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Being a bereaved parent:

Early bereavement experiences and perspectives on paediatric palliative care and bereavement services

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Résumé

La mort d'un enfant est considérée comme l'une des expériences les plus difficiles à laquelle une personne puisse faire face. Les cliniciens, les hôpitaux et plusieurs organismes ont pour objectif d'aider les parents endeuillés, mais leurs efforts sont compliqués par un manque de recherche dans le domaine du deuil parental. Cette thèse est composée de trois articles, soit deux revues de littérature et une étude empirique, qui tentent de combler cette lacune et d'informer les services en soins palliatifs pédiatriques et les services de soutien au deuil en particulier.

Le premier article porte sur les besoins des patients recevant des soins palliatifs pédiatriques et de leurs familles. Par le biais d'un méta-résumé de la recherche descriptive et qualitative récente, 10 domaines de besoins ont été identifiés qui correspondent aux lignes directrices actuelles en soins palliatifs pédiatriques et de fin de vie. Ces besoins sont présentés de manière à être facilement applicables à la pratique. Cependant, les résultats mettent aussi en évidence plusieurs aspects des soins identifiés comme déficitaires ou problématiques qui mériteraient une attention particulière dans le cadre de politiques futures.

Dans le deuxième article, l'objectif était de résumer une vaste littérature d'une manière utile aux cliniciens. À cette fin, une synthèse narrative a permis d'intégrer la recherche quantitative et qualitative dans le domaine du deuil parental. Les résultats mettent en évidence les éléments susceptibles de favoriser l'adaptation des parents au deuil, éléments qui suggèrent par le fait même des avenues possibles de soutien et d'intervention. Cette synthèse a cependant cerné dans la littérature certaines failles méthodologiques qui rendent l'applicabilité clinique des résultats difficile.

L'objectif du troisième article était d'informer les services de suivi et de soutien au deuil auprès des parents en se renseignant directement auprès de parents endeuillés. À cette fin, 21 parents (dont 8 couples) et 7 membres du personnel impliqués dans des activités de suivi de deuil de 2 hôpitaux pédiatriques ont été interrogés dans le cadre d’une description interprétative, et l'application clinique des résultats a été vérifiée par le biais de réunions avec des collaborateurs de recherche et les décideurs des centres hospitaliers. Les résultats décrivent comment les parents ont fait face à leur détresse dans la phase précoce de leur deuil, ainsi que leurs points de vue sur la façon dont les divers services de suivi de deuil ont été aidants. Les résultats suggèrent que les parents gèrent leurs sentiments intenses de douleur par une alternance de stratégies axées soit sur leur deuil ou sur leur quotidien et que dans plusieurs cas leurs relations avec autrui les ont aidé. Cette étude a également permis d'élucider la façon dont divers services de soutien aide les parents à aborder leur deuil. Les implications cliniques de ces résultats sont discutées ainsi que des recommandations à l’intention de ceux qui sont impliqués dans la provision des services en deuil.

Mots-clés : pédiatrie, soins palliatifs, soins fin-de-vie, dual-process model, coping, soutien social, qualitatif, description interprétative, oncologie pédiatrique, soins intensifs pédiatriques.

Abstract

The death of a child is considered one of the most stressful and difficult experiences a person can face. Clinicians, hospitals, and other organizations want to help and support bereaved parents through their grief, but their efforts are hampered by a lack of research in the area of parental bereavement. This dissertation is comprised of two literature reviews and one empirical study that attempt to address this gap and inform services in paediatric palliative care in general, and in bereavement support in particular.

The first article consists of an examination of the needs of patients receiving paediatric palliative care and their families. By metasummarizing the descriptive and qualitative research in the area, 10 need domains were found. The results were generally in agreement with current guidelines in paediatric palliative and end-of-life care; however, there were several aspects of care that were reported as lacking or problematic that are not addressed in these guidelines and that should be considered in future guideline and policy creation.

In the second article, parents' adaptation to their grief and elements found to influence their adaptation were examined. The aim was to synthesize the relevant literature in a way that could be useful to clinicians; to this end, a narrative synthesis method was employed in order to synthesize both quantitative and qualitative research in the area of parental bereavement. The results suggest important elements to keep in mind when assessing how parents adapt to their grief. The results also suggest aspects related to better adaptation, which could serve as potential avenues for support and intervention. However, this review also demonstrated certain methodological issues in the literature that hinder the synthesis and clinical applicability of the findings.

The objective of the third article was to inform bereavement follow-up and support services through the use of an interpretive description methodology. To this end, 21 bereaved parents (including 5 parental couples) and 7 hospital staff involved in bereavement follow-up activities at two paediatric hospitals were interviewed, and the clinical applicability of the results verified through various meetings with project collaborators and service/program providers. The results of the study describe how parents coped with their grief in the early phase of their bereavement, as well as their perspectives on how various bereavement follow-up services helped them cope. We found that parents regulate their intense feelings of grief through either loss-oriented or restoration-oriented strategies, including attempts to reorganize their self-identity and connection to their deceased child; often parents' relationships with others help them cope in these ways. The insights we gained from the respondents also allowed us to elucidate how various bereavement support and follow-up services were helpful. These results are discussed along with the clinical implications and how these findings can inform bereavement service providers.

Keywords: pediatric, palliative care, end-of-life care, dual-process model, meaning reconstruction, social support, qualitative, interpretive description, pediatric oncology, pediatric intensive care.

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List of abbreviations

CHU: Centre hospitalier universitaire

CIHR: Canadian Institutes of Health Research

DSM-5: The Diagnostic and Statistical Manual of Mental Disorders (5th ed)

HCP: Health care professional

PPC: Paediatric palliative care

PEOLC: Paediatric end-of-life care

PTSD: Post-traumatic stress disorder

SIDS: Sudden infant death syndrome

I dedicate this thesis to Malcolm and to all the other loved ones we lost too soon.

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Introduction

The loss of a child is widely recognized as leading to one of the most profoundly painful, intense, and devastating types of bereavement, and often impacts families for a lifetime (Field & Behrman, 2003; Rando, 1986). Many studies have demonstrated that the death of a child has a greater impact on the mortality and psychosocial outcomes of the bereaved than other types of loss (Li, Laursen, Precht, Olsen & Mortensen, 2005; Li, Precht, Mortensen & Olsen, 2003; Pudrovska, 2009; Rosenberg, Baker, Syrjala & Wolfe, 2012; Rubin et al., 2009; Wortman & Boerner, 2007).

Parents of children with life-limiting and life-threatening illnesses often want support from the paediatric hospital, both during their child's illness and following the death (Contro, Larson, Scofield, Sourkes & Cohen, 2002; D'Agostino, Berlin-Romalis, Jovcevska & Barrera, 2008; Decinque et al., 2006). The importance of providing quality paediatric palliative care has also been emphasized by the Canadian Association of Hospice Palliative Care, the Canadian Paediatric Society, the American Pediatric Association, and the Institute of Medicine (Aerde, 2001; Canadian Hospice Palliative Care Association, 2006; Committee on Bioethics and Committee on Hospital Care, 2000; Field & Behrman, 2003) as well as in a Canadian study that surveyed practitioners' views on research priorities in paediatric palliative care (PPC) (Steele et al., 2008). These reports highlight that care for children with life-threatening and life-limiting illnesses must take into account and respect their physical and psychological situation as well as the psychological well-being of their families (Committee on Bioethics and Committee on Hospital Care, 2000; Field & Behrman, 2003). After the death of the child, bereavement care for the family, particularly the parents, should be a significant focus of PPC (Canadian Hospice Palliative Care Association, 2006; Committee on Bioethics and Committee on Hospital Care, 2000; Field & Behrman, 2003; Groupe de travail sur les normes en matière de soins palliatifs pédiatriques, 2006). Bereavement care is not only considered an important component of PPC, but it is also considered a crucial component of a continuum of care for parents of all children who die, no matter what the cause of death, including accidental and perinatal deaths (Groupe de travail sur les normes en matière de soins palliatifs pédiatriques, 2006).

To address the needs of patients and their families, paediatric hospitals are increasingly offering both PPC and bereavement care services. In order to most effectively target services and support parents through this very difficult and stressful period (the end-of-life and/or death of their children), many researchers, clinicians, and organizations (e.g., hospitals or non-governmental organizations) argue that these services should be informed by an empirically-validated understanding of parents' actual needs and experiences (Canadian Hospice Palliative Care Association, 2006; Commitee on Bioethics and Committee on Hospital Care, 2000; Decinque et al., 2006; Murphy, Johnson & Lohan, 2003). The Institute of Medicine and Canadian Hospice Palliative Care Association have both called for more research in paediatric palliative care (PPC) and paediatric end-of-life care (PEOLC) (Canadian Hospice Palliative Care Association, 2006; Field & Behrman, 2003), and since the early 2000s there has indeed been an increase in PPC offerings as well as in research on parental bereavement. However, there remain gaps in the dissemination of research and in the integration of new knowledge generated through research into actual PPC and PEOLC services (Decinque et al., 2006; Steele et al., 2008; Widger & Picot, 2008; Widger et al., 2007). Such gaps are representative of a general challenge in health-related research: the need for *knowledge translation*. As the

Canadian Institutes for Health Research articulates in their call to action, "Knowledge translation is critical for bridging the gap between knowledge that has been generated through research and knowledge that is used to inform policy, practice, and programs with the goal of improving the health of Canadians and the global community, and reducing health inequities" (CIHR-Institute of Population and Public Health, 2014).

The present dissertation is a response to the priorities identified above, and its overarching aim is to bridge the research-practice divide in the related areas of PPC and bereavement care. It comprises three articles, the first two of which are literature reviews that systematically summarize and synthesize large bodies of evidence in these respective domains in a way that is useful to clinicians and/or policy makers. The pertinent background research that informs this thesis is presented, in depth, in these two extensive reviews, rather than as a separate section in this introduction. Figure 1 summarizes how the three articles relate to one another.

The aim of the first article[*] is to gain a better understanding of the needs of patients and families receiving PPC and PEOLC services in North America. Since 2000, there has been an increase in qualitative and descriptive quantitative research in this area (Canadian Hospice Palliative Care Association, 2006; Committee on Bioethics and Committee on Hospital Care, 2000; Field & Behrman, 2003). Qualitative and descriptive quantitative approaches to research are both valuable and complementary, and it is the synthesis of their findings that make them most clinically applicable (Sandelowski & Barroso, 2003; Sandelowski, Barroso, & Voils, 2007; Sandelowski, Trimble, Woodard, & Barroso, 2006). In the quantitative research

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paradigm, a synthesis of findings can be achieved through meta-analysis, while in the qualitative and descriptive paradigms, a metasummary allows a systematic integration of findings to present the universal concepts relevant to the topic in a clinically meaningful way (Sandelowski & Barroso, 2007; Sandelowski et al., 2007; Sandelowski et al., 2006). In the first article, literature on PPC and PEOLC is subjected to a metasummary with the goal of developing a clinically-relevant understanding of the PPC needs of patients and their families, which could inform the creation of high quality PPC and PEOLC services and guidelines.

A subset of PPC needs identified in the first review relate to parental bereavement, which constitutes the area of focus of the second article. There is a growing body of quantitative and qualitative studies exploring the experiences of bereaved parents and their adaptation to the loss. The findings of these studies, however, must be synthesized in order to facilitate their applicability to clinical practice. Moreover, while these disparate studies have collectively identified many elements related to the experiences of bereaved parents (e.g., circumstances of the death, age of the child, and quality of the relationship between spouses), the impact of these elements on post-death psychosocial outcomes for the parent remains unclear (Arnold, Gemma, & Bushman, 2008). A particularly pressing avenue for knowledge translation, then, concerns the synthesis of findings relating to parents' experiences and factors related to poorer outcomes or, conversely, better adaptation. For the second article, quantitative and qualitative research on the psychosocial outcomes and adaptation of bereaved parents published since the year 2000 was collected, with the goal of synthesizing the research and providing clinical implications based on the empirical evidence in the area. Following guidelines proposed by Pope, Mays and Popay (2007), a narrative synthesis methodology was employed, which is "an approach to evidence synthesis that relies primarily on the use of words and text to summarise and explain the findings of multiple studies" (Pope, Mays, & Popay, 2007; pg. 102). In contrast to the metasummary methodology employed in the first article, which in a sense seeks to 'quantify' themes from qualitative and descriptive quantitative studies, narrative synthesis seeks to 'qualify' quantitative and qualitative research by producing a narrative digest of the findings.

One methodological issue common to many studies reviewed in the second article concerns the wide range of ages of the children who died. Although a synthesis of these studies affords a general understanding of parental bereavement, there remains a dearth of research specifically involving bereaved parents of minor aged children who die at paediatric hospitals. Since these hospitals are increasingly providing bereavement services to parents, and keeping in mind the imperative of grounding services on a firm evidentiary basis, addressing this research gap has important clinical implications. This provides the rationale for the third article, which is an empirical investigation of the experiences of bereaved parents in the first year following the death of their minor aged child, a much understudied area of bereavement research (Decinque et al., 2006; D'Agostino, Berlin-Romalis, Jovcevska, & Barrera, 2008). Specifically, this study examines how parents coped with their grief in the early phase of their bereavement, as well as their perspectives on how various bereavement follow-up services helped them cope. Data for this study was collected through in-depth interviews conducted with 21 bereaved parents, as well as 7 health care providers involved in conducting bereavement follow up at the participating hospitals. The data thus gleaned were analyzed using an *interpretive description* methodology. Originally developed in nursing, interpretative description is specifically designed to produce clinically applicable findings (Thorne, 2008; Thorne, Kirkham, & MacDonald-Emes, 1997; Thorne, Kirkham, & O'Flynn-

Magee, 2008). Intersecting psychological research and service provision viewpoints, and undertaken in collaboration with two paediatric hospitals in Montreal, the aim of this study is to provide information useful for paediatric hospitals, community services and clinicians that provide bereavement follow-up and support to families dealing with the death of a child.

Contributions of the coauthors

For each article presented in this dissertation, the author of this thesis was the main contributor in all steps of the research process, from the research designs to the writing of the articles. Marie Achille and Robin Cohen (McGill University) supervised the research process and reviewed all written work. For the first article, the analysis and interpretation of the reviewed articles was done in close collaboration with Tziona Lugasi. For the second article, all studies were reviewed and analyzed by the author of this thesis, who also wrote the manuscript. This manuscript was subsequently reviewed and revised by Marie Achille, Robin Cohen, and Wendy Lichtenthal. For the third article, the empirical study, Marie Achille, Robin Cohen, Stephen Liben, Marie-Claude Proulx and Mary Ellen Macdonald contributed to the project development, interpretation of the results and translation of the findings of the empirical study into services at the Montreal Children's Hospital, and Nago Humbert and Antoinette Petti contributed to the project development, interpretation of the results and translation of the findings of the empirical study into services at CHU Sainte-Justine.

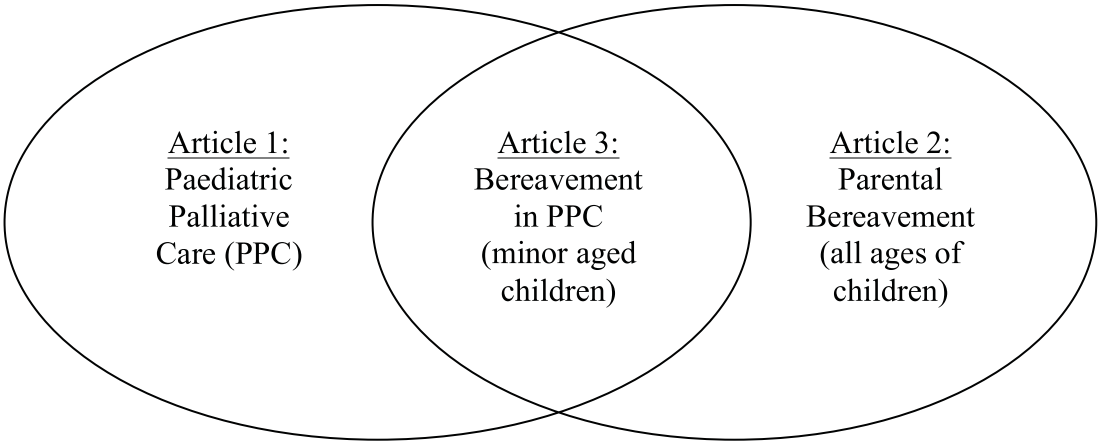

Figure 1. Concept map of the broad areas of focus of the three articles of the thesis

Article 1

Paediatric Palliative Care in Canada and the United States: A qualitative metasummary of the needs of patients and families

Pediatric Palliative Care in Canada and the United States: A qualitative metasummary of the needs of patients and families

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Abstract

Objective: Qualitative research is becoming more common in pediatric palliative care and end-of-life care. The present article systematically reviews and summarizes qualitative and survey-based research on pediatric palliative and end-of-life care pertaining to the needs of patients and their families.

Method: Twenty-one qualitative and survey-based studies published between 2000-2010 that met the selection criteria were retrieved from MEDLINE, PsycInfo, and CINAHL. All studies reported on the needs of patients and families receiving pediatric palliative and end-of-life care–from either the patient's, parent's, sibling's or health care provider's perspective. Findings from these studies were aggregated using a metasummary technique.

Results: Findings were extracted and grouped into the following ten thematic domains pertaining to patient and family needs: interactions with staff, health care delivery and accessibility, information needs, bereavement needs, psychosocial needs, spiritual needs, pain and symptom management, cultural needs, sibling's needs, and decision making.

Conclusions: The results of this metasummary highlight the needs of patients and families to be taken into consideration in the creation of quality pediatric palliative and end-of-life care services and guidelines.

Introduction

Each year approximately 48,000 children between the ages of 0-19 years old die in the US (Kochanek, Kirmeyer, Martin, Strobino, & Guyer, 2012), and approximately 3500 die in Canada (Statistics Canada, 2009). Fortunately, nowadays these deaths are relatively rare; nonetheless, the death of a child impacts families for a lifetime (Field & Behrman, 2003). Thus, care for children with life-threatening and life-limiting illnesses must take into account and respect not only the physical situation of these patients but also the psychological well-being of the patient and their families (Field & Behrman, 2003).

There are numerous studies and recommendations for palliative care for adults that have led to an increase in services and improved care for adult patients. In contrast, only in the last decade has there been a rise in research in pediatric palliative care and end-of-life care (PPC and PEOLC, respectively). While the provision of PPC services has been found to ease children's suffering and provide an improved end-of-life care environment for children (Duncan, Joselow, & Hilden, 2006), more research in the area is imperative as adult literature in palliative and end-of-life care cannot easily be applied to children (Malloy, Sumner, Virani, & Ferrell, 2007; Widger & Wilkins, 2004). Moreover, the research to date suggests that US and Canadian healthcare systems do not adequately meet the needs of children with life-threatening and life-limiting illnesses or those of their families (Widger et al., 2007; Wolfe et al., 2000). In order to address this deficiency, several North American organizing bodies have provided guidelines for health care providers (HCPs) and hospitals to improve the situation of patients and families receiving PPC or PEOLC (Canadian Paediatric Society, 2008; Canadian Paediatric Society, 2001; Commitee on Bioethics and Committee on Hospital Care, 2000; Field & Behrman, 2003).

Currently, much of the research on PEOL and PPC is qualitative in nature. Quantitative studies give a very valuable but often partial description of complex processes such as parental bereavement, whereas qualitative studies, offer a complementary in-depth exploration of human experience (Denzin & Lincoln, 2005; Patton, 2002). Recently there has been a push to synthesize qualitative research so that it may be used for evidence-based practice. When qualitative studies in a particular topic area are taken together–through systematic techniques such as metasummary–the collected findings allow for an accurate representation of the universal concepts relevant to the topic (Sandelowski & Barroso, 2003b; Sandelowski, Barroso, & Voils, 2007; Sandelowski, Voils, & Barroso, 2007). In the present article, qualitative and survey-based research from the perspectives of families, patients, and HCPs on the needs of patients and families receiving PPC or PEOLC is subjected to a metasummary with a view to inform guidelines and ensuring that they are up to date.

Method

Metasummary Methodology. Metasummary is a type of systematic review where qualitative and descriptive quantitative findings are collected through topical or thematic surveys of the data collected by a review of the relevant literature (Paterson, Canam, Thorne, & Jillings, 2001; Sandelowski, Barroso, & Voils, 2007). Sometimes used as a precursor to metasynthesis, this method involves extracting findings from various studies, then grouping these findings and abstracting common findings based on topical and thematic similarities (Bondas & Hall, 2007; Paterson et al., 2001; Sandelowski & Barroso, 2003a; Sandelowski & Barroso, 2007; Thorne, Jensen, Kearney, Noblit, & Sandelowski, 2004). In qualitative metasummary all findings are given equal relevance regardless of specific qualitative methodology and without prior evaluation of methodological quality. In qualitative research the method stated is often found to be neither an indicator of the method actually used nor does it influence the findings (Sandelowski & Barroso, 2003b; Sandelowski, Voils, & Barroso, 2007). Therefore, we extracted findings from articles that were relevant to our research question and objective and did not analyze the exact methodology used other than it being qualitative, survey-based, and amendable to the techniques of metasummary (i.e. topical or thematic summaries of the data). The following two calculations were then performed to give an indication of the occurrence of particular findings and impact of particular articles (Figure 1) (Onwuegbuzie, 2003; Sandelowski & Barroso, 2007; Sandelowski, Barroso, & Voils, 2007). The *proportional frequency of the finding* (PFF) indicates the number of times a finding is reported across all included articles; the *proportional intensity of the article* (PIA) calculates the total number of findings extracted from a given article (Onwuegbuzie, 2003; Sandelowski & Barroso, 2007; Sandelowski, Barroso, & Voils, 2007). Readers familiar with metasummary and metasynthesis techniques may be accustomed to seeing the terms *frequency effect size* and *intensity effect size* used to denote PFF and PIA, respectively (Onwuegbuzie, 2003; Sandelowski & Barroso, 2007; Sandelowski, Barroso, & Voils, 2007). To avoid confusion, however–especially among those for whom the term ‘effect size’ has a particular and uninfringeable meaning–we have herein opted to employ the terms PFF and PIA for descriptive clarity.

Article Retrieval. We conducted a comprehensive literature review using MEDLINE, PsycINFO, and CINAHL databases. Keywords used for database searching fell into three linked categories: 1) child*, pediatric, paediatric, or adol* 2) end-of-life, terminal*, or palliative and 3) hosp*, service, program, need, or perspective (*denotes truncation). To confirm that the retrieved sample comprehensively represented the existing publications on the topic, we scrutinized bibliographies from the included articles and related clinical recommendations and literature reviews. The search was last updated in January 2011.

Inclusion and exclusion criteria. In order to be included in our review, articles had to: a) focus on perspectives of either parents, patients, or health care providers in Canada or the US on aspects of PPC and PEOLC; b) empirically examine these perspectives using thematic surveys, surveys with open-ended question, and/or qualitative methods; c) be published in an English peer-reviewed journal; d) be published between 2000 to 2010. We chose a ten-year time frame to highlight the increases in both qualitative health research and PPC services at this time and to provide a current and up-to-date review. We included studies conducted in either Canada or the USA in order to collect findings that would be specifically relevant to patients, families, and HCPs in Canada and the USA as these two countries serve similar populations and are at similar stages of development of PPC programs (Knapp, Mulligan-Smith, & American Academy of Pediatrics Committee on Pediatric Emergency Medicine, 2005; Liben, Papadatou, & Wolfe, 2008; Morrison, Maroney-Galin, Kralovec, & Meier, 2005). The aim of the current review is to give a snap-shot of PPC services in Canada and the US; therefore, research conducted in the UK, Australia and other jurisdictions was not included even though there is much research in PPC coming from these areas. Twenty-one articles met these criteria and were included in the review.

Procedure. Two authors (MS and TL) assessed the studies to determine if they were relevant to the review and recorded the research question or statement of purpose, research method, sample size, and participant characteristics (Table 1). The articles were then metasummarized using techniques described by Sandelowski and Barroso (Figure 1)

(Sandelowski & Barroso, 2003a; Sandelowski & Barroso, 2003b; Sandelowski & Barroso, 2007; Sandelowski, Barroso, & Voils, 2007). The term *finding* was used to indicate any integrated conclusions and discoveries offered by researchers regarding the experiences they were studying (Paterson et al., 2001; Sandelowski & Barroso, 2007). The research team (MS, TL and MA) met on a regular basis to discuss how the findings would be grouped and to develop the abstracted findings to represent each group. Discrepancies between authors were discussed and resolved through consensus on the most accurate way of representing the finding. These findings were then grouped into thematic domains. For the calculation of PFF and PIA, each report was treated as one unit of analysis, and each finding was weighted equally (Onwuegbuzie, 2003; Sandelowski & Barroso, 2003a; Sandelowski & Barroso, 2007). The PIA was calculated by dividing the number of findings extracted from one particular article by the total number of findings extracted in our review (Table 2). The PFF was calculated by dividing the number of articles or studies with the finding by the total number of studies in our review (Table 2).

Results

Across the studies reviewed, ten thematic domains relating to patient and family needs were found. These are described below.

Health care delivery and accessibility. Needs related to health care delivery and accessibility were cited in thirteen of the twenty-one studies reviewed (Table 2). Continuity, consistency, and coordination of care were reported in eleven of the studies and were the focus of the Heller & Solomon, 2007 article. This form of care has been reported as serving to build relationships, promote caring, and encourage sharing of expertise and information about the child between HCPs (Heller, Solomon, & for the Initiative for Pediatric Palliative Care (IPPC) Investigator Team, 2005). Health care providers have reported the need for patients to receive care outside the hospital (Donnelly, Huff, Lindsey, McMahon, & Schumacher, 2005; Jones, 2006). Home visits by HCPs and the ability to transition in and out of hospital are considered essential to quality pediatric palliative and end-of-life care (Contro, Larson, Scofield, Sourkes, & Cohen, 2002; Donnelly et al., 2005). Health care providers have also highlighted the importance of giving the child the choice of where to die (Donnelly et al., 2005). However, parents have reported that community-based hospice programs are poorly prepared to serve pediatric patients (Contro et al., 2002). Although descriptive research conducted with parents has reported that the number of deaths in the intensive care unit have decreased and hospice care discussions have increased and are occurring earlier (Wolfe et al., 2008), parents have also reported several important obstacles to home death (Contro et al., 2002; Zelcer, Cataudella, Cairney, & Bannister, 2010). Parents and HCPs have emphasized the need for services and competent pediatric-trained HCPs to be available and accessible to families and patients from the time of diagnosis up until and including the bereavement period (Donnelly et al., 2005; Meyer, Ritholz, Burns, & Truog, 2006; Widger & Picot, 2008). In addition, parents have reported the occurrence of negative events and preventable oversights that may be addressed by staff that are more competent in PPC and PEOLC (Contro et al., 2002; Zelcer et al., 2010).

Interactions with staff. Needs related to interactions with staff were highlighted in thirteen of the studies reviewed and was the main focus of the Hsaio, Evans & Zeltzer, 2007 study (Table 2). Interactions with staff were reported as problematic in three of the studies (Contro et al., 2002; Hsiao, Evan, & Zeltzer, 2007; Widger & Picot, 2008) and needs in this area were mentioned in all thirteen. Parents, patients and staff have all mentioned the importance for continual and ongoing relationships between staff and families and all want to be involved in discussions about the child's care (Contro, Davies, Larson, & Sourkes, 2010; Contro et al., 2002; Davies, Contro, Larson, & Widger, 2010; Donnelly et al., 2005; Hsiao et al., 2007; Konrad, 2008; Mack et al., 2005; Meert et al., 2008; Meert, Thurston, & Briller, 2005; Meyer et al., 2006; Widger & Picot, 2008). Furthermore, families have reported wanting a familiar person to deliver difficult news in a sensitive and caring manner (Contro et al., 2002; Hsiao et al., 2007; Mack et al., 2005). The manner in which staff communicate was divided into two groups: 1) parents want honest and straightforward communication (Contro et al., 2002; Hsiao et al., 2007; Mack et al., 2005; Meert et al., 2008; Meyer et al., 2006; Widger & Picot, 2008) and 2) parents want staff to show sensitivity, empathy and competency when they communicate with them (Donnelly et al., 2005; Heller et al., 2005; Hsiao et al., 2007; Konrad, 2008; Meert et al., 2008; Meert et al., 2005; Meyer et al., 2006; Widger & Picot, 2008).

Information needs. Information needs were mentioned in nine out of the twenty-one articles reviewed (Table 2). Five of the studies reported the simple need for more information (Contro et al., 2010; Hsiao et al., 2007; Jones, 2006; Meert et al., 2008; Widger & Picot, 2008). Parents and HCPs have noted that parents need to be prepared for what to expect from their child’s illness and potential treatments (Hsiao et al., 2007; Jones, 2006). However, parents have reported feeling as if information was withheld from them and that they did not get updated as frequently as they wanted about their child's condition (Meert et al., 2008; Widger & Picot, 2008). Additionally, parents reported that the information given to them was often contradictory or confusing (Hsiao et al., 2007; Meert et al., 2008; Widger & Picot, 2008), especially for non-English speaking families (Cohen et al., 2002; Donnelly et al., 2005).

Bereavement needs. Bereavement needs were reported in nine out of the twenty-one studies reviewed and was the main focus of the Macdonald et al. (2005) and D'Agostino, Berlin-Romalis, Jovcevska, and Barrera (2008) studies (Table 2). Six of the studies reviewed reported parents wanting care to extend from the time of diagnosis through to the bereavement period (Contro et al., 2002; D’Agostino et al., 2008; Heller et al., 2005; Meert et al., 2008; Widger & Picot, 2008). Families also mentioned developing a strong bond with the treating hospital and feeling abandoned if this bond was broken (D'Agostino et al., 2008; Macdonald et al., 2005). Parents reported wanting mementos such as handprint or a hospital bracelet (Meert et al., 2008; Widger & Picot, 2008) and for staff involved in the child's care to follow-up with them after the child's death with acts such as cards, memorial services, and telephone calls (D'Agostino et al., 2008; Meert et al., 2008; Widger & Picot, 2008). However, parents have also reported that returning to the treating hospital can be emotionally challenging (Macdonald et al., 2005). Parents have reported needing help to prepare for their child's death and for what to expect at the time of death including funeral arrangements, and bereavement counseling services (D'Agostino et al., 2008; Jones, 2006; Meert et al., 2008; Widger & Picot, 2008). Moreover, parents want bereavement services to be available immediately after the child's death (or even before) and they want these services to be both flexible and consistent (D'Agostino et al., 2008). In line with the psychosocial needs, parents also desire contact with other families that have had a child who died (D'Agostino et al., 2008).

Psychosocial Needs. Psychosocial needs were reported in nine of the studies reviewed and were the main focus of the Jones (2006) study (Table 2). The psychosocial needs of patients and families have importance in their own right but also affect other needs. For example, the need for patient dignity and respect is reported in several studies as a patient need, but is also cited as playing a crucial role in communication needs (Hsiao et al., 2007). Parents and HCPs have reported that patients and families need emotional support (D'Agostino et al., 2008; Donnelly et al., 2005; Hsiao et al., 2007; Jones, 2006; Meert et al., 2005), which includes services such as counseling (D'Agostino et al., 2008; Jones, 2006; Meert et al., 2005) or play therapy (Donnelly et al., 2005; Jones, 2006). Socially, patients, parents and HCPs have reported that patients need access to peers and other children going through similar experiences (Davies et al., 2005; Donnelly et al., 2005; Jones, 2006). In addition, patients and HCPs have reported that patients need some semblance of a ‘normal’ life with developmentally appropriate activities (Davies et al., 2005; Donnelly et al., 2005; Jones, 2006). Health care providers and parents have reported that parents need access to other families in similar situations (Donnelly et al., 2005; Jones, 2006). This finding is similar to the parent networking finding in the bereavement domain; however, this finding relates more to social support while the child is still alive, whereas the other finding relates to social support after the child has died (for example, through bereaved parents support groups). Lastly, along with needing social support from peers, families need unrestricted access to their child and vice versa (Donnelly et al., 2005; Meert et al., 2005), especially as the child approaches the end-of-life (Contro et al., 2010).

Spiritual Needs. Spirituality was touched upon in eight of the studies and is the main focus of the Meert et al. (2005) and Robinson et al., (2006) studies (Table 2). Some of the reported spiritual needs were more religious in nature, such as the need for prayer (Meert et al., 2005; Robinson, Thiel, Backus, & Meyer, 2006), whereas others are not necessarily associated with religion, such as the need for hope and for the child to be remembered after death. Parents have highlighted their striving to maintain hope while accepting their child's prognosis (Zelcer et al., 2010). Bereaved parents have mentioned the transcendental quality of the parent-child relationship and the need to maintain a bond with their child throughout illness and after the child's death (Contro et al., 2010; Donnelly et al., 2005; Meert et al., 2008; Meert et al., 2005; Robinson et al., 2006). Some of these parents have also mentioned their search to find meaning from their child's death by looking for the good their child has brought to others and finding reasons to go on living (Meert et al., 2005; Meyer et al., 2006). To address some of these issues, parents have mentioned wanting guidance in line with their own values (Donnelly et al., 2005; Meert et al., 2005; Robinson et al., 2006) and access to spiritual counselors or clergy (Contro et al., 2010; Jones, 2006; Meert et al., 2005; Robinson et al., 2006).

Pain and symptom management. Six of the reviewed studies mentioned the need to relieve pain and symptoms of patients (Table 2). Two other articles related to pain and symptoms of PPC patients (Hendricks-Ferguson, 2008; Wolfe et al., 2000) were identified, but the results in these articles were more inventories of pain and symptoms experienced by patients and did not frame the findings in terms of what is needed or lacking in pain and symptom management. In the included articles, when physicians were questioned about the needs of their patients, they reported that pain and symptoms need to be assessed consistently and managed effectively (Donnelly et al., 2005). However, research involving parents and HCPs has shown discrepancies between the high degrees of pain reported by parents and HCPs' perceptions that pain was well managed (Contro et al., 2002; Wolfe et al., 2008). A crucial aspect of pain and symptom management is the need for the patient to be comforted and soothed (Contro et al., 2002; Donnelly et al., 2005). Despite the fact that alleviation of pain was reported by parents as very important, parents have also reported that they do not want alleviation of pain to impair consciousness or impact their ability to communicate with their child (Meert et al., 2008). Interestingly, a study by Wolfe and colleagues (2008 - not included) that compared a baseline cohort (1990-1997) to a follow-up cohort (1997-2004) found that parents reported less child suffering from pain and dyspnea in the follow-up cohort (Wolfe et al., 2008).

Cultural needs. Cultural needs were reported in six of the studies reviewed (Table 2). These findings were taken from research conducted with parents of various languages and cultures (Mexican American, Chinese American, and Spanish-speaking families) (Contro et al., 2010; Contro et al., 2002; Davies et al., 2010; Davies, Larson, Contro, & Cabrera, 2011) discussing their own needs and from research conducted with HCPs on their views of quality PPC and EOLC (Donnelly et al., 2005; Harper et al., 2007). Families and HCPs have reported the importance of providing care and information that is culturally sensitive (Contro et al., 2002; Davies et al., 2010; Davies et al., 2011; Harper et al., 2007) and fair (Davies et al., 2011). Furthermore, parents who do not speak English face communication issues that may impede their child's treatment and their own comprehension of what is happening to their child (Contro et al., 2010; Contro et al., 2002; Davies et al., 2010) that could be addressed by providing translators (Donnelly et al., 2005) and ensuring that non-English speaking families know there are interpreters available (Davies et al., 2010).

Decision-making. Decision-making needs were mentioned in six of the studies reviewed (Table 2). We identified–and excluded–several studies with findings related to decision-making but which were often in terms of *factors* involved in decision-making rather than parent/patient *needs* related to decision-making (Hays et al., 2006; Hinds et al., 2001). In the included studies, parents and HCPs have reported the importance of treating patients and families with respect and allowing them to have a say in treatment decisions (Donnelly et al., 2005; Jones, 2006; Meert et al., 2005). Furthermore, families and patients need adequate information to support their decision-making, including assessment of the goals of care (Davies et al., 2010; Donnelly et al., 2005; Jones, 2006; Meyer et al., 2006).

Siblings' needs. Five of the reviewed articles mentioned siblings' needs (Table 2). Health care providers have reported that care needs to be more family-oriented (Contro et al., 2002; Donnelly et al., 2005; Harper et al., 2007) and should include siblings (Harper et al., 2007). Families have reported that the impact on siblings is often under-recognized (Konrad, 2008); they do not receive the care they need (Contro et al., 2002) and parents lack information on how to support them (Contro et al., 2010; Davies et al., 2010). To address this need, parents and HCPs want more support and counseling (Contro et al., 2010; Contro et al., 2002; Davies et al., 2005; Jones, 2006), and services for siblings (Contro et al., 2002; Davies et al., 2005; Jones, 2006).

