Mulrow & Haynes (1997) define systematic reviews as:

> ...scientific investigations in themselves, with pre-planned methods and an assembly of original studies as their 'subjects'. They synthesize the results of multiple primary investigations by using strategies that limit the bias and random error. These strategies include a comprehensive search for all potentially relevant articles and the use of explicit, reproducible criteria in the selection of articles for review. Primary research designs and study characteristics are appraised, data are synthesized, and results are interpreted (p.377).

Phases of the Review Process

The systematic research review was comprised of 5 phases as shown in the framework of Appendix B: identification of literature, selection of articles, study quality assessment, data extraction, and data synthesis. In accordance with the recommendations of Khan, Ter Riet, Glanville, Sowden & Kleijnen (2000) and others, methods aimed at limiting the bias and random errors frequently associated with review articles were incorporated into each step.

Identification of Literature. Identification of relevant literature by means of an unbiased search strategy is crucial to the establishment of a comprehensive list of primary studies that might be suitable for answering the review questions (Khan, Ter Riet, Glanville, et al. 2001; Ohlsson, 1994). The validity of the findings of the review is directly related to the comprehensiveness of the literature search that is used to identify the relevant studies.

The basis for the search was a collection of about 90 articles identified in the scoping search and already entered into Endnote, a bibliographic database program (Niles & Associates, 1988-94). The search strategy was further refined during this stage.

A variety of complementary search strategies was used to identify potentially relevant articles beginning with an electronic search of Medline, CINAHL, Health STAR, ERIC, PsychINFO, and CancerLit. This search included literature dating back to 1980. Due to limited resources, the search was limited to published English language articles. Key words used in the search were taken from the titles and abstracts of relevant articles that were already gathered and included "bereavement", "parental bereavement", "grief", "paediatric death", "paediatric chronic illness" and "sibling bereavement". The search strategy is shown in Table 4.

Table 4. Search Strategy: Databases/Search Terms/Hand Searches

Databases (to July 2002)	Search Terms	Hand Searches
Medline 1966-2002 CINAHL 1982-2002 PsychInfo 1980 – 2002 CancerLit 1980 – 2002 ERIC 1980 – 2002 Social Sciences Index Cochrane Database Current Contents (to July 20, 2002)	bereavement, parental bereavement, sibling bereavement, pediatric death, grief, pediatric palliative care, terminal care, end-of-life, combined with: chronic illness, pediatric chronic illness, bereavement outcomes, AND names of individual chronic illnesses, e.g. cancer, leukemia, diabetes, congenital heart disease, AIDS. AND names of prominent authors	Death Studies Journal of Palliative Care Omega Nursing Research Reference lists of each retrieved article

The search focused on the years 1980 to the present since this is the period in which the options of home care and hospice care have developed rapidly. The reference lists of all articles reviewed for relevance were manually checked for studies not previously identified through other sources. This step is necessary since, as Mulrow and Oxman (1997) found, only 30% to 50% of articles are identified by computer databases such as Medline. In addition indexes of certain journals such as Death Studies and Omega were checked for potentially relevant articles.

Glanville (2001) notes that the development (generation) of a search strategy is an iterative process. Strategies are built up from a series of trial searches and discussions of the results of those searches. The search strategies for this review were based on combinations of what Glanville terms "facets" which are intended to capture the topic and can include method of study. Accordingly, as shown in Table 4, facets of the search strategy included the populations mentioned in the research question, namely parents, siblings, and pediatric populations in addition to other criteria of the research question such as chronic illness, bereavement and bereavement outcomes.

An updating search was conducted during the last month of the review. A systematic approach to recording and managing references was employed. All references were entered into End Note and assigned unique numeric identifiers.

Selection of Studies. The selection process should be explicit and should be conducted in such a way to minimize the risk of errors of judgement (Khan & Kleijnen, 2001). This is a multi-stage process. An explicit set of selection criteria were developed in addition to a set of standard working definitions (Appendix C). In order to be considered for review, articles had to meet the following criteria: 1) be empirical, 2) the majority of deaths in the study be of children under the age of 18 years from chronic illness, and 3) bereavement outcomes for parents or siblings had to be included.

The Selection Tool (Appendix D) was piloted by two reviewers using a randomly chosen subset of 20 articles. A sample of 20 articles was selected randomly once 100 articles had been located as recommended by Hayward (1997). Based on these results (the first kappa was 0.68, see Appendix E), the tool was revised twice. The same procedure was followed for each revision, i.e. a subset of 20 articles was randomly chosen and assessed by each reviewer. After the third revision, there was complete agreement between reviewers and the primary reviewer independently screened the remaining articles. Mathematical assessment of agreement is particularly important during the pilot phase when evidence of poor agreement should lead to a revision of the selection criteria or to an improvement of their coding (Khan, 2000). After the first kappa, agreement dramatically improved when whole articles were read, rather than just abstracts. It was found that abstracts did not clearly define the populations of children involved, that is, did not identify whether children had died from chronic illness. Throughout the process the predefined strategies of consensus and arbitration were used to resolve disagreements.

Studies that did not meet the selection criteria were placed on an Excluded Studies Table that cites pertinent data along with the reasons for exclusion (Appendix F). An excluded studies table contains information about studies that initially appeared to meet the criteria, but on closer inspection, had to be excluded (Mulrow & Oxman, 1997).

Study Quality Assessment. The critical analysis of a group of studies requires an organized approach to evaluation of each study. An assessment tool was developed specifically for the body of literature in question to assess criteria that included design and allocation, sample, and methods of data collection and analysis (Appendix G). The assessment tool was pre-tested and revised by the two reviewers. It combines criteria from University of Salford (2000) checklists for quantitative and qualitative studies with criteria used by Beck (1997), the Research Appraisal Checklist (RAC) developed by Duffy (1985), the prototype introduced by Smith and Stullenbarger (1991) and the checklist developed by Downs and Black (1997). It is designed to assess the salient characteristics of both qualitative and quantitative studies.

Based on recommendations made in Downs and Black (1997) and by the author of a similar MN thesis (C. Berry, personal communication, March 2001), it was decided to make a two-part quality tool. In these studies, it was found that a number of articles camouflaged poor methodological quality with excellent reporting (C. Berry). Space limitations for published research often preclude the inclusion of some information about studies such as precise descriptions of sampling and data analysis so that the written report focuses only on conclusions (Broome, 2000). Lemmer et al. (1999) note that lack of methodological information in journal articles is common in reports of qualitative studies.

As a result studies that are poor methodologically, can be assessed a high quality mark because of good reporting. As shown in Appendix G, the first half of the tool assesses quality of reporting, while the second half assesses the research quality of the study. Each section is a checklist that assigns a score of 1 if a particular component is present and a score of 0 if the element is absent. This type of dichotomous scoring is in keeping with the recommendation of Greenland (1994) that component analysis is a simple method of assessing quality. The potential total score for the quality tool was 17 with a total of 9 marks available fore reporting and 8 for method. For each selected study, two reviewers applied the tool and differences in scoring were settled by discussion. The use of two reviewers helps to reduce subjectivity and bias.

Data Extraction. After quality assessment of the studies, the primary reviewer independently extracted findings from the studies utilizing a data extraction tool that was developed, pre-tested and modified by both reviewers for this review (Appendix H). The tool was designed to extract relevant features and results of the studies including basic themes revealed.

In order to identify sources of ambiguity, the two reviewers conferred and revised the form twice. The extraction tool records background information on each paper such as the country where the study takes place, the discipline that produced the study as well as information about the purpose of the study, the research methods, the composition of the sample, and the type of setting.

Subsequently, the information was transferred to a data synthesis table (Appendix I) that allowed for regrouping of the articles according to author and quality score. Basic themes and limitations of the studies were recorded in this table.

Data Analysis. Studies that were assigned a quality score of 8 or greater (out of 17) were eligible for analysis. There was no a priori rule regarding the level of quality necessary for study to be eligible for inclusion in the review. The reviewers decided to collate the quality scores and hoped there would be a natural break in the scores. When the scores were reviewed, there was no natural break that allowed for this type of decision. Lemmer et al. (1999), in a qualitative review of studies on health visiting, found it necessary to include all articles because some articles that scored poorly overall contained important issues or sections whose omission would be detrimental to the review. For this study, the reviewers decided that papers had to receive a passing mark of 4 out of 8 in the methods section in order to qualify for inclusion.

The results were summarized but not statistically combined. As recommended by Mulrow and Oxman (1997), a systematic approach was taken to this summary. A stepwise approach involved the preparation of tabular summaries of the characteristics and themes of the studies (Appendix I). The information from the tabular summaries was aggregated according to author and location of sample, parental or sibling bereavement or both, type off chronic illness, purpose, type of investigation. Common themes and differences among the studies were then explored in relation to the research questions.

Conclusion

Measures were employed to reduce bias at every step of the review process. The two reviewers brought different areas of the review process. One reviewer had expertise in the areas of chronic illness and bereavement outcomes while the second reviewer was more familiar with the systematic review process. Both reviewers acted as checks on each other. At all times differences were resolved by consultation and field notes were recorded of discussions and decisions. The use of valid and reliable tools contributed to the effort to reduce bias. As noted, the tools were piloted and amended by the two reviewers.

Chapter 4

Findings

The findings of the systematic research review are described in this chapter which is divided into three main sections. The first outlines the decisions the reviewers made regarding inclusion issues; the second describes the evaluation process and findings; and the third addresses the major themes extracted from the studies.

Inclusion Issues

Initially the process of determining inclusion of studies seemed straightforward. In order to be included in the review, a paper had to report on an empirical study of bereavement outcomes for parents and/or siblings of children who had died of chronic illness. One of the first decisions to be made was whether or not to include case studies as empirical work. In the past, case studies have been classified in reviews as non-empirical (Pinch, 1995). However, Yin (1994) states: "a case study is an empirical inquiry that investigates a contemporary phenomenon within its real-life context when: the boundaries between phenomenon and context are not clearly evident; and when multiple sources of evidence are used" (p. 13). Researchers agree that case-study research should follow pre-specified procedures (Keen & Packwood, 1995; Stake, 1995; Yin, 1994). Yin outlines the five components of research design as follows: a) the study questions, b) the propositions, if any, c) the unit(s) of analysis, d) the logic linking the data to the propositions, and e) the criteria for interpreting findings (p.20). In addition, careful attention must be paid to the selection of cases for study (Stake, 1995). These components apply to any empirical research study. Based on this information, it was decided that case studies should be eligible for inclusion. In revising the Selection Tool, it was decided to include the criterion of being empirical as the first question.

The reviewers discussed the issue of what constituted family members for purposes of the review; for example, whether or not to include an article if family members other than parents or siblings were studied. It was decided that articles in which relationships other than parents or siblings were studied would be excluded from the review. It was felt that the introduction of other relationships would obfuscate the results of the review. Accordingly, the Selection Tool question "Does the study sample include family members of children (under the age of 18 years of age) who have died from chronic illness?" was amended to include three subsections. The subsections are: mothers and/or fathers, siblings, and children under the age of 18 who have died from chronic illness (Appendix D).

The final issue concerned the ages of the children who had died from chronic illness. It was discovered that some studies included children who were over the age of 18 years. In order not to exclude what might be valuable information, it was decided that if the majority of children who died from chronic illness were under the age of 18, the study would meet the inclusion criteria. Item 2c of the Selection Tool was reworded accordingly. (Appendix D). Two articles accepted for inclusion did not specify the ages of the children (Saiki-Craighill, 2001a; Saiki-Craighill, 2001b). In these articles, the researcher referred to young mothers of young children and both reviewers agreed that the sample likely met the inclusion criterion.

Evaluation Process and Findings

Quality Scores. 187 studies were reviewed for inclusion. Of these, 34 met the eligibility criteria of the selection tool (Appendix J). The total score achievable was 17, 8 for Reporting, and 9 for Methods. Four studies received a perfect score of 8 for Methods (Davies, 1987; Milo, 1987; Spinetta, Swarner & Sheposh, 1981; Wood & Milo, 2000). Only one study received a perfect score of 9 for Reporting (Birenbaum, 2000).

Nine of the 34 studies were assigned a score of less than 8 on the quality assessment tool (Dunlop, 1984; Heiney, 1991; Hongo et al, 1995; Lauer, Mulhern, Bohne & Camitta, 1983; Martinson, Lee & Kim, 2000; Martinson, McClowry, Davies & Kuhlenkamp, 1994; Moore, Gilliss & Martinson, 1988; Pettle & Lansdown, 1986; Tietz, McSherry & Britt, 1977; Wolfe, 1997). Two studies received a score of 8 but only a score of 3 for Methods, and so were excluded from further investigation. (Collins, Stevens, & Cousens, 19998; Martinson, Davies & McClowry, 1987). Data was evaluated for 34 studies and extracted from 22 studies.

The remaining studies, 153 in total, were placed on the Excluded Studies List (Appendix F) for a variety of reasons: they were not empirical studies, bereavement outcomes were not addressed, or the articles did not focus exclusively on families with children who had died from chronic illness. Many studies focused on mixed samples of children who had died from a variety of causes. These causes included motor vehicle accidents and suicide resulting in sudden death.

Chronic Illnesses. Twenty of the 23 articles focused exclusively on families in which children had died from cancer or leukemia (Birenbaum 2000; Birenbaum & Robinson, 1991; Birenbaum, Robinson, Philips, Stewart & McCown, 1983; Birenbaum, Stewart & Philips, 1996; Collins et al. 1998; Davies, Deveau, deVeber, Howell, Martinson, Papadatou, Pask & Stevens, 1998; Davies, 1988; Davies, 1987; Gilliss, Moore & Martinson, 1991; Heiney, Ruffin & Goon-Johnson, 1993; Lauer, Mulhern Bohne & Camitta, 1985; Lauer, Mulhern Schell & Camitta, 1988; Martinson, Davies & McClowry, 1991; Martinson et al.1987; McClowry, Davies, May, Kulenkamp & Martinson, 1987; Mulhern, Lauer, & Hoffman, 1983; Rando, 1983; Saiki, Martinson, & Inano, 1994; Saiki-Craighill, 2001; Spinetta, Swarmer & Sheposh, 1981. One article focused on 2 families in which children had died from congenital heart disease and a genetic disorder (Jacob & Scandrett-Hibdon, 1994). The samples for the other two articles (Milo, 1997; Wood & Milo, 2000) described families whose children had a variety of life-limiting conditions including microcephaly, agenesis of the corpus callosum, epilepsy, cerebral palsy with cataracts, and spastic quadriplegia with seizures.

Authors and Samples. Khan and Kleijnen (2001) note that it is misleading to include in a review the results of several reports of the same trial. It is important to identify serial publications where papers report accumulating numbers of participants or increasing length of follow-up. It was noted that a number of the studies included for this systematic review seemed to be based on the same samples. Khan and Kleijnen seem to be concerned about multiple papers that address the same hypothesis and use statistical analyses thereby artificially inflating sample sizes. In the studies selected for review, there seemed to be multiple papers that used the same or similar samples. However, unlike the reports described by Khan and Kleijnen, these focussed on different concepts and questions. Nevertheless, he articles were grouped in order to determine if there were overlapping samples (Appendix K).

It was found that there were 5 groups plus 6 independent samples as shown in

Table 5.

