UNDERSTANDING LIVED EXPERIENCES OF BEREAVED PARENTS OF CHILDREN WITH CHRONIC LIFE-THREATENING ILLNESS: TOWARDS A CULTURE-SPECIFIC AND MEANING-ORIENTED NARRATIVE e-WRITING INTERVENTION (NeW-I) FOR ANTICIPATORY GRIEF SUPPORT IN SINGAPORE

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STATEMENT OF ORIGINALITY

I certify that all work submitted for this thesis is my original work. I declare that no other person's work has been used without due acknowledgement. Except where it is clearly stated that I have used some of this material elsewhere, this work has not been presented by me for assessment in any other institution or University. I certify that the data collected for this project are authentic, the investigations were conducted in accordance with the ethics policies and integrity standards of Nanyang Technological University, and that the research data are presented honestly and without prejudice.

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SUPERVISOR DECLARATION STATEMENT

I have reviewed the content of this thesis and to the best of my knowledge, it does not contain plagiarized materials. The presentation style is also consistent with what is expected of the degree awarded. To the best of my knowledge, the research and writing are those of the candidate except as acknowledged in the Author Attribution Statement. I confirm that the investigations were conducted in accordance with the ethics policies and integrity standards of Nanyang Technological University and that the research data are presented honestly and without prejudice.

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AUTHORSHIP ATTRIBUTION STATEMENT

This thesis contains material from 4 peer-reviewed journal papers and 3 accepted international conference presentations in which I am listed as an author.

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- Prof Andy Ho provided the initial project direction, as well as revised, and finalized the manuscript drafts.
- I co-designed the study with Prof Andy Ho, worked with our collaborators at NTU LKCMedicine library to collect the data, screened the articles at both title/abstract review stage and full-text review stage, analyzed the data and gathered feedback from the research team to refine the analysis, and prepared and edited the manuscript drafts.

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LIST OF ABBREVIATIONS

BGQ	Brief Grief Questionnaire
BSFC-s	Burden Scale for Family Caregivers-Short
CCF	Children’s Cancer Foundation
CRS	Club Rainbow Singapore
DT	Dignity Therapy
FACIT-sp-12	Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being scale
FDI	Family Dignity Intervention
HCA	HCA Hospice Care
HHI	Herth Hope Index
ICPCN	International Children's Palliative Care Network
ISS	Inventory of Social Support
KQOL	Kemp Quality of Life scale
NeW-I	Narrative e-Writing Intervention
NHPCO	National Hospice and Palliative Care Organization
PHQ-9	Patient Health Questionnaire - 9
PPC	Pediatric Palliative Care
WHO	World Health Organization

ABSTRACT

It is a misconception that death occurs only in later life. Statistics show that an estimated 6.3 million children under age 15 died in 2017, with the vast majority of deaths - 5.4 million - occurring in the first five years of life. Chronic life-threatening illnesses such as cancer, congenital malformations and heart and respiratory diseases are one of the prevalent causes of child mortality. In Singapore, while deaths among children and youths (age<19) have been steadily declining over the past decade, the number of child deaths caused by chronic conditions has increased by about 27% from 120 in 2014 to 152 in 2016. This means that every year, both globally and locally, tens of millions of parents, grandparents and extended families are left in a state of despair and devastation due to the death of a young child in the family.

Despite these worrying figures, there is a paucity of information on how parents cope with their child's end-of-life trajectory and mortality, leading to vast inadequacy of parental support services for addressing anticipatory grief, loss, and bereavement around the world. The present doctoral research was conceived to address this critical gap in knowledge and practice through a three-pronged study. First, an international qualitative systematic review was carried out to comprehensively understand the lived experience of parents who experienced the chronic and life-threatening illness of their child and his or her subsequent death. Second, developed from the findings of the systematic review, a first-of-its kind qualitative research in the Asian context was subsequently conducted to elicit the lived experience of parents in Singapore whose children suffered and died from a chronic life-threatening illness. Finally, informed by the findings of the first and second study, a strength-based and meaning-oriented anticipatory grief e-intervention for parents facing their child's chronic life-threatening illness and potential death was developed and piloted in Singapore via an open-label mixed methods study. The methodologies and findings from each study are concisely summarized below.

Study 1 systematically reviewed the lived experience of parents across the world who lost their child to a chronic life-threatening illness. A comprehensive search of 6 major databases was conducted by adhering to the PRISMA guidelines. The SPIDER tool was employed to screen articles for appropriateness, and the method of Thematic Synthesis was adopted for full-text analysis of 25 high qualitative studies, of which none originated from Asia. Thirteen emerging themes were identified in the data which were further organized into a four-phase *Parental Bereavement Trajectory of Child Loss*, including Liminal Margin, Holding Space, Navigating Losses, and Reconstructing Lives. This trajectory enhances understanding about the parental bereavement experience of child loss and provides direction to subsequent research with grieving parents.

Study 2 critically examined the lived experience of parents who lost their child to a chronic life-threatening illness in Singapore. The overarching motivation of Study 2 was to bridge the research gap in our understanding of parental grief and bereavement due to child loss within the Asian context which had been identified in Study 1. Strength-based and meaning-oriented interviews

were conducted with 25 parental units (i.e., 6 couples, 13 lone mothers, 4 lone fathers, and 2 primary parental figures). The grounded theory approach to analysis revealed 7 themes and 25 sub-themes, which were further organized into a *Trauma to Transformation Model of Parental Bereavement*. This model shows the milestones in participants' lived experience of their child's chronic life-threatening illness and death. The model begins with participants' emotional turmoil as a result of their child's chronic life-threatening illness diagnosis, followed by participants' mourning of their child's death and the losses which accompanied the death, and finally, participants' experience of posttraumatic growth through reflection of their journey of caregiving and child loss. The model further describes the deliberate behaviors or 'rituals' that helped participants to regain power over their lives, sustain an intimate bond with their child beyond death, and transcend their loss by deriving positive outcomes from their experience. Finally, the model denotes that the lived experiences and well-being of participants were embedded within the health-and-social-care ecosystems in which they reside, and in turn impacted by it. These themes and their corresponding sub-themes provide key insights to researchers and clinicians about anticipatory grief and bereavement support services for grieving Asian parents around the globe.

Study 3 developed, piloted, and evaluated a novel evidence-based Narrative e-Writing Intervention (NeW-I) in Singapore to advance psycho-socio-spiritual support for parent-caregivers facing their child's chronic life-threatening illness. NeW-I was informed by Study 1 and Study 2 of this research and was

supported by anticipatory grief interventions literature for improving holistic well-being for seriously ill patients and their families. NeW-I, a meaning-and-strength-focused and therapist-facilitated mobile app was tested via a two-arm pilot randomized controlled trial comprising an intervention and control group. Data collected from intervention (*n* = 26) and control participants (*n* = 28) at baseline, post-intervention and one-month follow-up assessments was examined. Between-group analysis via Mann-Whitney U Tests showed that intervention participants had significantly higher levels of perceived social support than control participants upon intervention completion. Within-group analysis via Wilcoxon Signed-Rank tests revealed that intervention participants experienced significant improvement in their quality of life, overall spiritual well-being, sense of meaning and peace, sense of temporality, future orientation and perceived social support immediately post-intervention as compared to baseline. Additionally, participants experienced a significant decrease in subjective caregiver burden at post-intervention as compared to baseline and continued to experience lower levels of subjective caregiver burden at one-month follow-up. Qualitative framework analysis of post-intervention feedback highlighted participants' satisfaction with the opportunity to reflect on their caregiving experiences, acceptance of an internet-and-narrative-based platform for self-expression and structured counseling support, and compatibility of the NeW-I therapeutic-protocol with participants' needs. Taken together, findings from this pilot investigation indicate that NeW-I could enhance holistic pediatric palliative services in Singapore and a full-scale community trial with a larger and more diverse sample is warranted.

This doctoral research is a first-of-its kind series of studies that comprehensively and holistically examined the lived experience of bereaved parents globally and in Singapore; building on this novel body of knowledge, it further developed and piloted a culture-specific and evidence-based intervention to support parent-caregivers of children with chronic life-threatening illness. The research highlights both the cross-cultural commonalities and differences in the experiential narratives of grieving parents, as well as attests to the efficacy of a therapist-facilitated e-counseling platform that integrates meaning-focused and strength-based narrative writing intervention for enhancing the psycho-socio-spiritual well-being of parent-caregivers facing anticipatory grief. The work is discussed in the light of previous literature. Further, practical recommendations are offered for enhancing culturally sensitive parental grief support services. Finally, clinical implications of the research findings together with future research directions are elucidated.

The following is excerpted from the works of Emily Perl Kingsley, Mother of Jason Kingsley who was born with Down Syndrome. Through this poem, Emily hopes to share her unique experience of raising her son who was born with a chronic illness.

WELCOME TO HOLLAND

“When you’re going to have a baby, it's like you’re planning a vacation to Italy. You’re all excited. You get a whole bunch of guidebooks, you learn a few phrases so you can get around, and then it comes time to pack your bags and head for the airport.

Only when you land, the stewardess says, ‘Welcome to Holland.’

You look at one another in disbelief and shock, saying, ‘Holland? What are you talking about? I signed up for Italy.’

But they explain that there’s been a change of plan, that you’ve landed in Holland and there you must stay.

‘But I don’t know anything about Holland!’ You say. ‘I don’t want to stay!’

But stay you do. You go out and buy some new guidebooks, you learn some new phrases, and you meet people you never knew existed. The important thing is that you are not in a bad place filled with despair.

You’re simply in a different place than you had planned. It's slower paced than Italy, less flashy than Italy, but after you’ve been there a little while and you have a chance to catch your breath, you begin to discover that Holland has windmills. Holland has tulips. Holland has Rembrandts.

But everyone else you know is busy coming and going from Italy. They’re all bragging about what a great time they had there, and for the rest of your life, you’ll say, ‘Yes, that’s what I had planned.’

The pain of that will never go away. You have to accept that pain, because the loss of that dream, the loss of that plan, is a very, very significant loss. But if you spend your life mourning the fact that you didn’t get to go to Italy, you will never be free to enjoy the very special, the very lovely things about Holland.”

By Emily Perl Kingsley

CHAPTER ONE

INTRODUCTION

The past few decades have seen a remarkable decline in worldwide child and adolescent mortality — nearly 50% reduction from 1990 to 2015 (Haylett & Tilley, 2018). Yet, a staggering number of young lives continue to be lost each year due to various causes (Connor et al., 2017). Statistics show that an estimated 6.3 million children under age 15 died in 2017, with the vast majority of deaths — 5.4 million — occurring in the first five years of life (Suzuki & Kashiwase, 2018). In the twenty-first century, the primary burden of disease among children and youths has shifted from infectious diseases to chronic illnesses (Burns et al., 2010).

According to recent statistics published by the Centers for Disease Control and Prevention, the leading medical causes of child and youth mortality include chronic life-threatening illnesses such as cancer, heart and respiratory diseases, congenital abnormalities and deformations (Cunningham et al., 2018). Chronic illnesses are prolonged and rarely cured completely, affecting a child's regular activities with many requiring hospitalizations, home health care, and even extensive medical care (Mokkink et al., 2008). Additionally, chronic conditions that are life-threatening have uncertain prognosis and little hopes for cure (Liben et al., 2008). As a result, adaptations and adjustments in multiple life domains become a necessary process for survival (Stanton et al., 2007).

Within the local context of Singapore, the number of child and youth deaths (age<19) has been steadily declining over the past decade - from 283 reported in 2009 to 219 reported in 2016 (Registry of Births and Deaths, 2019). However, it is worrying that the number of child deaths caused by chronic conditions has increased by about 27% from 120 in 2014 to 152 in 2016 (Committee on the Rights of the Child, 2017). This means that the number of parents, grandparents and extended families left heartbroken and devastated following a child's death can amount to thousands each year in the city-state.

Child Mortality and Parental Bereavement

There is agreement in bereavement literature that the parent-child relationship is perhaps the strongest relationship there is, and the death of a child is the most profound of all losses (Silverman et al., 1996). The experience of child loss has no precedent; no other experience can prepare a parent to face this loss as well as the prolonged heart-wrenching and disabling nature of such grief (Rosof, 2014). The emotional pain suffered by parents due to the loss of their child has been compared to a physical injury that would require staying in an Intensive Care Unit (Finkbeiner, 2012). An illustration of the suffering resulting from the death of one's child can be seen in a condolence letter written by Sigmund Freud to his friend, in which he describes the loss felt by him even nine years after the death of his daughter, Sophie.

> *"Although we know that after such a loss the acute stage of mourning will subside, we also know we shall remain inconsolable and will never find a substitute. No matter what may fill the gap, even if it be filled completely, it nevertheless remains something else. Actually, this is how it should be. It is the only way of perpetuating that love which we do not wish to relinquish"* (Freud, 1961).

Indeed, the death of a child is a traumatic experience for parents, as the loss shatters their self-concept and views about the world (Janoff-Bulman, 2010). Research shows that parental bereavement is associated with a range of physical and emotional symptoms including anger, sorrow, loneliness, meaninglessness and physical pain (Barrera et al., 2009). Bereaved mothers, in particular, have a higher risk of mortality, especially in the first two years following child loss (Espinosa & Evans, 2013). Compared to parents of healthy children, bereaved parents also report greater physical and psychological health problems, psychiatric hospitalizations and poorer quality of life in the long-term, regardless of race or ethnicity (Li et al., 2005; Murphy et al., 1999; Song et al., 2010; Youngblut et al., 2013).

In addition to taking a toll on their physical and mental health, the death of a child also has social and relational consequences for bereaved parents. Specifically, in the 20th century, the death of a child is considered out-of-the-ordinary; and hence, a relatively small proportion of people witness the death of a child within their own family or community (Davies, 2004). Child death is considered to be ‘untimely’ and ‘out of turn’, disturbing the natural order of the universe in which children do not die before their parents (Mun & Ow, 2017; Rando, 1985a), thus distilling into stigma. Further, although all bereaved individuals may be socially stigmatized, bereavement due to child loss is considered to be far more socially ‘leprous’ as many parents find that they are treated ‘differently’ by their family and friends after their child’s death (Rando, 1985a).

Disenfranchised Grief and Hidden Sorrow

The term ‘Disenfranchised Grief’ was coined by Doka (1999) who defines it as “the grief experienced by those who incur a loss that is not, or cannot be, openly acknowledged, publicly mourned or socially supported.” Doka further explained that “isolated in bereavement… can be much more difficult to mourn and reactions are often complicated.” For instance, it is common for bereaved parents to be offered words of ‘comfort’ such as “It is okay, you are still young; you can have another child.” Such expressions from family members and friends undermine the legitimacy of the death and the realness of emotional pain experienced by bereaved parents, thereby complicating the process of grieving. Doka emphasized that it was paramount for society to recognize and meet the needs of individuals whose grief remained un-acknowledged, regardless of the emotional or financial costs that this may pose.

Attig (2004) added that disenfranchised grief marked a failure on the part of society to empathize with the suffering of the bereaved by denying them the right to suffer or to cope with the loss. Family and friends have a duty to invite mourners to remember the deceased, take a genuine interest in the stories and memories that mourners have to share, consider means of preserving these memories concretely (such as through writing or recording), and reflecting upon and cherishing the enduring meanings that these stories contain (Attig, 2004). Doka (2005) further elaborated that when death was due to a prolonged illness, families faced the additional stress of coping with the physical, financial, social and psychological demands that typically accompany a chronic condition. Such limiting longstanding illness could result in a state of ambivalence for friends and family who hope to end the patient's suffering while simultaneously hoping that the patient does not succumb to the disease.

Marital and Other Complications Following Child Death

Apart from the poor social outcomes of disenfranchised grief, the stress of a child's illness and death can impact a couple's relationship. Husbands and wives may have different styles of coping with grief, and it is common for anger to arise when each partner does not openly share their grief – resulting in challenges in communication, decline in sexual intimacy and overall irritability (Schwab, 1992). Newer studies also confirm that gender differences in grieving styles can create an asymmetry between husbands and wives, resulting in marital complications (Alam et al., 2012; Barrera et al., 2007; Bergstraesser et al., 2015; Rogers et al., 2008). Bergstraesser et al. (2015) explained that parents' role distribution in nurturing their child, whereby mothers conventionally are their child's primary caregiver while fathers 'escape' into their professional duties, may be responsible for the difference between spouses in grieving styles and the seemingly poorer bereavement consequences for mothers. The authors further elaborated that one partner in a relationship may have a greater need to talk about their grief than their spouse, and successful coping as a couple was associated with mutual respect for each partner’s unique grieving style.

In addition to such communicative and emotional difficulties, the death of a child can become a tormenting realization for parents about the limitation of their protective powers. For instance, when a child passes on, parents may experience guilt at what they see as a caregiver failure, or a sense of relief from their caregiving burden – which may cause insurmountable shame (Raphael, 1994). Newer reports have also documented the complicated nature of parental grief following child loss including feelings of disbelief in the death, anger towards their life circumstances, self-blame and guilt over their perceived inability to care for their child appropriately, and suicidal ideation (Zetumer et al., 2015).

Other research suggests that healthcare professionals who were directly involved in looking after dying children may face challenges in accepting such deaths and consider them to be unnatural (Liben et al., 2008). Such taboo and negativity towards child death on the part of professional workers could greatly hinder their working and supportive relationships with family caregivers, posing further challenges to bereaved parents who suffered the tragic loss of a beloved child.

Lived Experience of Parent-Caregivers of Children with Chronic Life-Threatening Illnesses

Along with the increase in child mortality due to chronic life-threatening illnesses, the proportion of children and young persons living with such conditions is also rising, with 32 in 10,000 people being affected in the age group of 0 to 19 years (Burns et al., 2010; Fraser et al., 2012). Due rapid advancements in health and medical technologies, children diagnosed with complex medical conditions tend to live longer, but with prolonged dependency (usually on their parents) and disability (Fraser et al., 2012). This means that the number of parent-caregivers attending to the diverse and complex medical needs of their ailing child is ever-growing. In order to understand the complex experience of parents who provide care to their chronically ill child since the time of his or her diagnosis through end-of-life, as well as the unique grieving of such parents following their child's mortality, a number of studies have been conducted (Rallison & Raffin-Bouchal, 2013; Somanadhan & Larkin, 2016; Steele & Davies, 2006) and recommendations have been proposed to appropriately address the needs of caregiver and grieving parents. The term 'battling the dragon' appears to accurately capture the lived experience of such parent-caregivers who constantly fight a host of adversities as part of their everyday life (Davies et al., 2004), to relentlessly support their child in the face of impending death (Rallison & Raffin-Bouchal, 2013).

Several studies confirm that the stress of repeated cycles of treatments and relapse, which typically accompany caregiving for a child with a complex chronic condition is multifaceted. Specifically, parents need to navigate the practical and financial burdens of caregiving (Corden et al., 2002), demands on their marital relationship (Bergstraesser et al., 2015), and inadequate parental attention towards their other healthy children (Alam et al., 2012; Jordan et al., 2015). Further, caregiving for chronically ill children involves frequent interactions with healthcare professionals, but such interactions could sometimes worsen parents' level of distress if they do not feel adequately supported by their healthcare professionals or adequately involved in making decisions regarding their child's care (Jordan et al., 2015; Meert et al., 2008). Overall, caregiver parents can experience clinically significant levels of distress, moderate to severe levels of fatigue and poor quality of life (Remedios et al., 2015). These deleterious outcomes can also continue into bereavement, resulting in increased risk of complicated grief and mortality for parents following the death of their child (Barrera et al., 2007; Li et al., 2003; Zetumer et al., 2015).

Problem Statement

Till date, no empirical investigation in Singapore or in Asia has critically examined the difficulties experienced by parent-caregivers of children suffering from a chronic life-threatening illness; neither has there been any research to assess the unique needs and concerns of parental grief and bereavement in local and regional contexts. It is further alarming to note that despite the notable number of parents who lose a child every year, there is no psycho-socio-spiritual intervention that is sensitive to the nuances of an Asian cultural context and supports this vulnerable group of bereaved parent-caregivers locally. The present research has therefore been conceived to bridge this critical knowledge gap via a three-pronged mixed methods study.

First, an international qualitative systematic review was carried out to comprehensively understand the lived experience of parents who experienced the chronic and life-threatening illness of their child and his or her subsequent death. Attention was paid to each stage in parents' journey from the diagnosis of their child's chronic life-threatening illness to caregiving, end-of-life, bereavement and post-bereavement adjustment. Second, inspired by the findings of the international qualitative systematic review, a first-of-its kind qualitative research in the Asian context was subsequently conducted to elicit the lived experience of parents in Singapore whose children suffered and died from a chronic life-threatening illness. The challenges faced by parents and the strengths that kept them going were examined, while factors and mechanisms which helped them cope with their challenges were identified. Finally, informed by the findings of the first and second study, a strength-based and meaning-oriented anticipatory grief e-intervention for parents facing their child's chronic life-threatening illness and potential death was developed and piloted in Singapore via an open-label mixed methods design.

Research Objectives

This research comprehensively examined the lived experience of parents — both globally and locally — who cared for their child with a chronic life-threatening illness and experienced his or her eventual death as a result of the condition. Informed by this in-depth understanding of the parental lived experience of caregiving and child loss as well as other relevant literature in this area, this research also involved the development, implementation and evaluation of a culture-specific psycho-socio-spiritual intervention to enhance well-being, reduce distress and address anticipatory grief among parent-caregivers' of children living with a chronic life-threatening illness. The objectives of each of the 3 studies are as follows:

The first study titled 'The Parental Bereavement Trajectory of Child Loss: A Thematic Synthesis of Qualitative Articles on the Parental Lived Experience of a Child's Chronic Life-Threatening Illness and Death' (hereon referred to as Study 1) comprehensively examined the lived experience of parents who have lost their child to a chronic life-threatening illness globally. The specific objectives of Study 1 were as follows:

1) To systematically search the major databases of qualitative research articles within the scholarly area of psychology and health services according to the PRISMA guidelines, and use the SPIDER tool to screen articles for appropriateness and relevance;
2) To explore the underlying themes and constructs interwoven through grieving parents' narratives across the identified research articles, so as to identify shared commonalities in the experience of grief and loss, as well as identify factors that support or impede parental bereavement;
3) Through the process of theory building, develop a systematic model that can inform pediatric palliative care as well as grief support services globally; and

4) Identify any potential gaps that may exist in the qualitative literature on parental bereavement and child loss which would need to be addressed by future research.

The second study titled ‘Trauma To Transformation: The Lived Experience of Bereaved Parents of Children with Chronic Life-threatening Illnesses in Singapore’ (hereon referred to as Study 2) explored the lived experience of parents who had lost their child to a chronic life-threatening illness in Singapore, their unique challenges and needs, and how they addressed and transcended these challenges. For this purpose, meaning-oriented and strength-focused qualitative interviews were conducted with 25 parental units (i.e. 6 couples, 13 lone mothers, 4 lone fathers, and 2 primary parental figures). The specific objectives of Study 2 were:

1) To provide a platform for parents who have lost their child due to a chronic life-threatening illness to share their lived experience in a safe, empathic and supportive environment;
2) To explore the underlying themes and constructs interwoven through all bereaved parents’ narratives, so as to identify shared commonalities in the experience of grief and loss, as well as factors that support or impede parental bereavement; and
3) Through the process of theory building, develop a culture-specific model for informing and advancing pediatric palliative care as well as grief support services in Singapore and other Asian contexts.

Finally, the third study titled ‘Development, Implementation and Evaluation of a Pilot Study Protocol for a Novel Narrative E-Writing Intervention (NeW-I) for Parents of Children with Chronic Life-threatening Illnesses in Singapore’ (hereon referred to as Study 3) developed and tested a novel evidence-based Narrative e-Writing Intervention (NeW-I) to address the inadequacies in delivering holistic support to parent-caregivers of children with chronic life-threatening illness. NeW-I was informed by the findings of Study 1 and Study 2 as well as relevant literature of anticipatory grief as well as meaning and narrative interventions. The specific objectives of Study 3 were as follows:

1) To develop a standardized protocol for a culture-specific and meaning-oriented Narrative e-Writing Intervention (NeW-I) for anticipatory grief and bereavement support for parent-caregivers facing the chronic life-threatening illness and eventual death;
2) To evaluate the efficacy of NeW-I in enhancing quality of life, spiritual well-being, hope and social support as well as decreasing caregiver burden, depressive symptoms, and risk of complicated grief among parent-caregivers; and
3) To examine the challenges and pitfalls in the design and implementation of NeW-I through an integrated feasibility and acceptability study for informing large-scale implementation of the intervention.

Research Paradigm

In view of the importance of operationalizing key terminology, this research adopts the following definitions of grief, bereavement and mourning:

Grief is understood as a unique and personal response to loss – which allows for the inclusion of emotional, social, cognitive, physical and behavioral responses – by focusing on the experience of the loss identified by the individual rather than the type of response to the loss (Harris, 2009); bereavement is defined as the condition of having lost a loved one due to his or her death; and mourning refers to the culturally appropriate ways in which grief is communicated (Davies, 2004).

Next, in view of the complexity and intricacy of the questions being researched through this investigation, a single methodology would not suffice. For this reason, a mixed method paradigm with both qualitative and quantitative approaches was deemed appropriate. Such mixed methods research designs have increasingly been gaining popularity in counseling psychological research (Hanson et al., 2005).

Study 1 adopted a rigorous qualitative systematic review approach to uncover and understand the entire trajectory of parents' lived experience of their child being diagnosed with a chronic life-threatening illness, caring for them throughout the illness trajectory and bereavement following his or her death. Such qualitative systematic reviews can be invaluable since they have the scope to bring together research evidence in a way that can illuminate our understanding of the lived experience of individuals who have suffered, draw reasonable explanations to answer the question of 'why'. Such an understanding can pave the way for theory building and consolidation of evidence in a way that can inform practice guidelines (Seers, 2015).

Study 2, which was a qualitative investigation, adopted an idealist ontology, a constructivist-interpretivist epistemology and a phenomenological paradigm. Such an approach has the potential to acknowledge the collaboration of participants as part of the research process and appreciate the unique and complex nature of their individual experiences (Rennie, 1994; Rennie et al., 2002). Qualitative inquiry with its subjective, exploratory and interpretative philosophy has been gaining momentum and recognition within the realm of psychology (Rennie et al., 2002). Even within the narrower confines of bereavement literature, qualitative research has been gaining popularity because of its ability to appropriately and adequately reflect the complexity of grievers' experiences (Collins et al., 2016; DeCinque et al., 2006; Meert et al., 2008; Rossetto, 2014; Titus & de Souza, 2011). In fact, in 2002, the journal 'Death Studies' explicitly recognized the inherent closeness between qualitative investigations and applied research with dying patients and bereaved relatives by devoting a special issue to qualitative studies in thanatology (Carverhill, 2002).

Study 3 adopted a mixed methods research design to create an opportunity for data triangulation (Hanson et al., 2005). Specifically, qualitative data (interviews with participants after their engagement with the intervention) and quantitative data (participants' psychometric assessment scores before and after their engagement with the intervention protocol) were collected and examined simultaneously. Equal priority was given to both types of data. Their analyses were conducted independently, and integration occurred at the stage of data interpretation. Converging quantitative and qualitative findings at the interpretation stage thus allowed for confirmation, corroboration, and cross-validation of study findings.

Chapter Summary

This introductory chapter has provided a comprehensive overview of child mortality around the world and in Singapore, the causes for loss of young lives and the impact of child mortality on surviving family members. Further, this chapter has identified the knowledge gap in our understanding of the lived experience of parents of children suffering from a chronic life-threatening illness, the needs and concerns of parental grief and bereavement within the local context of Singapore and the lack of a culturally appropriate psycho-socio-spiritual intervention for supporting grieving parent-caregivers. Finally, this chapter has laid out the objectives of this research and the research paradigm that will be adopted to fulfil these study objectives.

CHAPTER TWO

LITERATURE REVIEW

The goal of this literature review is to identify and explicate the following: (i) the key theoretical perspectives about parental grief and bereavement, (ii) the importance of pediatric palliative care for supporting young patients and their parent-caregivers facing serious illness and impending mortality, (iii) professional interventions and services that are available globally and locally for bereaved parents of children with chronic life-threatening conditions as well as parent-caregivers whose children are living with such conditions, (iv) the concept of anticipatory grief and its impact on post-bereavement adjustment, (v) the relevance of the meaning-reconstruction framework and narrative intervention in supporting end-of-life caregiving, and (vi) the evolving significance of the internet in providing counselling therapy. Thus, this chapter provides the direction for this research.

Theoretical Perspectives about Parental Grief and Bereavement

For most of the twentieth century, the literature on grief was developed by psychiatrists who based their models on those used by Western health professionals (Arnold et al., 2007). The first model of grief was proposed by Sigmund Freud who posited that grieving meant being able to detach oneself from the deceased person, whereby successful recovery could occur only when this process of disconnecting had been completed and the bereaved individual had the capacity to ‘move on’ to build new attachments (Freud, 1961). This perspective of grief and loss was further advanced by Bowlby, who proposed a three-stage model of grief: searching, despair and reorganization (Bowlby, 1961). Parkes examined the impact of bereavement on physical and mental health, and successfully identified risk factors at the time of bereavement that would predict later adjustment (Parkes, 1964, 1976; Parkes & Brown, 1972). Specifically, Parkes (1983) explained that in order to ‘recover’ from bereavement, it was necessary for the bereaved individual to work through his or her preoccupied thoughts about the deceased loved one and the loss experience and modify his or her assumptive world to make sense of the world in the absence of the deceased.

Kubler-Ross (1969), in her seminal work on patients with terminal illness, proposed that grief work involved going through the five stages: denial, anger, bargaining, depression and acceptance in coming to terms with their own death or the death of their loved one. In response to criticism about the fixed order of these stages, Kubler-Ross clarified that the stages did not progress in a linear and predictable manner, and they reflected merely how people cope with illness and dying, not with how they grieve (Doka, 2017; Kubler-Ross & Kessler, 2014). In his early works, Worden (1991, as cited in Olson & McEwen, 2004) believed that grief work comprised restructuring of one’s thoughts about the deceased, the experience of the loss and the changed world within which the bereaved individual must live without the deceased. He proposed four tasks that were necessary to adapt to the loss. These include accepting the reality of the loss, processing the pain associated with the grief, adjusting to a world without the deceased and withdrawing emotional energy from the deceased and reinvesting it in other relationships.

In sum, the majority of the traditional theoretical perspectives about grief focused on resolving grief by detaching from the deceased. However, while these models may have been useful in working with individuals who had lost their spouse, parents or grandparents, they were not very relevant to bereaved parents, for whom it was inconceivable to detach from their deceased child and reinvest energy in another relationship instead (Arnold et al., 2007). Arnold et al further explained that many of the conventional standards which indicated unresolved or abnormal grief were expected and normal aspects of parental grief. The next two decades witnessed a new and evolving approach to understanding grief. For instance, Worden (2018) revised the fourth of the four tasks of mourning and posited that bereaved individuals needed to find lasting connections with the deceased while simultaneously embarking on a new life. Studies with parents who had lost their children enriched knowledge and comprehension of parental bereavement, particularly the unique ways in which grieving parents maintained connections with their late children – that is, by preserving their children's possessions, telling stories about their children and engaging in rituals and memorial practices surrounding their children (Davies, 2004; Klass, 1993; Talbot, 2002). Such practices have together been termed as 'Continuing Bonds' and will be described in detail in the following section.

Continuing Bonds

Continuing bonds can be understood as an ongoing psycho-spiritual relationship between the bereaved person and the deceased person (Stroebe & Schut, 2005). A range of behaviours may fall under the umbrella of continuing bonds, including but not limited to reminiscing about the deceased (Marwit & Klass, 1995), browsing through photographs of the deceased or engaging in activities which the deceased would have enjoyed (Foster et al., 2011), narrating stories about the deceased or keeping belongings of the deceased (Silverman & Nickman, 1996 in Root & Exline, 2014) as well as engaging in philanthropic behaviours which honor the deceased (Foster et al., 2011; Meert et al., 2005).

Historically, continuing bonds were considered as a maladaptive response to the death of a loved one, and successful grief resolution was thought to be synonymous with detachment from or the severing of connections with the deceased, also known as the ‘breaking bonds’ perspective (Raphael & Nunn, 1988). In a review of research examining the evidence in favour of both continuing and relinquishing of bonds between the bereaved and the deceased, Stroebe and Schut (2005) explained the rationale for the breaking bonds perspective that had dominated grief and bereavement literature until the 1980s. Specifically, it was felt that bereaved individuals needed to withdraw emotional energy that had been committed to the deceased so that it could be available for new relationships and life goals in the present, and failure to do so could restrict the bereaved from seeking out alternative means to satisfy those needs which were formerly fulfilled in their relationship with the deceased. However, since the late 1990s, a growing body of research has rejected the idea of detaching from the deceased and instead focuses on a sustained relationship between the griever and the deceased. For instance, Silverman & Nickman proposed that bereaved individuals maintained an ongoing connection with their deceased loved ones by actively constructing a mental representation of them (Silverman & Nickman, 1996 in Root & Exline, 2014). Other researchers posited that maintenance of continuous bonds with the deceased was in fact a normal and natural part of bereavement and a key component of adjustment to the loss (Davies, 2004; Root & Exline, 2014).

In the case of parents who have been bereaved by the death of their young child, sharing memories and mementos with others (including their child's photographs, toys, clothes and handprints) can aid parents in meaningfully sustaining the relationship they share with their child within their inner and social worlds (Davies, 2005). Other ways of being connected with their child such as continuing to converse with their late child, imagining their child in his or her afterlife, visiting their child's grave, or associating with organizations that were meaningfully connected to the child's life and death can also aid parents to find comfort and reassurance, thereby assisting them in coping with their grief and smoothing the transition from the past to the present (DeCinque et al., 2006; Price & Jones, 2015). Thus, keeping a connection with the deceased can be viewed as a coping strategy that creates a link between the bereaved individual and their deceased loved ones, helping to moderate the emotional pain associated with the loss (Root & Exline, 2014).