Discussion and Implications

This metasummary provides a comprehensive and global view of the needs of patients and families receiving PPC or EOLC in Canada and the US through the perspectives of patients, families, and HCPs. Through the collection and analysis of the qualitative and survey findings in the area, we have found that patient and family needs can be categorized around ten general need domains: health care delivery and accessibility, interactions between staff and families, information needs, bereavement needs, psychosocial needs, spirituality needs, pain and symptom management, cultural needs, decision-making and needs of siblings. The PIA gives an indication as to how many findings one article contributed to the metasummary. The highest PIAs were found for the articles by Donnelly et al., (2005); Jones (2006) and Meert et al., (2005) respectively. These articles contributed the most findings to the metasummary because these articles examined broadly the needs of patients and/or families receiving pediatric palliative or end-of-life care. Article that had a lower PIA focused on specific aspects of care or needs such as cultural needs, bereavement care etc. The high PFF of the health care delivery and accessibility needs and interactions with staff needs shows that these domains are touched on in many of the articles and are frequently mentioned as problematic by families and HCPs. Lower PFFs were found for sibling, decision-making, pain and symptom management, and cultural needs. However, a low PFF does not indicate that there is less need in the area, but rather that these domains are less represented in the qualitative and survey-based research. In fact, all ten domains are important in consideration of policies to address patient and family needs. Moreover, the domains and categories we have discovered are also in agreement with current guidelines in PPC and PEOLC which emphasize the need for continuity and integration of care (Commitee on Bioethics and Committee on Hospital Care, 2000), developmentally appropriate care and respect for patients and families (Field & Behrman, 2003), care from diagnosis through to bereavement (Commitee on Bioethics and Committee on Hospital Care, 2000; Field & Behrman, 2003), and attention to symptom and pain control, and the emotional, psychological and spiritual needs of patients (Canadian Paediatric Society, 2008). However, we have found that a) many parents are still reporting these aspects of care as lacking or problematic and b) that there are more specific needs being reported by patients & families that should be addressed in guideline and policy creation.

Although every attempt was made to review the literature systematically and comprehensively there remain several limitations to this metasummary. Firstly, this review was restricted to published literature and did not include theses or dissertations. Secondly, although several of the studies examined pediatric palliative care services or the care of seriously ill and dying children more generally (Contro et al., 2010; Contro et al., 2002; Davies et al., 2010; Davies et al., 2011; Donnelly et al., 2005; Harper et al., 2007; Hsiao et al., 2007; Konrad, 2008; Widger & Picot, 2008), some of the studies where specific to children who died of cancer (D'Agostino et al., 2008; Jones, 2006; Mack et al., 2005), in the intensive care unit (Macdonald et al., 2005; Meert et al., 2008; Meert et al., 2005; Meyer et al., 2006; Robinson et al., 2006), and in hospice (Davies et al., 2005; Hendricks-Ferguson, 2008). We did not compare findings across hospital units or type of illness, in that findings from intensive care, oncology, palliative care services, and hospices were grouped together so that needs unique to these types of care were not highlighted specifically. Nonetheless, overall the findings from the more specific studies agreed with the findings from the broader studies on general PPC services. Lastly, although this article highlights the general needs of PPC patients and families, there are important details in relation to specific illnesses and conditions beyond the scope of this metasummary that should be considered in guideline and policy creation.

This being said, this metasummary has several notable strengths. This metasummary provides a concise and comprehensive review of recent literature in PPC and PEOLC. By coalescing various studies taken from the perspectives of patients, families, and HCPs, we have gained insight into the needs of patients and families receiving PPC and PEOLC in Canada and the US. Furthermore, by focusing on research conducted in these regions in the last decade we have produced a current snapshot of the most relevant and important needs in this field. Novel techniques such as metasummary provide a means to link qualitative research findings to evidence-based practice. By systematically summarizing qualitative research on these needs, we hope to aid clinicians in providing care that is most helpful to patients and their families and in assessing the extent to which additional services or resources may be needed to further develop their respective institutions to meet the needs of their clientele. This metasummary is part of a larger review of the needs in PPC and PEOLC of patients, families and health care providers that we hope will further elaborate and guide clinical practice and research in PPC and PEOLC.

Our review highlights the most frequently reported needs (such as health care delivery and accessibility) as well as needs that are less frequently mentioned but equally important for clinicians and policy makers to address (such as sibling needs). However, there is a dearth of research on whether current services actually meet these needs, apart from a few studies on implementation of various PPC services (Browning, Solomon, & for the Initiative for Pediatric Palliative Care (IPPC) Investigator Team, 2005; Duncan, Spengler, & Wolfe, 2007; Harper et al., 2007) or preliminary evaluations of implemented programs and services (such as the Davies et al. 2005 and Macdonald et al. 2005 articles reviewed herein). Therefore, there is still a great deal of research to be done to discover a) how best to meet the needs of patients and families, b) how to implement PPC services and PEOLC practices, and c) if the implemented services and practices are able to meet the needs of patients and families.

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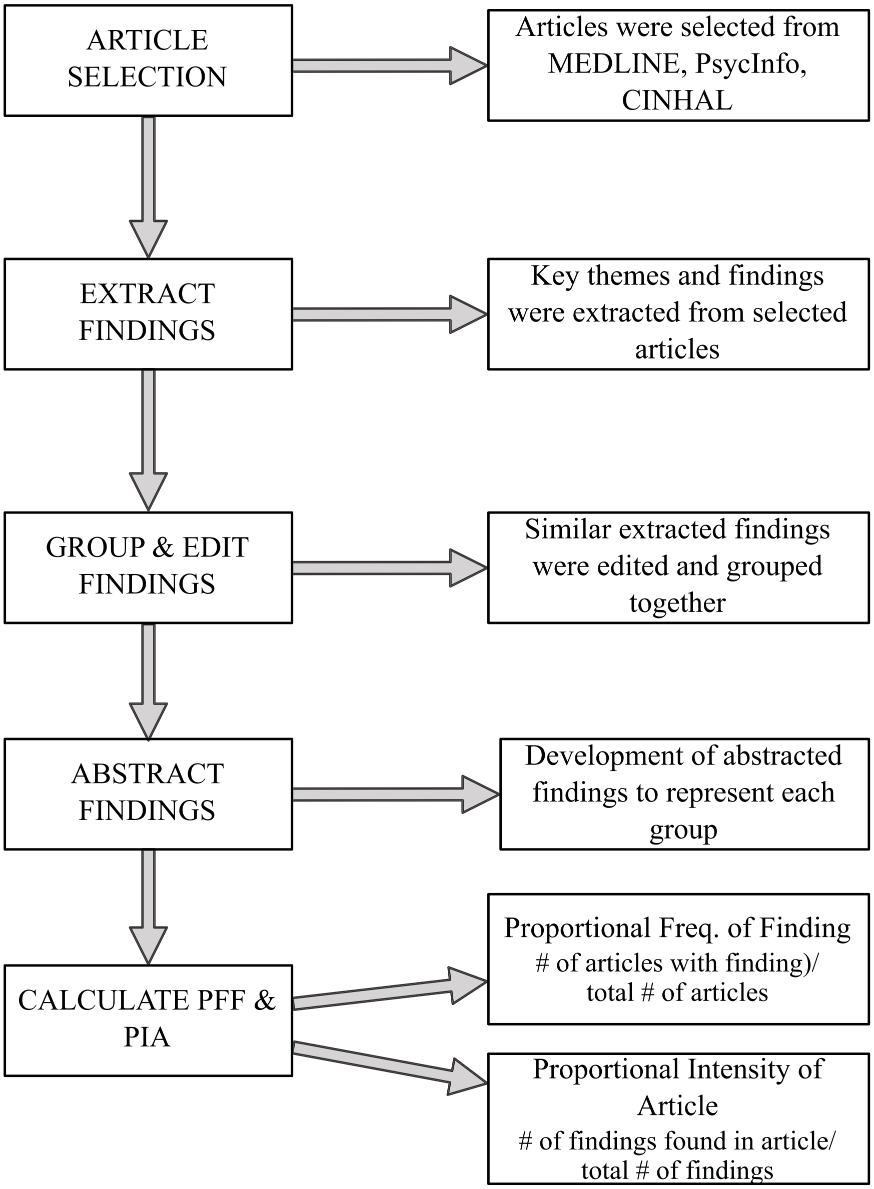
Zelcer, S., Cataudella, D., Cairney, A. E., & Bannister, S. L. (2010). Palliative care of children with brain tumors: A parental perspective. *Archives of Pediatrics & Adolescent Medicine*, *164*(3), 225-30. doi:10.1001/archpediatrics.2009.284



PFF, Proportional frequency of finding; PIA, proportional intensity of article.

Figure 1. Metasummary procedure.

Table 1. Characteristics of studies included in the metasummary

Author (year)	Study purpose/research question(s) as reported by the authors	Research Design/ Methodology	Data Collection Methods	Sample	Age of child*	Setting	Country (Prov., State)
Contro et al. (2002)	To obtain personal accounts of families' experiences in order to learn ways to improve care for pediatric patients and their families.	Qualitative exploratory and descriptive study	Interviews	44 families	Range = several hours – 15yrs	Hospital	United States (CA)
Contro et al. (2010)	To examine the experiences of Mexican American family members who immigrated to the United States and then experienced the death of a child.	Retrospective Design using Grounded Theory Methodology	Interviews	50 family members from 30 families	Not reported.	Hospital	United States (CA)
D'Agostino et al. (2008)	What are the views of bereaved parents of cancer patients regarding existing bereavement services? What do they find helpful in dealing with their loss. What additional services they would like to see offered to bereaved parents by the treating center?	Grounded Theory	Survey with open-ended questions and Focus groups	7 bereaved parents of children who died of cancer	Range = 6.20 - 14.64 yrs Mean = 8.91yrs	Hospital	Canada (ON)
Davies et al. (2005)	To report on the impact of the respite and end-of-life components of the Canuck Place program on both the ill children and their siblings.	Participatory Action Research	Interviews and survey with Likert-type & open-ended questions	25 ill children and 41 siblings	**Range = 6 – 18 yrs **Mean = 10.8yrs	Hospice	Canada (BC)
Davies et al., (2010)	To learn about experiences of Mexican American and Chinese American families requiring pediatric palliative care. Specifically, parents' perceptions of information sharing by health care providers during their child's hospitalizations and at their child's death.	Grounded Theory	Interviews	36 bereaved parents (26 Mexican American and 10 Chinese American) from 28 families	Range = 1d – 20yrs Mean = 4.45yrs	Hospital	United States (CA)
Donnelly et al. (2005)	To develop an empirically based conceptual model of the needs of children with life-limiting conditions.	Concept map	Web survey with Likert-type & open-ended questions	25 health care professionals	Not reported.	Online	United States (NY)

Harper et al. (2007)	Not reported.	Focus group	Focus groups	10 focus groups with 6 - 10 health care providers per group	Not reported.	Hospital	United States (TN)
Heller (2005)	Not reported.	Qualitative study	Interviews	36 bereaved parents	Range = 7ds – 18 yrs	Hospital	United States (not reported)
Hsiao (2007)	To identify the aspects of physician communication that children with life-limiting illness and their parents perceived to be facilitative or obstructive in pediatric palliative care.	Grounded theory	Interviews	20 parent child dyads	**Range = 9 – 21 yrs **Mean = 14.25 yrs	Hospital & hospice	United States (CA)
Jones (2006)	Not reported.	Grounded Theory	Focus groups and survey with Likert-type & open-ended questions	131 social workers	Not reported.	Mail out survey	United States (various)
Konrad (2008)	What qualities were helpful in your relationships with health care professionals? What qualities were unhelpful in your relationships with healthcare professionals? What aspects of the parenting experience do professionals least understand or acknowledge? What do you want professional caregivers to understand about your experience?	Phenomenology	Interviews	12 mothers caring for seriously ill or dying children	Range = birth – 15 yrs*****	Non-profit pediatric palliative care program	United States (ME)
Mack et al. (2005)	To ascertain parents' and physicians' assessments of quality of end-of-life care for children with cancer and to determine factors associated with high-quality care as perceived by parents and physicians.	Survey	Telephone survey with ratings of care and Likert-type questions	144 bereaved parents	Range = 0.3-25.3 yrs Median = 8.9 yrs	Hospital	United States (MA, MN)
Meert et al. (2005)	To gain a deeper understanding of parents' spiritual needs during their child's death and bereavement.	Prospective design, Qualitative Study	Interviews	33 bereaved parents	Range = 3ds – 24yrs Median = 4.5 yrs	Hospital	United States (MI)
Meert et al. (2008)	To describe parents' perceptions of their conversations with physicians regarding their child's illness and death in the pediatric intensive care.	Qualitative Study	Interviews	56 bereaved parents	Range = 0 – 20 yrs Median = 1.6 yrs	Hospital	United States (CPCCRN clinical centers)
Robinson et al.	To identify the nature and the role of	Qualitative study using	Survey with Likert-	56 bereaved parents	Range = newborn	Hospital	United

(2006)	spirituality from the parents' perspective at the end of life in the PICU and to discern clinical implications.	content analysis	type & open-ended questions		– 18 yrs		States (MA)
Widger (2008)	To describe the quality of care provided before, at the time of, and following the death of an infant, child or adolescent from the perspective of the parent.	Mixed-methods study	Survey with open-ended, yes/no & Likert-type questions	38 bereaved families	Not reported	Tertiary care center	Canada (eastern provinces)
Wolfe (2008)	To determine whether national and local efforts have led to changes in patterns of care advanced care planning, and symptom control among children with cancer at the end of life.	Survey	Questionnaire with Likert-type & open-ended questions	102 parents of children who died of cancer between 1990-1997 (baseline) and 1997-2004 (follow-up)	Mean (baseline) = 10.8 yrs Mean (follow-up) = 10.4 yrs	Hospital & tertiary care center	United States (MA)
Zelcer (2010)	To explore the end-of-life experience of children with brain tumors and their families.	Qualitative study using thematic analysis	Focus groups	25 parents of 17 children who had died of brain tumors	Range = 1 – 19yrs	Hospital	Canada (ON)

Note: We have reported the research question and methodology as described by the authors. *age of child at the time of death, **age of child participant, ***as described by study participants, ****member states of National Association of Children's Hospitals and Related Institutions, *****age at time of diagnosis.

Table 2. Frequency and intensity effects sizes of included studies and findings

ABSTRACTED FINDINGS	*PFF * (%)*	Donelly, 2005	Jones, 2006	Meert, 2005	Contro, 2002	Meert, 2008	Hsaio, 2007	Widger, 2008	Davies, 2010	Contro, 2010	Konrad, 2008	Mack, 2008	D'agostino, 2008	Meyer, 2006	Wolfe, 2008	Harper, 2007	Davies, 2005	Robinson, 2006	Zelcer, 2010	Heller, 2005	Macdonald, 2005	Davies, 2011
*PIA ** (%)*		61.9	57	55	33	36	29	29	29	29	21	19	17	17	14	12	12	12	12	10	10	7
Health care delivery and accessibility	**62**	*	*	*	*	*	*	*			*			*	*	*			*	*		
Continuity, consistency and coordination	**52**	*	*	*	*	*	*	*			*			*		*				*		
Services outside the hospital	**24**	*	*		*										*				*			
Access and availability of services	**14**	*					*							*								
Fewer negative incidents and preventable oversights	**10**				*			*														
Interactions with staff	**62**	*	*	*	*	*	*	*	*	*	*	*		*						*		
Honest and straightforward communications	**43**	*	*	*	*	*	*				*	*		*								
Parent & patient involvement	**33**				*	*	*	*	*		*	*										
Ongoing relationships with staff	**38**			*		*	*	*	*	*	*									*		
Sensitivity and empathy from staff	**24**			*		*		*			*			*								
Sensitive delivery of difficult news	**19**				*		*				*	*										
Sense of competency	**10**	*									*											
Information needs	**43**		*	*		*	*	*	*	*		*			*							
More information	**24**		*			*	*	*	*													
Clear & understandable information	**29**			*		*		*	*	*		*										
Preparation for illness progression & treatment effects	**19**		*				*		*						*							
Bereavement needs	**43**		*	*	*	*		*				*	*							*	*	
Continuity with treating hospital	**29**				*	*		*					*							*	*	
Preparation for death & bereavement	**19**			*				*				*	*									
Bereavement services	**19**		*					*					*								*	
Mementos	**14**					*		*													*	
Parental networking	**10**		*										*									
Psychosocial needs	**43**	*	*	*			*				*		*			*	*		*			
Emotional support	**33**	*	*	*			*				*		*			*						
"Normal" life	**24**	*	*				*										*		*			
Dignity and respect	**14**	*		*			*															
Social support for families	**19**	*	*	*						*												
Social support for patients	**10**	*	*																			
Patients and families need access to one another	**10**	*		*																		
Spiritual needs	**38**	*	*	*		*				*				*				*	*			
Maintaining a connection to the child	**29**	*		*		*				*								*	*			
Access to spiritual councelors or clergy	**14**		*	*														*				
Guidance according to one's own values	**19**	*		*						*								*				
Religious activities (such as prayer)	**10**			*														*				
Meaning making	**10**			*										*								
Hope	**5**																		*			
Pain and symptom management	**29**	*	*	*	*	*									*							
Consistent pain assessment	**5**	*																				
Effective pain & symptom management	**24**	*	*		*	*									*							
Patients need to be comforted and soothed	**10**	*		*																		
Cultural needs	**29**	*			*				*	*						*						*
Culturally sensitive care	**29**	*			*				*	*						*						*
Translators	**10**	*							*													
Fair treatment	**5**																					*
Decision making	**29**	*	*	*					*					*	*							
Control of treatment decisions	**14**	*	*	*																		
Adequate information to make decisions	**19**	*	*						*						*							
Support during decision-making	**14**	*	*											*								
Siblings' needs	**24**	*	*		*					*							*					
Support & counseling	**19**		*		*					*							*					
Specific services for siblings	**14**		*		*												*					
Family-oriented care	**14**	*			*											*						

** PFF: Proportional frequency of finding*

*** PIA: Proportional intensity of article*

Article 2

A narrative synthesis of quantitative and qualitative research on the psychosocial outcomes and adaptation of bereaved parents

A narrative synthesis of quantitative and qualitative research on the psychosocial outcomes and adaptation of bereaved parents

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Running head: Adaptation of bereaved parents

Abstract

There is a growing body of quantitative and qualitative studies exploring the experiences of bereaved parents and their adaptation and adjustment to life following the death of their child. These disparate studies have collectively identified many aspects related to the psychosocial post-loss outcomes of bereaved parents (e.g., circumstances of the death and age of the child who died). In order to use these findings to improve practice and further develop empirically based bereavement services, however, they must be synthesized in a clinically relevant manner. The purpose of this review is thus to synthesize this research and suggest clinical implications based on the empirical evidence in the area.

Method: Using a narrative synthesis technique, quantitative and qualitative research on the psychosocial outcomes and adaptation of bereaved parents published between 2000 and 2013 was collected and analyzed.

Results: The results suggest important elements to consider when assessing a parent's adaptation to their grief including: antecedents; circumstances surrounding the death; the social context; and various coping methods. The results also indicate psychosocial aspects related to better adaptation which could serve as potential avenues for support and intervention, such as meaning making and personal growth. These results are discussed along with the clinical implications of the findings and methodological issues in the literature that hinder the synthesis and clinical applicability of the findings of the various studies.

Introduction

In contemporary North American society, experiencing the death of a child is relatively rare, but the impact of this loss affects families for a lifetime (Field & Behrman, 2003). Moreover, many studies have demonstrated that the death of a child has a greater psychosocial impact on the bereaved than other types of loss (for example, Hunt & Greeff, 2011; Nolen-Hoeksema, Larson & Larson, 1998; Pudrovska, 2009; Rosenberg, Baker, Syrjala & Wolfe, 2012; Rubin et al., 2009; Sanders, 1980; Wortman & Boerner, 2007).

In order to address the needs of families in which minor-aged children have died paediatric hospitals are increasingly offering bereavement follow-up services to parents (D'Agostino, Berlin-Romalis, Jovcevska & Barrera, 2008; Decinque, Monterosso, Dadd, Sidhu, Macpherson & Aoun, 2006); deJong-Berg & Kane, 2006; Macdonald et al., 2005; Wintermeyer-Pingel, Murphy & Hammelef, 2013). Several authors have argued that to best meet the needs of parents, bereavement services should be evidence-based and theory driven, but have found, however, that this is not necessarily the current state of clinical practice (Decinque et al., 2006; Murphy, Johnson & Lohan, 2003b; Wortman & Boerner, 2007). Therefore, there is still an important gap between evidence-based research conducted with bereaved parents and actual hospital and community based psychosocial services offered to these parents (Murphy, Johnson & Lohan, 2003b; Sandler, Kondo & Ayers, 2011).

The current state of the research on parental grief is such that there are many qualitative studies examining parents’ experiences, and many quantitative (mostly correlational) studies examining the relationships between particular factors (such as cause of death) and the psychosocial outcomes of the parents. In order to use these studies to improve practice and further develop empirically based bereavement services, however, they must be synthesized in a clinically relevant manner. Such a synthesis (a) affords clinicians a broader view of how parents adapt to their grief, in order to best target their interventions; and (b) provides policy makers with a summary of the relevant evidence that can be translated into policy change and program development. Techniques such as narrative synthesis, wherein research findings are collected and explained through a narrative text, allow for exactly this type of representation of the concepts pertinent to improving clinical practice (Pope, Mays, & Popay, 2007).

In the following narrative synthesis, we review recent literature on the psychosocial outcomes of parents after the death of a child and how they adapt to their grief over time, and discuss implications of these findings for clinical practice and bereavement support service provision.

Method

With the goal of responding to the current knowledge translation gap in research on and services provided to bereaved parents, we conducted a systematic literature search using thematic analysis in order to produce a narrative synthesis of the findings. Following guidelines proposed by Pope, Mays and Popay, a narrative synthesis is "an approach to evidence synthesis that relies primarily on the use of words and text to summarise and explain the findings of multiple studies" and is considered useful for synthesizing both quantitative and qualitative research (Pope et al., 2007). The present review was conducted in two phases. In the first phase, (a) classic theories and concepts on grief, and (b) reviews examining the empirical evidence for these theories and other assumptions and myths about grief (Murphy, Johnson & Lohan, 2003b; Neimeyer, 2004; Wortman & Boerner, 2007; Wortman & Silver, 1989) were analyzed and their reference lists scrutinized for snowball searching (in phase 2). The analysis in phase 1 provided us with an overall structure for the review and areas of interest to explore in phase 2. In the second phase, MEDLINE, PsycINFO, and CINAHL databases were searched for research published between Jan. 2000 and Nov. 2013 that specifically examined the post-loss adjustment and psychosocial outcomes of bereaved parents using the following Boolean search: ((grief OR bereave* OR death OR dying) AND (parent OR infant OR newborn OR paediatric OR child* OR adolescent)). In addition, a snowball search was conducted, wherein the reference lists of articles analyzed in phase 1 and found in the database search of phase 2 were scanned for other potentially relevant studies (Greenhalgh and Peacock, 2005). To be included in the review, the articles had to be written in English, published in a peer-reviewed journal, include bereaved parents as participants, and examine psychosocial outcomes (such as grief intensity, depression or anxiety) and/or adaptation. The full-text articles where then assessed by the first author (MS) for inclusion in the review in terms of several criteria, namely: research question, methodology and methods (including data collection and analysis), and applicability to bereaved parents. Findings from the analysis of the chosen articles were then categorized following the structure obtained in phase 1. In total, 58 publications presenting research conducted with bereaved parents were retained and included in the review. The characteristics of the studies reviewed are provided in Table 1.

Results

In order to provide a clear synthesis of bereaved parents' post-loss adaptation and psychosocial outcomes, we have categorized our findings according to the following aspects:

antecedents, circumstances surrounding the death, reactions to the death (emotional, cognitive and behavioural), the social context of the parents' grief, and lifelong adaptation and growth (Figure 1). In each section, we first review the evidence related to this specific aspect, and then proceed to discuss what implications these findings might have for clinical interventions and services for helping and supporting bereaved parents through their grief. We also note where the evidence base is insufficient or inconclusive, and suggest avenues for future research.

Antecedents

In this section we explore the circumstances before the death of the child that were reported to have an impact on the psychosocial outcomes of parents after the death.

Age of the child who died

Though some research indicates that the age of the child who dies may have an impact on the parent's post-death experiences, the evidence is far from conclusive. In a study examining grief and depression in couples whose children had died, Wijngaards-de Meij et al. (2005) found that grief was most intense up to the age of 17 years old at which point the intensity of grief appears to decrease. When Keesee et al. (2008) tried to replicate the findings of the Wijngaards-DeMeij et al. (2005) study, they found a different association between age, measures of grief severity and complicated grief, reporting that parents who had older children who died had more severe grief symptomology. In a later study, WijngaardsDeMeij et al. (2008b) found that the death of older children was indeed associated with more depression among parents whereas grief symptoms increased with the age of the child up to the age of 17, at which point the grief symptoms had a tendency to decrease with age (maximum age of deceased child was 29 years). In seeming opposition to these findings, however, a study by Pudrovska (2009) exploring parents in mid-life reported that the detrimental effect of a child's death on parents' mental health was not moderated by the age at which the child died or the time elapsed since the child's death (Pudrovska, 2009). Dyregrov and colleagues (2003) were also unable to find a significant relationship between age of the child and parent's post-death psychological distress at 6 to 23 months after the death (maximum age of deceased child was 29 years).

Clinical implications. At this point, the findings related to the age of the child are too varied to present clear implications for clinical practice. However, the age of the child does impact service provision, as paediatric hospitals are increasingly offering bereavement services to parents, and thus these particular services are targeted towards parents whose minor age children have died. Also, the age of the child may be closely related to the cause of death. In Canada, for example, infants more often die from congenital complications whereas adolescents more often die from accidents (Statistics Canada, 2006). One must therefore be careful in the interpretation of results relating to age, as what may be reported by authors as an effect of age may in fact be due to the cause of death or some combination of these two factors. We suggest that future research should take this possible correlation into consideration when reporting on age-related effects (for example, control for cause when investigating age).

Family conditions before the death

Several authors have spoken to the importance of familial relationships before the child's passing on post-death outcomes for parents. Pre-death relationships with close family members have been found to have an impact on how parents grieve (Barrera et al., 2007), and the presence of other children born before or after the death of the child has been found to be positively linked to resilience during grief (Rogers, Floyd, Seltzer, Greenberg & Hong, 2008). The quality of the pre-death relationship with the deceased child may also be an important contributor to parents' post-death psychological outcomes, as negative relationships with the child before the death have been associated with greater grief difficulties for the parent (Feigelman, Jordan & Gorman, 2008).[1]

Clinical implications. It may be important for clinicians working with bereaved parents to assess the quality of relationships with spouses, children, parents, friends and other family members, before the death and after it, in order to find possible areas of stability and instability, which may impact how the parent grieves and adapts. Approaches such as Family Focused Grief Therapy may provide interesting avenues for interventions with bereaved parents. This form of therapy, developed in adult palliative care, evaluates the family for risk of poor psychosocial outcome and intervenes accordingly before the patient dies and continues during bereavement (Kissane, Lichtenthal & Zaider, 2007; Kissane et al., 2006).

Circumstances surrounding the death

Several authors have posited that the circumstances surrounding the death of the child have an impact on parents' post-loss experiences (Arnold, Gemma & Cushman, 2005; Wijngaards-de Meij et al., 2008). In this section we examine various circumstances surrounding the death of the child, such as the cause of death, interactions with hospital staff

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[1] It should be noted that this study included adolescent and adult children, with only 8 percent being under the age of 15. This finding, then, seems to be applicable primarily, if not exclusively, to situations in which the child dies in late adolescence or adulthood.

and other health care professionals while the child was ill, organ donation, and memorial services and funerals.

Cause of death

According to our review, the most researched aspect of circumstances surrounding the death, in terms of psychosocial impact on the parents post-loss, is the cause of death. Much of the research in this area centers on the question: How does the way the child died affect how the parents grieve? Here we first present studies examining the impact of sudden and traumatic deaths, followed by comparisons between sudden deaths and deaths from long-term illnesses, which is followed by a focused discussion on the unique aspects of bereavement after the death of a child from long-term illness.

In terms of sudden and traumatic deaths, Murphy and colleagues have extensively studied the psychological and physical impact on parents of losing a child in this way (Murphy et al., 1998; Murphy, 1996; Murphy, Johnson & Lohan, 2002b; Murphy, Johnson & Lohan, 2003c; Murphy, Johnson & Weber, 2002; Murphy, Johnson, Wu, Fan & Lohan, 2003a). In their 2002 study, Murphy et al. found that five years post-death, the majority of parents whose adolescent or young adult children died by accident, suicide, or homicide met diagnostic criteria for mental distress; moreover, about three times as many of these mothers (28%) and twice as many of these fathers (13%) met diagnostic criteria for post-traumatic stress disorder (PTSD) when compared to normative samples (Murphy, Johnson & Lohan, 2002a). A later study by Dyregrov et al. (2003) found that 57-78% of parents bereaved by suicide, accident, or Sudden Infant Death Syndrome (SIDS) scored above cut-off levels for traumatic grief, and showed symptoms of PTSD, complicated grief reactions, and general health problems at one-and-a-half years after the death of their child.

Comparing violent and non-violent deaths, Hogan, Greenfield, and Schmidt (2001) reported that parents whose children died by violent means had significantly higher scores on measures of panic when compared to parents whose children died of non-violent causes regardless of the time since death. These authors also found that, in particular, parents whose children died by murder had more feelings of blame and anger and these feelings remained over time. More recent studies by Keesee et al., (2008), and Lichtenthal et al. (2013) have reported that parents whose children have died violent deaths have significantly higher complicated grief scores than parents whose children died through non-violent means.

In other studies in which cause of death was a variable, however, differences in parental grieving have not always been as clearly marked, or as stable over time. For example, in a study comparing groups of parents whose child died by either suicide, traumatic death, or natural causes, Feigelman, Jordan, and Gorman, B. S. (2008) found that losing a child to suicide was associated with more grief difficulties and general mental health problems, but these associations were weak and no other major differences between the groups were found. Moreover, the authors found that the differences between parents whose children died of suicide and other causes levelled off at 3-5 years post-death (Feigelman, Jordan & Gorman, 2008). A 2013 study by Bolton and colleagues comparing bereaved parents whose children died of suicide to those whose children died of motor vehicle accidents reported that these parents showed few differences in post-death outcomes.[2]

Several studies have highlighted unique aspects of grief related to losing a child to illness (such as cancer). In the Hogan et al study (2001), they found that parents whose children died of illness had higher despair than the other three types of deaths (accident, suicide or homicide) at three years post-death (Hogan, Greenfield & Schmidt, 2001).[3] This agrees with findings from studies examining parents whose children died of cancer and other illnesses that speak to the impact caregiving for an ill child had on the parents after the loss (Barrera et al., 2007; Barrera et al., 2009; Rosenberg, Baker, Syrjala & Wolfe, 2012). It seems that for many parents whose children die of illnesses such as cancer, the grief experience begins at the point their child is given a life-limiting/life-threatening diagnosis; this is termed anticipatory grief (Evans, 1994; Titus & de Souza, 2011). In qualitative research conducted with parents whose children died of various illnesses (such as neurological disorders and various forms of cancer) parents reported reflecting on what their world would be like after the death, and what adjustments would need to be made internally and to family life to accommodate the fact that the care of their child no longer took a central role in their life (Barrera et al., 2007; Titus & de Souza, 2011). In quantitative research examining the impact of anticipatory grief on post-loss outcomes after infant deaths, Tan et al. (2012) found that

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[2] In both the Feigelman and Bolton studies the children who died where mostly over 19 years of age (see Table 1). It remains unclear if their findings would similarly apply to parents of minor-aged children.

[3] It is important to note here that Hogan et al. (2001) examined differences between groups of bereaved parents whereas Murphy et al. (2003) compared bereaved parents to normative samples.

parents who acknowledged negative outcomes earlier in the course of the illness reported less distress around the time of death and during bereavement. In addition, parents in this study felt less distressed when they were actively involved in end-of-life care decisions.

Clinical implications. From a service provision perspective, the cause of the child's death may influence if and how the family will be followed afterwards. For example, a clinician may want to further evaluate for symptoms of PTSD or other signs of trauma when the parent perceives the death as traumatic. Moreover, when the death of the child is not sudden or violent, as with children who have longer-term illnesses, there may be the opportunity to provide support to the parents before their child dies (Tan, Docherty, Barfield, & Brandon, 2012), in addition to helping the parents adapt to the loss of the caregiving role after the death (Barrera et al., 2007).

Interactions with hospital staff and health care professionals

Interactions with health care and mental health professionals may have an important impact on parents' bereavement experiences, as these interactions serve as a potential means of obtaining information and making sense of the child's death, and a source of emotional support for parents. For example, Meert, Thurston and Thomas (2001) found that emotional attitudes of staff and the adequacy of the information they provided to parents were correlated with intensity of early and long-term grief symptoms. Research examining infant deaths indicates that parents want to be informed about the circumstances of the death, even if this information may be difficult to take in (Clarke and Booth 2011). In research conducted in paediatric intensive care, the authors found that although 59% of parents whose child died wanted to meet with their child's intensive care physician post-death, only 13% actually had this meeting scheduled (Meert et al., 2007). In a subsequent study, when they asked the physicians about possible barriers to conducting follow-up meetings with parents, Meert et al. (2011b) identified several barriers including but not limited to: an unwillingness of physicians to meet with parents and the lack of a system for meeting initiation and planning.

The quality of the interactions with health care and mental health professionals also appears to have an impact post-death (Greeff, Vansteenwegen, & Herbiest, 2011; Janzen, Cadell, & Westhues, 2003). In a study by Janzen, Cadell and Westhues (2003) which collected advice bereaved parents would give to HCPs, the parents mentioned that the way HCPs interact with them post-death can be helpful to them and support them in the beginning of their grief process, but it can also be unhelpful and make their grieving process more difficult (Janzen, Cadell, & Westhues, 2003). A later study by Hunt and Greeff (2011) confirmed these results, and also found that parents often reported interactions with mental health professionals as negative experiences. Some of the reasons given for this were: a lack of similarity of experience (in that the HCPs had not experienced the death of a child); 'text-book' advice; the young age of counsellors; inappropriate counselling; and the mistiming of interventions.

Clinical implications. These findings suggest that health care and mental health professionals would benefit from clear guidelines and training on communicating and interacting with families after the death of a child (Meert et al., 2011b; Meert et al., 2007; Meert et al., 2001). In addition, more research must be done to understand how health care and mental health professionals can interact with parents in a way that is beneficial to those parents.

Circumstances shortly after the death

Several specific circumstances after the death of the child such as handling of the body, organ donation, viewing the body and saying farewell, and funeral/memorial services have been implicated in parents' post-loss outcomes.

Concerning viewing the body and saying goodbye, three separate studies conducted with bereaved parents have found that parents who have an opportunity to say goodbye to their child (either while their child is still alive or after the child has died) and view their deceased child's body have better psychological outcomes post-death, such as lower levels of grief as measured by Inventory of Complicated Grief (Arnold et al., 2005; Hunt & Greeff, 2011; Wijngaards-de Meij et al., 2008b). Other studies have found that parents who were unable to see or touch their infants expressed particularly strong regret (Arnold, Gemma and Cushman 2005), and that parents who had not viewed their child's body felt a lack of closure (Hunt and Greeff, 2011). In the literature examining stillbirths, there has been some debate as to whether or not it is beneficial for parents to hold their deceased infants (Benini, Ferrante, Chiara and Jankovic, 2012). A study by Benini, Ferrante, Chiara, and Jankovic (2012) attempted to create a unified position statement to this regard; the vast majority of the contributors to the study (i.e., directors of paediatric departments representing nine countries) felt that holding the baby, whether alive or dead, is a normal wish, and the authors provided evidence that it can be a valuable and cherished experience for bereaved parents.

Shortly after the time of death, parents may be asked if they choose to donate their child's organs. Although a thorough examination of this topic is beyond the scope of this article, there are several studies particular to outcomes in bereaved parents worth noting.

Merchant et al. (2008) examined the positive and negative aspects of organ donation and associated impact on depression and grief symptoms; they found that if donor families felt there were negative aspects about the donation process, these families were more likely to be bothered by symptoms of PTSD, whereas families that felt comforted about donation were less likely to be bothered by feelings of depression. On the other hand, Bellali and Papadatou (2006) found donating and non-donating parents were similar in the grieving processes, but that it was the meaning attributed to the decision to donate or not that facilitated or hindered their adjustment post-death (Bellali & Papadatou, 2006).

Another decision parents are confronted with shortly after the death of the child is whether or not to conduct an autopsy. In a 2013 study, Wiener et al. found that only a minority of parents recalled discussing an autopsy with health care professionals; the majority who did not recall having this discussion said they would have considered an autopsy if the topic had been broached. In a meta-analysis conducted by Gold et al. (2007), the authors found that most parents who were offered one elected to have an autopsy performed, but did not receive follow-up information with results and felt frustrated in trying to get this information from the hospital. Moreover, a study by MacDonald et al. (2006) found that protracted waiting for the results of the autopsy increased parents’ distress and, at times, complicated their decision to have more children.

After facing decisions on organ donations and autopsies; parents must next decide whether to have their deceased child buried or cremated. Wijngaards-de Meij et al. (2008b) found that, in and of itself, this decision did not have an impact on psychological adjustment post-death. They did find, however, that parents whose child was laid out for viewing had less grief.[4] Also, parents have reported regret at not having a specific location as a memorial to their child (Hunt & Greeff, 2011).

Clinical implications. Very soon after the death of their child, parents are confronted with having to make two irreversible decisions: whether to opt for organ donation, and whether or not to have an autopsy conducted. It is important for parents to feel supported during this time. In addition, Gold et al.'s (2007) findings suggest that when an autopsy is conducted, HCPs should provide families with a timely follow-up. It may also be helpful for parents to be given an opportunity and encouraged to find their own way to say good-bye to their deceased child (Wijngaards-de Meij et al., 2008b). Benini et al. (2012) offered interesting recommendations for the care of deceased children and their families that centered on giving the family time with the child's body and choice in line with their beliefs. Where memorial services and funerals are concerned, parents' individual religious and spiritual preferences must of course be respected. That being said, it seems important for most parents to have some sort of memorial to the deceased child.