Table 5: Grouping by Authors and Samples

Group 1

ID#	Authors & Year	Sample	Location	Comments
78	Lauer, ME Mulhern, RK Bohne, JB Camitta, BM 1985	19 Home care siblings 17 hospital care siblings 7 years since death	Milwaukee Children's Hospital	
74	Lauer, ME Mulhern, RK Schell, MJ Camitta, BM 1988	24 Home Care families 12 Non home care families 7 years since death	Midwest Children's Cancer Center, Milwaukee, Wisconsin	Extension of #80 (excluded QS = 6) and #109
109	Mulhern, RK Lauer, ME Hoffman, RG 1983	37 deceased children 13-14 months (average) since death	Midwest Children's Cancer Center, Milwaukee, Wisconsin	See Above

Group 2

ID#	Authors & Year	Sample	Location	Comments
95	Martinson, IM Davies, EB McClowry, SG 1987	58 families (71 siblings) 29 siblings, 8-18 years of age 7-9 years post death	Midwestern	longitudinal study
94	Martinson, IM Davies, B McClowry, S 1991	26 families, 40 mothers 2-7 years post death follow-up study	36% small cities rural Minneosta, rest North Dakota, Wisconsin	longitudinal study
47	Gilliss, CL Moore, IM Martinson, IM 1991	77 families – 2 cohorts of parents	Minneapolis/St. Paul, North Dakota, Wisonsin	longitudinal study
99	McClowry, SG Davies, EB May, KA Kulenkamp, EJ Martinson, IM 1987	49 families siblings 7-9 years post death	25 St. Paul, Minn 25 cities and rural areas in Minn. 8 neighbouring states	longitudinal study

Group 3

ID#	Authors & year	Sample	Location	Comments
12	Birenbaum, LK Stewart, BJ Phillips, DS 1996	80 parents (48 families – part of larger study on terminal care (1991) deceased child 13 – 19 years		part of longitudinal study
10	Birenbaum, LK Robinson, MA Phillips, DS Stewart, BJ McCown, DE 1989	37 families 61 siblings (4 to 16 years)	2 western states 3 major medical centres 6 private practice physicians	
173	Birenbaum, LK 2000	37 families 61 siblings 3-19 years	2 western states 3 major medical centres	
11	Birenbaum, LK Robinson, MA 1991	87 parents, 48 families	3 major medical centres, 6 private practice physicians. 2 northwestern states (1983-86)	part of longitudinal study

Group 4

ID#	Authors & year	Sample	Location	Comments
30	Davies, B 1987	34 families	¾ Washington & Arizona ¼ Alberta	
27	Davies, B. 1988	34 families	Arizona, Washington, Alberta	
31	Davies, B Deveau, E DeVeber, B Howell, D Martinson, I Papadatou, D Pask, E Stevens, M 1998	21 mothers	8 Canada 5 Norway 4 Greece 2 Hong Kong 2 U.S.A.	

Group 5

ID#	Authors & Year	Sample	Location	Comments
164	Wood, JD Milo, E 2000	8 fathers 3 – National Fathers' Network 3 – wives in similar project 3 – referred by others	2 small towns in agricultural area 1 rural 5 metropolitan area Washington State? (funding)	
175	Milo, EM	8 mothers	Seattle Washington?	

The group 1 studies (Lauer, Mulhern, Schell & Camitta, 1988; Lauer, Mulhern, Bohne & Camitta, 1985; Mulhern, Lauer & Hoffman, 1983) address different aspects of the issue of the differences between home care and hospital care of dying children. The group 2 papers (Gilliss, Moore & Martinson, 1991; Martinson, Davies & McClowry, 1991; Martinson, Davies & McClowry, 1987; McClowry, Davies, May; Kulenkamp & Martinson, 1987) focus on sibling self-concept, parental depression, and family dynamics in response to bereavement. The papers in group 3 Birenbaum, Robinson, Phillips, Stewart, McCown, 1989; Birenbaum & Robinson, 1991; Birenbaum, Stewart &

Phillips, 1996; Birenbaum, 2000) are based on questions regarding sibling bereavement behaviour, and parental health. The group 4 papers (Davies, 1987; Davies, 1987; Davies, DeVeau, et al. 1998) study family environments, the response of mothers to the death of children to cancer, the question of how families deal with a deceased child's clothing. The two studies from group 5 (Milo, 1997; Wood & Milo, 2001) include samples from the same geographic area (Seattle, Washington) and 3 subjects in the second study were spouses of subjects in the first study. These two studies focused on the experiences of mothers and on the subjective emotional experience of fathers who had lost a child with a developmental disability. The remaining six studies focused on independent samples and questions: 21 families in California (Spinetta, Swarmer & Sheposh, 1981); 54 parents in Cleveland, Ohio (Rando, 1983); 5 parents in South Carolina (Heiney, Ruffin, & Goon-Johnson, 1995); 13 Japanese families (Saiki, Martinson, Inano, 1994). 24 Japanese mothers (Saiki-Craighill, 2001); 2 mothers in Tennessee (Jacob & Scandrett-Hibden, 1994).

The majority of these articles are from the discipline of nursing. There are three exceptions: one from medicine (Spinetta, Swarner & Sheposh (1981) and two from educational psychology (Milo, 1997; Wood & Milo, 2001).

Design Level. The design level of the studies was assessed using the research classifications outlined by Brink and Wood (1994). These designs range from Level I (exploratory/descriptive) to Level III (experimental). All of the studies were found to be Level I and were exploratory or descriptive in nature. These were studies that addressed one variable in one population. Five of the studies were assessed as being Level I, Exploratory (Davies, 1987; Jacob & Scandrett-Hibden, 1994; McClowry, Davies, May, Kulenkamp & Martinson, 1987; Saiki-Craighill, 2001; Saiki, Martinson & Inano, 1994). The remaining studies were Level I, Descriptive.

Statements of Purpose. Varied aims were addressed by the studies. The group 1 studies addressed the effects of home care versus non-home care in the palliative phase of the illness on the subsequent bereavement adjustment of parents and siblings. Group 2 studies investigated parental depression and psychological symptoms as well as sibling self-concept 7 to 9 years after a child's death. Group 3 looked at sibling's behavioural responses after a child's death as well as parental health and the family response. Group

4 researchers investigated family environments and the relationship of the family environment to subsequent sibling behaviour, described what families did with deceased children's clothing, and included a study that compares the bereavement reactions of mothers from five countries. The Group 5 studies provided the most succinct purpose statements with one study investigating mothers' experiences of losing a child with a disability and the other focusing on the subjective emotional experience of fathers who have lost a child with disabilities. The independent group, Group 6, focused on issues such as the effect of communication patterns on coping (Spinetta, Swarner, & Sheposh, 1981); the effects of support group participation (Heiney, Ruffin, & Goon-Johnson, 1995); grieving mothers (Jacob & Scandrett-Hibdon, 1994); the experiences of Japanese mothers and families who lost a child to cancer (Saiki-Crighill, 2001; Saiki, Martinson, & Inano, 1994); and parental grief and adaptation (Rando, 1983).

Methods Used. Semi-structured interviews were used in the majority of studies often alone, but also in combination with quantitative tools such as the EMI (Emotions Profiles Index) (Heiney et al. 1995); the GEI (Grief Experience Inventory) (Rando, 1983); MMPI (Minnesota Multiphasic Inventory) (Lauer, Mulhern, Schell & Camitta, 1988); the FES (Family Environment Scale); the SCL-90R and the SCL-90 (Martinson, Davies & McClowry, 1991); the Piers Harris Self-Concept Scale (Martinson, Davies & McClowry, 1987); the Duke UNC Health Profile (Birenbaum, Stewart & Phillips, 1996); and the CBCL (Child Behavior Check List) (Birenbaum, 2000). Small sample sizes limited the value of these tools. Most samples were too small for anything more than descriptive analyses.

Definitions of Terms. Each article was checked to determine if definitions of the concepts involved in grief and bereavement were provided (bereavement, bereavement outcome, mourning, grief, adjustment, adaptation, coping). Primary researchers need to define operational concepts at the outset of their studies in order to ensure that the qualities they are studying are relevant and to ensure consistency. Only one researcher defined bereavement. Bereavement is "the perception of loss of a sibling by death that includes the processes of psycho-social and physiological reactions" (Birenbaum, L.K., 2000, p. 383). Birenbaum also defines the terminal phase in three articles as "the time in which the ill child's physician and family agree that the usual course of curative treatment has been exhausted and the child has a low probability of surviving the course (p. 96, Birenbaum & Robinson, 1991).

Only one definition of grief was found. Saiki-Craighill (2001) defines grief "as encompassing the physical, psychological, and social reactions to loss." (p. 260). Jacob and Scandrett-Hibdon (1994) outline a conceptual definitions and characteristic signs and symptoms of grief. In all other articles the terms "grief", and "bereavement" are the most commonly used terms, but no clear definitions are given.

Extraction of Themes

Prior to eliciting themes from the Data Synthesis Table, the studies were divided into three groups: those that address parental reaction, those that describe sibling bereavement outcomes, and those that describe both. In addition, the studies were further divided according to quality score: those that received a score of 10 or more and those that received a score of 8 or 9. The themes for each study were placed in tables according to Quality Score and composition of sample (i.e. parents, families, siblings) .

Themes from Studies with Quality Scores Greater than or Equal to 10. The themes from this group of studies are outlined in Tables 6, 7, and 8.

Table 6. Themes: Studies with quality score greater than or equal to 10. Studies that address parental issues.

ID#	Quality Score	Themes
11	10	- cohesion and expression higher than norm after death - -grief reaction = developmental crisis – opportunity for positive change and growth
30	15	- belongings are memories with meanings - can vary with family member - discrepant meanings can influence bereavement outcome
31	11	- mothers in 5 countries have similar experiences - coping = comfort comes from supportive relationships - most difficult = missing child's presence (empty space?) - difficulty with emotions - 58.8% of mothers say fathers have most difficulty
169	12	- child's death changes lives - intense pain and grief – continuous struggle to adapt and prepare for future - support group gives high satisfaction

175	16	- mothers felt set apart because their love for child and their loss not validated by others - mothers had to work through two difficult transitions - one of the defining experiences of their lives and transformed them in positive ways - profound shift in sense of identity, world view, relationships, spirituality, and priorities (with parenting and loss of child) - mothers able to restore sense of well-being in the world, after birth/diagnosis, and after death - used cognitive coping strategies of construing benefits or gains, finding meaning, re-establishing control - mothers use many cognitive coping strategies to transform their experience from one of pain to one of growth and meaning.
164	16	- bereavement marked by double loss: disability then death - fathers use stoicism - primary coping strategy: activity rather than talk or social support - all experience isolation, with disability, then with death - dominant theme – valued professionals who were straightforward with information (intense need for facts) - 3 themes/models for fathers: protector, ally, or seeking distance from family and pain of loss - celebrate and normalize child – each father identified features or memories that made child unique - two distinct styles to fathers' stories: the hunter and ministry - men grieve for their wives - men grieve significantly differently from wives - lack of social support for fathers

Table 7. Themes: Studies with quality score greater than or equal to 10. Studies that address family issues.

ID#	Quality Score	Themes
136	16	- age of child at death not related to long-term parental adaptation - best adjusted parents have consistent philosophy of life - gave siblings information and emotional support at age-appropriate level
99	15	- time for bereavement process not limited to 2 years - after 7-9 years families feel pain and loss - "empty space" in lives - 3 patterns of grieving – getting over it feeling the emptiness keeping the connection

27	10	- larger number of surviving children, greater extent of participation in social and recreational life – greater chance rules and procedures run family life - FES scores show bereaved families more like normal than distressed families - families with higher Cohesion, Active/Recreational Orientation, and Moral/Religious emphasis have children with fewer behavioural problems up to 3 years after death

Table 8. Themes: Studies with quality score greater than or equal to 10. Studies that address sibling issues.

ID#	Quality Score	Themes
10	10	- siblings of children who have died from cancer exhibit higher levels of internalizing and externalizing behaviour problems and significantly different levels of social competence than normal children - internalizing scale significant: somatic complaints, depression, social withdrawal, obsession anxiety, immaturity obsessive compulsion, uncommunicativeness
173	16	- adolescents may be most at risk - show more age-adjusted bereavement behaviours than other groups

Summary. Parents and families describe the presence of an “empty space” in their lives (Davies, DeVeau et al. 1998; McLowry, Davies et al. 1987). This feeling of emptiness remains with family members for an indefinite period of time. After seven to nine years, families continue to feel pain and loss that they describe as an “empty space” (McLowry et al. 1987). There is a sense that bereavement is not a time-limited process. Families experience intense pain and grief that represents a developmental crisis, a major transition in their lives (Birenbaum & Robinson, 1991; Heiney, Ruffin & Goon-Johnson, 1995; Milo, 1997). Families describe a period of intense pain and grief followed by a sense of having to regroup and prepare for the future (Heiney et al.). Mothers describe a profound shift in their sense of identity, world view, relationships, spirituality, and priorities (Milo, 1997). Families follow different patterns in order to cope with the feelings of pain and emptiness. One way is to maintain a connection to the child. Davies (1987) found that the deceased child’s belongings represent memories with meanings that vary among family members. In summary, the death of a child represents a major developmental transition for families and family members find that they must find coping mechanisms in order to deal with feelings of emptiness and connectedness to the missing child and in order to plan for the future.

Two studies show that mothers and fathers grieve in significantly different ways (Milo, 1997; Wood & Milo, 2000). Mothers use cognitive coping strategies to find meaning in bereavement while the main coping strategy for fathers is activity (Milo, 1997; Wood & Milo, 2000). Mothers find comfort in supportive relationships (Davies et al, 1998) and tend to use cognitive coping strategies of finding meaning, construing benefits or gains, and re-establishing control (Milo, 1997). Fathers, on the other hand, tend to be stoic, have an intense need for factual material and a straightforward approach from professionals, and grieve for their wives (Wood & Milo, 2000). They prefer activity to social support and talk. Two articles identify the issue of parents' experience of two difficult transitions: the experience of becoming a parent of a chronically ill child followed by the bereavement experience (Milo, 1997; Wood & Milo, 2000).

Only one study in the group was designed to focus solely on the bereavement of children (Birenbaum, 2000). Preliminary data shows that adolescents may be more at risk than other age groups of children and show more age-adjusted bereavement behaviours than other groups. However, these reactions might be mitigated by individual family environments. Studies of family environment and the effects of family communication patterns on coping show better adjustment for children in families where parents have a consistent philosophy of life, who have ongoing, viable support systems, and who give siblings information and emotional support at age-appropriate levels (Davies, 1988; Spinetta, Swarmer & Sheposh, 1981).

Themes from Studies with Quality Scores of 8 or 9. The themes from the studies that received quality scores of 8 or 9 are similar to those above and are outlined in Tables 9, 10 and 11.

Table 9: Studies with quality scores greater than or equal to 8 (less than 10). Studies that address parental issues.

ID#	Quality Score	Themes
162	8	- mothers experience numbing of emotion then depression - emerge from experience to create story of child's life in relation to own - waves of sadness, then gradually stabilize
117	9	- parental bereavement may not diminish over time
160	8	- 5 major concepts: distress, protection, rumination, support, acceptance - conceptual definition of maternal grief: "The grieving mother experiences physical and emotional distress, an overwhelming need to review the events surrounding the birth, life, and death of the child, protects herself and others from the pain and loss, seeks and receives support, and gradually proceeds to acceptance."
74	8	- Home care and Non-Home care parents have significantly different patterns of bereavement - Home care – first month most difficult. Non-home care first 6 months followed by first month - Home care – spouse is primary support – have significantly stronger relationships with spouse, siblings, firmer religious connections, more adequate coping abilities, less residual guilt
134	8	- sick child becomes centre of family - Japanese families uncomfortable with outside help - parental relationships closer or more distant depending on stability of family environment - mothers' symptoms worse than siblings' or fathers' - parental view of world changes
12	8	- parents' health not adversely affected by death. - social scale – prior to death mothers have lower mean. at 4 months and 1 year after death – no significant difference from norm
94	9	- bereaved parents do not "recover" they appear to change as the integrate the loss into their lives - parents vulnerable or at high risk for depression event several years after death (i.e. no difference 2 years or 7years later) - parents feel presence of "empty space" 7 years later - parental depression unrelated to gender
47	9	- somatic rather than behavioural expressions of distress

Table 10: Studies with quality scores greater than or equal to 8 (less than 10). Studies that address family issues.