Meaning Reconstruction

The notion of meaning reconstruction which stems from the field of constructivist psychology, has emerged as a central tenet of coping in grief and bereavement literature (Holland et al., 2006). According to Neimeyer (2000), reconstructing one’s narrative about death and its meaning can be viewed as a critical stepping stone for grieving individuals in their journey towards healing.

Neimeyer et al. (2010) posited that after the loss of a loved one, individuals generally undertake either of the following two meaning making processes. Firstly, individuals may try to assimilate their experience of the loss into their pre-loss beliefs, thus maintaining consistency with their existing self-narrative. Psychologically, this would comprise reconstructing their perception of the loss in a way that supports their central views about themselves and the world. For example, bereaved individuals may develop explanations for the loss that are consistent with their religious beliefs, or they may engage in downward social comparison. Secondly, individuals may try to accommodate the loss by re-organizing or widening their views and narratives about themselves to embrace the realness of the loss. For example, bereaved individuals may recognize and cherish the personal growth, learning outcomes and gains that accompanied the experience of loss (Tedeschi & Calhoun, 2004) and engage in ‘restoration-oriented coping’ which involves testing previously unexplored social roles and identities (Stroebe & Schut, 1999, 2010). Regardless of whether bereaved individuals assimilate or accommodate their grief experience, the goal is to re-establish a coherent worldview and self-narrative (Neimeyer et al., 2010).

Several studies have emphasized bereaved parents’ process of meaning reconstruction after the death of their child through both assimilation and accommodation processes. The studies found that some bereaved parents may attribute meaning to the limited lifespan of their child by recalling inspirational attributes in their child and the mark they have left behind (Foster et al., 2009). Other parents may relate the loss of their child to a journey of self-discovery and learning (Jordan et al., 2015; Reilly et al., 2008). Still others may aspire to make their child’s death count for something so that the deceased’s life would not be rendered meaningless (Rossetto, 2014). In sum, a large number of bereaved parents seek to uncover purpose and meaning in the tragedy of their child’s death, making it “count” and to reconstruct who they are in the physical absence of their child in their lives (Bogensperger & Lueger-Schuster, 2014; Titus & de Souza, 2011).

Post-Mortem Ritualization

Rituals can be explained as specific behaviors or activities that give “symbolic expression to certain feelings and thoughts of the individual”; they may be a “habitually repetitive behavior or a one-time occurrence” (Rando, 1985b). Death rituals, in particular, are of vital importance in the lives of human beings because they assist the survivor in coping with the physical and psychological stressors created by the death and offer a sense of meaning and validation to life transitions (Castle & Phillips, 2003).

Cacciatore and Flint (2012) explain that bereaved parents often yearn to have a physical and psychological connection to their late child. For such parents, rituals can serve as a powerful tool to: (i) sustain a continuing bond with their child, (ii) aid parents in coping by creating a sense of power and control over what appears to be an uncontrollable state of life, and (iii) facilitate posttraumatic growth by creating opportunities for parents to honor and memorialize the child.

They further explain that the psychological presence and physical absence that follows the death of one’s child can create ambiguity and stress for bereaved parents. In such circumstances, rituals offer a sense of continuing bonds, thereby affirming parents’ psychological proximity to their child, and validating their relationship with their child by continuing to recognize them as a beloved family member. Further, the shattered world assumptions and social roles that result from the untimely death of a child can leave bereaved parents feeling helpless and out-of-control (Janoff-Bulman, 2010). Rituals can help to lessen this feeling of powerlessness by helping bereaved parents to acquire a sense of control over their pain and suffering (Cacciatore & Flint, 2012). It is therefore vital for clinicians working with grieving parents to recognize the important role of rituals in coping with bereavement and explore ways in which rituals can help to (i) create a space in the life of bereaved parents to carry on a relationship with their deceased child, (ii) learn and grow from their experience of loss, and (iii) achieve healing and transformation in the process (Cacciatore & Flint, 2012; Castle & Phillips, 2003).

Posttraumatic Growth and Transformation

Since time immemorial, both suffering and the potentiality of growth as an outcome of suffering have been acknowledged as intrinsic to the human condition, but it is only recently that empirical research has focused attention on the possibility of personal growth following a trauma (Black & Wright, 2012). This phenomenon of experiencing positive change and psychological benefits as an outcome of a struggle with highly challenging life events has been termed as

Posttraumatic Growth by (Tedeschi & Calhoun, 2004), while other researchers have labelled a similar phenomenon as ‘adversarial growth’ (Linley & Joseph, 2004) and ‘stress-related growth’ (Park et al., 1996).

In their landmark research, Calhoun and Tedeschi studied individuals who had experienced traumatic events such as the loss of a loved one, focusing their attention on the growth outcomes experienced by such persons as a result of the crisis (Calhoun & Tedeschi, 2014). They found that majority of their participants had experienced changes in their perception of themselves. Specifically, participants reported feeling psychologically stronger, more capable and ready to face future crises as a result of their experience of grief and loss. Participants also reported positive changes in their relationship with their social networks. In discussing their findings, Tedeschi, Calhoun and Cann (2007) explained that positive changes associated with the trauma did not replace grief and other distressing outcomes of loss; instead, these positive changes occurred concurrently with and to some extent, as a result of having to face grief and loss. Taku, Calhoun, Cann and Tedeschi (2008) further highlighted that traumatic events such as crises or the loss of a loved one challenge an individual’s beliefs and worldviews, and a restructuring of such beliefs and worldviews is necessary in order to understand and make meaning of the traumatic experience. They posited that such restructuring of beliefs occurs via a cognitive process called rumination, which can be of two types: (i) Intrusive rumination (spontaneous automatic thoughts about the traumatic event) generally occurs in the immediate aftermath of an event. (ii) Deliberate rumination (intentional thoughts about the traumatic event) generally occurs after the initial shock and distress of the event has subsided. While intrusive rumination is more likely to result in distress, deliberate rumination serves as a starting point for posttraumatic growth.

In a systematic review of articles examining bereaved parents' experience of post-traumatic growth, Waugh et al. (2018) posited that the trauma of child loss can result in posttraumatic growth for bereaved parents, notably in the areas of changed self-perception and social relationships, improved appreciation of life, and re-thinking of priorities and existential changes. In their review, they found that mothers tended to report greater posttraumatic growth experiences than fathers. Further, posttraumatic growth was more prevalent in bereaved parents with the passage of time since their child's death and religion played an important role in influencing how posttraumatic growth was experienced. Importantly, the review identified important areas for clinical facilitation to smooth the process of posttraumatic growth for grieving parents including being with other parents who had experienced a similar loss, engaging with supportive social networks that respect and validate continuing bonds with their late child, and an ability to find meaning in the experience of loss (Waugh et al., 2018).

Posttraumatic growth could be valuable for understanding the nature of grief and healing for bereaved parents. For example, Foster et al. (2009) documented the role of posttraumatic growth among 63 bereaved parents who had lost their child to cancer in the United States, while Hynson et al. (2006) found evidence for posttraumatic growth among 69 parents who had lost their child to a range of chronic condition in Australia. However, because of limitations in the scope and sample size of studies conducted till date, it is unclear whether findings from these studies would be universally applicable. Clearly, more mixed methods and rigorous qualitative studies are needed which can offer insight on the parental experience of post-traumatic growth following the loss of their child.

Palliative Care and Pediatric Palliative Care

> *"The goal is to add life to the child's years, not simply years to the child's life."*
>
> — American Academy of Pediatrics (2000)

The World Health Organization (WHO) defines palliative care as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (World Health Organization, 2020). Pediatric Palliative Care (PPC) is a subspecialty of palliative care which is focused on providing holistic and integrated care across the illness trajectory to enhance the quality of life of children and young persons with a life-limiting condition (Collins et al., 2016). Such care includes the family and extends into the domains of physical, psychological, social, and spiritual wellbeing (Liben et al., 2008).

According to the WHO, palliative care for children can be defined as "the active total care of the child's body, mind, and spirit, and also involves giving support to the family. It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease.” The WHO further explains that it is necessary for healthcare professionals to assess and reduce the physical, psychological, and social distress faced by a child receiving palliative care services. For pediatric palliative care to be delivered efficiently, a multidisciplinary approach must be adopted which includes the child’s family as well as any resources that might be available within the community. Finally, pediatric palliative care can be delivered in specialized care facilities, community healthcare institutions and even in children’s homes (Sepúlveda et al., 2002).

Along similar lines, the International Children's Palliative Care Network (ICPCN) recommends that children’s palliative care must be recognized as a unique service which provides every child and young person with a life-threatening condition and their families with the best quality of life and care, which encompasses physical, emotional, spiritual and developmental aspects of care (International Children’s Palliative Care Network (ICPCN), 2015). Himelstein et al. (2004) recommended that pediatric palliative care must coincide with disease curation and healing, and it must be introduced to the patient and family early in the illness trajectory, such that the diagnosis and treatment are not restricted to the disease process. Further, the authors proposed that diagnosis and treatment of the disease can in fact become a means for enhancing quality of life, preserving dignity, and reducing pain and suffering for seriously sick children in culturally appropriate ways.

The Association for Children’s Palliative Care and the Royal College of Pediatrics and Child Health developed the first systematic categorization of children's illnesses that stood to gain from a palliative care approach. Specifically, PPC is suitable for any condition whose trajectory can be described by one or more of the following categories (Williams et al., 2008; Wood et al., 2010):

1. Conditions for which curative treatment may be possible but could fail, such as advanced cancer or cancer with a poor prognosis, complex and severe heart disease.
2. Conditions in which there may be long periods of intensive treatment to prolong life and allow participation in normal childhood activities, but untimely death is still possible, such as cystic fibrosis, muscular dystrophy, and renal failure cases in which dialysis or transplantation are not possible.
3. Progressive conditions without cure where treatment is centered on alleviation of pain and may span several years, such as Batten's disease, progressive metabolic disorders, and chromosomal abnormalities like trisomy 13 or trisomy 18.
4. Conditions with severe neurological disability which may result in weakness and vulnerability to health complications, such as severe cerebral palsy, extreme prematurity, and severe brain malformations.

The National Hospice and Palliative Care Organization (NHPCO, 2009) provided a detailed description about the contrast between palliative care in the case of children versus in the case of adults. Specifically, the NHPCO pointed out the following:

First, children are not merely small adults. There are differences between infants, children, and adolescents with regards to their physical, cognitive and emotional development, which in turn impacts the process of diagnosis of their illness, prognostic certainty, treatment plans, illness-related communication and decision making.

Second, children have varying degrees of physiological resilience, which can make it difficult to predict their future. Many medically complex children are born with uncommon conditions, which can make it challenging to diagnose and manage their illness.

Third, many communities do not have a large enough number of children with life-threatening medical conditions, and hence there is insufficient expertise to look after such children. Because of this, children with complex medical conditions and their families may have to travel to locations far from their home to seek treatment. This alienates sick children and their families from their practical and emotional sources of support, may impact parents' jobs, and places additional demands on family relationships and finances.

Fourth, unlike adults, children do not have a legal voice. Their healthcare decisions are often managed by their parents. This can pose challenges in terms of formal advance directives for young patients.

In addition, it is important to note that many of the challenges that are faced by children with complex medical conditions and their families are rooted in larger social, economic, and cultural problems. Therefore, care for medically complex children must take into account the larger communities of which the children are a part (such as their school, neighborhood, and place of worship), and their continuing interaction and development in these communities must be incorporated into their care plan. Finally, the grief associated with a child loss can have deleterious, long-term impact for the parents, siblings, extended family, and the community.

In summary, pediatric palliative care acknowledges that people of all age groups, including children, can die. Professional care must focus on relieving the young patients' pain and suffering as well as incorporating care for the patient's family, both before and after death.

Professional Interventions and Services for Parents of Children with Chronic Life-Threatening Conditions

There is empirical evidence regarding the adverse impact of child loss on bereaved parents (Attig, 2004; Raphael, 1994; Schwab, 1992). But one might wonder whether parents bereaved by the loss of their child need professional assistance to cope, and more importantly, whether formal intervention programs are effective in helping bereaved parents cope. Such questions have in current times become a topic of investigation.

Post-Loss Interventions and their Impact on Parental Well-Being

A number of professional interventions have focused on parents mourning the loss of a child (Chambers & Chan, 2000; Flenady & Wilson, 2008; Harvey et al., 2008). Such interventions can be in the form of professionally facilitated or peer-led support groups where parents have the opportunity to connect with others who have had similar experiences (Aho et al., 2012; DiMarco et al., 2001; Heiney et al., 1995) or they can be psychoeducational in nature, thereby equipping parents with necessary knowledge, skills, emotional competency, and other resources to enhance coping (Murphy et al., 1998; Murray et al., 2000).

Hospital-based intervention programs generally take the form of ongoing communication and connection with bereaved parents through activities such as contacting of the bereaved family, visiting the funeral home, psycho-educational meetings with parents and their social support network, periodic sending of letters or notes and phone calls on the deceased child’s birth and/or death anniversary; evidence indicates that most parents are appreciative of such efforts from their late child’s healthcare team (Berrett-Abebe et al., 2017; Borgman et al., 2014; Contro & Sourkes, 2012; Oliver et al., 2001). Other intervention services have focused on the couple relationship post-bereavement, thereby helping couples to better understand each other and express their grief-related feelings and thoughts more effectively to each other as well as to other members of their family (Reilly-Smorawski et al., 2002). Some research also indicates that mindfulness-based intervention may have positive outcomes for grieving parents by helping to improve their ability to withstand painful emotional states, enhancing their ability to respond to experiences with conscious awareness, and decreasing distressing symptoms and enhancing overall well-being (Cacciatore et al., 2013); however, keeping in view that Cacciatore et al.’s study employed a case study methodology, there is need for more research to establish the robustness of these findings.

In a systematic review spanning of randomized controlled trials of bereavement support interventions for parents who had experienced child loss which spanned three major databases (MEDLINE, PsycINFO and CINAHL), Endo et al. found that only nine research articles had been published on the development, implementation, and efficacy of structured interventions to support bereaved parents of young children (Endo et al., 2015). More interestingly, Endo et al. concluded that despite a total sample size of more than 200 bereaved individuals, there was little evidence to support the effectiveness of professionally facilitated interventions for bereaved family members following the loss of a child. In other words, considerable caution must be exercised before assuming that any bereavement support intervention for parents will be better than none at all.

Services for Parent-Caregivers and their Impact on Parental Well-Being

A number of professional interventions and welfare initiatives have been implemented with the aim of providing support and relief to parent-caregivers of children facing chronic life-threatening conditions. One common type of intervention is support groups of parents facing similar challenges, whose benefits include discovering a common social identity, access to a platform for learning pragmatic skills and knowledge, learning from and deriving inspiration from others, experiencing personal growth and having an opportunity to support others – also known as the helper-therapy principle (Shilling et al., 2013). Examples of peer support groups include the Butterfly Project by the National Health Service in the UK (Nottingham University Hospitals NHS Trust, 2020) and the Living Room by Cancer Support Community in the US and Canada (Leukemia and Lymphoma Society, 2016). Such peer support groups facilitate conversations among families of children facing chronic life-threatening conditions with the aim to augment practical and emotional support from the time of diagnosis, throughout the child's life, through end-of-life and bereavement. However, not all parent-caregivers may benefit from support groups, as the process of disclosing personal details to strangers could be perceived as daunting for some individuals, while others may face scheduling difficulties amidst their hectic caregiving responsibilities (Nicholas & Keilty, 2007).

Another common welfare initiative to support parents of children with chronic life-threatening illnesses is Respite Care, which aims to momentarily relieve parents of their daily caregiving responsibilities, thereby improving family functioning through stress relief and time for self-care (Neufeld et al., 2001). For example, programs like Chai Lifeline Canada (Chai Lifeline Canada, 2020) and No Barriers USA (No Barriers, 2019) organize outings and retreats where the children are looked after by trained staff and volunteers while parent-caregivers have the opportunity to take time out for self-care and rest, recharge and foster new friendships with other parents who can empathize with their difficulties, provide support and share useful resources to enhance caregiving. In Singapore, similar family outings are organized by Star PALS/HCA Hospice Care (HCA Hospice Care, 2018a), in addition to monthly respite care services which allow parent-caregivers to run errands or take time off while their children are looked after by trained personnel at home (HCA Hospice Care, 2018b).

However, not all communities have such respite services due to inadequate resources and shortage of expertise required to provide care to children with uniquely challenging conditions (Neufeld et al., 2001).

More recently, the Temasek Foundation Cares — Caregiver Support Program for Families with Chronically Ill Children on Long-term Home Care was implemented in Singapore in collaboration with KK Women's and Children's hospital. The pilot program was designed to support caregivers of children with chronic illnesses via counselling services and home-based respite care. Findings showed that in a sample of 110 participants, 70% of participants reported a reduction in stress levels and 86% indicated reduced risk of depression, thereby suggesting that the program was relatively successful in meeting its objectives. Importantly, this program drew attention to the barriers faced by parent-caregivers which prevent them from receiving potentially helpful interventions. Specifically, of the 179 caregivers who were invited to participate, 69 caregivers declined due to unavailability of time for participation and the discomfort of having strangers in their homes. This means that future initiatives for parent-caregivers must be mindful of such barriers and design the intervention in a way that is sensitive to the needs and limitations of the target population.

In sum, there appears to be a dearth of research on and a general lack of empirical evidence to support the efficacy of bereavement intervention for parents post the loss of their child. While there are some interventions and programs which are designed to improve the well-being of parents caring for their children with chronic life-threatening illnesses, such interventions are often unable to address the complex and multifaceted challenges that parent-caregivers face, especially those concerning the impending death of their child and anticipatory grief. Moreover, the majority of the interventions for parent-caregivers are embedded within the Western context (for example, the Butterfly Project, the Living Room, Chai Lifeline Canada and No Barriers USA) with limited availability in Asia and Singapore, while empirically informed interventions for improving the lives of families where a child is living with a chronic life-threatening illness are limited in number and efficacy. This has resulted in a critical gap in holistic healthcare service delivery in pediatric palliative care in the local context.

Understanding and Working with Anticipatory Grief

As mentioned in the previous section, an important concern for parent-caregivers is coming to terms with the impending mortality of their child with chronic life-threatening illness and coping with the resulting anticipation that they face. In fact, the concept of anticipatory grief has been awarded considerable research attention in the past few decades and will be described in detail in this section.

Anticipatory grief can be understood as grief which occurs prior to a loss, and is distinguished from grief which occurs at or after a loss (Aldrich, 1974). Parkes (1976) explained that it was imperative for family members to recognize and accept the grief that they experienced in regard to the expected and impending death of a patient in order to successfully navigate their grief both before and after bereavement. Since the term ‘Anticipatory Grief’ was originally coined (Lindemann, 1944), it has increasingly gained currency in discussions surrounding families and patients facing a chronic terminal illness such as cancer (Sweeting & Gilhooly, 1990).

Research suggests that anticipatory grief occurs in a series of stages, namely, feeling shocked about the impending loss, denying the realness of the loss, and eventually accepting the loss (Kubler-Ross, 2009; Okawa et al., 2001). This mental process is integral to adaptation and acceptance of the patient’s illness and death and is not merely a response to it (Rando, 2000). Although anticipatory grief can be viewed as a normal response or experience when death is expected amongst loved ones, many individuals struggle to cope with and process this grief, resulting in the need for psychological and emotional interventions to aid mourners in successfully coping with the imminent loss (Worden, 2018).

Impact of Anticipatory Grief on Post-Bereavement Adjustment

Working through grief when the loss is still anticipated can ease the process of coping with the mortality of a loved one, since the individual has the space and time to process the loss prior to its actual occurrence (Pine, 1974). Since the 1970s, several studies have examined anticipatory grief in caregivers of dying patients. Clayton et al. (1973) found that caregivers who showed depressive symptoms at the time of the terminal illness were likely to manifest depressive symptoms one month after the death of their loved one. Gerber (1974) posited that lengthy exposure to anticipatory grief may account for poor subsequent adjustment.

Some authors have challenged the concept of anticipatory grief, insisting that grief is exclusive to the experience of loss and cannot be experienced in advance (Doka, 1985; Fulton, 2003; Glick et al., 1974). In a direct address of these contradictory findings, Reynolds & Botha (2006) presented their consolidated analysis of the literature, and explained that much of the inconsistent and contradictory findings related to anticipatory grief could be attributed to the lack of a precise and consistent operational definition, along with numerous methodological issues. The authors highlighted that there was need for further research to document the impact of anticipatory grief on post-loss adjustment so that the findings could meaningfully inform clinicians and interventionists working with individuals facing impending and actual loss of a loved one.

In recent times, studies have reported that low levels of death preparedness among caregivers of patients with severe illnesses can result in adverse bereavement outcomes such as complicated grief, depression and anxiety (Nielsen et al., 2016). At the same time, bereavement interventions in anticipation of the death of a loved one served as a protective factor against poor health outcomes for family caregivers (Cheng et al., 2010; Flanagan-Kaminsky, 2013; Meichsner & Wilz, 2016). Toyama and Honda (2016) explained that pre-bereavement interventions could help free family caregivers from feeling trapped in their caregiver role, assist them in recognizing their emotions, accept the impending death of their loved one and begin to grieve. Notably, the authors found that a pre-bereavement intervention which employed a narrative approach could help Asian family caregivers to work through their anticipatory grief and express their trapped emotions.

Particularly in the context of parent-caregivers facing their seriously ill child’s impending mortality, research shows that when anticipatory grief is appropriately addressed prior to death, it is positively associated with preparedness at the time of death and fewer atypical outcomes subsequent to death (Rando, 1983). Other recent evidence indicates that parents who received psychological support at their child’s end-of-life and a platform to discuss their child’s impending death either with healthcare practitioners or with other parents faced with a similar situation had more favorable bereavement outcomes (Kreicbergs et al., 2007). Thus, the data highlights that psychosocial interventions for supporting parent-caregivers’ experience of loss and grief need to be targeted not only post-death, but simultaneously alongside palliative care provision to their child.

Coping with Anticipatory Grief at the End-of-Life

While there are only a handful of empirically-supported high-quality interventions for addressing anticipatory grief in patients facing end-of-life and their families, all of the interventions till date are associated with positive outcomes such as improvement in quality of life, death preparedness, spiritual well-being as well as a decrease in levels of anxiety, depression, suffering and distress (Patinadan et al., 2020). Dignity therapy is one of the more notable and well-examined approaches to addressing anticipatory grief at the end-of-life (Chochinov et al., 2005, 2011; Guo et al., 2018; Julião et al., 2013, 2014;

Vuksanovic et al., 2017). Dignity therapy (DT), which is based on Chochinov's model of dignity conserving care (Chochinov et al., 2002) is a brief, individualized psychotherapy that aims to relieve psycho-emotional and existential distress of patients facing the end of life by providing them with the opportunity to reflect on experiences that are important to them, speak about things that they would like to be remembered by and wisdom that they like to transmit to others. A dignity therapy interview session is transcribed, edited and developed into a 'generativity document' by the dignity therapist, and presented to the patient at the close of therapy. Studies examining the efficacy of dignity therapy indicate that it is successful in improving patients' quality of life, spiritual well-being and sense of dignity and reducing their sense of sadness and depression (Chochinov et al., 2011). Other research has reported improvements in terminally ill patients' levels of anxiety and depression (Julião et al., 2013, 2014) and a greater sense of generativity and ego-integrity following dignity therapy (Vuksanovic et al., 2017).

Inspired by the tenets of dignity therapy (Chochinov et al., 2002) as well as a vast body of research that examined the contract of dignity in the Asian context, Ho et al. (2017) developed Family Dignity Intervention (FDI) which is tailored to the needs and cultural nuances of Asians facing end-of-life by including not just patients but also their family in the therapeutic dialogue. Apart from reflection and articulation of important life experiences, FDI also focuses on the expression of appreciation, finding reconciliation, and passing on wisdoms for sustaining the family lineage. It is the first known evidence-based culturally sensitive intervention for holistic end-of-life care in Asia which is currently being tested via a multi-center randomized controlled trial (U.S. National Library of Medicine, 2018). Preliminary findings have provided robust evidence of FDI's efficacy in enhancing patients' quality of life, hope, positive life outlook, life value, life meaning and perceived social support, while family caregivers also experienced significant increase in hope, life value and positive life outlook, as well as significant decrease in caregiver stress and depressive symptoms compared to the control group (Ho, et al., 2019a). While these findings are encouraging, there is no documentation of the effectiveness of FDI in enhancing quality of life and well-being of young patients and their family caregivers. Further, an extensive search of literature did not reveal any intervention which would addresses anticipatory grief among Asian parent-caregivers facing their child's end-of-life and death.

Meaning-Reconstruction and Narrative Intervention to Support End-of-Life Caregiving

According to Gilbert (1996), the majority of the traditional approaches to grief therapy fall short because of the underlying assumption that all mourners must respond to loss in a similar emotional level and fashion. In contrast, the meaning-reconstruction model lays emphasis on the unique features of each individual's grief reaction, such that no two grievers are assumed to be experiencing the same thoughts and feelings in response to a loss (Gilbert, 1996). Rather, each individual is seen as actively constructing a unique phenomenological world and occupying a unique position within this world in relation to social forces such as culture, gender and spirituality (Neimeyer & Keesee, 1998). Further, the meaning-reconstruction model acknowledges that although bereavement may appear to be a ‘choice-less’ process that mourners have unwittingly become a part of, it in fact propels mourners to enter a phase of expedited decision making – for instance, grievers need to make a choice of whether they want to direct their attention on doing grief work of sorting through their turbulent feelings or make practical adjustments to their daily life in the aftermath of the loss (Attig, 1991). In that sense, the meaning-reconstruction model can greatly add value to the lives of grievers by helping to identify the various choices grievers have to revise their life narratives.

Recounting the narrative about the death of a loved one can help to reconstruct the narrative in a manner that assimilates the loss into the life of the griever and adjusts their relationship, regardless of the physical presence of the deceased (Ring, 1980). Research on stress and emotion suggests that a narrative approach can potentially be helpful to individuals in reframing their emotional experiences (Lazarus, 2006). Specifically, a narrative approach can be successfully employed to assist an individual to explore their emotional experience and restructure it in a manner that is more adaptive. Empirical data supports the effectiveness of the narrative approach in helping individuals get in touch with emotions that are challenging to accept (Morris et al., 2015) and for individuals with chronic pain to generate new meaningful stories about life (Dysvik et al., 2013).

Other research employing a narrative approach suggests that family caregivers often find themselves in a unique isolated experience, talking can help to restructure their negative emotional appraisal of situations into more positive ones (Williams et al., 2013). In sum, these studies together indicate that while a narrative intervention cannot change the reality of the loss, it could aid in restructuring the meaning and significance of the story associated with illness and death. However, there is no known study which assesses the efficacy of using a narrative intervention to assist bereaved parents in coping with the loss of their young child due to a chronic life-limiting condition.

Expressive Writing as a Therapeutic Tool

Over the past two decades, expressive writing or written disclosure therapy has been extensively used in counseling psychology to heal individuals suffering from physical and mental stress (Brinkman-Stoppelenburg et al., 2014; Halpert et al., 2010; Lumley et al., 2011; McGuire et al., 2005; Rosenberg et al., 2002; Sloan et al., 2008; Smyth et al., 1999). The underlying mechanism which brings about benefits associated with expressive writing has also received some attention. One argument is that writing provides a platform for emotional catharsis or release which is known to have robust therapeutic benefit (Pennebaker, 1997). Others cite that writing can assist individuals to engage in cognitive processing of their painful memories and emotions thereby resulting in more adaptive and integrated representations of the self and others (Harber & Pennebaker, 1992). Still others insist that self-expression through writing facilitates the creation of a structured narrative over time which encourages continuous processing and search for meaning in one’s traumatic experiences (Smyth et al., 2001).

There is some evidence about the optimal conditions for engaging in writing therapy. Specifically, it is suggested that a private space with minimal disturbance such as one’s home, writing about recent events that one has not yet engaged in self-disclosure about and a minimum of three sessions of at least fifteen minutes each is more beneficial (Frattaroli, 2006). Other evidence identifies population groups that may be more suitable for participating in expressive writing. Precisely, since the inherent nature of writing implies that the individual requires reading and writing skills, very young children and illiterate individuals are unsuitable for expressive writing interventions (Mugerwa & Holden, 2012). Writing for therapeutic gains is also found to be unfitting for persons who are chronically depressed, highly disturbed, suffering from psychoses or post-traumatic stress disorder (Ashworth et al., 2003). Interestingly, some studies also suggest that writing as a means of emotional expression may be most therapeutic for individuals who are ambivalent about expressing their emotions or individuals who consider stoicism during stressful times to be a highly regarded personal value (Lu & Stanton, 2010; Norman et al., 2004). Finally, there is some data that writing as a therapy may result in increased short-term distress for patients with chronic physical illness, but this negative state does not persist beyond the immediate writing experience, implying that the process of writing about emotionally traumatic experiences does not pose a risk for such patients (Hockemeyer et al., 1999). More research is needed to verify these findings and assess their generalizability in diverse populations.

Online or Cyber Counseling Interventions

For more than half a century, different mediums such as letters, telephone and closed-circuit televisions have been employed to deliver counselling interventions where face-to-face interactions are not feasible (Perle et al., 2011). With the advent of the digital revolution, mental health service delivery also shifted online, resulting in a corresponding upsurge in the number of websites offering psychoeducation, internet-based support groups, self-help programs, and one-to-one counseling with a therapist carried out via emails, text messaging and internet-based voice or video calls (Abbott et al., 2008; Barak et al., 2008; Ybarra & Eaton, 2005). An online psychological intervention may be defined as "any delivery of mental or behavioral health services, including but not limited to therapy, consultation, and psychoeducation, by a licensed practitioner to a client in a non-face-to-face setting through distance communication technologies such as telephone, asynchronous email, synchronous chat, and videoconference" (Mallen & Vogel, 2005, p. 764). An internet-based intervention is "a primarily self-guided intervention program that is executed by means of a prescriptive online program operated through a website and used by consumers seeking health and mental health related assistance. The intervention program itself attempts to create positive change and or improve/enhance knowledge, awareness, and understanding via the provision of sound health related material and use of interactive web-based components" (Barak et al., 2009).

Effectiveness of Online Psychotherapeutic Interventions

A number of studies have examined the effectiveness of such online psychological interventions and the consensus is that internet-based mental health care services are equivalent in efficacy to their face-to-face counterparts (Barak et al., 2008; Gainsbury & Blaszczynski, 2011; Kaltenthaler et al., 2004; Lichtenthal et al., 2019; Newman et al., 2011). In a review of the effectiveness of randomized controlled trials of self-help internet interventions, a decrease in risk factors and improvement in symptoms was reported for conditions including depression, anxiety, stress, insomnia, headache, eating disorder and encopresis (Griffiths & Christensen, 2006). Further, therapist-supported computerized interventions can be a less-intensive and economical method of delivering empirically-founded treatments for a range of psychological conditions including anxiety, depression and other mood disorders (Newman et al., 2011). In a comprehensive review and meta-analysis of web-based psychological interventions and their effectiveness, Barak et al. (2008) reported an overall effect size of 0.53, which is in the medium range, and similar to effect sizes obtained in conventional face-to-face psychological interventions. Moreover, the authors noted that written forms of online communication such as chatting and emailing were more effective than internet-based audio and video modalities.

Other studies have also examined the process of online text-based counseling, including factors such as therapeutic alliance, session impact and client attitudes towards such sessions. Specifically, it has been reported that online live-chat therapists use a variety of strategies to build rapport and gather information in order to counterbalance the absence of nonverbal cues (Williams et al., 2009). Some authors fear that online chats can make it more challenging for therapists to interpret their client’s verbal and non-verbal expressions and provide relevant direct guidance, as compared to face-to-face sessions (Mallen et al., 2011). Other authors opine that the relatively slower pace of online chat sessions may restrict the variety of strategies that are employed (Williams et al., 2009). Moreover, it is possible that online chat counseling could hinder the establishment of a therapeutic alliance (Fenichel et al., 2002). In direct address of these legitimate concerns, Hanley (2012) emphasized that online therapeutic alliance is directly affected by why the individual chose to get help via an online chat platform, the therapist’s own online communication skills (for example, usage of emoticons), technical barriers, and sense of control over the session (for example, nature of the intervention and frequency of interactions). Further, these difficulties in fostering a virtual therapeutic relationship can be counterbalanced by the intervention-recipient’s enhanced readiness to self-disclose when communicating online, also known as the Online Disinhibition effect (Suler, 2004).

An Integrative Approach: Online Narrative Writing Intervention Platform

Expressive writing can be an important tool in the realm of counseling interventions, which is further enhanced by its cost-effective nature and ease of accessibility for participants (Mugerwa & Holden, 2012). Additionally, online counseling in written form has the potential to address mental health concerns of a varied client population (Hanley, 2012; Suler, 2004), including caregivers of patients living with chronic illnesses (Ko, 2011). Drawing from these suppositions, it can be reasonably predicted that integrating the advantages of writing as a means of expression and the feasibility of internet-based platforms would result in an efficacious intervention strategy for parents of children with chronic life-threatening illness who suffer from intense negative affect due to the trauma of caregiving and death of their child. Narrative writing on an e-platform can also be useful for parents who are currently caring for a child with chronic illness since they can engage in such an activity within the comforts of their home and without extensive financial investment. Further, parents of young children in the 21st century are educated and cognizant of information technology (Leu et al., 2004). They are likely to be frequent consumers of texting apps and electronic written communications such as email (Carbonell et al., 2013).