Reactions to the death

In this section we explore the emotional and cognitive-behavioural reactions that emerge in the wake of losing a child that have been reported as related to post-loss outcomes and adjustment to life.

Emotional reactions

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[4] It should be noted, however, that certain religions (such as Judaism) do not lay out the body for viewing, a potential confounding variable not addressed in the Wijngaards-de Meij (2008b) study.

In the acute phase of grief, bereaved parents have reported feeling disappointment, anger, hate, blame, and bitterness (Hogan et al., 2001; Hunt & Greeff, 2011; Malkinson & Bar-Tur, 2005; Wheeler, 2001). Parents have also reported feeling intense distress and sadness, regret, shock, and despair for many years following the loss (Hogan et al., 2001; Hunt & Greeff, 2011; Malkinson & Bar-Tur, 2005; Wheeler, 2001; Wing, Burge-Callaway, Rose Clance, & Armistead, 2001). In addition, lasting depression and anxiety were found to be commonly reported emotional reactions to infant loss (Wing et al., 2001). In research conducted with parents whose child died of cancer specifically, parents also reported feelings of intense distress, sadness, regret, emotional pain, and anger, but these parents also mentioned feeling relieved that the child was no longer suffering (Barrera et al., 2009; Gilmer et al., 2012). Nonetheless, parents have reported that although the feeling of loss decreases in intensity, it persists over time (Arnold et al., 2008; Arnold et al., 2005; Malkinson & Bar-Tur, 2005; Rogers et al., 2008).

Several researchers have examined how bereaved parents regulate the difficult emotions they experience after the death of their child (Hooghe, Neimeyer, & Rober, 2012; Znoj & Keller, 2002). Adaptive emotion regulation is described as the capacity to tolerate adverse feelings or the ability to remain calm even during stressful encounters; this is often involuntary and happens automatically (Znoj & Keller, 2002). The strategies used by parents to regulate their emotions were found to be behavioural (e.g., avoidance of situations that trigger the emotions) and cognitive (e.g., by misinterpreting what others say) in nature and were moderately yet consistently related to physical health and emotional distress (Hooghe et al., 2012; Znoj & Keller, 2002); in general, bereaved parents who exhibit effortless emotion regulation were found to have less depression and better physical health (Znoj & Keller, 2002). In contrast, Znoj found that avoidance, as a forced strategy of dealing with emotions, or distortion, as a cognitive procedure to dampen emotional impact, was associated with lower scores on physical health and higher scores on depression and posttraumatic stress symptoms (Znoj & Keller, 2002). Bereaved parents have also been found to come to terms better with upsetting emotions when compared to a control group of age-matched peers from the general population (Znoj & Keller, 2002).[5]

Clinical implications. From a clinical standpoint, feelings of distress after the death of one's child are to be expected, but there has been debate on the presentation and universality of distress, and which emotional reactions, if any, warrant intervention (see Stroebe, Stroebe, Schut, Zech, & van den Bout, 2002; Wortman & Boerner, 2007; Wortman & Silver, 1989 for a detailed review for bereavement in general). Though intense distress may be common in bereaved parents, Tedeschi and Calhoun (2004) warn that if clinicians assume that distress is inevitable, they may feel the parent is not grieving adaptively if they do not exhibit distress, thus directing their interventions to address a problem that may not, in fact, exist. Following from the findings of Hooghe et al. (2012) and Znoj & Keller (2002), clinicians may want to consider how parents regulate their emotions in various situations and help them to develop adaptive ways to deal with the intense emotions related to their grief when necessary. They might also keep in mind that emotional distance can be adaptive, so that as much as parents may need to feel close to their deceased child and maintain the memory of and bond with this

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[5] The experience and regulation of negative emotions were often mentioned in the literature. It is worth noting, however, that parents also mentioned positive emotional experiences, such as happiness, shortly after the death of their child (Bonanno, Moskowitz, Papa, & Folkman, 2005; Murphy, 2008).

child, they may also need distance from the intense emotional pain associated with their loss (Hooghe, Neimeyer, & Rober, 2012; Znoj & Keller, 2002). Lastly, clinicians may want to consider affective indicators of disorders, such as those described in the proposed DSM-5 criteria for persistent complex bereavement disorder (such as an intense sorrow and emotional pain lasting for at least 12 months)(Appendix A; American Psychological Association, 2013).

Cognitive and behavioural reactions

Parents have reported several general cognitive and behavioural reactions to the death of their child, including loss of memory, disbelief, sensory effects, paranormal effects, dreams and visions, a sense of loss of a future for the child, and mentally searching for closure or understanding (Hunt & Greeff, 2011). Two studies were reviewed that explored these reactions in bereaved parents over time. Early cognitive reactions may include inability to accept the reality of the death (including disbelief and associated feelings of numbness) (Wheeler, 2001) and disorganization (i.e. difficulty maintaining day-to-day functioning, which may include difficulties with memory, concentration, and learning new things) (Hogan et al., 2001). Later reactions may include questioning (how, why), and acceptance of (or inability to accept) the death (Wheeler, 2001).

There has been interesting research on how parents cope with preoccupations and intrusive thoughts about their deceased child (Wheeler, 2001; Wing et al., 2001). Intrusive thoughts are often associated with avoidance behaviours in patients with PTSD. However, though bereaved parents seem to have higher rates of intrusive thoughts when compared to age- and gender-matched individuals, they do not appear to have higher levels of avoidance in reaction to these thoughts (Znoj & Keller, 2002). This feature of parental grief may distinguish grief reactions from PTSD symptoms (Znoj & Keller, 2002). Furthermore, if the parent is exhibiting avoidant behaviours, it may be important to consider to what extent avoidance may or may not be adaptive (see Shear, 2010 for a review). For example, avoidance may give parents respite from the intense emotional aspects of their grief; but continual use of avoidance of emotions and thoughts related to grief may indicate the parent is experiencing complicated grief (Shear, 2010). In any case, there remains a need for more research on bereaved parents in this area.

Another way parents may cope with difficult thoughts is through trying to see the positive aspects of their grief (also known as positive reframing). Positive reframing has been found to have impact on how bereaved parents adapt to their grief and may lead to positive changes and personal growth (Barrera et al., 2007; Gilmer et al., 2012; Riley, LaMontagne, Hepworth, & Murphy, 2007). We explore further how parents find benefits from the loss and the positive changes they experience in the upcoming section on adaptation over the life span.

Clinical implications. The cognitive and behavioural reactions mentioned above may be useful for various aspects of clinical intervention and services for bereaved parents. Knowledge on general and time-dependent cognitive and behavioural reactions can be used to help normalize parents' grief experiences, and it may also help clinicians to pinpoint problematic cognitions that could lead to poorer psychological outcomes. In addition, cognitive or cognitive-behavioural methods that encourage skill-building (with emphasis on cognitive flexibility) and positive reinterpretation (when appropriate) may be potential avenues for mental health professionals to explore when helping parents adapt to their grief (Riley et al., 2007). Clinicians also need to be careful when assessing and treating bereaved parents for trauma symptoms, as these individuals do not appear to exhibit trauma symptoms in the same manner as patients with PTSD (for example, traumatized bereaved parents may not exhibit avoidant behaviours). As an example of a possible intervention, Malkinson and Brask-Rustad developed a cognitive-behavioural couples therapy for traumatic bereavement that they examined specifically in parents (Malkinson & Brask-Rustad, 2013). It is important to note that the studies reviewed in this area are all correlational in design, and more work needs to be done to ascertain whether or not the associations between these reactions and post-death outcomes are indeed causal. In addition, more research is needed that examines the cognitive-behavioural grief reactions of bereaved parents in particular, which may be different from other bereaved individuals. The work of Shear and colleagues (2005) takes some initial steps in this direction by exploring a Complicated Grief Treatment (CGT); however, in their study they found that parents had a lower response to CGT than other bereaved individuals.

Social Context of Grief

Some authors have highlighted the significance of the social context for grief in general (Stroebe & Schut, 1999; Walter, 1996) and parental grief specifically (Barrera, et al., 2009; MacDonald et al., 2005; D’Agostino et al., 2008; Klass, 1997; Riches & Dawson, 1996). In the following section, we will first summarize findings that relate to social networks in a general sense, before moving on to consider the parents' relationships with their surviving children and spousal partners.

Social networks and support

Bereaved parents have reported support coming from family, friends, colleagues (Arnold et al., 2008; Barrera et al., 2007; Laakso & Paunonen-Ilmonen, 2002), and even strangers (Tan et al., 2012). Social support is often appreciated by parents (Arnold et al., 2005; Barrera et al., 2009; Titus & de Souza, 2011; Wheeler, 2001), with parents mentioning practical support (such as information, and instrumental help like lending a hand with cooking and caring for surviving children), and emotional support (such as consolation and caring, listening, understanding hugs) as particularly helpful during their bereavement (Barrera et al., 2009; Hunt & Greeff, 2011; Laakso & Paunonen-Ilmonen, 2002). In addition, parents spoke about finding support from people who made them feel comfortable enough to speak about their experiences, who helped them remember the positive aspects of their child's life and their situation, and who gave them permission to grieve at their own pace (Barrera et al., 2009; Hunt & Greeff, 2011).

However, interactions with others may also be perceived as non-supportive or problematic (Barrera et al., 2009; Laakso & Paunonen-Ilmonen, 2002; Titus & de Souza, 2011). These findings are consistent with research on bereavement in general (spousal, parental etc.), where unhelpful social interactions were significantly correlated with greater rates of depression (Ingram, Jones, & Smith, 2001). Parents have also reported unwarranted interference and advice as particularly unhelpful (Barrera et al., 2009; Laakso & Paunonen-Ilmonen, 2002). On the other hand, parents sometimes feel ignored or rejected by friends after the death of their child (Arnold et al., 2005; Barrera et al., 2009; Laakso & Paunonen-Ilmonen, 2002). Parents often speak of support as helpful (Riley et al., 2007; Wing et al., 2001), and thus it may seem that social support should aid in parents' adaptation to the loss. In the general bereavement literature, however, there are mixed findings on the impact of social support on post-death outcomes of the bereaved. In a 2005 review of research on bereavement by Stroebe, Schut, and Stroebe, they did not find evidence for the assumption that social support moderates distress (Stroebe, Schut, & Stroebe, 2005). In a study by Murphy, Chung and Johnson (2002) examining parents after the violent death of their adolescent or young adult children the authors found no significant effect of social support on distress over time (Murphy, Chung, & Johnson, 2002). On the other hand, a Riley et al. (2007) study with mothers who had infants who died found that a support-seeking coping disposition was related to greater reports of personal growth, including changes to self-identity and improved relationships. Moreover, mothers who perceived they had more available social support also reported less intense grief responses and complicated grief (Riley et al., 2007). It is important to mention, however, that parents often do not want to burden their friends and family with their intense emotions of grief (Toller, 2005); this reticence can lead to the parents' isolation, which is often found to be associated with depression (Barrera et al., 2009; Rosenblatt, 2000).

Clinical implications. Grieving necessarily takes place within a social context. It is therefore important for clinicians to assess social networks, the quality of the relationships therein, and whether the parents' support needs are being met, while keeping in mind how the parent perceives the support available to them (Haber, Cohen, Lucas and Baltes, 2007). This knowledge can help clinicians make more informed decisions as to if and how to intervene, or refer to other services when appropriate.

Relationships with surviving children

In cases where the deceased child had siblings, bereaved parents often recognize and worry that these children are suffering. Some parents report feeling unable to make time for their children, or overlooking their children's suffering because they are preoccupied with their own personal grief (Hunt & Greeff, 2011; Malkinson & Bar-Tur, 2005). This in turn may lead to a complicated relationship between parent and child in some cases, reported to last for many years (Ibid.). During the acute phase of grief, the relationship with the deceased child may occupy a central role for the parent, at the expense of their relationship with the parent's living children (Barrera et al., 2009) which parents have mentioned regretting later in life (Malkinson & Bar-Tur, 2005). Conversely, other parents have felt a heightened sense of love, connection, and need to protect their surviving children (Arnold et al., 2005; Malkinson & Bar-Tur, 2005).

Relationships with surviving children may in fact buffer some of the possible negative consequences of parental grief. Barrera et al. (2009) found that the vast majority of parents with surviving children reported these children as serving as sources of stability, strength, support, and purpose in life (Barrera et al., 2009). A study by Rogers et al. found that parents with children born either before or after the death were less likely to experience a marital disruption (Rogers, Floyd, Seltzer, Greenberg, & Hong, 2008), while a study by Li et al., 2005 found that when parents whose child died had other children, mothers and fathers both had a lower risk of hospitalization for affective disorders, and mothers also had a lower risk of hospitalization for schizophrenia and substance abuse (Li, Laursen, Precht, Olsen, & Mortensen, 2005). Barrera et al. (2009) reported that many parents mentioned wanting to ensure that surviving children were coping with the death in a constructive manner, and that this desire helped parents grieve by pushing them to discuss the family's experience of the illness and death (Barrera et al., 2009). However, a small number of parents in the Barrera et al. (2009) study felt their relationships with living children were a source of distress and heartbreak; some mentioned issues in these relationships that existed before the death of the child, particularly while the deceased child was ill and undergoing treatment.

Clinical implications. Considering these findings, clinicians should find a balance between helping parents maintain a continuing bond to their deceased child and maintaining their relationships with their living children. Moreover, parents may need counselling on how to help their surviving children traverse the grief of their sibling. Lastly, findings in this area highlight the importance of providing services and support to the family as a whole, for example with interventions that are family focused (such as Family Focused Grief Therapy mentioned previously).

Relationships with spouses

Many authors have explored the impact of the death of a child on parental conjugal relationships. A common belief is that the separation or divorce of parents is common after the death of a child, if not inevitable (Murphy, Johnson, & Lohan, 2003b). There is no convincing evidence, however, to support this view. In fact, in the over 100 studies they examined, Murphy and colleagues (2003b) only found two controlled studies that supported high divorce rates among bereaved parents when compared to the general population (Lehman et al., 1987; Najmen et al., 1993). Moreover, several critical reviews and empirical studies suggest that the frequency of separation and divorce between bereaved parents has been greatly inflated (see Murphy et al., 2003b for a detailed review) and that most couples are able to deal with the death with their spousal relationship intact (Malkinson & Bar-Tur, 2005). In fact, conjugal relationships may serve as a source of stability and support that are integral components of adjustment to bereavement (Barrera et al., 2009; Gilmer et al., 2012), and a base for meaning making (Titus & de Souza, 2011) for the parents. This being said, some couples do indeed experience difficulty. Studies have reported parents experiencing marital disruption (Rogers et al., 2008), reduced communication with their spouse resulting in distancing leading to divorce (Arnold et al., 2005), feelings that the spousal relationship was a source of instability and distress (Barrera et al., 2009), or that the relationship was destroyed after the death of their child (Malkinson & Bar-Tur, 2005).

Studies inquiring into how parents navigate their lives together after the death of their child report that parents experience tensions between being open or closed when deciding to talk with their partner, and between grieving together or individually (Hooghe, Neimeyer, & Rober, 2011; Hooghe et al., 2012; Toller, 2005; Toller, 2008; Toller & Braithwaite, 2009). Along the same lines, attempts to protect a spousal partner by regulating one's own emotions has been associated not only with more grief symptoms for the individual, but also for their spouse (Stroebe et al., 2013).

Clinical implications. Clinicians should be aware that, contrary to some assumptions, most parental relationships seem to traverse the death of a child intact, and may indeed be positively affected over the long term (Barrera et al., 2009; Gilmer et al., 2012). Where there is conjugal discord following the death of a child, the clinician may want to assess if such issues predate the death. When tension arises due to communication difficulties post-death, and where these difficulties seem to be associated predominantly with the death itself and not with some pre-existing issue, clinicians might help parents understand that their spouse may have different ways of coping and communicating throughout their bereavement (Toller & Braithwaite, 2009; Wijngaards-de Meij et al., 2008a) and techniques such as those used in Family Focused Grief Therapy may also be appropriate (Kissane, Lichtenthal & Zaider, 2007; Kissane et al., 2006).

Coping

Coping methods and strategies

The concept of coping (defined as dealing with a difficult situation) is germane to our exploration of how parents adapt to life following the death of their child, for the parents must cope with various stressors related to this loss. Many different conceptualizations of coping have been proposed, both in terms of stressful situations in general and with regard to bereavement in particular (Anderson, Marwit and Chibnel, 2005; Carver, Scheier, & Weintraub; Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986; and Park & Folkman, 1997). Below we synthesize those findings related to coping that we found in our review of the parental bereavement literature published since 2000.

Hunt and Greeff (2011) described coping strategies that bereaved parents reported as task-focused (such as taking medication, joining a support group, participating in hobbies and outings), emotion-focused (such as various forms of verbal expression, using humour or sarcasm, regulating their own emotions through self-talk) and avoidance-directed (such as pretending that the death had not occurred, avoiding triggers that remind them of the death of their child, keeping busy to avoid thinking). In a study of mothers bereaved of infants, Riley et al. (2007) used Carver et al.'s COPE scale (1989) to explore how differences in coping disposition influence grief responses (Riley et al., 2007), and found that active methods (taking direct action, planning, and problem solving) correlated to less frequent or intense grief responses, but not necessarily to less complicated grief, in the mothers they studied. The authors speculate on this finding by stating that active coping may not be effective when separation distress is overwhelming; at these times, coping methods such as distancing and withdrawal may be more effective (Riley et al., 2007).

Finding general coping theories useful but ultimately limited in the study of bereavement, Stroebe and Schut (1999) developed the Dual Process Model (DPM) to explain how individuals cope with grief in relation to the death of a loved one. The DPM distinguishes between loss-oriented coping (such as grief work or letting go) and restoration-oriented coping (such as attending to life changes or doing new things), and the bereaved individual is thought to oscillate between these two ways of coping throughout their bereavement. Interestingly, though the Riley et al. (2007) study used a different theoretical model (the COPE) (Carver et al., 1989) their finding that active coping may be less adaptive than avoidance at certain points in bereavement could be seen to agree with the Dual Process Model. A case study by (Hooghe et al., 2012) found that bereaved couples cope with grief though a dynamic process balancing confrontation and avoidance. However, they problematized the oscillation process in the DPM, stating that the processes reported by the couples seemed more simultaneous than oscillatory. Wijngaards-de Meij et al. (2008) developed an inventory to examine the impact of dual process coping methods (loss- or restoration-oriented) on psychological adjustment in bereaved parents. The authors reported that the degree of loss-orientation (as measured on a

Likert scale) predicted negative psychological adjustment, while the degree of restoration-orientation coping was associated with improved adjustment. This is an interesting finding, if we recall that central to the DPM is the idea that both loss and restoration-oriented coping are inherent in grief. Wijngaards-de Meij et al. (2008) address this point in their discussion, and assert that being high in loss-orientation is not necessarily associated with high levels of depression, as long as high levels of restoration-orientation accompany the loss-orientation.

Clinical implications: It is important for clinicians to understand the diverse ways parents may cope, and under what circumstances some of these coping strategies might be maladaptive or likely to have a negative impact on post-loss experiences. Other than the few studies mentioned in this review, however, there is relatively little research investigating specific coping strategies or dispositions of bereaved parents and how these may influence post-death outcomes (Barrera et al., 2007; Stroebe & Schut, 2010; Wortman & Boerner, 2007). Moreover, as can be seen by the findings presented herein, what studies do exist draw on different conceptualizations of the construct of coping, making comparisons across studies difficult. The DPM is promising in that, unlike its predecessors, it was developed to study coping with relation to stressors specific to bereavement. Recent research using the DPM in studying bereaved parents supports the idea that both loss-oriented and restoration-oriented coping are a normal part of the grieving process, though, as the Wijngaards-de Meij et al. (2008) study suggests, an imbalance towards loss-orientation may be associated with higher levels of depression, which seems clinically relevant.

Spirituality and religion

Spirituality and religion have been implicated in helping the bereaved cope with their grief. However, the existing results on the impact of spirituality and religion on post-death outcomes are mixed (Wortmann & Park, 2008), and there are few studies that examine this relationship over time or compare bereaved individuals in terms of types of loss or to their non-bereaved counterparts. For a more detailed discussion on the impact of religion and spirituality on adjustment post-death in bereaved individuals in general, we refer the reader to Wortmann and Park's 2008 review on the subject; reviewed below are findings related specifically to bereaved parents.

Bereaved parents often report spiritual and religious beliefs as helpful (Arnold et al., 2008; Murphy et al., 2002). In the Murphy et al. study (2002), the authors found that religious coping was positively related to acceptance for mothers (but not fathers) at four-months post-death; interestingly, however, this type of coping was not related to mental distress or PTSD outcomes at 5 years after the death, despite parents describing religious beliefs and practices as helpful in coping with their grief (Murphy et al., 2002). On the other hand, Meert, Thurston and Thomas (2001) reported that parents whose child died in paediatric intensive care and who used spiritual coping had less early and long-term grief symptoms as measured by the *Texas Revised Inventory of Grief* (Faschingbauer, 1981; Meert et al., 2001).

The effects of spirituality on parents' adaptation post-death may be explained through meaning making. For example, in a study on infant death, Uren and Wastell (2002) found spirituality to be negatively associated with grief through helping the parent find meaning in the loss (Uren & Wastell, 2002). In addition, in a later study Murphy, Johnson and Lohan (2003) reported that religious coping was associated with finding meaning at five years post-death and that finding meaning was also associated with lower levels of mental distress (Murphy et al., 2003). We should note, however, that these are correlational studies, and do not necessarily imply a causal relationship between finding meaning through spirituality and improved psychosocial outcomes post-loss.

Clinical implications. For clinicians it is important to respect individual differences and the multi-dimensional nature of religion and spirituality (Wortmann & Park, 2008). It is also worth noting that parents may change their spiritual and/or religious beliefs as they traverse their bereavement (Arnold et al., 2008; Gilmer et al., 2012; Lichtenthal, Currier, Neimeyer, & Keesee, 2010; Wortman & Boerner, 2007). Allowing for these differences, however, we can perhaps identify certain common aspects of spirituality and religion likely to be important points for intervention, such as maintaining a connection to the deceased child (discussed previously) and meaning reconstruction (discussed in the following section).

Relationship to the deceased child

Contrary to the earlier psychoanalytical conceptualizations of grief (Freud, 1961; Lindman, 1944), research conducted with bereaved parents since the 1980's has repeatedly shown that detachment from their dead child is not a psychological goal for bereaved parents (Klass, 1993; Klass, 1997; Klass, 2006; Rando, 1986; Rosenblatt, 2000; Walter, 1996; Wheeler, 2001). These parents report having a strong and lasting emotional bond to their children (Arnold et al., 2005; Malkinson & Bar-Tur, 2005; Rubin & Malkinson, 2001; Toller, 2005), which they often feel is important to maintain (Arnold et al., 2005; Meert et al., 2005; Murphy et al., 2003; Wheeler, 2001). For example, some bereaved parents may express a passive bond with their child, where they simply feel their child's presence, whereas other parents may attempt to maintain bonds to their deceased children through more active techniques such as communicating with their deceased children, journal writing, visiting the grave, or rituals (Barrera et al., 2009; Foster et al., 2011).

Clinical implications. It is most likely not necessary for parents to relinquish bonds to their deceased child in order to adapt to life after this loss. Indeed, one way in which clinicians might help parents is in supporting them in maintaining some type of bond with their deceased child. This suggestion, however, should come with a caveat: some research in general bereavement indicates that there are important individual differences in attachment styles, and certain attachment styles may predispose an individual to maladaptive grief reactions (Field, Gao & Paderna, 2005; Stroebe, Schut & Boerner, 2010; Wayment & Vierthaler 2011).

Meaning reconstruction

Meaning reconstruction (also called meaning-making) has received significant attention in the literature on bereaved parents because of the profound challenges that those who experience the untimely death of a child often face in finding meaning in the death and in their lives. The meaning-making process is often ignited by distress that arises from a discrepancy between the appraised meaning of a situation and one's existing global meaning framework (Park, 2010). Individuals try to reduce the discrepancy and the related distress through meaning-making processes such as sense-making (i.e., how one makes sense of the loss through causal attributions) and benefit-finding (i.e., a focus on positive consequences of the loss experience, such as enhanced empathy, reordered life priorities, or a closer connection to other people or God) (Davis, Nolen-Hoeksema, & Larson, 1998; Keesee, Currier, & Neimeyer, 2008).

Finding meaning in one's life after the loss of a child can be a tremendous struggle, as being a parent to the deceased child typically plays such a key role in one's sense of purpose and identity (Barrera et al., 2009; Rogers et al., 2008). Many bereaved parents have reported searching for meaning in order to reconstruct their shattered beliefs about themselves and the world (Barrera et al., 2009; Keesee et al., 2008; Lichtenthal et al., 2010; Matthews & Marwit, 2003; Meert, Thurston, & Briller, 2005; Murphy, Clark Johnson, & Lohan, 2003; Uren & Wastell, 2002; Wheeler, 2001). More specifically, bereaved parents have reported sense-making themes such as: attributing the loss to God's will or other spiritual, religious, existential or scientific beliefs; attributing the loss to some greater purpose of the child's life; seeking information in order to make sense of the death; and contemplating how the death could have been prevented (Barrera et al., 2009; Lichtenthal, Currier, Neimeyer, & Keesee, 2010; Lichtenthal, Neimeyer, Currier, Roberts, & Jordan, 2013; Murphy, Clark Johnson, & Lohan, 2003; Wheeler, 2001). In terms of benefit-finding, parents have reported themes such as increased empathy, compassion and sensitivity towards others, gaining new insights into the meaning of life, and improved coping ability and close relationships (Barrera et al., 2009; Lichtenthal et al., 2010; Lichtenthal et al., 2013; Murphy et al., 2003; Wheeler, 2001).

In addition, how the child died may also impact how the parent reconstructs meaning after the loss. Lichtenthal et al. (2013) compared meaning reconstruction in parents whose children died of violent causes versus parents whose children died from non-violent causes. Significant differences were found, with parents whose children died of violent causes less often reporting benefit-finding themes of improved coping and less fear and more often reporting that they could not make sense of the loss. On the other hand, not being able to make sense of the loss is a common finding in research with bereaved parents regardless of how the child died (Cleiren, 1993; Lehman, Wortman, & Williams, 1987; Wheeler, 2001; Wortman & Silver, 1989). Lichtenthal et al. (2010), for example, found that nearly half of their sample of parents bereaved by a range of causes reported that they could not make sense of the death, and approximately one-fifth reported that they could not identify any benefits related to this experience.

Concerning how the search for meaning correlates with post-death psychosocial outcomes: some studies have found that sense-making was associated with reduced grief severity and better post-loss adjustment (Keesee, Currier, & Neimeyer, 2008; Uren & Wastell, 2010). Along similar lines, Murphy et al. (2003) found that finding meaning was associated with better adjustment in parents who experienced the sudden death of a child. In terms of finding benefits, Rogers et al. (2008) found that having a sense of purpose in life predicted long-term functioning, especially in fathers. In contrast, the research appears to indicate that bereaved parents who struggle to find meaning are at greater risk of difficulties with adaptation to life after the death. For example, Lichtenthal et al. (2010) reported that bereaved parents were at increased risk of potentially meeting criteria for prolonged grief disorder (PGD) when they could not make sense of or identify positive consequences associated with their loss. Furthermore, parents who try but fail to find meaning may experience the grief process as particularly painful, intense and debilitating (Keesee et al., 2008). Then again, there are some parents who simply do not feel compelled to search for meaning; interestingly, research appears to indicate that these parents show no major differences compared to those who searched and then found meaning (Keesee et al., 2008).

Clinical implications. Findings such as those presented above lend credence to recently developed interventions oriented towards helping the bereaved through the reconstruction of meaning. Meaning-Centered Grief Therapy (MCGT) is designed to help the bereaved through the existential challenges that often follow the loss of a child (Neimeyer & Lichtenthal, in press). There is as yet no published study on MCGT, though a pilot study of MCGT for parents bereaved by cancer is currently underway.

Adaptation and growth over the life span

In the following section we explore how parents adapt to their grief over the life span by examining research on physiological adaptation to the loss, differences between how mothers and fathers adapt to their grief, positive change and personal growth, and general adaptation to grief over time.

Physiological adaptation to the loss

Recent research has begun to highlight the physiological reactions parents experience after the death of a child. However, a review by Hendrickson (2009) found that many studies on the relationship between specific health outcomes and parental grief often have contradictory results and lack methodological quality. Hendrickson noted that the research done in the early 2000's by Li and colleagues avoided some of these issues by examining mortality (a more inclusive measure than specific health outcomes) using a large database (Hendrickson, Jack and Beck, 2009). In terms of overall mortality rates, Li, Precht, Mortensen, and Olsen (2003) found that, compared to age-matched controls, bereaved mothers had an increased mortality, especially when the child died from unnatural causes (between 1 and 18 years after the death), and that bereaved fathers had an increased mortality rate when the child died from unnatural causes (though only at three years following the death) (Li et al., 2003). In another study using a large database in Sweden, Rostila et al. (2012) found bereaved mothers to have an increased risk of mortality, when compared to non-bereaved parents, which was even greater following the death of minor children (between the ages of 10 to 17 years) from unnatural causes (primarily accidents and suicides) (Rostila, Saarela, & Kawachi, 2012). In this study the bereaved fathers also showed an increased risk of mortality but this risk was not prominent until after 8 years following the death. In a 2013 study conducted in Israel with over 1000 participants, the authors found that the death of a child at any age was a significant predictor of mortality even at 20 years after the death for both mothers and fathers when compared to non-bereaved parents (Cohen-Mansfield, Shmotkin, Malkinson, Bartur, & Hazan, 2013). Examining specific physiological changes within the first year of bereavement, a review by Buckley et al. (2012) found that bereaved parents tended to have increased neuroendocrine activation, altered sleep, immune imbalance, inflammatory cell mobilization, and prothrombotic response, as well as hemodynamic changes (Buckley et al., 2012). In terms of the physical symptoms and sensations described by parents in qualitative studies, bereaved parents have reported a severe lack of energy (Hunt & Greeff, 2011), and feelings of intense physical pain (Barrera et al., 2009; Hunt & Greeff, 2011).

Clinical implications. Transmitting the knowledge to parents that strong physical sensations are often a normal part of the acute grief period can help to reassure concerned parents that the intense pain and fatigue they are feeling is normal and often temporary. Moreover, knowing the impact on mortality, clinicians may want to incorporate healthpromoting coping behaviours, such as exercise, into their treatment plans as these coping methods have been found to correlate to better early grief experiences, and several authors have suggested that this may help to counteract the impact of the loss on the parents' mortality (Li et al., 2003; Meert et al., 2001)[6].

Differences between mothers and fathers

The majority of research involving bereaved parents and parents of children with life-limiting and life-threatening illness has involved mostly mothers and relatively few fathers (Macdonald, Chilibeck, Affleck, & Cadell, 2010; Stroebe, Stroebe, & Schut, 2003). Consequently, many of the results mentioned in this review are from studies that had a greater number of mothers than fathers participating (Table 1), thus limiting the generalizability and applicability of some findings to fathers. Fortunately, there are some studies that focused specifically on bereaved fathers (e.g. Aho, Tarkka, Astedt-Kurki, & Kaunonen, 2006; Davies, Baird, & Gudmundsdottir, 2013; Wood & Milo, 2001), which have begun to shed light on fathers' experiences during and after their child's death and counter this discrepancy.

In studies that examine gender differences in psychological outcomes and adaptation after the death of a child, mothers are often reported to have higher intensity of grief reactions and symptoms (Alam, Barrera, D'Agostino, Nicholas & Schneiderman 2012; Keesee et al., 2008; Wijngaards-de Meij et al., 2008b), feel a greater sense of traumatization (Rubin et al., 2009), and more depression (Wijngaards-de Meij et al., 2008b) than fathers. Moreover, being a woman was found to predict post-traumatic psychological distress and complicated grief

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[6] It is important to note here that the link between coping strategies and the mortality of bereaved parents remains unclear.

after the death of a child to suicide, accident, or SIDS (see Dyregrov, Nordanger, & Dyregrov, 2003 for details). Barrera et al. (2007) found that an "overwhelming grief pattern" appeared to be gender-related, with only mothers showing symptoms of this type of bereavement; these mothers also had depression symptoms in the clinical range. Wing et al. (2001) report that mothers whose infants died of SIDS had higher levels of somatic symptoms, preoccupation, yearning and intrusive thinking than fathers (Wing et al., 2001). Alam et al (2012) similarly found that mothers expressed more intense grief reactions; the mothers also reported, however, that these reactions lessened over time, which was not necessarily the case for the fathers interviewed.

In terms of how fathers adapt to their grief, they have been reported to have more denial of the emotional impact of their infant's death in the first two years after the death than mothers (see Wing et al., 2001 for a more detailed discussion). Interestingly, recent research examining long-term effects of stressful life events, including the death of a child, has found that in late midlife and early old age, fathers show elevated distress and diminished purpose in life, while for mothers of the same age the death of a child was not related to depressive symptoms or purpose in life (Pudrovska, 2009). In seeming opposition to these findings, however, several other studies examining psychological outcomes of bereaved parents have found that, over time, distress and grief symptoms decrease for both men and women (Murphy et al., 2002; Wijngaards-de Meij et al., 2008b; Wing et al., 2001). It should be noted that the Pudrovska study was longitudinal in design and involved a very large sample size (n > 10,000).

There are also mixed findings on differences in how mothers and fathers cope with their grief. The gender socialization hypothesis (Murphy et al., 2002; Wichstrøm, 1999) predicts that mothers will be more emotion-focused and fathers more problem-focused in coping with their grief. A recent qualitative study by Alam et al. (2012) partly agreed with this prediction, reporting that fathers often coped with the loss by focusing on work and other instrumental tasks, whereas mothers ways of coping were more affective and relational in nature, for example by focusing on positive memories of the deceased child or caring for bereaved siblings. On the other hand, in an earlier study by Murphy et al. (2002) the authors could not find significant evidence for the gender socialization hypothesis; rather they found that although mothers did use emotion-focused strategies and fathers more problem-focused strategies, both mothers and fathers used gender-neutral strategies (such as planning, positive reinterpretation and growth, and religion) more often than these gender-specific strategies.

Clinical implications. In terms of psychological outcomes, both mothers and fathers appear to have difficulty, and it is not necessarily the case that one parent needs more help than the other, but that the kind of help they might need (and when they might need it) could differ between mothers and fathers. Research should continue to address the lack of knowledge about fathers' experiences and post-death outcomes; in the meantime, clinicians should be made aware of this bias in the literature, because services and interventions based on findings from the existing research are heavily based on mothers' experiences. Moreover, comprehension of these differences is useful in helping parents to understand the reactions of their spouse and other important people in their life, because–as mentioned previously–

differences in ways of grieving and coping can cause conflict in parental relationships (Stroebe et al., 2013; Toller & Braithwaite, 2009).

Changes to self-identity

Several authors have studied changes in parents' self-identity after the death of their child. Bereaved parents are faced with contradictions to their former self-identity such as being a parent who no longer has a child to parent (especially if it was their only child), and feeling like friends and family no longer understand their experiences or behaviours related to their connection to their deceased child (Toller, 2008). Facing these challenges to the concept of the self can be particularly difficult for parents (Barrera et al., 2009; Riches & Dawson, 1996). For example, in a 2009 study examining the experiences of parents after the death of a child from cancer, parents described feeling as though developing an integrated identity would mean rejection of their dead child and the end of their role as a parent (Barrera et al., 2009).

Clinical implications. It appears that for some parents, internal adjustments (including changes to self-identity) are difficult. Although we found no research specifically studying the post-death outcomes of parents who have difficulty changing their self-identity, authors such as Hogan, Greenfield and Schmidt (2001) have stated that transforming the old self and evolving to a new sense of self is a necessary process of bereavement and maybe particularly difficult for bereaved parents (Maccallum & Bryant, 2013). For clinicians, it is important to accompany and support bereaved parents as they traverse these types of changes. Interventions based on narrative approaches may be helpful for parents experiencing difficulties in changes to their self-identity (and other concepts of the self), as sharing personal stories with others has been found to help the bereaved internalize events and accommodate changes to self-concept (Harter, Japp, & Beck, 2005; Titus & de Souza, 2011). As Parkes stated, the concept of self is internal but it is maintained through our relationships with others (Parkes, 1988).