ID#	Quality Score	Themes
109	8	- parents and siblings of patients provided with home care infrequently display evidence of psychopathology - Non-home care parents more defensive, deny problems, higher somatic complaints and depression - Non-home care siblings significant scores on Fear and Neurotic behaviour
95	8	- 7-9 years after death, bereaved siblings score higher in self-concept than normative groups; bereaved siblings felt they had gained maturity and psychological growth from the experience
10	10	- siblings of children who have died from cancer have significantly lower levels of social competence than normal children - on CBCL have high levels of internalizing and externalizing behaviours - internalizing scale shows: somatic complaints, depression, social withdrawal, obsession anxiety, immaturity, obsessive compulsion and uncommunicativeness (NB parents and teachers completed scale)

Table 11: Studies with quality scores greater than or equal to 8 (less than 10). Studies that address sibling issues.

ID#	Quality Score	Themes
78	8	- Home care siblings prepared for death, received consistent information and support from parents, involved in most activities, present for death, and viewed own involvement as most important aspect of experience - Non-home care siblings inadequately prepared, isolated from dying child and parents, unable to use parents for support and information, unclear as to circumstances of death and useless in terms of their involvement. - (HC?) siblings consistent with norms on behaviour, social competence, and self-perception, higher in pro-social behaviour

Summary. In this set of studies, there is the same sense that the process of bereavement has no time limit (Martinson, Davies, McClowry, 1991; Rando, 1983). The Martinson group notes that bereaved parents do not recover, that they appear to change as they integrate the loss into their lives. This idea of a developmental crisis is affirmed by findings from other studies including studies of mothers and families in Japan (Saiki, Martinson, Inano, 1994; Saiki-Craighill, 2001). One study found that parental physical health is not adversely affected (Birenbaum Stewart & Phillips, 1996). Again, mothers have somatic expressions of grief rather than behavioural (Gilliss, Moore & Martinson, 1991; Jacob & Scandrett-Hibdon, 1994; Saiki-Craighill, 2001). Jacob and Scandrett-Hibdon provide their conceptual definition of the process of maternal grief: "The grieving mother experiences physical and emotional distress, an overwhelming need to review the events surrounding the birth, life, and death of the child, protects herself and others from the pain and loss, seeks and receives support, and gradually proceeds to acceptance" (p. 61).

The focus of the majority of studies in this group was on the effects of home care as opposed to hospital care for the end-of-life phase of the child's illness. These studies show significantly different patterns of bereavement between home care and non-home care families. Families provided with home care infrequently displayed signs of psychopathology (Mulhern, Lauer & Hoffman, 1983). In contrast, they displayed stronger family relationships, firmer religious convictions, more adequate coping abilities, and less guilt than families who chose non-home care (Lauer, Mulhern, Schell & Camitta, 1988).

The studies of Japanese families showed that the ill child had become the centre of attention in the family environment (Saiki, Martinson & Inano, 1994). It was found that siblings of children who have died from cancer have significantly lower levels of social competence than normal children (Birenbaum, Robinson, Philliips, Stewart & McCown, 1989), suggesting that the normal children paid the price of their parents' increased attention on their ill sibling. Home care siblings were prepared for the death, received consistent information and support from parents, were involved in most activities, were present for the death, and viewed their own involvement as the most important aspect of the experience (Lauer, Mulhern, Bohne & Camitta, 1985). This study found that home care siblings were consistent with norms on behaviour, social competence, and self-perception, and scored higher in pro-social behaviour.

Chapter 5. Discussion

The discussion is in two parts. The first part provides a discussion of the results of the review along with recommendations for practice and research. The second part addresses the method used to obtain these results, namely the systematic research review.

Bereavement Literature and Outcomes of Review

The research studies that address bereavement outcomes for families who have experienced the death of a child due to chronic illness are heterogeneous in nature. They address a variety of purposes within the broad aim of determining bereavement outcomes and use a number of different methods to elicit information. Such samples are the result of broad questions. The positive aspect of heterogeneity is that it allows reviewers to examine consistency of findings across various types of studies and to consider their applicability in a variety of patient care settings (Mulrow, Langhorne & Grimshaw, 1997). The negative aspect is that it can introduce ambiguity into the process of synthesis. One purpose of the review of bereavement outcomes for families in which a child had died of chronic illness was to assess the state of research and publication in the area. This purpose could only be achieved by stating a broad purpose at the outset and by including as broad a range of studies as possible.

Some methodological flaws must be considered before any interpretation of results takes place. Many studies did not provide specific details regarding the age ranges of the family members or the time since the death of the child. Age ranges of siblings of the deceased children, when cited, tend to cover an extensive range: 4 to 16 years (Birenbaum, Robinson, Phillips, Stewart & McCown, 1989); 3 to 19 years (Birenbaum, 2000), and 9 to 18 years (Martinson, Davies, MCClowry, 1987). Similarly, age ranges of the deceased child tend to be extensive: 1 to 19 years (Birenbaum, Stewart, Philips, 1996; Davies, 1988); 10 months to 37 years (Milo, 1997); 4 to 13 years (Mulhern, Lauer & Hoffman, 1983) and 5 months to 16 years (Wood & Milo, 2001). This wide variation in ages either at the time of the study or at the time of death can obscure important developmental differences (Walker, 1993). There are several important developmental stages in the first 18 years of life. Two major ones are the move from the family to the wider community that occurs at the ages of 4 to 6 years and the transition from childhood to adolescence that occurs at ages 11 to 13 years. It is reasonable to assume that the experience of bereavement could have an effect on these transitions or that the response to bereavement could be affected by the particular transition the child is experiencing. Consideration of developmental differences occurs in only one study (Birenbaum, 2000) and this is because the instrument used, the Child Behavior Checklist (CBCL) is designed for administration to different age groups (3 to 5, 6 to 11, and 12-19 years).

In comparing the studies, there is wide variation in the time since death. Rando (1983) interviewed parents whose child had died from 2 months to 3 years previously. Other researchers looked at the period 7 to 9 years since the child's death (Martinson, Davies, & McClowry, 1987); 2 to 36 months (Davies, 1988); 1 to 7 years (Milo, 1997); within 3 years of the death (Spinetta, Swarner, & Sheposh, 1981); and 2 to 26 months (Heiney, Ruffin & Goon-Johnson, 1995). Only one researcher (Birenbaum, 1996) took repeated measures at four times: before the child's death, at 2 weeks, 4 months, and 2 years after the death.

In many of the studies, sampling methods were poorly described. Only seven researchers described their samples clearly by including a description of inclusion/exclusion criteria, the size of the sample and pertinent characteristics, and the selection process for the sample (Davies, 1987; Davies, 1988; Heiney, Ruffin & Goon-Johnson, 1995; McClowry, Davies, May, Kulenkamp & Martinson, 1987; Milo, 1997; Rando, 1983; and Wood & Milo, 2000). The selection process including the number of potential subjects lost at each step should be reported very carefully to facilitate interpretation of results.

Some researchers attempted to measure aspects of psychological functioning (Birenbaum, Robinson, Philips, Stewart & McCown, 1989; Davies, 1988; Martinson, Davies & McClowry, 1987 & 1991(Heiney, Ruffin & Goon-Johnson, 1995; Mulhern, Lauer & Hoffman, 1983). The tools used include subscales of the Emotions Profile Index (EPI) (Heiney, Ruffin, & Goon-Johnson, 1995; the CBCL (Child Behavior Check List) (Birenbaum, 2000; Birenbaum, Robinson, Phillips, Stewart & McCown, 1989; Davies, 1988); the depression subscale of the SCL-90 (Martinson, Davies & McClowry, 1991); and the Family Environment Sacel of the MMPI, the Minnesota Multiphasic Personality Inventory (Mulhern, Lauer & Hoffman, 1983). The use of single measures such as self-concept or the use of one instrument such as the CBCL may not capture enough of the variables involved in grief to explain adaptive or maladaptive responses (Walker, 1993). Many variables can contribute to the process of grief such as social support, family environment or communication, and coping strategies. The utility of using these scales as isolated tools or as a complement to a semi-structured interview is questionable given the possible vulnerability of the populations involved. Milo (1997) conducted semi-structured, open-ended interviews of mothers but also requested that the mothers complete the GEI (Grief Experience Inventory) at home. The return rate for the GEI was poor at first, and even after several reminders, only seven of eight mothers returned the scales. Milo confirmed in discussion with the mothers that they were extremely resistant to expressing their bereavement experience in an objective, impersonal way.

Another issue is that from the information given in the studies, it is impossible to determine characteristics of these populations prior to the diagnosis of chronic illness and in most cases, prior to the terminal phase of the illness. As previously stated, Birenbaum (2000) and Birenbaum, Stewart & Phillips (1996) attempted a longitudinal study in which they collected data at one point prior to the children's deaths. In actual fact, because children were entering and leaving the study at different times, data were not analyzed over time. Instead, the study became a multiple cross-sectional analysis. While a child's death represents a major change in a family (McCown & Davies, 2001), as previously noted, chronic illness introduces multiple and ongoing stressors into the family environment (Melnyk, Feinstein, Moldenhouer & Small, 2001). A number of models have been developed for chronic illness such as chronic sorrow first described by Olshansky in 1962, time bound models which contend that adaptation to the child's illness occurs over a period of time and implies eventual acceptance of the condition, and the vulnerable child syndrome in which an overprotective parenting style is manifested (Knafl, & Zoeller, 2000; Melnyk et al., 2001). The impact on the parents and siblings varies with the type and severity of chronic illness. Siblings grieve within the context of the bereaved family and of a bereaved interpersonal network (Hogan & DeSantis, 1994). Without knowledge of prior circumstances, such as the pre-death sibling relationship or the amount of cohesion in the family, inferences about the impact of the child's death are tenuous at best (Toedter, Lasker & Campbell, 1990).

It would be particularly important to have background material on the families who chose home care in the series of studies in Group 1 (Lauer, Mulhern, Bohne & Camitta, 1985; Lauer, Mulhern, Schell & Camitta, 1988; Mulhern, Lauer & Hoffman, 1983). In the reports on these studies, the issue of self-selection of participants is not addressed. Instead, the researchers attempt to make the case that home care produces better outcomes for families as compared to hospital-based care. Such a conclusion is not warranted without consideration of the possibility that the families who managed to provide palliative care in their homes had very different pre-death characteristics from the families who were unable or unwilling to do so.

There are a few other practical issues to consider regarding methodology. When more than one sibling per family was interviewed, the issue of non-independence of data was not addressed in the analysis. In the majority of articles very little information was provided regarding methods to assure rigor within the studies. There was also a tendency for researchers who had published related articles to refer the reader to other journals to elicit information regarding such essential information as sample characteristics or method. Finally, as has been noted above, very few researchers defined the concepts they were studying.

Implications for Future Research

Studies that focus on longitudinal research to examine how the process of bereavement changes from the phase prior to death to several years beyond the death are needed. If, as Koop and Strang (1997) assert, the principles of palliative care include support systems to help the patient's family to cope during the period of illness as well as during the period of bereavement, then there is a need to better understand the pre-bereavement period and how it affects the process. In addition, studies should be designed to account for the two transitions that are experienced by families that include a child who dies from chronic illness, first with the diagnosis of chronic illness and then with the death of the child. Further study is needed of bereavement outcomes for chronic illnesses such as congenital heart disease to see if bereavement patterns are similar.

The majority of studies focus on bereavement outcomes for mothers. Verification of differences in grief patterns between mothers and fathers is needed. In addition, studies on siblings of children who die from chronic illness are needed. As Bakke and

Pomietto (1986) state, “most sibling observations have been done without regard to either the individual sibling’s performance prior to the terminal illness situation, or to the unique aspects of the relationship between the sibling and the dying child” (p. 74).

There seems to be an assumption in most studies, that problem behaviours should exist, that manifestations of grief are abnormal. Birenbaum (2000), among others, has stated that there is a need for better descriptions of normal bereavement behaviour. There is a need for studies with qualitative designs to elicit these behaviours.

Content of published articles should be a focus of researchers as well as editors. As was noted above, many researchers failed to describe components such as sample characteristics and selection, methods of data collection, and methods of data analysis. Research journals often impose restrictions that make it difficult for researchers to present findings in enough detail for assessment and synthesis (Estabrooks, Field & Morse, 1994). Two papers in the review, Milo (1997) and Wood and Milo (2000) received scores of 16 out of 17 on the Quality Assessment Tool. They received perfect scores for methodology and lost one mark because terms such as grief and bereavement were used but not defined. Both of these articles were published in the journal “Death Studies” as were a number of the articles reviewed. Therefore, the publication criteria were similar for many of the studies assessed and more researchers should have been able to publish articles that contained the same depth of detail as that of Wood and Milo. In both articles, the researchers outlined detailed statements of purpose, clear descriptions of sample characteristics and selection, explicit descriptions of methods, analysis and outcomes, as well as providing discussion sections that addressed clinical and research implications. It is recommended that researchers pay careful attention to detail when preparing articles for publication and that editors develop carefully considered criteria for publication.

Clinical Implications

Despite the methodological issues apparent in the studies, there are some recommendations that can be made to clinicians. Certain themes were apparent regardless of quality score. These include the fact that the time factor for bereavement is limitless, that families experience an empty space in their lives, and that bereavement represents a major transition or developmental crisis for all those involved. It is also apparent from the studies by Milo (1997) and Wood and Milo (2000) that for families of children who die from chronic illness, there are two transitions to consider, the first the adjustment to chronic illness and the second, the death of the child. Clinicians need to be aware of these two crises in the lives of family members. As previously mentioned, there seems to be an assumption that problem behaviours (especially in siblings) should exist and that services should be premised on those behaviours. In other words that families and siblings only need help if their behaviours are abnormal. Clinicians should be aware that families in crisis need support and sometimes guidance regardless of how their grief is manifested. Clinicians should read research studies carefully and be aware of the quality of methodology and analysis.

Conclusion

This systematic research review shows that with a broad purpose statement, and with a pragmatic approach to synthesis, it is feasible to combine qualitative and quantitative studies in one review. A set of studies using a mixture of different designs of varying validity is a challenge, but the challenge can be met successfully.

Limitations of the review include the lack of in-depth synthesis and overlapping categories in the Quality Assessment Checklist. The purpose for the review was stated as a broad, Level 1 Exploratory-Descriptive statement. In keeping with the Level of the question, the synthesis presents a description of the studies found and a preliminary description of the themes revealed by those studies. The intention of the synthesis section was to extract common themes without attempting an in-depth analysis because of the heterogenous nature of the studies. It would be feasible to group studies with common aims and similar methodology in order to produce a more complicated synthesis.

Revision of the Quality Assessment Checklist (Appendix G) is recommended. It was found that in both halves of the tool, in the Reporting Section and in the Methodology Section, certain criteria were dependent on each other. For example, if criterion 1.4 regarding reporting of sample characteristics and selection is assigned a score of 0, then criterion 1.5 which asks if all aspects of the method are explicit enough for replication, would receive a 0. In addition, the tool might have been strengthened had criterion 1.3 of the Reporting Section not included the requirement that terms such as grief and bereavement must be defined. The tool would have been strengthened if this issue had been dealt with separately.