Despite these scattered findings which form the pillars of the narrative e-writing model, there is no known study which explores expressive writing on an online platform as an intervention strategy for parents facing the chronic life-threatening illness of their child or parents bereaved by the death of their child due to a chronic life-threatening illness. This discovery is rather surprising since one would imagine that new-generation parents caring for their terminally ill child would be hard pressed for time to attend face-to-face counseling services. Yet the prevalence of information technology has made it possible to overcome these barriers of space and time and provide psychosocial support to clientele with diverse needs. Currently, with the increasing demand for evidence-based interventions, it becomes crucial to carry out a formal evaluation research with rigorous methodology and clearly defined criteria and objectives, to assess the potential efficacy of a therapist-supported narrative writing e-platform in improving mental health outcomes for parents of children with terminal illness.

The Uniquely Singaporean Culture: Ethnic Composition, Family Centeredness and Digital Readiness

To understand the perspectives and experiences elicited by participants within any investigation, it is important to discuss the cultural context in which the investigation occurred. The following section provides a brief description of the cultural context within which the doctoral research described in this thesis was conducted.

This study was conducted in Singapore – one of the most plural societies in Southeast Asia whose residents (Singapore citizens and permanent residents) are of predominantly Chinese origin (approximately 74% of the population), followed by those of Malay (approximately 13%) and Indian (approximately 9%) origin (Department of Statistics Singapore, 2020). A variety of cultural and religious beliefs and practices intersect these ethnic diversities with 33.3% of the population identifying themselves as Buddhists, 18.3% as Christians, 14.7% as Muslims, 10.9% as Taoists, 5.1% as Hindus, and 17% as others (Tan, 2012). Similar to other Asian communities such as China, Japan, Hong Kong, South Korea, Malaysia and Indonesia, the Confucian value of prioritizing the larger community or country before oneself is regarded highly while Western ideologies such as individualism, hedonism and self-centeredness are discouraged in Singapore (Tan & Tan, 2014; Velayutham, 2007). In fact, research shows that Singapore is the least individualistic and most collectivistic country in a study involving participants from the USA, Hong Kong and Singapore (Hwang et al., 2003).

In Singapore, as in other Asian communities, family, rather than the individual, is seen as the basic unit of life (Ho, 2013; Ho et al., 2014; Tan, 2012), and important decisions such as those concerning health and well-being are made in consideration with the family (Ho et al., 2020). Following an extensive research with end-of-life patients and their family caregivers in Hong Kong, Ho (2013) explained the powerful role of family integrity, mutual support and reciprocal relationship when working with Asian patients and their families facing serious illness and impending mortality. However, because of the Asian cultural taboos surrounding death, communication tends to be primarily pragmatic in nature, focusing on physical care with little opportunities for emotional connections (Ho et al., 2017). Hence, in order to reduce suffering and increase a sense of hope and meaning in patients and their families facing illness and impending death, family must be a critical component of any palliative care intervention in an Asian community (Ho et al., 2017, 2014). The important role of family in end-of-life and palliative care has been documented in a number of studies in Singapore as well (Dutta et al., 2019; Ho et al., 2017; Krishna et al., 2014; Lee et al., 2013).

In addition to its multicultural composition and adoption of collectivistic values, another unique feature of Singapore particularly within the context of this doctoral research is its digital readiness. Concisely, Singapore is the world's second most digitally competitive country (Yip, 2019) with residents using their smartphones and tablets everywhere and for everything from social networking to online research on a daily basis (Digital News Asia, 2017; WARC, 2017). It is therefore reasonable to posit that app and web technology could play a vital role in bolstering palliative care and delivering interventions within this digitally savvy cultural context.

Context of the Current Research

Presently, there is limited literature across the globe and no known study in the Asian context which examines the lived experience of parental grief and bereavement due to a child's chronic life-threatening condition. Further, there is no known evidence-based psycho-socio-spiritual intervention which addresses the needs and challenges of Asian parents who are caring for their child with a chronic life-threatening illness. This doctoral research aimed to bridge this gap in findings via a three-pronged mixed methods investigation. Specifically, this research examined the lived experience of parental bereavement internationally by comprehensively studying relevant research articles that had been published throughout the world since the year 2000. In the following section, the research explored the lived experience of Asian parents who cared for their child with a chronic life-threatening condition who subsequently died as a result. The focus of the study was on identifying similarities and differences between the international and local lived experience of parental bereavement and identifying strategies for enhancing well-being of parent-caregivers in the local context. Finally, the research developed, implemented and evaluated a culture-specific and meaning-oriented anticipatory grief e-intervention titled ‘Narrative e-Writing Intervention (NeW-I)’ for parents who are caring for their child living with a chronic life-threatening condition. This intervention was inspired by the findings of the systematic international literature search and the local lived experience of parental bereavement, as well as informed by the cultural specificities of the Singaporean context in which the intervention was trialed. It is hoped that the findings from this doctoral research can inform pediatric palliative care services and policy, as well as set the tone for future studies in this area, thereby enhancing quality of life and well-being for grieving parents of young children - a vulnerable group that often falls between the gaps of holistic service delivery.

Chapter Summary

This chapter has provided a thorough literature review on the emerging perspectives that enhance understanding of parental grief and bereavement and the goals of pediatrics palliative care as outlined by notable institutions such as the WHO, Association for Children’s Palliative Care and the Royal College of Pediatrics and Child Health. This chapter further points out the inadequacies in existing interventions and services that are designed for parents grieving the actual or impending loss of their child, and introduces the concept of anticipatory grief as being vital for providing care and support to parents facing child loss. Finally, the meaning reconstruction framework and narrative intervention, together with the use of the internet as a therapeutic medium are proposed as potentially useful empirical foundations for supporting grieving parents, especially in the Asian context. Essentially, this chapter illuminates the fundamental basis of the present research.

CHAPTER THREE

METHODOLOGY

This chapter describes the methodology adopted by this research which comprised a three-pronged mixed methods study. The chapter has been divided into three broad sections, each of which elucidates one of the three studies which together make up this research. This includes: (i) A qualitative systematic review of global experience of parental bereavement; (ii) A Singapore-based qualitative inquiry on the lived experience of parents who cared for and subsequently lost their child suffering from a chronic life-threatening illness; and (iii) The development, implementation and evaluation of an open-label mixed methods pilot randomized controlled trial for a novel internet-based narrative writing intervention for parent-caregivers of children facing chronic life-threatening illnesses in Singapore.

Study 1: Design and Framework for a Qualitative Systematic Review to Understand the Parental Lived Experience of a Child's Chronic Life-Threatening Illness and Death

Study 1 of this research comprised a qualitative systematic review which was carried out to survey the relevant literature that would inform and shape the subsequent research journey. The following section discusses the methodology of Study 1 in detail.

Search Strategy and Inclusion Criteria

In February 2017, a comprehensive and systematic search of literature was performed across six key databases including MEDLINE, PsycInfo, CINAHL, ERIC (EBSCO), ProQuest and Social Science Citation Index. This search was subsequently updated in February 2018. The Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) framework informed and guided the review (Liberati et al., 2009). A search strategy was designed in accordance with the SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) tool (Cooke et al., 2012). Unlike other well-known tools such as PICO/ PICOS, whose reliability is restricted to systematic reviews which have a quantitative research question, the SPIDER tool is known to be appropriate for systematic reviews focusing on qualitative studies (Cooke et al., 2012). The specific search terms that were adopted for the purpose of this systematic review are as follows:

> *(((bereaved parents) OR (bereaved NEAR/3 parent* OR parental grief) OR (Grie* NEAR/5 parent*)) AND ((infant mortality) OR (child mortality OR end of life NEAR/3 child*) OR (death* OR passing* OR pass* OR demise* OR decease* OR depart* OR died OR dying*)) AND ((child* OR adolescent* OR teenager* OR teen* OR juvenile*) OR (critically* ill* OR chronic* ill*)) AND (child* OR adolescent* OR teenager* OR teen* OR juvenile* OR infant* OR baby OR bab* OR toddler* OR kid* OR youngster*) NOT (((parental deaths) OR (childhood bereavement OR parental deaths) OR (accident* OR suicide*) OR (homicide* OR murder*)))) AND la.exact("ENG")*

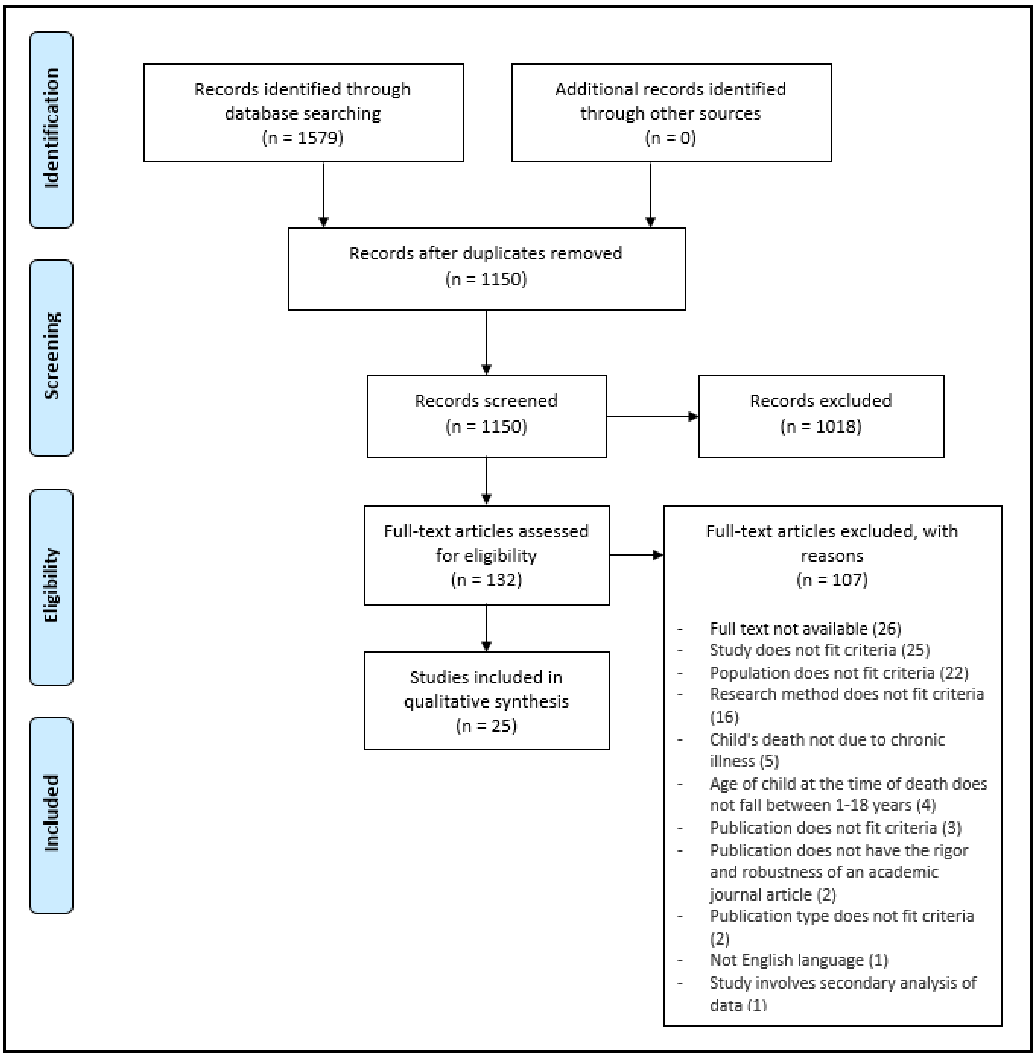
Identified journal articles were included in the review if they met the following three criteria. First, the sample comprised parents whose child suffered from a chronic life-threatening condition and subsequently died as a result of it. Second, the focus of the research was the lived experience of these parents as they journeyed from caregiving to anticipation of death to bereavement. Third, the study design involved face-to-face or telephonic verbal interviews and the study was either qualitative in nature or employed a mixed methods approach with a notable qualitative component. For the purpose of this systematic review, a ‘parent’ was operationally defined as any adult who was the primary family caregiver of the child. Further, it was a requirement that the child’s age at the time of his or her death must have been between 1 to 18 years. Research articles involving parents whose child had deceased within the first year of his or her life were excluded because the objective of this review was to examine the lived experience of parents who had undergone the death of a child whom they have spent ample time caring for, rather than a newborn or infant. Only original studies published in English between 2000 and 2017 were retained for analysis, since recent findings would be able to provide greater insight to academicians and clinicians working in this field. Articles were excluded from the review if they had a quantitative research design. Articles examining case studies were also excluded since they are typically concerned with individual cases, whereas qualitative research employing other analytical methods such as thematic or content analysis, framework analysis or grounded theory have greater transferability and can potentially inform the development of new theory

(Williams, 2002b). Keeping in view that only a small number of qualitative research articles examined the parental lived experiences of a child's chronic life-threatening condition and subsequent death, three articles that utilized a mixed methods design were also included in the systematic review. These three articles had a sizable component of qualitative data, and only such qualitative data from these studies was reviewed.

Screening Process and Data Extraction

All identified articles underwent a rigorous screening process which involved multiple stages. A four-member study team (as detailed in the Authorship Attribution Statement) carried out the screening process to eliminate individual researcher bias from interfering with the stringency of the research. In the first stage, the title and abstract of all articles obtained through the systematic search were appraised by two researchers of the study team to determine whether they adhered to the inclusion criteria. If an article was deemed appropriate by either researcher, it was moved to the next stage of full-text analysis. An article was included in the review only if two researchers independently arrived at the same decision. In the event of a conflict between two researchers regarding the appropriateness of an article for inclusion, the third researcher engaged in another round of full-text screening, and the third researcher's decision stood final. Fifty percent of the excluded articles were also checked by the third researcher to confirm their exclusion from the review. Details of the screening process are shown in Figure 3.1.

Figure 3.1. PRISMA Flow Diagram of Screening Process of Qualitative Systematic Review



The data from each article was extracted into a spreadsheet, and subsequently assessed according to the criteria for quality assessment described by Thomas and Harden (2008). This includes evaluation of five criteria pertaining to adequate description of the study’s objectives, context, rationale, methodology, and findings; and four criteria pertaining to use of appropriate strategies to ensure reliability and validity of data collection tools and method of analysis. An article was incorporated in the final analysis only if it was found to fit the research question of the present systematic review and had clearly stated methods of quality control for data collection and analysis.

Data Analysis

Only first order constructs including quotations from respondents in the primary studies were treated as data points, which allowed the elicitation of participants' voices in their purest form while eliminating the risk of the primary author's own interpretation of the data from influencing the overall analysis (Toye et al., 2014). Data analysis followed the three-stage process of thematic synthesis (Thomas & Harden, 2008). In the first stage, line-by-line coding of text was conducted to develop descriptive themes, and create analytical categories, which construct new interpretations and explanations of the data. Following this, inductive codes were developed to capture the meaning and content of a cluster of similar quotes. Finally, the inductive codes were classified into four temporal phases to capture the entire trajectory that parents experience from the time of a child's terminal diagnosis, their treatment, the final day of life, and finally the changes brought about by the death of their child. Regular coding and debriefing meetings were conducted with research team members to maximize credibility, criticality, and authenticity. The coding framework, interpretation of data, and confirmation of themes and theme categories were agreed upon by all members, finalized by the fourth researcher and compared to existing literature to ensure investigator triangulation and theory triangulation.

Study 2: A Constructivist Meaning-Oriented Study Design to Examine the Lived Experience of Bereaved Parents of Children with Chronic Life-Threatening Illnesses in Singapore

Study 2 of this research aimed to bridge the knowledge gap identified in Study 1 - specifically, that there were no Asian studies conducted on the parental bereavement experience stemming from a child's death due to chronic illness, and the unique needs and concerns of Asian bereaved parents remained unknown. Study 2 comprised a constructivist meaning-oriented study which aimed to understand the lived experience of bereaved parents in Singapore from the time of their child's diagnosis through bereavement, thereby serving as a first-of-its kind Asian study to inform the development of culturally sensitive holistic support services for parents facing impending and actual child loss. The following section discusses the methodology of Study 2 in detail.

Approach, Design and Research Questions

Study 2 took on an idealist ontology, whereby reality is considered to be mind-dependent and can only be uncovered through socially constructed meanings. A constructivist-interpretivist epistemology was adopted such that knowledge was co-created via a facilitated dialogue between the participant and the researcher. Inspired by the approach adopted in other qualitative and meaning-focused research (Ho, 2013), it was kept in view that experiences of grief and loss can be deeply personal as well as influenced by cultural expectations and values, and a constructivist approach would allow appreciation of the multiple truths and realities of participants' experiences. In this study, a constructivist approach empowered the researcher to establish a partnership with the participants, respectfully enquire about their feelings and thoughts surrounding their loss and meaningfully reconstruct their lived experience and the meaning that they ascribed to this experience together with them. Further, the researcher's own observations and reflections of participants' experiences also influenced the process of meaning-creation. Creswell et al. (2007) and Ho (2013) elaborated that in qualitative research, the creation and co-construction of knowledge is founded on the interaction between the researcher and the participant, and participants may frequently learn based on participating in the research experience as well as their interactions with and learning from another person's (that is, the researcher's) perspective. From the researcher's point of view, a co-constructive approach allows examination of the essence of participants' experiences and not just their explanations for it. Therefore, the end product of such a study would describe the meaning, lived experiences and views of participants, blended with the researcher's own observations and reflections.

Study 2 also adhered to a phenomenological paradigm which means that it honored participants' subjective experiences and their ability to find and create meaning through them. The findings which were generated through this ontological and epistemological approach and research paradigm have 'moderatum generalization', that is, these findings can be replicated in a situation with comparable physical features and shared cultural norms and values as those of participants in the present study (Ormston et al., 2013; Williams, 2002a).

The overarching research questions being investigated in Study 2 were: (1) How do parents in Singapore journey from the diagnosis of their child's chronic life-threatening illness to his or her death? (2) How do bereaved parents in Singapore experience life after their child's death? (3) How can psychosocial care be enhanced so that bereaved parents of children with chronic life-threatening illnesses in Singapore better cope with their experience of loss, and be provided with opportunities for meaning making leading to posttraumatic growth? In the present study, the term 'chronic' refers to an illness that is prolonged and unlikely to be cured (Stanton et al., 2007), and the term 'life-threatening' refers to illnesses characterized by an uncertain prognosis and little or no consensus among professionals regarding a reasonable hope for cure (Liben et al., 2008).

Sampling Framework

This study employed a method of purposive sampling. Specifically, the research team liaised with three community collaborators, namely HCA Hospice Care (HCA), Children's Cancer Foundation (CCF), and Club Rainbow Singapore (CRS), to invite family units of lone or couple parents who lost their child to a chronic life-threatening illness to participate in the research. Such a sampling framework allowed exploration of the experience of parental bereavement due to a wide range of chronic life-threatening illnesses. In this study, a parent was operationally defined as the child's primary family caregiver with whom the child fostered a close bond. The target sample size was 25, which is considered appropriate by previous studies examining lived experiences and the notion of data saturation (Marshall, 1996).

Inclusion and Exclusion Criteria

To participate in this study, parents needed to meet the following inclusion criteria: (1) They previously had a child diagnosed with a chronic life-threatening illness between the ages of 0-19 years. (2) Their child had passed away due to such conditions in the subsequent years. (3) A minimum period of 6 months had elapsed between their child's death and the study interview. Parents were excluded from the study if they were unable to communicate in English, Mandarin or Malay, they were unable to provide informed consent, or they showed signs of depressive symptoms or any other major mental illness.

Participant Recruitment

The appointed staff at HCA, CCF and CRS identified potential participants for this study, contacted them via telephone and explained the purpose and objectives of the research. This telephone call also served as a screening tool to ensure that participants fit the sampling framework and had the capacity and interest to participate in the study. Contact details of those who verbally agreed were passed to the research team. Next, the research team contacted the participants via telephone to arrange an interview appointment. The research team received 31 referrals, of which 27 families agreed to participate. Two family units showed depressive symptoms during the interview; their data were excluded from the final analysis and concerns about their well-being were shared with the referral organization for subsequent follow-up. No demographic differences were noted between the families that refused to participate and the families that were deemed ineligible as compared to the families that were studied as part of this investigation.

Data Collection

Between August 2017 and April 2018, parents who had lost a child to a chronic life-threatening illness in Singapore were invited to share their bereavement experiences. The meaning reconstruction interview framework (Neimeyer, 2006b) was adopted and a semi-structured interview guide was developed. This interview guide covered different aspects of participants' experiences of providing care to their child with a chronic life-threatening condition, the evolution of their relationships throughout this process, coping with end-of-life, coming to terms with their child's death, their experiences with health-and-social care systems, adjustment to loss and grief, and the types of support that helped them to cope (see Appendix 2 for the complete semi-structured meaning-oriented interviewing guide). The researcher was interested in participants' subjective appraisal of these events as well as their underlying values and beliefs which affected their appraisals. The interview guide was first pilot-tested within the research team, following which meaning-oriented interviews were carried out with one family unit at a time, with either one or both parents present. The interviews were conducted by two trained members of the research team, at least one of whom was certified in thanatology by the Association of Death Education and Counseling and had the clinical competence to work with family caregivers in pediatric palliative settings. On the day of the interview, participants first completed an informed consent form. They were then invited to engage in a 60-to-90-minute interview. At the end of the interview, participants received a cash voucher worth 30 Singapore dollars as an appreciation for their time.

After completion of each interview, the researchers held a debriefing session to review their experience and impressions of the narratives shared by participants. Such an approach ensured investigator triangulation and promoted multiple perspectives in observation and data interpretation. All interviews were conducted in a safe and private venue such as an interviewing room at HCA or at the participants' respective homes. Further, all interviews were audio-recorded and subsequently transcribed verbatim. All transcripts were checked for accuracy and quality assurance. Twenty-two interviews were conducted in English, while three interviews were conducted in Mandarin and their transcripts were translated to English. The transcription and translation were verified by two researchers for authenticity.

Data Analysis

The Microsoft Word software was used for transcribing the audio-recordings. Next, the transcriptions were imported into QSR NViVo 11 for analysis. The grounded theory approach to data analysis (Holstein & Gubrium, 2003) was adopted. This involved several steps of line-by-line coding, followed by axial coding and selective coding which generated conceptual themes. In the final stage of analysis, all major categories, themes and sub-themes were operationally defined, inter-relationships between them were proposed and then supported with relevant quotes from transcripts. This resulted in the development of a model which explained the analysis and findings (see Figure 5.1).

Study 3: Study Design of a Pilot Randomized Controlled Trial to Develop, Implement and Evaluate a Novel Narrative e-Writing Intervention for Parents Facing their Child's Chronic Life-Threatening Illness

Study 3 was informed by the first 2 studies of this research. It was further inspired by a review of literature which revealed that globally, pediatric palliative care interventions predominantly emphasized the stages of grief and psychological tasks that grieving parents must accomplish after their child's death (Endo et al., 2015). Within the local context of Singapore, no empirically supported intervention was found to support parents of children facing chronic life-threatening illnesses in their psycho-socio-spiritual needs and provide them with the necessary psychoeducational resources. The design of Study 3 keeps in view the important role of family in end-of-life and palliative care when working with Asian populations such as those in Singapore (Dutta et al., 2019; Ho et al., 2017; Krishna et al., 2014; Lee et al., 2013). Moreover, it is consistent with Singapore's status as a forerunner in community-wide digital readiness, whereby use of smartphones is part and parcel of people's daily lives (Digital News Asia, 2017; WARC, 2017; Yip, 2019). Within this cultural context, an internet-based solution that focuses on parents' experiences within their family lives as they care for their child living with a chronic life-threatening illness was deemed to be an appropriate intervention for augmenting pediatric palliative services. Further, an online platform and the sense of anonymity it presents to participants (Suler,

2004) would also acknowledge the unique needs of Asian family caregivers who tend to be uncomfortable with emotionally charged conversations even during times of death, dying and bereavement (Ho, 2013). Thus, Study 3 of this research integrated the key elements that would be crucial for a pre-loss intervention for parents of children with chronic life-threatening illness and designed Narrative e-Writing Intervention (NeW-I) to bridge the gap in pediatric palliative care delivery and research in the local context. NeW-I is a novel online, therapist-facilitated, strength-focused, and meaning-oriented intervention that aims to improve psycho-socio-spiritual well-being and reduce distress of parents facing their child's chronic life-threatening illness. The following section discusses the methodology of Study 3 in detail.

Design, Objectives and Hypothesis

The design, implementation and evaluation of the pilot protocol of NeW-I is informed by the Medical Research Council Framework for the Development and Evaluation of Complex Interventions which upholds the standards of designing and evaluating complex interventions for improving health outcomes (Campbell et al., 2000; Lakshman et al., 2014). NeW-I is also guided by the meaning reconstruction framework (Neimeyer, 2006a), the narrative approach to anticipatory grief (Toyama & Honda, 2016), and holistic end-of-life care interventions including dignity therapy (Chochinov et al., 2005; McClement et al., 2007) and family dignity intervention (Ho et al., 2017), as well as by Study 1 and Study 2 of this research. An open-label mixed methods randomized controlled trial design consisting of two groups was adopted: (1) intervention group (participants would adhere to the structured NeW-I protocol) and (2) control group (participants would engage in a journaling exercise that is unrelated to their child's condition and their role as a caregiver). This study had three key objectives, which were as follows:

1) To develop a standardized protocol for a culture-specific and meaning-oriented Narrative e-Writing Intervention (NeW-I) for anticipatory grief and bereavement support for parent-caregivers facing the chronic life-threatening illness and eventual death;
2) To evaluate the efficacy of NeW-I in enhancing quality of life, spiritual well-being, hope and social support as well as decreasing caregiver burden, depressive symptoms and risk of complicated grief among parent-caregivers; and
3) To examine the challenges and pitfalls in the design and implementation of NeW-I through an integrated feasibility and acceptability study for informing large-scale implementation of the intervention.

It was hypothesized that participants in the intervention group who successfully completed NeW-I would experience improved quality of life, spiritual well-being, sense of hope and perceived social support, and reduced depressive symptoms, subjective caregiver burden and risk of complicated grief as compared to control participants. It was also expected that participants would find NeW-I to be a convenient and user-friendly service.

Sampling Framework and Recruitment Procedures

The target sample size for this pilot study was 25 participants per arm, which was informed by the finding that for a main trial designed with 90% power and two-sided 5% significance, a pilot sample size of 25 per arm is needed to detect a small effect size of 0.2 in the primary outcome measure (Whitehead et al., 2016). This target effect size of 0.2 is considered reasonable since meta-analytical evidence indicates that even highly acclaimed psychotherapy studies (as defined by a skilled and experienced therapist, therapeutic integrity, $N \geq 50$) for the treatment of depression have an average effect size of 0.22 (Cuijpers et al., 2010). In order to achieve this target sample size of 25 participants per arm, both purposive sampling and open recruitment were employed in this study.

In terms of purposive sampling, social workers by the collaborating organizations (namely, KK Women's and Children's Hospital, Club Rainbow Singapore, Muscular Dystrophy Association Singapore and Rare Disorders Society Singapore) identified potential participants from amongst their beneficiaries and introduced the study to them. Such a sampling strategy allowed for maximum variation in the sampling, since it enabled the researcher to recruit participants whose children had been diagnosed with a variety of chronic life-threatening illnesses. If potential participants verbally consented to be a part of the study, their contact information was shared with the researcher, who then contacted the participants via telephone, explained the study procedures in detail and introduced the NeW-I app.

In terms of open recruitment, the rationale was that it would offer all parents in the community whose children were diagnosed with a chronic life-threatening condition to have fair and equal opportunity to be a part of a potentially useful intervention. Posters were placed in strategic locations across Singapore such as offices of leading pediatric palliative service providers providing information regarding the study. Flyers were also printed for distribution amongst parents who expressed interest. When interested participants contacted the researcher, they were explained the study procedures, introduced to the NeW-I app and provided with details of how to register.

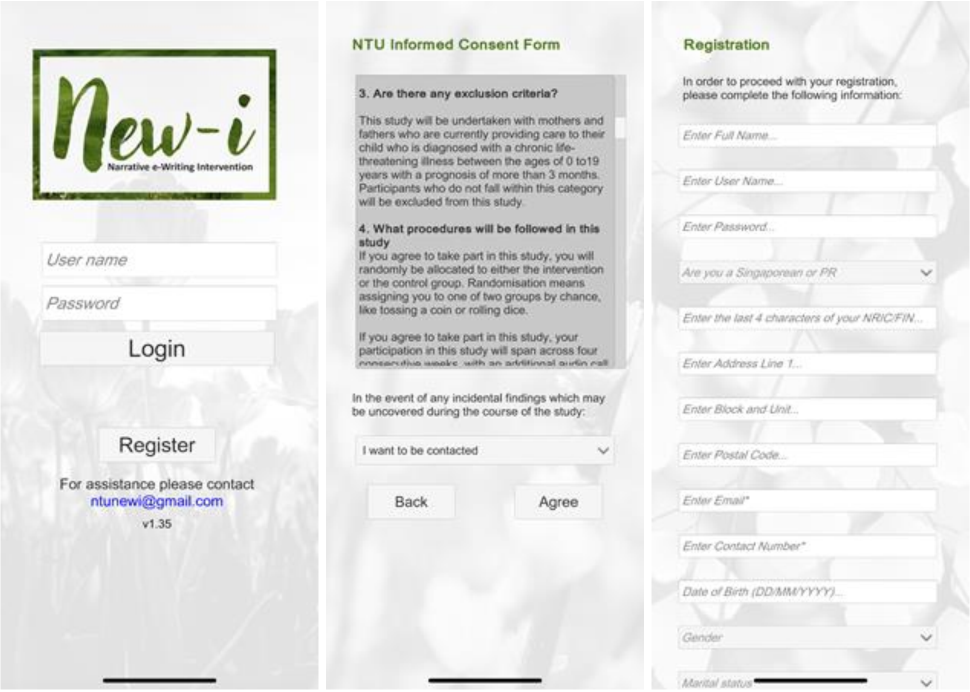
Inclusion and Exclusion Criteria

To be eligible for participation in this study, it was necessary for the individual to be a parent whose child had been diagnosed with a chronic life-threatening illness and had a prognosis of more than 3 months at the time of enrollment. For the purpose of this study, a ‘child’ was defined as children and young persons between the ages of 0-19 years (Government of Singapore, 2019). It was also necessary for the individual to be able to speak, read, and write in English and provide informed consent. Individuals were excluded from this study if they were suffering from severe depressive symptoms and psychological distress as identified by two screening tools. Specifically, to protect participants’ well-being during the pilot testing of NeW-I, those who did not meet the stated cut-off scores of Patient Health Questionnaire - 9 (indicated by a score greater than 19) and Kessler Psychological Distress Scale (indicated by a score greater than 29) were excluded. It was believed that conventional treatment and therapy would be more useful for such individuals (Andrews & Slade, 2001; Kroenke et al., 2001). In addition, if participants ceased to meet the inclusion criteria in the course of the study (for example, due to their child's unexpected death), they were excluded from the study and presented with alternative resources for seeking psychosocial support. However, the data that had been collected until the time of their participation was kept and analyzed so that a thorough and comprehensive appraisal of the study could be conducted.

App and Intervention Procedure

NeW-I was delivered to participants via a smartphone app that was facilitated by a therapist at the backend. When participants initially logged on to the app, they were directed to a study participation and informed consent page that provided details about study procedures, rights of research participants and protection of confidentiality (refer to Figure 3.2). After participants endorsed this online informed consent form on the NeW-I platform, they were directed to a demographic information page. This was followed by a screening page where participants completed the PHQ-9 and the K-10. Those who passed the screening assessments were confirmed their study participation and were requested to wait for a phone call from the research team. Those who did not pass the screening assessments were thanked for their time and provided resources for psychosocial support.

Figure 3.2. Screenshots of Landing Page of NeW-I app, the Informed Consent Page and Registration Page



For assistance please contact ntunewi@gmail.com

v1.35

NTU Informed Consent Form

3. Are there any exclusion criteria?

This study will be undertaken with mothers and fathers who are currently providing care to their child who is diagnosed with a chronic life-threatening illness between the ages of 0 to19 years with a prognosis of more than 3 months. Participants who do not fall within this category will be excluded from this study.

4. What procedures will be followed in this study

If you agree to take part in this study, you will randomly be allocated to either the intervention or the control group. Randomisation means assigning you to one of two groups by chance, like tossing a coin or rolling dice.