Positive change and personal growth

Research with the bereaved predating the year 2000 has been criticized for focusing only on the negative and pathological outcomes of grief and ignoring the potential positive outcomes (Wortman & Boerner, 2007). As could be expected, parents often report the negative aspects of their child's death, such as their intense emotional pain and feelings of loss. But they also report positive aspects, such as various benefits found (as previously discussed) and positive changes or growth within themselves. The idea of positive change and growth after loss has been defined and conceptualized in many different ways by clinicians and researchers. For example, Calhoun & Tedeschi developed the concept of posttraumatic growth (PTG) (Tedeschi & Calhoun, 2008), whereas Park, Cohen, & Murch (1996) spoke of stress-related growth (Park, Cohen, & Murch, 1996) and more commonly, the term personal growth has been used (Frantz, Farrell, & Trolley, 2001; Gamino et al., 2000; Hogan & Schmidt, 2002). In this article, we use the term 'personal growth' as a catch-all to refer to all these different constructs, using the specific terms PTG and stress-related growth only when referring to findings in which these terms were used.[7]

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[7] The previously discussed concepts of meaning reconstruction are related to (and somewhat overlap with) positive change and personal growth. As with many aspects of research in this area, there are inherent difficulties in defining the constructs involved, making it difficult (if not impossible) to establish clear conceptual boundaries between one area (i.e. meaning reconstruction) and another (i.e. personal growth). Rather than subsume the latter

Bereaved parents have reported many different aspects of personal growth and various positive changes they have experienced (many of which are analogous to the benefit-finding themes mentioned previously). Parents have reported changes in values and worldviews, for example, a shift from a consumerist view to one that places more importance on family and community (Barrera et al., 2009), a deepened spiritual and religious understanding (Lichtenthal et al., 2013; Wheeler, 2001), changes in priorities (Gilmer et al., 2012; Wheeler, 2001), and a new path of self-discovery and realization (Titus & de Souza, 2011). Positive changes or growth may also involve a new understanding of and appreciation for life, or new aspects of life (Barrera et al., 2009; Lichtenthal et al., 2010; Lichtenthal et al., 2013; Wheeler, 2001), or more compassion, empathy and sensitivity to the suffering of others (Arnold et al., 2005; Barrera et al., 2009; Lichtenthal et al., 2010; Lichtenthal et al., 2013). Parents may experience positive changes to their self-identity, including feeling as though they have become a better person; knowing they are able to survive something they once considered unbearable (Wheeler, 2001); feeling more competent, strong, and courageous (Arnold et al., 2005; Hogan & Schmidt, 2002; Hogan et al., 2001); and that the loss had taught them something (Barrera et al., 2007; Titus & de Souza, 2011). Lichtenthal et al. (2010) found that parents who reported positive changes in priorities also had lower complicated grief scores. Engelkemeyer and Marwit (2008) examined the impact of post-traumatic growth on grief severity, and found that PTG was inversely associated with the severity of grief symptoms.

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conceptual category within the former, however, we have chosen to address them separately as some of the literature reviewed in this article addresses the idea of personal growth as a distinct construct. In this section, we review this personal growth literature, including the relevant findings in the meaning reconstruction literature on positive change.

Personal growth appears to take time. For example, personal growth scores were higher in groups of parents whose children had died more than 3 years prior to the study compared to parents whose child had died less than 3 years prior (Hogan et al., 2001); Engelkemeyer and Marwit (2008) similarly found that, over time, bereaved parents had higher levels of growth and less grief. Furthermore, Hogan et al. 2001 found that parents reported a period of deep introspection and existential questioning, and following that, they felt they were now different than they were before their child died, seeing themselves as more tolerant, forgiving, compassionate, resilient and loving (Hogan et al., 2001). It should be noted, however, that sometimes parents report experiencing no change or negative changes (Gilmer et al., 2012). For example, Barrera and colleagues found that approximately 35% of parents reported having difficulty incorporating aspects of their bereavement experience into their worldview and perspective on life (Barrera et al., 2009).

What leads to personal growth? Riley and colleagues (2007) examined cognitive reactions related to personal growth and found that mothers with an active coping disposition (as described earlier in the section on coping) described more personal growth and positive change. They also found that mothers who had higher scores on measures of personal growth more commonly sought the support of others, had a greater perceived social support, and used positive reframing (Riley et al., 2007). The ability to derive meaning from one's loss has been credited with leading to PTG (Calhoun & Tedeschi, 2001). Similar to what is argued in the meaning making literature, several authors have also proposed that growth occurs through revising shattered assumptions about the world and the self (Tedeschi & Calhoun, 2004) (Engelkemeyer & Marwit, 2008; Parkes, 2006). In the study by Gamino, Sewell & Easterling

(2000) the authors found that personal growth and adaptive grieving were correlated with seeing some good resulting from the death, saying goodbye, spirituality and positive memories of the child. On the other hand, the study by Engelkemeyer and Marwit (2008) found that only time since loss and self-worth were significant predictors of PTG and that perceived meaningfulness and benevolence of the world were not significantly related to total growth (Engelkemeyer & Marwit, 2008).

Clinical implications. It may be worthwhile for researchers and clinicians to consider potential positive aspects of the grief experience, as this is so often taken to be a solely negative phenomenon. Several authors have suggested that, based on the types of findings summarized above, interventions that encourage personal growth or positive reframing may be beneficial for bereaved parents (Riley et al., 2007; Calhoun & Tedeschi, 2001). Some notes of caution are warranted, however. For one, clinicians should take care to validate parents' unique experiences of loss in how they word and propose assessments and interventions related to personal growth and positive reframing; they should also be cognizant of the fact that for many parents, it takes time before they are able to notice aspects of personal growth (Lichtenthal et al., 2010).

General adaptation over time

For most parents, it appears that grief symptoms continue throughout the life span (Arnold et al., 2005; Malkinson & Bar-Tur, 2005; Rogers et al., 2008; Rubin & Malkinson, 2001). Statistically speaking (and allowing for individual variations) bereaved parents appear to be worse off throughout their life on many psychosocial indicators when compared to non-bereaved parents (Li et al., 2005; Pudrovska, 2009; Rogers et al., 2008; Rosenberg, Baker, Syrjala, & Wolfe, 2012; Rubin et al., 2009). However, many parents do find a way to resume productive lives and regain functioning in many areas (Arnold et al., 2005; Lehman et al., 1987; Malkinson & Bar-Tur, 2005; Rogers et al., 2008; Rubin & Malkinson, 2001). This is evidenced by the studies mentioned previously on meaning reconstruction, positive change, and personal growth and various positive outcomes reported in the literature (such as closer relationships, and an increased appreciation for life) (Barrera et al., 2009). Moreover, studies have shown that, over time, many grief symptoms do indeed have a tendency to decrease (Feigelman et al., 2008; Murphy et al., 2003a; Rogers et al., 2008; WijngaardsDeMeij 2008).

Clinical implications. Even though most parents are capable of traversing the acute phase of grief, there are other parents who appear to “get stuck” and remain preoccupied by the death of their child to the point that they cannot regain a new equilibrium or adapt to life (symptoms such as these are included in the diagnostic criteria for prolonged grief disorder) (Prigerson et al., 2009; Rubin et al., 2009). From a service provision standpoint, it is important to identify these parents, but with an important caveat. To a certain extent, lasting grief symptoms are to be expected in bereaved parents; that is, the persistence of symptoms is not, in and of itself, abnormal. It is therefore crucial to conduct more research into how to identify high-risk individuals for severe and lasting problems (such as PTSD, and prolonged grief disorder), and to have a better idea of when intervention may be indicated and services should be offered (Rogers et al., 2008; Rosenberg et al., 2012; Stroebe, Folkman, Hansson, & Schut, 2006).

Discussion

General clinical implications

On the basis of the extant research conducted with bereaved parents since 2000 (Table 1), here we identify some broad suggestions for clinicians working with bereaved parents. Keeping in mind that some intense reactions in the acute phase of grief are common, clinicians should assess for risk of development of complicated or persistent grief disorder, symptoms of trauma (traumatic grief or PTSD), and other psychiatric symptoms. Also, grief does not exist in a vacuum; bereaved parents are members of families and communities, and their interactions with others may contribute significantly to how they experience their grief. It is therefore important to assess social networks and the quality and stability of relationships therein. Based on these assessments, clinicians can then decide if and how to intervene, and whether or not to refer to other services.

Our review also highlights research related to certain interventions that may be potentially useful in helping bereaved parents. Interventions that encourage continuing bonds with the deceased, when appropriate, and narrative approaches that include sharing and reconstruction of self-identity and meaning may help parents traverse adjustments to internal constructs of the self and the relationship to the deceased. When appropriate (and when parents are open to the idea) interventions that encourage positive change and healthy adaptation to loss such as meaning-making interventions and/or cognitive or cognitive behavioural methods that encourage positive reinterpretation and skill-building may help parents adapt to life after the death of their child and get parents through moments where they may be stuck in their grief.

Methodological issues

During the course of our review, certain methodological issues in the studies became apparent. Some of these issues have also been noted in the general bereavement literature (Genevro et al., 2004; Stroebe, Stroebe, & Schut, 2003). In addition to these, we found other important issues in the studies relating specifically to bereaved parents.

The most frequently used data collection methods in bereavement research are large-scale surveys and in-depth semi-structured interviews (Stroebe et al., 2003), and we found this to also be true of the literature on bereaved parents. In the quantitative studies, the analysis of variables was largely correlational. Stroebe et al. (2003) noted the lack of control and comparison groups in bereavement studies in general. In the research on bereaved parents reviewed herein, only the studies by Znoj et al. (2002), Mathews and Marwit (2003), Parkes (2006) and Rogers et al. (2008) had control or comparison groups (consisting of: individuals from the general population (Znoj & Keller, 2002), other bereaved psychiatric patients (Parkes, 2006), and non-bereaved parents (Matthews & Marwit, 2003; Rogers et al., 2008) (see Table 1). Therefore, there were few quantitative studies involving bereaved parents that examined cause and effect relationships between certain risk factors or coping methods on post-death psychological outcomes of parents; in the qualitative research, authors often did not articulate which qualitative methodology they were using, so that it was not clear how the data was interpreted.

Another methodological issue we uncovered was that the samples of the studies reviewed were largely heterogeneous for several participant characteristics (see Table 1). Within single studies, participants varied greatly in the age of the child who died (e.g. age ranged from infants to 25 years) and cause of death (congenital illness, SIDS, longer-term illnesses, accidents, homicide, and suicide) (Arnold et al., 2005; Feigelman et al., 2008; Hunt & Greeff, 2011). While this heterogeneity is not a problem a priori (and may be suited to certain research questions), it does present the potential for confounding variables when examining other psychosocial factors. Moreover, many of the reviewed studies grouped bereaved individuals together, making it difficult to extrapolate which findings applied to bereaved parents specifically (for example Bonanno et al., 2005; Genevro et al., 2004; Rubin et al., 2009)[8]. We also found some studies and reviews where the authors cite research as being specific to bereaved parents, when the reported finding actually pertained to a general bereavement study.

Conversely, the samples of the studies reviewed were largely homogenous on several other characteristics. Perhaps most importantly, the samples included mostly Caucasian women. Also, some studies explored very specific types of loss, such as the Malkinson and Bar-Tur (2005) study where all the children who died were male and served in the military. This of course relates to the tension between internal and external validity. On the one hand, more homogeneous samples are less likely to introduce extraneous variables into the inquiry. On the other hand, they are problematic in terms of generalization or transferability of the findings to groups or individuals outside the normative sample. Thus the importance of noting that, in general, studies on parental bereavement are skewed towards the mothers', and not the fathers', perspectives and experiences.

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[8] In the present study, we have tried, wherever possible, to glean findings on bereaved parents from these mixed studies and indicate which findings come from general bereavement studies (i.e., where the relationship to the deceased was not explored as a theme or variable).

In addition, as is the case for many reviews of empirical literature, the terminology used in the various studies was at times difficult to reconcile. Most notably, there was considerable variation and/or ambiguity with terms related to acceptance, meaning making, relationship to the self, and personal growth.

Lastly, we identified one issue of particular importance to knowledge translation and the applicability of findings to clinical settings: namely, that much of the recent research examines parents' experiences, but not necessarily how aspects of these experiences, and various other factors (e.g. cause of death), may impact adaptation post-death. From a services standpoint, it is important to determine psychosocial factors related to successful adaptation on the one hand, and risk factors for poorer outcomes (such as the development of persistent grief reactions or PTSD) on the other hand, in order to best target their interventions and support.

Conclusion

In the current review, we collected and synthesized research relating to the psychosocial outcomes of bereaved parents and how they adapt to their grief over time; we also elucidated how this research can be used to inform interventions and services provided to these parents. In doing so, we hope to a) afford researchers and clinicians a broader view of the experiences of bereaved parents and potential elements of risk for the development of persistent grief and other psychiatric disorders, b) present possible avenues for clinical intervention and support, and c) provide policy makers with a summary of the relevant evidence that can be translated into policy change and program development.

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Table 1. Characteristics of studies of bereaved parents published between 2000-2013 and included in the review

First author (year)	**Participants**	**Age of child**	**Cause of death***	**Time since death of child****	**Research approach**
Aho (2006)	8 fathers	Ranged from 40 minutes to 2 years and 3 months Mean not given	Illness (heart defect and associated complications, and other illnesses)	Ranged from 2.5 months to 2 years and 5 months Mean not given	Qualitative
Alam (2013)	13 mothers and 5 fathers	Ranged from 8 months to 20.7 years. Mean not given	Cancer (leukaemia or central nervous system tumours)	Interviews at 6 and 18 months	Qualitative
Arnold (2005)	72 mothers and 2 fathers (all nurses)	Ranged from birth to 48 years (mean was 13 years) Mean age of children who died older than one year was 22 years	Four categories of cause: congenital, prematurity/ birth-related complications, unexpected, and illness	Ranged from 1 year (or less) to 62 years Mean at the time of the survey was 24.4 years	Mixed qualitative and quantitative, this article presents the quantitative findings
Arnold (2008)	Same sample as Arnold 2005 72 mothers and 2 fathers (all nurses)	Ranged from birth to 48 years (mean was 13 years) Mean age of children who died older than one year was 22 years	Four categories of cause: congenital, prematurity/ birth-related complications, unexpected, and illness	Ranged from 1 year (or less) to 62 years Mean at the time of the survey was 24.4 years	Mixed qualitative and quantitative, this article presents the qualitative findings
Barrera (2007)	13 mothers and 7 fathers	Ranged from 9 days to 17.83 years Mean was 8.31 years	Cancer, congenital heart disease, and other causes (meningitis, drowning, and kidney disease)	Ranged from 4 to 19 months Mean not given	Qualitative
Barrera (2009)	18 mothers and 13 fathers	Ranged from 8 months to 20.7 years Mean was 9.2 years	Cancer (leukemia, central nervous system tumours, sarcomas, neuroblastomas, non-Hodgkin's lymphoma, and Hurler's disease)	6 months	Qualitative
Bellali (2006)	13 mothers and 9 fathers	Ranged from 2 to 16 years Mean not given	Head injury resulting from an accident (either traffic, school or at home)	Ranged from 8 months to 6 years and 7 months Mean was 3 years and	Qualitative

				4 months	
Bolton (2013)***	Suicide group: 506 fathers and 757 mothers Accident group: 417 fathers and 616 mothers Controls: 506 fathers and 757	Suicide group: 171 children between the ages of 0-18y and 691 children over the age of 19 years. Mean age was 30 years Accident group: 156 children between the ages of 0-18y and 976 children over the age of 19 years. Mean age was 25 years	Suicide or accident	2 years	Quantitative
Bonanno (2005)	64 bereaved participants (44 conjugally bereaved and 20 bereaved parents) Number of mothers and fathers not provided	Range and mean not given	Not given	Ranged from approximately 4 to 18 months Mean not given	Quantitative
Clarke (2011)	13 bereaved parents Number of mothers and fathers not provided	Neonates	Not given	Mean was 8 months Range not given	Mixed quantitative and qualitative
Contro (2002)	45 mothers and 23 fathers	Ranged from hours after birth to over 15 years (maximum age not given) Mean not given	Cancer, cardiac illness, prematurity and other non-specified	Ranged from 6 months to 2 years and 6 months	Qualitative
Dyregrov (2003)	232 parents from 140 families Number of mothers and fathers not provided	Suicide group: Ranged from 11 to 29 years. Mean was 22 years. Accident group: Ranged from 0 to18 years. Mean was 11 years SIDS group: Ranged from 0 to 1 year. Mean was 2.5	Suicide, accident or SIDS.	Ranged from 6 to 1 year and 11 months Mean was 15 months (for SIDS and suicide), and 14 months (for accidents)	Mixed quantitative and qualitative

		years.			
Engelkemeyer and Marwit (2008)	111 bereaved parents Number of mothers and fathers not provided	Range not given (all had died before the age of 25 years) Mean was 15 years	Homicide, accident, and various forms of illness	Ranged from 1 to 31 years Mean was 7 years and 3 months	Quantitative
Feigelman (2008)	459 mothers and 81 fathers	Ranged 15 to 35 years Mean not given	Suicide, accident, homicide or some other ambiguous circumstances	Range and mean not given	Quantitative
Foster (2011)	41 families including 36 mothers, 24 fathers, and 39 siblings.	Range not given Mean was 12 years	Various forms of cancer	Ranged from 6 to 19 months post-death Mean not given	Qualitative
Gilmer (2012)	36 mothers and 24 fathers (also included 39 siblings)	Range not given Mean was 12 years	Various forms of cancer	Ranged from 6 to 1 year and 7 months Mean 10.7 months	Qualitative
Hogan (2001)	Study 1: 304 mothers Study 2: 165 mothers and 44 fathers	Study 1: Range not given Mean was 16 years Study 2: Range not given Mean was 15 years	Illness, accident, homicide, suicide or other not specified	Range and mean not given for either study	Quantitative

Hogan (2002)	129 mothers and 38 fathers	Ranged not given Mean was 20.35 years	Illness, accident, homicide, suicide or other not specified	Range and mean not given	Quantitative
Hooghe (2011)	1 couple	13 years old	Brain cancer	Not given	Qualitative
Hooghe (2012)	1 mother and 1 father (i.e., 1 parental couple)	6 months old	Leukemia	6 years	Qualitative
Hunt (2011)	18 mothers and 4 fathers (included 3 couples)	Ranged from birth to 31 years Mean not given	Variety of natural and unnatural causes (bacterial meningitis, glandular fever, aneurism/embolism, cancer, cardiac illness, car accident, drowning, homicide, suicide, and birth complications)	Ranged from 2 to 22 years Mean not given	Qualitative
Jind (2003)	At Time 1: 62 mothers and 48 fathers Time 2: 41 mothers and 30 fathers	Ranged from third trimester foetus to age of 2 years. Mean not given	Not given	Time 1: 1 to 14 weeks post-loss Time 2: 15 to 61 weeks post-loss	Quantitative
Keesee (2008)	127 mothers and 30 fathers	Ranged from 0 to 47 years Mean was 17 years	Six categories of cause: miscarriage or stillbirth; natural anticipated (e.g., cancer); natural sudden (e.g., heart attack); accident (e.g., motor vehicle accident); suicide; and homicide.	Ranged from 0 to 40 years Mean was 6 years	Quantitative
Laakso (2002)	Surveyed 91 mothers Interviewed 50 mothers	Ranged from 0 to 7 years Mean not given	Not given	Ranged from 1 to 6 years Mean not given	Mixed quantitative and qualitative

Li (2003) ***	11 221 mothers and 9841 fathers Non-bereaved controls: 157 917 mothers and 135 828 fathers	Ranged from 0 to 17 years. Mean not given	Two categories of cause: natural causes (e.g., cancer, congenital and perinatal diseases), and unnatural causes (e.g., accidents and suicide)	Ranged from 1 to 18 years Mean not given	Quantitative
Li (2005) ***	1 082 503 individuals in cohort Number of mothers and fathers not provided	Ranged from birth to 18 years Mean not given	Two categories of cause: natural causes (e.g., cancer, congenital and perinatal diseases), and unnatural causes (e.g., accidents and suicide).	Not given	Quantitative
Lichtenthal (2010)	Same sample as in Keesee et al., 2008 127 mothers and 30 fathers	Ranged from 0 to 47 years Mean was 17 years	Six categories of cause: miscarriage or stillbirth; natural anticipated (e.g., cancer); natural sudden (e.g., heart attack); accident (e.g., motor vehicle accident); suicide; and homicide.	Ranged from 0 to 40 years Mean was 6 years	Mixed quantitative and qualitative
Lichtenthal (2013)	123 mothers and 29 fathers	Ranged not given Mean was 16.8 years	Categories of cause: perinatal loss (e.g., stillbirth); natural anticipated (e.g., cancer); natural sudden (e.g., heart attack); accident (e.g., motor vehicle accident); suicide; and homicide	Range not given Mean was 5.9 years	Mixed quantitative and qualitative
Macdonald (2006)	8 mothers and 4 fathers	Ranged from birth to 20 years Mean not given	Trauma, chronic and critical illnesses (rare musculoskeletal syndrome, spina bifida, cardiac disease, and cerebral palsy)	Ranged from 9 to 18 months (prior to recruitment) Mean not given	Qualitative
Malkinson (2005a)	25 mothers and 22 fathers	Ranged from 19 to 30 years Mean not given	No cause given Died during wartime or military service	Not given	Qualitative Content analysis of interviews

Matthews (2003)***	45 mothers and 19 fathers of murdered children 29 mothers and 5 fathers whose children had died from an illness 31 mothers and 6 fathers whose children died in accidents (automobile, drowning, bicycle, etc.), 25 non-bereaved control 121 mothers and 10 fathers non-bereaved control	Ranged not given Mean was 18.2 years	Homicide, accident, and illness	Range not given Mean was 5 years and 6 months	Quantitative
Meert (2001)	43 mothers, 6 fathers, and 8 female legal guardians	Not given	Cause categorized by chronicity of illness (acute or chronic) and expectedness of death (expected, unexpected, both, or neither) No other cause of death provided	Ranged from 2.3–5.7 years Mean was 3.4 years	Quantitative
Meert (2005)	20 mothers, 12 fathers and 1 legal guardian	Ranged from 3 days to 24 years Mean not given, median was 4.5 years	Congenital heart disease, trauma, malignancy, respiratory failure, and other illnesses	2 years	Qualitative
Meert (2007)	37 mothers and 17 fathers	Ranged from 0.0 to 20.8 years Mean was 1.6 years	Sudden or unexpected, lethal congenital anomaly, chronic potentially curable disease and chronic progressive condition with intermittent crisis	Ranged from 4 to 15 months Mean not given	Qualitative
Merchant (2008)	27 parents Number of mothers and fathers not provided	Range not given Mean was 36.8 years	Motor vehicle accident, heart attack, stroke or other	Range not given Mean was 3 years and 11 months	Quantitative
Murphy (2002)***	261 bereaved parents Intervention group: 101 mothers and 52 fathers Control group: 70 mothers and 38 fathers	Ranged from 12 to 28 years Mean not given	Accidents, suicide, homicide, or other violent cause	Ranged from 6 to 28 weeks (preceding entrance into the study) Participants were followed prospectively up to	Quantitative (RCT)

				five years post-death.	
Murphy (2002a)	Baseline sample from Murphy 2002 (261 bereaved parents) At 5 years: 115 mothers and 58 fathers from baseline sample	Ranged from 12 to 28 years Mean was 20.7 years	Accidents, suicide, homicide, or other violent cause	At first time of measure ranged from 6 weeks to 7 months Second time of measure at 5 years Means not given	Quantitative
Murphy 2002b)	Baseline sample from Murphy 2002 (261 bereaved parents) At 5 years: 115 mothers and 58 fathers from baseline sample	Ranged from 12 to 28 years Mean was 20.7	Accidents, suicide, homicide, or other violent cause	Ranged from 6 weeks to 7 months Mean not given	Quantitative
Murphy (2003a) ***	Baseline sample from Murphy 2002 (261 bereaved parents) At 5 years: 115 mothers and 58 fathers from baseline sample	Range not given Mean was 20.7 years	Accidents, suicide, homicide, or other violent cause	At 4, 12, 24, and 60 months	Quantitative (RCT)
Murphy (2003c)	Baseline sample from Murphy 2002 (261 bereaved parents) At 5 years: 115 mothers and 58 fathers from baseline sample	Range not given Mean was 20.7 years	Accidents, suicide, homicide, or other violent cause	At 4, 12, 24, and 60 months	Quantitative
Parkes (2006a)***	Bereaved parents: 25 mothers and 4 fathers Comparison group: 151 psychiatric patients bereaved of other types of loss	Ranged from miscarriage to over 17 years Mean not given	Not given	Not given	Quantitative

Pudrovska (2009)	2,296 fathers and 2,784 mothers	Ranges not given 1993 sample mean was 12.4 years 2004 sample mean was 17.6 years	Not given	Not given	Quantitative
Riley (2007)	35 bereaved mothers	Range not given Mean was 12 years	Most frequent causes were accidents and neonatal infant deaths (other causes not given)	Ranged from 2 to 30 months Mean was 15.7 months	Quantitative
Rogers (2008)***	Bereaved parents: 284 mothers and 144 fathers Comparison group: 284 mothers and 144 fathers	Ranged from infancy to age 34 years Mean was 10.23 years	Complications of pregnancy, childbirth, and the puerperium, or by congenital anomalies, external causes of injury and poisoning, (including accidents and suicide), or illnesses, including neoplasms and other diseases	Ranged from a 3 months to 34 years Mean was 18.05 years	Mixed qualitative and qualitative
Rosenblatt (2000)	29 mothers and 29 fathers	Ranged from birth to 33 years Mean not given	Not given	Ranged from 8 months to 3 years Median of 7 years	Qualitative
Rubin (2009)	116 bereaved parents Number of mothers and fathers not provided	Not given	Range reported for total sample and not specifically for bereaved parents	Ranged from one to 186 months (15 years and 5 months). Mean was 49 months	Quantitative
Tan (2012)	7 mothers and 7 fathers	Ranged from 23 to 108 weeks Mean not given	Complex congenital heart disease, genetic or metabolic disease, or extreme prematurity	Ranged from before death of child to 6 months after death Mean not given	Qualitative

Titus (2011)	9 mothers and 1 father	Ranged from 5 days to 17 years Mean not given	Various illnesses	Ranged from 1 to 5 years	Qualitative
Toller (2005)	16 parents (12 mothers and 4 fathers)	Ranged from 5 months to 35 years Mean was 14.1 years	Illness, suicide or accidents	Ranged from 6 months to 29 years Mean was 8.2 years	Qualitative
Toller (2008)	36 mothers and 17 fathers	Ranged from 0 to 42 years Mean was 7.7 years	Illness, stillbirth or birth defects, suicide, accidents, or SIDS	Ranged from 6 months to 29 years Mean was 9.7 years	Qualitative
Toller (2009)	24 mothers and 13 fathers	Ranged from 0 to 42 years (only 4 were adults) Mean was 14.3 years	Illness, stillbirth or birth defects, suicide, accidents, or SIDS	Ranged from six months to 19 years Mean was 6.75 years	Qualitative
Uren (2002)	108 mothers	Stillbirths and neonates Range and mean not given	Not given	Ranged from 2 to 207 months (17 years and 3 months) Mean not given	Mixed quantitative and qualitative
Wheeler (2001)	137 mothers and 39 fathers	Ranged from birth to 48 years Mean not given	Not given	Ranged from 1 month to 40 years Mean not given	Qualitative
WijngaardsDeMeij (2005)	219 mothers and 219 fathers	Ranged from 0 to 30 years Mean was 10.2 years	Neonatal death or stillbirth, illness or disorder, accident, SIDS, suicide, or homicide	6, 13, and 20 months	Quantitative
WijngaardsDeMeij (2008a)	Same sample as in WijngaardsDeMeij (2005) 219 mothers and 219 fathers	Ranged from 0 to 30 years Mean was 10.2 years	Neonatal death or stillbirth, illness or disorder, accident, SIDS, suicide, or homicide	6, 13, and 20 months	Quantitative

WijngaardsDeMeij (2008)	Same sample as in WijngaardsDeMeij (2005) 219 mothers and 219 fathers	Ranged from 0 to 30 years Mean was 10.2 years	Neonatal death or stillbirth, illness or disorder, accident, SIDS, suicide, or homicide	6, 13, and 20 months	Quantitative
Wood (2001)	8 fathers	Ranged from 5 months to 16 years Mean not given	Complications from pre-existing disabilities	Range and mean not given	Mixed qualitative and quantiative
Znoj (2002) ***	Bereaved parents: 117 mothers and 59 fathers Control group: 72 women and 52 men	Ranged from stillborn to adulthood (maximum age of child not given) Mean not given	Sudden infant death, stillborn, early birth, chronic disease, acute disease, accident, suicide or drug overdose	Range not given Mean was 5.10 years	Quantitative

* Cause as defined and categorized by the authors of the study. **Time since death at the time of participation. *** Studies including control or comparison groups.

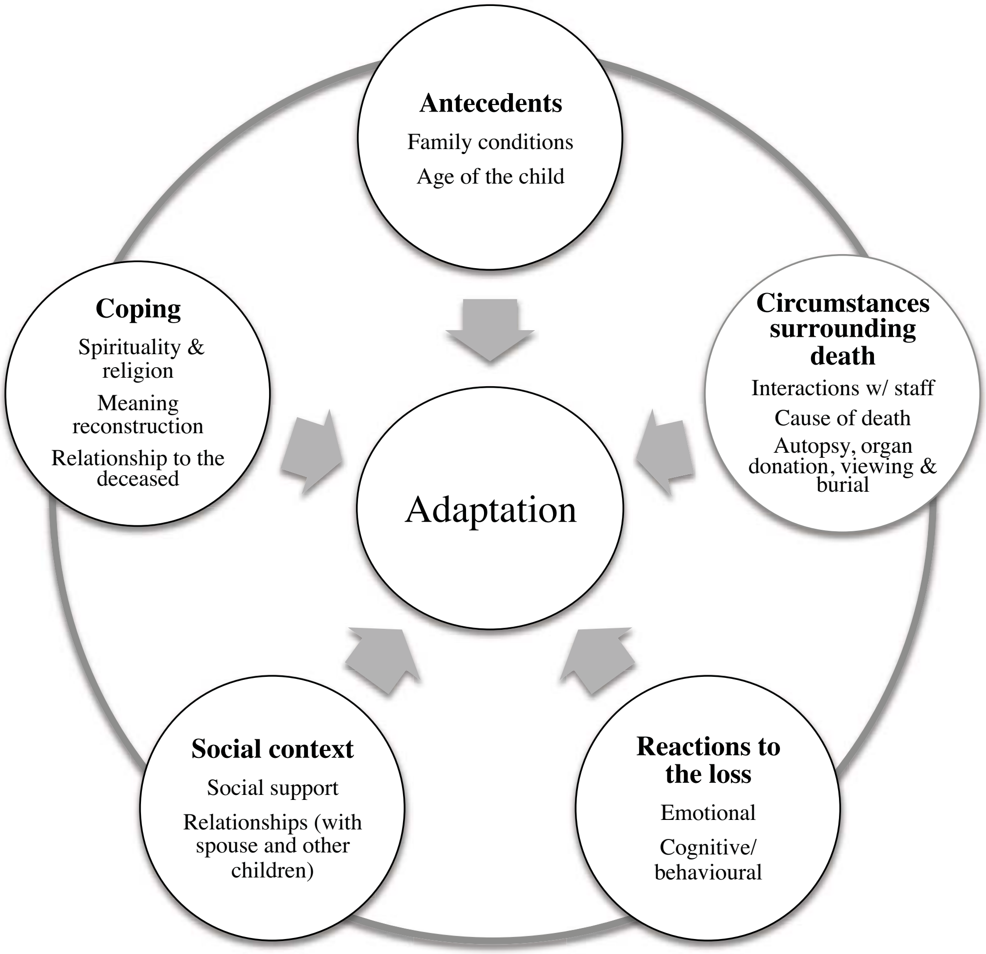

Figure 1. Elements impacting adaptation post-loss.

Article 3

Understanding how bereaved parents cope with their grief in order to inform the services provided to them

Understanding how bereaved parents cope with their grief in order to inform the services provided to them

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Running head: Understanding how bereaved parents cope

Abstract

The death of a child is recognized as one of the most devastating and intense forms of grief an individual may face. To address the needs of bereaved parents, paediatric hospitals are increasingly offering bereavement follow-up services to parents during the first year after the death of their child. However, very little research examines parents' experiences in the first year following their loss. Our objective was to explore some of these experiences, including how the parents coped with their grief, as well as their perspectives on how various bereavement follow-up and support services helped them cope. This objective was explored with the ultimate goal of informing bereavement follow-up and support services.

An interpretive description methodology was chosen to pursue the research goals and produce clinically applicable findings. Twenty-one bereaved parents were interviewed (10 of these as parental dyads), in addition to seven hospital staff involved in bereavement follow-up activities at two paediatric hospitals. Through exploring the perspectives of both mothers and fathers, and both target users (i.e. bereaved parents) and service providers (i.e. staff conducting the follow-ups), we were able to describe how parents coped with their grief, including the impact of various relationships and follow-up services. The data was analysed using constant comparative methods, and multiple immersions into the data and related background literature. The clinical applicability of the results was verified through meetings with project collaborators and service/program providers at both paediatric hospitals.

We found that in the first year after the death of their child, parents experienced waves in the emotional intensity of their grief. They regulated their grief through either loss-oriented or restoration-oriented strategies, including attempts to: make sense of the loss; find positive aspects related to their experiences; and reorganize their self-identity and connection to their

deceased child. Parents' relationships with friends, family and staff were integral in helping them cope with their losses. In addition, many of the bereavement follow-up and support services were considered helpful because they assisted parents with these various aspects of coping, such as by helping parents maintain a connection to their deceased child. Collectively, the results yield insights that can aid service providers in accompanying parents in a way that optimizes outcomes for these parents and the families, friends, and communities to which they belong.

Introduction

The death of a child is recognized as leading to one of the most devastating and intense form of grief (Davies, 2004; Rando, 1986), and many studies have demonstrated that the death of a child has a greater negative impact on the mortality and psychosocial outcomes of the bereaved than other types of loss (Li, Laursen, Precht, Olsen & Mortensen, 2005; Li, Precht, Mortensen & Olsen, 2003; Pudrovska, 2009; Rosenberg, Baker, Syrjala & Wolfe, 2012; Rubin et al., 2009; Wortman & Boerner, 2007). In research examining the needs of bereaved parents of minor-aged children, parents have mentioned a need for support from the paediatric hospital, especially in the first year after the death (Contro, Larson, Scofield, Sourkes & Cohen, 2002; D'Agostino, Berlin-Romalis, Jovcevska & Barrera, 2008; Decinque et al., 2006). This need has also been emphasized by the Canadian Hospice Palliative Care Association, the Canadian Paediatric Society, the American Pediatric Association, and the Institute of Medicine (Aerde, 2001; Canadian Hospice Palliative Care Association, 2006; Committee on Bioethics and Committee on Hospital Care, 2000; Field & Behrman, 2003). To address the needs of bereaved parents, paediatric hospitals in North America are increasingly offering bereavement follow-up services to parents throughout the first year after the child's death, such as sending sympathy cards, conducting follow-up meetings and calls with parents, and holding commemorative services at the hospital (D'Agostino et al., 2008; deJong-Berg & Kane, 2006; Macdonald et al., 2005; Wintermeyer-Pingel, Murphy & Hammelef, 2013). The intent of these services is not necessarily to intervene but rather to facilitate and support the grieving process (Decinque et al., 2006; deJong-Berg & Kane, 2006).

Several authors have argued that, in order to effectively support parents through this difficult and emotionally fraught period, bereavement services should (a) be based on an empirically-validated understanding of parents' actual experiences, and (b) integrate current psychological theories of grief (Decinque et al., 2006; Murphy, Johnson & Lohan, 2003). These authors, however, further suggest that this may not be the general state of clinical practice (Decinque et al., 2006; Murphy et al., 2003), an argument also made by Wortman and Boerner in their analysis of general bereavement research and practice (Wortman & Boerner, 2007). Therefore, there is still an important gap between evidence-based research conducted with bereaved parents and actual hospital and community based psychosocial services offered to these parents (Murphy et al., 2003; Sandler, Kondo & Ayers, 2011).

Unfortunately, and as reported in the second article of this thesis, there is very little research examining bereaved parents' experiences with grief in the first year following their loss. Some initial steps have, however, been made in this direction. On the one hand, there are a few studies that have examined specific follow-up services offered to parents, such as commemorative practices for parents whose children died in the paediatric intensive care unit (Macdonald et al., 2005), and follow-up phone calls to parents whose children died of cancer (Darbyshire et al., 2013). However, these studies did not expressly examine the psychological processes involved in supporting parents through their grief. On the other hand, some qualitative research has examined parents' coping in the first year, examining parents' experiences at 6 months and 18 months post-death (Alam, Barrera, D'Agostino, Nicholas & Schneiderman 2012; Barrera et al. 2007, and Barrera et al., 2009); these authors, however, did not link their research to existing bereavement follow-up or support services. In recent parental bereavement, then, the intersection of psychological research and service provision remains largely unexplored.

The purpose of the present study was thus to gain an understanding of how bereaved parents coped with their grief in the first year after the death of their child, as well as their perspectives on how various bereavement follow-up and support services helped them cope. The ultimate objective was to provide information useful for paediatric hospitals, community services and clinicians that seek to provide bereavement follow-up and support to families dealing with the death of a child.

Method

Design

An interpretive description methodology was chosen to pursue the research goals and produce clinically applicable findings. This qualitative approach, originally developed in nursing, draws on aspects of grounded theory and naturalistic inquiry, and allows the researcher to describe a phenomenon of interest in such a way that knowledge applicable to the clinical context of heath disciplines is generated (Thorne, 2008).

Participants

After obtaining ethics approval from the participating hospitals, parents whose child died at most one year (Group 1, 5 mothers and 3 fathers), or from one to five years (Group 2, 10 mothers and 3 fathers), before the interview were recruited from two tertiary care paediatric hospitals in a large urban centre. The characteristics of the parents who participated in the study are provided in Table 1. Parents ranged in age from 29 to 60 years, and included 15 mothers and 6 fathers of children who ranged in age from several days to 19 years. The children died of a variety of illnesses, including various neurodegenerative, congenital disorders and paediatric cancers. The majority of the interviews with parents (19) were conducted in French. In addition, 7 health care professionals (HCPs; 4 nurses, 2 psychologists and 1 social worker) who conducted various bereavement follow-up practices at the two participating paediatric hospitals were recruited and interviewed.