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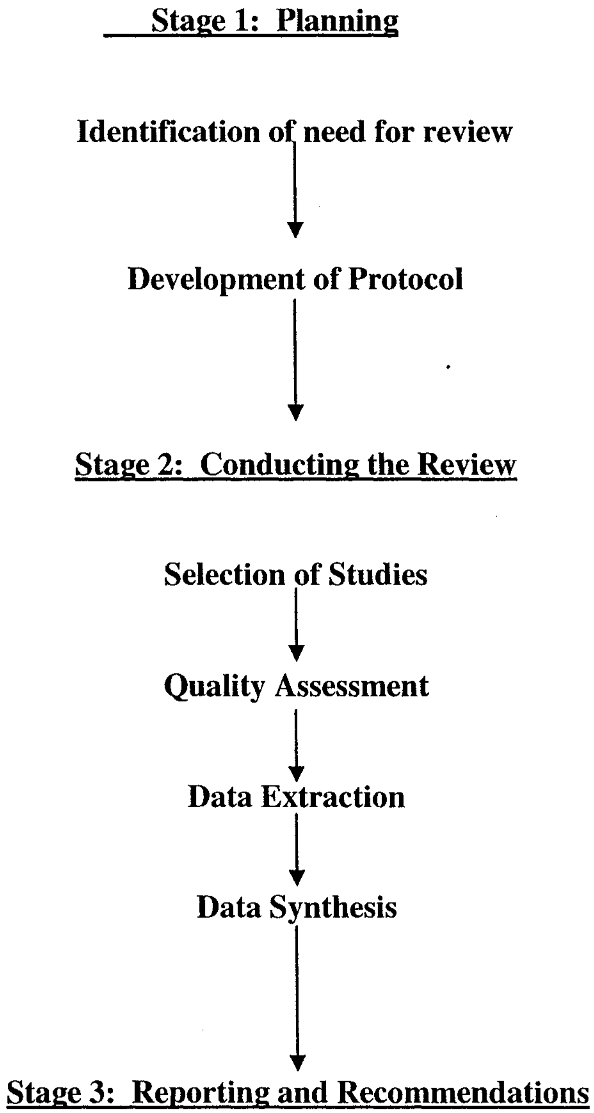
Yuen, D.E. (1999). Current approaches to evidence-based practice. In E. Silverman (Ed) Human Milk for Very-Low-Birth-Weight Infants. Report of the 108th Ross Conference on Pediatric Research. Columbus OH: Ross Products Division, Abbott Laboratories.

Zhao, S. (1991). Metatheory, metamethod, meta-data-analysis. What, why, and how? Sociological Perspectives, 34(3), 377-390.

Appendix A
Stages of the Systematic Review Process

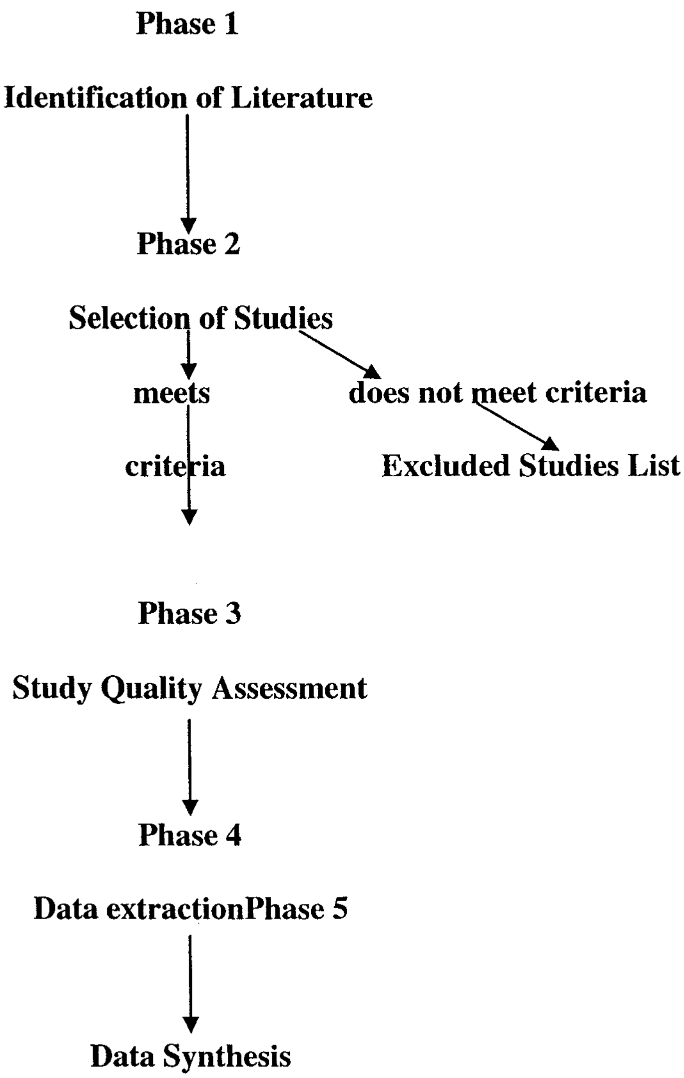


Adapted from: Khan, K.S., Ter Riet, G., Glanville, J., Sowden, A.J. & Kleijnen, J. (Eds), (2000). Undertaking Systematic Reviews of Research on Effectiveness. CRD's Guidance for Carrying Out or Commissioning Reviews. 2nd Edition. CRD Report No. 4, York: NHS Centre for Reviews and Dissemination. University of York.

Appendix B

The Review Process

Stage 2: Conducting the Review



Appendix C

Baseline Definitions

1. **Bereavement:** "If grief is the reaction and bereavement the situation consequent upon the death, then mourning is the process of management, adaptation, and resolution" (Corr, Martinson, & Dyer, 1985, p.221). Klass (1997) – "Grief can be defined as the processes by which persons move from equilibria in their inner and social worlds before a death to a new equilibria in their inner and social worlds following bereavement" – page
2. **Bereavement Outcome:** Will be taken to encompass the above process, i.e. a bereavement outcome includes the grief reaction, the situation, and the mourning process.
3. **Chronic Illness:** "A state of unwellness produced by disability or disease requiring medicosocial intervention over an extended interval and affecting many aspects of an individual's life. (Curtin & Lubkin, 1990, p. 18).

    Includes: Life-limiting Disease: Any illness which is likely to progress and terminate life before adulthood (Goldman, 1994). **and Life-threatening Disease:** Any disease in which medical intervention might be successful but which carry a substantial chance or mortality in childhood, such as cancer, leukemia, or conditions leading to major organ failure (Goldman, 1994).
4. **Hospice:** hospice care is both a concept for caring and a system of comprehensive interdisciplinary services involving continuity of care, pain and symptom management, bereavement program (Martinson, 1995) Pediatric hospice care addresses the physical, psychosocial, and spiritual needs of the dying child and provides support to family members during the illness and after the death of the child.
5. **End of Life Care** Care provided prior to death. The health care received by the child in the weeks and months before death. Can be: Palliative Care: some form of active total care for a person (and their family)) whose illness is in a terminal phase, or Cure-oriented care whose purpose is to achieve remission.

Palliative Care: "The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of best quality of life for patients and their families". (Davies & Steele, 1996, p.5).
"the combination of active and compassionate therapies intended to comfort and support individuals and their families who are living with, or dying from, a progressive, life-threatening illness, or are bereaved" (Viola et al, 1998, p. 2).

6. **Family Members.** Parents and/or siblings of children with chronic illness. Articles that include relationships other than parents/siblings will be excluded.

7. **Qualitiative Research:** The non-numerical analysis of data gathered by distinctive methods such as in-depth interviews, focus groups, and participant observation (Dixon Woods, Fitzpatrick, & Roberts, 2001, page 125).

8. **Systematic Reviews.** Scientific investigations with pre-planned methods and an assembly of original studies as their subjects. Synthesize the results of multiple primary investigations using strategies that limit the bias and random error. These strategies include a comprehensive search for all potentially relevant articles and the use of explicit, reproducible criteria in the selection of articles for review. Primary research designs and study characteristics are appraised, data are synthesized, and results are interpreted (Cook, Mulrow & Haynes, 1997, p.377).
"A systematic review is "the application of scientific strategies that limits bias to the systematic assembly, critical appraisal and synthesis of all relevant studies on a specific topic." quoted in Lemmer et al (1999

Appendix D
Selection Tool – *Version #3*

Reference: ____

Level of Review (Please Check One): Title:_____Abstract:____Article:_____

Reviewer:_____________________**Date of Review:**___________________________

Selection Criteria:
(Please circle **Y**(es) or **N**(o) if each of the following criteria are met)

1. Does this describe empirical work? **Y** **N**

2. Does the study sample include family members of children (under the age of 18 years of age) who have died from chronic illness?

   2a Mothers and/or fathers? **Y** **N**

   2b Siblings **Y** **N**

   2c Children 18 years or less who have died from chronic illness (majority under 18). **Y** **N**

3. Are bereavement outcomes for family members included? **Y** **N**

ACTION: (Include article if you answered Yes to 1, 2a and/or 2b, 2c, and 3)
Check Maybe if you are unsure of the category)

INCLUDE________**EXCLUDE**________**MAYBE**__________

Please list reason(s) for exclusion:

____

____

____

____

____

____

If there is a discrepancy between reviewers, please list reasons:

____

____

____

Please list articles from reference list that should be retrieved:

____

____

____

____

Appendix E

Kappa Calculation

		Reviewer 2		
		Include	Exclude	Row totals
Reviewer 1	Include	A) 3	B) 0	3
	Exclude	C) 1	D) 15	17
	Column Totals	4	16	20

K(appa) = ($P_0 – P_1/1\text{-}P_0$) = Pc

P_0 = (18/20) – 0.9

Pc = (3/20) x (5/20) + (17/20)(15/20) = 0.0375 + .64 = 0.678

K = (0.90 – 0.678)/(1-0.678) = 0 .68

Each reviewer scrutinized 20 articles.

Appendix F. Excluded Studies

Author & Publication Year	Article Name & Journal	ID#	Reason for Exclusion
Bakke, K. & Pomietto (1986)	Family care when a child has late stage cancer. A research review. CNF, 13(6), pp71-76	1	a review
Balk, D. (1983)	Effects of sibling death on teenagers. Journal of School Health, 53: pp 14-78	2	not 2c
Balk, D.E. (1991)	Sibling Death, Adolescent Bereavements, and Religion. Death Studies, 15, 1-20.	3	not 2c
Balk, D.E. (1997)	Models for understanding adolescent coping with bereavement. Death Studies, 20, 367-387.	184	Not 1
Batten, M. & Oltjenbruns, K.A. (1999)	Adolescent sibling bereavement as a catalyst for spiritual development: A model for understanding. Death Studies, 23(6), 329-546.	176	Not 2 c Sudden deaths
Baumer, J.H., Wadsorth, J., & Taylor B. (1988)	Family recovery after death of a child. Archives of Disease in Childhood, 63: 942-947.	4	Not exclusively chronic illness
Berman, L.E.A. (1977-78)	Sibling loss as an organizer of unconscious guilt: A case study. American Journal of Psychotherapy. 31: 417-425.	5	not 2c
Binger, C.M., Ablin, A.R., & Feuerstein (1969(	Childhood Leukemia. New England Journal of Medicine. 280: 414-418.	6	not bereavement
Bircumshaw, D. (1993)	Palliative care in the acute hospital setting. Journal of Advanced Nursing. 18: 1665-1666.	7	Not empirical
Birenbaum, L.K. (1995)	Family research in pediatric oncology nursing. Journal of Pediatric Oncology Nursing 12(1). 25-38	8	not 2 or 3
Birenbaum, L.K. (1989)	The relationship between parent-sibling communication and coping of siblings with death experience	9	not 2c
Bohannon, J. (1990-91)	Grief responses of spouses following the death of a child: longitudinal study. Omega 23, 153-159.	14	not 2c
Brabant, S., Forsyth, C., & McFarlin, G. (1994)	Religiosity related to grief levels of bereaved mothers and fathers, Omega 31(1), 67-85.	17	not chronic
Brabant S., Forsyth, C.J., & McFarlin, G. (1994)	Defining the family after the death of a child. Death Studies, 18(2), 197-206.	178	not chronic

Braun, M. & Berg, D. (1994)	Meaning reconstruction in the experience of parental bereavement. Death Studies, 18, 105-129.	18	Causes of death unclear.
Burne, S.R., Dominica, F., & Baum, J.D. (1984)	Helen House – a hospice for children: analysis of the first year. British Medical Journal, 289, 1665-1668	20	not empirical
Burnett, P.W., Middleton, Raphael & Martinek (1997)	Measuring core bereavement phenomena. Pyschological Medicine, 17(1), 49-57.	21	Includes bereaved spouses.
Cain, A.C., Fast, I, & Erickson, M.E. (1984)	Children's disturbed reactions to the death of a sibling. American Journal of Orthopsychiatry, 34, 741-752.	22	not 2c
Carlson, P., Simacek, I, Henry, J. & Martinson I.M. (1985)	Helping parents cope. A model home-care program for the dying child. Issues in Comprehensive Pediatric Nursing, 8, 113-127.	23	not empirical
Cohen, D., Friedrich, W.M., Jaworski, T.M. Copeland, I, & Pendegrass, T (1994)	Pediatric Cancer. Predicting sibling adjustment. Journal of Clinical Psychology, 50(3), 303-319.	25	not bereavement
Contro, N., Larson, J., Scofield, S., Sourkes, B., & Cohen, H. (2002)	Family perspectives on the quality of pediatric palliative care. Archives of Pediatric Adolescent Meedicine, 156, 14-19.	168	no bereavement outcomes
Corr, C.A. & Corr, D.M. (1988).	In our opiniojn…What is pediatric hospice care? Children's Health Care, 17(1), 4-11.	26	not empirical
Davies, B. (1983)	Sibling bereavement: Research-based guidelines for nurses. Seminars in Oncology Nursing, 9(2), 107-113.	28	not empirical
Davies, B. (1996)	Assessment of need for a children's hospice program. Death Studies, 20, 247-268.	29	not empirical
Davies, B. (1995)	Canuck Place: A hospice for dying children. The Canadian Nurse, April, 22-25.	32	not empirical
Davies, G., Reimer, J.C., & Martens, N. (1994)	Family functioning and its implications for palliative care. Journal of Palliative Care, 10(1), 29-36.	33	not bereavement
Davies, B., Spinetta, J.J., & Martinson, I. (1986)	Manifestations of levels of functioning in grieving families. Journal of Family Issues, 7(1), 22-31.	34	not 2c
Davies, B. & Steele, R. (1996)	Challenges in identifying children for palliative care. Journal of Palliative Care, 12(3), 5-8.	35	not empirical
Davies, B. & Dalla Lana, R. (1994)	Parental bereavement over the life course: A theoretical intersection and empirical review. Omega, 29(1), 47-69.	37	A lit review

Dowd, S.B. (1988)	Death, dying and grief in transcultural context: Application of the Giger and Davidhizer assessment model. The Hospice Journal, 13(4), 33-47	38	not 2c
Downey, G. & Silver, R.C. (1990)	Reconsidering the attribution – Adjustment relation following a major negative event. Coping with the loss of a child. Journal of Personality and Social Psychology, 59(5), 925-940.	39	not 2c
Drenovsky, C.K. (1994)	Anger and the desire for retribution among bereaved parents. Omega 29(4), 303-312	40	not 2c
Duffy, C.M. (1990)	Home-based palliative care for children – Part 2: The benefits of an established program. Journal of Palliative Care, 6(2), 8-14.;	41	not empirical
Fainsinger, R.L. (2000)	Home versus hospice inpatient care: Discharge characteristics of palliative care patients in an acute care hospital. Journal of Palliative Care, 16(1), 29-34	43	not 2c
Fortin, M., Coutu-Wakulczyk, G. & Engelsmann, F. (1989)	Contribution to the validation of the SCLII-90-R in French-speaking women. Health Care for Women International, 10(27), 27-41.	44	not 2 and 3
Forrest, J. Wooley, S. & Baulm. B. (1989)	Life-threatening illness and hospice care. Archives of Disease in Childhood, 64, 697-702.	53	not 3
Frager, G. (1996)	Pediatric palliative care: B uilding the model, bridging the gaps. Journal of Palliative Care, 12(3), 9-12.	45	Opinion, not empirical
Gibbons, M.B. (1992)	A child dies, a child survives: The impact of sibling loss. Journal of Pediatric Health Care, 6(2), 65-72.	46	Not chronic illness
Gilbert, K.R. (2001)	"We've had the same loss, why don't we have the same grief?" Loss and differential grief in families. Death Studies, 20, 269-283.	185	not empirical
Goldman, A. (1996)	Home care of the dying child. Journal of Palliative Care. 12(3), 16-19.	48	not 2c
Goldman, A., Beardsmore, S., & Hunt, J. (1990)	Palliative care for children with cancer – home, hospital, or hospice? Archives of Disease in Childhood, 109, 641-643.	49	Not 1 commentary
Gyulay, E. (1989)	Grief responses. Issues in Comprehensive Pediatric Nursing, 12, 1-31.	50	not 2c
Hagemeister, AK, & Rosenblatt, PC (1997)	Grief and the sexual relationship of couples who have experienced a child's death.	177	Not chronic illness
Hall, P., Stone, G., & Fiset, V.J. (1998)	Current reviews – Palliative care: How can we meet the needs of our multicultural communities? Journal of Palliative Care, 14(2), 46-49.	51	not 1