If you agree to take part in this study, your participation in this study will span across four consecutive weeks, with an additional audio call

In the event of any incidental findings which may be uncovered during the course of the study:

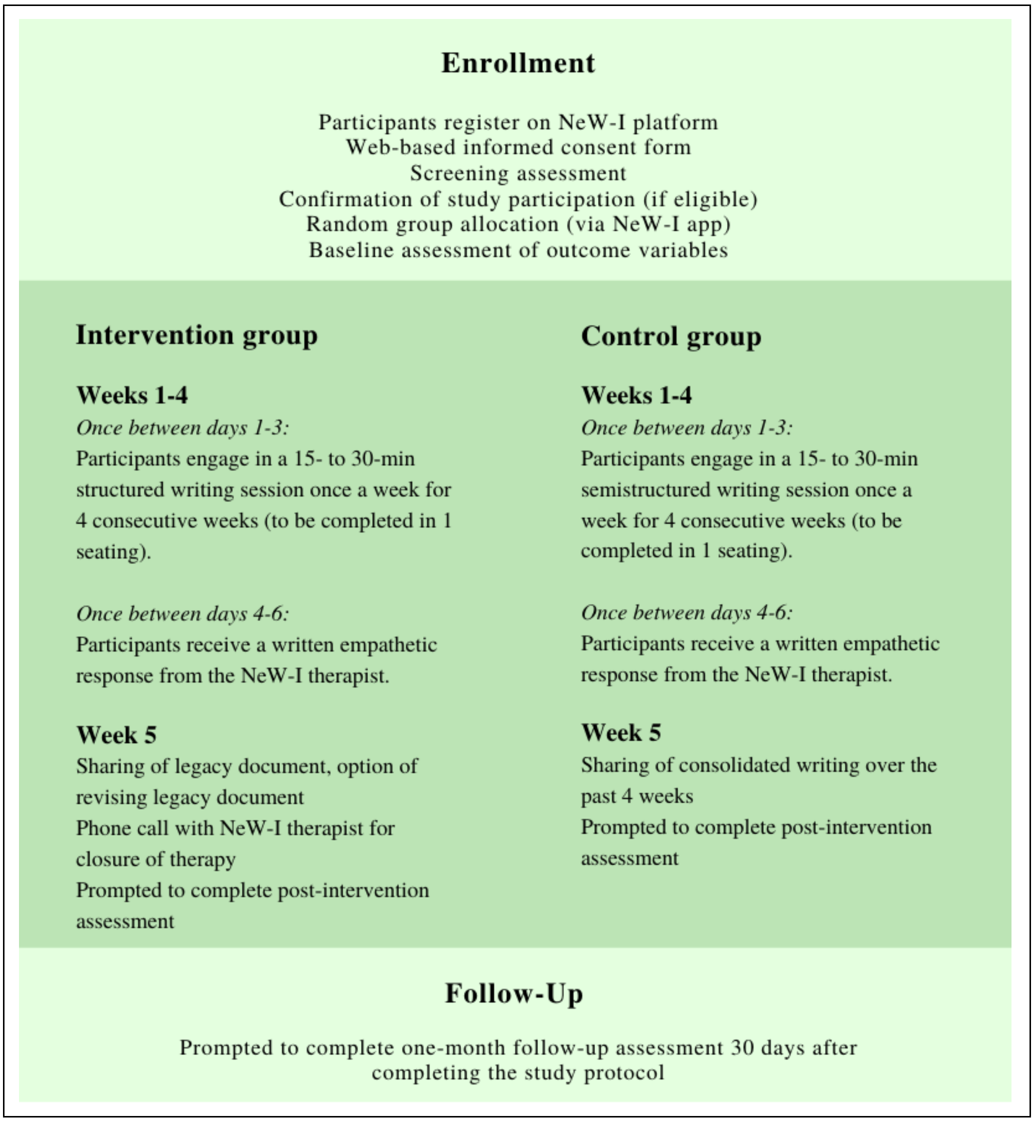
I want to be contacted

Registration

In order to proceed with your registration, please complete the following information:

Individuals who passed the screening assessments received a phone call from the NeW-I team as a means of identity-checking. Following this, participants completed baseline outcome measures. This was followed by random allocation of participants to either the intervention or the control group which was done via the NeW-I platform by using a computerized random number generator. If a given child's mother and father participated in the study, the group allocation of the parents was determined randomly, and both parents completed the baseline, post-intervention and one-month follow-up assessments independently. Participants were then directed to the first writing session. Participants could choose to begin the first writing session immediately, or delay for a maximum period of 3 days. The day on which participants began the first writing session was considered to be day 1 of week 1. Participants who did not begin their first writing session within 3 days were dropped from the study. However, a concession period of 7 days was given to participants who had a genuine reason for their inability to stick to the protocol (such as unexpected changes in their child's health condition) and had expressed a keen interest to participate in the study. A similar concession period of 7 days was also maintained for participants who were unable to stick to the study protocol in weeks 2, 3 and 4 (such that each participant could only be given one concession during the entire duration of their study participation). Detailed study procedures are described in Figure 3.3.

Figure 3.3. Description of NeW-I study procedures



Enrollment

Participants register on NeW-I platform
Web-based informed consent form
Screening assessment
Confirmation of study participation (if eligible)
Random group allocation (via NeW-I app)
Baseline assessment of outcome variables

Intervention group

Weeks 1-4

Once between days 1-3:
Participants engage in a 15- to 30-min structured writing session once a week for 4 consecutive weeks (to be completed in 1 seating).

Once between days 4-6:
Participants receive a written empathetic response from the NeW-I therapist.

Week 5

Sharing of legacy document, option of revising legacy document
Phone call with NeW-I therapist for closure of therapy
Prompted to complete post-intervention assessment

Control group

Weeks 1-4

Once between days 1-3:
Participants engage in a 15- to 30-min semistructured writing session once a week for 4 consecutive weeks (to be completed in 1 seating).

Once between days 4-6:
Participants receive a written empathetic response from the NeW-I therapist.

Week 5

Sharing of consolidated writing over the past 4 weeks
Prompted to complete post-intervention assessment

Follow-Up

Prompted to complete one-month follow-up assessment 30 days after completing the study protocol

Both intervention and control group participants followed the procedures described in Figure 3.3. There were 4 weekly sessions of writing. A template was provided to ensure that participants' writings were in line with the session objectives. To improve participants' adherence to the study protocol, they received an automated notification on their phone app and email each time a fresh writing session was activated for them. Participants were assured of anonymity and confidentiality of their writing to encourage open and honest self-expression. The structured writing for each session was designed such that it would require 15 to 30 minutes for completion, since exposure and time to process ideas through written disclosure over at least 3 sessions of 15 minutes each can produce effective outcomes (Frattaroli, 2006). A countdown timer which was built into the app also ensured that participants completed their writing within this time frame.

After participants completed their weekly writing, the NeW-I therapist provided weekly written constructive feedback, empathic support and psychoeducation. The objective of such psychoeducation was to equip participants with the knowledge and means to access resources that they could utilize to provide better quality of care to their child. The relevant information was obtained by the research team from the medical and social work professionals who were part of the research team, prior to beginning the intervention.

Intervention Group Protocol

As shown in Table 3.1, for intervention group participants, each weekly session had a unique objective, reflective writing questions and counseling goals. These have been elucidated below in detail.

Table 3.1. Content and Questions for NeW-I Reflective Narrative Writing

	Week 1	Week 2	Week 3	Week 4
Objective	To provide participants with a platform to reflect on the emotional, practical and financial demands of caring for a child with chronic life-threatening illness, and the means to cope with these challenges.	To explore avenues where participants can seek more information about their child's illness and resources for caregiving.	To explore the sources of support which participants have within their close network of family and friends.	To explore how participants (and their children) can rise above illness-related challenges and live their lives as fully as possible.
Questions for reflective writing	1) Tell us a little about your child and what you love about them. 2) Tell us about the challenges that you have encountered when caring for your child. 3) What has been your biggest challenge so far? How have you coped with it? 4) What are three things that have helped you cope in your caregiving journey?	1) How satisfied are you with the knowledge and information that you have about your child's condition? What has been helpful in providing you with the knowledge and information? 2) What are some forms of support that have been helpful for you in providing quality care to your child? How were these forms of support helpful? 3) What would help you to feel more competent as your child's caregiver? What is one thing you could do to make that difference?	1) Tell us about some people who have been helpful or supportive in your caregiving journey. How have they helped you to cope during difficult times? 2) On a scale of 1 to 10, with 1 being "Not at All" and 10 being "Very Much", how satisfied are you with your spousal relationship? (Please omit this question if it does not apply to you). What might make that score a little higher? 3) What are some things that others could do for you that could further help you in your caregiving journey?	1) Tell us what you love best about your child. What quality about them makes you proud? 2) What would a good day for your child look like right now? What makes it a good day? 3) Tell us about an enjoyable moment with your child. What are some things you can do to make an enjoyable moment happen?

	Week 1	**Week 2**	**Week 3**	**Week 4**
Counselling goals	1) To affirm the strengths that have helped participants to survive and thrive. 2) To provide psychoeducation about local social welfare organizations that can provide them with support.	1) To acknowledge participants' efforts to seek power and control over their seemingly uncontrollable lives through illness literacy. 2) To provide psychoeducation about sources for seeking more information about their child's illness, treatment options and resources for caregiving.	1) To reframe that they are indeed blessed to have the support of their spouse/ family and/or friends to help them to cope with this challenging period. 2) To reframe participants' sharing from sessions 1, 2 and 3 by taking the semantic content as it is but providing an alternative viewpoint of perceiving the situation.	1) To assist participants (and their children) in building meaningful and cherished memories through reflecting on achievements and fulfilment of dreams. 2) To examine ways in which participants can enhance the quality of their child's life in his or her final days.

Week 1. In week 1, participants reflected on the demands of caring for a child with chronic life-threatening illness, and the means to cope with these challenges. Sample writing questions included: (1) "Tell us a little about your child and what you love about them." (2) "Tell us about the challenges that you have encountered when caring for your child." (3) "What has been your biggest challenge so far? How have you coped with it?" (4) "What are three things that have helped you cope in your caregiving journey?" The intervention goal for week 1 was to affirm the strengths that have helped participants to survive and thrive and to provide participants with psychoeducation about local social welfare organizations that could provide them with additional support.

Week 2. In week 2, participants considered avenues where they could seek more information about their child's illness and resources for caregiving. Sample writing questions included: (1) "How satisfied are you with the knowledge and information that you have about your child's condition? What has been helpful in providing you with the knowledge and information?" (2) "What are some forms of support that have been helpful for you in providing quality care to your child? How were these forms of support helpful?" (3) "What would help you to feel more competent as your child's caregiver? What is one thing you could do to make that difference?" The intervention goal for week 2 was to acknowledge participants' efforts to seek power and control over their seemingly uncontrollable lives through illness literacy and to provide psychoeducation about sources for seeking more information about their child's illness, treatment options and resources for caregiving.

Week 3. In week 3, participants examined the sources of support which they had within their network of family and friends. Sample writing questions included: (1) “Tell us about some people who have been helpful or supportive in your caregiving journey. How have they helped you to cope during difficult times?” (2) “On a scale of 1 to 10, with 1 being “Not at All” and 10 being “Very Much”, how satisfied are you with your spousal relationship? (Please omit this question if it does not apply to you.) What might make that score a little higher?” (3) “What are some things that others could do for you that could further help you in your caregiving journey?” The intervention goal for week 3 was to reframe that participants were indeed blessed to have the support of their spouse, family and/or friends to help them to cope with the challenges of caregiving. Further, participants’ sharing from sessions 1, 2 and 3 was positively restructured by the NeW-I therapist by taking the semantic content as it is but providing an alternative viewpoint of perceiving the situation.

Week 4. In week 4, participants explored how they (and their children) could rise above illness-related challenges and live their lives as fully as possible. Sample writing questions included: (1) “Tell us what you love best about your child. What quality about them makes you proud?” (2) “What would a good day for your child look like right now? What makes it a good day?” (3) “Tell us about an enjoyable moment with your child. What are some things you can do to make an enjoyable moment happen?” The intervention goal for week 4 was to assist participants (and their children) in building meaningful and cherished memories through reflecting on achievements and fulfilment of dreams and to examine ways in which participants could enhance quality of life in their child's final days.

Legacy Document, Post-Intervention Assessment and Follow-Up. After completion of the first four weeks of the intervention, participants' written narrative was reviewed and edited by the therapist and a compiled and edited document of their narrative expression during the first four weeks of the intervention was created within the next 3-4 days. This process was inspired by the tenets of dignity therapy (Chochinov et al., 2005) and family dignity intervention (Ho et al., 2017). Edits to participants' writings included clarifications such as deleting colloquialisms, chronological revisions, editing any material that might cause harm or suffering to the recipient(s) of the document and locating one or more statements within the written narrative that would be suitable for an appropriate ending. Participants thus received this 'legacy' document and at the same time, they were invited to review it and suggest edits where desired. In week 5, after completion of an exit interview with the therapist, participants were encouraged to complete a post-intervention assessment. An automated prompt was sent to participants via the NeW-I app at the one-month mark to complete the one-month follow-up assessment.

Control Group Protocol

As shown in Table 3.2, for control group participants, the objective was consistent across the 4 weeks, that is, participants engaged in weekly writing sessions that were unrelated to their child's illness. This allowed participants to experience the therapeutic benefits of narrative writing. Each weekly writing session comprised a single open-ended question, thereby allowing participants to respond in any manner that they found acceptable. Sample questions included: (1) “Tell me about your day?” (2) “How has the past week been for you?” (3) “What do you find most challenging right now?” (4) “What do you find most comforting right now?” Participants were invited to write for 15-30 minutes once per week for 4 consecutive weeks. Simple empathic weekly feedback was provided by the therapist to encourage continuous participation. In week 5, a consolidated document that included all unedited journal writings together with a brief summary statement of appreciation by the therapist was shared with control group participants to indicate conclusion of participation. Thereafter, participants were encouraged to complete their post-intervention outcome assessment, and subsequently an automated prompt was sent one month later to complete the one-month follow-up outcome assessment.

Table 3.2. Content and Questions for Control Group Reflective Writing

	Week 1	**Week 2**	**Week 3**	**Week 4**
Objective	To engage participants in a weekly writing session that is unrelated to their child's illness and allows them to experience the therapeutic benefits of narrative writing			
Question for reflective writing	This week, we'd love to know a little bit about you. Tell us what an average day in your life looks like. Feel free to share with us any and every detail that you find comfortable to talk about!	This week, we'd like to know about what the past week has been like for you? Feel free to share with us in as much detail as you like!	This week, we'd like to know what is the biggest challenge (e.g., emotional, financial, practical etc.) that you are facing right now? Do feel free to add on anything else about this challenge that you would like us to know!	This week, we'd like to know what you find most comforting right now (e.g., family, relationships, work, hobbies and other activities etc.). Tell us about what makes this thing comforting for you?

Description of Interventionists

The NeW-I intervention protocol was delivered by a single interventionist in the research team, who was assisted by a second interventionist in delivering the control protocol during peak periods of data collection. Both interventionists were trained in death education and grief counselling, had the clinical competence to work with family caregivers in pediatric palliative settings and received closed supervision and mentorship by a senior counsellor in the research team and the Principal Investigator of the study. All team members had successfully completed research integrity modules under the provisions of Nanyang Technological University's Institutional Review Board and adhered to the Board's guidelines for safeguarding participants' identity and confidentiality.

Evaluation of Outcomes

To evaluate the effectiveness of NeW-I, both quantitative and qualitative data were recorded and analyzed independently. These analyses were integrated in the final stage of intervention evaluation.

Quantitative Outcome Measures

Via the NeW-I platform, both intervention and control group participants filled out a socio-demographic form at baseline and were then assessed on a battery of standardized and validated measures across 3 time-points, namely, baseline assessment (T1), immediately after completing the intervention or control protocol or post-intervention assessment (T2) and one month after completing the intervention or control protocol or one-month follow-up assessment (T3). For each completed assessment, participants received a voucher worth 30 Singapore dollars. The primary outcome measure was participants' quality of life, as measured by the Kemp Quality of Life Scale (KQOL, Siebens et al., 2015). Secondary outcomes were assessed using a modified version of the Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being scale (FACIT-Sp-12, Bredle et al., 2011), the Herth Hope Index (HHI, Herth, 1992), the Patient Health Questionnaire - 9 (PHQ-9, Kroenke et al., 2001), the Burden Scale for Family Caregivers-Short (BSFC-s, Graessel et al., 2014), the Inventory of Social Support (ISS, Hogan & Schmidt, 2002) and a modified version of the Brief Grief Questionnaire (BGQ, Shear et al., 2006). The following section provides a brief description of each of these scales.

Kemp Quality of Life Scale (KQOL). The KQOL is a single-item self-report measure of quality of life in adults (Siebens et al., 2015). The item "Taking everything in your life into account, please rate your overall quality of life." is scored on a 7-point Likert rating scale such that 1 = Life is very distressing, 4 = Life is so-so and 7 = Life is great. A higher score is indicative of better quality of life. Siebens et al. explain that the KQOL considers quality of life to be a single entity that has two extremes - positive and negative. There is also a midpoint which denotes that the individual's quality of life is neither positive nor negative and he/she is merely getting by. In essence, this midpoint emphasized that the absence of a negative quality of life does not imply that the individual experiences a positive quality of life. The KQOL is positively correlated with functional measures of activities of daily living, depression, and measure of social activities in adults facing chronic conditions such as cerebral palsy and polio. The brevity of the measure and its previous use in populations of an Asia Pacific origin made it an ideal choice in the present study which assesses quality of life among Asian adult family caregivers who are caring for their children with chronic conditions and are pressed for time.

Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being scale (FACIT-Sp-1*: *modified version). The FACIT-Sp-12 is a 12-item self-report questionnaire that assesses the broad measure of spiritual well-being with content not limited to any one religious or spiritual tradition (Bredle et al., 2011). Each item is scored on a 5-point rating scale such that 0 = Not at all, 1 = A little bit, 2 = somewhat, 3 = Quite a bit and 4 = Very much. Items 4 and 8 are reverse scored. A higher total score is indicative of greater spiritual well-being. Bredle et al. explain that the scale comprises three subscales which help facilitate an in-depth exploration of the components that constitute spiritual well-being. These subscales are as follows: (i) Meaning, (which comprises item numbers 2, 3, 5 and 8) (ii) Peace (which comprises item numbers 1, 4, 6 and 7), and (iii) Faith (which comprises item numbers 9, 10, 11 and 12). Sample items include “I have a reason for living” (meaning subscale), “I have trouble feeling peace of mind” (peace subscale) and “I find strength in my faith or spiritual beliefs” (faith subscale). The FACIT-Sp-12 has good internal consistency overall ($\alpha = 0.89$) and across all three subscales (Meaning: $\alpha = 0.78$, Peace: $\alpha = 0.83$, Faith: $\alpha = 0.87$) (Munoz et al., 2015). Validity and reliability of the FACIT-Sp-12 has been demonstrated among large and ethnically diverse populations, and the scale has been used to examine spiritual well-being across numerous religious beliefs, including individuals who identified themselves as ‘spiritual but not religious’ (Monod et al., 2011). In this study, items 11 and 12 of the FACIT-Sp-12 were modified in a way that would make it more relevant to the parent-caregivers of children with chronic life-threatening illnesses for whom it was intended (refer to Appendix 8 for the modified version of the FACIT-Sp-12 used in the present study). Specifically, this involved replacing phrases that referred to ‘my illness’ in the original scale with ‘my child’s illness’ in the modified scale employed in the present study.

Herth Hope Index (HHI). The HHI, an abbreviated version of the Herth Hope Scale, is a 12-item self-report questionnaire that is designed to capture the multidimensional nature of hope in a brief and uncomplicated manner (Herth, 1992). Each item is scored on a 4-point rating scale such that 1 = Strongly disagree, 2 = Disagree, 3 = Agree and 4 = Strongly agree. Items 3 and 6 are reverse scored. A higher score is indicative of greater hope. Herth et al. established the psychometric properties of the HHI including its high internal consistency ($\alpha = 0.97$), high 2-week test-retest reliability ($\alpha = 0.91$) and moderate divergent validity ($r = –0.73$). The scale comprises three subscales of hope, which are as follows: (i) Inner sense of temporality and future orientation (which comprises item numbers 1, 2, 6 and 11), (ii) Inner positive readiness and expectancy (which comprises item numbers 4, 7, 10 and 12), and (iii) Interconnectedness with self and others (which comprises item numbers 3, 5, 8 and 9). The construct validity of each of these three subdomains has been supported through factorial isolation (Herth, 1991, 1992). Sample items include “I believe that each day has potential” (Inner sense of temporality and future orientation), “I can see a light at the end of the tunnel” (Inner positive readiness and expectancy) and “I have deep inner strength” (Interconnectedness with self and others). The HHI has demonstrated good reliability and validity in diverse samples (Hirano et al., 2007; Soleimani et al., 2019).

Patient Health Questionnaire - 9 (PHQ-9). The PHQ-9 is a 9-item self-report questionnaire that assesses the severity of depressive symptoms (Kroenke et al., 2001). Kroenke et al. opined that compared to other measures of depression, the PHQ-9 is relatively brief, yet has comparable sensitivity and specificity. Each item is scored on a 4-point rating scale such that 0 = Not at all, 1 = Several days, 2 = More than half of the days and 3 = Nearly every day. Sample items include “Little interest or pleasure in doing things” and “Feeling down, depressed or hopeless”. A higher score is indicative of greater depressive symptoms. An individual whose score is greater than 19 is considered to have severe depressive symptoms and it is expected that they would benefit from antidepressants and psychotherapy (Kroenke et al., 2001). Kroenke et al. established the psychometric properties of the PHQ-9 including its high internal reliability (α = 0.86 to 0.89) and high test-retest reliability (α = 0.84). Further, the PHQ-9 has high internal consistency (α = 0.89) and is highly correlated with other measures of depression and anxiety (Beard et al., 2016).

Burden Scale for Family Caregivers-Short (BSFC-s). The BSFC-s is a 10-item self-report instrument that assesses total subjective burden of family caregivers (Graessel et al., 2014). Sample items include “I often feel physically exhausted” and “My relationships with other family members, relatives, friends and acquaintances are suffering as a result of the care”. Each item is scored on a 4-point rating scale such that 0 = Strongly agree, 1 = Agree, 2 = Disagree and 3 = Strongly disagree. For the purpose of this study, all items were reverse scored during the analysis, therefore, a higher score was indicative of greater caregiver burden. The BSFC-s has high internal consistency (α = 0.92) which indicates that it is a one-dimensional measure of subjective caregiver burden (Graessel et al., 2014). The validity and reliability of the BSFC-s has been established across different care settings and studies (Pendergrass et al., 2018).

Inventory of Social Support (ISS). The ISS is a 5-item self-report questionnaire that examines an individual's perception about the social support that is available to them (Hogan & Schmidt, 2002). Sample statements include "I can express my feelings openly and honestly" and "There is at least one person I can talk to about my feelings". Each item is scored on a 5-point Likert rating scale such that 1 = Does not describe me very well, 2 = Does not quite describe me well, 3 = Describes me fairly well, 4 = Describe me well, 5 = Describes me very well. A higher score is indicative of greater perceived social support. Psychometric properties of the ISS were established by Hogan & Schmidt (2002) who found that the scale had a high internal consistency (α = 0.76), which indicates that it is a one-dimensional measure of perceived social support, as well as high test-retest reliability (r = 0.86).

Brief Grief Questionnaire (BGQ*: *modified version). The BGQ is a 5-item self-report instrument for screening complicated grief (Shear et al., 2006). Sample items include "How much are you having trouble accepting the death of __________?" and "How much does your grief still interfere with your life?" Each item is scored on a 3-point rating scale such that 0 = Not at all, 1 = Somewhat and 2 = A lot. A higher score is indicative of more grief. The BGQ has high internal consistency (α = 0.75) and its validity and reliability have been established across different samples, including Asian samples (Ito et al., 2012). In this study, the BGQ items were modified in a way that would make it more relevant to the parent-caregivers of children with chronic life-threatening illnesses for whom it was intended (refer to Appendix 8 for the modified version of the BGQ used in the present study). Specifically, this involved replacing phrases that referred to ‘death of __________’ in the original scale with ‘life-threatening illness of your child’ in the modified scale employed in the present study.

Quantitative Data Analysis

The SPSS software package was used for statistical analysis of quantitative data. The intervention and control groups were compared on the primary outcome (quality of life) as well as secondary outcomes (spiritual well-being, hope, depressive symptoms, perceived burden of family caregivers, perceived social support and risk of complicated grief) using the Mann-Whitney U test. The rationale for using the Mann-Whitney U test is that the data comprised a continuous variable, it was not normally distributed, and the sample size was limited (*Mann Whitney U Test in SPSS Statistics*, 2018). Within-group differences for both the intervention and control groups in scores obtained at baseline, immediately after completing the intervention/control protocol (post-intervention assessment) and one month after completing the intervention/control protocol (one-month follow-up assessment) were tested using the Wilcoxon Signed-Rank test. The rationale for using the Wilcoxon Signed-Rank test is that the data comprised a continuous variable, it was not normally distributed, and the sample size was limited (Rosner et al., 2006; *Wilcoxon Signed Rank Test in SPSS Statistics*, 2018). In addition, appropriate effect sizes were calculated, and the rates of recruitment, attrition and missing data in both groups were estimated.

Acceptability and Feasibility Study

To evaluate the acceptability and effectiveness of NeW-I, all intervention participants were invited to participate in a semi-structured interview at the post-intervention assessment. This interview explored the following broad areas: (i) impact of the intervention on participants, (ii) aspects of the intervention that participants found to be helpful, (iii) aspects of the intervention that participants found to be unhelpful and how they could be improved, (iv) challenges encountered by participants in completing the intervention, and (v) scope for enhancing intervention usability.

To assess the feasibility of implementing and delivering NeW-I, the research team maintained an audit trail of the time needed to provide feedback to participants and restructure their narrative writing, deviations from the intervention protocol (if any), uncompleted interventions and their reasons, and NeW-I therapists' perceptions of competence, observations of participants' experiences and responses and difficult or deviant cases. All feedback provided to participants was vetted by at least two members of the research team for data monitoring, quality and safety assurance.

Qualitative Data Analysis

The QSR NVIVO software was used to manage the data. The Framework method of analysis was used which was both deductive (arising from pre-set aims and objectives) and inductive (arising from participants view) in nature. Such a method was chosen since it is more structured than other methods of qualitative analysis, the process is more explicit and informed by a-priori questions and the analysis can be easily understood by readers (Gale et al., 2013). The framework analysis was informed by Proctor’s Taxonomy of Outcomes for Implementation Research (Proctor et al., 2011), which postulates that the impact of actions taken to implement new programs can be assessed through eight conceptually unique outcomes. For the purpose of this study, four implementation outcomes informed the analysis, of which include: (i) Acceptability, which refers to participants’ perceptions and attitudes towards the intervention; (ii) Adoption, which refers to participants’ intentional decision to try the new and evidence-based practice; (iii) Appropriateness, which refers to participants’ beliefs about the extent to which the new intervention was relevant in their setting to address identified issues; and (iv) Sustainability, which refers to participants’ views about whether the new intervention could be maintained in the long-term.

Ethical Considerations

This research adheres to globally accepted ethical standards and is mindful of major ethical concerns with regards to including informed consent, privacy and confidentiality of participants, which have been highlighted in scholarly works (Christians, 2005). This, together with careful consideration of the nature of qualitative bereavement research, has been integrated into the design of this research, so as to minimize potential adverse effects of the research on participants. Study 1 of this research which was a qualitative systematic review considered only those research articles that had been published in internationally recognized peer-reviewed journals. For Study 2 and Study 3 which involved direct contact with participants, approval was sought from

Nanyang Technological University’s Institutional Review Board [Reference number IRB-2017-03-044 and IRB-2018-07-009 for Study 2 and Study 3 respectively]. A detailed description of the areas covered by these ethical reviews is provided below.

First, the vulnerable nature of the population that was part of this research was kept in view. To ascertain that potential participants fit the sampling framework, were of sound mind and had the capacity to engage in the study, an initial telephone assessment was first conducted with all potential participants.

Second, all participants were verbally informed about the purpose of the research and all relevant procedures that would be involved including the recording of their data and who would have access to these records. In Study 2, if participants verbally consented to participate, they were handed the informed consent form, encouraged to read it and then provide their endorsement. In Study 3, following participants’ verbal consent to participate, they were advised to log in to the NeW-I app where they were prompted to an informed consent form and their online consent was ascertained. Participants were then directed to complete a screening assessment before they could begin the intervention protocol. Individuals who did not pass the screening assessment were prompted to a web page which expressed appreciation for their time and interest and provided information about alternative sources of psycho-socio-emotional help.

Third, during the process of data collection (that is, meaning-oriented interviews in Study 2 and online narrative writing in Study 3), the researcher was mindful of the following aspects: (i) participants’ emotional state, (ii) ensuring that participants felt safe and supported, (iii) providing them with adequate time for reflection and expression, and (iv) reminding them that they could choose to discontinue their participation at any point without any consequences if they no longer felt comfortable to engage in the research.

Fourth, the researcher was trained and certified in counseling psychology and thanatology and was therefore competent to provide psycho-emotional support to participants during the on-site qualitative interviews and online narrative writing sessions. Further, a referral support system was developed with the collaborating organizations in the community including HCA, CCF and CRS so that participants who appeared to be in need of greater psychological and emotional support could receive appropriate follow-up care.

Although there have been concerns about depending on family caregivers to retrospectively provide data about the end-of-life experience of their deceased loved ones, such an approach is in fact legitimate and can yield useful information to make recommendations for clinical services provided to the grieving and dying (McPherson & Addington-Hall, 2003; Takesaka et al., 2004). There also exist studies which document that participating in research that explore experiences of bereavement following the death of a family member can be personally beneficial for participants (Beck & Konnert, 2007; Denhup, 2014; Eileg et al., 2013; Koffman et al., 2012). Other concerns have centered on the process of inviting family caregivers of dying patients to participate in palliative care research, but evidence suggests that such participation could benefit family caregivers since it provides them an opportunity to reflect on their experiences and express their needs, while being comforted through the feelings of being heard, valued and cared for (Aoun et al., 2017). There is also evidence that engagement in a meaningful narrative when the loss is still anticipated can enhance family connectedness (Parkes, 1976) and help family caregivers gradually transition into coping (Sweeting & Gilhooly, 1990).

In sum, the present research has been conceptualized in a manner that protects participants' well-being whilst facilitating their acceptance and integration of loss.

Research Rigor and Trustworthiness

This section discusses the methodological rigor observed in this research. Study 1 and Study 2 were purely qualitative studies and adhered to the four criteria that are key to safeguarding trustworthiness of qualitative research, of which include, credibility, transferability, dependability and conformability (Guba, 1981; Shenton, 2004).

Credibility is concerned with the extent to which the findings are congruent with reality and the degree of confidence in the accuracy of one's findings, which can be operationally achieved through different means such as prolonged engagement with the data, peer debriefing, triangulation and member checking (Guba, 1981; Shenton, 2004). The present researchers were immersed in the data for several months by familiarizing themselves with previous findings in this area, building rapport with the partnering organizations involved in the research to understand their culture as well as prolonged engagement with the transcripts to examine and compare emerging patterns. Periodic debriefing sessions were arranged for the research team to discuss evolving interpretations and test alternative notions. Investigator triangulation was achieved through these peer debriefing sessions as well as through meetings and discussion of interpretations with practitioners in the partnering organizations. Site triangulation was achieved by recruiting participants from multiple organizations to prevent local factors unique to an organization from influencing the findings. Emerging theories and inferences from the data from initial respondents were verified with subsequent respondents which allowed for a formative understanding of patterns observed by the researcher.

Transferability refers to the extent to which the findings from an investigation are applicable to other social contexts and phenomenon; which can be operationally achieved through theoretical or purposive sampling and providing “thick” detailed description of the dataset to permit comparisons to be made (Guba, 1981; Shenton, 2004). For the present study, participant recruitment was guided by stringent inclusion/ exclusion criteria in order to maximize the amount of relevant information being gathered. Further, detailed descriptions of the studied phenomenon were recorded to permit comparison of this context to other contexts where it is found appropriate.

Dependability is the degree to which the findings of a study are consistent and can be replicated across time and researchers, which can be operationally achieved through detailed methodological description and maintenance of an audit trail (Guba, 1981; Shenton, 2004). To enhance dependability in this research, a chronological list of steps undertaken from conception till completion of the project was chronicled, along with the relevant documents at each step.

Conformability alludes to the extent to which the findings reflect ideas and experiences of the participants rather than the researcher’s own characteristics and preferences, which can be operationally achieved through the practice of reflexivity and peer debriefing, triangulation and recognition of potential shortcomings in the study (Guba, 1981; Shenton, 2004). As noted above, peer debriefing and investigator and site triangulation formed an integral component of the inquiry process. Moreover, epistemological assumptions which guided the research questions, the researchers’ own beliefs as well as possible shortcomings of the investigation were clearly described in presentations and reports of the study findings.

Study 3 was a mixed methods study. The qualitative component of Study 3 adhered to the aforementioned criteria for safeguarding trustworthiness of qualitative research. Reliability of the quantitative findings obtained in Study 3 were ensured by calculating and reporting reliability estimates for all instruments used in the study across baseline, post-intervention assessment and one-month follow-up assessment.

Chapter Summary

This chapter has provided a detailed elaboration of all the research methods involved in the three studies which together make up this research, including description of sampling, data collection and data analysis. This chapter also offers insight on the ethical considerations as well as rigor and trustworthiness of this research.

CHAPTER FOUR

FINDINGS FROM STUDY 1: THE PARENTAL BEREAVEMENT TRAJECTORY OF CHILD LOSS

This chapter presents the findings of Study 1 which involved an international qualitative systematic review of relevant published journal articles from 2000 to 2017. Thematic synthesis of data was conducted to gain a comprehensive understanding of the lived experience of parents who have experienced the chronic and life-threatening illness of their child and his or her subsequent death.

Scope and Quality Assessment

The SPIDER tool was employed to rigorously evaluate the quality of the 25 research articles which were included in the qualitative systematic review of parental bereavement due to a child’s chronic illness and subsequent death (Cooke et al., 2012). The objective of this quality assessment was to determine whether the included articles were fit to answer the research question of the review and to ensure that unreliable conclusions would not be drawn by the research team from primary data (Thomas & Harden, 2008). It was found that in most of the included studies, the sample population comprised lone mothers (predominantly) and/or lone fathers (to a lesser extent). Only a handful of studies investigated mother-father dyads and only three studies focused entirely on bereaved fathers. In most of the studies, participants were recruited from local pediatric care centers that worked with families of children suffering from chronic and life-threatening conditions. The phenomena of interest for the included studies varied, for example, examining factors that help parent-caregivers to cope with their child’s serious illness, understanding the needs of bereaved parents, and exploring how bereaved parents transition from the trauma of their child’s death and find meaning in their experience of caregiving and loss. Typically, the primary authors embraced the format of semi-structured face-to-face interview, followed by thematic analysis of the data that was collected. Details about research ethics and approval from the relevant institutional review board were not provided by seven of the included studies. The majority of the primary studies explained how trustworthiness of research findings had been achieved (such as procedures of members checking and/ or identification of deviant cases). Table 4.1 presents an overview of all the included studies.