Data collection and analysis

Twenty-one bereaved parents were interviewed (10 of these as mother-father pairs) as to how they coped in the first year, what was helpful or not helpful during this time, and their perspectives on various bereavement follow-up and support services (offered either in the hospital or the community). Parents in Group 1 were asked to speak to their current experiences and parents in Group 2 were asked to think back to their experiences in the first year after the death. These two groups were formed because although we were interested in first-year experiences, we were concerned that during this period in their grief parents may have difficulty expressing and describing their experiences due to the intensity of their grief and lack of time to fully process the events. On the other hand, we were also concerned that parents speaking retrospectively back to this period (i.e., after the first year had passed) may have forgotten important elements/issues over time and have potential hindsight biases. Therefore we triangulated our data by having these two groups. The interviews were guided by a set of questions and inquiring probes with broad questions pertaining to their experiences in the first-year post-loss and what was helpful (or not helpful) during that period, followed by questions specific to various bereavement follow-up services and practices. To enhance methodological rigour and to add to the clinical understanding of the phenomenon, we also interviewed hospital HCPs who conduct bereavement follow-up activities, with questions pertaining to how they go about following-up with parents and what issues (if any) hinder their ability to do that follow-up. In addition, commemorative services (offered at the hospitals as part of the bereavement follow-up and support services) were also observed, in order obtain a richer understanding of parents' descriptions of the services. The data collection and analysis were done concurrently using an iterative process. Interviews with parents and HCPs were audio-digitally recorded and transcribed verbatim. Transcripts were then analysed for emergent themes and categories using constant comparative methods, and multiple immersions into the data and related background literature by the first author (MS). For additional analytical triangulation, results were discussed and further analyzed through a process of peer debriefing with the co-authors. The clinical applicability of the results was then verified through multiple meetings with project collaborators and service/program providers at both paediatric hospitals. On the basis of this analysis, we generated an interpretive description of how parents coped with their grief in the first year after their child died, and how various bereavement follow-up and support services helped (or did not help) them cope with this life-altering event.

Results

The results are organized into four large categories that describe how the parents we interviewed coped in the first year after the death of their child. The first section examines how parents coped with the emotional reactions to their loss, and with the discrepancies between their beliefs and inner worlds. This is followed by an exploration of the social context of the parents’ grief and how social support was related to coping in the first year post-death. We follow this with findings on how parents used external resources to cope. Lastly, we discuss the issues of time and timing: that is, the effect that the passing of time has on grief, and how this impacts when services should be offered to bereaved parents.

I. Individual experiences of coping with grief

Through the analysis of the parents’ recollections of their individual experiences, the following themes were developed: firstly, an oscillatory aspect to the coping process; secondly, coping as a process of reconstruction of meaning in one’s life; and thirdly, a reorganization of the relationship to the deceased child.

Oscillations in grief and in coping.

Before we examine how parents coped with grief, we must first examine what parents felt they needed to cope with. As would be expected, the death of a child triggered many negative emotions, such as guilt, frustration and intense sadness. Parents in Group 2 described their grief as most intense during the first year post-loss. After this point, moments of intense grief were often triggered by reminders such as anniversaries or missed milestones (such as the moment when the child would have graduated from high school, if they had survived). The parents interviewed described the intensity of these negative emotions as having ups and downs, with moments of more intense grief followed by moments of less intense grief and vice versa. That is, parents' feelings of grief and loss came in waves of varying intensity.

Similarly to how the intensity of their feelings oscillated, so too did the parents' ways of coping with these feelings. In coping, parents went back and forth, at times wanting to actively process the events and experience the emotions related to the loss, at other times preferring to keep a distance and focus on getting back to "normal life". One of the ways parents mentioned actively processing their experiences and feelings of loss was through talking about their child, and their grief, with others. The HCPs interviewed also mentioned that parents seemed to need to recount the circumstances of the death and their feelings related to the loss. Parents noted that talking about the loss was helpful because it allowed them a means for maintaining a connection to their child, and to reflect on and process their grief at the child's death. However, parents were quite particular as to when, where, and with whom they shared their experiences and feelings, and emphasized the importance of having a safe space to speak where they felt understood and not judged. If the parent could not find a safe space, they would not share their feelings or talk about the loss. Another reason parents gave for not 'opening up' to others was that they did not feel capable of sharing due to the intensity of their feelings of grief. One mother described the experience this way: "You know, when you are crying and things are going 2000 miles an hour in your head? You are not capable of getting the words out; you are not capable of expressing yourself." Indeed, many parents reported that, in the very early stages or acute phase of their grief, just being functional while living with these intense emotions was challenging, let alone delving into their feelings with others. Moreover, parents sometimes made an intentional choice to process the loss by themselves. As one mother recounted:

> I decide when I'm going to go into it. When I let myself go … when the kids are not around, … I stay home and have a sort of breakdown… I cry and I get it out all in one shot. It tires me out. I sleep. Then the next day I'm okay. But, I would never do that in front of anyone else.

Just as parents sometimes chose not to share their experiences with others, parents also at times avoided or kept a distance from situations and objects associated with their child. One father explained it as: “To protect ourselves, we find a refuge.” Going through the child’s possessions and deciding what to keep, give to others, or throw away was mentioned as particularly difficult for parents in the first year post-loss. Parents recounted not being capable of looking at their child’s possessions or only being able to do so for short periods of time. One mother reflecting back on this time said: “I went step by step… I didn’t do it right away. I think it took me three years to give anything away.” This task challenged parents to balance their intense emotions of grief with their strong desire to keep the memory of their child alive. Mothers and fathers also reported occupying themselves with various tasks in order to distract themselves from their grief. Interestingly, only a few mothers alluded to distraction as a means to cope with their grief. “When you have an occupied mind, you do not go back… I have to keep my mind occupied,” said one mother, while another said, “All I was able to do is craft for a long time…because then I'd forget a bit.” On the other hand, all but one of the fathers interviewed mentioned that keeping busy by going back to work was helpful to them, because it served as a distraction from their grief, it occupied their time, and allowed these fathers an opportunity to receive support from coworkers.

In brief, parents either actively regulated their emotions through attempts at processing the events and affects related to their loss (either on their own or through sharing with others), or avoided possible triggers, or distracted themselves from their thoughts and feelings. Below, we present other themes related to how parents cognitively processed the death of their child.

Meaning reconstruction

Throughout the discourse of many of the parents, it was clear that the death of their child changed their lives in fundamental ways, to the degree that the parents narrated their lives as occurring before and after the turning point of their child's death. The parents went on to mention the various ways they adapted to, and found meaning in, this fundamental change in their world. Similar to the meaning reconstruction model proposed by Gillies & Neimeyer (2006), and Neimeyer et al. (2006), we found that parents found meaning through making sense of the loss, finding benefits or positive aspects from the experience, and reorganizing self-identity.

Making sense. Sense-making themes were apparent in the discourses of several of the parents. One way parents tried to make sense of the loss was through seeking information to better understand their child's illness or cause of death, either online or through staff such as genetic counsellors. Parents also relied on their own spiritual or existential beliefs to help them understand their child's death, sometimes reporting their child's life and death as serving some greater purpose, such as bringing happiness and courage to others. In order to make sense of their relationship to their deceased child, some parents also sought the support of spiritual counsellors, and two parents consulted mediums. On the other hand, many parents did not mention any attempts to try to make sense of the loss.[1] One parent, moreover, mentioned never "accepting" the death of her child, and thus not feeling the need to make any further sense of the loss.

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[1] This does not mean that they did not try to make sense, only that the parents did not mention it, nor did we ask guiding questions about this specifically.

> Everybody... had a reason why it happened. But I was the only one that didn't have an answer. And that was very (nervous laugh) frustrating. ...

Benefit-finding. Though the death of their child had been an overwhelmingly painful experience for the parents, and obviously not one they would have willingly chosen to abide, they were nonetheless often able to perceive benefits that had resulted from their loss. For example, parents mentioned feeling less anxious and more confident in life, knowing that nothing worse could happen as they had already “been through the worst.” Parents also mentioned changes in their perspectives on how they live their lives, such as making a conscious decision to slow down and do less, to focus more on oneself, or to not fear death. Parents whose child died after an extended illness were sometimes able to find benefits related to the illness itself, such as providing them a chance to get to know their child better. One interesting finding was that parents often reported helping others as a way of coping. Thus, as well as discovering benefits or positive aspects of their experiences, some parents tried to create benefits through actions such as fundraising or supporting/helping other bereaved parents. Parents mentioned specifically that giving back would give their child’s life a greater purpose, which was also related to making sense of the loss.

Reorganizing identity and sense of self. After the death of their child, parents reported trying to reconstruct not only a sense of meaning of the world around them, but also their sense of self. For example, in terms of self-identity, some parents were faced with changed roles. One father spoke to how he had to reorganize his self-identity from being a parent to a living child to being a father of a deceased child. In parents whose child had had a long-term illness or disability, and where the care of this child took a central role in the parent's life, parents had to adapt, after the death, to the loss of this role. One couple, whose daughter was disabled and cared for in the home for many years, presented to the interviewer all the adaptations they had made in their home to care for their child, and spoke about not knowing what to do with these things now that their child was gone. In addition, several parents mentioned positive changes to their sense of self. One mother said she learnt to be more assertive through the illness and subsequent death of her son, and one father said he no longer feared death. Along with changes in the sense of self and identity came an acknowledgement of one’s own internal resources. In fact, a couple of the parents mentioned that what was most helpful during the first year of bereavement was their own internal strength.

Relationship with the deceased

Another aspect of the parents’ individual experience of grief related to maintaining a bond with their child who was no longer physically present in the world. They often spoke about their continuing connection to their deceased child and their attempt to maintain the child’s memory. Parents found many ways of maintaining this connection, including talking about their child with others, creating a trust in the child’s name, or participating in rituals such as visiting the memorial/burial site. Some parents spoke of simply feeling their child’s “presence” or “energy”, or receiving symbolic messages from their child in the form of a butterfly or a flower. Parents also mentioned how it was important to continue the memory of their child, that their child not be forgotten. In fact, all the parents interviewed spoke in some way about how they maintain the memory of their child, either through sharing with others and talking about their child, and/or by keeping souvenirs and memorabilia of their child's life.

> We made a special booklet for the people close to us… that…that really helped me a lot to live with the grief … that I had that… it was an extraordinary therapy.

In addition, parents took pleasure in remembering positive aspects of their child's personality. Indeed, some parents even felt that their child's personality actually helped them cope. For example, one couple mentioned that seeing their baby be so brave through all the treatments encouraged them to be brave after his death. Another couple spoke about their teenage daughter's positive attitude and how, like her, they tried to keep a positive attitude through their grief.

II. Coping within a social context

In the first year after the death of their child, the parents were faced with reorganizing their identity and sense of self, revising their comprehension of the world, and finding a way to maintain some sort of relationship to the deceased. These themes all relate to processes that were deeply individual, but which were also embedded within a social context. That is to say that when the parents grieved, they did not do so in a vacuum, but coped with their grief partly through their interactions with others. In this section, we describe the role of these interactions on the coping process. First, we examine how different social relationships impacted the parents' coping, before discussing some general themes that emerged relating to grieving in a social context.

Relationships with immediate family

Coping as a couple. The first intrapersonal relationship we explore is that between the two parents, who in many cases grieved both as a dyad and as two individuals.[2] Ten of the interviews were conducted with both the mother and the father at the same time, which allowed parents to elaborate on how they coped, both as a couple, and as two individuals coping with the loss together. Several parents spoke of their spouse as a source of support, or of having to fulfill this supportive role for their spouse. As one father put it: "I wanted [my wife] to live it at her rhythm, so that she could grieve; I had to be by her side." Two of the couples interviewed, moreover, mentioned that the loss brought them closer together and strengthened their relationship.

However, both mothers and fathers noted important differences between how they and the other parent coped with their grief. For one, there was the issue of communication. Several mothers felt that while they wanted to talk about the loss (either between spouses or with others: support groups, for example), their partners (who in this study were all men) generally did not. Indeed, mothers used support groups more often, and in turn reported these as being more helpful, than did their spouses (we address this difference in more detail later, in our findings relating to external bereavement services). Interestingly, several of the HCPs interviewed noted that fathers would talk to them about their experiences (sometimes at great length) during follow-up calls. Another difference that emerged was that, as previously discussed, all but one of the fathers mentioned that going back to work was helpful in addressing their grief; none of the mothers, however, found this similarly helpful for themselves. As one mother put it: "I work to live, I don't live to work…For my husband, work

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[2] Most (18 out of 21) of the parents interviewed had a spousal partner.

is a real investment, like it is for many men … For me it is not that at all." Also in contrast to the fathers, a couple of the mothers mentioned that returning to work was difficult, either due to insensitive comments from coworkers or an inability to focus on work-related tasks because of their grief.

For some parents, these differences in how they and their spouse coped with the death were not particularly problematic, and three parents explicitly noted the importance of respecting how their partner grieved. As one mother said: "There was a psychologist who told me that eventually we'll have to live [the loss] more together...but we're living different things," to which her husband added, "We're living it together, too, but I respect that [that we're living it differently]." On the other hand, some parents found such differences particularly challenging:

> It was difficult to not have the same tools or the same things that help you.
>
> It was too heavy [for him]… He did not want to see me sad, he didn't even want me to talk about it.

HCPs also mentioned the importance of informing parents that their spouse may react differently to the loss:

> There are often different reactions between the two parents… And they won't necessarily talk about it...often they are mutually protecting each other, and it's one of the things that you have to normalize: that not only do men and women generally live with grief differently, but that any two people will live it differently.

For two of the participants, there were pre-existing issues with the relationship with the other parent that were particularly problematic during the first year after the death. Both these parents mentioned seeking extra support services (such as the services of a psychologist or social worker) in order to address these issues and better cope with the loss.

Relationships with surviving children. The parents' immediate family also often included other children. Several parents described these children as a source of support and noted that their shared loss brought them closer together. However, all parents who had other children had concerns about how these children were grieving, and several parents mentioned not knowing how to talk about the loss with their other children. As one mother put it: "I sort of understood how she was feeling but I did not know how to bring it up, maybe she's too young… I have no idea how a young person sees something like that, a loss like that." Indeed, some parents felt that they needed extra help to support their children through their grief; some actively sought (and found) external resources in this regard. A couple of parents, however, still felt they lacked resources on how to help their other children. Additionally, one mother was unsatisfied with the amount of follow-up support offered to her children. Another theme that emerged was the necessity of balancing the parents' concern for their children with their own grief-related needs. As one mother put it: "I knew that I could help them, but I also had to help myself." This concern was echoed by the HCPs, who specifically mentioned helping parents assist their surviving children as a focus of their interventions and follow-up practice. In addition, some families decided to get a pet as a way to aid themselves and their children cope with their grief.

Relationships with extended family, friends, and coworkers.

Beyond their immediate family, the parents discussed how their relationships with extended family, friends, and co-workers also impacted how they coped. As previously discussed, the parents all seemed to need safe spaces in which to grieve, and when their pre-existing social and family ties were able to supply this safe space, parents felt their influence to be helpful. The qualities parents most valued in their relationships were the ability to be present, to listen, and to have a non-judgmental attitude. As one mother put it: "[it helped] just knowing they were there, even if they didn't say anything." Although many parents felt their extended families where supportive and helpful during the first year after the loss, for several parents, relationships with extended family were problematic. For example, some parents felt that extended family (such as the child's grandparents, aunts and uncles) did not understand what they were going through while their child was ill, or the deep bond they felt to their child after their child's death. In effect, the parents often reported that the nature of their relationships with friends and family changed after the death of their child. For example, one mother said she used to give all of herself to her friends and family, but after her son died, she had to set limits with how much energy she put into those relationships. Another area where parents felt conflict in their social circle was that they sometimes felt they were not permitted to feel happy or express positive emotions because their child had recently died. As one mother recounted: "When I went back to work, [someone] came to me and said, 'Why are you laughing?' you know like, 'Why are you having fun, why are you smiling?' " Furthermore, we noticed differences between mothers and fathers in terms of who they went to for support. For a majority of the mothers, the support of a close friend was mentioned as particularly helpful in coping with their grief. As one mother put it: "A friend is someone who you can talk to without barriers, without judgment; this is rare, but I have friends like that." In comparison to their female counterparts, the fathers more often mentioned receiving support from coworkers.

New relationships developed during the child's hospitalization: other bereaved parents and healthcare providers.

The parents who had spent a great deal of time at the hospital with their child spoke about how they developed close, and often supportive, relationships with other parents whose children were also hospitalized. They also often mentioned developing bonds with the staff that cared for their child at the paediatric hospitals. Relationships with other parents in similar situations were considered helpful because they allowed the parents to see they were not alone, and that others understood what it was like to have a sick child, or to have a child who died. In addition, seeing other parents going through comparable experiences served to validate and normalize the intense emotions and reactions they were experiencing. Parents also noted that these other parents were unlikely to say insensitive and hurtful things, such as “at least you can have other children”. As for relationships with HCPs, parents often reported that, after the child died, they experienced a double-loss: that of their child, and of their supportive relationships with staff.

> It wasn’t just the loss of [name of child]…. You know, we got to know people at the hospital for eight years… a third of our working life was spent there. You see the same people… get to know the same people, then from one day to the next it finishes there.

Broad view of coping in a social context. As previously mentioned, the idea of a “safe space to speak” came up on numerous occasions with both parents and HCPs. Some parents highlighted the lack of understanding that they experience from other people in their day-to-day lives. Indeed, as Wortman and Boerner (2007) point out, bereaved individuals often lack places where they can speak comfortably about their experiences because for many North Americans, speaking about death is a taboo or uncomfortable subject (Wortman &

Boerner, 2007). As one mother put it: “I found understanding what I went through, understanding my loss, acknowledging it, was…practically non-existent in the outside world.” This state of affairs perhaps makes those “safe” relationships all the more precious to grieving parents. They appeared to use their relationships to help them continue their bond with their deceased child, as well as to maintain the memory of their child in the minds of others.

III. Coping with the help of support services

In this section, we explore parents’ perspectives on if and how various institutional support services (i.e., bereavement follow-up from the paediatric hospital and specific bereavement support services) helped them cope with the loss.

Support needs

When asked about bereavement support and follow-up services offered by the paediatric hospital or the community, parents expressed varying levels of need for such services. On the one hand, many parents felt they had sufficient social networks and were well supported, and therefore did not feel a need to use support services. As one mother said, “There were people who helped me in all the spheres of my life, so I did not feel the need for additional help on that … I already had a lot.” In addition, parents mentioned being naturally inclined to depend on themselves and use their own internal resources. Some parents, on the other hand, did not feel adequately supported: either pre-existing relational problems were present, the family was in another country, or the individuals they would normally go to for support were unavailable due to their own grief (e.g., the other parent, or grandparents). As explained by one mother: “…the grandparents, the aunts as well, they are also affected and are not any more help.”

Most of the parents who felt the need for extra support actively sought it out through various bereavement services (such as support groups, social workers, psychologists, or nurses). Some families who were already receiving support from either a social worker or psychologist before their child died continued to be followed by these HCPs after the death. Several parents, however, found it difficult to get information and resources that met their bereavement support needs. For example, one mother mentioned that the bereavement support group she was referred to, and wanted to attend, was too difficult for her to access using public transit. In addition, parents emphasized wanting information on services even if they were not sure whether they would use those services. As one parent related: “I allowed myself to try [different resources]…I permitted myself to say when something wasn’t working for me…and I moved on to try other things.” Interestingly, we also noticed a difference between mothers and fathers in terms of bereavement support services used. In general, mothers consulted available services (such as support groups) more often. Some fathers, however, did access psychosocial services; these fathers tended to consult individual services (such as that of a psychologist or social worker) more often than support groups.[3]

Support services with other bereaved parents

As mentioned previously, parents often created relationships with other parents of sick children during the time of their child’s illness. In a similar vein, they also reported receiving support from other bereaved parents they met after their child died. Bereaved parents most often cited being connected through support groups. Parents described the type of support they

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[3] Either the fathers we interviewed said this, or the mothers mentioned that their spouse (who we did not interview) had accessed these services.

received at these groups in both similar and different terms than that received from other relationships. On the one hand, and in a similar way to their more supportive relationships with friends, family, and HCPs, support groups provided a safe space to speak where parents did not feel judged. On the other hand, support groups had the added benefit of giving parents a space to feel understood by others who knew what it was like to have a child who died. They also mentioned that interacting with other bereaved parents allowed them to see that they were not alone, and helped them gain some perspective on their intense emotions and reactions: "You see that you actually went forward in your grief...When you see the point [other parents] are at in that moment, and where you're at now…."

Support groups therefore helped some parents cope, but parents also mentioned that participating was emotionally difficult; in one mother's words: "when I left there, I was destroyed". Two mothers whose infants died said that at first they were concerned about participating in groups with parents of older deceased children (one, however, eventually did participate, and said it was especially helpful for her). Other parents we interviewed did not attend these types of activities in the first year. Some among them wanted to attend, but logistical issues made it impossible to do so; one mother, for example, could not find childcare. Some, however, simply did not want to share their experiences or feelings ("I didn't want to talk about it"), while others felt sufficiently supported and did not feel the need. Parents also mentioned that in the first year after the loss they did not feel ready or emotionally capable of participating in a support group (but did note that later on they were more interested in participating).

In addition, several mothers found support from other parents online through forums and blogs. As one mother said: “I found a world of support out there with women who had my obstetrical issues … and had lost kids due to the same issues … I spent a lot of time chatting with women all around the world.” However, at least for one of the mothers, searching online for blogs in the first year after the loss was difficult because it was overwhelming and “brought up many intense emotions”.

Support and follow-up from the paediatric hospital

At the two paediatric hospitals participating in the study, various follow-up services were offered. We asked the parents for their perspectives on these services, as well as the role they played in helping them cope. Both hospitals conducted commemorative services for families and staff. Overall, parents reported that these services were helpful because they allowed them a chance to feel a connection to their deceased child (this was especially noted for the candle-lighting ceremony at one of the hospitals). Parents felt that although the service was emotionally difficult and that it was tough to see that so many children had died, it was also reassuring to see that they were not alone. Moreover, the service provided a continued contact between the hospital staff and the bereaved families. The parents appreciated seeing the staff and other parents they had come to know while their child was ill. It should be mentioned, however, that not all parents attended these services, either because a parent did not have a desire to attend (i.e. it did not suit their personal needs and/or desires), or because the service occurred at a time when they were not yet emotionally ready for it. The choice of when to attend the service was important to parents, along with knowing they would be invited again if they did not choose to attend at that time. Some neonatal and paediatric palliative care hospital departments gave memory boxes to the parents, containing such items as locks of hair, hospital bracelets and other souvenirs. Parents kept the memory boxes they received, and several parents mentioned going back to them, to look through their contents and/or to add mementos. Sympathy cards from hospital staff were also commonly sent to families as part of the bereavement follow-up, and these too were often kept as cherished souvenirs. Parents noted that the memory box helped them to maintain the memory of, and a connection with, their child, whereas the sympathy cards were appreciated by the parents because receiving them indicated that the staff had not forgotten about them and their child. As one mother put it, "When I read it I said, 'Oh, they have not forgotten about us… we have not gone by unnoticed in the world.' "

Hospitals also followed-up with phone calls to parents (made by various HCPs, i.e. doctors, nurses, social workers, psychologists, and spiritual care workers). According to the HCPs interviewed, these follow-up calls had three general objectives: 1) to provide a form of continued contact with the hospital; 2) to assess for risks of maladaptive grieving (i.e. non-supportive/negative relationships, financial stresses, and difficulties in day-to-day living); and 3) to refer to services or continued support for family, when appropriate. Staff also specifically mentioned normalizing grief reactions and providing support to siblings (either directly or through informational support given to parents). For the HCPs interviewed, the follow-up phone calls were crucial and they often mentioned wishing they had more time to spend on these calls. On the other hand, most of the parents did not discuss the follow-up calls in detail. Parents who did elaborate on these calls, however, mentioned that they were helpful because they provided them with: emotional and information support (when social support was lacking); a place to speak about their loss with someone who was there when their child was sick (or associated with that setting); and a means for continuing a connection with or sharing the memory of their deceased child.

In summary, parents generally had positive opinions concerning the bereavement follow-up they received. They specifically appreciated the HCPs open-door attitude ("call us when you need us") and their being “present” (i.e. available and attentive). Parents were also very grateful for the help they received while their child was sick, and after their child died many parents felt a need to thank the staff that had helped them. In fact, several parents noted the importance of being able to thank individual staff for their help, and that such expressions of gratitude were helpful in addressing their grief.

Other bereavement support services

In addition to those services mentioned above, parents and HCPs mentioned other bereavement services offered through the public healthcare system, at either the paediatric hospital where the deceased child was treated or in the community (e.g. community health clinics), or privately (e.g. from grief counsellors or private practice psychologists). Parents sought the assistance of social workers and psychologists to address various issues related to their bereavement, such as: dealing with contradictory emotions (such as wanting the child to live but not wanting the child to suffer); relational issues with the other parent; support for siblings; normalization of their physical and cognitive reactions; and reassurance. According to the parents, these services were helpful because they provided a place to be open to speak about their loss and their child with someone neutral (who was not directive or prescriptive), and who listened to and accepted them. However, some community services were critiqued for not offering enough sessions or a long enough follow-up, and for lacking expertise on supporting bereaved parents. It is important to note that some parents received follow-up services from non-governmental organizations (NGOs) while their child was sick, and two of these organizations also provided bereavement support. Parents with children who died of cancer more often mentioned receiving bereavement follow-up services from NGOs than parents whose children died due to other causes. Partially in response to this discrepancy in service provision, HCPs underlined the importance of assessing what other services (from the hospital or NGOs) were in place and if these services were meeting the parents' needs, so that could adapt their follow-up accordingly.

IV. Time and timing

Another set of themes that emerged from our interviews with parents and staff pertained to the effects of the passage of time in the grieving process, as well as the timing of certain bereavement follow-up or support services and interventions on how parents coped with the death of their child.

Changes over time

The current study focused on how parents coped with grief in the first year following the death of their child, as this is often when paediatric hospitals are looking to provide services to parents. As mentioned previously, parents described their grief during the first year after the death of their child as extremely intense, to the point that some altogether avoided certain people, events, or other reminders. However, many parents also noticed that the intensity of their negative emotions of grief decreased over time, while their functionality in daily life increased. They also often emphasized the importance of letting time pass, and the comfort of knowing, through their relationships with other bereaved parents, that the intense emotions and physical sensations would decrease over time. For example, one mother used the metaphor of a light at the end of a long tunnel to describe how, with time, she eventually would feel better. Another participant said her main advice to parents would be to encourage them to just get through that first year, because in the second year they will begin to see things more clearly. This sentiment was echoed by the HCPs, several of whom spoke about "accompanying the family" throughout their bereavement. Importantly, HCPs related that this accompaniment may last longer than the one-year period that is currently the norm for follow-up, and several of the staff referred to "an open-door policy", where parents could call whenever they felt they needed help or support (even after the first year).

Timing of services

This last point brings up the concept of timing for services. At the two paediatric hospitals participating in the study, bereavement follow-up was to continue throughout the first year post-death, after which point the parent was to be referred to other psychosocial services if necessary. Both parents and staff mentioned issues with the timing of these various bereavement follow-up and support services. Firstly, HCPs and parents both drew attention to the fact that many parents do not feel ready to participate in certain bereavement support activities (such as support groups or the commemorative service offered by the paediatric hospital) in the first year after the death of their child. As one mother pointed out, a continual presence (follow-up calls, sympathy cards) and contact from the paediatric hospital was helpful in the first year, but services requiring a more active participation on the part of the parent were only helpful after she had time to become more functional and gain perspective. Parents also noted that during the phase of acute grief, they had difficulty reading long texts or actively seeking resources and tools to address their grief. Furthermore, several HCPs stressed the importance of assessing the needs of the family and continuing to do so for more than a year at times as, similarly to the parents, they had noticed that parents' grief tends to come in waves, with emotions, memories and physical sensations that wax and wane in intensity over time.

Discussion

Through the in-depth analysis of interviews conducted with both parents and HCPs, and multiple discussions with service providers on the clinical applicability of findings, we have provided a detailed description of how parents coped with their grief in the first year after the death of their child, and of how various bereavement follow-up and support services helped them cope. Our findings are presented from a systemic viewpoint, situating parents' individual experiences of coping within the greater social and institutional contexts in which they grieve. In this discussion, we elaborate on these findings in terms of the recent theories and empirical research in the area, while highlighting the clinical implications of these results and the theoretical models to which they relate.

Our finding that parents seem to go back and forth between actively processing their grief and focusing on other aspects of their lives seems to conform to the Dual Process Model of Coping in Bereavement (DPM) (Stroebe & Schut, 1999; Stroebe & Schut, 2010). According to the DPM, grieving individuals are thought to oscillate between loss-oriented coping (LOC) and restoration-oriented coping (ROC). The former refers to coping processes that focus directly on the stress of the loss itself (such as grief work, intrusion of grief, letting-go-continuing-relocating bonds/ties, and denial/avoidance of restoration changes); the latter refers to coping processes that focus on adjusting to life after the loss (such as attending to life changes, doing new things, distraction from grief, denial/avoidance of grief, and new roles/identities/relationships). Importantly, both LOC and ROC are considered important ways of coping with the loss of a loved one. Neither is inherently better or more adaptive than the other; rather, the DPM maintains that adaptive grieving is often characterized by the alternation between these two coping processes.

If, as our results imply, the ways in which parents cope with their grief does indeed alternate between these two types of coping processes over time, then we recommend that clinicians be aware of this oscillatory aspect of grieving, so that they might accompany the parents through these different facets of the grieving process. For example, such accompaniment may involve understanding that though the parent will sometimes be ready and willing to actively process the loss, at other times he or she may exhibit certain avoidance behaviours (including not wanting to consult with psychosocial care workers) that may, in fact, be adaptive. Perhaps the ideal in this respect would be establishing an "open-door" policy, where parents can consult when they so need (and not necessarily at a specific time or within a fixed number of sessions).

We should note, however, that the DPM has been critiqued for not adequately addressing "whether individuals are actively and purposively choosing to loss-orient or restoration-orient, or whether they are passively defaulting to strategies due to lack of options" (Carr 2010). The parents we interviewed did indeed describe purposively choosing to loss-orient or restoration-orient. These choices, however, were highly impacted by and sensitive to various triggers: coming across an object that reminds the parent of the child, for example, or finding oneself (or not) in a ‘safe space’ to speak about the loss. Taking a cue from the field of situated action theory (Schuman, 1987), we should recognize the “emergent, contingent nature of human activity, the way activity grows directly out of the particularities of a given situation” (Nardi, 1996). Indeed, one particularly important situating factor that emerged in our study was the social context in which parents grieved.

Another concept from the general bereavement literature being explored with bereaved parents is meaning-making. Meaning-making is somewhat of an umbrella term for describing several specific processes that contribute to adaptation to bereavement and other stressful life experiences (Park, 2010). Though many conceptualizations of related concepts have been proposed (see Park 2010 for a review), the model that seemed to best fit our results related to how parents cognitively processed the death was the meaning reconstruction model proposed by Gillies and Neimeyer (2006). In this model, the authors describe meaning reconstruction as involving making-sense, benefit-finding, and changes to self-identity. Making-sense refers to constructing an explanation of a loss based on one’s beliefs/worldviews; benefit-finding refers to ascribing positive value to aspects related to or following from the loss, e.g. increased appreciation of life and improved relationships; identity-change posits that by reconstructing meaning in our lives in response to a loss, we necessarily reconstruct ourselves. In our analysis of the data, aspects related to meaning emerged in parents’ descriptions of how they coped. In this way, our findings are similar to those of other studies on the experiences of bereaved parents (Wheeler, 2001), and of parents in the first year of grief in particular (Alam et al., 2012; Barrera et al., 2009). The clinical applications of such findings are currently being explored through recently developed interventions oriented towards supporting the bereaved in their reconstruction of meaning (Park 2010). Meaning-Centered Grief Therapy (MCGT) aims to address the existential challenges that often accompany the loss of a child, by facilitating the kinds of meaning making processes described above (Neimeyer & Lichtenthal, in press). Such intervention efforts are in the early stages, and the efficacy of these types of interventions has only just begun to be evaluated. Furthermore, we did not find any published clinical trials examining the usefulness of meaning reconstruction interventions in bereaved parents specifically, although a pilot study of MCGT for parents bereaved by cancer is currently underway (Neimeyer & Lichtenthal, in press). We suggest that further research in this area is warranted, in order to ascertain whether interventions aimed at helping parents find meaning are indeed beneficial. Moreover, given that meaning reconstruction is a process, we note the potential utility of longitudinal research designs in exploring this phenomenon (for example, see O'Connor and Barrera's 2014 study of changes in self-identity in bereaved parents).

Yet another area of bereavement research and theory that proved to be germane in our analysis concerned the idea of maintaining a connection to the deceased child. There was, for many years, a debate in the grief literature as to whether, as Freud had said, the grieving person should strive to 'let go' of bonds to the deceased. After the seminal work of Klass, and Riches and Dawson (Klass, 1993; Klass, 1997; Klass, 2006; Riches & Dawson, 1996a; Riches & Dawson, 1996b), however, it is now recognized that continuing bonds to their deceased child is an important coping task for bereaved parents. Similarly, Neimeyer, Baldwin and Gillies discuss the importance of reorganizing bonds to the deceased in their 2006 paper on meaning reconstruction in adults (Neimeyer, Baldwin & Gillies, 2006). Recent research by Barerra (2009) and Darbyshire (2013), moreover, suggests that one of main stressors in coping for bereaved parents is the potential for a loss of connection to their child. In the present study, the parents we interviewed all mentioned, in some way, the importance of continuing a bond to their deceased child, which is consistent with the results of a 2011 study by Foster et al. Moreover, many forms of support these parents perceived as helpful in their coping were felt to be so precisely because they afforded a means of maintain this connection. One example of this is the follow-up phone calls from HCPs; while the rationale for these calls is to allow the HCPs to evaluate the parents' needs, these calls were often perceived by the parents as a chance to maintain a connection to their child by talking with someone who had known him or her. This finding, which has analogues in research by Darbyshire et al. (2013) specifically examining follow-up calls, provides insight into why certain bereavement follow-up practices are important in helping parents cope.

As we mentioned before in our discussion of the DPM, the parents' experiences of coping, though highly personal in nature, were affected by various situational factors. One particularly salient contextual aspect that emerged from our findings was the broader social world in which parents lived. This should not be surprising; humans, after all, are social beings, who create narratives in their lives through interactions with others (Neimeyer & Stewart, 1998; Walter, 1996). This social element, however, is often neglected in psychological models of bereavement. As Neimeyer and Stewart (1998), Barrera et al. (2009), and Hooghe et al. (2012) highlight, grieving happens within a social field, and it is therefore imperative to understand the interpersonal factors involved in the grieving process (Barrera et al., 2009; Hooghe et al., 2012; Neimeyer & Stewart, 1998). In relating how parents' experiences of grief were shaped by their relationships, then, our findings shed light on social and interactional processes that affect how parents coped with grief in the first year post-loss. Indeed, many of the aspects related to how parents coped were inherently interpersonal in nature. In particular, parents noted how relationships were helpful for maintaining a collective memory of their child, a continued connection to their child, and a safe space to reconstruct meaning and process the loss (and other loss-oriented stressors). In other words, supportive relationships provided a forum for parents to engage in the types of individual coping processes described in the meaning reconstruction and DPM paradigms. Conversely, where, for any number of reasons, such support was lacking, parents voiced a need for external support from services such as psychology and social work.

Keeping in mind the findings of Gamino, Sewell, Hogan and Mason (2009) and Neimeyer and Currier (2009) that services are most efficacious for at-risk individuals, service providers may want to assess how the parents perceive the availability and quality of social support received from family, friends, co-workers, or any other person who will play a significant role in their lives while they grieve. Indeed, previous research in general bereavement has reported a positive relationship between perceived social support and health and coping (Stroebe & Stroebe 1993, Hogan & DeSantis 1994, Robinson 1995, Thuen 1995), and research conducted with bereaved parents has found that perceived social support is associated with fewer grief responses and less complicated grief, and positively associated to measures of personal growth (Riley et al., 2007). Furthermore, our finding that parents' needs for, and sources of, interpersonal support changed over time suggests the need to periodically reassess the parents’ perceived social support. Well-established and often-used measures of perceived social support such as the Inventory of Socially Supportive Behaviors (Barrera, Sandler & Ramsay, 1981) and the Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet & Farley 1988), and measures of perceived social support during bereavement, such as the Inventory of Social Support (Hogan & Schmidt, 2002) may offer clinicians a basis for assessing support needs in the bereaved parents they follow. This being said, there remains a need for future research to validate these measures for clinical use with bereaved parents.

Our findings that (a) surviving children could be an important source of social support for bereaved parents, and that (b) parents expressed concerns about how these children were grieving, is consistent with research by Barrera et al. (2013) which examined parental perceptions of siblings' grieving after the death of a child to cancer. Furthermore, our interviews with HCPs, who specifically mentioned helping parents assist their surviving children as a focus of their interventions and follow-up practice, lead us to agree with Barrera et al.'s call for accessible and targeted bereavement counseling resources for bereaved siblings. Lastly, our finding that some families decided to get a pet as a way to aid themselves and their surviving children cope with their grief suggests a potential avenue for future research.