Hazzard, A., Weston, J., & Gutterres, C. (1992)	After a child's death: Factors related to parental bereavement. Developmental and Behavioral Pediatrics, 13(1), 24-30.	52	Not exclusively chronic illness.
Hilgard, J.R. (19969)	Depressive psychotic states as anniversaries to sibling death in childhood. Intern Psychiatric Clinics. 6, 197-207.	55	not 2c
Hofer, M.A., et al (1992)	A psychoendocrine study of bereavement. Psychosomatic Medicine, 34, 481-507.	56	not 2c
Hogan, N.S., & DeSantis (1994)	Things that help and hinder adolescent sibling bereavement. Western Journal of Nursing Research, 18(2), 132-153.	186	Not exclusively chronic illness.
Huber, R. & Gibson, J.W. (1990)	New evidence for anticipatory grief. The Hospice Journal, 6(1), 49-67.	58	not 2c
Hull, M.M. (1991).	Hospice nurses – caring support for caregiving families. Cancer Nursing, 14(2), 63-70	59	not 1
Ishibashi, A. (1996)	Four concepts that distinguish pediatric oncology care in Japan from that in the United States: Telling the diagnosis, length of hospitalization, home care, and support systems. Journal of Pediatric Oncology Nursing, 13(4), 226-232.	60	not 2c
Jacob, S.R. (1993(	An analysis of the concept of grief. Journal of Advanced Nursing, 18, 1787-1794.	61	not 2c
James, L. & Johnson, B. (1997)	The needs of parents of pediatric oncology patients during the palliative care phase. Journal of Pediatric Oncology Nursing, 14(2), 83-95.	62	not 3
James, N. & Field, D. (1992)	The routinization of hospice: Charisma and bureaucratization. Social Science & Medicine, 34(12), 1363-1375.	63	not 2 or 3 focuses on theme of hospice
Janssens, R.M., Zylic, A., & Ten Have, H. (1999).	Articulating the concept of palliative care: Philosophical and theological perspectives. Journal of Palliative Care, 15(2), 38-44.	64	not 2c
Jurk, I., Eker, H., & Jones, J. (1981).	Families responses and mechanisms of adjustment following death of children with cancer. Australian Pediatric Journalo, 17, 85-88.	65	not 3
Kato, P.M. & Mann, T. (1999).	A synthesis of psychological interventions for the bereaved. Clinical Psychology Review, 19(5), 275-296.	66	not 2c
Kerner, J.B., Harvey, et al (1979)	The impact of grief. A retrospective study of family function following loss of a child with cystic fibrosis. Journal of Chronic Diseases, 32, 221-225.	67	Prior to 1980.

Kinsella, G. et al (1998)	Current reviews – A review of the measurement of caregiver and family burden in palliative care. Journal of Palliative Care, 14(2), 37-45.	68	not 1
Klass, D. (1986-87)	Marriage and divorce among bereaved parents in a self-help group. Omega. 17, 237-249.	69	not 2c
Klass D. (1992-93).	The inner representation of the dead child and the world views of bereaved parents. Omega, 26(4), 255-272.	70	not 2c
Klass, D. (1933)	Solace and immortality: Bereaved parents' continuing bond with their children. Death Studies, 17, 343-368.	180	Not exclusively 2c.
Klass, D. (1997)	The deceased child in the psychic and social worlds of bereaved parents during the resolution of grief. Death Studies, 21(2),	183	Not 1
Klass, D. & Marwit, S.J. (1988)	Toward a model of parental grief. Omega, 19(1), 31-50.	71	Not 1
Schwab, S. (1990)	Paternal and maternal coping with the death of a child. Death Studies, 14: 407-422.	30	not exclusively chronic illness
Kopecky, E.A. et al (1997)	Review of a home-based palliative care program for children with malignant and non-malignant disease. Joiurnal of Palliative Care, 13(4), 28-33.	72	not 1
Krell, R. & Rabbin, L. (1979)	The effects of sibling death on the surviving child: A family perspective	73	not 2c
Krell, R. & Rankin, L. (1979)	After the child dies. Journal of Pediatrics, 88, 140-146.	75	not 2c
Laizner, A.M. et al (1993).	Needs of family caregivers of persons with cancer: A review. Seminars in Oncology Nursing, 9(2), 114-120.	76	Not pediatric. review
Lang, A., Gottlieb, L.N., & Amsel, R. (1996)	Predictors of husbands' and wives' grief reactions following infant death: The role of marital intimacy. Death Studies, 20 (1), 33-57.	181	Not exclusively 2c
Lauer, M.E. (1997)	Ongoing challenges in pediatric hospice care. Acta Paediatrica, 1037-1039.	77	not 1
Lauer, M.E. et al (1986)	Utilization of hospice/home care in pediatric oncology. Cancer Nursing 9(3), 102-107.	79	not 1
Lehna, C.R. (1998)	A childhood cancer sibling's oral history. Journal of Pediatric Oncology Nursing, 15(3), 163-71.	81	not 3
Lesar, S., Gerber, M.M., & Semmel, M.I" (1996)	HIV infection in children: Family stress, social support and adaptation. Exceptional Children 62(3), 224-236.	82	

Levetown, M. (1996).	Ethical aspects of pediatric palliative care. Journal of Palliative Care 12(3), 35-39.	83	Not 2 or 3
Levy, M., Duffy, et al (1990)	Home-based palliative care for children – Part I: The Institution of a program. Journal of Palliative Care, 6(1), 11-15	84	Not 2 or 3.
Kempson, D.A. (2001)	Effects of intentional touch on complicated grief of bereaved mothers. Omega, 42(4), 341-353.	166	causes of death unclear; some seem to be sudden death (portion of sample from MADD)
Potts, S., Farrell, M. & O'Toole (1999)	Treasure weekend: supporting bereaved siblings. Palliative Medicine 13, 51-56.	171	Not empirical.
Laakso, H. & Paunonen-Ilmonen, M. (2001)	Mothers' grief following the death of a child. Issues and Innovation in Nursing Practice, 36(1), 69-77.	167	Not exclusively 2cMixed sample 3/4 less than 1 year, 1/3 newborns
Liben, S. (1998)	Pediatric palliative medicine: Obstacles ot overcome. Journal of Palliative Care 12(3), 24-28.	85	Focus on palliative care
Liben S. (1998)	Home care for children with life-threatening illness. Journal of Palliative Care, 14(3), 33-38.	86	not 3
Mahon, M.M. & Page, M.L. (1995)	Childhood bereavement after the death of a sibling. Holistic Nursing Practice, 9(3), 15-26.	87	not 2c
Malacrida, C. (1999)	Complicated mourning: The social economy of perinatal death. Qualitative Health Research, 9(4), 504-519.	88	not 1
Mangurten, H.H. (1990)	Home death and hospital follow-up of the dying infant. Journal of Perinatology. 7(4), 302-306.	89	not 1
Martinson, I. (1996)	An international perspective on palliative care for children. Journal of Palliative Care, 12(3).	90	Not empirical
Martinson, I. & Chang, G. (1993)	Chinese families after the death of a child from cancer. European Journal of Cancer Care, 2, 169-173.	91	not 1
Martinson, I.M.(1995)	Children's hospice. Omega, 31(4), 253-261.	93	Not empirical
Martinson, I.M" & Henry, W.F. (1980)	Home care for dying children. Some possible societal consequences of changing the way in which we care for dying children. Hastings Center Report, 10, 5-7.	96	Not empirical

McCown, D.E. & Davies, B. (1995)	Patterns of grief in young children following the death of a sibling. Death Studies, 19(1), 41-53.	188	Not exclusively 2c
Meyers, H.I. (1989)	Spiritual care in pediatric hospice. The American Journal of Hospice Care, 12.	100	not 1
Miles, M.S. (1992).	A comparison of guilt in bereaved parents whose children died by suicide, accident, or chronic disease. Bereavement Guilt. 203-215.	102	Not exclusively 2c
Miles, M.S. & Crandall, EKB (1983).	The search for meaning and its potential for affective growth in bereaved parents. Health Values: Achieving High Level Wellness, 7(1), 19-23.	103	not exclusively 2c
Miles, M.S. & Demis, A.S. (1984)	Towards the development of a theory of bereavement guilt: Sources of guilt in bereaved parents. Omega, 14(4), 299-314.	104	Not 2c
Moriarty, H.J. Carroll, R., & Cotroneo, M. (1996).	Differences in bereavement reactions within couples following death of a child. Research in Nursing & Health, 19, 461-469.	106	not 2c
Moules, N.J. (1998)	Legitimizing grief: Challenging beliefs that constrain. Journal of Family Nursing. 4(2), 142-166.	107	not exclusively chronic
Mount, B.M. (1994)	Palliative care – A passing fad? Understanding and responding to the signs of the times. Journal of Palliative Care. 10(1), 5-7.	108	Not empirical
Newton, Bergin & Knowles (1986)	Parents interviewed after their child's death. Archives of Disease in Childhood. 61, 711-715.	110	Not 2c
Oliver, L.E. (1999)	Effects of a child's death on the marital relationship: A review. Omega, 39(3), 197-227.	111	not 2c
Papadatou, D. (1997)	Training health professionals in caring for dying children and grieving families. Death Studies, 21(6), 575-600.	112	Not 1
Papadatou, D, Yfantopoulos, J., & Kosmidis, H.V. (1996)	Death of a child at home or in hospital: Experiences of Greek mothers. Death Studies, 20, 215-235	174	Not 3
Pettingale, K.W. et al (1994)	Changes in immune status following conjugal bereavement. Stress Medicine, 10, 145-150.	113	Not 2
Poznanski, E. (1972)	The replacement child: a saga of unresolved parental grief. Journal of Pediatrics, 81, 1190-93.	114	not 2c
Prong, L.L. (1995).	Childhood bereavement among Camobodians: Cultural considerations. The Hospice Journal, 10(2), 51-64.	115	Not 1,2,3

Rando, T. (1985)	Bereaved parents: Particular difficulties, unique factors, and treatment issues. Social Workers, Jan/Feb, 19-23.	116	Not 1
Rando, T.A. (1988)	Anticipatory grief: The term is a misnomer but the phenomenon exists. Journal of Palliative Care, 4(1), 70-73.	118.	Not empirical
Rando, T.A. (1992-93)	The increasing prevalence of complicated mourning: The onslaught is just beginning. 26(1), 43-59	119	Not empirical
Rasmusson, C.H. & Johnson, M.E. (1994)	Spirituality and religiosity: relative relationships to death anxiety. Omega, 29(4), 313-318.	120	not 1
Rosenblatt, B. (	A young boy's reaction to the death of his sister. Journal of the American Academy of Child Psychiatry.	121	not 2c
Roskin, M. (	Suffers for the bereaved: The impact of social factors on the emotional health of bereaving parents. International Journal of Social Psychiatry, 311-319.	122	Causes of death unknown
Roy, D.J. (1998)	Home care: Images and reflections. Journal of Palliative Care. 14(3), 3-5.	123	Not 1
Ruden, B. (1996)	Bereavement follow-up: An opportunity to extend nursing care. Journal of Pediatric Oncology Nursing, 13(4), 219-225)	124	not 1
Sagara, M. & Pickett, M. (1998)	Sociocultural influences and care of dying children in Japan and the United States. Cancer Nursing, 21(4), 274-281.	125	Not 1
Sanders, C.M. (1979-80)	A comparison of adult bereavement in the death of a spouse, child, and parent. Omega, 10(4), 303-322.	126	Not 2c
Sanders, C.M. (1982-83)	Effects of sudden vs chronic illness death on bereavement outcome. Omega, 13(3), 227-241.	127	not 2C
Schriever, S.H. (1990)	Global Exchange. Journal of Palliative Care, 6(1), 42-49.	129	Not 1
Schulz, R. et al (1997)	The effects of bereavement after family caregiving. Aging & Mental health, 1(3), 269-282.	130	Not 1
Schwab, R. (1990)	Paternal and maternal coping with the death of a child. Death Studies, 14, 407-422.	179	Not exclusively 2c

Schwab, R. (1996)	Gender differences in parental grief. Death Studies, 20(2), 103-113.	182	Not exclusively 2c (50% of cases murder, suicide, accident.
Schweitzer, S.O., et al (1993)	The costs of a pediatric hospice program. Public Health Reports, 108(1), 37-44.	131	Not 3
Segal, S., Fletcher, M., & Meekison, W.G. (1986)	Survey of bereaved parents. Canadian Medical Association Journal. 134(1). 38-42.	132	Not 2c
Sidmore, K.V. (2000)	Parental bereavement: levels of grief as affected by gender issues. Omega, 40(3), 351-374.	128	not 2c
Shapiro, E.R. 1995).	Grief in family and cultural context: Learning from Latino families. Cultural Diversity and Mental Health, 1(2), 169-176.	133	not 2c
Smart, L.S. (1993)	Parental bereavement in Anglo-American history. Omega, 28(1), 49-61.	135	not 2 or 3
Stajdhuhar, K.I. & Davies, B. (1998)	Death at home: Challenges for families and directions for the future. Journal of Palliative Care, 14(3), 8-14.	137	Not 1
Stein, A. et al (1989)	Life threatening illness and hospice care. Archives of Disease in Childhood. 64, 6976-702	138	not 1
Talbot, K. (1996)	Transcending a devastating loss: The life attitude of mothers who have experienced the death of their only child. The Hospice Journal, 11(4), 67-82)	139	not 2c – 73% accidental
Talbot, K. (1997)	Mothers now childless: Survival after the death of an only child. Omega, 34(3), 177-189.	140	not 2c – 73% accidental
Talbot, K. (1997-98)	Mothers now childless: Structures of the life-world. Omega. 36(1), 45-62.	141	not 2c
Talbot, K. (1998)	Mothers now childless: Personal transformation after the death of an only child. Omega, 38(3), 167-186.	142	not 2c
Tong, K.L. (1994)	The Chinese palliative patient and family in North America: a cultural perspective. Journal of Palliative Care. 10(1), 26-28.	144	not 1 or 2
Vachon, M.L.S. (1994)	Psychosocial needs of patients and families. Journal of Palliative Care. 14(3), 49-56.	145	not 2
Vernick, J. & Karon, M. (1965)	Who's afraid of death on a leukemia ward? American Journal of Diseases in Children. 109, 393-397.	146	not 2 a or b

Videcka-Sherman, L. (1982)	Coping with the death of a child: A study over time. American Journal of Orthopsychiatry. 52(4), 688-698.	147	not 2c – maj. accidental or murder
Videck-Sherman, L. & Lieberman, M. (1985).	The effects of self-help and psychotherapy intervention on child loss. American Journal of Orthopsychiatry, 55, 70-82.	148	not 2c
Walker, K.N., MacBride, A., & Vachon, M.L.S. (1977)	Social support networks and the crisis of bereavement. Social Science & Medicine, 11, 35-41.	149	not empirical
Wallace, B. (1995)	Suffering, meaning, and the goals of hospice care. The American Journal of Hospice & Palliative Care, May/Jue, 6-9.	150	not empirical
Weggel, J.M. (1997)	Palliative Care: New challenges for advanced practice nursing. The Hospice Journal, 12(1), 43-56.	151	not empirical, not 2 or 3
Wheeler, I. (1993-94)	The role of meaning and purpose in life in bereaved parents associated with a self-help group. Compassionate Friends. Omega, 28(4), 261-271.	152	Not 2c, includes suicide.
Whitfield, J.M., Siegel, R.E., Glicken, A., Harmon, R.J", Powers, L.W., Goldson, E.J. (1982).	1The application of hospice concepts to neonatal care, 136., 421-424	153	Not empirical
Whittam, E.H. (1993)	Terminal care of the dying child – Psychosocial implications of care. Cancer (Supplement). 71(10), 3450-3462.	154	Not empirical
Williams, P.D. (1997)	Siblings and pediatric chronic illness: A review of the literature. International Journal of Nursing Studies, 34(4), 312-323.	155	not 3
Worden, J.W., Davies, B., McCown, D. (2002)	Comparing parent loss with sibling loss. Death Studies, 23(1), 1-15.	187	Not exclusively 2c
Wyatt, G.K. et al (1999)	A profile of bereaved caregivers following provision of terminal care. Journal of Palliative Care, 15(1), 13-25.	157	not 2c
Zelauskas, B. (1991).	Siblings: the forgotten grievers. Issues in Comprehensive Pediatric Nursing, 5, 1-31.	158	Not empirical

Article #_________

Appendix G

Version #4

Checklist for Measurement of Study Quality

Title of Article:____

Authors: ____**Year**_________

Reviewer:________________________**Date of Review:** __________________

Give only one rating for each category: If characteristic is present, mark **Yes (1)** If the characteristic is absent, mark **No (0).** If you are not certain, mark **Unable to Determine (?).** **If** the category is not applicable, mark **NA.** Total the scores for each category.