Table 4.1 Overview of Studies Included for Data Analysis in Study 1

Author, Year, Country	**Aim**	**Design, data analysis and quality assessment**	**Sample**
Barrera et al., 2007, Canada	To investigate patterns of parental bereavement.	Mixed methods design with semi-structured interviews and content analysis. Trustworthiness achieved through data triangulation. Ethical approval reported.	*N* = 13 mothers + 7 fathers. Child death due to cancer, congenital heart disease, meningitis, or drowning in the last 19 months.
Bergstraesser et al., 2015, Switzerland	To explore grief processes of bereaved parents putting particular focus on dyadic coping.	Mixed methods design with in-depth interviews and content analysis. Trustworthiness achieved through inter rater reliability and member checking. Ethical approval reported.	*N* = 23 parent units. Child death due to oncological and non-oncological life-limiting disease 12 months to 5 years prior to interview.
Berrett-Abebe et al., 2017, USA	To understand how parents experienced participating in a hospital-based bereavement support program.	Focus group discussion with phenomenological analysis. Rigor achieved by investigator and interdisciplinary triangulation. Ethical approval reported.	*N* = 6 mothers + 2 fathers. Child death due to cancer in the last 1 to 6 years.
Corden et al., 2002, UK	To investigate the financial circumstances of bereaved parents.	Semi-structured interviews with framework analysis. Rigor achieved by inter-researcher consensus on finalization of data charts. Ethical approval reported.	*N* = 12 parent units + 4 mothers. Child death to oncological and non-oncological life-limiting disease in the last 2 years.

Author, Year, Country	**Aim**	**Design, data analysis and quality assessment**	**Sample**
Davies et al., 2004, USA	To generate descriptions and theoretical explanations of the experiences of fathers whose children were diagnosed with irreversible illness from diagnosis, death and bereavement.	In-depth unstructured interviews with grounded theory analysis. Credibility achieved via members checking and maintaining an audit trail. Ethical approval reported.	*N* = 8 fathers. Child death due to cancer, spinal muscular atrophy, and Tay Sachs in the last 12 to 36 months.
Davies et al., 2013, USA	To describe fathers' perspectives of professional care provided to the ill child and the family as a whole during the illness and through the dying process.	In-depth interviews, field notes, genograms, and reflexive journaling with grounded theory analysis. Rigor achieved by inter-researcher consensus on interpretations of findings and conceptual models. Ethical approval reported.	*N* = 60 fathers. Child death due to life-limiting illnesses such as cancer, genetic disorders and heart disease 3 to 36 months prior to interview.
Davies, 2005, UK	To explore bereaved mothers' stories of loss and their lived experiences of their child's end-of-life care.	Open and non-directive interviews with hermeneutic analysis. Rigor achieved by maintaining an audit trail and documenting the process of data analysis in detail. Ethical approval reported.	*N* = 10 mothers. Child death due to a life-limiting illness in the last 3 years.
DeCinque et al., 2006, Australia	To explore the experiences and needs of parents who received hospital-based bereavement support.	Unstructured interview with thematic analysis. Inadequate information to assess methodological rigor. Ethical approval reported.	*N* = 9 parent units. Child death due to cancer between Jan 1997 and Dec 1998.
Denhup, 2017, USA	To describe the lived experience of bereaved parents who experienced the death of a child due to cancer.	In-depth interviews with phenomenological analysis. Rigor achieved by prolonged engagement with the data, triangulation, peer debriefing and member checking. Ethical approval reported.	*N* = 5 mothers + 1 father. Child death due to cancer at least 1 year before the interview.

Author, Year, Country	**Aim**	**Design, data analysis and quality assessment**	**Sample**
Dias et al., 2017, USA	To examine parental bereavement challenges during the first six months following the death of their child.	Individual interviews with content analysis. Ethical approval reported.	*N* = 5 mother + 5 fathers. Child death due to complex chronic conditions 6 months before the interview.
Foster et al., 2009, USA	To explore bereaved parents' and siblings' reports of legacies created by children.	Open-ended interview with content analysis. Trustworthiness achieved through inter-researcher consensus on the coding scheme and member checking. Ethical approval reported.	*N* = 36 mothers + 24 fathers. Child death due to advanced cancer.
Foster et al., 2011, USA	To examine how family members experience continuing bonds within the first year of a child's death.	Mixed methods design, semi-structured interview with content analysis. Trustworthiness achieved through inter-researcher consensus on the coding scheme and member checking. Ethical approval reported.	*N* = 36 mothers + 4 fathers. Child death due to cancer.
Gear, 2014, Australia	To identify and explore the informal social supports that bereaved parents found helpful following the death of their child.	Semi structured interview with content and thematic analysis. Inadequate information to assess methodological rigor. Ethical approval NOT reported.	*N* = 7 mothers + fathers. Child death due to brain tumor, leukemia, non-Hodgkin lymphoma, and genetic disorders in the last 4-11 years.
Grinyer, 2012, UK	To analyze the content of a session of a parental bereavement support group.	Recordings of support group sessions with qualitative fortuitous method of analysis. Accuracy of translation and data interpretation achieved through inter-researcher consensus. Ethical approval reported.	*N* = 3 parent units + 2 mothers. Child death due to cancer.

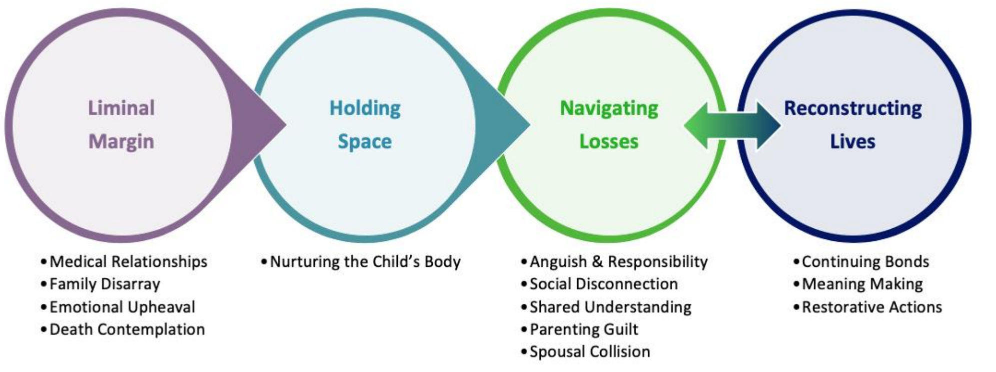
Author, Year, Country	**Aim**	**Design, data analysis and quality assessment**	**Sample**
Hooghe et al., 2017, Belgium	To examine the different meanings and processes related to talking and not talking with the partner about personal grief experiences after the loss of a child.	In-depth interview with thematic analysis. Inadequate information to assess methodological rigor. Ethical approval NOT reported.	*N* = 12 couples + 2 lone mothers. Child death due to cancer.
Hynson et al., 2006, Australia	To explore the impact of the research process on bereaved parents, and to identify what elements enhance the experience of research participation.	In-depth interview with thematic analysis. Inadequate information to assess methodological rigor. Ethical approval reported.	*N* = 45 mothers + 24 fathers. Child death due to chronic progressive condition.
Jordan et al., 2015, Ireland	To explore the experiences of parents caring for their dying children throughout the illness trajectory and subsequent death.	Face-to-face interviews with interpretative analysis. Rigor achieved through comprehensive treatment of all data, identification of deviant cases and memo writing. Ethical approval NOT reported.	*N* = 16 mothers + 9 fathers. Child death due to both malignant and non-malignant conditions in the last 24 months.
Meert et al., 2008, USA	To describe parents' perceptions of their conversations with ICU physicians regarding their child's terminal illness and death.	Semi-structured telephone interviews with qualitative analysis. Inadequate information to assess methodological rigor. Ethical approval reported.	*N* = 39 mothers + fathers. Child death due to terminal illness 3-12 months prior to interview.
Olson-Garriott et al., 2015, USA	To understand the experience of fathers who went on to have a subsequent child after losing a child in pediatric palliative care.	In-depth semi structured interviews with phenomenological analysis. Inadequate information to assess methodological rigor. Ethical approval NOT reported.	*N* = 11 fathers. Child death in a hospital or hospice 3-6 months prior to interview.

Author, Year, Country	**Aim**	**Design, data analysis and quality assessment**	**Sample**
Price et al., 2011, UK	To explore parents’ experiences of caring for their dying child throughout his or her illness and subsequent death.	Semi-structured in-depth interviews with interpretive qualitative approach to identify common themes and processes. Relevant procedures (Silverman, 2006) to address the validity and reliability of the analysis. Ethical approval reported.	*N* = 6 mothers + 9 fathers. Child death due to life-limiting condition 6-24 prior to interview.
Reilly et al., 2008, UK	To explore bereavement experiences of mothers who lose a child with an intellectual disability.	Semi-structured interviews with interpretative phenomenological analysis. Inadequate information to assess methodological rigor. Ethical approval reported.	*N* = 9 mothers. Death of a child with intellectual disability at least 12 months prior to the interview. The authors argue that parents of children with intellectual deficit are likely to outlive their children, encounter a range of stressors associated with their child’s current and future medical and personal needs and suffer from greater mental health problems than parents of typically developing children.
Rossetto, 2014, USA	To explore meaning making and philanthropic behaviors of bereaved parents' following the deaths of their children.	In-depth interviews with narrative analysis. Inadequate information to assess methodological rigor. Ethical approval NOT reported.	*N* = 7 mothers + 4 fathers. Child death due to different causes (only data from death due to cancer has been included).

Author, Year, Country	Aim	Design, data analysis and quality assessment	Sample
Schormans, 2004, Canada	To understand foster parents' experience of the death of a foster child with disabilities.	Semi-structured interviews with grounded theory analysis. Trustworthiness achieved by lengthy, rich and descriptive interviews, peer debriefing and member checking. Ethical approval NOT reported.	*N* = 6 mothers + 2 fathers. Child death due multiple disabling conditions, many of which are known to be terminal 2-14 years prior to interview.
Titus & de Souza, 2011, USA	To explore parents' experiences of grief before and after the death of their child.	Written/ typed responses to questions with qualitative analysis. Inadequate information to assess methodological rigor. Ethical approval NOT reported.	*N* = 9 mothers + 1 father. Child death due to an unstated type of terminal prognosis. 1–5 years prior to the interview.
Vega et al., 2014, Chile	To understand the lived experiences that help parents to revive after the death of their child due to cancer.	In-depth interview with phenomenological analysis. Inadequate information to assess methodological rigor. Ethical approval reported.	*N* = 3 mothers + 5 fathers. Child death due to cancer at least 1 year prior to interview.

The studies covered in this review have a total sample size of over 500 bereaved parents from across eight countries: United States (*n* = 11), UK (*n* = 5), Australia (*n* = 3), Canada (*n* = 2), Switzerland (*n* = 1), Belgium (*n* = 1), Ireland (*n* = 1), and Chile (*n* = 1), who were interviewed by the research team either alone or as a couple. Thematic synthesis of the data from these primary studies led to the development of a parental bereavement trajectory of child loss (see Figure 4.1).

Figure 4.1. Parental Bereavement Trajectory of Child Loss



Parental Bereavement Trajectory of Child Loss

As shown in Figure 4.1, the Parental Bereavement Trajectory of Child Loss comprises 13 themes that shed light on the lived experience of parents who faced the chronic life-threatening illness of their child and his or her subsequent death as a result. These themes have been further grouped into four phases. The first two phases are chronological in nature as they follow the illness progression from prognosis to death, while the final two phases are integrative in nature whereby parents move back and forth between phases as they gradually accommodate their loss and grief. Taken together, the four phases and the themes therein describe the experiences, feelings, thoughts, and relational behaviors related to parents' end-of-life caregiving and loss of their child. These four phases and their relevant themes are elucidated below.

Phase 1: Liminal Margin

When speaking about health and illness, the term "liminal" is often used to chronicle the disruption of life caused by the illness whereby known structures and routines are abandoned (Little et al., 1998). In this research, the term "liminal margin" has been adopted to chronicle the first phase in the parental bereavement trajectory, specifically, the period from the diagnosis of the child's chronic chronic life-threatening condition until the final days of his or her life. This phase comprises four themes, namely Medical Relationships, Family Disarray, Emotional Upheaval and Death Contemplation. Each of these themes has been described below in detail.

Medical Relationships (Number of articles theme has appeared in: N = 7)

Across the journal articles included in this systematic review, it was found that interactions with healthcare professionals were an important aspect of caring for a child with a chronic life-threatening illness. For some parents, such interactions were smooth and pleasant, thereby aiding them in effectively navigating the chaos that followed their child's diagnosis.

> "And they literally, they will embrace you. If you walked up there tomorrow, they would not forget who you were, they would not forget who your child was, even though you haven't been there in

> three years, they would treat you like you were family." (Berrett-Abebe et al., 2017, p. 353)

However, this systematic review also highlighted concerns about healthcare professionals' ability to appropriately support parents through their child's illness trajectory, end-of-life and bereavement. Several articles revealed parents' experience of an apathetic healthcare service that failed to satisfy their needs and concerns. For instance, many parents expressed their frustration with physicians who tended to use medical jargon in communications about the child's illness and prognosis.

> "They were explaining a lot of medical terms [that I] didn't know. I said, "Wait a minute, time out folks, let's try this again, because I don't understand what you're trying to say. I don't understand those big $100 words. Let's cut it down to $5 words." (Davies et al., 2004, p. 127)

Some parents expressed feeling exasperated with a healthcare system that over-emphasized disease curation, with little importance being given to the psycho-socio-spiritual domains of care and how these could be incorporated into the treatment plan.

> "You nearly feel like standing up and saying actually there was a child involved here you know there's a family involved you know." (Price et al., 2011, p. 1387)

Other parents discussed that the common practice of concealing the child's diagnosis and prognosis from parents often created false hope for a better clinical outcome. Instead, if physicians could set realistic expectations early in the illness trajectory, parents could be better prepared for their child’s impending death and accordingly make informed decisions about their child’s care and end-of-life.

> “If they say this kid’s not gonna make it, or whatever, they need to tell the family that. The family deserves to know that rather than being led on. It's easier to prepare.” (Meert et al., 2008, p. 6)

In sum, receiving respect, sensitivity and compassion from their child’s healthcare team was an important source of support for parents during the challenging liminal phase. Parents’ relationship with their child’s medical team made a meaningful impact on their caregiving journey when human-to-human connections were prioritized. At the same time, an apathetic attitude of healthcare professionals and inadequate or dishonest medical communication could become a source of additional stress for parents.

Family Disarray (N = 6)

For parents whose child was diagnosed with a chronic life-threatening condition, family life tended to be dominated by their child’s treatment and changes in his or her health condition.

> “We became controlled by James’ blood counts and the state of his immune system... We were so frustrated by thwarted efforts to plan family time!” (Titus & de Souza, 2011, p. 455)

Parents explained that typically, their conversations were centered on pragmatic concerns such as their child’s medical issues, financial worries, or looking after their other healthy children. Husbands and wives were often unable to find time to invest in their spousal relationship.

> "[Wife] and I had very little time and energy for each other. It seemed like all of our conversations were about practical concerns." (Davies et al., 2004, p. 125).

For many parents, the definition of what was 'normal' changed completely to accommodate the chaos and stresses that surrounded their family life and caregiving.

> "The children were just farmed out here and there. We took turns coming home really to try and give some normality to our other children but... family life with sick children isn't what normal people associate with family life." (Jordan et al., 2015, p. 845)

Emotional Upheaval (N = 5)

The period of caring for their child with chronic life-threatening illness was described by parents as a perplexing and isolating experience that they had unwillingly become a part of.

> "You feel that you've been taken out of your life and put into somebody else's movie... the wrong movie." (Davies et al., 2004, p. 121)

However, the feelings of shock, confusion, and disbelief that parents experienced when they initially found out about their child's illness gradually became a part of their daily life and narrative.

> “When we were first told of the diagnosis, all that you can remember really is the fact that it was terminal. But you learn to live with it.” (Reilly et al., 2008, p. 550)

Much like a roller coaster, parents’ journey of caring for their seriously ill child was characterized by frequent highs and lows and a constant unpredictability about their child’s health status and prognosis.

> “Most of those hopes for a “normal” life disappeared quickly… Soon we just hoped that Craig had two good days in a row.” (Titus & de Souza, 2011, p. 454)

Death Contemplation (N = 3)

A notable theme in many of the reviewed articles was the incongruence between children’s eagerness and parents’ hesitance to talk about death and dying.

> “The kids themselves would talk about dying. The parents didn’t want to accept that. We didn’t want to talk about it.” (DeCinque et al., 2006, p. 76).

However, since professional interventions to facilitate a conversation about end-of-life and the process of dying were rare, such discussions were often left unarticulated until the final days. There were some parents who, even after their child’s death, could only make assumptions about what their child’s viewpoints might have been regarding his or her illness and death.

> "We never talked about death and dying to him... I don't think he ever knew that this was gonna take his life... I really can't say with confidence that he did," (Foster et al., 2009, p. 4)

The reviewed literature also highlighted the potential benefits that parent-caregivers could derive from psychoeducation regarding expectations about their child's end-of-life, normal and unusual grief responses and recommendations for healthy coping within the present health-and-social care system.

> "I think if they (hospital staff) could get the parents on their own and explain to them the process of dying... I would have liked to have understood the process of the whole thing..." (DeCinque et al., 2006, p. 76).

Phase 2: Holding Space

The second phase of the parental bereavement trajectory is termed Holding Space. It encapsulates the different emotions that parents experienced at the time of their child's death. Only one prominent theme - namely, Nurturing the Child's Body - was derived from the four studies that offered input about this crucial and potentially fragile period.

Nurturing the Child's Body (N = 4)

The review of the literature revealed parents' need to come to terms with their loss in a space that is private, non-judgmental, and compassionate. Parents who had some protected time to continue their caregiving role after their child's death (such as by holding on to their child or dressing them according to parents' wishes before the last rites and rituals) appreciated it.

> “And I washed her in pink Next stuff that she wore and she was in her pink ball gown, pink tights, pink pants. I said I’ll never bury her in a nappy.” (Price et al., 2011, p. 1388)

Some parents desired to make tangible and intangible memories with their child’s physical body which would remain with them when the physical body no longer existed.

> “I was able to take B into the garden that they have, after she died. It was the summer and we sat under a parasol. I had tea. This was just me and my mum and we sat, as we used to in my mum’s garden, and we took photos.” (Davies, 2005, p. 296)

Phase 3: Navigating Losses

The third phase in the parental bereavement trajectory is marked by parents’ navigation of their intense emotions surrounding child loss, the precarious nature of their marital and social relationships and their need to re-establish routine and normalcy in their everyday life. The five themes of this phase which emerged from the data are Anguish and Responsibility, Social Disconnection, Shared Understanding, Parenting Guilt and Spousal Collision. Each of these themes has been elucidated below.

Anguish and Responsibility (N = 11)

Newly bereaved parents often found themselves oscillating between setting time aside to grieve and express their own feelings surrounding their child’s death and attending to their family and work commitments.

> “I have to do my grieving on my own private time and then pull myself together so that I can carry on with my responsibilities.” (Barrera et al., 2007, p. 152)

For many parents, the agony of losing their child was deepened when they realized that they had lost not only their child but the entire world they built around caring for them.

> “You feel really, really isolated because the circles that you’ve been moving in like the hospices, doctors, nurses, school... it's like your whole world has collapsed.” (Reilly et al., 2008, p. 551)

Other parents explained that life — as they had known it to be — had changed in so many ways since their child’s death that it appeared to be a new life altogether.

> “There’s a point in my life where there is line zero - before Joshua died [is] on top [of the line] and below [the line] Joshua died is now. Here on in ... that is my new point... day one. There’s nothing in my life that I don’t think has changed.” (Denhup, 2017, p. 352)

Social Disconnection (N = 9)

The distinctive nature of parental bereavement due to child loss and the intense emotions associated with it could barely be explained to others. As a result, bereaved parents were often left feeling alienated from their relatives and friends.

> “It's a really strange feeling. Everybody’s going around, they’ve no idea what situation you’re in and they’re just doing their everyday thing which you used to do.” (Jordan et al., 2015, p. 849)

Further, bereaved parents explained that many of their relatives and friends refrained from speaking about their late child for fear of eliciting sadness and pain, or because they were uncomfortable about broaching the topic. But ironically, recounting their child's memories aided parents in processing their turbulent feelings, while avoiding the topic of their child's life story and death made them feel as though their child had been removed from their family simply because he/she was no longer physically present.

> "I suppose they think that if we mention Kate it will upset us. I find it more upsetting if people don't refer to Kate, as if she is not part of the family." (DeCinque et al., 2006, p. 72)

There were some bereaved parents who found it psychologically safer to detach themselves physically from their former social network:

> "I used to shop two suburbs away. I could just sit and everything would happen around me. I felt safe." (Gear, 2014, p. 178)

Shared Understanding (N = 8)

Bereaved parents found it helpful to connect with other grieving parents, to whom they could openly express their suffering and from whom they could receive acknowledgement and validation, in their journey of reconciliation with their loss.

> "Because you don't have to explain what you're feeling. They know... And it helps a lot" (Reilly et al., 2008, p. 556)

The opportunity to interact with others who had experienced similarly devastating circumstances such as themselves served to lessen bereaved parents' feelings of alienation.

> "I think it's good to be able to have connections, see faces, and realize that you're not alone." (Berrett-Abebe et al., 2017, p. 353)

Parenting Guilt (N = 7)

Several parents recalled the period of end-of-life caregiving for their sick child with a sense of guilt, as they reflected about the different ways in which they had deprived the healthy siblings of their sick child of parental care, attention and time.

> "And I can remember sort of feeling bad at times thinking you know that they were being neglected." (Jordan et al., 2015, p. 845)

Other bereaved parents worried whether they could ever be good carers for their surviving child, amidst navigating their own grief and sadness. Many were concerned that their surviving children might continue to grapple with unresolved grief even years later:

> "Both of us [parents] have found a way to cope, but sometimes we have the impression that our two older kids have not worked through their grief." (Bergstraesser et al., 2015, p. 133)

Some bereaved parents mentioned that as a way of compensating for their past neglect, they now consciously took time out to engage in activities that would facilitate rekindling of their relationship with their surviving children.

> “My daughter and I, we hang out a lot. We do a lot of neat things together. I think we have become very close” (Barrera et al., 2007, p. 153)

Spousal Collision (N = 5)

The demands of end-of-life caregiving and the devastation of child loss had a deleterious impact on grieving parents’ relationship with their spouse.

> “I was in a tremendous crisis, with aggression and fury, which extended over months. I was so angry, had quarrels with [husband] and raged against him even if he did not deserve it.” (Bergstraesser et al., 2015, p. 132)

For couples whose relationship with their spouse was strained prior to their child’s diagnosis, the illness and subsequent death compounded the prevailing stressors.

> “James’ father and I had marital stress before James’ illness... Two months before James died, I found out his dad was having an affair. I do believe that affair happened because it was a place for James’ dad to feel in control… by the time James’ died, I found out the affair was still going, so I told my husband to leave.” (Titus & de Souza, 2011, p. 455)

In addition, because of gender differences between men and women in coping with grief, for some couples, the loss of their child resulted in further friction in what was already a fragile spousal relationship.

> “I’m working, and then she wants to say something. I don’t want that at that time, because... there’s no way I can keep on working [if we would talk].” (Hooghe et al., 2018, p. 5)

In sum, although bereaved mothers and fathers experienced the same demanding situation, they were often incapable of supporting each other in their grief. In fact, spouses sometimes aggravated each other’s suffering rather than relieving it.

Phase 4: Reconstructing Lives

The profound grief of losing one’s child was relatively permanent. For bereaved parents, the transition from mere survival towards transformation, personal growth and rebuilding of their life necessitated accepting the loss as a part of themselves and redefining the bond they shared with their late child. The three themes of this phase which emerged from the data are Continuing Bonds, Meaning Making and Restorative Actions. Each of these themes has been elucidated below.

Continuing Bonds (N = 11)

In order for bereaved parents to reconstruct their lives after the death of their child, it was important to acknowledge and accept their child’s death, integrate their loss within their redefined life, and maintain a relationship with the personhood of their child despite the absence of his or her physical body. Some parents chose to maintain their late child’s room as it were, refusing to make any changes to it, as a gesture of their continuing relationship with their child. Others found that physical contact with their child’s belongings, doing activities that their child used to enjoy or visiting their child's grave helped to sustain the parent-child bond.

> "I have a little bear that was made out of one of his blankets like uh, kind of just cuddle with that, remember him wrapped up in it." (Dias et al., 2017, p. 321)

Still other parents found that engaging with auditory and visual reminders that held a significant memory of their child helped to affirm their child's precious position in their lives:

> "So every time I hear that song I always think about her... music... that was her passion" (Foster et al., 2009, p. 5)

In addition, remembering qualities of their late child which they appreciated and cherished, such as his or her care and love for family members played an important role in helping parents to cope. Some parents also took up philanthropic projects which were symbolic of their sustained relationship with their child:

> "She was a competitive swimmer… and so we're still doing that. We've got a fund for a scholarship in her name." (Foster et al., 2011, p. 6)

Meaning Making (N = 9)

For bereaved parents, the ability to ascribe meaning and purpose to their child's life, illness and death was a critical step in coming to terms with their loss.

> "It gives us some satisfaction to know that he was here for a purpose and that's the way we sort of look at it and we use it that way." (Hynson et al., 2006, p. 808)

Across the studies that were reviewed, it was evident that engaging in philanthropic projects not only helped parents to maintain continuing bonds with their late child, but also facilitated the creation of meaning.

> "We'll take everything that we can, and turn it into a positive experience by taking this foundation and giving other families financial aid, and answering their questions, and trying to be there for them if we can." (Rossetto, 2014, p. 533)

There were other parents who remembered their child's inspirational qualities and the impact that he/she had made on others, even within his or her short lifespan. Some parents also associated their journey of child loss and healing with self-discovery, learning and achievement of personal growth.

> "I've been there, you know, and I've survived it, so it kind of makes you a much stronger person." (Reilly et al., 2008)

Restorative Actions (N = 6)

Many of the articles that were reviewed emphasized that bereaved parents would sometimes set aside their pain and sadness and engage in activities (such as watching a film), which were unrelated to their child's death, thus seeking a sense of respite from their grief.

> “Sometimes we need a break; then we might say: "Now we’ll watch a movie, just any movie. Yes, we’ll take a little break.” (Bergstraesser et al., 2015, p. 133)

Other parents took a break from their upsetting thoughts and feelings by filling their day with numerous activities, which could be home and/or work related.

> “I also do my husband’s billing, laundry and stuff, but usually it works in between being in and out of the shopping and various things...” (Barrera et al., 2007, p. 159)

Distracting oneself, even temporarily, as a means of coping was especially helpful to fathers who frequently failed to receive social validation for the loss that they were experiencing.

> “I entrenched myself — over the weekends... until my wife complained and was concerned about my way of coping. And yes, she was right, I tried to catch up again; I tried hard to find a way back” (Bergstraesser et al., 2015, p. 132)

Summary of Findings from Study 1

This chapter presented a detailed description of the findings of Study 1. Concisely, articles that were obtained through a systematic search of literature were analyzed, data were extracted and re-constructed into a novel parental bereavement trajectory of child loss with four distinguishable phases. This trajectory draws attention to parents’ lived experience of the liminal margins of their child’s chronic life-threatening diagnosis, to holding space for the period of their child’s death, to navigating losses associated with grief and mortality surrounding their child’s death, and finally reconstructing their lives through acknowledgement of possible ways of restoring normalcy, maintaining continuing bonds and ascription of meaning to their experience of loss.

CHAPTER FIVE

FINDINGS FROM STUDY 2: THE TRAUMA TO TRANSFORMATION MODEL OF PARENTAL BEREAVEMENT

This chapter presents the findings of Study 2 which involved a Singapore-based qualitative meaning-oriented inquiry to understand the experience of parents who had lived through the chronic life-threatening illness and death of their child in the local context. Emphasis is placed on the challenges faced by parent-caregivers and bereaved parents, their unmet needs, and the strategies they adopted to address these difficulties.

Characteristics of Study Participants

Study participants comprised 6 married couples, 13 lone mothers, 4 lone fathers and 2 primary parental figures (*N* = 25 parental units). The mean age of the participants was 49.35 years (SD = 10.47). All participants were Singapore citizens or Permanent Residents. No mixed-race marriages were reported by participants. Majority of the participants' children had been diagnosed with cancer between the ages of 10 to 19 years. The period of caregiving for their child varied greatly across the sample. Most participants had at least one surviving child. Demographic characteristics of the participants are shown in table 5.1.

Table 5.1. Demographic Characteristics of Participants in Study 2

	Age	**Sex**	**Marital status**	**Ethnicity**	**Child's diagnosis**	**Child's age at diagnosis**	**Child's age at death**	**Years since demise**	**No of surviving children**
P1	50-59/50-59	M/F	Mar	Chinese	Cancer	10-14	10-14	2	1
P2	50-59/50-59	M/F	Mar	Chinese	Cancer	15-19	15-19	2	2
P3	50-59	F	Mar	Chinese	Cancer	0-4	25-29	1	2
P4	60-69/50-59	M/F	Mar	Chinese	Cancer	10-14	15-19	2	1
P5	40-49	F	Mar	Malay	Cancer	NK	15-19	4	3
P6	40-49/30-39	M/F	Mar	Malay	Cancer	0-4	5-9	2	2
P7	30-39	F	Mar	Indian	Cancer	0-4	0-4	1	2
P8	30-39	F	Mar	Malay	Cancer	10-14	10-14	2	2
P9	60-69	F	Sin	Indian	Muscular dystrophy	5-9	15-19	0.6	1
P10	40-49	F	Mar	Chinese	Cancer	10-14	10-14	4	2
P11	40-49	M	Wid	Chinese	Undisclosed	0-4	10-14	1	1
P12	40-49	M	Mar	Indian	Brain tumor	10-14	10-14	4	1
P13	40-49	F	Mar	Chinese	Brain tumor	0-4	0-4	4	1
P14	40-49	F	Div	Malay	Cancer	0-4	5-9	4	3
P15	40-49	F	Mar	Malay	Cancer	10-14	10-14	5	3
P16	60-69/60-69	M/F	Mar	Malay	Kidney failure	0-4	15-19	3	1
P17	50-59	F	Mar	Chinese	Cerebral palsy	0-4	15-19	2	2
P18	50-59	F	Mar	Chinese	Blood clot in the brain	5-9	15-19	3	-
P19	30-39/30-39	M/F	Mar	Chinese	Spinal muscular atrophy	0-4	0-4	2	-
P20	40-49	F	Mar	Indian	Cerebral palsy	0-4	15-19	1	2
P21	70-79	M	Wid	Chinese	Multiple diagnoses	0-4	30-34	1	1
P22	30-39	F	Mar	Malay	Multiple diagnoses	0-4	0-4	0.5	2
P23	50-59	F	Mar	Malay	Cancer	0-4	5-9	0.6	-
P24	40-49	F	Mar	Chinese	Congenital heart disease	0-4	10-14	3	-
P25	30-39	M	Mar	Chinese	Cancer	0-4	0-4	0.6	1
Mean	49.35					4.73	12.06	2.21	1.44
SD	10.47					5.05	7.21	1.36	0.92

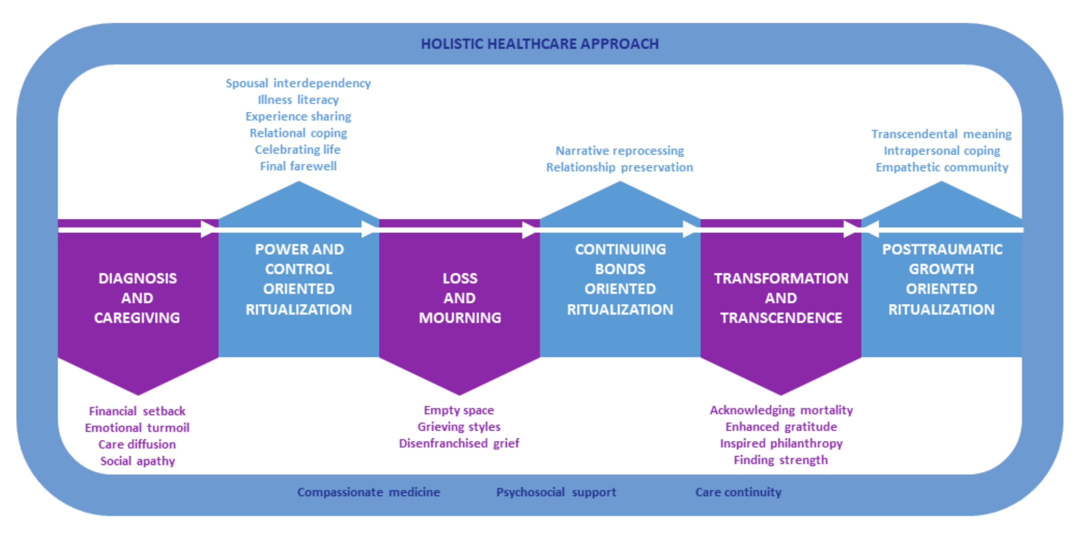
Note. M: Male. F: Female. Mar: Married. Div: Divorced. Sin: Single. Wid: Widowed. NK: Not Known. All ages are mentioned in years.

Trauma to Transformation model of Parental Bereavement

The 7 emergent themes and 25 sub-themes from the data which encapsulate the lived experience of Asian bereaved parents of children with chronic life-threatening illness have been represented in a novel Trauma to Transformation model of Parental Bereavement (see Figure 5.1). This model demonstrates the milestones in participants' lived experience of their child's chronic life-threatening illness and death, beginning from the diagnosis of their child's chronic life-threatening illness and the subsequent emotional turmoil (Theme 1), the mourning of their child's death and the losses which accompanied the death (Theme 3) and participants' experience of posttraumatic growth through reflection of their journey of caregiving and child loss (Theme 5). The model further shows the deliberate behaviors or 'rituals' that helped participants to regain power over their lives (Theme 2), sustain an intimate bond with their child beyond death (Theme 4), and transcend their loss by deriving positive outcomes from their experience (Theme 6). Finally, the Trauma to Transformation model denotes that the lived experiences and well-being of participants were embedded within the health-and-social-care ecosystem, and in turn impacted by it (Theme 7). In sum, Themes 1 and 2 describe how Asian parents journey from the diagnosis of their child's chronic life-threatening illness to his or her end-of-life. Themes 3 and 4 explore Asian parents' lived experience and coping in the immediate aftermath of their child's death. Themes 5 and 6 examine Asian bereaved parents' lived experience after the loss of their child.