The socially embedded nature of grieving also relates to why certain bereavement services and follow-up practices offered by the hospitals or broader community were considered helpful by the parents. Indeed, when parents were asked about their perspectives on these services, their responses had much in common with their descriptions of the support they received from their network of family and friends. Commemorative services, sympathy cards, and follow-up calls allowed for sharing the memory of the deceased child with the staff and other families they had come to know throughout their child's illness; follow-up calls and support groups fostered a 'safe space' to speak about the loss (or, to use the DPM's terminology, provide an appropriate situation in which to engage in loss-oriented coping). Relationships with HCPs, moreover, not only provided a context for processing grief; in many cases these relationships were valued by the parents in their own right, having become woven into the fabric of the parents' lives during the days, weeks, months, or years of their child's illness. After the death of their child, some parents faced the added stressor of losing these relationships, which echoes similar findings by Darbyshire et al. (2013). Accordingly, one of the ways the services were helpful was in helping to continue these relationships after the death of the child. In addition to the previous recommendation about assessing parents' perceived social support, then, we also recommend that clinicians examine other aspects of social support more specific to bereaved parents, such as their relationships with staff. Although we are unaware of any existing measures in the bereavement literature that exactly address this type of relationship, clinicians could incorporate questions to this regard during their assessments of parents' support needs.

Another general finding of the present study which may have clinical relevance concerns differences in coping that related to gender. For example, the fathers we interviewed more often mentioned going back to work as helpful in coping with their grief in the months following the death of their child, whereas mothers did not, which echoes similar findings by Alam et al. (2012). Also, mothers more often mentioned benefiting from support groups, whereas fathers more often consulted for individual services, either from a social worker or psychologist. On the basis of these findings, we advance that one area of clinical importance concerns whether current services are equally appealing to (and beneficial for) both mothers and fathers. In fact, some research has begun to address these questions (see Aho et al. 2011 for an example). In their seminal exploration on gender and grief, Martin and Doka (1999; updated in Doka & Martin, 2010) explored differences in coping in men and women and identified two patterns of coping, which they label *instrumental* and *intuitive*. They report that the former pattern is more often exhibited by men and the latter by women, which they argue is due to contemporary patterns of male and female socialization. They are careful to note, however, that in a given individual, there can be substantial overlap in these patterns (that is, they are not mutually exclusive), and that though these patterns are *influenced* by gender, they are not *determined* by it. Even if we do want to generalize on the basis of gender, however, ours and others' findings highlight the fact that any two people may exhibit very different ways of coping, which has important implications for support services and clinicians working with couples.

Finally, the parents' perspectives on the impact of the passage of time on grief, and on the timing of services offered to them, have direct implications for clinicians and service providers. As is well established, experiences of grief change over time (Murphy, Johnson and Lohan, 2003; Rubin and Malkinson, 2001), and the parents and HCPs we interviewed seemed well attuned to this fact. In addition to our previous recommendation that services be provided in a way that is sensitive to how parents' grieving processes may evolve over time, our findings also suggest that, although follow-up services are considered important in the first year (Contro, Larson, Scofield, Sourkes & Cohen, 2002; D'Agostino, Berlin-Romalis, Jovcevska & Barrera, 2008; Decinque et al., 2006) some parents may not yet be "ready" to make use of such services during this period, particularly those services which require an active participation on their part (e.g., memorial services and support groups).

Losing a child is recognized as one of the most devastating and intense forms of grief. To address the needs of bereaved parents, paediatric hospitals are increasingly offering bereavement follow-up services to parents during the first year after the death of their child. The imperative, however, to base such services on a firm empirical and theoretical basis has so far been hindered by the relative dearth of research examining parents' early bereavement experiences. Findings from studies such as this can help service providers operate from a deeper, more systemic understanding of parents' lived experiences of grief, and more effectively target services and resources to help parents in need through this difficult and profoundly meaningful period in their lives.

That being said, we should highlight certain limitations to the present study. For one, the transferability of the findings is somewhat limited by the lack of internal diversity in the sample of bereaved parents; the vast majority of parents were of Caucasian/European backgrounds, and we do not know to what degree our findings would apply to parents of markedly different cultural heritages. In addition, there was an absence of parents whose children died from violent deaths or accidents; this presents an important limitation of the study, as cause of death has been found in previous research to be associated with how a parent copes with the loss (Murphy et al., 2002; Lichtenhal et al., 2013). Also, we did not obtain the perspectives of parents who were not followed by any of the recruiting hospital departments, or who otherwise chose not to participate in the study. Another limitation stems from the fact that our findings were based on what the parent themselves reported as being helpful, and not psychological (psychometric) measures of change (e.g., in depression, anxiety, grief intensity/symptoms, or trauma symptoms); therefore, we cannot speak to associations between grief symptoms and experiences, nor can we establish any cause and effect relationships. Finally, though our 2-group study design served as an effective means of triangulation (with one group being within the first year post-death and the other group retrospectively recalling the first year), this design is limited with regards to one of the themes that emerged in our results: time and timing. We did not specifically set out to study the effect of the passage of time on grief and coping or the timing of services, and though we were able to glean some interesting findings in this regard, it is possible that a longitudinal design might be better suited to studying these particular phenomena in depth.

These limitations notwithstanding, the documentation of patterns and themes relating to parents' grieving process, and their needs for and perceptions of services offered to them, yields insights that might strengthen our collective capacity to accompany parents in a way that optimizes outcomes for these parents and the families, friends, and communities to which they belong.

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Table 1. Characteristics of bereaved parents who participated in the study

Characteristic	***Number of participants (%)***
Age of parent	
20 to 30 years	2 (9)
31 to 40 years	3 (14)
41 to 50 years	13 (62)
51 to 60 years	3 (14)
Primary speaking language	
French	18 (86)
English	2 (9)
Bilingual	1 (5)
Gender of parent	
Female	15 (71)
Male	6 (29)
Annual household income	
Less than $10 000	3 (14)
$30 001 - 50 000	1 (5)
$50 001 - 70 000	3 (14)
$70 001 - 90 000	4 (19)
More than $90 000	10 (48)
Employment (at time of interview)	
Employed	14 (67)
Retired	2 (9)
Unemployed	4 (19)
Maternity leave	1 (5)
Education (e.g. Primary school or less)	
Primary school or less	1 (5)
High school or technical school graduate	2 (9)

Some college or university	4 (19)
College/university graduate	14 (67)
Relationship to other parent	
Married	11 (52)
Common-law	5 (24)
Separated	3 (14)
Friends/Dating	2 (10)
Other children (y/n)	
Yes	17 (81)
No	4 (19)
Time since death (at recruitment)	
1 year or less	8 (38)
1 to 5 years	13 (62)
Cultural background or Ethnicity	
Caucasian	20 (95)
African-Canadian	1 (5)
Gender of child	
Female	7 (33)
Male	14 (67)
Cause of death	
Neurodegenerative/neurological disorder	5 (24)
Cancer	6 (28)
Congenital disorder	10 (48)
Child's age	
Infant (0 – 1 y)	10 (48)
Child (1 – 13 y)	4 (19)
Adolescent (13 – 19 y)	7 (33)

General Discussion

Following a call for more research in PPC and PEOLC (Institute of Medicine and the Canadian Hospice and Palliative Care Association), there has been a corresponding increase in research in these areas, including parental bereavement, since the early 2000s (Canadian Hospice Palliative Care Association, 2006; Field & Behrman, 2003). There remains, however, a lack of dissemination and integration of new knowledge generated through research into actual PPC and PEOLC services (Decinque et al., 2006; Steele et al., 2008; Widger & Picot, 2008; Widger et al., 2007). This thesis was comprised of three articles that each attempts to span the research-practice divide in the related areas of PPC and bereavement care.

Summary of the findings and original contributions

The first article sought to present a clinically relevant understanding of the paediatric palliative care needs of patients and their families. With this goal in mind, literature on PPC and PEOLC was subjected to a metasummary. Our findings identified 10 general domains of PPC and PEOLC needs of patients and families: health care delivery and accessibility, interactions between staff and families, information needs, bereavement needs, psychosocial needs, spirituality needs, pain and symptom management, cultural needs, decision-making and needs of siblings (see Article 1-Table 2, pg.38). These needs, furthermore, were found to be consistent with current guidelines for PPC and PEOLC. However, we also found that a) many parents are still reporting these aspects of care as lacking or problematic and b) that there are certain needs being reported by patients and families that should be addressed in guidelines and policy creation. These findings have the potential to inform the development of quality PPC and PEOLC services. This study also provided the groundwork for the empirical study undertaken for the third article by affording an in-depth understanding the service context of paediatric palliative care.

The second article built on the insights gained in the first article by focusing on parental bereavement, specifically on adaptation post-loss and the factors that may impact how parents adapt to their grief. As with the first article, the overriding goal was to synthesize a large body of research in a way that could serve to improve practice and further develop empirically based services. To this end, we employed a narrative synthesis technique, wherein quantitative and qualitative research conducted since the year 2000 was collected and analyzed in order to integrate findings related to psychosocial adaptation of bereaved parents and highlight the clinical implications thereof. Our results, summarized in Article 2-Figure 1 (p.116), suggest important elements to consider when assessing symptoms of trauma and related disorders and/or the potential development of persistent grief reactions, such as the proposed DSM-5 criteria for persistent complex bereavement disorder, formerly known as complicated or prolonged grief (American Psychological Association, 2013; see Appendix A). When providing support to bereaved parents, it is recommended that clinicians take into consideration: antecedents (e.g., family conditions, age); circumstances existing before the death (e.g., cause, and interactions with staff and HCPs) and surrounding the death (e.g., autopsies, organ donations, viewing of the body, and burials); social factors (e.g., relationships between spouses and surviving children); and various coping methods (e.g., avoidance). This review also described elements related to better adaptation, which could further serve as potential avenues for support and intervention (e.g., meaning-making and factors related to positive change and personal growth). Based on these assessments, clinicians can decide whether and how to intervene, and whether to refer to other services. Our analysis also underscored certain methodological issues in the literature on bereavement that hinder the synthesis of results, such as grouping large ranges of ages of the children who died and of causes of death when evidence suggests that there may be important differences in adaptation to grief based on these factors. In sum, this review contributes to bereavement research and service provision by a) affording researchers and clinicians a broader view of the experiences of bereaved parents and potential elements of risk for the development of persistent grief and other psychiatric disorders, b) presenting possible avenues for clinical intervention and support, and c) providing policy makers with a summary of the relevant evidence that can be translated into policy change and program development.

In reviewing the literature related to PPC and parental bereavement, it became apparent that there was a general lack of research examining bereaved parents' experiences in the first year following their loss. Moreover, one implication for future research that emerged in the second article was the need for a more complete understanding of the psychological processes of coping in parental bereavement. The third article thus sought to describe how parents coped with their grief in the early phase of their bereavement, as well as their perspectives on various bereavement follow-up services. Intersecting psychological research and service provision viewpoints, this study aimed to provide information useful for paediatric hospitals, community services and clinicians who provide bereavement follow-up and support to families dealing with the death of a child. We explored aspects of coping of specific relevance to bereavement follow-up services, and verified our findings through continuous collaborations with health professionals working at the two participating paediatric hospitals. This included meetings with stakeholders and policy makers throughout the data collection and analysis phases of the project, interviewing clinicians who conduct bereavement follow-up, and observing commemorative services at the two participating hospitals.

In the section that follows, global themes across the three articles of the thesis are presented; Table 1 (pp. 180 - 1) is a digest of these themes over the time course of PPC and bereavement care. This is followed by a discussion of the implications for theory and clinical practice in bereavement care.

Global themes

Two themes we found in all three articles that speak to the distinctly individual and personal nature of parental bereavement are meaning-making and the parent's relationship with the deceased child. In the first article, the review of patient and family needs in PPC, both meaning-making and maintaining a connection to the deceased child were identified as spiritual needs of families following the death of the child. In the literature that we reviewed in the second article, and in our analysis in the empirical study, meaning-making and relationship to the deceased were conceptualized not only as spiritual needs, but also as cognitive coping processes that may or may not have spiritual undertones.

Another global theme that emerged was the importance of social networks in the grieving process. In the first article, social support was identified as a psychosocial need for patients receiving PPC and their families. The findings from the second and third articles demonstrated that social support was also crucial during bereavement for many parents. These articles, however, also introduced an important qualification with regards to the social aspects of grief: not all social relationships are a source of support. That is to say that though family, friends, and colleagues might surround a grieving parent, not all of these relationships will necessarily be perceived by the parent as supportive, and some may even be seen as problematic. The results of the empirical study indicated that those relationships that parents feel to be genuinely supportive might be so for many reasons. They may offer practical help (such as preparing meals and caring for other children), emotional support (giving consolation), and a 'safe space' in which to speak about their experiences and help them remember the positive aspects of their child’s life and their situation. These social relationships can be seen as being used by the parent to engage in various coping methods, such as engaging in loss-oriented coping by talking to a friend about the loss. One type of particularly intimate and complex social relationship that bereaved parents might have is with their surviving children. A theme that emerged across all three articles was parents’ concern for the surviving siblings, and the results of the second and third articles suggests that surviving children may be an important source of social support for bereaved parents. Both these findings are consistent with research by Barrera et al. (2013).

Another important source of social support for several of the parents interviewed in the empirical study came from their relationships with other bereaved parents. These relationships allowed parents to feel understood by others who knew what it was like to have a child who died, and to see that they were not alone. A parallel could be drawn here to a finding from the review of PPC and PEOLC needs, namely that parents of sick children may need access to other families in similar circumstances. Taken together, these findings suggest that, both before and after the death of an ailing child, many parents seek out and benefit from relationships with those who are perhaps uniquely able to empathize with their situation.

In all three articles, we noted the particular importance of familial relationships in PPC and bereavement. In the first article, we identified PPC and PEOLC needs for both the patients and their parents and siblings, and highlighted the need for family-oriented services in PPC settings. In a similar vein, our research on bereavement underscored the central impact of family on the grieving process. For one, we explored how parents grieved together. Parents who have a spousal partner grieve both as individuals and as a couple, wherein each partner can be both the giver and recipient of support. Though these parents are mourning the same loss, however, they may have markedly different ways of coping. Some previous research (e.g., Barrera, 2009) and the results of our empirical study suggest that parents are generally aware of and sympathetic to these differences. Our review of parental bereavement research also suggests that, contrary to commonly circulating myths on divorce rates of bereaved parents (as explored in Murphy, Johnson, & Lohan, 2003b), most spousal couples traverse the loss of their child with their conjugal relationship intact, perhaps even strengthened; in our empirical study, the only relationships that did not stay intact had had pre-existing difficulties before the child's death. Another common thread across the three articles is that siblings' needs are an important, though often under-recognized, aspect of PPC and bereavement care. Parents’ concern for the reactions of these children was found both in the studies reviewed and in the empirical study.

One theme that overlaps both service provision and social support themes is that parents want continued contact with the paediatric hospital and HCPs after the death of their child. This was found to be a bereavement need in the first article, and important to many of the parents interviewed for the third article. Parents often spoke of the caring and supportive relationships they built with HCPs while their child was sick; indeed, some of the parents reported that when these connections were suddenly broken off after the death, they experienced a double loss: that of their child and of their relationships with staff. It is important to note, however, that parents also report negative interactions with staff in both the PPC and bereavement literature, as cited in the first and second articles respectively, and findings reported in the second article suggest that such negative interactions may impact how parents adapt to their grief.

The related themes of information and decision-making are particularly pertinent to service provision in PPC and bereavement care. Our review of PPC needs found that parents need some say in treatment decisions, and that they require adequate information for making these decisions. In the second article, we found that decision-making continues after the child's death, when parents are faced with making decisions relating to viewing the body, organ donation, and burial / cremation. In the empirical study, we found that, during bereavement, parents sometimes seek information to help them make sense of their child's death; our findings also suggest, however, that in the acute phase of grief parents may not feel capable of taking in a lot of information at once.

The first and third articles both explored service delivery and accessibility. In the review of PPC needs, HCPs reported that families needed support from services outside the hospital (i.e., in the wider community). This contrasts somewhat with our finding from the empirical study that many parents did not use community services or feel a need for support from external services during the first-year of their bereavement (the reason being that these parents already felt sufficiently well-supported). This leads to speculation as to whether or not parents' needs for community-based support services are greater when their child is sick. On the other hand, the findings in the PPC needs article that community-based hospice programs are often not prepared to take on paediatric patients somewhat parallels a finding in the empirical study that community clinics and services were criticized for lacking expertise on supporting bereaved parents. Taking these concerns at face value highlights the importance of ensuring that community-based palliative care and bereavement care offerings meet the needs of paediatric patients and their families.

Implications for theory

One of the critiques from the general bereavement literature is that authors rarely link their findings to pre-existing theories and models, which is crucial for translating research findings to clinical settings. Whereas several different conceptualizations of coping with grief have proliferated in recent years (as we reported in our review of bereavement literature), there has been little comparison and integration between these theories and little development of existing models that describe the psychological phenomenon of bereavement. With this in mind, we undertook a thorough and critical examination of extant theories and models. We first identified those theories and models that have recently been researched with bereaved parents specifically, then chose those that seemed most promising for (a) connecting the findings of our empirical investigation to wider discourses in the field, and (b) maximizing the clinical relevance of the analysis.

In the second article, we reported that the Dual Process Model (DPM) may be useful for describing the coping experiences of bereaved parents. Several themes that emerged in our empirical study of parents' early bereavement experiences were in agreement with the DPM, most notably with respect to the oscillation between loss-oriented and restoration-oriented coping. That being said, we note certain important issues with the DPM that, in the opinion of the thesis' author, hinder both its explanatory power and its clinical applicability. Chief among these is the DPM's overall neglect of situational factors that seem to impact how parents cope with the death of their child, particularly factors related to the social and institutional contexts within which they grieve (Carr, 2010; Hooghe, Neimeyer, & Rober, 2012). Our analysis in the empirical study, conversely, presented a more integrated and systemic description of coping in parental bereavement, including the place of bereavement follow-up services in the coping process. Presented graphically in Figure 1 is the primary author’s proposed expansion of the DPM, which incorporates our findings in this regard. Herein the parents' individual loss and restoration-oriented coping processes originally proposed by Stroebe and Schut (1999 and 2010) are conceptualized as occurring within wider spheres of influence: namely, social and institutional systems. Also, the author proposes a modification to how meaning-reconstruction is incorporated within the DPM. In a later version of the DPM (2010), Stroebe and Schut had posited that meaning-reconstruction was contained within both the loss-oriented and restoration-oriented coping. In our analysis, however, we conceptualize meaning reconstruction as distinct individual coping process in its own right, though one that may relate to aspects of both loss and restoration-oriented coping.

Clinical implications of the thesis

A central objective of this thesis was to produce clinically relevant findings. This prevailing objective drove the choice of methodologies for the three articles and motivated our collaborations with stakeholders and policy makers in paediatric palliative care and bereavement services. Where each individual article presented its own specific set of clinical implications, the following section will outline some general clinical implications that can be gleaned from this thesis as a whole. In doing so, I will draw on the systemic view of coping in bereavement mentioned above, where individual psychological processes of coping were situated within broader social and institutional contexts. I will use this framework to integrate pertinent findings on bereavement from all three articles.

Understanding bereavement as an individual experience. After the death of their child, parents' emotional reactions may come in waves of intensity, and, as described in the DPM, they may oscillate between actively processing the loss (loss-oriented coping) and focussing on getting back to everyday life (restoration-oriented coping). That is, both the intensity of their grief and the ways in which parents cope with the associated emotions and cognitions will most likely change over time. It therefore befits clinicians to be aware of, and accompany the parent through, these changes, ideally offering an "open-door" policy where parents can consult when they so need, and not necessarily at a specific time or within a fixed number of sessions. Clinicians should also seek to understand the antecedents and circumstances surrounding the death, as these may also have an impact on how the parent grieves. Moreover, some implications arise from ours and others' findings on differences in how mothers and fathers adapt to the loss and cope with their grief (Alam, Barrera, D'Agostino, Nicholas, & Schneiderman, 2012; Hooghe, Neimeyer, & Rober, 2011; Hooghe et al., 2012), and on how some bereavement services (such as support groups) seem to be more commonly used by mothers than fathers (Laakso & Paunonen-Ilmonen, 2002). Though clinicians working with couples should not assume that such differences will be gender-specific in all cases, they should nonetheless be aware that each parent may have markedly different experiences and support needs. Policy makers, for their part, should provide services that allow parents to cope in ways that are natural and adaptive for them. This could be through providing parents with information on various resources, including both group and individual modalities.

Recognizing the relational aspects of bereavement. Though deeply personal and idiosyncratic in nature, grieving does not take place in a vacuum. Rather, it is affected by the social context within which the parent grieves, and some important implications are associated with the impact of relationships on how parents cope with and adapt to the death of their child. For one, clinicians and service providers should keep in mind the family dynamics of parental bereavement, as parents are often faced with the unique challenges related to grieving both as individuals and as a parental dyad, while sometimes having to care for other children, who may themselves be grieving. Moreover, the findings from all three articles indicate that parents want and need social support before and after the death of their child, from friends, family, HCPs, and other parents of sick or deceased children. It is not, however, simply a question of a social network being present, but whether the parent perceives this network as meeting their needs (Haber, Cohen, Lucas, & Baltes, 2007; McDowell & Serovich, 2007). Clinicians, therefore, should try to assess not only the existence of social support networks, but also the degree to which this support is perceived as helpful by the parent in meeting their support needs.

Bereavement and service provision. The socially embedded nature of grief also relates to why certain bereavement services and follow-up practices offered by the hospitals or broader community were considered helpful by the parents. The results of the third article suggest that bereavement follow-up services can be useful in helping to continue relationships with HCPs and hospital staff after the death of the child. This research further indicates that maintaining these relationships for some time following the death of the child may also be important to the HCPs themselves. With this in mind, therefore, and allowing for the fact that paediatric hospitals must necessarily work within certain budgetary and time constraints, these hospitals should nonetheless endeavour to allow their staff and families the means for continued contact, especially in the first year after the death (Darbyshire et al., 2013; Wender, E., & Committee on Psychosocial Aspects of Child and Family Health, 2012).

The previous point relates to the implications of the temporal aspect of bereavement. Our findings indicate that although parents appreciate being offered bereavement services, they may for some time feel unable and “not ready” to make use of these services, especially in the first few weeks and months as they attempt to regain basic functioning after the initial trauma of the loss. Due to the dynamic and changing nature of bereavement needs over the course of the grieving process, it is important for clinicians to consider the timing of these services and to provide a certain flexibility to parents with regard to when and how they can access these services.

Limitations

The literature reviews presented in the first two articles were limited by certain characteristics of the studies reviewed. Firstly, the specific qualitative methodology or methods used in the included studies were often not articulated, making it difficult to fully understand how the data was interpreted or if the methods used best suited the research questions. This was addressed in the empirical study by using an established approach to qualitative investigation, i.e., interpretive description. Moreover, in all three articles efforts were made to find the most appropriate methodologies for the research questions (be it in the reviews or empirical study) and to be as transparent as possible as to the methods used in the text of the articles.

In the second literature review, the ability to glean pertinent clinical implications was limited by the homogeneity of the studies for factors such as gender and cultural background of the parent and by the heterogeneity of the studies for factors such as relationship to the deceased, and age and cause of death of the child. On the one hand, more homogeneous samples are less likely to introduce extraneous variables into the inquiry. On the other hand, they are problematic in terms of generalization or transferability of the findings to specific clinical settings where the person receiving the service is not adequately represented by the sample used in the research. With the goal of producing findings that would be clinically applicable to paediatric hospitals, we chose to focus the empirical study on bereaved parents whose minor-aged children died. In an effort to generate a description of coping across these minor-ages (i.e., from 0 to 18 years of age) and causes of death, efforts were made to recruit an internally diverse sample of parents in terms of the gender of the parent, the age of the child (within the 0 to 18 year range), and the cause of death. Despite these efforts, in the end our findings were limited by the lack of diversity in cause of death (most children died of illnesses), and cultural background (most parents were Caucasian) of the participants. Attempts were also made to recruit fathers, though we were only somewhat successful in that regard (we recruited 15 mothers and 6 fathers). That being said, we were able to recruit 5 couples, and interviewing these 10 participants jointly with their spousal partner allowed for interesting results on how parents grieve together.

Directions for future research and policy development

On the basis of the studies contained in this thesis, the following avenues for future research can be identified. Firstly, there is a need for more efficacy studies on existing bereavement follow-up and support services and programs for parents and families, as currently there is little research examining whether follow-up services being offered by paediatric hospitals are actually helpful to parents, or on how these programs can best target parents' needs. In terms of interventions, there has been much debate as to the efficacy of interventions for grief in general, and with parents in particular (Flenady & Wilson, 2008; Forte, Hill, Pazder, & Feudtner, 2004; Jordan & Neimeyer, 2003; Rowa-Dewar, 2002; Schut, Stroebe, Van den Bout, & Terheggen, 2001; Stroebe, Schut, & Stroebe, 2005; Wortman & Boerner, 2007). As new methods for supporting and helping bereaved parents are developed, such as meaning making and narrative approaches, these also must be subject to efficacy research.

That being said, in order to actually impact the services provided to bereaved parents, research in the field must be translated to the actual clinical settings for which the results are applicable (CIHR-Institute of Population and Public Health, 2014). Indeed, there is a general need for more knowledge translation in the areas of PPC and bereavement support research and practice, including the continued dissemination of results to clinical settings, and/or collaborations between researchers, practitioners, and policy makers. With this in mind, the results of the present thesis have been, and continue to be, communicated to service providers and policy makers at both participating paediatric hospitals through various knowledge translation activities. At one hospital, our results were used to further develop the commemorative service (for example, clearly communicating to the parents that they can choose if and when they attend these services), and inform guidelines on the timing of follow-up practices (e.g., allowing more flexibility as to when and for how long the parent is followed) and on how information on resources and other textual materials are given to parents. At the other hospital, a secondary needs assessment analysis on the data from this hospital was conducted. The recommendations from this analysis, which highlighted both parents and health care providers' needs, were presented to the central committee of palliative care services, and the primary author wrote a brief report that was included in a larger policy-development report on bereavement follow-up services. Upcoming knowledge translation activities include presentations at selected adult hospitals on how to communicate with bereaved parents, as well as presentation to clinicians and researchers in PPC on psychological aspects to keep in mind when working with bereaved parents.

Concluding reflections

As long as we have been human, we have mourned for those who have preceded us in death. Bereavement is a part of life and not a condition to be 'cured'. The death of a child, however, seems to be particularly difficult burden for those who must bear it. As deJong-Berg and Kane (2006) eloquently write, "Society abhors the loss of life within a population that is typically associated with hope, potential and the future" (p. 484). It is undoubtedly positive that, compared to earlier times or less advantaged areas of the world, relatively few children die in modern developed societies; an upshot of this, however, is that the now uncommon loss of a child has come to be seen as unnatural in our modern age, so much so that it can shatter a parent's assumptive world to its foundations and leave them feeling alone in their pain. There is, of course, much variation between individuals and across the cultures to which they belong, in the ways they cope with grief and adapt to loss. Some, perhaps most, parents may be able to adapt to the loss of their child on the strength of their own personal and relational resources; they may even traverse this period having experienced growth and gained a more positive, or at least meaningful, outlook on the world. Others, however, may be so affected by the loss as to develop complicated/prolonged/persistent grief, lasting trauma or PTSD, depression, or anxiety (Appendix A). If clinicians and service providers are to effectively help such parents, they need a firm evidentiary basis for their interventions and programs. In this thesis, we have responded to this need by synthesizing large bodies of related literature and undertaking an empirical investigation into parents' experiences in the first year after the death of their child. In doing so, we have endeavoured to bridge the gap between research and practice in PPC and bereavement care, bringing the power of empirical inquiry to bear on the deeply existential issues that surround parental bereavement.

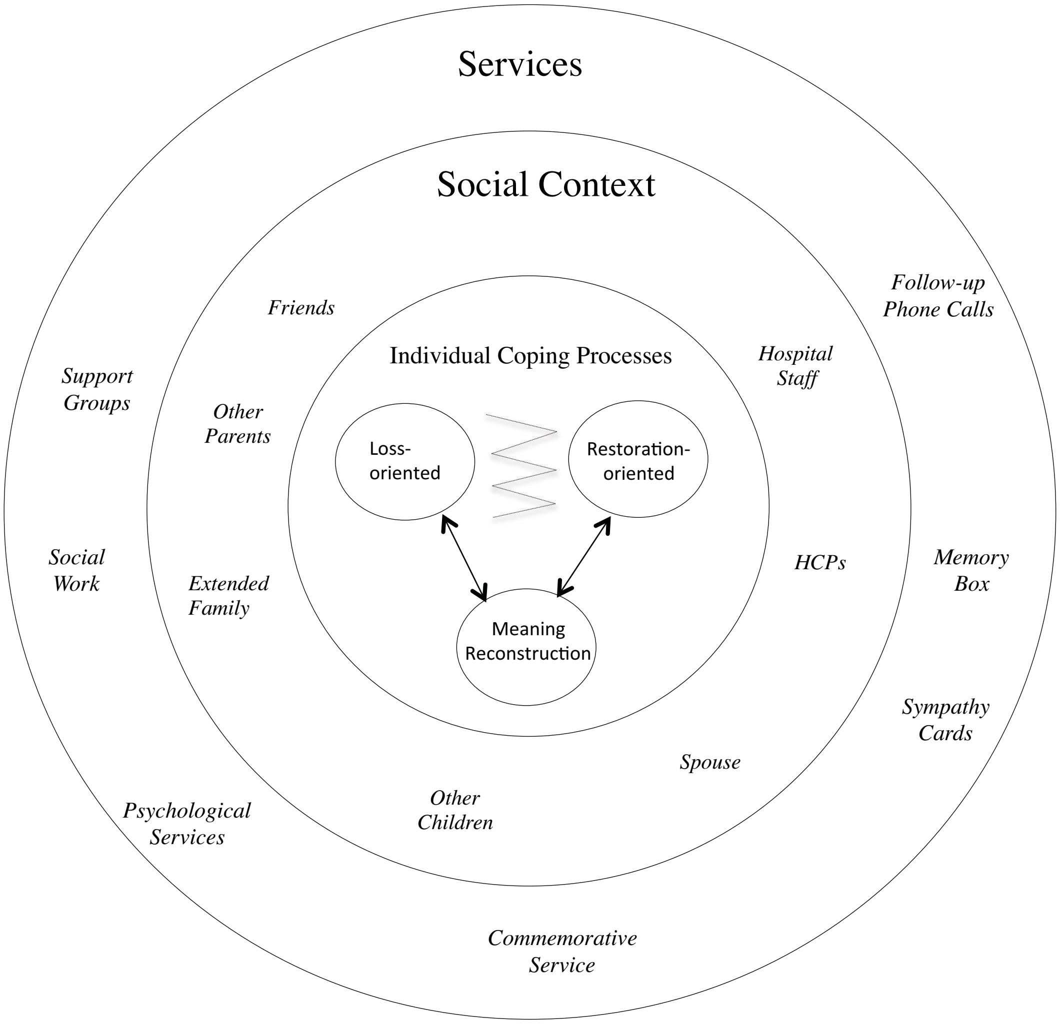

Figure 1. A systemic view of coping with grief

Note: Adapted from Stroebe & Schut 1999 and 2010.

Table 1. Global themes of thesis across time course of PPC and bereavement care

	Global Themes	Before the death occurs	Immediately surrounding death	During bereavement
Individual coping processes	*Meaning-making / reconstruction*	Meaning-making is described as a spiritual need in the PPC literature (1).		Parents attempt to reconstruct meaning in their lives after the death of their child (1, 2, 3). For parents, meaning reconstruction may involve benefit finding (1, 2, 3), attempts to make sense of the death and their grief (2, 3), and changes to their sense of self (3).
	Relationship with deceased child			Parents often report feeling a strong and lasting bond to their deceased child (1, 2, 3), and note the importance of maintaining these bonds and the memory of their child in their own minds and the minds of others (3).
Relationships / social context	*Social networks in general*	Parents report needing social support during their child's illness (1)		Supportive relationships provide a 'safe space' in which to process the loss (2, 3). Some relationships may be perceived by parents as non-supportive or problematic (2, 3).
	Family			Individuals in a spousal couple may have markedly different ways of coping with the loss (2, 3).
				Most spousal couples traverse the loss of their child with the relationship intact, perhaps even strengthened (2, 3). Some couples do experience disruption / discord (2, 3); this may be associated with pre-existing problems (3).
		Families report that the impact on siblings is often under-recognized, and they do not receive the care they need (1).	During the acute phase of grief, grieving for the deceased child may occupy a central role for the parent, at the expense of their relationship with their living children (2).	Surviving children can be a source of support for parents (2, 3). However, many parents want to ensure that these children are coping in a constructive manner, and may seek help in this regard (2, 3).
	Other parents	Parents of sick children may need access to other families in similar situations (1).		Relationships with other bereaved parents offer a 'safe space' to speak and to feel understood by someone who has been through similar experiences (3).

Health and psychosocial service provision	*Service delivery and accessibility*	HCPs report that families need support outside the hospital (1).	Community-based hospice programs may be poorly prepared to serve paediatric patients (1).	Parents express varying degrees of need for support services during bereavement (3).
		Continuity, consistency, and coordination of care important in PPC (1).		Some community services were critiqued for not offering a long enough follow-up, and for lacking expertise on supporting bereaved parents.
				Choice of when to access services is important to parents; they may not feel "ready" during the first-year. (3).
	Information and decision-making	Families require adequate information when making decisions (1).	In the acute phase of grief, parents may not feel capable of taking in a lot of information at once (3).	Parents sometimes seek information to help them make sense of their child's death (3).
		Parents need some say in treatment decisions (1).	Shortly after the death, parents are faced with making decisions relating to viewing the body, organ donation, and burial / cremation (2).	
	Relationships with HCPs	Parents need sensitive and caring delivery of difficult news (1).	Problematic interactions with staff are sometimes reported (1, 2) and can make parents' grieving process more difficult (2).	
		Continual and ongoing relationships between staff and families important to parents, patients, and staff (1).		Continued contact with HCPs important for parents (1, 2, 3). Continued contact with parents important for HCPs (3).

The numbers in the parentheses indicate which article from the thesis the finding is reported in.

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Appendix A

Proposed DSM-5 Criteria for Persistent Complex Bereavement Disorder

Diagnostic Features

Persistent complex bereavement disorder is diagnosed only if at least 12 months (6 months in children) have elapsed since the death of someone with whom the bereaved had a close relationship (Criterion A). This time frame discriminates normal grief from persistent grief. The condition typically involves a persistent yearning/longing for the deceased (Criterion B1), which may be associated with intense sorrow and frequent crying (Criterion B2) or preoccupation with the deceased (Criterion B3)

A. The individual experienced the death of someone with whom he or she had a close relationship.

B. Since the death, at least one of the following symptoms is experienced on more days than not and to a clinically significant degree and has persisted for at least 12 months after the death in the case of bereaved adults and 6 months for bereaved children:

1. Persistent yearning/longing for the deceased. In young children, yearning may be expressed in play and behavior, including behaviors that reflect being separated from, and also reuniting with, a caregiver or other attachment figure.
2. Intense sorrow and emotional pain in response to the death.
3. Preoccupation with the deceased.
4. Preoccupation with the circumstances of the death. In children, this preoccupation with the deceased may be expressed through the themes of play and behavior and may extend to preoccupation with possible death of others close to them.

C. Since the death, at least six of the following symptoms are experienced on more days than not and to a clinically significant degree, and have persisted for at least 12 months after the death in the case of bereaved adults and 6 months for bereaved children:

- **Reactive distress to the death**
  1. Marked difficulty accepting the death. In children, this is dependent on the child's capacity to comprehend the meaning and permanence of death.
  2. Experiencing disbelief or emotional numbness over the loss.
  3. Difficulty with positive reminiscing about the deceased.
  4. Bitterness or anger related to the loss.
  5. Maladaptive appraisals about oneself in relation to the deceased or the death (e.g., self-blame).
  6. Excessive avoidance of reminders of the loss (e.g., avoidance of individuals, places, or situations associated with the deceased; in children, this may include avoidance of thoughts and feelings regarding the deceased).
- **Social/identity disruption**
  7. A desire to die in order to be with the deceased.
  8. Difficulty trusting other individuals since the death.
  9. Feeling alone or detached from other individuals since the death.
  10. Feeling that life is meaningless or empty without the deceased, or the belief that one cannot function without the deceased.
  11. Confusion about one's role in life, or a diminished sense of one's identity (e.g., feeling that a part of oneself died with the deceased).
  12. Difficulty or reluctance to pursue interests since the loss or to plan for the future (e.g., friendships, activities).

D. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.

E. The bereavement reaction is out of proportion to or inconsistent with cultural, religious, or age-appropriate norms.

Specify if: **With traumatic bereavement:** Bereavement due to homicide or suicide with persistent distressing preoccupations regarding the traumatic nature of the death (often in response to loss reminders), including the deceased's last moments, degree of suffering and mutilating injury, or the malicious or intentional nature of the death.

Source: American Psychological Association. (2013). Conditions for future study. In *The diagnostic and statistical manual of mental disorders (5th ed).* Arlington VA: American Psychiatric Publishing.

Appendix B

Ethics approvals from McGill University Health Centre Research Ethics Board for recruitment at the Montreal Children's Hospital

L'Institut de recherche
du Centre universitaire de santé McGill
The Research Institute
of the McGill University Health Centre

May 5, 2011

Dr. Stephen Liben
MUHC - MCH
Room F-122

Re: MUHC Authorization to Conduct Human Subjects Research 10-222-PSY

Dear Dr. Liben,

We are writing to confirm that the study titled *"Parental Bereavement: Recent Bereavement Experiences and an Exploration of Current Bereavement Services and Practices"* was submitted for all institutional reviews required by McGill University Health Centre policy.