CRITERION	SCORE
1.0 Reporting	
1.1 **Is the purpose of the paper clearly stated?** Yes – There is a clear statement of what the researchers were trying to find out, why it is important, and what is its relevance. This can take the form of clearly stated objectives, questions, or hypotheses. No – Purpose is not stated or the purpose is poorly or unclearly stated.	
1.2. Does the background section clearly justify the study? Yes – There is evidence of a literature review focusing on pertinent, up-to-date literature available at the time. - A sense that literature is evaluated and that the evaluation is even-handed No – No evidence of a literature review or literature review is scant	
1.3. **Are the variables and/or phenomena of interest clearly described?** If the following terms are used, are they defined and used consistently throughout the report? e.g. *grief, mourning, bereavement, bereavement outcome, adjustment, adaptation, coping.*	
1.4. Are the characteristics of the people in the sample clearly described, including inclusion and exclusion criteria? Yes – Clear description of inclusion/exclusion criteria, characteristics of people, size of sample, number of groups (if appropriate). Selection of sample (informants, settings, events) is described including identification of source population. No – Description lacks significant detail.	
1.5. **Is the description of ALL aspects of the method explicit enough to permit replication?** Yes – Clearly stated purpose, clear description of sample selection and how assigned to groups, clearly described methods of data collection and analysis. No – Above criteria only partially met.	
1.6 **Are the main findings of the study clearly described?** Yes - Outcome data should be reported for all major findings so that the reader can check the major analyses and conclusions. Main outcomes to be measured should be described in the introduction and methods section.	

CRITERION	SCORE
1.7 **Generalizability/transferability. Are the purpose of the study, context and/or setting and sample described in sufficient detail that the reader can determine generalizability/transferability?** Yes – Are there sufficient details regarding the setting? (should indicate if setting is typical or representative of care settings and in what respects). There should be some attempt to rule out selection bias by comparing dropouts/refusals to participants. Study should be set in a broader context in terms of findings and relevant theory.	
1.8 Is relevance of findings to clinical practice explicitly addressed?	
1.9 Are recommendations for further research explicitly addressed?	
Sum =	

CRITERION	SCORE
2.0. **Research Method**	
2.1. Is the overall design appropriate for the questions/hypotheses of the study?	
2.2. **Was the sample method appropriate to address the purpose?** Yes - For example, if quantitative method is chosen, is random or consecutive sampling chosen? If qualitative method is chosen, is respondent-driven sampling appropriate?	
2.3. Was the method of data collection appropriate to address the purpose? Yes – data collection protocol is described. Role researcher adopts in setting (if qualitative) is described. Process of field work is described (How data elicited, type and range of questions, interview guide, length and timing of observation work; note taking) No – Description lacks significant detail (e.g. "an interview was conducted", "questionnaires were administered", "available data were used").	
2.4. **Is the data analysis appropriate to achieve the purpose of the study?** (Were study participants contacted to verify results, if appropriate? If statistical tests were used, are they appropriate?) Yes – Outcome measures are well-validated. There is adequate evidence to support analysis.	
2.5. Do the findings logically derive from the data analysis? No - There are missing data - inappropriate data analysis to justify stated findings.	
2.6. Are conclusions logically derived from findings	
2.7. Are recommendations for clinical application consistent with findings?	
2.8 Are recommendations for further research consistent with findings?	
Sum =	
TOTAL SUM =	

Comments:

Appendix H

Version #3

DATA EXTRACTION FORM

General Information

Study Unique Identifier: ________

Title: ____

Author(s): ____

Journal: ____

Year of Publication: __________ **Country:** ______________ **Language:** ____________

Years Data Collected: ____

Reviewer: __________________

Funding Source for study (please check one):

Government_________________
Private______________________
Unfunded____________________
Unclear______________________

Notes: (E.g.: If study is reported in other journals, please record)

____
____
____
____
____
____
____

Discipline: (Check discipline of journal with a J and of primary author with an A)

Health Sciences:

_____Nursing
_____Medicine
_____Health Promotion/Public Health
_____Other (Please specify________________________)

Social Sciences:

_____Sociology
_____Psychology

Other (Please specify): _______________________________________

Quality Score: Reporting: ___________
Methodology:__________
TOTAL: ___________

Specific Information

Purpose:

Aims of Study (Research Question(s)/Hypotheses:

Aims of this paper (if different from above):

Study Population (Sample) Characteristics & Setting

Sample size: ______________________________

Sample Characteristics:

Inclusion/Exclusion criteria: Specified Yes __________ No________

If yes please list:______________________________

Children (deceased): # of children: ___________ Age ranges:__________________

If breakdown by gender given:

#of males_____________________ Ages___________________________

#of females___________________ Ages___________________________

Diagnoses: ____

Average length of illness: ______________________________

Other characteristics: __________________________________

____

Family Members:

# of parents ______________ **Age Range**______________

# of fathers______________ **Ages**______________

# of mothers______________ **Ages**______________

Siblings (Record gender and age if given) ______________________

____

____

Other (List other pertinent family characteristics):______________________

____

____

____

____

____

Setting for palliative care (Mark all that apply):

______**Hospital**
______**Home**
______**Hospice**
______**Other (specify**______________________________**)**

Location:

______**Urban**
______**Rural**
______**Unspecified**
Other (specify,e.g. geographical location ______________________
____**)**

Research Design (Methods):

Quantitative: **Yes** **No**
(Skip if not applicable)

______**Prospective**
______**Retrospective**

Qualitative: **Yes** **No**
(Skip if not applicable)

______**Grounded Theory**
______**Phenomenology**
______**Ethnography**
______**Other (please specify):**__________________________

Design: (Mark all that apply ✓)

Level I: **Exploratory/Descriptive**

Exploratory __________________
(Sample: Small or total population.
Methods: Qualitative and unstructured data
Analysis: Content analysis and constant compartison)

Descriptive __________________
(Sample: Total population or sample
Methods: Mixed: qualitative, quantitative, structure, unstructured, data
Analysis: Descriptive statistics; content analysis; charts and graphs)

Level II: **Descriptive Survey**

Correlational ________________
(Sample: Probability – as large as possible
Methods: Structured or quantitative data collection
Analysis: Correlational analysis or tests of associations

Comparative ________________
(Sample: Nonrandom assignment to groups
Methods: Structured or quantitative data collection
Analyhsis: Differences between group means)

Level III: **Experimental**

Quasi-experimental ________________
(Sample: Nonrandom assignment to groups
Methods: Structured or quantitative data
Analysis: Differences between sets of scores)

Experimental ____________________

(Sample: Random assignment to groups
Methods: Structured or quantitative
Analysis: Differences between sets of scores)

Other (specify): ______________________________

Instruments used: (Please list) ______________________________

Research Variables:

Independent: ______________________________

Dependent: ______________________________

Analysis: **(describe – i.e. outline type of analysis done and whether or not it was appropriate)** __________

Findings

(List prominent themes that emerge from the data)

Other **(e.g. comment on whether links to theory are made)**

Definitions (Please write definition. If word used, but no definition provided, please indicate with a check mark ✓ If other definitions used (e.g. "terminal phase"), please record. __________

Bereavement____

Bereavement Outcome____

Mourning____

Grief____

Adjustment____

Adaptation____

Coping____

Other____

# of references cited ____

Appendix I
Data Synthesis Table

ID#	Quality Score	Author/Year Location Discipline	Purpose	Sample	Method	Themes and Limitations
136	T = 16 R = 8 M = 8	Spinetta, J.J. Swarner, J.A. Sheposh, J.P. 1981 U.S.A. Medicine	To study effect of communication patterns on coping. Goals: (1) to determine if families adapted well to life without child (2) are differences in level of adjustment due to ways in which parents handle diagnosis, treatment regimen.	23 sets of parents whose child died from cancer within 3 years in one of two centres (California) siblings in 21 families 2 sets of parents divorced and 1 set separated prior to diagnosis. Sample demo details unknown Diagnosis - cancer	Level 1: Descriptive Pilot Study Taped interviews – content analysis Postdeath Adaptation Measure Multiple regression of five variables derived from interviews	1. Age of child at death not related to long-term level of parental adaptation. 2. Best adjusted parents: (a) had consistent philosophy of life during course of illness (b) who had a viable and ongoing support person to whom they could turn (c) who gave child information and emotional support at level consistent with child's questions, age, and developmental level. 3. Family coping efforts during course of illness can make a difference in post death adaptation.

ID#	Quality Score	Author/Year Location Discipline	Purpose	Sample	Method	Themes and Limitations
164	T = 16 R = 8 M = 8	Wood, J.D. Milo, E. 2000 U.S.A. Educational Psychology *cf #175	1) What is the subjective emotional experience of fathers who have lost a child with developmental disabilities, and how is it unique? 2) How do fathers who have parented a child with a severe developmental disability and then lose that child manage to cope and make sense of their experience? 3) What strategies do they use to cope? 4) What variables may account for individual differences among the fathers? 5) How do fathers' responses differ from mothers' as reported by Milo (1997)?. 6) When a child with a developmental disability dies, what can healthcare professionals and	8 fathers 3 from The National Fathers' Network 3 referred by others 3 had wives in a similar project 2 small towns in agricultural area, and 1 rural. All married with children Deceased children: ages 5 months to 16 years. 4 male, 4 female. Diagnoses: microcephaly, agenesis of corpus callosum, lissencephaly, epilepsy and hypomelanosis of Ito, cerebral palsy with cataracts, spastic quadriplegia and seizures.	Level 1: Descriptive Semi-structured interviews – 11/2 to 2 hours. GEI (Grief Experience Inventory) – 135 items, 12 scale profile subscales including Denial, Atypical responses, Social Desirability. Bereavement: despair, anger, guilt, social isolation, loss of control, rumination, depersonalization, somatization, and death anxiety. Focus group once themes consolidated and developed (4 fathers attended) Analysis: constant comparative analysis GEI – fathers	GEI: fathers did not differ by more than one standard deviation from the other two groups on any scale. Interviews: 1. Bereavement marked by a double loss: disability then death. 2. Fathers used stoicism 3. Primary coping strategy: activity rather than talk or social support. 4. All experienced isolation, first by disability, then by death. 5. Dominant theme – valued professionals who were straightforward with information. Intense need for facts. Felt angry and helpless with professionals. Anger at professionals gave focus to the anger and helplessness of grief. 6. 3 themes/models for the father role: protector, ally, or seeking distance from family

			specialists in death and dying do to help fathers cope in an optimal way?		compared to mean of reference group of bereaved parents and to mean of mothers in similar study (Milo, 1997).	and pain of loss. 7. Celebrating and normalizing child: each father identified features or memories that made child unique. 8. Two distinct styles to fathers' stories: used two metaphors – hunter and ministry. "hunters" told stories with directness that was scientific or clinical. Experiences reinforced a fatalistic attitude to life. "ministry" metaphor – fathers described grieving as more emotionally expressive with a community. public aspect of grieving brought comfort. Active in Fathers' Network, law, or church. Commented more frequently Study supports recent findings that many marriages remain strong. Focus group: showed that men grieved for their wives. Fathers adamant that men do not grieve less – feel they grieved significantly differently

						from wives. In general, lack of social support for fathers. Limitations: Self-select process of participating in study influences type of subject. Divorced fathers were difficult to recruit.

ID#	Quality Score	Author/Year Location Discipline	Purpose	Sample	Method	Themes and Limitations
175	T= 16 R = 8 M = 8	Milo, E.M. 1997 U.S.A. Ed. Psych *cf #164	1. What is the experience of mothers who have lost a child with a developmental disability, and how is it unique? 2. Do mothers who have parented a child with a developmental disability through emotionally challenging months or years, only to lose that child, manage to cope and make sense out of their experience, or do they experience a sense of devastation and hopelessness? 3. What strategies do mothers use to regain a sense of hope, mastery, and control in a world that has been challenged by the birth and then the death of their developmentally disabled child. 4. Are coping strategies used by all of these	8 mothers selected from a roster of approx. 20 compiled by local Assoc. for Retarded Citizens parent outreach coordinator. 4 mothers had attended special loss bereavement group. 4 recruited by letter or phone from a list of those invited but declined to join group Ages 31 – 72; 5 30-39, 1 = 40, 1= 51, 1 = 72.	Level 1: Descriptive. Semi-structured, open-ended interview (Questions listed). GEI self- admin., mailed in after interview. Interviews – constant comparative analysis Analysis recursive – moved between theoretical framework of bereavement, parenting child with disability, cognitive coping strategies, and the data. GEI -	1. Mothers felt set apart because their love for child and their loss were not validated by others. 2. Mothers had to work through two difficult transitions. 3. Mothers, generally felt this was not an experience they would have expected or welcomed, but that it had been one of the defining experiences of their lives and had transformed them in positive ways. 4. The experience had power to profoundly shift the mothers' sense of identity, world view, relationships, spirituality, and priorities, sometimes first with the birth and parenting experience and once again with loss of child. 5. Mothers usually able to restore sense of well-being in the world, both after birth or

			mothers, and what differences may be associated with those who do and do not use the strategies? 5. When the early death of a child with a developmental disability is inevitable, what can professionals specializing in death and dying do to help families cope in an optimal way?			diagnosis, and once again after death of their "special child". 6. Mothers used the cognitive coping strategies of construing benefits or gains, finding meaning, re-establishing control, and using homour more than they used downward comparison. 7. There were differences in the use of cognitive coping strategies associated with outcome. 8. Two mothers were exceptional cases that did not fit the more typical pattern. One mothers' assumptive world was not shattered and she did little cognitive shifting. Another continues to see world as unpredictable and dangerous. Mothers use many cognitive coping strategies to transform their experience from one of pain to one of growth and meaning.