Finally, Theme 7 offers insight to healthcare professionals about improvements in psychosocial care and holistic health services that would positively impact Asian parents' well-being during their child's illness trajectory through bereavement.

Figure 5.1. Trauma to Transformation: The lived experience of Asian bereaved parents of children with chronic life-threatening illness



Theme 1: Diagnosis and Caregiving

The first theme in the Trauma to Transformation model is Diagnosis and Caregiving, which refers to participants' reactions when they learned about their child's chronic life-threatening illness and the challenges that they encountered throughout their child's illness trajectory and end-of-life. This theme comprises 4 sub-themes, namely, Financial Setback, Emotional Turmoil, Care Diffusion and Social Apathy.

Financial Setback (Number of interviews theme appeared in: N = 19)

The N clearly indicates that survival needs such as financial worries were participants' most critical concern following their child's chronic life-threatening diagnosis. Participants emphasized the costly nature of treatments.

> "One pill for cancer did not come cheap; one hundred dollars a day, and that added up to three thousand dollars a month." (P11, father)

Many participants had to quit employment to fulfil their caregiving duties which further added to the financial difficulties faced by the family.

> "Ever since my son had fallen sick, I had to stop working […] then my husband's income wasn't stable, so we started having financial issues." (P13, mother)

Emotional Turmoil (N = 16)

Participants shared feeling alarmed and confused when they initially received the news of their child's diagnosis.

> "Shocked [...] we really cannot believe he was that sick." (P23, primary parental figure)

Other participants were concerned about the long-term implications of their child's condition.

> "I want to know, two years later what is going to happen to her, five years later what is going to happen to her. Can she blend into society, would she be able to go to school?" (P17, mother)

Still other participants described feeling stuck in limbo as they maneuvered the complicated and protracted process of diagnosing their child's condition.

> “Me going through this for the first time, I was totally lost. And at that time, they [doctors] are not able to share more things with me. So, I feel like […] don’t know who to look for.” (P22, mother)

Care Diffusion (N = 14)

Participants explained that caring for a child with chronic life-threatening illness was a full-time commitment of time and energy. As a result, the needs of their other healthy children would often be neglected. Some participants relied on the assistance of family members and friends to care for their healthy children.

> “I neglected my son a little bit as I let go a lot to other people to handle him and I focused more on my daughter.” (P10, mother)

Participants also described the emotional difficulties that their healthy children encountered and felt regretful for not having the capacity to attend to them.

> “We went out together. I was holding her [sick child] hand, then my youngest daughter told me, ‘Mummy why every time you only hold JieJie (elder sister), you never hold me […]’ Then I explained to her […] She does understand, but understanding is one part […] Feeling is another thing.” (P3, mother)

Social Apathy (N = 11)

A number of participants voiced their upset about the community-wide indifference and ignorance regarding the challenges faced by families caring for a child with a complex medical condition. Many sick children endured demeaning remarks about their appearance which had changed as a result of the illness and treatment.

> “The children, so-called, laugh at her […] said in Chinese words ‘botak’, [which] means bald.” (P3, mother)

Family members of sick children often endured insensitive social attitudes.

> “The teacher [of the healthy sibling] was like ‘stop with all your stupid family story [...] Don’t ask for any sympathy or be attention seeker.’” (P14, mother)

Theme 2: Power and Control Oriented Ritualization

The second theme in the Trauma to Transformation model is Power and Control Oriented ritualization. This theme encompasses the rituals adopted by participants to bring a sense of order into their seemingly uncontrollable lives which now seemed to be dominated by treatments and hospital visits. The 6 sub-themes within this theme are Spousal Interdependency, Illness Literacy, Experience Sharing, Relational Coping, Celebrating Life and Final Farewell.

Spousal Interdependency (N = 18)

Participants and their spouses established a ritual of alternating caregiving responsibilities, so that the child’s primary family caregiver could take a break for self-care and rest.

> “When he (spouse) was not working, or when he had a few hours off, he would look after him (sick child), then I would go out for a while. Even if I only get to walk around in the lobby [of the hospital], I was happy […] I had to leave for that period, for myself to take a breather.” (P13, mother)

Participants noted that support from their spouse was typically pragmatic in nature, often revolving around solution-focused tasks and conversations. There was little emphasis on heart-to-heart discussions about thoughts and feelings.

> "Talk, not so much. [We were] physically present [for each other] as much as possible. Functional needs first, survival mode. [We] talked a bit about the diagnosis, or what we thought was the best place to go or the next step to go on." (P1, father)

Illness Literacy (N = 15)

Participants reached out to seek a number of resources to find out more information about their child's condition.

> "We went there (Singapore Cancer Center). I did my homework. I asked the doctor dozens of questions." (P2, mother)

They believed that having knowledge about the illness and different care plans would empower them to collaborate with medical professionals in making informed decisions that would be most suitable for their child.

> "You research some stuff, you try to bring it up to the doctor [...] like for example, we brought up the use of the Cough Assist and eventually they allowed us to use it." (P19, mother)

Experience Sharing (N = 13)

Many participants reached out to other parent-caregivers who were facing similar challenges such as themselves for reciprocal support and informational exchange.

> "We talk to them (parents of other sick children) [about] what are we expecting, the daily needs that we need to do for them […] if our equipment breaks down, what do we do?" (P19, mother)

The more experienced parents who had been caregivers for their sick children for a prolonged period of time often embraced the role of comfort-providers for "newcomers" whose children had been recently diagnosed and who were experiencing elevated levels of anxiety and distress.

> "We extended our help or talked to those 'newcomers' warded in the hospital. We spoke to them about our experience, such as the procedures. Most of them didn't know what to do […] so we shared our experiences with them." (P4, father)

Relational Coping (N = 10)

Participants coped with the demands of looking after their sick child by engaging their family members in day-to-day caregiving tasks. This augmented participants' perceived power in managing challenges associated with the illness. Participants recognized and channeled the strengths of their different family members so that caregiving duties could be fulfilled and simultaneously, each family member would feel involved in care provision for the child.

> "I want my parents to feel that they are involved in making him recover by cooking for him […] because we [husband and wife] don't have time to cook." (P2, father)

Participants also noted that spending time with their loved ones helped them to face challenges such as their child’s prolonged hospital admissions together as a family.

> “Daddy makes sure that at any point where they have free time, he will grab the opportunity and bring everybody together to the hospital. Although it's not a happy place, it's where the family would be together.” (P6, mother)

In addition, participants shared their emotional and practical availability with other family members who were experiencing difficulties in providing care to the sick child.

> “My daughter needed help at that time, she was alone […] She has to work and then who’s going to look after my grandson? So, I felt it was my duty to look after him.” (P23, primary parental figure)

As their child progressed along the illness trajectory and his or her condition deteriorated, participants’ hopes for recovery were replaced with preparation for mortality. At such times, participants continued to adopt rituals which empowered them to feel in greater control of their lives. The following two sub-themes describe the ways in which participants asserted power and control at the close of their child’s life.

Celebrating Life (N = 18)

Participants aspired to support their child in celebrating life, transcending challenges brought on by the illness and fulfil their child’s dreams and desires.

> “Try to fulfill whatever wish they wish for […] once they are gone, you are not able to do all these things.” (P5, mother)

They experienced the satisfaction of realizing their parental role in the final days of their child’s life by spending meaningful time with their child and fulfilling their child’s wishes.

> “We went to shop for baking stuff, after which we booked a café. Then there was a so-called chef, and all the waiters came down, taught him cake-making. There was a party, everyone joined and made ice cream.” (P25, father)

Final Farewell (N = 22)

In the closing moments of their child’s life, participants were steadfast in fulfilling their parental roles. They comforted their child and attempted to alleviate his or her concerns about dying.

> “When I hold on to him, when daddy holds on to him, we spoke to him and we told him that it was going to be alright.” (P7, mother)

In instances where the child’s death could be predicted from the gradual decline in his or her body functions, participants arranged for their child to be comfortable at home and invited loved ones to visit and bid farewell.

> “I called everyone […] they came to say their final goodbyes to him […] Then Saturday, he left us at 3 am.” (P13, mother)

In other instances, where the child’s death was unexpected, participants regretted not having the time and space for a meaningful goodbye.

> “I feel very guilty [...] I’m thinking that I’m not beside him at that time, maybe we don’t know what is in his mind. Maybe the few days before he passed away, I can take leave and stay with him […] I didn’t know he would leave me very soon, I thought it was going to be like every day.” (P20, mother)

Theme 3: Loss and Mourning

The third theme is Loss and Mourning, which refers to the period in the immediate aftermath of the child’s death and the complex blend of emotions that participants experienced as they processed their loss. The sub-themes comprising this theme include Empty Space, Grieving Styles and Disenfranchised Grief.

Empty Space (N = 18)

Participants reflected that the death of their child had created a void that would never be filled.

> “There’s always that empty space here. Even after he was buried, sometimes my husband says, ‘Eh we used to call them all 3 to come for dinner right, now we can only call 2.’” (P8, mother)

This sense of emptiness was especially striking for the parent who was the child’s full-time primary caregiver.

> “Like every other day you’ll be planning your schedule because he has a medical appointment [...] and now suddenly you no longer have to plan for him.” (P7, mother)

Participants shared that bereavement brought with it the awareness that they had lost not only their beloved child but the entire world they had built around care provision for their child.

> "The house became very quiet. When she was around with the equipment all that, at least you can hear the sounds of the machines beeping […] so after that suddenly no machine sounded no nothing." (P19, mother)

Grieving Styles (N = 10)

Parents in a married relationship discovered that though they had experienced the loss of the same child, they had different ways of mourning this loss.

> "He is quieter about it and I want to talk about it. But then when I want to talk to him about it, he doesn't, he's not ready." (P6, mother)

Participants reflected that such differences could be attributed to personality characteristics and the type of involvement that each parent had in caring for the child, rather than gender.

> "Maybe it's not just about men and women. It's about character… My husband likes to talk. I don't like to talk much. I write [...] but if I were a stay-at-home mother, that bond would be very close. But I don't. So that feeling is not the same as him. He has many beautiful memories rather than me. He feels the loss more than me." (P15, mother)

Disenfranchised Grief (N = 8)

Bereaved parents' intense anguish and the significance of the loss in their lives and social roles often did not receive validation from the community.

> "They (refers to her husband's aunts) told me, 'You should try for another child with your husband.' I don't want to." (P18, mother)

Some participants recounted that overt expression of their grief and agony had been considered improper.

> "Every day I sit alone, I cry […] my son notices. He says, 'Please, what are you looking and crying for? Over already now.'" (P9, primary parental figure)

Theme 4: Continuing Bonds Oriented Ritualization

The next theme in the model is Continuing Bonds Oriented Ritualization, which refers to the rituals adopted by participants to maintain psychological and spiritual proximity with their child, which in turn helped them to cope with the feeling of helplessness brought on by his or her death. This theme consists of 2 sub-themes, namely, Narrative Reprocessing and Relationship Preservation.

Narrative Reprocessing (N = 20)

Participants engaged in narrative recounting of their child's life story, thereby ascribing a sense of personhood, meaning and purpose to their child's life.

> "He got to spend time with his family, he got to celebrate his father's birthday. He got his friends to come and visit. He got to make sushi

> with one of his friends who had the same diagnosis as him." (P8, mother)

Many participants proudly talked about the courage and strength with which their child had endured pain and suffering.

> "He was pretty strong even though how bad the chemo went, the side-effects came in, vomiting all this, he is accepting it quite well." (P2, father)

Participants thus searched for meaning and personal growth in their loss through recounting the inspirational qualities of their child.

> "And through these 15 years, along the way, when I'm down and out, I look at her. Why is it that she (deceased child) can enjoy life even in that state? Why am I so upset over small things or things that I can control, or I can get rid of?" (P17, mother)

Relationship Preservation (N = 12)

It was important for participants to preserve and validate their relationship with their late child, regardless of his or her physical existence.

> "When people ask me how many children I have, I will reply saying, 'I have two children.' 'Where's the older child?' 'He passed away.' I don't want to say that I only have one son now. I want to acknowledge him." (P13, mother)

Participants also desired to commemorate their child and share his or her inspirational qualities with the world.

> “I want people to read his story, his goodness, whatever he went through, the positive things that we achieved […] I want to put all that into one book.” (P15, mother)

Theme 5: Transformation and Transcendence

The fifth theme in the model is Transformation and Transcendence, which refers to the process of transformation achieved by participants as they reflected on the devastating journey they had been through, including caring for their child throughout his or her illness trajectory, their child’s end-of-life, losing their child and finally their ability to transcend this traumatic experience. This theme comprises 4 sub-themes, namely, Acknowledging Mortality, Enhanced Gratitude, Inspired Philanthropy and Finding Strength.

Acknowledging Mortality (N = 11)

Participants shared that the loss of their child had brought about reflection about the fragile and vulnerable nature of human life in an unpredictable and uncontrollable world.

> “Life can be too short. God can just take [loved ones away] anytime.” (P6, father)

Often, this resulted in participants re-evaluating their lives and expressing greater appreciation for aspects of their life which they had previously taken for granted, especially their family relationships.

> “I was very career driven in the past. Now family is more important... the time I spend with my daughter, the time I spend with my wife.” (P25, father)

Enhanced Gratitude (N = 11)

Participants described that the experience of caregiving and child loss had enhanced their ability to notice and cherish the positive aspects of their lives.

> "We're very lucky to be here in Singapore, we got so much help from people, all walks of life, from different kinds of races also." (P23, primary parental figure)

They felt that this in turn improved their well-being, decreased feelings of regret and smooth the process of acceptance of the loss.

> "It is not a sudden death. It's a period where you can have that bonding, that moment, that quality time, instead of just being abruptly taken […] God gave you that period you have to be with her, enjoy every second so you don't have regrets." (P14, mother)

Inspired Philanthropy (N = 9)

Participants found that serving others helped them to find meaning in their loss.

> "She [wife] does a bit of administration for them [welfare organization] […] Some of our weekends are spent going to some of the beneficiaries' families […] we found great meaning in it so yeah, we help out in this cause." (P19, father)

They clarified that the difficulties they had faced in caring for their child and his or her unique needs had increased their sensitivity towards other people's needs, and this now motivated them to provide assistance to others whenever they found an opportunity.

> "We were also moving with wheelchairs and we had difficulties. So now I see old people moving on their own, I go and help automatically." (P12, father)

Other parents explained that they felt indebted towards the people and organizations who had supported them during the period of caregiving. They now felt dutiful to give back and help in whatever ways they could.

> "Right now, I volunteer at the center two times a week [...] My grandson benefited a lot from the session in school, received a lot of love from the staff and teachers from the center, so I feel I have to give what I can." (P23, primary parental figure)

Finding Strength (N = 8)

Several participants reported that the challenging experience of caregiving and loss had made them stronger and more resilient from within.

> "I realized that I have become more cheerful [...] A lot of things are actually unimportant, and I can choose not to care about them [...] I feel that my worldview has gotten bigger too." (P13, mother)

Participants' ability to persist in spite of the challenges they had encountered in providing care to their sick child made them realize the courage and strength they possessed within themselves.

> "After all this, I'm really a warrior mother. I'm not like others, I'm more than others so I can do much better than others." (P20, mother)

Theme 6: Posttraumatic Growth Oriented Ritualization

The sixth theme in the Trauma to Transformation model is Posttraumatic Growth Oriented Ritualization. Essentially, although participants' agony of losing their child loss tended to reduce over time, the memory of their child and the sadness of losing them was relatively enduring. This relatively permanent pain facilitated participants to continue to adopt rituals which would empower them by bringing about positive change and growth outcomes in their lives. Such rituals further enhanced participants' experience of transformation and transcendence in their journey of grief and loss, as represented by the bidirectional arrow in the Trauma to Transformation model. The 3 sub-themes within this theme include Transcendental Meaning, Intrapersonal Coping and Empathetic Community.

Transcendental Meaning (N = 23)

Participants' transcended their grief by actively focusing on the bigger picture beyond the loss of their child. Such transcendental meanings were often person-centric, whereby participants' personal values and beliefs influenced the way in which they made sense of their child's death.

> "Even though today he passed away, tomorrow the sun still rises.
> So, all of you got to accept the fact that he is not going to be here.
> Things carry on." (P2, father)

For other participants, faith-based beliefs shaped their perspectives about child loss.

> “The greatest comfort I have is that I know she is with Jesus.” (P3, mother)

Still other participants viewed their child’s death as a termination of his or her misery and suffering.

> “If you cannot make him better, you take him away […] you take him away rather than I see him suffer.” (P15, mother)

Intrapersonal Coping (N = 14)

Participants shared the different strategies that they employed to cope with their individual grief and to express and process their feelings.

> “It's only when I drive, I go back from [location name], it's a long way right? 1 hour, 35 minutes sometimes. That is where (makes crying sound).” (P15, mother)
>
> “The nearest park here is [name of Park]. So, there is a favorite spot for me that I will go to. I’ll spend time reading the Bible, I’ll bring a book and start to write […] as I write, I cry.” (P1, mother)

Others found that filling their schedule with activities helped in coping with their grief.

> “Through work, I gradually learned not to think about him. At home, I occupy myself with housework or I go out and walk around […] this is how I get by day by day.” (P18, mother)

Empathetic Community (N = 13)

Participants recounted that it had been helpful for them to be a part of support groups that connected them with other parents who had experienced a similar kind of grief.

> "We have a closed group of us grieving parents. I gained help from there. They are all parents who lost their children in any way, in any form, at any age. But all feel the same pain." (P3, mother)

They believed that the unique suffering and emotional pain of a bereaved parent could only be understood and validated by somebody who had experienced it firsthand.

> "Only those who have gone through this would understand." (P18, mother)

Participants who had come to terms with their loss found it meaningful to join such groups, because it provided them a platform to demonstrate their empathy and encouragement for others.

> "I don't mind talking to them or motivating them in life and telling them about things that I went through." (P14, mother)

Theme 7: Holistic Healthcare Approach

The final theme in the model is Holistic Healthcare Approach, which emphasized that participants' relationship with their healthcare providers, and their views about the extent to which their healthcare provider felt compassion and care towards their child impacted their personal well-being. There are 3 sub-themes within this theme, namely, Psychosocial Support, Compassionate Medicine and Care Continuity.

Psychosocial Support (N = 19)

Participants expressed their appreciation for the psychological and emotional care provided by their social workers and counsellors during the challenging period of caregiving for their sick child.

> "I really appreciate [them]. They counselled the girl (sick daughter). They counselled me [...] be there for me to talk about whatever I want to talk." (P15, mother)

They believed that it was important for their mental well-being to be able to talk openly about their fears and worries.

> "Sometimes they (parents) also need vitamins. Vitamins are not like A, B vitamins. It's like support […] counseling, motivating." (P20, mother)

Psychosocial support also helped to smooth the transition for participants from being a parent-caregiver to being a bereaved parent.

> "They come and visit and see what they can help (during the child's wake) ... They also asked me if I could let them know if I needed any help." (P24, mother)

Compassionate Medicine (N = 17)

Participants felt that there was a need for physicians to show greater compassion towards their young patients and respect the family's wishes for quality of life for their child.

> "They saw the children as patients. They never treated them as children. Whenever they needed to poke the children to find veins and these types of things, they were rough." (P7, mother)
>
> "The doctor wanted to save his life, not his leg. But to us parents, I rather let him have a leg. Since it [cancer] cannot be cured I rather let him enjoy the rest of his life." (P2, mother)

Others added that a compassionate physician would have the capacity to acknowledge and validate the child's suffering.

> "This doctor, very fresh in the morning, 'How is your pain, [on a scale of] 1 to 10?' My son said, '100'. 'Couldn't be a 100.' When he said the pain is 100, you can say it's very painful, right? How could you say it couldn't be like that? Did you feel his pain? Have you ever had cancer and relapsed before?" (P8, mother)

Care Continuity (N = 14)

Participants favored an integrated approach to their child's care that comprised disease-directed treatments together with emotional support and comfort provision.

> "When I say some [healthcare professionals] with passion, while checking on her, they played with her, that kind of thing, to make her feel more comfortable." (P19, mother)

However, only a small proportion of parents perceived themselves to be recipients of such holistic care, as can be seen from the number of parents who emphasized the need for greater compassion in medical care. Additionally, participants also expressed that a quality healthcare service would involve clear, adequate and consistent communications from the physician regarding their child’s treatment and prognosis.

> “Some people tend to explain it in a very technical jargon form […] what do you mean by MRD, minimal residual disease? What do you mean by blood peripheral blast? These kinds of terms sound very intimidating at times.” (P25, father)

Summary of Findings from Study 2

This chapter presented a detailed description of the findings of Study 2. Concisely, data obtained through meaning-oriented interviews with participants were analyzed using a grounded theory approach and organized into a Trauma to Transformation Model of Parental Bereavement. This model illustrates the key milestones in participants’ lived experience of their child’s chronic life-threatening illness and death, beginning from their child’s chronic life-threatening prognosis and the ensuing emotional turbulence, the grief resulting from the loss of their child and other associated losses, and participants’ experience of posttraumatic growth resulting from reflection about their journey of caregiving and child loss. The model also describes the rituals that aided participants to reclaim control over their lives, maintain a continuing bond with their child beyond death, and rise above their loss through emphasis on the positive outcomes of their experience. Finally, the model shows that participants’ lived experiences and well-being were intrinsically related to and impacted the health-and-social-care services that they received. In particular, participants highlighted that receiving compassionate care from their healthcare professionals that was delivered in jargon-free language and aligned with their own hopes regarding their child’s quality of life played an important role in impacting their psychological and emotional well-being. The implications of these findings for healthcare professionals working with parent-caregivers and bereaved parents and have been discussed in detail in Chapter Seven.

CHAPTER SIX

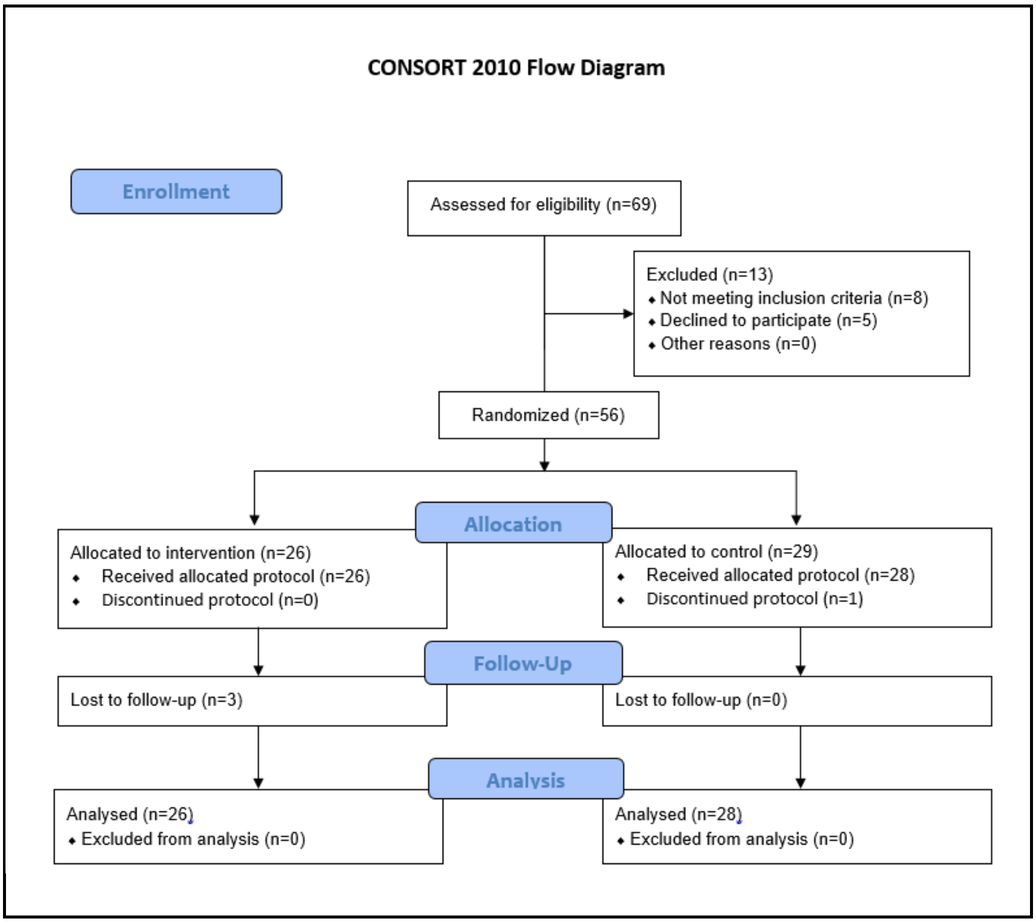
FINDINGS FROM STUDY 3: PILOT RANDOMIZED CONTROLLED TRIAL OF A NOVEL NARRATIVE E-WRITING INTERVENTION (NEW-I) FOR SUPPORTING PARENT-CAREGIVERS OF CHILDREN WITH CHRONIC LIFE-THREATENING ILLNESSES

This chapter presents the findings of Study 3 which involved the development, implementation and evaluation of an open-label mixed methods pilot randomized controlled trial of a novel Narrative e-Writing Intervention for parent-caregivers of children facing chronic life-threatening illnesses in Singapore.

Eligibility, Attrition and Characteristics of Study Participants

As shown in Figure 6.1, 69 potential participants registered on the NeW-I app by endorsing the online consent form and completing the demographic questionnaire were screened for eligibility. Of these, 13 potential participants were excluded from the study because they did not meet the inclusion criteria (*n* = 8) or they declined to participate in the study after completing the screening assessment (*n* = 5). The remaining participants were randomized to either the intervention (*n* = 26) or the control group (*n* = 29). Subsequently, 1 control participant discontinued the study citing personal reasons. At the post-intervention or follow-up stage, 3 intervention participants were lost to attrition. However, their data was retained for the baseline and post-intervention assessment.

Figure 6.1. CONSORT flow diagram of participants' progress in the NeW-I study



Detailed demographic details of the participants are shown in Table 6.1. Briefly, the sample for the present study comprised 54 parents of children with chronic life-threatening illness who were randomly allocated to either intervention group (*n* = 26) or control group (*n* = 28). Majority of the participants were female (83.33%), married (96.3%), of Chinese ethnicity (62.96%) and had completed a minimum education level of Polytechnic Diploma or Bachelor's degree (68.52%). Participants' employment status varied across the sample. All but one of the participants were Singapore citizens or Permanent Residents.

Furthermore, majority of the participants had a sick child who was in the age group of 6 to 15 years (68.52%) and they had at least 1 other healthy child. The child’s diagnosis varied greatly across the sample, including cerebral palsy, epilepsy as well as renal, muscular, neurodegenerative and rare genetic diseases. Participants who received the NeW-I intervention protocol did not differ statistically from those receiving the control protocol on primary and secondary outcome measures at baseline (all ps > 0.1 as revealed by Mann–Whitney U tests).

Table 6.1. Demographic Characteristics of Participants in Study 3

	IG *N* = 26	CG *N* = 28		IG *N* = 26	CG *N* = 28
Sex			**Employment status**		
Male	4	5	Full-time Employed	5	8
Female	22	23	Part-time Employed	1	5
Marital status			Self-Employed	0	1
Married	25	27	Unemployed	13	11
Divorced	1	1	Others	7	3
Ethnicity			**Child's present age**		
Chinese	17	17	0 - 5 years	3	4
Malay	4	8	6 - 10 years	8	13
Indian	3	2	11 - 15 years	9	7
Others	2	1	16 - 20 years	6	4
Religious beliefs			**Number of healthy children**		
Christian/ Catholic	8	7	0	7	5
Muslim	5	8	1	10	11
Hindu	2	1	2 or more	9	12
Buddhist	5	9	**Child's diagnosis**		
Taoist	2	0	Cerebral Palsy	13	7
None	4	2	Epilepsy	1	4
Others	0	1	Renal Disease	2	2
Education level			Neuromuscular Disease	1	2
Secondary or below	1	3	Neurodegenerative Disease	3	0
GCE 'N' or 'O' level	4	5			
GCE 'A' Level	1	3	Rare Genetic Disease	5	8
Polytechnic Diploma	5	4	Others	1	5
Bachelor's Degree	9	8			
Postgraduate Degree	5	4			
Professional Certificate	1	1			

Note. IG: Intervention Group. CG: Control Group.

Preliminary Evidence for Intervention Efficacy

Numerous improvements were observed in intervention participants' scores from baseline (T1) to immediate post-intervention (T2), and their scores continued to remain higher than baseline at the one-month follow-up (T3). See Table 6.2 for baseline, post-intervention and one-month follow-up descriptive statistics for both the intervention and control group.

The intervention and control group were compared on the primary and secondary outcomes using a Mann-Whitney U Test (see Table 6.3). Results showed that intervention participants had significantly higher levels of perceived social support than control participants ($z = -2.27$, $p < 0.05$, $r = 0.31$, $\text{Mdn}_{\text{Intervention}} = 3.7$, $\text{Mdn}_{\text{Control}} = 3$) at immediate post-intervention. No statistically significant differences were seen between intervention and control participants at one-month follow-up.

Table 6.2. Descriptive Statistics for NeW-I Intervention and Control Groups

	Intervention group					
	T1 (*N* = 26)		T2 (*N* = 26)		T3 (*N* = 23)	
	M (SD)	*MD*	*M (SD)*	*MD*	*M (SD)*	*MD*
Quality of Life	4.38 (1.27)	4	5 (1.39)	5	4.57 (1.16)	5
Spiritual Well-being	2.51 (0.75)	2.67	2.78 (0.72)	2.83	2.64 (0.87)	3.08
Meaning	2.83 (0.97)	3	3.1 (0.83)	3.38	2.91 (1.02)	3.25
Peace	2.24 (0.71)	2.25	2.67 (0.76)	2.75	2.33 (0.92)	2.25
Faith	2.47 (1.23)	2.5	2.58 (1.17)	2.75	2.67 (1.25)	2.75
Hope	2.88 (0.53)	2.96	2.96 (0.49)	3	2.89 (0.58)	3
Temporality & Future	2.7 (0.66)	2.75	2.83 (0.56)	2.88	2.68 (0.7)	2.75
Positive Readiness & Expectancy	2.95 (0.51)	3	3.02 (0.57)	3	2.99 (0.68)	3
Interconnectedness	2.97 (0.55)	3	3.03 (0.45)	3	3.01 (0.47)	3
Depressive Symptoms	0.6 (0.45)	0.56	0.65 (0.42)	0.61	0.64 (0.62)	0.44
Caregiver Burden	1.87 (0.57)	1.75	1.7 (0.56)	1.55	1.7 (0.71)	1.8
Social Support	3.25 (1.07)	3.3	3.58 (1.06)	3.7	3.31 (1.08)	3.2
Complicated Grief	1.02 (0.44)	1	0.87 (0.36)	0.9	0.87 (0.59)	0.8
	Control group					
	T1 (*N* = 28)		T2 (*N* = 27)		T3 (*N* = 28)	
	M (SD)	*MD*	*M (SD)*	*MD*	*M (SD)*	*MD*
Quality of Life	4.64 (1.19)	5	4.7 (1.1)	5	4.86 (1.21)	5
Spiritual Well-being	2.79 (0.7)	2.92	2.65 (0.8)	2.83	2.7 (0.8)	2.79
Meaning	3.13 (0.59)	3.25	2.91 (0.77)	3	2.99 (0.8)	3.25
Peace	2.28 (0.8)	2.13	2.34 (0.9)	2.25	2.39 (0.88)	2.38
Faith	2.96 (0.97)	3.13	2.69 (1.14)	3	2.71 (1.05)	2.88
Hope	3.03 (0.41)	3	3.06 (0.42)	3	3.03 (0.48)	3
Temporality & Future	2.89 (0.47)	2.88	2.94 (0.47)	2.75	2.88 (0.48)	2.88
Positive Readiness & Expectancy	3.12 (0.43)	3.25	3.07 (0.46)	3	3.14 (0.59)	3
Interconnectedness	3.07 (0.44)	3	3.15 (0.47)	3	3.07 (0.49)	3
Depressive Symptoms	0.72 (0.48)	0.61	0.63 (0.4)	0.56	0.55 (0.39)	0.5
Caregiver Burden	1.74 (0.51)	1.8	1.77 (0.56)	1.8	1.69 (0.68)	1.65
Social Support	3.05 (0.54)	3	3.17 (0.76)	3	3.35 (1.09)	3.5
Complicated Grief	1.01 (0.5)	1	0.98 (0.52)	0.8	0.82 (0.45)	0.8

Note. T1: Baseline assessment. T2: Post-intervention assessment. T3: One-month follow-up assessment.

Table 6.3. Between-Group Comparison of Primary and Secondary Outcomes for Intervention and Control Groups

	T1		T2		T3	
	z	*p*	*z*	*p*	*z*	*p*
Quality of Life	0.80	0.42	-1.16	0.25	-0.82	0.41
Spiritual Well-being	-1.45	0.15	-0.55	0.58	-0.04	0.97
Meaning	-0.92	0.36	-1.15	0.25	-0.03	0.98
Peace	-0.11	0.91	-1.3	0.19	-0.08	0.94
Faith	-1.59	0.11	-0.27	0.79	-0.17	0.86
Hope	-0.83	0.41	-0.13	0.89	-0.47	0.64
Temporality & Future	-0.67	0.5	-0.39	0.7	-0.74	0.46
Positive Readiness & Expectancy	-1.14	0.25	-0.05	0.96	-0.48	0.63
Interconnectedness	-0.48	0.63	-0.61	0.54	-0.32	0.75
Depressive Symptoms	-1.01	0.31	-0.09	0.93	-0.17	0.86
Caregiver Burden	-0.69	0.49	-0.85	0.4	-0.3	0.76
Social Support	-0.79	0.43	**-2.27**	**0.02*** **r = 0.31**	-0.15	0.88
Complicated Grief	-0.08	0.94	-0.58	0.56	-0.16	0.87

Note. * denotes p < 0.05. T1: Baseline assessment. T2: Post-intervention assessment. T3: One-month follow-up assessment.