The Psychiatry/Psychology (PSY) Research Ethics Board (REB) has notified us that ethical approval to conduct your study has been provided.

Please refer to the MUHC Study Code **10-222-PSY** in all future correspondence relating to this study.

Important Note: You are required to advise the MUHC once the study has been initiated. Please complete the Study Status Report through the *eReviews* system to indicate the date the study became active. Instructions for accessing and using the *eReviews* system are available on the RI MUHC website.

On behalf of the MUHC, we wish you every success with the conduct of the research.

Sincerely,

[redacted]

Miguel Burnier, MD, PhD
Associate Director for Clinical Research
The Research Institute of the McGill University Health Centre

cc: REB Study File
RI MUHC Study File

December 22, 2011

Dr. Stephen Liben
MUHC – MCH
Room F-122

Re: “Parental Bereavement: Recent Bereavement Experiences and an Exploration of Current Bereavement Services and Practices”

Dear Dr. Liben:

We are writing in response to your correspondence of December 6, 2011 requesting Research Ethics Board review of a proposed revision to the research study referenced above. The amendment was presented for Full Board review of the PSY Research Ethics Board at its meeting of December 21, 2011.

The Committee had the following concerns in regards to the proposed revisions;

1) The Committee understood that the letter to potential participants was created to address the need for additional information about the person conducting the study interview. What specific information did parents request in regards to the interviewer? The Committee thought that the inclusion of personal information about the interviewer, although well intended, was not appropriate. The Committee was also concerned that such a personal detail might affect the discussion. Please delete the following sentence. “I was motivated to go into this type of work by the experiences of my own family after the loss of my older brother”.

2) In regards to bereavement follow-up: If you are going to conduct additional interviews with health care professionals acting as contact people, you will need to provide the Committee with an additional consent document for this population. How will you identify and recruit these health care professionals?

3) The Committee felt that the proposal for the researchers to observe the memorial service and take notes may be perceived by family members as too intrusive. The Committee was also uncertain of the value of this data. The Committee recommends that you propose an alternative method of collecting inofmration for this aspect of the bereavement process.

4) The Committee approved the inclusion of participants whose child died at home.

We look forward to receiving your comments and revisions prior to providing a final decision. The Committee agreed that the Chair will review your response and revisions. Any revisions should be highlighted and the documents provided with new version dates.

Sincerely,

Lawrence Annable, BSc, Dip. Stat.
Chair,
PSY Committee

Cc: 10-222-PSY

Appendix C

Consent forms for the participants recruited from the Montreal Children’s Hospital

Centre universitaire de santé McGill
McGill University Health Centre

Participant Information and Consent Form
Parents

Study: Parental bereavement: recent bereavement experiences and an exploration of current services and practices.
Principal Investigator: Stephen Liben, MD, Palliative Care Program, Montreal Children's Hospital
Co-investigators:
Moire Stevenson, Ph.D. Student, Department of Psychology, Université de Montréal, ; [contact info deleted]________________________
Marie Achille, Ph.D., Associate professor, Department of Psychology, Université de Montréal
Robin Cohen, Ph.D., Associate Professor, Departments of Oncology and Medicine, McGill University
Mary-Claude Proulx, Clinical Nurse Specialist, Palliative Care Program, Montreal Children's Hospital

Mary Ellen Macdonald, Ph.D, Program Head, Palliative Care Program, Montreal Children's Hospital and Assistant Professor, Oral Health and Society, Faculty of Dentistry

Introduction

You have been invited to participate in a research study that explores the experiences of parents whose child has recently died. It is important that you understand the risks and benefits of participation and what is expected of you before accepting to participate in this research study. This document provides this information and we suggest you read it carefully before deciding to participate. If you agree to participate in this study, please sign this form and a copy will be given to you for you to keep.

Purpose of the Study

The purpose of the research project is to better understand how recently bereaved parents address their grief. In order to explore how parents address their grief we will be speaking with bereaved parents about their experiences during the first year after their child's death and what they found helpful or unhelpful during this time. We plan to speak with parents that have recently lost a child and parents that have lost a child up to five years before the time of their participation. The findings may be used to guide the services and practices that are provided to bereaved parents.

What Participation Involves

If you agree to participate, you will be asked to participate in a face-to-face interview with the study co-investigator, Moire Stevenson, who is doing this study as part of her doctoral thesis.

We expect that the interviews will last between 30 minutes and two hours. The length depends on how long you want to talk. During this interview, you will be invited to discuss your life during the first year after the death of your child and any other experiences during this time. We will also inquire as to your perspective on various services and practices provided by the hospital or that you have discovered elsewhere. Lastly, you will be asked some to provide some basic information such as your age, education, and work experience.

If you agree, the interview will be audio-recorded to help the research team understand and explore all the details of the interview. A research assistant who has signed a confidentiality agreement will type these recordings. Only the research team will have access to the information collected. You will be able to obtain a copy of the typed interview, if desired.
You may also be invited to participate in a second interview at a later date. It will be up to you whether or not you want to do so.

Risks and Benefits

We understand that speaking about your child's death may be difficult and upsetting, however, some parents appreciate the opportunity to talk about their experiences. This project may help other parents in the future. Throughout the study, you will be free to not answer a question, to move on to the next one, to take a break, or to withdraw from the study entirely. If at any time you feel you want or need psychological support, we can provide you with a list of local services and/or put you into contact with a local grief counselling service.

Cost and reimbursement

We do not offer any compensation for participation in this project. We also do not expect that you will have any costs related to your participation in this project.

Participants' Rights

Participation in this study is voluntary. You have the right to ask questions at any time, to refuse to answer questions, or to stop participating in the study by simply saying so. There are neither penalties nor loss of benefits for refusal to participate. If you choose to end your participation in the study, you will have the choice as to whether the information collected up to that point be kept as part of the study or destroyed.

Confidentiality and Data Security

All your responses will be kept strictly confidential and will only be available to the research team. You will not be identified by name in any notes or recordings, rather an identification number will be assigned to you for the study. All paper data will be kept in a locked cabinet in a locked office at Université de Montréal and all computerized data will be password protected.
The results from this study will be published and presented in various research meetings, however study participants will not be identified. When direct quotations are used in

publications or presentations personal details and identifiers will be modified to protect the identity of the participant.

All data/information (including transcripts and audio-recordings) from this study will be retained for 7 years after publication; after which they will then be destroyed.

It is possible that the Research Ethics Board of the MUHC may access the study records, however, this would only be done for quality assurance reasons and to ensure the proper management of study records.

Contact Information

If you have any questions regarding your rights as a research participant please contact the Montreal Children's Hospital Ombudsman at [contact info deleted]. If you have questions concerning other matters related to this study, please contact Moire Stevenson [contact info deleted].

Declaration of Consent

Your signature on this form indicates that you have understood the information regarding your participation in the research study and agree to participate. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. You are free to withdraw from this study at any time. In addition, a copy of this form will be given to you for you to keep.

The study has been explained to me and my questions have been answered to my satisfaction. I freely agree to participate in this study.

Signature of participant: ___________________________ Date: ______________________

Signature of investigator:___________________________ Date: ______________________

Centre universitaire de santé McGill
McGill University Health Centre

Renseignements pour les participants et formulaire de consentement
version pour parents

Titre de l'étude : Ce qui aide les parents endeuillés? Expériences de deuil récent et exploration des services et des pratiques actuelles.

Chercheur principal :
Stephen Liben, M.D., Département des soins palliatifs, Hôpital de Montréal pour enfants

Co-chercheurs :
Moire Stevenson, Étudiante au Ph.D., Département de Psychologie, Université de Montréal, [contact info deleted] ____________________________

Marie Achille, Ph.D., Professeure agrégée, Département de psychologie, Université de Montréal

Robin Cohen, Ph.D., Professeure agrégée, Département d'oncologie et de médecine, Université McGill.

Marie-Claude Proulx, RN, Conseillère cadre en soins infirmiers spécialisés, Département des soins palliatifs, Hôpital de Montréal pour enfants

Mary-Ellen Macdonald, Ph.D., Directrice des programmes, Département des soins palliatifs, Hôpital de Montréal pour enfants

Introduction

Nous vous invitons à participer à une étude qui s'intéresse à l'expérience des parents qui ont récemment vécu la mort d'un enfant. Il est important que vous compreniez les risques ainsi que les bénéfices liés à votre participation avant d'accepter d'y participer. Ce formulaire de consentement renferme les informations sur la recherche susmentionnée et nous vous invitons à le lire attentivement. Si vous souhaitez participer à la présente étude, vous devrez d'abord signer ce formulaire et nous vous en remettrons une copie.

Nature de l'étude

La recherche a pour but de mieux comprendre comment les parents récemment endeuillés composent avec leur deuil. Afin d'explorer cette question, nous mènerons des entretiens auprès de parents endeuillés pour savoir comment ils ont vécu cette expérience pendant de la première année qui a suivi la mort de leur enfant et sur ce qui les a aidé à passer à travers de cette période éprouvante. Nous planifions nous entretenir avec des parents qui viennent de perdre un enfant ainsi qu'avec d'autres parents qui ont perdu un enfant dans les cinq ans précédant cette entrevue. Les résultats pourront être utilisés pour guider le développement ou la modification des services et pratiques offerts aux parents endeuillés.

Participation à la recherche
Si vous acceptez de participer, nous vous demanderons de rencontrer Moire Stevenson, co-chercheur et étudiante à l'Université de Montréal, qui réalise cette étude dans le cadre de son doctorat.

Nous nous attendons à ce que l'entrevue dure de 30 minutes à deux heures. La longueur de l'entrevue dépendra de vous. Elle abordera votre vie durant la première année suivant la mort de votre enfant, ainsi que votre perspective sur les services et pratiques offerts à l'hôpital ou ailleurs. Des questions d'ordre générale telles que des informations au sujet de votre âge, votre niveau de scolarité et votre emploi vous seront également posées.

Si vous êtes d'accord, l'entrevue sera enregistrée pour aider la chercheuse à comprendre et explorer tous les détails de l'entrevue. Les enregistrements des entrevues seront transcrits par une assistante de recherche qui aura signé au préalable un accord de confidentialité. Seule l'équipe de recherche aura accès de l'information enregistrée et transcrite. Vous pourrez obtenir une copie de la transcription si vous souhaitez.

Suite à votre participation à une première entrevue, il est possible que vous soyez invité(e) à participer à une deuxième entrevue dans le futur; vous serez libre de choisir de participer ou non à cette deuxième entrevue.

Avantages et inconvénients
Le fait de participer à cette recherche vous offre une occasion de réfléchir et de discuter en toute confidentialité de votre expérience personnelle face au deuil. Nous comprenons que de raconter votre expérience puisse être difficile; il se peut aussi que d'avoir l'occasion d'en parler soit réconfortant. Ce projet pourra aider d'autres parents dans l'avenir. À n'importe quel moment durant l'entrevue, vous pouvez faire une pause, mettre fin à l'entrevue ou à votre participation au projet. Si la discussion suscite des réflexions ou des souvenirs émouvants ou désagréables, n'hésitez pas à en parler avec la chercheuse qui mène l'entrevue. Celle-ci pourra vous donner le nom d'une personne-ressource en mesure de vous aidé.

Indemnité
Nous n'offrons pas d'indemnité pour participer à ce projet. Aucun coût ne sera lié à votre participation.

Participation volontaire et droit de retrait
Vous êtes libre de participer à ce projet de recherche. Vous pouvez poser des questions quand vous le voulez, refuser de répondre à une question ou mettre fin à votre participation à n'importe quel moment sans qu'il y ait de conséquences négatives ou préjudices à votre endroit et sans avoir à justifier votre décision. Si vous décidez de mettre fin à votre participation, vous pourrez choisir que vos données soient conservées pour le projet ou qu'elles soient détruites.

Confidentialité et gestion des données

Toutes vos réponses seront conservées dans la confidentialité absolue. Les noms des participants n'apparaîtront dans aucun rapport et les divers documents de recherche seront codifiés. Seule l'équipe de recherche aura accès à la liste des noms et des codes. Le matériel de recherche, incluant les données, les enregistrements, et les transcriptions seront conservés dans un classeur verrouillé dans un bureau fermé à clé à l'Université de Montréal. Toutes les données en format électronique seront protégées par un mot de passe.

La recherche fera l'objet de publications dans des revues scientifiques et de présentations à des congrès scientifiques. Aucun participant ne pourra y être identifié ou reconnu. Lorsque les publications ou présentations contiendront des citations exactes, toute information personnelle sera modifiée pour protéger l'identité du participant.

Les donnés (enregistrements, transcriptions) seront conservées pendant une période minimum de sept ans après la publication de l'étude. Elles seront ensuite détruites de façon confidentielle par le déchiquetage du matériel papier ou la suppression des dossiers informatisés.

Il est possible que le Bureau d'éthique de la recherche du Centre universitaire de santé McGill accède aux archives de l'étude dans le but d'assurer la qualité et la bonne gestion des archives.

Renseignements supplémentaires

Si vous avez des questions sur vos droits comme participant vous pouvez communiquer avec le médiateur de l'Hôpital de Montréal pour enfants au [contact info deleted]. Si vous avez des questions sur la recherche, vous pouvez communiquer avec Moire Stevenson au [contact info deleted]

Déclaration de consentement

Votre signature sur ce formulaire indique que vous avez bien compris l'information concernant votre participation à cette étude et que vous souhaitez y participer. Ce faisant, vous ne renoncez à aucun de vos droits et ne libérez les chercheurs et les institutions impliquées de leurs responsabilités professionnelles et légales. Vous recevrez une copie de ce formulaire à conserver.

Je suis satisfait(e) des explications, précisions et réponses que le chercheur m'a fournies, le cas échéant, quant à ma participation à ce projet. Je consens librement à participer à cette étude

Signature du participant:___________________________________Date:

Signature de chercheuse:___________________________________Date:

Centre universitaire de santé McGill
McGill University Health Centre

Participant Information and Consent Form
Health Care Providers

Study: Parental bereavement: recent bereavement experiences and an exploration of current services and practices.
Principal Investigator: Stephen Liben, MD, Palliative Care Program, Montreal Children's Hospital
Co-investigators:
Moire Stevenson, Ph.D. Student, Department of Psychology, Université de Montréal,
[contact info deleted]
Marie Achille, Ph.D., Associate professor, Department of Psychology, Université de Montréal
Robin Cohen, Ph.D., Associate Professor, Departments of Oncology and Medicine, McGill University
Marie-Claude Proulx, Clinical Nurse Specialist, Palliative Care Program, Montreal Children's Hospital

Mary Ellen Macdonald, Ph.D, Program Head, Palliative Care Program, Montreal Children's Hospital and Assistant Professor, Oral Health and Society, Faculty of Dentistry

Introduction

You have been invited to participate in a research study that explores the experiences of parents whose child has recently died and the services provided to them. As you are a health care professional assisting in the recruitment for the project and providing bereavement follow-up support to families, I would like to learn more on how you go about conducting the bereavement follow-up. It is important that you understand the risks and benefits of participation and what is expected of you before accepting to participate in this research study. This document provides this information and we suggest you read it carefully before deciding to participate. If you agree to participate in this study, please sign this form and a copy will be given to you for you to keep.

Purpose of the Study

The purpose of the research project is to better understand how recently bereaved parents address their grief. In order to explore how parents address their grief we will be speaking with bereaved parents about their experiences during the first year after their child's death and what they found helpful or unhelpful during this time. We plan to speak with parents that have recently lost a child and parents that have lost a child up to five years before the time of their participation. In addition, we are speaking with health care providers conducting bereavement follow-ups with parents in order to have more information on what was actually done during the follow-up and to further elaborate on what the parents found helpful. The findings may be used to guide the services and practices that are provided to bereaved parents.

What Participation Involves

If you agree to participate, you will be asked to participate in a face-to-face interview with the study co-investigator, Moire Stevenson, who is doing this study as part of her doctoral thesis. We expect that the interviews will last between 30-60 minutes. The length depends on how long you want to talk. During this interview, you will be invited to discuss how you conduct parental bereavement follow-ups with the parents of patients whose care you were involved with.

With your consent, the interview will be audio-recorded to help the research team understand and explore all the details of the interview. A research assistant who has signed a confidentiality agreement will type these recordings. Only the research team will have access to the information collected. You will be able to obtain a copy of the typed interview, if desired.

Risks and Benefits

Throughout the study, you will be free to not answer a question, to move on to the next one, to take a break, or to withdraw from the study entirely.

Cost and reimbursement

We do not offer any compensation for participation in this project. We also do not expect that you will have any costs related to your participation in this project.

Participants' Rights

Participation in this study is voluntary. You have the right to ask questions at any time, to refuse to answer questions, or to stop participating in the study by simply saying so. There are neither penalties nor loss of benefits for refusal to participate. If you choose to end your participation in the study, you will have the choice as to whether the information collected up to that point be kept as part of the study or destroyed.

Confidentiality and Data Security

All your responses will be kept strictly confidential and will only be available to the research team. You will not be identified by name in any notes or recordings; rather an identification number will be assigned to you for the study. All paper data will be kept in a locked cabinet in a locked office at Université de Montréal and all computerized data will be password protected.

The results from this study will be published and presented in various research meetings, however study participants will not be identified. When direct quotations are used in publications or presentations personal details and identifiers will be modified to protect the identity of the participant.

All data/information (including transcripts and audio-recordings) from this study will be retained for 7 years after publication; after which they will then be destroyed.

It is possible that the Research Ethics Board of the MUHC may access the study records, however, this would only be done for quality assurance reasons and to ensure the proper management of study records.

Contact Information

If you have any questions regarding your rights as a research participant please contact the Montreal Children's Hospital Ombudsman at [contact info deleted]. If you have questions concerning other matters related to this study, please contact Moire Stevenson - [contact info deleted].

Declaration of Consent

Your signature on this form indicates that you have understood the information regarding your participation in the research study and agree to participate. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. You are free to withdraw from this study at any time. In addition, a copy of this form will be given to you for you to keep.

The study has been explained to me and my questions have been answered to my satisfaction. I freely agree to participate in this study.

Signature of participant: ____________________________ Date:

Signature of investigator:____________________________ Date:

Centre universitaire de santé McGill
McGill University Health Centre

Renseignements pour les participants et formulaire de consentement
version pour le personnel

Titre de l'étude : Ce qui aide les parents endeuillés. Expériences d'un deuil récent et examen des services et des pratiques actuelles.
Chercheur principal :
Stephen Liben, M.D., Département des soins palliatifs, Hôpital de Montréal pour enfants
Co-chercheurs :
Moire Stevenson, Étudiante au Ph.D., Département de Psychologie, Université de Montréal, [contact info deleted]
Marie Achille, Ph.D., Professeure agrégée, Département de psychologie, Université de Montréal
Robin Cohen, Ph.D., Professeure agrégée, Département d'oncologie et de médecine, Université McGill.
Marie-Claude Proulx, RN, Conseillère cadre en soins infirmiers spécialisés, Département des soins palliatifs, Hôpital de Montréal pour enfants
Mary-Ellen Macdonald, Ph.D., Directrice des programmes, Département des soins palliatifs, Hôpital de Montréal pour enfants

Introduction

Nous vous invitons à participer à une étude qui s'intéresse à l'expérience des parents ayant récemment vécu le décès d'un enfant. Comme vous êtes un professionnel de la santé qui aidez à inscrire des participants dans le projet et qui offrez un suivi aux familles endeuillées, j'aimerais en savoir davantage sur la façon dont vous menez le suivi auprès de ces familles. Il est important que vous compreniez les risques ainsi que les avantages liés à votre participation avant d'accepter d'y participer. Ce formulaire de consentement renferme les informations sur la recherche susmentionnée et nous vous invitons à le lire attentivement. Si vous souhaitez participer à la présente étude, vous devrez d'abord signer ce formulaire et nous vous en remettrons une copie.

Nature de l'étude

L'étude a pour but de mieux comprendre comment les parents récemment endeuillés vivent cette période difficile. Afin d'étudier cette question, nous mènerons des entretiens auprès de parents endeuillés pour savoir comment ils ont vécu cette expérience pendant l'année qui a suivi la mort de leur enfant. Nous leur demanderons également ce qui les a aidés à surmonter cette période éprouvante. Nous prévoyons nous entretenir avec des parents qui viennent de perdre un enfant de même qu'avec d'autres parents qui ont perdu un enfant au cours des cinq dernières années précédant leur participation à cette étude. En outre, nous parlerons avec les fournisseurs de soins de santé qui exercent des suivis auprès de parents endeuillés, afin de recueillir plus de renseignements sur les démarches qui ont été réalisées au cours du suivi, et pour apporter des précisions sur les ressources que les parents auront trouvé utiles pour les aider à surmonter cette épreuve. Les résultats de cette étude peuvent être utilisés pour améliorer les services et les pratiques présentement offerts aux parents endeuillés.

Participation à la recherche

Si vous acceptez de participer à cette étude, nous vous demanderons de rencontrer Moire Stevenson, co-chercheure et étudiante à l'Université de Montréal, qui mène cette étude dans le cadre de son doctorat. Les entrevues dureront entre 30 et 60 minutes. La longueur de l'entrevue dépendra de vous. Au cours de cette entrevue, vous serez invité à nous décrire comment vous exercez le suivi des parents endeuillés, avec ces parents auprès de qui vous avez travaillé. Avec votre consentement, l'entrevue sera enregistrée pour aider la chercheure à comprendre et examiner tous les détails de l'entrevue. Les enregistrements des entrevues seront transcrits par une assistante de recherche qui aura signé un accord de confidentialité au préalable. Seule l'équipe de recherche aura accès de l'information enregistrée et transcrite. Vous pourrez obtenir une copie de la transcription si vous souhaitez.

Avantages et inconvénients

Pendant toute la durée de l'étude, vous serez libre de ne pas répondre à certaines questions, de passer à la suivante, de faire une pause ou de vous retirer complètement de l'étude.

Indemnité

Nous n'offrons pas d'indemnité pour participer à ce projet. Nous ne prévoyons aucun coût lié à votre participation.

Participation volontaire et droit de retrait

Vous êtes libre de participer à ce projet de recherche. Vous avez le droit de poser des questions à en tout temps, de refuser de répondre aux questions ou de mettre fin à votre participation en nous disant simplement non. Vous ne subirez aucune pénalité ou préjudice si vous refusez de participer. Si vous décidez de mettre fin à votre participation, vous pourrez choisir que vos données soient conservées pour le projet ou qu'elles soient détruites.

Confidentialité et gestion des données

Toutes vos réponses seront conservées dans la confidentialité absolue et ne seront consultées que par l'équipe de recherche. Les noms des participants n'apparaîtront dans aucun rapport et les divers documents de recherche seront codifiés. Seule l'équipe de recherche aura accès à la liste des noms et des codes. Le matériel de recherche, incluant les données, les enregistrements, et les transcriptions seront conservés dans un classeur verrouillé dans un

bureau fermé à clé à l'Université de Montréal. Toutes les données en format électronique seront protégées par un mot de passe.
La recherche fera l'objet de publications dans des revues scientifiques et de présentations à des congrès scientifiques. Aucun participant ne pourra y être identifié ou reconnu. Lorsque les publications ou présentations renfermeront des citations exactes, toute information personnelle sera modifiée pour protéger l'identité du participant.
Les donnés (enregistrements, transcriptions) seront conservées pendant une période minimum de sept ans après la publication de l'étude. Elles seront ensuite détruites de façon confidentielle par le déchiquetage du matériel papier ou la suppression des dossiers informatisés.
Il est possible que le Bureau d'éthique de la recherche du Centre universitaire de santé McGill accède aux archives de l'étude dans le but d'assurer la qualité et la bonne des données de recherche.

Renseignements supplémentaires

Si vous avez des questions sur vos droits en tant que participant vous pouvez communiquer avec le médiateur de l'Hôpital de Montréal pour enfants au [contact info deleted]. Si vous avez des questions sur la recherche, vous pouvez communiquer avec Moire Stevenson au [contact info deleted].

Déclaration de consentement

Votre signature sur ce formulaire indique que vous avez bien compris l'information concernant votre participation à cette étude et que vous souhaitez y participer. Ce faisant, vous ne renoncez à aucun de vos droits légaux et ne libérez les chercheurs et les institutions qui participantes de leurs responsabilités professionnelles et légales. Vous recevrez une copie de ce formulaire à conserver.

Je suis satisfait(e) des explications, précisions et réponses que le chercheur m'a fournies, le cas échéant, quant à ma participation à ce projet. Je consens librement à participer à cette étude

Signature du participant:___________________________________Date: ___________________

Signature de chercheure:____________________________________Date: __________________

Appendix D

Ethics approvals from the Research Ethics Committee of CHU Sainte-Justine

CHU Sainte-Justine
Le centre hospitalier universitaire mère-enfant

Pour l'amour des enfants

Université de Montréal

Le 12 novembre 2012

Docteur Nago Fred-Alain Humbert
Anesthésie
Étage 3 Bloc 9

OBJET: Titre du projet: Ce qui aide les parents endeuillés? Expériences du deuil et exploration des services et des pratiques actuelles

No. de dossier: 3569

Responsables du projet: Nago Fred-Alain Humbert M.D., chercheur responsable au CHU Sainte-Justine. Chercheur principal: Moire Stevenson, Université de Montréal. Collaborateurs: Antoinette Petti, Lysanne Daoust, Marie Achille et S. Robin Cohen, Université McGill

Cher Docteur,

Votre projet cité en rubrique a été approuvé par le comité d'éthique de la recherche en date du 7 novembre 2012. Vous trouverez ci-joint la liste des documents approuvés ainsi que vos formulaires d'information et de consentement estampillés dont nous vous prions de vous servir d'une copie pour distribution. Notez que pour une collaboration avec un (ou plusieurs) tiers (institutions ou entreprises privées) impliquant des transferts de fonds et/ou données et/ou matériel biologique, une entente (contrat) doit être conclue avec le Bureau des ententes de recherche (BER).

Tous les projets de recherche impliquant des sujets humains doivent être réexaminés annuellement et la durée de l'approbation de votre projet sera effective jusqu'au **7 novembre 2013**. Notez qu'il est de votre responsabilité de soumettre une demande au comité pour que votre projet soit renouvelé avant la date d'expiration mentionnée. Il est également de votre responsabilité d'aviser le comité dans les plus brefs délais de toute modification au projet ainsi que de tout effet secondaire survenu dans le cadre de la présente étude.

Nous vous souhaitons bonne chance dans la réalisation de votre projet et vous prions de recevoir nos meilleures salutations.

[redacted]

Jean-Marie Therrien, Ph.D., éthicien
Président du Comité d'éthique de la recherche

JMT/mhl
c.c. : BER

3175, Côte-Sainte-Catherine
Montréal (Québec)
H3T 1C5

Le 12 novembre 2012

Docteur Nago Fred-Alain Humbert
Anesthésie
Étage 3 Bloc 9

OBJET: Titre du projet: Ce qui aide les parents endeuillés? Expériences du deuil et exploration des services et des pratiques actuelles

No. de dossier: 3569

Responsables du projet: Nago Fred-Alain Humbert M.D., chercheur responsable au CHU Sainte-Justine. Chercheur principal: Moire Stevenson, Université de Montréal. Collaborateurs: Antoinette Petti, Lysanne Daoust, Marie Achille et S. Robin Cohen, Université McGill

CHU Sainte-Justine
Le centre hospitalier universitaire mère-enfant

Pour l'amour des enfants

Université de Montréal

Cher Docteur,

Votre projet cité en rubrique a été approuvé par le comité d'éthique de la recherche en date du 7 novembre 2012. Vous trouverez ci-joint la liste des documents approuvés ainsi que vos formulaires d'information et de consentement estampillés dont nous vous prions de vous servir d'une copie pour distribution. Notez que pour une collaboration avec un (ou plusieurs) tiers (institutions ou entreprises privées) impliquant des transferts de fonds et/ou données et/ou matériel biologique, une entente (contrat) doit être conclue avec le Bureau des ententes de recherche (BER).

Tous les projets de recherche impliquant des sujets humains doivent être réexaminés annuellement et la durée de l'approbation de votre projet sera effective jusqu'au **7 novembre 2013**. Notez qu'il est de votre responsabilité de soumettre une demande au comité pour que votre projet soit renouvelé avant la date d'expiration mentionnée. Il est également de votre responsabilité d'aviser le comité dans les plus brefs délais de toute modification au projet ainsi que de tout effet secondaire survenu dans le cadre de la présente étude.

Nous vous souhaitons bonne chance dans la réalisation de votre projet et vous prions de recevoir nos meilleures salutations.

[redacted]

Jean-Marie Therrien, Ph.D., éthicien
Président du Comité d'éthique de la recherche

JMT/mhl
c.c. : BER

3175, Côte-Sainte-Catherine
Montréal (Québec)
H3T 1C5

CHU Sainte-Justine
Le centre hospitalier universitaire mère-enfant

Pour l'amour des enfants

Université de Montréal

Le 30 avril 2013

Docteur Nago Fred-Alain Humbert
Anesthésie
Étage 3 Bloc 9

OBJET: Titre du projet: Ce qui aide les parents endeuillés? Expériences du deuil et exploration des services et des pratiques actuelles

No. de dossier: 3569

Responsables du projet: Nago Fred-Alain Humbert M.D., chercheur responsable au CHU Sainte-Justine. Chercheur principal: Moire Stevenson, Université de Montréal. Collaborateurs: Antoinette Petti, Lysanne Daoust, Marie Achille et S. Robin Cohen, Université McGill

Cher Docteur,

Nous avons pris connaissance de votre formulaire pour une demande de modification à un projet daté du 25 mars 2013 dans lequel vous nous informez que vous désirez apporter un amendement au projet mentionné en rubrique.

L'amendement porte sur :
☐ Des modifications apportées au protocole (l'entretien se fait dorénavant avec le personnel qui fait le suivi avec les parents et pas uniquement avec celui qui se charge du recrutement).
☐ L'ajout de questions d'entrevue pour les entretiens avec le personnel.
☐ La modification du questionnaire sociodémographique pour les parents en y intégrant également deux questions dans le but d'avoir une meilleure description de leurs expériences..

Par la présente et en date du 24 avril 2013 nous acceptons votre demande d'amendement, cependant nous précisons que cette acceptation est effective à la condition que seuls les prénoms des enfants soient consignés aux questions 11 et 13 et non le nom complet (prénom et nom complet/questionnaire démographique). Et ce afin afin de protéger la confidentialité des réponses des parents participants). Vous trouverez ci-jointe la liste des documents

Nous vous souhaitons bonne chance dans la continuité de votre projet et vous prions de recevoir nos meilleures salutations.

[redacted]

Geneviève Cardinal, juriste
Vice-Présidente du Comité d'éthique de la recherche

GC/sa
c.c. : BER

3175, Côte-Sainte-Catherine
Montréal (Québec)
H3T 1C5

CHU Sainte-Justine
Le centre hospitalier universitaire mère-enfant

Pour l'amour des enfants

Université de Montréal

Le 15 mai 2013

Docteur Nago Fred-Alain Humbert
Anesthésie
Étage 3 Bloc 9

OBJET: Titre du projet: Ce qui aide les parents endeuillés? Expériences du deuil et exploration des services et des pratiques actuelles

No. de dossier: 3569

Responsables du projet: Nago Fred-Alain Humbert M.D., chercheur responsable au CHU Sainte-Justine. Chercheur principal: Moire Stevenson, Université de Montréal. Collaborateurs: Antoinette Petti, Lysanne Daoust, Marie Achille et S. Robin Cohen, Université McGill

Cher Docteur,

Votre demande d'amendement a été approuvée par notre comité en date d'aujourd'hui. L'amendement porte sur une modification au protocole : l'envoi d'une lettre détaillant l'étude à la famille par courrier dans les jours suivant l'appel téléphonique.

Veuillez trouver ci-joint la liste des documents approuvés.

Nous vous souhaitons bonne chance dans la continuité de votre projet et vous prions de recevoir nos meilleures salutations.

[redacted]

Jean-Marie Therrien, Ph.D., éthicien
Président du Comité d'éthique de la recherche

JMT/mhl

3175, Côte-Sainte-Catherine
Montréal (Québec)
H3T 1C5

CHU Sainte-Justine
Le centre hospitalier
universitaire mère-enfant

Pour l'amour des enfants

Université de Montréal

Le 18 décembre 2013

Docteur Nago Fred-Alain Humbert
Anesthésie
Étage 3 Bloc 9

OBJET: Titre du projet: Ce qui aide les parents endeuillés? Expériences du deuil et exploration des services et des pratiques actuelles

No. de dossier: 3569

Responsables du projet: Nago Fred-Alain Humbert M.D., chercheur responsable au CHU Sainte-Justine. Chercheur principal: Moire Stevenson, Université de Montréal. Collaborateurs: Antoinette Petti, Lysanne Daoust, Marie Achille et S. Robin Cohen, Université McGill

Cher Docteur,

Votre projet cité en rubrique a été renouvelé par le comité d'éthique de la recherche en date du 3 décembre 2013. Vous trouverez ci-joint la liste des documents approuvés. Étant donné qu'il était indiqué dans votre rapport annuel que le recrutement des participants était terminé, les membres du Comité n'ont pas réexaminé votre formulaire d'information et de consentement.

Tous les projets de recherche impliquant des sujets humains doivent être réexaminés annuellement et la durée de l'approbation de votre projet sera effective jusqu'au **3 décembre 2014**. Notez qu'il est de votre responsabilité de soumettre une demande au Comité pour le renouvellement de votre projet avant la date d'expiration mentionnée. Il est également de votre responsabilité d'aviser le Comité de toute modification à votre projet et/ou tout événement pouvant toucher à la sécurité des participants.

Nous vous souhaitons bonne chance dans la continuité de votre projet et vous prions de recevoir nos meilleures salutations.

[redacted]

Patrick A. Gogognon, éthicien
Responsable du suivi annuel du Comité d'éthique de la recherche

PG/mhl

3175, Côte-Sainte-Catherine
Montréal (Québec)
H3T 1C5

Appendix E

Consent forms for the participants recruited from the CHU Sainte-Justine

CHU Sainte-Justine
Le centre hospitalier universitaire mère-enfant
Université de Montréal

Renseignements pour les participants et formulaire de consentement
Version : parents

Titre de l'étude : Ce qui aide les parents endeuillés? Expériences de deuil récent et exploration des services et des pratiques actuelles.

Chercheur responsable au CHU Sainte-Justine :
Nago Humbert, Directeur, Unité de consultation en soins palliatifs pédiatriques, CHU Sainte-Justine.

Chercheur principal du projet :
Moire Stevenson, Étudiante au Ph.D., Département de psychologie, Université de Montréal, [contact info deleted] ____________________________

Collaborateurs :
Antoinette Petti, Infirmière clinicienne, Unité de consultation en soins palliatifs pédiatriques, CHU Sainte-Justine.

Lysanne Daoust, Infirmière clinicienne, Unité de consultation en soins palliatifs pédiatriques, CHU Sainte-Justine.

Marie Achille, Ph.D., Professeure agrégée, Département de psychologie, Université de Montréal

Robin Cohen, Ph.D., Professeure agrégée, Département d'oncologie et de médecine, Université McGill.

Source de financement :
Ce projet est financé par le Conseil de recherches en sciences humaines (CRSH).

Introduction
Nous vous invitons à participer à une étude qui s'intéresse à l'expérience des parents qui ont récemment vécu la mort d'un enfant. Il est important que vous compreniez les risques ainsi que les bénéfices liés à votre participation avant d'accepter d'y participer. Ce formulaire de consentement renferme les informations sur la recherche susmentionnée et nous vous invitons à le lire attentivement. Si vous souhaitez participer à la présente étude, vous devrez d'abord signer ce formulaire et nous vous en remettrons une copie.

Nature de l’étude
La recherche a pour but de mieux comprendre comment les parents récemment endeuillés composent avec leur deuil. Afin d’explorer cette question, nous mènerons des entretiens auprès de parents endeuillés pour savoir comment ils ont vécu cette expérience pendant de la première année qui a suivi la mort de leur enfant et sur ce qui les a aidé à passer à travers de cette période éprouvante. Nous planifions nous entretenir avec des parents qui viennent de perdre un enfant ainsi qu’avec d’autres parents qui ont perdu un enfant dans les cinq ans précédant cette entrevue. Les résultats pourront être utilisés pour guider le développement ou la modification des services et pratiques offerts aux parents endeuillés.

Participation à la recherche
Si vous acceptez de participer, nous vous demanderons de rencontrer Moire Stevenson, chercheur et étudiante à l’Université de Montréal, qui réalise cette étude dans le cadre de son doctorat.

Nous nous attendons à ce que l’entrevue dure de 30 minutes à deux heures. La longueur de l’entrevue dépendra de vous. Elle abordera votre vie durant la première année suivant la mort de votre enfant, ainsi que votre perspective sur les services et pratiques offerts à l'hôpital ou ailleurs. Des questions d’ordre générale telles que des informations au sujet de votre âge, votre niveau de scolarité et votre emploi vous seront également posées.

Si vous êtes d'accord, l'entrevue sera enregistrée pour aider la chercheuse à comprendre et explorer tous les détails de l'entrevue. Les enregistrements des entrevues seront transcrits par une assistante de recherche qui aura signé au préalable un accord de confidentialité. Seule l'équipe de recherche aura accès de l'information enregistrée et transcrite. Vous pourrez obtenir une copie de la transcription si vous souhaitez.