ID#	Quality Score	Author/Year Location Discipline	Purpose	Sample	Method	Themes and Limitations
173	T = 16 R = 9 M = 7	Birnbaum, LK 2000 U.S.A. (published in UK) Nursing *cf #10, #173	Can bereavement behaviours (those outside the normal for age) be identified from a well established behavioural problem instrument? If so, can these behaviours be measured in a short children's bereavement questionnaire?	61 children from 37 families 75% of families referred, agreed to participate 8 families = child did not die during study 6 families = entered post death 4 families = study ended before eligible for 4th data point. Maximum # children at one time = 51 Referrals: 3 major medical centres, 6 private practising physicians in 2 western states of U.S.A. Predominantly Caucasian, 5 families with minority member. 56% fathers and 61% mothers with post secondary ed. 30 siblings = male 31 siblings = female Diagnoses: cancer	Level 1: Descriptive (An exploratory secondary analysis from a prospective longitudinal design that examined the effects of home care on families' responses to dying and death (Birnbaum, 1987). CBCL – 112 item parent form Groupings 3-5, 6-11, 12-19 years. Data analysed (cross-sectional) for most frequently reported behaviour problems approx. 2 months prior to death. A particular behaviour had to be reported by at least 30% of parents prior to death and 12 months after deaths. Generated 34 items used to describe and compare siblings' psychosocial responses.	Adolescents may be more at risk than other age groups – they show more age-adjusted bereavement behaviours than other groups. Provides basis for future testing – no definitive conclusions can be drawn. Limitations: multiple siblings and issue of independence of data not addressed. No indication of what siblings like prior to diagnosis.

ID#	Quality Score	Author/Year Location Discipline	Purpose	Sample	Method	Themes and Limitations
30	T = 15 R = 7 M = 8	Davies, B. 1987 Canada Nursing *cf #27, #31	Description of what 34 families did with deceased child's clothes.	34 families of total pop 39 ¾ Washington & Arizona ¼ Alberta source: 2 pediatric oncology clinics, pediatric oncologist private practice, Candlelighters group. deceased children: 32 males ages 1 – 19; 2 female. Illness length from less than 12 months to more than 36 months. parents 35 – 44 years 12 families – death within 12 months of interview; for 14 within 13 to 24 months; and for 8 families, between 25 and 36 months since death. siblings 34 female and 21 male, aged 6 – 16 years. Diagnoses: cancer. one pretest- cardiac	Level 1: Exploratory semi-structured interviews of families with siblings present (2 ¼ hrs; 12 cases used for creating categories for content analysis key words and ideas recorded by hand.	Belongings are memories with meanings – meanings may vary among family members. Discrepant meanings can influence bereavement outcome.

ID#	Quality Score	Author/Year Location Discipline	Purpose	Sample	Method	Themes and Limitations
99	15 R=8 M=7	McClowry, SG Davies, EB May, KA Kulenkamp, EJ Martinson, IM 1987 U.S.A. Nursing *cf #47, #94, #99	To describe what happens to families several years after experiencing a death from childhood cancer.	49 of 58 families 28 couples interviewed together (7-9 years after child's death). 150 interviews with 46 mothers, 33 fathers/stepfathers and 71 siblings. Mothers' mean age = 44.4 Fathers' mean age 41.9 (4 fathers died since child's death) Siblings' mean age = 18.7 Minnesota	Level 1: Exploratory Semi-structured interviews; audiotaped. Analysis: grounded theory: constant comparative analysis (hypothesized connections between categories – propositions generated to reflect relationship of concepts – hypotheses proposed in form of substantive theory)	1. Time required for bereavement process longer than 1 or 2 years (After 7-9 years, family members till express pain and loss). 2. Instead of "letting go" families outline presence of an "empty space" in their lives. 3. Three different patterns of grieving: "getting over it", "feeling the emptiness", and "keeping the connection".

ID#	Quality Score	Author/Year Location Discipline	Purpose	Sample	Method	Themes and Limitations
169	T = 12 R= 7 M = 5	Heiney, S.P. Ruffin, J. Goon-Johnson, K. 1995 U.S.A. Nursing	To investigate the effects of participation in a support group on selected parameters of psychosocial functioning of bereaved parents whose child died from cancer.	99 families from pediatric oncology centre invited 5 parents who attended all seven sessions included. 2 fathers, 3 mothers (2 couples) participated in Bereaved Parents Support Group (BPSG). ages 21 – 48 (M= 37). Time since child's death (2-26 months, M = 19 months)	Level 1: Descriptive one group pretest/post-test design: data collection before second group session and after 7th session. EPI: Emotions Profile Index Cohesion Evalluation Scales III (FACES-III) to measure family adjustment. Social Adjustment Scale Self-Report (SAS-SR) to measure social adjustment. Bereaved Parents Support Group Evaluation and therapists' process log. Analysis: process log – Yakom's curative	1. No statistically significant differences found on scales. 2. Process log showed: intense pain and grief – continuous struggle to adapt to present and prepare for future. Child's death changed lives. High satisfaction with group sessions. Limitations: Small sample size – nonparametric statistics more appropriate? size too small for comparative analyses.

					factors model. Paired t-tests for EPI Sample means for FACES III and for SAS-SR	

ID#	Quality Score	Author/Year Location Discipline	Purpose	Sample	Method	Themes and Limitations
31	T = 11 R = 5 M – 6	Davies, B. Deveau, E. DeVeber, B. Howell, D. Martinson, I. Papadatou, D. Pask, E. Stevens, M. 1998 U.S.A. & Europe Nursing *cf #27, #30	To describe: How mothers experienced: diagnosis of cancer in child. terminal period of child's life coping with death	21 mothers aged 28-46 (M32.6) – with child who had died of cancer up to 6 months prior to interview. 8 from Canada 5 from Norway 4 from Greece 2 from Hong Kong 2 from U.S.A. diagnoses: wide-range home/hospital sample method unclear	Level I: Descriptive used SCL-90 Semi-structured (30-90 minute interviews) 4-point Likert scale re: health care workers Analysis: SCL-90 data tabulated for means and SD's – not reported in this article. SS inter – analyzed in IWG meeting. pairs of researchers coded 2 mother's data, then team reflected.	1. Almost no difference among mothers from different countries. Coping with bereavement: comfort from supportive relationships. most difficult – missing child's presence difficulty with emotions of grief(pain, dizziness, lack of sleep) 58.8% say fathers having most difficulty. Experienced changes within selves, e.g. turn to or from religion, become more considerate of others and assertive, increased coping skills, more readily express anger, more isolated (3), some closer . 43.9% changes in family communications. 28.6% guarded communications. Regrets = actions/interactions with child. For some regret rooted in lack of consistency in staff caregiving. preferred to care for children at home.

ID#	Quality Score	Author/Year Location Discipline	Purpose	Sample	Method	Themes and Limitations
27	T = 10 R = 6 M = 4	Davies, B. 1988 Canada Nursing *cf #30, #31	To describe family environments of families in which a child died from cancer. To compare those families with normal and distressed families To examine relationships between family environments and CBCL results of siblings	34 families, child died of cancer 2 – 36 months prior to data collection. one surviving child 6-16 yrs Dec child: 23 male, 11 female, aged 1-19. Siblings; 14, 6- 11 and 20 12-16. 30 families – 2 parent Arizona, Washington, Alberta Diagnoses: Cancer	Level 1: Descriptive Family Environment Scale CBCL (Total Behaviour problem scales, total internalizing, total externalizing, total social competence. Interview re sibling response, parent and family responses. Descriptive stats for FES and CBCL content analysis	The larger the number of surviving children, the greater the extent of participation in social and recreational activities and greater extent to which rules and procedures used to run family life. FES scores indicated bereaved families more like normal than distressed families. Families with higher Cohesion, Active/Recreational Orientation, and Moral\Religious emphasis have children with fewer behavioural problems up to 3 years after siblings' death. The higher the score, the higher the social competence.

ID#	Quality Score	Author/Year Location Discipline	Purpose	Sample	Method	Themes and Limitations
11	T =10 R = 5 M = 5	Birenbaum, LK Robinson, MA 1991 UK Nursing *cf #10, #173	An investigation of families' responses to their child's dying and death from cancer.	87 parents + 34 parents from 19 families home/hospital/hospice urban Diagnoses: cancer	Level 1: Descriptive (cross-sectional) Family Relations Index (family expression, cohesion and conflict) Health Services Utilization Interview (I professional services & II care activities	Cohesion and expression are higher than the norm after death (but not before) – grief reaction following the death of a child represents a developmental crisis which has growth-promoting qualities. Opportunities for positive change & growth.

ID#	Quality Score	Author/Year Location Discipline	Purpose	Sample	Method	Themes and Limitations
10	T = 10 R = 5 M = 5	Birenbaum, LK Robinson, MA Phillips, DS Stewart, BJ McCown, DE 1989 U.S.A. Nursing *cf #11 & #173	To investigate patterns of behavioural responses of children during and after the terminal phase of their sibling's illness (1year post death)	37 total families 61 siblings, but 13 with data at all 4 points. (aged 4 to 16 years) 2 western states, 3 major medical centres Diagnoses: cancer cf: #11	Level 1 Descriptive. Prospective repeated measures (4) CBCL – Parents – Total Behaviour Problem Scale, 2 subscales – Internalizing and Ext. Beh., Social competence. Teachers: Adaptive Functioning Scale	Primary finding: siblings of children who are ill with or who have died from cancer exhibit high levels of internalizing and externalizing behaviour problems and significantly lower levels of social competence than normal children. Internalizing scale significantly diff at all 4 points: indicates somatic complaints, depression, social withdrawal, obsession anxiety, immaturity, obsessive compulsion, and uncommunicativeness. Early assessment and intervention recommended for children prior to death of sibling.

ID#	Quality Score	Author/Year Location Discipline	Purpose	Sample	Method	Themes and Limitations
47	T = 9 R = 4 M = 5	Gilliss, C.L. Moore, I.M. Martinson, I.M. 1991 U.S.A. Nursing *cf #47, #94, #95	To determine the applicability of the SCL-90R for assessing parental bereavement.	77 families - 2 cohorts of parents of children who had died 2 years earlier from cancer. Already in longitudinal study. no data on refusals or withdrawals. 56 mothers aged 22-60(M37) Minneapolis/St. Paul North Dakota, Wisconsin	Level 1 Descriptive Exploratory factor analysis Semi-structured interviews SCL-90R administered at home	Exploratory factor analysis showed one predominant factor that accounted for 30% of variance in self-reports of distress – many items reflected a somatic rather than a behavioural expression of distress.

ID#	Quality Score	Author/Year Location Discipline	Purpose	Sample	Method	Themes and Limitations
117	T = 9 R = 5 M = 4	Rando, T. 1983 U.S.A. Nursing	Hypotheses not stated. 8 variables hypothesized to influence parental grief and adaptation. 1. amount of support during terminal illness 2. amount of previous losss 3. sex of parent 4. parental evaluation of child's treatment 5. parental anticipatory grief 6. parental participation in child's care during hospitalization	54 parents (27 couples) **Inc/Exc:** parents living together reside 3 hrs drive from Cleveland; child dies from cancer 2 month to 3 years previously. Age range of parents: 26 to 58 (M=40). 3 fathers not biological parents 41% both parents work 1 set of black parents rest Slovak/German Diagnoses: cancer	Level I Descriptive Retrospective Grief Experience Inventory (GEI) Parental Experience Assessment Form (PEAF) Structured Interview (Audiotaped) – open-ended questions Hospital Medical charts Analysis: Chi sqare Exact probabilities method for calculating p when expected frequency less than 5 Student E test	1. Parental bereavement may not diminish over time; may intensify. 2. Need research to study what is "appropriate" and "optimum" amount of anticipatory grief and parental participation in hospitalization. 3. parents where children had longer illnesses (more than 18 mo) and who had had high previous loss, do poorer. lessens coping ability increases intensity of anger and hostility. 4. Support during illness facilitates process of anticipatory grief and is associated with less abnormal grief after the death. 5. Mothers and fathers similar in grief.

ID#	Quality Score	Author Year Location	Purpose	Sample	Method	Themes and Limitations
95	T = 8 R = 5 M = 4	Martinson, I.M. Davies, E.B. McClowry, S.G. 1987 U.S.A. Nursing *cf # 47, #94, #95, #99	1. What is the long-term effect, if any, on the self-concept of children whose sibling died from cancer? 2. Within the group of bereaved siblings, what factors may contribute to optimal level of self-concept?	58 families (71 siblings) Midwestern families in home care program for dying child (Martinson, 1980) 7-9 years post death Average length of illness: 24.5 months. Siblings: 29 9-18 years of age (M=8.5 years) Diagnoses: cancer?	Level 1: Descriptive Piers Harris Self-concept scale Descriptive stats one sample t-test to compare sample to standardized means content analysis of 6 highest and 6 lowest scores	1. Comparing unfavourable to deceased sibling – low esteem. High esteem seen as special by parents. 2. Feeling displaced – by addition of other children to replace deceased child low concept. reinforced feelings of responsibility for death. high esteem – parents complimentary – refered as valued & special manifests in over-achieving and parental caregiving. high esteem parent siblings while low esteem looked after parents. Limitation: self-concept not measured prior to death. home care program may have provided optimal experience for families.

ID#	Quality Score	Author/Year Location Discipline	Purpose	Sample	Method	Themes and Limitations
78	T = 8 R = 3 M = 5	Lauer, M.E. Mulhern, R.K. Bohne, J.B. Camitta, B.M. 1985 U.S.A. Nursing	To examine children's perceptions and involvement during their sibling's terminal home care or hospital experience and to correlate those factors to subsequent adjustment after the sibling's death.	Population unknown Home Care – 12 families; 19 siblings = 9 male 10 female Hospital – 7 families: 17 siblings = 9 male 8 female Care Setting: home hospital (Milwaukee Children's) Diagnoses:	Level 1: Exploratory Qualitative Semi-structured interviews with open-ended questions. 3 time periods: weeks preceding death time of death 1 year post death	1. Home care siblings were prepared for death, received consistent information and support from parents, were involved in most activities, present for the death, and viewed own involvement as most important aspect of experience. 2. Non-home care: inadequately prepared, isolated from dying child and parents, unable to use parents for support and information, unclear as to circumstances of death and useless in terms of their involvement.

ID#	Quality Score	Author/Year Location Discipline	Purpose	Sample	Method	Themes and Limitations
74	T = 8 R = 3 M = 8	Lauer, M.E. Mulhern, R.K. Schell, M.J. Camitta, B.M. 1988 U.S.A. Nursing *extension of #78, #80 and #109	To determine whether the favourable adjustment of home care parents in early bereavement is predictive of a more satisfactory resolution of grief on a long-term basis. Whether early evidence of less favourable adjustment of non-home care parents had diminished, intensified, or remained constant over time.	Home Care: 24 families; 23 mothers, 17 fathers Mean Age = 41 Non Home Care – 12 mothers, 10 fathers Mean age = 47 Treated at Midwest Children's Cancer Centre. Time since death: HC = M7.1 years NHC = M 7.2 years Duration of terminal care: HC = 19 months NHC = 17 months white, middle to lower socio-economic Population unknown Diagnoses: cancer	Level 1: Descriptive Structured questionnaires (not described) Minnesota Multiphasic Personality Inventory (MMPI – 168) completed in homes and mailed in with follow-up telephone call Analysis: chi square Fisher's exact test t-tests – MMPI	HC and NHC report significantly different patterns of bereavement. HC – first month post death most difficult NHC – 6 months and then 1st month HC- spouse primary support; NCH clergy, friends, support groups. 16% of HC and 45% of NHC sought mental health services. Home care parents report significantly stronger relationships with spouse and siblings, firmer religious connections, more adequate coping abilities and less residual guilt. MMPI – NHC more frequent indications of maladjustment including somatization, depression, and interpersonal problems. More optimal adjustment of HC reported 5 years earlier has been maintained.