Wilcoxon Signed-Rank Tests were conducted to determine within-group changes for both the intervention and control group (see Table 6.4). Results showed that intervention participants experienced significant improvement in quality of life ($z = -3.26$, $p < 0.01$, $r = 0.45$, $Mdn_{T1} = 4$, $Mdn_{T2} = 5$), overall spiritual well-being ($z = -2.76$, $p < 0.01$, $r = 0.38$, $Mdn_{T1} = 2.67$, $Mdn_{T2} = 2.83$), the meaning ($z = -2.31$, $p < 0.05$, $r = 0.32$, $Mdn_{T1} = 3$, $Mdn_{T2} = 3.38$) and peace ($z = -3.08$, $p < 0.01$, $r = 0.43$, $Mdn_{T1} = 2.25$, $Mdn_{T2} = 2.75$) subscales of spiritual well-being, the inner sense of temporality and future orientation subscale ($z = -1.92$, $p < 0.05$, $r = 0.27$, $Mdn_{T1} = 2.75$, $Mdn_{T2} = 2.88$) of hope and perceived social support ($z = -2.45$, $p < 0.01$, $r = 0.34$, $Mdn_{T1} = 3.3$, $Mdn_{T2} = 3.7$) at T2 compared to baseline. Moreover, intervention participants also experienced a significant decrease in subjective caregiver burden ($z = -2.57$, $p < 0.01$, $r = 0.36$, $Mdn_{T1} = 1.75$, $Mdn_{T2} = 1.55$) at T2 compared baseline, and continued to experience lower levels of subjective caregiver burden ($z = -2.35$, $p < 0.05$, $r = 0.34$, $Mdn_{T1} = 1.75$, $Mdn_{T3} = 1.8$) at the one-month follow-up. It was also observed that compared to baseline, control participants experienced significant decrease in risk of complicated grief ($z = -2.41$, $p < 0.02$, $r = 0.32$, $Mdn_{T1} = 1$, $Mdn_{T3} = 0.8$) at the one-month follow-up, a finding that was not observed in the intervention group. Lastly, contrary to expectation, control participants had slightly higher levels of perceived social support than intervention participants at the one-month follow-up.

Table 6.4. Within-Group Change in Primary and Secondary Outcomes for Intervention and Control Groups

	Intervention Group				Control Group			
	T1 vs. T2		T1 vs. T3		T1 vs. T2		T1 vs. T3	
	z	*p*	*z*	*p*	*z*	*p*	*z*	*p*
Quality of Life	**-3.26**	**0.001*** **r = 0.45**	-1.81	0.07	-0.46	0.64	-1.31	0.19
Spiritual Well-being	**-2.76**	**0.01*** **r = 0.38**	-1.48	0.14	-1.26	0.21	-0.40	0.69
Meaning	**-2.31**	**0.02*** **r = 0.32**	-0.88	0.38	-1.91	0.06	-1.04	0.3
Peace	**-3.08**	**0.002*** **r = 0.43**	-1.7	0.09	-1	0.32	-0.88	0.38
Faith	-1.13	0.26	-1.08	0.28	**-2.15**	**0.03*** **r = 0.29**	-1.88	0.06
Hope	-1.54	0.12	-1.51	0.13	-0.31	0.76	-0.77	0.44
Temporality & Future	**-1.92**	**0.05*** **r = 0.27**	-0.85	0.39	-0.47	0.64	-0.21	0.84
Positive Readiness & Expectancy	-0.69	0.49	-1.07	0.29	-0.64	0.52	-0.82	0.41
Interconnectedness	-1.05	0.3	-0.91	0.36	-1.5	0.13	-0.42	0.68
Depressive Symptoms	-0.77	0.44	-0.34	0.73	-0.47	0.64	-1.52	0.13
Caregiver Burden	**-2.57**	**0.01*** **r = 0.36**	**-2.35**	**0.02*** **r = 0.34**	-0.42	0.68	-0.77	0.44
Social Support	**-2.45**	**0.01*** **r = 0.34**	-0.26	0.79	-1.27	0.2	-1.72	0.09
Complicated Grief	-1.83	0.07	-1.55	0.12	-0.26	0.79	**-2.41**	**0.02*** **r = 0.32**

Note. * denotes p < 0.05. T1: Baseline assessment. T2: Post-intervention assessment. T3: One-month follow-up assessment.

Finally, Cronbach's Alpha Estimates were calculated for all the quantitative outcome measures across baseline, post-intervention assessment and one-month follow-up assessment (see Table 6.5). High inter-item correlations (alpha values ranging from 0.7 to 0.95) (Streiner, 2003; Tavakol & Dennick, 2011) were observed for spiritual well-being ($\alpha_{T1} = 0.87$, $\alpha_{T2} = 0.88$, $\alpha_{T3} = 0.9$), the meaning ($\alpha_{T1} = 0.79$, $\alpha_{T2} = 0.78$, $\alpha_{T3} = 0.82$) and faith ($\alpha_{T1} = 0.87$, $\alpha_{T2} = 0.89$, $\alpha_{T3} = 0.86$) subscales of spiritual well-being, hope ($\alpha_{T1} = 0.89$, $\alpha_{T2} = 0.89$, $\alpha_{T3} = 0.92$), the temporality and future orientation ($\alpha_{T1} = 0.79$, $\alpha_{T2} = 0.76$, $\alpha_{T3} = 0.81$) and positive readiness and expectancy ($\alpha_{T1} = 0.73$, $\alpha_{T2} = 0.79$, $\alpha_{T3} = 0.9$) subscales of hope, depressive symptoms ($\alpha_{T1} = 0.79$, $\alpha_{T2} = 0.74$, $\alpha_{T3} = 0.85$), caregiver burden ($\alpha_{T1} = 0.87$, $\alpha_{T2} = 0.89$, $\alpha_{T3} = 0.93$) and social support ($\alpha_{T1} = 0.75$, $\alpha_{T2} = 0.9$, $\alpha_{T3} = 0.93$). This supports the reliability of the findings obtained in the present study.

Table 6.5. Cronbach's Alpha Estimates for Quantitative Outcome Measures in Study 3

	Number of items	α_{T1}	α_{T2}	α_{T3}
Quality of Life	1	-	-	-
Spiritual Well-being	12	0.87	0.88	0.9
Meaning	4	0.79	0.78	0.82
Peace	4	0.69	0.81	0.86
Faith	4	0.87	0.89	0.86
Hope	12	0.89	0.89	0.92
Temporality & Future	4	0.79	0.76	0.81
Positive Readiness & Expectancy	4	0.73	0.79	0.9
Interconnectedness	4	0.56	0.6	0.63
Depressive Symptoms	9	0.79	0.74	0.85
Caregiver Burden	10	0.87	0.89	0.93
Social Support	5	0.75	0.87	0.93
Complicated Grief	5	0.61	0.68	0.78

Note. T1: Baseline assessment. T2: Post-intervention assessment. T3: One-month follow-up assessment.

Qualitative Analysis of Participants' Post-Intervention Feedback

Feedback provided by intervention group participants upon completion of the NeW-I protocol was analyzed using Framework analysis which adhered to Proctor's conceptual outcomes for implementation research (Proctor et al., 2011). Four key themes emerged which include: (i) Meaningful Opportunity for Reflection, (ii) Congruity with Parent-Caregivers' Needs, (iii) Compatibility of Online Narrative Writing, and (iv) Sustainability and Enhancement Recommendations. Taken together, these themes encapsulate the expressed attitudes and opinions of parent-caregivers who participated in the NeW-I pilot study.

Meaningful Opportunity for Reflection (*N* = 22)

This refers to the meaning and satisfaction that participants derived from the opportunity to reflect on their caregiving journey and journal the ups and down of their daily life as a caregiver. Participants explained that the reflective nature of the questions in each week's writing session had made them pause and think about their journey as a caregiver, including what they had done well and aspects that needed further attention.

> "It gives me a chance to pen down my thoughts, my feelings... It gives me a chance to relook at the situation. Because sometimes when you are in the situation, you just move through. But as I answer the [NeW-I reflective] questions, it gives me a reflection of what went well and what needs to be improved." (Mother of 13-year-old girl with Progressive Neurodegenerative Disease)

Taking a step back from their usual 'auto-pilot' mode of functioning empowered participants to look at their situation from a macro perspective and take note of the resources and support systems that they had gathered along the journey.

> "You are so caught up with the day-to-day looking after and the caregiving duties that need to be done, you don't have time to reflect on what has been going on for the past few years." (Mother of 6-year-old girl with Cerebral Palsy)
>
> "This intervention gave me the opportunity and space to look back on 11 years of caring for [son's name], and appreciate the twists and turns, changing dynamics, and people who have come into our lives." (Mother of 11-year-old boy with Cerebral Palsy)

Other participants shared that the opportunity to share their story helped them to feel validated in their experience as a caregiver and the challenges they had encountered.

> "I want to write everything as thoroughly as possible because this is the journey that I'm going through, so I want to be as real as possible." (Mother of 7-year-old boy with Cerebral Palsy)

Congruity with Parent-Caregivers' Needs (*N* = 24)

This refers to the extent to which participants perceived the reflective questions of each weekly writing session, the therapist's feedback after each weekly writing session and the consolidated legacy document received at the close of the intervention to be relevant and compatible to their needs. Participants shared their view that the guiding questions that preceded each week's writing session were insightful as they aided in interpreting and ascribing meaning to the experiences of caregiving.

> "When we write for some questions, you ask some questions to yourself, like, whether I am going to answer (it) this way or that way. So, the questions help me to be more confident and then, emphasize to (me) to be strong… Some of the questions help (to have) insights on life." (Mother of 11-year-old boy with Progressive Neurodegenerative Disease)

Participants further recounted that the affirming feedback they received from the NeW-I therapist after each week's writing session had served as encouragement to press on and find strategies to address their challenges, while at the same time providing knowledge about other resources in the community that they might possibly reach out to for support.

> "At least there is somebody you can talk to who understands what is going on in your life… I find that all the advice and suggestions given by you - like scrapbooking - I've never thought of it. So, at least it's something that will enhance my caregiving experience." (Mother of 18-year-old girl with Renal Disease)
>
> "The feedback (from the therapist) is a sort of affirmation. So being affirmative is very helpful… Being affirmed gives me a lot of empowerment." (Father of 20-year-old boy with Rare Genetic Disease)

Participants also expressed their gratitude and joy at receiving the legacy document after completing the intervention. In essence, the legacy document is a compiled and edited document of participants' narrative expression during the four weekly writing sessions which is structured in a manner that enables participants to find strength and hope in their experience of caring for their child.

> "That document opened up my bubble. My bubble tends to be at home with (child's name), so it opened that – I have a lot more invisible webs and links to others that I don't naturally see on a day-to-day basis. But nonetheless their presence and their imprint are quite strongly clear… So, that was the sweet part in the legacy document." (Mother of 11-year-old boy with Cerebral Palsy)

Other participants added that receiving a tangible record of their caregiving journey which they could share with others had helped them to open up about their struggles with their close network of family and friends and retell their story of caregiving and survival.

> "When I shared the legacy document with a few of my friends, they were really touched. They were like, 'I never knew you go through so much,' and they never knew those parts of me. It was a very impressive journey for me." (Mother of 12-year-old boy with Cerebral Palsy)

Compatibility of Online Narrative Writing (*N* = 14)

This refers to participants' openness to and degree of comfort in adopting an online, narrative writing platform to share their thoughts, feelings and experiences of caring for their child with a chronic life-threatening condition. Participants were appreciative of the flexibility of the online therapeutic platform which they could access in their own free time and from any convenient location. They elaborated that they found NeW-I to be more user-oriented than a face-to-face appointment with a therapist since the latter required committing to a fixed date and time, which could be difficult for full-time parent-caregivers amidst their several caregiving responsibilities.

> “(When) you get time, you can finish it (refers to weekly NeW-I writing sessions) … Even when (I am) with the family, I can find 20 minutes, sitting around with them also. But other than that, if we have to fix up appointments, I think that (is) very difficult for caregivers.” (Mother of 11-year-old boy with Progressive Neurodegenerative Disease)

Other participants felt that the relative anonymity and personal space offered by the NeW-I platform made it a less intimidating medium for self-expression than face-to-face conversations.

> “The convenience – I can do the thing anywhere… I also don’t need to have a face-to-face (appointment). I feel that if you say some things face-to-face, it’s a bit restricted.” (Father of 6-year-old boy with Rare Genetic Disease)
>
> “(When) you talk to someone face-to-face, you don’t have much time to think, so when I want to put my thoughts in my writing, it feels better.” (Mother of 7-year-old boy with Cerebral Palsy)

Although the greater personal space and anonymity of the NeW-I platform was especially useful to individuals who were relatively introverted, participants who perceived themselves to be extroverted and comfortable about sharing their challenges with others also found that they benefited from the additional support offered by NeW-I.

> "Sometimes, certain things, we feel shy to share (it) if we (are) face-to-face (with another person), you see. We feel it is better to stay anonymous." (Mother of 17-year-old girl with Renal Disease)
>
> "I am very vocal, so I talk a lot about what is happening. This for me is an additional resource… But if they [parents] are not very vocal or they don't talk much about what is happening to others then it would be a good experience for them." (Mother of 10-year-old boy with Cerebral Palsy)

Sustainability and Enhancement Recommendations (*N* = 23)

This refers to the recommendations put forth by participants about how NeW-I could be tailored to better meet the needs of parent-caregivers in Singapore. Several participants pointed out the challenge of completing their weekly writing session within a single 30-minute timeframe, while simultaneously fulfilling their caregiving responsibilities. A 'Pause' button and a 'Save as Draft' feature was suggested to be added into the app to overcome this challenge.

> "Do have a pause button during the writing session of 30 minutes, in case there is anything that we need to attend to urgently and we

> have to stop writing for a while. And also a save button in the app, so that whatever we write can be saved when we need to log out of the app." (Mother of 11-year-old boy with Cerebral Palsy)

Other participants felt that the guiding questions preceding the weekly writing sessions needed rephrasing so that there was greater clarity and comprehensibility. It was also proposed that a preview of the questions prior to each week's session would be useful in providing structure to participants' writing.

> "Sometimes I find the question is too short. And I can't get what kind of information you all request. Because every time I log in there is only 30 minutes and I have to really think about what I'm going to write… It will be great if I can have a preview of the question before I log in." (Mother of 2-year-old boy with Cerebral Palsy)

Some parents expressed their wish for NeW-I to be available in regional languages so that parent-caregivers who were not fluent in English could also seek support from the intervention platform.

> "I think our vocabulary, our English (is) already rusty. So sometimes while writing, we might forget spellings (of words) here and there, make some error(s)." (Mother of 17-year-old girl with Renal Disease)
>
> "Many of the caregivers don't speak English or don't understand English, so they will be more comfortable in their own language."

> (Mother of 11-year-old boy with Progressive Neurodegenerative Disease)

Participants also shared that it would be useful if their NeW-I engagement did not cease following the four weekly sessions and reception of the legacy document. They believed that full-time parent-caregivers who were maneuvering the ups and downs of looking after their child with a chronic life-threatening illness would benefit from periodic follow-up sessions where they could voice their concerns and seek support from a trained professional.

> “You can have a follow-up… find out if there are any problems, unease, or something that they (parent-caregivers) need further suggestions on how to handle.” (Mother of 17-year-old boy with Rare Genetic Disease)

In addition to the above, many participants felt that they would be more comfortable to do an online expressive writing intervention if it could be accessed from their laptop’s internet browser, since typing on the small screens of their mobile phones could get tedious.

> “It's very hard to key in on the phone. And then you have to do an abridged version - a simple version - because you can’t really write too much.” (Father of 10-year-old boy with Cerebral Palsy)

Finally, participants mentioned that it would be useful for them to know more about the NeW-I therapist’s expertise and areas of specialization so that they could better understand the difference between disclosing their challenges to the therapist as compared to opening up to their informal social network about issues they were facing.

> "The therapist needs to share what is his or her portfolio of experiences with regards to how he/she can help. Because I can do the same. I'm not a psychologist but I can help my friend when she feels depressed. So what's the difference between telling you as a therapist and telling me?" (Mother of 15-year-old boy with Epilepsy)

Evaluation of Resources to Manage and Implement the Study and Intervention

This section addresses the extent to which the research team has the training, administrative capacity, expertise, skill sets, and time required to carry out the study. It also explores the ethics involved in implementing the study, financial considerations, technology, and equipment required for the study. Keeping in view that there is no known internet-based intervention which employs writing as the medium of expression for parent-caregivers of children with chronic life-threatening illness, it becomes critically important to evaluate these domains. This will enable future clinicians who are interested in utilizing the NeW-I platform as part of their clinical work with parent-caregivers or researchers who wish to extend research with such parents to be prepared with the necessary resources.

Detailed records maintained by the research team revealed that the NeW-I pilot study did not experience any challenges with resources and the research team’s ability to manage the intervention. Physical workspace and computer-and-internet related resources were provided by the institution to which the research team was affiliated (that is, Nanyang Technological University, Singapore). The intervention was delivered by trained therapists who were certified in death education and grief counselling and had the knowledge, resources and clinical competence to work with family caregivers in pediatric palliative settings. All team members had successfully completed research integrity modules under the provisions of Nanyang Technological University’s Institutional Review Board and adhered to the Board’s guidelines for safeguarding participants’ identity and confidentiality.

Manpower needs to develop the NeW-I platform and deliver the intervention were correctly estimated. Specifically, one computer engineer was recruited to develop the online intervention platform and maintain it throughout the study period; one full-time PhD student was responsible for collecting and entering data, delivering the intervention, analyzing qualitative and quantitative data that arose from the study and drafting research reports and presentations periodically; one research associate assisted in collecting and entering data and delivering the control protocol during peak periods of participant recruitment; one senior counselor guided the PhD student and research associate for quality assurance of the therapist’s responses; and the Principal Investigator supervised the entire conduct of the project; management of research data and preparation of reports.

The research team encountered some minor unanticipated challenges in using the new medium of intervention delivery – a smartphone app – which reinforced the need to have adequate technical knowhow to develop and deliver the intervention. Specifically, technical malfunctioning of the app in the initial months of the intervention and delays in restarting the server following technical checks resulted in delay in participants' submission of their weekly writing entries, having to email their weekly writing entries instead of submitting it via the app delay in assessment responses. Some participants also faced challenges in completing their writing session within the stated timeline because they did not receive the notification regarding the activation of the new writing session in a timely manner. The research team sought out appropriate instruction from technical experts and resolved the issues efficiently and effectively.

Clinicians and researchers who are interested in using NeW-I to advance their work with parent-caregivers of children with chronic life-threatening illness must individually assess the resources at their disposal and their team's skills and capacity to manage the intervention prior to utilizing NeW-I as a therapeutic tool.

Summary of Findings from Study 3

This chapter presented a detailed description of the findings of Study 3. Concisely, quantitative results showed that intervention group participants had significantly higher levels of perceived social support than control participants. Further, compared to their baseline scores, intervention participants experienced significant improvement in their quality of life, overall spiritual well-being, sense of meaning and peace, inner sense of temporality and future orientation and perceived social support at the post-intervention assessment. They also experienced a significant decrease in subjective caregiver burden at the post-intervention assessment, as compared to their baseline scores, and continued to experience lower levels of subjective caregiver burden compared to baseline at the one-month follow-up. The vastly optimistic qualitative feedback provided by participants offered insight into the processes of NeW-I which contributed to its efficacy.

CHAPTER SEVEN

DISCUSSION

This chapter summarizes and elaborates on the lived experience of parents of children with chronic life-threatening illness from both a global and local perspective and discusses the usefulness of the newly developed intervention titled NeW-I in improving parent-caregivers' well-being. The chapter further considers the implications of the findings of this research for advancing pediatric palliative services and research – both globally and in the local context of Singapore.

Principal Findings and Significance of Study 1

Study 1 was a first-of-its kind qualitative systematic review which thematically synthesized findings from 25 international studies and provided a solid foundation to comprehensively understand the experience of parental bereavement due to the chronic life-threatening illness and death of one's child. It also accentuated the archetypical challenges faced by parents during the period of caregiving and bereavement, as well as the scope for growth and personal development at each transitional stage. These consolidated findings served to develop a new line of argument on the subject matter – one which pulled together supportive evidence and moved beyond the primary studies to offer novel insights about the data (Thomas & Harden, 2008). Specifically, analysis of the data in Study 1 led to the creation of the Parental Bereavement Trajectory of Child Loss with four distinguishable phases. This trajectory begins from the liminal margins of a child's chronic and life-threatening diagnosis, to holding space for the period of dying, to navigating losses associated with grief and mortality, and finally reconstructing lives through recognizing possible ways to restore normalcy, form continuing bonds, and ascribe meaning to the experience of loss (see Figure 4.1).

Findings from this systematic review agree with the Dual Process Model of coping with bereavement (Stroebe & Schut, 2010). In this study, bereaved parents can be seen alternating between loss-oriented coping processes such as longing and mourning for their late child (Davies et al., 2004; Foster et al., 2011), and restoration-oriented coping processes such as discovering new hobbies or returning to work and integrating their loss into their everyday life (Barrera et al., 2007; DeCinque et al., 2006). In particular, the two latter phases of Navigating Losses and Reconstructing Lives in the parental bereavement trajectory model emphasize that parental coping following their child’s death can oscillate between focusing on the loss and grieving and adjusting to restructured life and redefined relationship with their child regardless of his or her physical presence. Moreover, similar to the Grief To Personal Growth Model (Hogan & Schmidt, 2002), findings from this study highlight the value of being able to express one's feelings and emotions with another person candidly and without the fear of being judged – to smooth the progression from avoidance towards personal growth (Gear, 2014; Reilly et al., 2008). Data from this study underscores the importance of re-establishing family relationships and connecting with other people who can empathize and provide a listening ear to bereaved parents. Lastly, findings from this study affirm that child loss can transform bereaved parents’ worldviews permanently and that intervention programs for bereaved parents must facilitate reconstruction and rediscovery of meaning in life and hope for the future (Hogan & Schmidt, 2002).

Principal Findings and Significance of Study 2

Study 2 involved the first known Asian investigation that critically examined the lived experience of parents bereaved by their child’s death due to a chronic life-threatening illness. The participants in this study included middle-aged parents in Singapore whose children had been diagnosed with a range of illnesses including cancer, congenital abnormalities, muscular dystrophy etc. The period of being their child’s caregiver ranged from 5 months to 31 years for parents in this study. The stories and narratives elicited by this demographically varied sample led to the creation of the Trauma to Transformation Model of Parental Bereavement. This model shows the milestones in participants’ lived experience of their child’s chronic life-threatening illness and death, beginning from their child’s chronic and life-threatening diagnosis and the ensuing emotional turmoil (Theme 1), the grieving of their child’s death and the losses which accompanied his or her death (Theme 3) and participants’ experience of posttraumatic growth as an outcome of their journey of caregiving and child loss (Theme 5). The model also details the deliberate behaviors or ‘rituals’ that aided participants in regaining control over their lives (Theme 2), sustaining a bond with their child regardless of his or her physical presence (Theme 4), and transcending their loss by focusing on the positive outcomes that they derived from their experience (Theme 6). Finally, the model shows that participants’ lived experiences and well-being were rooted within their health-and-social-care ecosystem, and in turn affected by it (Theme 7). These findings provided useful recommendations for augmenting pediatric palliative services both globally and particularly for Asian populations. Moreover, Singapore is a multicultural community, comprising the major ethnic and religious groups in Asia (Hays, 2015; Singapore Department of Statistics, 2018). This means that findings from this Singapore-based research have ‘Moderatum Generalization’ (Ormston et al., 2013; Williams, 2002b) to other Asian communities as well.

In greater detail, participants in this study intentionally adopted ‘rituals’ which would empower them to actively shape their lives, both prior to and after their child’s death. This role of rituals in assisting grieving parents to sustain continuing bonds with their late child, achieve a sense of power and control over their lives and facilitate posttraumatic growth is in line with previous research on parental bereavement (Cacciatore & Flint, 2012; Castle & Phillips, 2003; Rando, 1985b). Next, to cope with the distress brought about by their child’s death, participants established new meaning structures including benefit-finding in and positive re-evaluation of their traumatic experience, sustaining continuing bonds with their late child, developing new worldviews and journeying towards personal growth. This supports earlier studies on meaning reconstruction in bereavement (Gillies & Neimeyer, 2006; Neimeyer, 2006b; Neimeyer & Anderson, 2002). Finally, along the lines of narrative identity theory, participants’ evolving narrative and interpretation of their child’s life promoted the creation of new meaning surrounding their self-narratives of grief and suffering (Adler et al., 2016; McAdams & McLean, 2013). Taken together, the stories and narratives elicited by participants provide valuable guidance to pediatric palliative service providers about the needs, challenges, and coping strategies of families where a child is diagnosed with a chronic life-threatening condition.

It is important to note that findings from Study 2 which involved Asian participants (who were predominantly of Chinese ethnicity, followed by Malay and Indian ethnicity) build on the findings of Study 1, an international qualitative systematic review of the lived experience of parental grief and bereavement in the Western context. Indeed, the value-addition of Study 2 is its contribution to literature on psychosocial support for parent-caregivers and bereaved parents in the Asian context. Specifically, Study 2 findings indicated that Asian parents whose children were living with chronic life-threatening conditions coped with their caregiving responsibilities by relying on their spouse for pragmatic support (Sub-theme: Spousal interdependency) as well as taking help from their extended family members and friends who adopted a collaborative approach to care for the sick child (Sub-theme: Relational coping). Thus, for the Asian parent-caregivers, support from their spouse and extended family members was vital in their caregiving journey and generally was instrumental in nature (for example, acts such as stepping in to provide respite care or cooking meals). This finding agrees with other research that Asian families tend to cope with a problem by adopting pragmatic strategies that focus on attention to possible solutions rather than examining feelings and causes surrounding the problem (Gehart, 2015; Ho et al., 2019). It is not yet clear how Western parents caring for their children facing chronic life-threatening conditions perceive family support and assistance – the available evidence indicates that they may both appreciate the involvement of their relatives and friends (Davies et al., 2004) as well as withhold sharing the burdens and obligations of caregiving with people outside their immediate family (Collins et al., 2016).

On the other hand, Asian parents in Study 2 discussed their disenfranchised grief after the death of their child such that family members did not respect and validate their grief and the severity of their emotional pain (Sub-theme: Disenfranchised grief). This contrasts sharply with research which shows that psycho-emotional support from extended family members is vital for bereaved parents in the Western context to cope with the trauma of child loss (Aoun et al., 2018). It can be reasonably postulated that the support of extended family members and friends would have been helpful for Asian parents in coping with the grief of child loss. However, due to the unusual nature of child death that accords it the perception of being a tragedy (Chong et al., 2012), as well as the prevalence of death taboos in Asia (Foo, 2017), parents found themselves excluded from receiving such support.

Principal Findings and Significance of Study 3

Study 3 developed, implemented and evaluated the first known evidence-based intervention for Asian parent-caregivers of children with chronic life-threatening conditions, thereby addressing a critical service gap in pediatric palliative care services in Singapore. In keeping with the gold standards of intervention research (Christ, 2014), the Narrative e-Writing Intervention pilot study was designed as an open-label mixed methods randomized control trial which aimed to investigate the efficacy of NeW-I in improving parent-caregivers' quality of life, spiritual well-being, hope, depressive symptoms, subjective caregiver burden, perceived social support and risk of complicated grief across three time-points – baseline, immediate post-intervention and one-month follow-up.

Results from the pilot RCT provided promising evidence of NeW-I clinical efficacy. Between-groups comparisons revealed that at the post-intervention assessment, intervention participants showed significant improvement compared to control participants in the level of perceived social support. Other areas of improvement in intervention participants as compared to control participants that were originally predicted were not observed in this study. In line with previous research documenting the therapeutic powers of journaling (Harrell, 2011; Ullrich & Lutgendorf, 2002; Utley & Garza, 2011), these findings suggest that the mere act of engaging in a journaling activity – even a journaling activity that is unrelated to their child's illness – can be a cathartic experience for parent-caregivers, thereby serving as a useful strategy for coping with the daily stresses of caregiving. The results further showed that at the one-month follow-up, control participants had slightly higher levels of perceived social support than intervention participants. This finding has raised concerns about the extent to which the 5 items in the ISS which was used to measure participants perceived social support are an appropriate measure of parent-caregivers' well-being. It is possible that a different measure of social support such as the 9-item Perceived Social Support for Caregiving scale (Goodman, 1991) might have been a more appropriate measure since the items would be more relatable for parent-caregivers in this study.

Within-groups comparisons showed significant improvements in intervention participants' scores from baseline to post-intervention in the domains of quality of life, overall spiritual well-being, sense of meaning and peace, hope in both temporality and future orientation, perceived social support, as well as significant reduction in participants' subjective caregiver burden. However, unlike intervention participants, control participants did not experience such significant improvement in their well-being through the journaling activity unrelated to their child's illness at the post-intervention assessment. This indicates that the structured NeW-I intervention protocol serves not only to maintain but further enhance and enrich parent-caregivers' psycho-socio-spiritual well-being. A larger NeW-I trial is required to verify these emerging ideas.

The encouraging results obtained from the quantitative data analysis were further corroborated by the qualitative feedback provided by NeW-I participants, as they emphasized it had been meaningful for them to journal their caregiving journey including its challenges and coping strategies. Participants also mentioned that the affirmation and positive reappraisal they received from their intervention engagement and the closure of therapy via a tangible record of their journey as a caregiver helped to widen their worldview and open up to their friends and family about the struggles that they typically faced. At the same time, participants suggested ways to strengthen the intervention such as addition of a ‘Pause’ button and a ‘Save as Draft’ feature, delivery of the intervention in not only English but also regional languages, follow-up sessions with the NeW-I therapist to discuss evolving concerns about caregiving and more knowledge about the NeW-I therapist’s professional background and competency.

The improvement in intervention participants’ scores at the post-intervention assessment compared to their scores at baseline as well as the optimistic qualitative feedback provided by participants *(Study 3 themes ‘Congruity with Parent-Caregivers’ Needs’ and ‘Compatibility of Online Narrative Writing’)* implied that NeW-I could be a useful addition to local pediatric palliative services for parent-caregivers of children with chronic life-threatening illnesses. Participants elaborated that they appreciated the convenience of accessing the intervention from any location and at any time as well as the intervention’s sensitivity to their need for privacy while sharing thoughts and feelings that they were uncomfortable to talk about face-to-face. This finding is similar to reports from other studies with Asian caregivers of end-of-life patients (Ho, 2013). Future investigations must be mindful of these prerequisite components of interventions for Asian parent-caregivers.

The decrease in intervention participants’ scores in various outcome assessments at the one-month follow-up compared to their scores at the post-intervention assessment as well as qualitative feedback obtained from participants *(Study 3 theme ‘Sustainability and Enhancement*

Recommendations') suggested that strategies must be incorporated into the NeW-I protocol to ensure long-term maintenance of treatment gains. Follow-up booster sessions have been employed as a maintenance strategy in numerous psychotherapeutic interventions (Gearing et al., 2013; Moos et al., 2001; Whisman, 1990), including those which are delivered via the internet (Heber et al., 2016). It can be reasonably foreseen that low-intensity follow-up booster sessions of NeW-I over a longer interval (for instance, bi-monthly sessions) could be a resource-effective way to maintain the positive treatment effects of NeW-I. Such booster sessions could invite parents to share their experiences of caregiving since their previous engagement with the NeW-I therapist, review the ideas that were discussed during the original NeW-I sessions and reflect on whether and how the knowledge and skills acquired during the NeW-I sessions were practiced in their daily life.

In addition, the recommendations proposed by participants *(Study 3 theme: Sustainability and Enhancement Recommendations)* also offer valuable insights about modifications that are required in the NeW-I platform to make it more accessible. These include the development of a NeW-I website which could be accessed from the larger screen of a computer, the ability to write in multiple brief time periods rather than one block of time, delivering the intervention in regional languages, and offering greater clarity regarding the professional competencies of the NeW-I therapist and the kind of support that he or she would be able to provide. It is important to collate the wisdoms derived from the pilot NeW-I trial into a detailed manual which could guide and inform clinicians and researchers providing services to parent-caregivers in Singapore and around the world.

Contrary to expectations, results showed that control participants experienced a significant reduction in their risk of complicated grief from T1 to T3. No significant changes were observed in intervention participants' risk of complicated grief at T2 and T3 as compared to their baseline scores. It is possible that the BGQ which was used in this study to assess participants' risk of complicated grief may not have been an appropriate measurement tool due to the following reasons. First, the items in the BGQ are designed to assess risk of complicated grief among bereaved persons, and their psychometric properties have not been established in the measurement of pre-death grief. Second, the revised phrasing of the BGQ statements in this study to make the scale appropriate for parent-caregivers was not subjected to necessary psychometric testing, which may have further compromised its usefulness. Future NeW-I trials may benefit from employing scales such as the Caregiver Grief Scale (Meichsner et al., 2016) which are designed for measurement of pre-death grief.

In addition to the aforementioned findings, records maintained by the research team revealed that 98.18% of the parents who started the NeW-I trial completed all study components and the post-intervention assessment, and 92.73% of the parents also completed the one-month follow-up assessment, a retention rate that is considerably higher than prior psychotherapy trials (Swift & Greenberg, 2012). Taken together, these findings from the pilot evaluation of

NeW-I suggest that it would be worthwhile to conduct a full-scale NeW-I trial in the community.