Suite à votre participation à une première entrevue, il est possible que vous soyez invité(e) à participer à une deuxième entrevue dans le futur; vous serez libre de choisir de participer ou non à cette deuxième entrevue.

Avantages et inconvénients
Le fait de participer à cette recherche vous offre une occasion de réfléchir et de discuter en toute confidentialité de votre expérience personnelle face au deuil. Nous comprenons que de raconter votre expérience puisse être difficile; il se peut aussi que d’avoir l’occasion d’en parler soit réconfortant. Ce projet pourra aider d’autres parents dans l’avenir. À n'importe quel moment durant l'entrevue, vous pouvez faire une pause, mettre fin à l'entrevue ou à votre participation au projet. Si la discussion suscite des réflexions ou des souvenirs émouvants ou désagréables, n'hésitez pas à en parler avec la chercheuse qui mène l'entrevue. Celle-ci pourra vous donner le nom d'une personne-ressource en mesure de vous aider.

Participation volontaire et droit de retrait
Vous êtes libre de participer à ce projet de recherche. Vous pouvez poser des questions quand vous le voulez, refuser de répondre à une question ou mettre fin à votre participation à n'importe quel moment sans qu'il y ait de conséquences négatives ou préjudices à votre endroit et sans avoir à justifier votre décision. Si vous décidez de mettre fin à votre participation, vous pourrez choisir que vos données et enregistrements soient conservées pour le projet ou qu'elles soient détruites.

Confidentialité et gestion des données
Toutes vos réponses seront conservées dans la confidentialité. Les noms des participants n'apparaîtront dans aucun rapport et les divers documents de recherche seront codifiés. Seule l'équipe de recherche aura accès à la liste des noms et des codes. Le matériel de recherche, incluant les données, les enregistrements, et les transcriptions seront conservés dans un classeur verrouillé dans un bureau fermé à clé à l'Université de Montréal. Toutes les données en format électronique seront protégées par un mot de passe. Les membres du CÉR et de l'organisme subventionnaire, CRSH, auront aussi accès aux données.

La recherche fera l'objet de publications dans des revues scientifiques et de présentations à des congrès scientifiques. Aucun participant ne pourra y être identifié ou reconnu. Lorsque les publications ou présentations contiendront des citations exactes, toute information personnelle sera modifiée pour protéger l'identité du participant.

Les donnés (enregistrements, transcriptions) seront conservées pendant une période minimum de sept ans après la publication de l'étude. Elles seront ensuite détruites de façon confidentielle par le déchiquetage du matériel papier ou la suppression des dossiers informatisés.

Renseignements supplémentaires
Si vous avez des questions sur vos droits comme participant vous pouvez communiquer avec le Commissaire local aux plaintes et à la qualité des services du CHU Sainte-Justine au [contact info deleted]. Si vous avez des questions sur la recherche, vous pouvez communiquer avec Nago Humbert [contact info deleted] ou Moire Stevenson au [contact info deleted]
[

Responsabilité
Vous ne renoncez à aucun de vos droits et ne libérez les chercheurs et les institutions impliquées de leurs s responsabilités professionnelles et légales. Vous recevrez une copie de ce formulaire à conserver.

Consentement
On m'a expliqué la nature et le déroulement du projet de recherche. J'ai pris connaissance du formulaire de consentement et on m'en a remis un exemplaire. J'ai eu l'occasion de poser des questions auxquelles on a répondu à ma satisfaction. Je suis satisfait(e) des explications, précisions et réponses que le chercheur m'a fournies, le cas échéant, quant à ma participation à ce projet. Je consens librement à participer à cette étude.

______________________	___________________________	________________
Nom du participant de 18 ans et plus (Lettres moulées)	Consentement (signature)	Date

J'ai expliqué au participant tous les aspects pertinents de la recherche et j'ai répondu aux questions qu'ils m'ont posées. Je leur ai indiqué que la participation au projet de recherche est libre et volontaire et que la participation peut être cessée en tout temps.

_____________________	_______________________	__________
Nom de la personne qui a obtenu le consentement	Signature	Date

CHU Sainte-Justine
Le centre hospitalier universitaire mère-enfant

Université de Montréal

Participant Information and Consent Form
Parents

Project: Parental bereavement: recent bereavement experiences and an exploration of current services and practices.

Investigator responsible for project at CHU Sainte-Justine:
Nago Humbert, Director, Consultation Unit in Palliative Care, CHU Sainte-Justine.

Principal Investigator of study: Moire Stevenson, Ph.D. Student, Department of Psychology, Université de Montréal, [contact info deleted];
[contact info deleted]

Co-investigators
Antoinette Petti, Clinical Nurse Specialist, Consultation Unit in Palliative Care, CHU Sainte-Justine.

Lysanne Daoust, Clinical Nurse Specialist, Consultation Unit in Palliative Care, CHU Sainte-Justine.

Marie Achille, Ph.D., Associate professor, Department of Psychology, Université de Montréal

Robin Cohen, Ph.D., Associate Professor, Departments of Oncology and Medicine, McGill University

Source of funding:
This project is funded by the Social Science and Humanities Research Council of Canada (SSHRC).

Introduction

You have been invited to participate in a research study that explores the experiences of parents whose child has recently died. It is important that you understand the risks and benefits of participation and what is expected of you before accepting to participate in this research study. This document provides this information and we suggest you read it carefully before deciding to participate. If you agree to participate in this study, please sign this form and a copy will be given to you for you to keep.

Nature and Purpose of the Study

The purpose of the research project is to better understand how recently bereaved parents address their grief. In order to explore how parents address their grief we will be speaking with bereaved parents about their experiences during the first year after their child's death and what they found helpful or unhelpful during this time. We plan to speak with parents that have recently lost a child and parents that have lost a child up to five years before the time of their participation. The findings may be used to guide the services and practices that are provided to bereaved parents.

What Participation Involves

If you agree to participate, you will be asked to participate in a face-to-face interview with the study co-investigator, Moire Stevenson, who is doing this study as part of her doctoral thesis.

We expect that the interviews will last between 30 minutes and two hours. The length depends on how long you want to talk. During this interview, you will be invited to discuss your life during the first year after the death of your child and any other experiences during this time. We will also inquire as to your perspective on various services and practices provided by the hospital or that you have discovered elsewhere. Lastly, you will be asked some to provide some basic information such as your age, education, and work experience.

If you agree, the interview will be audio-recorded to help the research team understand and explore all the details of the interview. A research assistant who has signed a confidentiality agreement will type these recordings. Only the research team will have access to the information collected. You will be able to obtain a copy of the typed interview, if desired. You may also be invited to participate in a second interview at a later date. It will be up to you whether or not you want to do so.

Risks and Benefits

Participating in this study will offer you the occasion to reflect and discuss your personal experiences with grief in complete confidentiality. We understand that speaking about your child's death may be difficult and upsetting, however, some parents appreciate the opportunity to talk about their experiences. This project may help other parents in the future. Throughout the study, you will be free to not answer a question, to move on to the next one, to take a break, or to withdraw from the study entirely. If at any time you feel you want or need psychological support, we can provide you with a list of local services and/or put you into contact with a local grief counselling service.

Participants' Rights

Participation in this study is voluntary. You have the right to ask questions at any time, to refuse to answer questions, or to stop participating in the study by simply saying so. There are neither penalties nor loss of benefits for refusal to participate. If you choose to end your participation in the study, you will have the choice as to whether the information collected up to that point be kept as part of the study or destroyed.

Confidentiality and Data Security

All your responses will be kept strictly confidential and will only be available to the research team. You will not be identified by name in any notes or recordings; rather an identification number will be assigned to you for the study. All paper data will be kept in a locked cabinet in a locked office at Université de Montréal and all computerized data will be password protected. The members of the Research Ethics Committee of CHU Sainte-Justine, and the funding body, Social Science and Humanities Research Council (SSHRC), will also have access to the data.

The results from this study will be published and presented in various research meetings, however study participants will not be identified. When direct quotations are used in publications or presentations personal details and identifiers will be modified to protect the identity of the participant.
All data/information (including transcripts and audio-recordings) from this study will be retained for 7 years after publication; after which they will then be destroyed.

Contact Information

If you have any questions regarding your rights as a research participant please contact the Local commission of complaints and quality of services of CHU Sainte-Justine at [contact info deleted]. If you have questions concerning other matters related to this study, please contact either Nago Humbert [contact info deleted] or Moire Stevenson [contact info deleted] [contact info deleted].

Declaration of consent

In no way does this form waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. You are free to withdraw from this study at any time. In addition, a copy of this form will be given to you for you to keep.

Consent

The nature and conduct of the study have been explained to me. I have read this consent form or it has been explained to me and I have received a copy. I have had the opportunity to ask questions, which have been answered to my satisfaction. After thinking about it, I agree to participate in this study. I authorize the research team to consult my child's medical record to obtain information relevant to this project.

___________________________	____________________________	________________
Name of participant 18 years and older (block letters)	Consent (signature)	Date

I have explained all the relevant aspects of the study to the participant and/or his parent/tutor and answered the questions that were asked of me. I have pointed out to them that participation in the study is completely voluntary and that they may stop their participation at any time.

__________________________	____________________________	________________
Name of person obtaining consent	Signature	Date

CHU Sainte-Justine
Le centre hospitalier
universitaire mère-enfant

Université de Montréal

Renseignements pour le personnel et formulaire de consentement

Titre de l'étude : Ce qui aide les parents endeuillés? Expériences de deuil récent et exploration des services et des pratiques actuelles.

Chercheur responsable au CHU Sainte-Justine :
Nago Humbert, Directeur, Unité de consultation en soins palliatifs pédiatriques, CHU Sainte-Justine.

Chercheur principal du projet :
Moire Stevenson, Étudiante au Ph.D., Département de psychologie, Université de Montréal, [contact info deleted]

Collaborateurs :
Antoinette Petti, Infirmière clinicienne, Unité de consultation en soins palliatifs pédiatriques, CHU Sainte-Justine.

Lysanne Daoust, Infirmière clinicienne, Unité de consultation en soins palliatifs pédiatriques, CHU Sainte-Justine.

Marie Achille, Ph.D., Professeure agrégée, Département de psychologie, Université de Montréal

Robin Cohen, Ph.D., Professeure agrégée, Département d'oncologie et de médecine, Université McGill.

Source de financement :
Ce projet est financé par le Conseil de recherches en sciences humaines (CRSH).

Introduction

Nous vous invitons à participer à une étude qui s'intéresse à l'expérience des parents qui ont récemment vécu la mort d'un enfant. Comme vous êtes un professionnel de la santé qui aide à recruter des participants pour le projet et qui offre un suivi de deuil aux familles, je voudrais en savoir plus sur votre façon de conduire le suivi de deuil avec les familles que vous suiviez. Il est important que vous compreniez les risques ainsi que les bénéfices liés à votre participation avant d'accepter d'y participer. Ce formulaire de consentement renferme les informations sur la recherche susmentionnée et nous vous invitons à le lire attentivement. Si vous souhaitez participer à la présente étude, vous devrez d’abord signer ce formulaire et nous vous en remettrons une copie.

Nature de l’étude

La recherche a pour but de mieux comprendre comment les parents récemment endeuillés composent avec leur deuil. Afin d’explorer cette question, nous mènerons des entretiens auprès de parents endeuillés pour savoir comment ils ont vécu cette expérience pendant de la première année qui a suivi la mort de leur enfant et sur ce qui les a aidé à passer à travers de cette période éprouvante. Nous planifions nous entretenir avec des parents qui viennent de perdre un enfant ainsi qu’avec d’autres parents qui ont perdu un enfant dans les cinq ans précédant cette entrevue. En outre, nous parlons avec les professionnels qui réalisent des suivis de deuil avec les parents afin d'avoir plus d'informations sur ce qui a été fait au cours du suivi et de donner des précisions sur ce que les parents trouvent utiles. Les résultats pourront être utilisés pour guider le développement ou la modification des services et pratiques offerts aux parents endeuillés.

Participation à la recherche

Si vous acceptez de participer, nous vous demanderons de rencontrer Moire Stevenson, co-chercheur et étudiante à l’Université de Montréal, qui réalise cette étude dans le cadre de son doctorat. Nous nous attendons à ce que l’entrevue dure de 30 minutes à une heure. La longueur de l’entrevue dépendra de vous. Au cours de cette entrevue, vous serez invités à discuter de la façon dont vous menez un suivi de deuil parental avec les parents de patients auxquels vous aurez donné des soins.

Avec votre consentement, l'entrevue sera enregistrée pour aider la chercheuse à comprendre et explorer tous les détails de l'entrevue. Les enregistrements des entrevues seront transcrits par une assistante de recherche qui aura signé au préalable un accord de confidentialité. Seule l'équipe de recherche aura accès de l'information enregistrée et transcrite. Vous pourrez obtenir une copie de la transcription si vous souhaitez.

Avantages et inconvénients

Le fait de participer à cette recherche vous offre une occasion de réfléchir et de discuter en toute confidentialité de votre expérience personnelle face au deuil. Nous comprenons que de raconter votre expérience puisse être difficile; il se peut aussi que d’avoir l’occasion d’en parler soit réconfortant. Ce projet pourra aider d’autres parents dans l’avenir. À n'importe quel moment durant l'entrevue, vous pouvez faire une pause, mettre fin à l'entrevue ou à votre participation au projet. Si la discussion suscite des réflexions ou des souvenirs émouvants ou désagréables, n'hésitez pas à en parler avec la chercheuse qui mène l'entrevue. Celle-ci pourra vous donner le nom d'une personne-ressource en mesure de vous aidé.

Participation volontaire et droit de retrait

Vous êtes libre de participer à ce projet de recherche. Vous pouvez poser des questions quand vous le voulez, refuser de répondre à une question ou mettre fin à votre participation à n'importe quel moment sans qu'il y ait de conséquences négatives ou préjudices à votre endroit et sans avoir à justifier votre décision. Si vous décidez de mettre fin à votre participation, vous pourrez choisir que vos données soient conservées pour le projet ou qu'elles soient détruites.

Confidentialité et gestion des données

Toutes vos réponses seront conservées dans la confidentialité. Les noms des participants n'apparaîtront dans aucun rapport et les divers documents de recherche seront codifiés. Seule l'équipe de recherche aura accès à la liste des noms et des codes. Le matériel de recherche, incluant les données, les enregistrements, et les transcriptions seront conservés dans un classeur verrouillé dans un bureau fermé à clé à l'Université de Montréal. Toutes les données en format électronique seront protégées par un mot de passe. Les membres du CÉR et de l'organisme subventionnaire, CRSH, auront aussi accès aux données.

La recherche fera l'objet de publications dans des revues scientifiques et de présentations à des congrès scientifiques. Aucun participant ne pourra y être identifié ou reconnu. Lorsque les publications ou présentations contiendront des citations exactes, toute information personnelle sera modifiée pour protéger l'identité du participant.

Les donnés (enregistrements, transcriptions) seront conservées pendant une période minimum de sept ans après la publication de l'étude. Elles seront ensuite détruites de façon confidentielle par le déchiquetage du matériel papier ou la suppression des dossiers informatisés.

Renseignements supplémentaires

Si vous avez des questions sur vos droits comme participant vous pouvez communiquer avec le Commissaire local aux plaintes et à la qualité des services du CHU Sainte-Justine au [contact info deleted]. Si vous avez des questions sur la recherche, vous pouvez communiquer avec Nago Humbert [contact info deleted] [[contact info deleted]] ou Moire Stevenson au [contact info deleted] [[contact info deleted]].

Responsabilité

Votre signature sur ce formulaire indique que vous avez bien compris l'information concernant votre participation à cette étude et que vous souhaitez y participer. Ce faisant, vous ne renoncez à aucun de vos droits et ne libérez les chercheurs et les institutions impliquées de leurs s responsabilités professionnelles et légales. Vous recevrez une copie de ce formulaire à conserver.

Consentement

On m'a expliqué la nature et le déroulement du projet de recherche. J'ai pris connaissance du formulaire de consentement et on m'en a remis un exemplaire. J'ai eu l'occasion de poser des questions auxquelles on a répondu à ma satisfaction. Je suis satisfait(e) des explications, précisions et réponses que le chercheur m'a fournies, le cas échéant, quant à ma participation à ce projet. Je consens librement à participer à cette étude.

Nom du participant de 18 ans et plus (Lettres moulées)	Consentement (signature)	Date

J'ai expliqué au participant et/ou à son parent/tuteur tous les aspects pertinents de la recherche et j'ai répondu aux questions qu'ils m'ont posées. Je leur ai indiqué que la participation au projet de recherche est libre et volontaire et que la participation peut être cessée en tout temps.

Nom de la personne qui a obtenu le consentement	Signature	Date

CHU Sainte-Justine
Le centre hospitalier
universitaire mère-enfant

Université de Montréal

Participant Information and Consent Form
Health Care Providers

Study: Parental bereavement: recent bereavement experiences and an exploration of current services and practices.

Investigator responsible for project at CHU Sainte-Justine:
Nago Humbert, Director, Consultation Unit in Palliative Care, CHU Sainte-Justine.

Principal Investigator of study: Moire Stevenson, Ph.D. Student, Department of Psychology, Université de Montréal, [contact info deleted]; [contact info deleted]

Co-investigators
Antoinette Petti, Clinical Nurse Specialist, Consultation Unit in Palliative Care, CHU Sainte-Justine.

Lysanne Daoust, Clinical Nurse Specialist, Consultation Unit in Palliative Care, CHU Sainte-Justine.

Marie Achille, Ph.D., Associate professor, Department of Psychology, Université de Montréal

Robin Cohen, Ph.D., Associate Professor, Departments of Oncology and Medicine, McGill University

Source of funding:
This project is funded by the Social Science and Humanities Research Council of Canada (SSHRC).

Introduction

You have been invited to participate in a research study that explores the experiences of parents whose child has recently died and the services provided to them. As you are a health care professional assisting in the recruitment for the project and providing bereavement follow-up support to families, I would like to learn more on how you go about conducting bereavement follow-ups. It is important that you understand the risks and benefits of participation and what is expected of you before accepting to participate in this research study. This document provides this information and we suggest you read it carefully before deciding to participate. If you agree to participate in this study, please sign this form and a copy will be given to you for you to keep.

Purpose of the Study

The purpose of the research project is to better understand how recently bereaved parents address their grief. In order to explore how parents address their grief we will be speaking with bereaved parents about their experiences during the first year after their child's death and what they found helpful or unhelpful during this time. We plan to speak with parents that have recently lost a child and parents that have lost a child up to five years before the time of their participation. In addition, we are speaking with health care providers conducting bereavement follow-ups with parents in order to have more information on what was actually done during the follow-up and to further elaborate on what the parents found helpful. The findings may be used to guide the services and practices that are provided to bereaved parents.

What Participation Involves

If you agree to participate, you will be asked to participate in a face-to-face interview with the study co-investigator, Moire Stevenson, who is doing this study as part of her doctoral thesis. We expect that the interviews will last between 30-60 minutes. The length depends on how long you want to talk. During this interview, you will be invited to discuss how you conduct parental bereavement follow-ups with the parents of patients whose care you were involved with.

With your consent, the interview will be audio-recorded to help the research team understand and explore all the details of the interview. A research assistant who has signed a confidentiality agreement will type these recordings. Only the research team will have access to the information collected. You will be able to obtain a copy of the typed interview, if desired.

Risks and Benefits

Participating in this study will offer you the occasion to reflect and discuss your personal experiences with grief in complete confidentiality. We understand that speaking about your child's death may be difficult and upsetting, however, some parents appreciate the opportunity to talk about their experiences. This project may help other parents in the future. Throughout the study, you will be free to not answer a question, to move on to the next one, to take a break, or to withdraw from the study entirely. If at any time you feel you want or need psychological support, we can provide you with a list of local services and/or put you into contact with a local grief counselling service.

Participants' Rights

Participation in this study is voluntary. You have the right to ask questions at any time, to refuse to answer questions, or to stop participating in the study by simply saying so. There are neither penalties nor loss of benefits for refusal to participate. If you choose to end your participation in the study, you will have the choice as to whether the information collected up to that point be kept as part of the study or destroyed.

Confidentiality and Data Security

All your responses will be kept strictly confidential and will only be available to the research team. You will not be identified by name in any notes or recordings; rather an identification number will be assigned to you for the study. All paper data will be kept in a locked cabinet in a locked office at Université de Montréal and all computerized data will be password protected. The members of the Research Ethics Committee of CHU Sainte-Justine, and the funding body, Social Science and Humanities Research Council (SSHRC), will also have access to the data.

The results from this study will be published and presented in various research meetings, however study participants will not be identified. When direct quotations are used in publications or presentations personal details and identifiers will be modified to protect the identity of the participant.

All data/information (including transcripts and audio-recordings) from this study will be retained for 7 years after publication; after which they will then be destroyed.

Contact Information

If you have any questions regarding your rights as a research participant please contact the Local commission of complaints and quality of services of CHU Sainte-Justine at [contact info deleted]. If you have questions concerning other matters related to this study, please contact either Nago Humbert [contact info deleted] or [contact info deleted]

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Responsibility

Your signature on this form indicates that you have understood the information regarding your participation in the research study and agree to participate. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. You are free to withdraw from this study at any time. In addition, a copy of this form will be given to you for you to keep.

Consent

The nature and conduct of the study have been explained to me. I have read this consent form or it has been explained to me and I have received a copy. I have had the opportunity to ask questions, which have been answered to my satisfaction. After thinking about it, I agree to participate in this study.

______________________	______________________	______________
Name of participant (block letters)	Consent (signature)	Date

I have explained all the relevant aspects of the study to the participant and answered the questions that were asked of me. I have pointed out to them that participation in the study is completely voluntary and that they may stop their participation at any time.

______________________	______________________	______________
Name of person obtaining consent	Signature	Date

Appendix F

Letters of invitation to participate in the study

[university hospital logo]

Invitation to participate in a research study

Parental bereavement: recent bereavement experiences and an exploration of current services and practices

Hello,

You are receiving this invitation because your infant or child was followed at the [name of hospital]. This is an invitation to participate in a study on the experiences of bereaved parents and their views on bereavement services and practices. I am sending you this letter to inform you about the research study and to see if you would be interested in participating.

Who is the researcher?
Moire Stevenson is a clinical psychology Ph.D. student and this project is part of her thesis research. Her research is focused on paediatric palliative care and the experiences of families dealing with severe illness and loss. Every loss and family is unique, and she wants to learn from your own personal experiences by meeting with you for an interview.

What is this study about?
The need for services to help parents whose child has died is clear, however there is a lack of information on how these services should be run and which practices are most helpful to bereaved parents. The goal of the study is to learn more about the experiences of bereaved parents and what is helpful to them throughout their bereavement experience. This will be useful to people providing bereavement follow-up practices and services to improve future services.

What does participation involve?
Participation in the project consists of an interview with Moire. The interview can last anywhere from 30 minutes to 2 hours, depending on how much you want to talk. She will ask you questions on your experiences in the first year after your child died and what you found helpful or not helpful during this time.

Interested in participating?
If you are interested in participating or want to know more about the study please contact Moire at the Health Psychology Lab at University of Montreal ___________________or by email ___________________

Sincerely,

[university hosptial logo]

Invitation pour participer à une étude de recherche

Parents endeuillés : Exploration des pratiques actuelles et des services offerts aux parents ayant vécu un deuil récent.

Madame, monsieur,

Nous prenons la liberté de vous écrire parce que votre bébé ou votre enfant a été suivi à [nom de l'hôpital]. Nous aimerions vous inviter à participer à une étude de recherche concernant les pratiques actuelles et des services offerts aux parents endeuillés, car nous aimerions connaître votre point de vue sur le sujet. Je vous envoie cette lettre pour vous donner des renseignements au sujet de l'étude et pour solliciter votre participation.

Qui est la chercheuse ?

Moire Stevenson est une étudiante inscrite au doctorat en psychologie clinique et la présente étude constitue sa thèse de doctorat. Sa recherche est axée sur les soins palliatifs pédiatriques et les expériences vécues par les familles confrontées à de graves maladies et le décès d'un être cher. Chaque deuil et chaque famille est unique. C'est pourquoi elle souhaite vous rencontrer afin que vous partagiez avec elle les expériences que vous venez de vivre.

Que vise la présente étude?

Il est clair que nous avons besoin de services pour assister les parents qui viennent de perdre un enfant. Toutefois, nous possédons que très peu d'informations sur la manière dont ces services devraient être offerts, de même que ce qui pourrait le plus les aider à passer à travers de cette période difficile. La présente étude vise à approfondir nos connaissances sur le sujet en parlant de vive voix avec les parents touchés par un deuil et discuter avec eux pour savoir ce qu'ils ont trouvé le plus aidant dans leur processus de deuil. Cette information aidera les intervenants offrant des suivis et des services liés au deuil à améliorer les services offerts à ces parents dans le futur.

Qu'est-ce que ma participation implique?

La participation à l'étude consiste à prendre part à un entretien avec Moire (co chercheuse). L'entrevue durera entre 30 minutes et deux heures. La durée de l'entrevue dépendra de l'information que vous serez prêt à partager avec elle. Elle vous posera des questions sur les expériences que vous avez vécues pendant la première année suivant le décès de votre enfant et sur ce que vous a aidé ou non à surmonter cette épreuve.

Intéressé à participer?

Si vous voulez participer ou désirez de plus amples informations sur l'étude, vous pouvez communiquer avec Moire au Laboratoire de psychologie de la santé de l'Université de Montréal au _______________ ou par courriel à:

Salutations distinguées,

Appendix G

Interview guide and sociodemographic questionnaire for parents

Interview Guide for Interview with Parents

Before the research interview begins:

The researcher will introduce the study, obtain informed consent, and explain that the interview will be recorded.

We are here today to talk about your experiences after the loss of your child and to discuss your views and perspectives on different services and practices offered by the hospital and in the community.

Before we begin I would first like to ask you some questions so that we can describe the people who took part in the study in terms of their background, education, etc. (Appendix IV).

DEMOGRAPHIC QUESTIONS

Date of interview ______________________________

1. Date of Birth : Month__________Day___________Year__________

2. What is your self-described cultural background? (examples: Black, Latino, Eastern European, Cree, etc)

3. What is your mother tongue?

4. What language are you more comfortable in, French or English?

5. Approximately, what is your annual family income?

Less than $10 000	1
$10 000 – 30 000	2
$30 001 – 50 000	3
$50 001 – 70-000	4
$70 001 – 90 000	5
More than $90,000	6

6. Are you currently employed, retired, or unemployed?

7. If you are currently working, what is your profession or type of work?
   7b) If you are not working, what is your profession or type of work?

8. What is the highest level of education you completed?

Primary school or less	1
Some high school or technical school	2
High school or technical school graduate	3
Some college	4
College graduate	5
University	6

9. What is the status of your relationship with the other parent? (e.g. married, common-law, divorced, etc)

10. Are you currently in a significant relationship with someone other than the father/mother of your child?

11. What is the name of your child that died?

12. When did your child die (date)?

13. Does (child's name) have any brothers or sisters? Any stepbrothers or sisters? If yes, how many, and how old are they?

INTERVIEW QUESTIONS

Give instructions about the interview:

I want to know about your experiences in your own words because your perspectives are important. My questions may seem large but feel free to give as much or as little detail as you want; this is more of a discussion than an interrogation. I am not looking for specific answers rather I would just like you to tell me your experiences and perspectives in your own words, this information will be used for my own research and to improve bereavement services, I am not directly associated with the hospital and I want to hear your opinions whether they are good, bad or neutral, so please feel free to speak with me without worry. Do you have any questions? Now I will start recording.

Experience

Please tell me about the circumstances surrounding the death of your child.

Probes: cause of illness or death, long-term illness, accident, immediately before death, the moments surrounding the death, immediately after the death.

What did you find helpful during this time considering (facing) what has happened?

Probes for period of time: in the time immediately before your child died, the first few weeks after their death, in the first year after.

Probes for bereavement: after the death, emotionally, psychologically, spiritually, with daily activities.

Were there other things that people did during this time that you found helpful?

What did you find unhelpful or problematic?

Were there other things that people did that you found unhelpful or problematic?

Probes: interactions with staff, other parents, particular/problematic issues, social support, how did particular action/statement make them feel.

Has this experience changed how you see the world?

If yes, how so?

Services

Were any bereavement services offered to you by the hospital, if so which ones?

Did you seek out any bereavement services?

Have you used any of these (said) services?

If so, which ones? What were your experiences with it? What helped? What didn't help? Was there anything that you felt was missing)?

Were there any other support services offered to you (i.e., counseling, support groups etc.)?

Were you offered any written materials (if so which ones, were they helpful, how so)?

Did you seek out any written materials on your own?

Which ones? Were they helpful? How so?

How do you feel the bereavement support offered by the MCH?
Has it been sufficient in meeting your needs? What do you find helpful or beneficial? What do you find lacking? What was not helpful or beneficial?

Follow-up Practices
Sympathy card from hospital
Did you receive any cards from the staff?
How did you feel when you received it?

Memorial service
Did you attend the memorial service?
Yes – *How was it for you? What are you opinions/perspectives/feelings about it? Would you recommend it to other bereaved parents?*
No – *Do you plan to attend? What are your thoughts about it?*

Memory box
Some departments will put mementos (loch of hair, hospital bracelet) in a commemorative box. Did you receive something similar?
(If yes): How do you feel about receiving something like that?
(If no): Do you think you would have liked to receive something like this? Why or why not?

Wrap-up

- *How do you feel (now that we are done the interview)?*
- *Do you have any other comments or issues you would like to mention?*
- *Are there any questions or issues you feel should be addressed in this study that have not already been mentioned in the interview?*
- *Do you think your partner would be interested in participating in an interview? (asked only when appropriate)*

Guide d'entrevue pour l'entrevue avec le parent

Matières :

- Enregistreur + piles
- Formulaire de consentement (x2)
- Journal de bord
- Papier et crayons

Au début d'entrevue:
La co-chercheuse introduira l'étude, **obtiendra le consentement éclairé** et expliquera que l'entrevue soit enregistrée.

- *Je vous invitais ici aujourd'hui pour parler de vos expériences après la mort de votre enfant et pour discuter vos perspectives sur les différents services et pratiques donnés par l'hôpital et la communauté.*

** commence l'enregistrement*

- *Avant de commencer, j'aimerais vous poser quelques questions pour but de décrire les gens qui ont participent dans l'étude en termes de leurs origines, éducation, et cetera (voir Annexe I questionnaire démographique).*

QUESTIONNAIRE DÉMOGRAPHIQUE

Code participant(e) : ___________________

1. Date de naissance: mois __________ jour ___________ année __________

2. Quelles sont vos origines culturelles? (par exemple : Caucasien/-ienne, Latino/-a, Europe de l'Est, autochtones, et cetera)

   ____

3. Quelle est votre langue maternelle? _______________________________

4. Êtes-vous plus à l'aise de faire l'entrevue en français ou anglais?

   ____

5. Approximativement, quel est le revenu annuel de votre famille?

Moins de $10 000	1
$10 000 – 30 000	2
$30 001 – 50 000	3
$50 001 – 70-000	4
$70 001 – 90 000	5
Plus que $90,000	6

6. Êtes-vous actuellement travailleur, retraités ou chômeurs?

   ____

7. Si vous travaillez actuellement, quelle est votre profession?

   ____

7b) Si vous ne travaillez pas, quelle est votre profession?

   ____

8. Jusqu'où vous êtes rendue dans vos études?

École primaire	1
Une partie d'école secondaire ou une école technique…	2
Gradué/-ée d'école secondaire ou une école technique..	3
Quelque CEGEP	4
Gradué/-ée de CEGEP	5
Quelque université	6
Gradué/-ée d'université	7

9. Quel est votre statut conjugal avec l'autre parent? (par exemple mariées, en union libre, divorcé, et cetera)

____

10. Est-ce que vous avez un nouveau conjoint/une nouvelle conjointe? **(le cas échéant)**

____

11. Est-ce que (nom de l'enfant) a des frères ou sœurs? Des demi-frères ou sœurs? Si oui, combien, et quel âge ont-ils?

____

____

____

____

____

____

Adresse :

QUESTIONS

Donnez des directives par rapport l'entrevue:

- *J'aimerais savoir vos expériences dans vos propres mots. Je cherche votre perspective.*
- *Mes questions pourraient être large, c'est libre à vous de décider jusqu'où vous voulez aller dans la description des éventements ou quoi que ce soit. Sentez-vous libre de répondre spontanément. Ceci est plus une discussion qu'une interrogation.*
- *Je ne cherche pas des réponses spécifiques, je préfère plutôt que vous parliez de vos expériences dans vos propres mots.*
- *Cette information sera utilisée pour ma recherche et qui a pour but d'améliorer les services d'aide aux personnes endeuillées.*
- *Je ne suis pas une employé de l'hôpital (je suis une chercheuse externe) et j'aimerais savoir vos opinions peu import si sont positives, neutres ou négatives, donc sentez-vous libre de parler avec moi sans inquiétudes ou hésitations. Avez-vous des questions? Je commence l'enregistrement.*

Leur expérience

- *Si vous vous sentez à l'aise de me parler, j'aimerais vous entendre sur les circonstances qui ont entouré la mort de votre enfant.*

Les enquêtes: date/année, cause de maladie ou mort, maladie de longue durée, accident, immédiatement avant l'incident, immédiatement après l'incident.

- *J'aimerais vous entendre sur ce que vous avez trouvé aidant dans ses circonstances.*

Les enquêtes pour le moment : pendant le période immédiatement avant que votre enfant a décidé (palliative care), les premières semaines après le décès, pendant le première année (Group 1 : cette première année).
Les enquêtes pour le deuil : après le décès, affectivement/émotionnellement, psychologiquement, avec les activités de quotidienne.

- *Est-ce qu'il y avait d'autres choses que les autres personnes ont fait pendant cette période que vous trouviez aidant?*

- *Est-ce que vous avez trouvé des choses pas aidantes, problématiques ou nuisibles? Quoi ou lesquelles?*

- *Est-ce qu'il y avait des choses faites par les autres personnes que vous avez trouvé pas aidantes, problématiques ou nuisibles? Quoi ou lesquelles?*

Les enquêtes: interactions avec le personnel ou d'autres parents, problèmes spécifiques, soutienne sociale, comment *ça* vous faisait sentir.

Les services

- *Est-ce que l'hôpital vous a offert des services de deuil? Lesquelles?*
- *Est-ce que vous avez cherché (ou cherche actuellement) des services de deuil?*
- *Est-ce que vous en les utilisés?*
  - *Lesquelles?*
  - *Quelles ont été vos expériences avec ce service?*
  - *Qu'est-ce que vous avez trouvé aidant ou pas aidant?*
  - *Pensez-vous qu'il y avait des choses manquantes ou pourrait être modifiés?*
- *Est-ce qu'il y a des services de soutient vous ont été offert par l'hôpital (p.ex., services psychologiques, groupes de soutien et cetera)?*
- *Est-ce que vous avez reçu des matériels imprimés comme des livres ou dépliants (lesquelles? aidant ou non? comment?)?*
- *Est-ce que vous avez cherché des matérielles imprimés, ou des émissions, films, documentaires ou sur la radio vous-même (lesquelles? aidant ou non? comment?)?*
- *Comment vous trouvez les services de deuil offert par l'hôpital?*
- *Est-ce que vous les trouvez satisfaisant et est-ce qu'ils répondent (répondait) à vos besoins? Qu'est-ce que vous aviez trouvé aidant ou bénéfiques? Qu'est-ce que vous aviez trouvé pas ou moins aidant?*

Les pratiques de suivi

Carte de sympathie de l'hôpital

- *Est-ce que vous avez reçu des cartes de sympathie du personnel de l'hôpital?*
- *Comment vous vous sentiez lorsque vous les avez reçus?*

Service commémoratif

- *Est-ce que vous êtes allé au service commémoratif à l'hôpital (une environ chaque 4 mois)?*
  - Oui – *C'était comment pour vous? Quelles sont vos opinions/perspectives/sentiments du service? Le recommandez-vous à d'autres parents endeuillés?*
  - No – *Est-ce que vous pensez y aller? Quelles sont vos penses/sentiments sur le sujet?*

Boite de souvenirs

- *Certains départements remettent des boite de souvenirs (p.ex., avec une pièce de cheveux, un bracelet de l'hôpital), est-ce que vous avez reçu quelques choses de semblables?*
  - Oui: *Comment vous vous sentez de recevoir quelques choses comme ça?*
  - Non : *Aimeriez-vous recevoir quelques choses comme ça? Pourquoi ou pourquoi pas?*

La fin d'entrevue

- *Comment vous vous sentez maintenant à la fin de l'entrevue?*
- *Avez-vous d'autres commentaires ou questions que vous aimeriez ajouter?*
- *Est-ce que vous pensez qu'il y a des questions ou problèmes qui devraient être abordées dans cette étude qui n'ont pas déjà été mentionné dans l'entrevue?*
- *Pensez-vous que votre mari (conjoint) voudrait participer au projet?* ***(le cas échéant)***

Appendix H

Guide for interviews with health care professionals

Interview Guide for Health Care Professionals

How do you go about providing bereavement follow-up to families?

Are you able to follow-up with families the way you want to?

What makes following-up with families difficult?

What do you feel would facilitate following-up with families?

Guide d'entrevue pour le personnel

Comment assurez-vous le suivi de deuil pour les familles?

Êtes-vous en mesure d'assurer le suivi auprès des familles tel que vous le souhaitez?

Qu'est-ce qui rend ces suivis difficiles?

Qu'est-ce qui facilite ces suivis auprès des familles?