ID#	Quality Score	Author/Year Location Disciline	Purpose	Sample	Method	Themes and Limitations
109	T = 8 R = 4 M = 4	Mulhern, R.K. Lauer, M.E. Hoffman, R.G. 1983 U.S.A. Nursing *cf #74, #78, #80	That following the patients' death, parents and siblings of patients provided with home care would manifest fewer indications of individual psychopathology and family dysfunction than parents and siblings of patients who did not have home care.	37 deceased children Home care: 23 fathers, 16 mothers, age range 25-54 (M=35). Non-Home care: 23-54 (M=41). Siblings: HC = 9 male, 19 female (4-13 years, M=7), 8 acute leukemia, 16 solid tumours NHC = 6 male 11 female (5-13 years, M=7). Diagnoses: 4 acute leukemia, 9 solid tumours	Level 1: Descriptive Parents: MMPI – 168 Minnesota Multiphasic Personality Inventory FES – Family Environment Scale (90 items) Louisville Behaviour Checklist – 164 items.	Parents & siblings of patients provided with home care infrequently display evidence of psychopathology. MMPI – different profiles NH parents more defensive, higher somatic complaints and depressive mood; tendency to deny problems, more difficulty with modulation of expression of anger, impulsiveness and social adjustment. Increased self-doubt, unreasonable fears and anxiety, increased scores on items implying feelings of alienation, confusion, and self-dissatisfaction. tendency to be socially withdrawn and uncomfortable. LBC = NH siblings significant scores on Fear and Neurotic behaviour. increased social isolation, sensitivity and fear, fewer socially valued qualities and more neurotic and somatic behaviours.FES = HC greater degree of family commitment & supporet & greater emphasis on ethical and religious values.

ID#	Quality Score	Author Year Location	Purpose	Sample	Method	Themes and Limitations
95	T = 8 R = 5 M = 4	Martinson, I.M. Davies, E.B. McClowry, S.G. 1987 U.S.A. Nursing *cf # 47, #94, #95, #99	1. What is the long-term effect, if any, on the self-concept of children whose sibling died from cancer? 2. Within the group of bereaved siblings, what factors may contribute to optimal level of self-concept?	58 families (71 siblings) Midwestern families in home care program for dying child (Martinson, 1980) 7-9 years post death Average length of illness: 24.5 months. Siblings: 29 9-18 years of age (M=8.5 years) Diagnoses: cancer?	Level 1: Descriptive Piers Harris Self-concept scale Descriptive stats one sample t-test to compare sample to standardized means content analysis of 6 highest and 6 lowest scores	1. Comparing unfavourable to deceased sibling – low esteem. High esteem seen as special by parents. 2. Feeling displaced – by addition of other children to replace deceased child low concept. reinforced feelings of responsibility for death. high esteem – parents complimentary – referred as valued & special manifests in over-achieving and parental caregiving. high esteem parent siblings while low esteem looked after parents. Limitation: self-concept not measured prior to death. home care program may have provided optimal experience for families.

ID#	Quality Scote	Author Year Location	Purpose	Sample	Method	Themes and Limitations
134	T = 8 R = 4 M = 4	Saiki, S.C. Martinson, IM Inano, M 1994 U.S.A. Nursing	To describe what happens in Japanese families who have lost their children to cancer. 1. What happens in families after death of child? 2. What were the family relationships like during this period? 3. How were parents involved in medical treatment? 4. What were the relationships like between parents/mothers & health professionals?	13 families members of Children's Cancer Association of Japan. Child died within 3 years & had at least one sibling 5-18 years old. 11 hospital 2 home Diagnoses: cancer	Level 1: Exploratory Semi-structured interviews analysis unclear	1. sick child became centre of family. 2. Japanese families not comfortable getting outside help. 3. Parental relationships became closer or more distant – in stable families, core systems mother & father and mother & sick child. In unstable families, just mother & child. 4. When family strongly committed to caring for sick child at home, home care worked well. 5. Physicians withheld diagnoses. -13 mothers, 8 fathers had poor health – insomnia, weight loss, etc. mothers' symptoms worse than siblings' or fathers' -parental view of world changed -parents relationships closer or more distant. 9 mothers satisfied with support, 2 neutral. -parents felt closer to sick child especially mothers -only 2 families told child diagnosis -4 families talked to siblings re disease prior to death -many focused on sick child -after death – coping associated

						with level of satisfaction with treatment, support groups, social support, home care & others -6 of 13 mothers had access to support groups -social support from outside family beside grandma, - rare -2 of 13 families chose home care for death - nurses viewed as technicians, not as supports

ID#	Quality Score	Author Year Location	Purpose	Sample	Method	Themes and Limitations
160	T = 8 R = 4 M = 4	Jacob, S. Scandrett-Hibdon, S. 1994 U.S.A. Nursing	To present case studies of 2 mothers grieving the deaths of their children.	2 mothers children: 1 male , 2 years 1 female, 9 mo Cause of death: congenital heart, genetic disorder	Level 1: Case studies Taped semi-structured interviews (themes unknown). Analysis: "grounded theory", but not described.	5 major concepts: distress, protection, rumination, support, acceptance. Major finding is a conceptual definition of maternal grief: "The grieving mother experiences physical and emotional distress, an overwhelming need to review the events surrounding the birth, life, and death of the child, protects herself and others from the pain and loss, seeks and receives support, and gradually proceeds to acceptance." Limitation: methodology unclear

ID#	Quality Score	Author Year Location	Purpose	Sample	Method	Themes and Limitations
162	T = 8 R = 3 M = 5	Saiki-Craighill,S. (Part I) 2001 U.S.A. (study done in Japan in Japanese) Nursing	To describe what Japanese mothers experienced after they lost a child to cancer and what occurred as they worked through their grief.	24 Japanese mothers who lost a child to cancer during the preceding year. Demo details of mothers and children unknown	Level 1: Exploratory 24 mothers who attended a support group were observed and interviewed. Interviews held before and after support group meetings from April 1996 to May 1998. 1 to 2 topics discussed each meeting. e.g. terminal stage, funeral, relationships to husbands and other children. Interviewed again 3 months after support group ended. Data collected and analyzed in Japanese.. concepts categorized and properties and dimensions of core categories and subcategories emerged	Mothers experienced numbing of emotions, followed by grieving period that included depression and difficulties dealing with outside world. As emerged from this, they created a story of their children's lives and deaths in relation to their own lives. Waves of sadness continued, but gradually stabilized. Obligations of Bhuddist services for 49 days and then at 1st and 2nd anniversary, distracted mothers from depression. Limitations: ages of mothers and children unknown.

ID#	Quality Score	Author/Year Location Discipline	Purpose	Sample	Method	Themes and Limitations
165	T = 8 R = 5 M = 3	Collins, J.J. Stevens, M.M. Cousens, P. 1998 Australia Medicine	1. To identify the benefits and difficulties encountered by families during child's palliative care. 2. To suggest strategies to overcome these difficulties. 3. To assess the parents' adjustment following their child's death.	18 of 22 families. 6 to 41 months after child's death. Age of mothers 20 – 51 (M=36). Age of fathers 30 – 60 (M=44) Siblings present at 6 interviews Children: 8 = acute leukemia rest = solid tumours age at death 4 months to 16 years. 16 died at home 3 in local or regional hosp. or RAHC 1 rented accommodation next to RAHC 11 families = Sydney 9 100 to 600 kms from RAHS in areas of NSW. Length of palliative care: 3 to 184 days (M = 34 days)	Level 1: Exploratory Semi-structured interviews and questionnaire. Interviews not recorded. Completed 17 item Current Adjustment Scale at conclusion of interview to measure long-term adjustment of parents. Regression analysis on scales.	Support at bereavement provided by friends, family, ministers, community nurses, family doctors, oncology unit staff. Few parents involved with community agencies. 17 families felt continued contact with hospital staff helped. Benefits of home care – felt most empowered there; friends free to visit, needs of all family members met most easily, place of privacy, quiet, and rest. Night time difficult – would benefit from support. Limitation: methodology unclear

ID#	Quality Score	Author/Year Location Discipline	Purpose	Sample	Method	Themes and Limitations
12	T = 8 R = 3 M = 5	Birenbaum, LK Stewart, BJ Phillips, DS 1996 U.S.A. Nursing #cf #11	To describe parents' health during the terminal illness of their child and during the first year following their child's death from cancer. 1. Does parents' health prior to and after the death of a child from cancer differ from that of a normative sample? 2. Does parents' health change, from before the death to after the death of a child from cancer, within the first year?	80 parents (48 families), 49 children with cancer. (part of larger study (Birenbaum & Robinson, 1991) 47 mothers 33 fathers children 1 – 19 years: 30% less than 5 40% 6 to 12 30% 13 to 19 55% male 33% leukemia/lymphoma 67% solid tumours. 32 % of children dies within 27 days of entering study 16% died 28 to 66 days 22% died 67-390 days from entry 14% died 2 weeks prior to families entering study.	Level 1: Descriptive Duke-UNC Health Profile Guttman scaling techniques used for social and physical scales. Families entered during terminal phase Home visits – ordered series of questionnaires and interviews.. Each parent completed self-administered questionnaire at four times: before child's death, at 2 weeks, 4 months, and 2 year after death. Pearson correlation coefficients between scale scores for mothers and fathers.	Parents' health not adversely affected. health of parents during and following their child's terminal illness did not differ significantly from a normative group of adults on the emotional and symptoms scales. Social scale: Prior to death mothers' have lower mean level compared to norm. Mothers' and fathers' at 4 months and 1 year after death no significant difference. Limitation: geographical differences in health status of young to middle-aged adults. In western U.S. better health behaviours.

Appendix J. Included Studies

ID#	Authors	Reporting Score (9)	Methods Score (8)	Total Score (17)
173	Birenbaum, L.K. (2000) Assessing children's and teenagers' bereavement when a sibling dies from cancer: a secondary analysis. Child: Care, Health and Development, 26(5), 381-400.	9	7	16
11	Birenbaum, L.K. & Robinson, M.A. (1991) Family relationships in two types of terminal care. Social Science & Medicine, 12(1), 95-102.	4	6	10
10	Birenbaum, L.S., Robinson, M.A. (1989-90). The response of children to the dying and death of a sibling. Omega, 20(3), 213-228.	5	5	10
12	Birenbaum, L.K., Stewart, B.J., Phillips, D.S. (1996). Health status of bereaved parents. Nursing Research, 45(2), 105-109.	3	5	8
165	Collins, J.J., Stevens, M.M., & Cousens, P. (1998). Home care for the dying child. A parent's perception. Australian Family Physician, 27, (7), 610-614.	5	3	8
30	Davies, B. (1987). Family responses to the death of a child: The meaning of memories. Journal of Palliative Care, 3(1), 9-15.	7	8	15
27	Davies, B. (1988). The family environment in bereaved families and its relationship to surviving sibling behavior. CHC, 17(1), 22-31.	6	4	10
31	Davies, B., Deveau, E., deVeber, B., Howell, D., Martinson, I., Papadatou, D., Pask, E., & Stevens, M. (1998). Experiences of mothers in five countries whose child died of cancer. Cancer Nursing, 21(5), 301-311	5	6	11
42	Dunlop, J. (1984). Special concerns in dealing with the death of a 21/2 year old: a case study. The American Journal of Hospice Care, 39-43.	0	0	0
47	Gilliss, C., Moore, I.M., & Martinson, , I.M. (1997). Measuring parental grief after childhood cancer: Potential use of the SCL-90R. Death Studies, 21, 277-287.	4	5	9

54	Heiney, S.P. (1991). Sibling grief: A case report. Archives of Psychiatric Nursing, 5(3), 121-127.	3	3	6
169	Heiney, S.P., Ruffin, J., & Goon-Johnson, K. (1995). The effects of a support group on selected psychosocial outcomes of bereaved parents whose child died from cancer. Journal of Pediatric Oncology Nursing, 12(2), 51-58.	7	5	8
57	Hongo, T. et al (1995). Analysis of the circumstances of death of 56 children suffering from cancer: Proposal for the development of terminal medicine in Japan. Acta Paediatrica Japonica 37. 604-609.	2	2	4
159	Jacob, S.R. & Scandrett-Hibden, S. (1994). Mothers grieving the death of a child. Case reports of maternal grief. Nurse Practitioner, 19(7), 60-65.	4	4	8
74	Lauer, M..E. Mulhern, R.K. Schell, Camitta, B.M. (1988) Long-term follow-up of parental adjustment following a child's death at home or hospital. Cancer, 63, 988-994.	3	5	8
78	Lauer, M.E., Mulhern, R.K., Bohne, J..B., & Camitta, B.M. (1985). Children's perceptions of their sibling's death at home or hospital: The precursors of differential adjustment. Cancer Nursing, 21-27.	3	5	8
80	Lauer, M.E., Mulhern, R.K., Wallskog, J.M., & Camitta, B.M. (1983). A comparison study of parental adaptation following a child's death at home or in the hospital. Pediatrics, 71(1), 107-112.	3	3	6
94	Martinson, I.M., Davies, B., & McClowry, S.G. (1991).Parental depression following the death of a child. Death Studies, 15, 259-267.	5	4	9
95	Martinson, I.M., Davies, E.B., & McClowry, S.G. (1987).The long-term effects of sibling death on self-concept. Journal of Pediatric Nursing, 2(4), 227-235.	5	3	8
170	Martinson, I.M,, Lee, H.O., & Kim, S. (2000). Culturally based interventions for families whose child dies. Illness, Crisis & Loss, 8(1), 17-31.	2	2	4

98	Martinson, I.M., McClowry, S.G., Davies, B. & Kuhlenkamp, E.J. (1994). Changes over time: A study of family bereavement following childhood cancer. Journal of Palliative Care, 10(1), 19-25.	2	2	4
99	McClowry, S.G., Davies, E.G., Kulenkamp, M.E.J., & Martinson, I.M. (1987). The empty space phenomenon: the process of grief in the bereaved family. Death Studies, 11, 361-374.	8	7	15
175	Milo, E.M. (1997) Maternal responses to the life and death of a child with a developmental disability. A story of hope. Death Studies, 21. 443-476.	8	8	16
105	Moore, I.M., Gillis, C.L., & Martinson, I.M. (1988). Psychosomatic symptoms in parents 2 years after the death of a child with cancer. Nursing Research, 37(2), 104-107.	3	3	6
109	Mulhern, R.K., Lauer, M.E., & Hoffmann, R.G. (1983) Death of a child at home or in the hospital: Subsequent psychologic adjustment of the family. Pediatrics, 71(5), 743-747.	4	4	8
160	Pettle Michael, S.A., & Lansdown, R.G. (1986). Adjustment to the death of a sibling. Archives of Disease in Childhood, 61, 278-283.	5	2	7
117	Rando, T. (1983). An investigation of grief and adaptation in parents whose children have died from cancer. Journal of Pediatric Psychology, 8(1), 3-20.	5	4	9
134	Saiki, S..C., Martinson, I.M., & Inano, M. (1994). Japanese families who have lost children to cancer: A primary study. Journal of Pediatric Nursing, 9,(4), 239-250.	4	4	8
162	Saiki-Craighill, S. (Part I) (2001). The grieving process of Japanese mothers who have lost a child to cancer, Part I: Adjusting to life after losing a child. Journal of Pediatric Oncology Nursing, 18(6), 260-268.	3	5	8

163	Saiki-Craighill, S. (Part II) (2001). The grieving process of Japanese mothers who have lost a child to cancer, Part II: Establishing a new relationship from the memories. Journal of Pediatric Oncology Nursing, 18(6), 268-275.	2	4	6
136	Spinetta, J.J., Swarner, J.A., & Sheposh, J.P" (1981). Effective parental coping following the death of a child from cancer. Journal of Pediatric Psychology, 6(3), 251-263.	8	8	16
143	Tietz, W, McSherry, M.S.W., & Britt, B. (1977) Family sequelae after a child's death due to cancer. American Journal of Psychotherapy,31(3), 417-425.	4	2	6
156	Wolfe, J.J. (1997). Hospice support for families facing multiple deaths of children. The American Journal of Hospice & Palliative Care, 9, 224-227.	1	1	2
164	Wood, J.D. & Milo, E. (2001). Fathers' grief when a disabled child dies. Death Studies, 25, 635-661.	8	8	16