Finally, records maintained by the research team showed that the NeW-I pilot trial in Singapore was feasible to implement under the circumstances that the research team was equipped with the necessary clinical expertise, therapeutic skills, knowledge about pediatric palliative care needs and resources in the local and global context and the technological competence to deliver the intervention. In sum, the aforementioned points unequivocally highlight that it is reasonable to initiate a larger NeW-I trial both within Singapore as well as in other Asian communities around the world.

Overall Integrative Findings

In summary, findings from Study 1 and Study 2 showed that parent-caregivers typically navigate a complex web of stressors including the practical and financial demands of caregiving, strained marital and social relationships, and neglect of other healthy children and family members, which puts them at greater risk of depressive symptoms, fatigue and overall poor quality of life (Dellve et al., 2006). Study 1 and Study 2 further posited that a pre-loss intervention that empowered parents to reflect on their caregiving experiences, explore and identify resources that could help them better cope with the challenges of caregiving, and support their child to live a meaningful life despite a chronic life-threatening illness could augment psychological well-being of parent-caregivers and protect against deleterious grief outcomes. Study 3 was a proof-of-concept pilot which provided psychotherapy to parent-caregivers using an internet-based narrative writing format. Findings demonstrated that such a format of intervention delivery was both feasible for the research team and acceptable to participants, thus supporting the growing body of research on the usefulness of online psychotherapeutic interventions (Barak et al., 2008; Gainsbury & Blaszczynski, 2011; Kaltenthaler et al., 2004; Lichtenthal et al., 2019; Newman et al., 2011). It is also heartening that internet-based interventions such as NeW-I have the potential to continue to provide care and service to parents after the death of their child, and therefore could facilitate the transition from caregiving to bereavement and alleviate secondary losses such as the resources parents have gathered to cope with caregiving (Lichtenthal et al., 2015).

Clinical and Research Implications of Findings

The following section addresses the implications of this research for clinicians and counselors working with grieving parents. The recommendations proposed below have been informed by: (i) the comprehensive understanding of global parental bereavement literature obtained in Study 1, (ii) the in-depth understanding of Asian parental bereavement obtained in Study 2, and (iii) the evidence from implementing a culturally tailored psycho-socio-spiritual intervention in Study 3.

Implications for Parent-Caregivers and Newly Bereaved Parents

Psychoeducation about Healthy Family Coping

During the challenging period of caregiving for their sick child and during early bereavement when parents are coping with their own overwhelming grief, many parents unintentionally neglect their other healthy children, which can subsequently create feelings of regret *(Study 1 sub-theme 'Parenting Guilt' and Study 2 sub-theme 'Care Diffusion')*. Many children who had siblings that suffered from a chronic life-threatening condition may display emotional and behavioral difficulties over time, as a result of their needs being overlooked (Ballard, 2004). Providing grieving parents of seriously ill children with psychoeducation and support, with emphasis on the needs of their healthy children and strategies to help their healthy children cope with the challenges in the family could be an important step to protect the well-being of their healthy children (DeCinque et al., 2006). Grieving parents could also be informed about interventions that are designed specifically for siblings of sick and/or deceased children so that they can help to connect their healthy children with a network of peers who face similar circumstances.

Enhancing Psychosocial Support

For Asian parent-caregivers in particular, rituals play an important role in promoting parents' perceived sense of control over their lives *(Study 2 themes 'Power and Control Oriented Ritualization', 'Continuing Bonds Oriented Ritualization' and 'Posttraumatic Growth Oriented Ritualization')*. This implies that pediatric palliative services may want to facilitate parent-caregivers' engagement in such rituals, thereby strengthening their resilience to cope with the challenges of caregiving. This could be done by providing resources and psychoeducation about topics such as self-care, healthy family coping, utilizing available sources of support and aiding their sick children to live life to the fullest.

Additionally, Study 3 of this research *(Study 3 theme 'Congruity with Parent-Caregivers' Needs')* shows that a narrative approach is suitable for such facilitation, since it allows clinicians to respectfully explore the value of the resources that are available to parents and facilitate the mobilization of these resources in a way that empowers parents to better cope with their caregiving demands. In fact, the process of engaging in weekly narrative writing about their caregiving experiences could itself be a ritual that enhances parents' resilience by drawing attention to the resources that they have and highlighting the positive outcomes of their journey of caregiving for their sick child, as can be inferred from the qualitative feedback provided by participants *(Study 3 theme 'Meaningful Opportunity for Reflection')*. The usefulness of a narrative approach in enhancing parent-caregivers' agency to cope with the challenges of looking after their sick children has been reinforced by previous literature as well (Hedtke, 2014). Indeed, providing such services early in the illness trajectory could enhance the quality of parents' memories of the days leading to their child's potential end-of-life and death, strengthen parents' sense of resilience, hope and perceived support from their social networks and safeguard against deleterious bereavement outcomes (Rini & Loriz, 2007).

Working with Asian Populations

It is important that counselling interventions designed for Asian parent-caregivers of children with chronic life-threatening illnesses emphasize family and social relations, since they are central to care and support provision at the end-of-life within the Asian cultural context *(Study 2 sub-themes 'Relational*

Coping' and 'Spousal Interdependency'), a finding that has also been highlighted in previous research involving Asian family caregivers of older terminally-ill patients (Ho et al., 2013). Strength-focused counseling strategies which focus on resources that parent-caregivers' have available to them (for instance, help from their spouse and other family members) can be helpful in reducing the stress of caregiving and encourage families to work together in meaningful ways, as can be seen from the improvement in parent-caregivers' perceived social support in Study 3. It may also be worthwhile for clinicians to tap on other modern psycho-socio-spiritual interventions such as Family Dignity Intervention (FDI) which are designed to improve palliative care in the Asian context (Ho et al., 2017). Although the existing research on FDI has focused on patient-family dyads (Ho et al., 2017), it is likely that the FDI method of meaning-oriented interviews can promote dyadic exchange for grieving parents, facilitate understanding of each other's distinctive sense-making and coping mechanisms in the aftermath of child loss, thereby creating a platform for parents and their families to better support each other.

Strengthening Physician-parent Alliance

This research emphasizes that relationships with medical professionals can be both a vital source of support as well as a major stressor for parent-caregivers of children with chronic life-threatening illness *(Study 1 sub-theme 'Medical Relationships' and Study 2 theme 'Holistic Healthcare Approach').* This implies that hospital staff must receive relevant knowledge and training to appropriately manage the needs of parent-caregivers (Price & Jones, 2015).

Parents must be provided with information about their child's illness and treatment plan in an understandable format and a treatment plan must be designed in a way that recognizes and respects the family's preferences of care for their child. This implies that healthcare professionals must engage parents in continuous conversations about decisions related to their child's health. It is important that this conversation is honest, at a pace that can be understood by parents, focuses on collaboration between the healthcare team and the parents in order to make decisions that are in the best interest of the child and acknowledges parents' concerns about their child's quality of life. By embracing such attitudes, healthcare professionals could augment psychological well-being for parents who are looking after their child with a chronic life-threatening illness (Gutman et al., 2018; Janusz & Walkiewicz, 2017).

Delivering Psychotherapy Online

Moreover, the internet can serve as a useful platform to deliver effective psychotherapeutic services to parent-caregivers of children facing chronic life-threatening illnesses *(Study 3 theme 'Compatibility of Online Narrative Writing')*. Findings showed that the flexibility and convenience of engaging with the online narrative-writing intervention at any time and from any location was helpful for parent-caregivers who often balance multiple work and caregiving responsibilities and therefore did not have the bandwidth to engage in sit-and-talk therapy. The suitability of using the internet to deliver mental health services to grieving parents has also been established in previous studies (Lichtenthal et al., 2019). Clearly, online psychotherapeutic services for parents facing actual and anticipated child loss are an underexplored area of research and service delivery that is deserving of greater attention.

Transitioning to Bereavement Support

For newly bereaved parents, findings *(Study 2 sub-theme 'Psychosocial Support')* highlighted that psychosocial support could facilitate a smoother role transition for parents from a 'caregiver' to a 'bereaved parent'. This means that pediatric palliative service providers need to initiate meaningful bereavement visits with families of late children to provide closure to parents' journey of caregiving, help parents to establish contact with support groups of other parents facing similar challenges and identify bereaved parents who may be in need of additional psychosocial support to cope with their grief experiences (Lichtenthal et al., 2015). It may also be useful to consider an internet-based platform that could connect newly bereaved parents with other parents who have experienced similar experiences which they could access from the convenience of their home. However, the key to ensuring parents' smooth transition from the role of a caregiver to that of a bereaved mother or father would be to provide psycho-emotional support services as early as initial prognosis and throughout the illness trajectory (Tan et al., 2012).

Implications for Bereaved Parents

Continuing Bonds with their Deceased Child

Studies show that bereaved parents place great value in keeping the memory of their late child alive (Hynson et al., 2006; Rossetto, 2014). This process of maintaining a continuous and enduring bond with their child can be facilitated through a number of meaningful activities such as providing assistance to other grieving parents who face similar challenges or taking up philanthropic work (DeCinque et al., 2006). It is therefore possible and recommended for counselors working with bereaved parents to encourage activities such as writing their child's biography or honoring their child's memory in meaningful ways — in other words, activities that would facilitate maintaining and enhancing continuing parent-child bonds (Davies, 2004; Talbot, 2002).

Meaning-Oriented Conversations

It is common for bereaved parents to experience a crisis of meaning following child loss, and research indicates that those who can find a sense of cognitive mastery and purpose in their experience of loss are able to achieve positive outcomes through their loss (Wheeler, 2001). Neimeyer (2006a, 2006b) suggested that meaning-focused therapeutic techniques such as reflective journaling and metaphors which capture the spirit of resilience in coping with end-of-life caregiving and loss can be useful tools for clinicians to assist parents in assimilating their difficult experiences into their life story. Indeed, it could be helpful for clinicians who work with grieving parents to be trained in facilitating meaning-oriented conversations.

Enhancing Social Connectedness

The distinctive nature of child loss can create a barrier between grieving parents and their network of family and friends *(Study 1 sub-theme 'Social Disconnection' and Study 2 sub-theme 'Disenfranchised Grief')*. One strategy to address this challenge would be for relevant organizations in the community to facilitate the creation of support groups comprising parents who experience similar crises. Engaging with other bereaved parents could help to lessen feelings of isolation and foster a safe environment for parents to express their emotionally charged experiences (Schormans, 2004; Vega et al., 2014). Hospitals could also be an important source of support by facilitating connections between grieving parents and trained counselors (psychological and emotional support), supporting the formation of self-help groups (social support with other bereaved parents), encouraging help from voluntary welfare organizations (educational and pragmatic assistance), as well as promoting day care services (social activities and support to patients and families), thereby transforming healthcare service delivery to be more comprehensive and coordinated (Ho & Tan, 2016). In fact, studies indicate that hospital-based psychosocial care can be an important supportive resource for bereaved families even many months after child loss (Berrett-Abebe et al., 2017; Lichtenthal et al., 2015). However, over and above these strategies, a more sustainable solution to address the fundamental issue of a divide between bereaved parents and their previous social networks would be to spread awareness and psychoeducation in the community regarding the ways in which friends and family can support grieving individuals, thereby setting the foundation for ‘compassionate communities’ that are sensitive to the needs of grieving individuals (Aoun et al., 2018).

Limitations and Future Directions

Despite its novelty and scholarly rigor, this research is not without its limitations. It is important that readers are aware of these limitations before generalizing the research findings to other samples and contexts.

Study 1 which was a qualitative systematic review only included studies which were at least partially if not entirely qualitative in nature. This means that a number of articles with potentially relevant data were excluded because of their purely quantitative methodology. Future investigations may consider a review of quantitative research articles pertaining to this topic which would supplement the findings from the present qualitative systematic review. Next, the data was analyzed using the method of thematic synthesis which allows attention to be drawn to the lived experience of respondents and inter-researcher consensus was valued in finalizing themes and phases. However, one cannot be certain that despite this attempt to minimize the researcher’s own bias from contaminating the analysis, the development of meaningful chronological phases and themes was immune to the researchers’ own subjectivity. It is recommended that future studies verify their analysis with more data sources including books, reports and news articles. Third, the primary authors of the articles included this systematic review may have reported only certain themes which they considered to be noteworthy. But inability to recognize a salient theme or sub-theme in the systematic review does not imply that such a theme does not exist. Moreover, stringent inclusion/exclusion criteria were applied in the screening of articles which means that articles which were deemed unfit for the purpose of this systematic review were eliminated at the earliest point of discernment. It could be the case that some of these studies which were screened out at a preliminary stage included data and ideas that would have been pertinent to the objectives of this review. In the future, researchers may want to review their list of excluded articles with their peers to reduce the possibility of article elimination due to stringency.

Study 2 which was a qualitative meaning-oriented inquiry could potentially be impacted by retrospective bias, since participants were questioned about their lived experience of caregiving and bereavement several months after child loss. It would be prudent for future studies to explore the perspectives and experiences of parent-caregivers who are actively looking after their child with a chronic life-threatening condition. Readers must also take note of the disproportionately high number of females in the research sample for all 3 studies in this research. It would be useful for future research to emphasize the lived experience of Asian caregiver-fathers and bereaved fathers of children facing chronic life-threatening conditions. Furthermore, it would also be beneficial for subsequent studies to be consistent with regards to interviewing parents either together with their spouse, or alone. In the present research, such variations in interviewing formats could have potentially confounded the findings. Moreover, the sample in Study 2 consisted of parents of children who had been diagnosed with a chronic life-threatening condition over a vast period of time, which could explain the variation in parents’ experiences with their healthcare provider. It is suggested that future studies are cautious of such variability in their sampling framework. Furthermore, Study 2 was conducted in Singapore, which comprises a population that is of predominantly Chinese ethnicity, followed by Malay and Indian ethnicities. It would be appropriate for future studies to examine the trajectory of parental bereavement among other Asian communities to determine the extent to which findings from this Singapore-based study can be generalized. In addition to the aforementioned points, it must be acknowledged that findings from this study are currently concentrated within the academic community. Keeping in view that these findings could meaningfully inform healthcare services for families of children living with chronic life-threatening illnesses, it is necessary to identify strategies through which the findings can be translated to clinicians and medical professionals working in pediatric palliative settings. Dissemination of findings via workshops and training programs must therefore be considered as a future direction. Finally, future research must examine the views and beliefs of healthcare professionals working in pediatric palliative settings. This will help to develop a comprehensive understanding of the care requirements of children receiving palliative services in Singapore, thereby offering greater insight into the nature and scope of improvement in pediatric palliative service delivery in the local context.

Study 3 which comprised a pilot evaluation of a novel internet-based and therapist-facilitated narrative writing intervention for parents of children with chronic life-threatening illnesses in Singapore had two important methodological limitations that must be highlighted. First, the sample was relatively small and homogeneous which limits the generalizability of the findings. Second, the intervention was delivered by a single interventionist which may have improved treatment fidelity but raises questions about the extent to which the findings can be applied to other contexts and population. Moreover, although significant within-group differences were observed for multiple outcome domains among intervention participants, only one between-group significant differences were observed on the domain of perceived social support, while other areas of predicted change were not supported by the data. Further research employing a larger and more diverse participant pool is necessary to determine the extent to which NeW-I is effective in improving parent-caregivers' well-being.

Concluding Remarks

> *"There are words like 'orphan', 'widow' and 'widower' in all languages. But there is no word in any language to describe a parent who loses a child."*
>
> — Neena Verma, A Mother's Cry... A Mother's Celebration

The grief of losing one's child and the disenfranchisement of such grief does not discriminate. Regardless of language, religion or race, thousands of surviving family members are devastated due to child loss each year, which significantly increases risks to their physical and psychological well-being for the remainder of their lives. For bereaved parents, the death of their child is akin to a torn chapter from the story of their lives — there are the parts that came before the incident, the parts that come after the incident and their child's death remains a key missing piece whose value is felt throughout their life story. For parent-caregivers who are caring for their seriously ill child for a prolonged duration of time, life can feel stuck in a capsule of liminality. Recognizing what parents and families need during this indefinite period of uncertainty, the critical juncture of end-of-life and the early days of bereavement is invaluable if the goal is to help them to cope with their suffering.

This research is the first known comprehensive and evidence-based documentation of the lived experience of bereaved parents globally and in Singapore, teasing out the obvious cross-cultural commonalities in the narratives of family caregivers of seriously ill children and highlighting the important cultural differences in coping with grief and loss. Moreover, this doctoral work also attests to the usefulness of meaning-focused and strength-based narrative writing using an internet-based platform to empower parents to take control of the narrative of their and their child's life and death, build and maintain sustainable bonds with their child that transcend the presence of a body and journey the path of personal growth and transformation. As researchers and practitioners, it is our responsibility to recognize these important ways in which we can provide compassionate care to the vulnerable and often-forgotten group of grieving parents, acknowledging their suffering and ability to grow through such suffering as part of our collective humanity.

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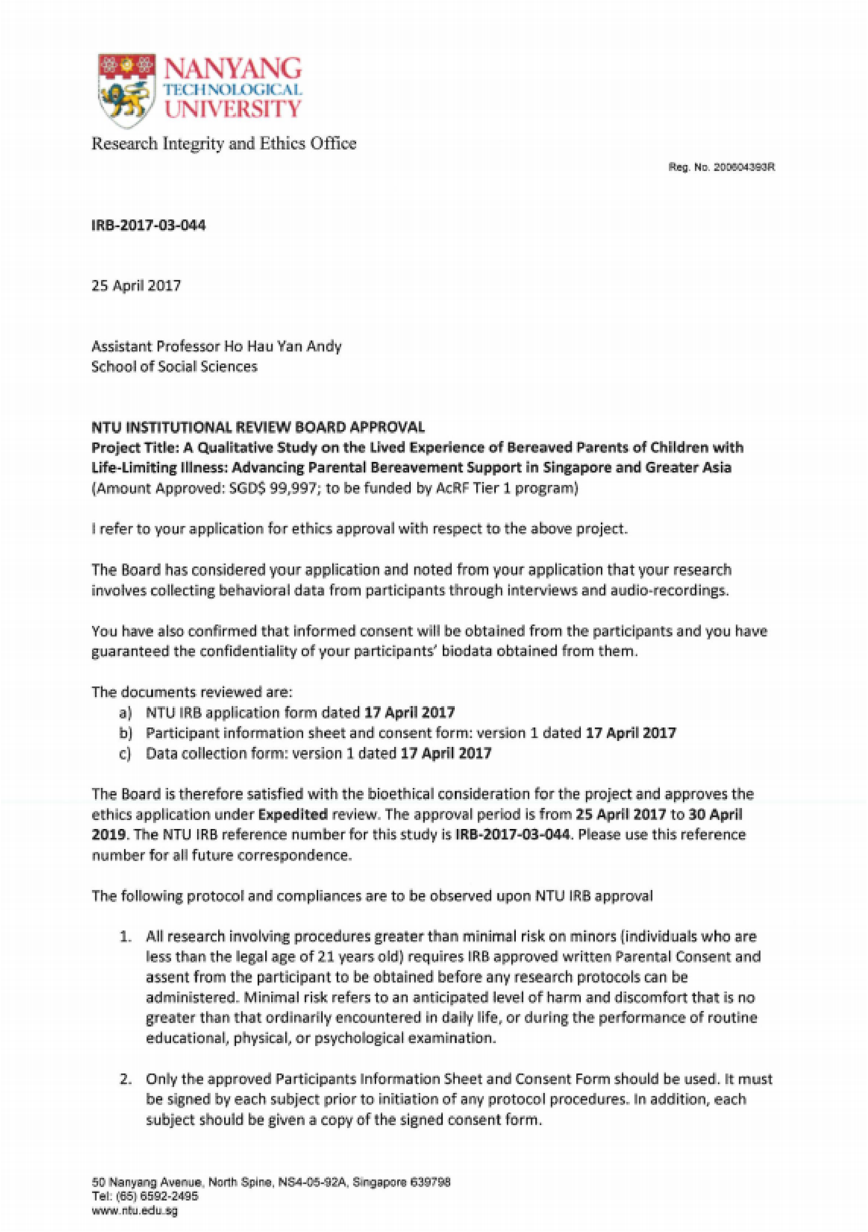
APPENDIX 1

NTU-IRB Letter of Approval for Study 2



NANYANG
TECHNOLOGICAL
UNIVERSITY
Research Integrity and Ethics Office

Reg. No. 200604393R

IRB-2017-03-044

25 April 2017

Assistant Professor Ho Hau Yan Andy
School of Social Sciences

NTU INSTITUTIONAL REVIEW BOARD APPROVAL
Project Title: A Qualitative Study on the Lived Experience of Bereaved Parents of Children with Life-Limiting Illness: Advancing Parental Bereavement Support in Singapore and Greater Asia
(Amount Approved: SGD$ 99,997; to be funded by AcRF Tier 1 program)

I refer to your application for ethics approval with respect to the above project.

The Board has considered your application and noted from your application that your research involves collecting behavioral data from participants through interviews and audio-recordings.

You have also confirmed that informed consent will be obtained from the participants and you have guaranteed the confidentiality of your participants' biodata obtained from them.

The documents reviewed are:

a) NTU IRB application form dated **17 April 2017**
b) Participant information sheet and consent form: version 1 dated **17 April 2017**
c) Data collection form: version 1 dated **17 April 2017**

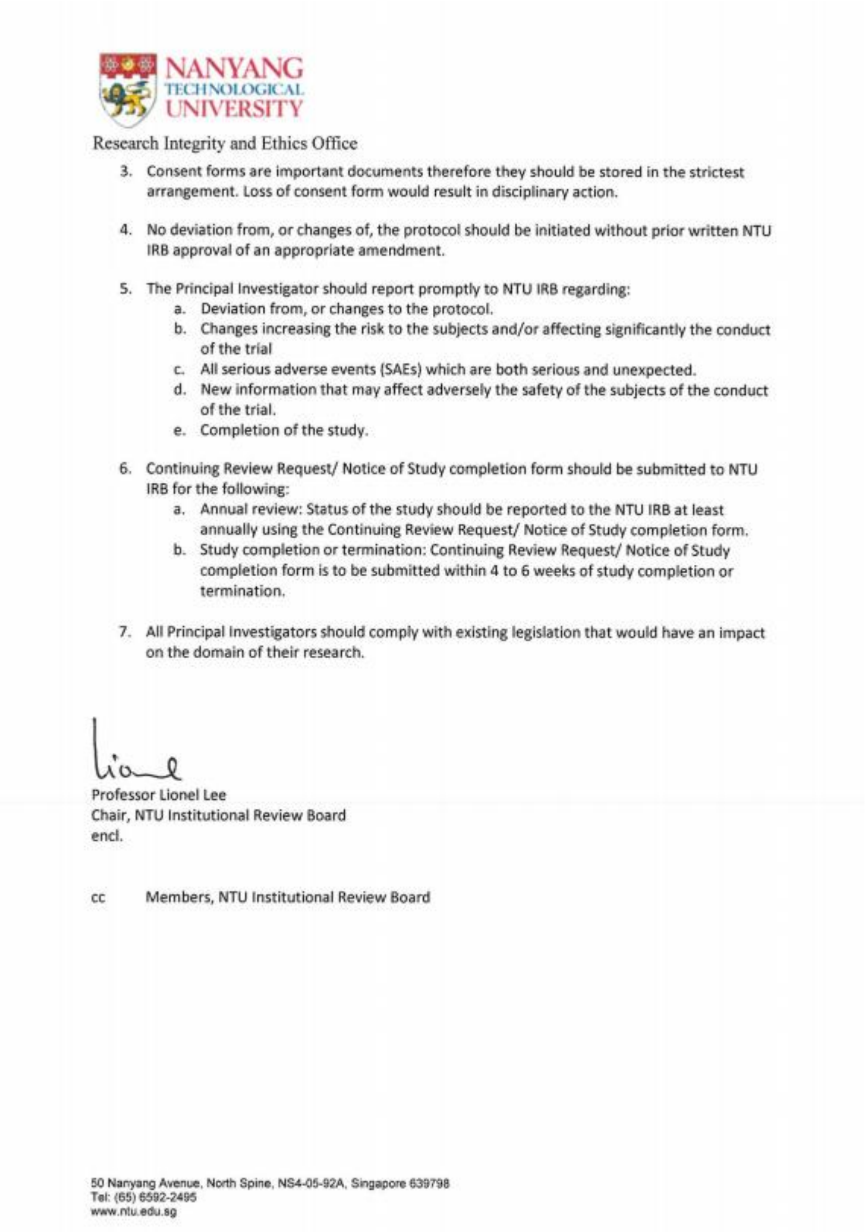
The Board is therefore satisfied with the bioethical consideration for the project and approves the ethics application under **Expedited** review. The approval period is from **25 April 2017** to **30 April 2019**. The NTU IRB reference number for this study is **IRB-2017-03-044**. Please use this reference number for all future correspondence.

The following protocol and compliances are to be observed upon NTU IRB approval

1. All research involving procedures greater than minimal risk on minors (individuals who are less than the legal age of 21 years old) requires IRB approved written Parental Consent and assent from the participant to be obtained before any research protocols can be administered. Minimal risk refers to an anticipated level of harm and discomfort that is no greater than that ordinarily encountered in daily life, or during the performance of routine educational, physical, or psychological examination.

2. Only the approved Participants Information Sheet and Consent Form should be used. It must be signed by each subject prior to initiation of any protocol procedures. In addition, each subject should be given a copy of the signed consent form.

50 Nanyang Avenue, North Spine, NS4-05-92A, Singapore 639798
Tel: (65) 6592-2495
www.ntu.edu.sg



3. Consent forms are important documents therefore they should be stored in the strictest arrangement. Loss of consent form would result in disciplinary action.

4. No deviation from, or changes of, the protocol should be initiated without prior written NTU IRB approval of an appropriate amendment.

5. The Principal Investigator should report promptly to NTU IRB regarding:
    a. Deviation from, or changes to the protocol.
    b. Changes increasing the risk to the subjects and/or affecting significantly the conduct of the trial
    c. All serious adverse events (SAEs) which are both serious and unexpected.
    d. New information that may affect adversely the safety of the subjects of the conduct of the trial.
    e. Completion of the study.

6. Continuing Review Request/ Notice of Study completion form should be submitted to NTU IRB for the following:
    a. Annual review: Status of the study should be reported to the NTU IRB at least annually using the Continuing Review Request/ Notice of Study completion form.
    b. Study completion or termination: Continuing Review Request/ Notice of Study completion form is to be submitted within 4 to 6 weeks of study completion or termination.

7. All Principal Investigators should comply with existing legislation that would have an impact on the domain of their research.

Professor Lionel Lee
Chair, NTU Institutional Review Board
encl.

cc Members, NTU Institutional Review Board

APPENDIX 2

Participants' Informed Consent Form and Information Sheet for Study 2

A Qualitative Study on the Lived Experience of Bereaved Parents of Children with Life-Limiting Illness: Advancing Parental Bereavement Support in Singapore and Asia

Participants' Informed Consent Form

You are invited to participate in a research study conducted by Dr. Andy H. Y. Ho, Assistant Professor of Psychology, School of Social Sciences, Nanyang Technological University, and in collaboration with HCA Hospice Care, Children Cancer Foundation, and Club Rainbow Singapore.

Purpose of the Study

The purpose of this study is to explore and understand your experience of caring for a child who was diagnosed with a life-limiting illness, starting from the point of prognosis, coping with end-of-life caregiving, coming to terms with death, and the eventual adjustment to loss, grief and bereavement. The findings generated will be developed into a culture-specific Parental Bereavement Care Model for informing and advancing theories and practices in pediatric palliative care and bereavement support services for Singapore and for all Asian communities around the world.

Procedures

Your participation in this study will first involve the completion of a simple demographic information sheet, and thereafter engage in an in-depth interview conducted by an experienced research counselor that focus on exploring the story between you and your child, the manner in which you as an individual and as a couple have experienced the challenges of your child's illness and end-of-life, as well as the strengths mechanism that keeps you going through the hardships. The entire interview session is expected to last for about 60-90 minutes. The interviews will be audiotaped and transcribed for analysis. Near the end of the study, you may be invited to attend a short meeting to review the research findings so as to ensure accuracy in analysis and interpretation.

Potential Risk

There are minimal risks for engaging in an experience sharing session. The experienced research counselor who will be conducting the interview with you will offer immediate support in the event that some aspects of the discussion causes you distress or discomfort. If you need further support, a referral can be made to the psycho-social team of your healthcare provider, and they will be able to provide you with follow-up assistance and consultations.

Potential Benefits

Your participation in this study will bring about the opportunity for you to share your story, as well as to reflect on the various factors and machinimas have helped you along your journey. Your participation will also contribute to our understanding of parental bereavement, of which will help to inform local policies and clinical practices for bereaved parents of young children in Singapore and Greater Asia.

Compensation

You (and your partner) will receive a total sum of $30 cash voucher as a token of our appreciation for your time and participation.

Confidentiality

All personal information and responses provided by you in the study will be treated as strictly confidential. Study data and audio records of the interview sessions will be stored securely and will be made available only to members of the research team. In follow-up reports and publications, your identifying information will be obscured or omitted.

Participation and Withdrawal

Your participation is voluntary. This means that you can choose to stop at any time without negative consequences.

Questions and Concerns

If you have any questions about this study, please contact Dr. Andy H. Y. Ho at Nanyang Technological University [14 Nanyang Drive, HSS-04-03, Singapore 637332; Telephone: 6316-8943; Email: andyhyho@ntu.edu.sg]. If you have questions regarding your rights as a research participant, please contact the Institutional Review Board of Nanyang Technological University [Telephone: 6592-2495].

SIGNATURE

I ________________________________ (Name of Participant) understand the procedures described above and agree to participate in this study.

I agree / do not agree to the audio-recording during the procedure.

Signature of Participant Date

Name & Signature of Researcher/Interviewer Date

Research Ethics Committee Approval Expiration date: [30/April/2019]

APPENDIX 3

Semi-Structured Meaning-Oriented Interview Schedule for Study 1

A Qualitative Study on the Lived Experience of Bereaved Parents of Children with Life-Limiting Illness: Advancing Parental Bereavement Support in Singapore and Greater Asia

Before the interview begins, the interviewer will provide a brief introduction of the study to establish rapport with the participant(s):

- Interviewer introduces himself/ herself and expresses gratitude to participants for their participation;
- Explanation of research objectives and processes;
- Ensuring that participants have understood their rights, signed a copy of the consent form and basic demographic form, also answering any questions or concerns that they may have.

Semi-Structured Interviewing Guide

1. Could you please describe to me what your life looked like prior to [child's name] diagnosis?
    (a) How was your relationship with your family?
    (b) How was your relationship with your spouse?
    (c) How was your relationship with [child’s name]?
    (d) How was your work/social life like?

2. What has life been like for you after [child's name] was diagnosed with the illness?
    (a) How did you come to know about his or her diagnosis?
    (b) What were you thinking at the time? How did you react? How did you feel?
    (c) How did the rest of your family and friends react to the news? (i.e. Parents and parents-in-law, other children, extended families, relatives, etc.)
    (d) How did you make sense of the challenges you were facing?

3. What was your experience like providing care to [child’s name]?
    (a) In what way has your daily life changed?
    (b) How have you and your spouse supported each other?
    (c) What were the involvements of the rest of your families and friends?
    (d) Did you seek help from other professionals (i.e. medical workers, social workers, counselors, school teachers) in caring for [Child’s name]? What was that experience like?

4. How has your relationship with [child’s name] changed throughout the process of illness?
    (a) Did you talk to [child’s name] about his or her illness?
        - If yes, how did he/she react? If no, what were your concerns?
    (b) Did you talk to [child’s name] about the type of care and treatment that he/she wanted?
        - If yes, what was this experience like? If no, what were your concerns?
    (c) Did you have a conversation with them about death?
        - If yes, what was this experience like? If no, what were your concerns?

5. What was your experience like as [child’s name] reaches the final phases of life?
    (a) Did you and your child have the chance to share with each other some lasting words, to engage in meaningful activities, or exchange gifts of remembrance as he/she approached the end-of-life? What were they? How these activities/objects helped you?
    (b) In the final days of life, did you feel prepared for [child’s name] departure?
        - What could have helped you feel more prepared?
    (c) What was it like for you when [child’s name] passed on?

6. How has your life changed after the passing of [child’s name]?
    (a) In what way has your daily life changed?
    (b) How has your relationship with your spouse evolved?
        - How have you supported each other through this time?
        - In what way does he/she support you/not support you?
        - Do you think there is something he/she could do to support you better?
        - Were there differences in how the two of you experienced loss and grief?
        - If there are, how do you reconcile such differences?
    (c) How has your relationship with the rest of your family evolved?
    (d) How has your relationship with your social network evolved?
    (e) How did you make sense of your life?

7. What was your experience like with the health-and-social care system throughout this journey?
    (a) In what way did they help you and your child to cope with the illness?
        - Was there something else they could have done to ease the process for you?
    (b) Did the health/social care professionals offer you any support during the last phases of life?
        - What were they? How did it help?

  (c) Are you receiving any form of support after [child's name]'s death?
    - If yes, what were they? How long did they last? How were they helpful?
    - If not, why? What type of support would you have like to receive?
  (d) What did you find most helpful from health-and-social care workers?
  (e) What did you find least helpful from health-and-social care workers?

8. Looking back at this experience, what helped you along your journey of caregiving and bereavement?
   (a) Did Religion/Spirituality/Faith have a role to play? How did this help? How has it evolved?
   (b) What are some of the other beliefs/values that helped you navigate through difficult times?
   (c) What are some of the inner strengths that you have for accepting and coping with your loss?
   (d) Has your community offered you any resources to support you through this process?
   (e) How have you made sense of your own experience throughout this journey?
   (f) Overall, have you experienced any personal growth or transformation from this journey?

9. If you have the opportunity to speak with someone who is currently going through a similar situation as you had, what kind of advice would you give to them?

10. As a parent who has been through this experience, is there a message that you would like to share with the world?

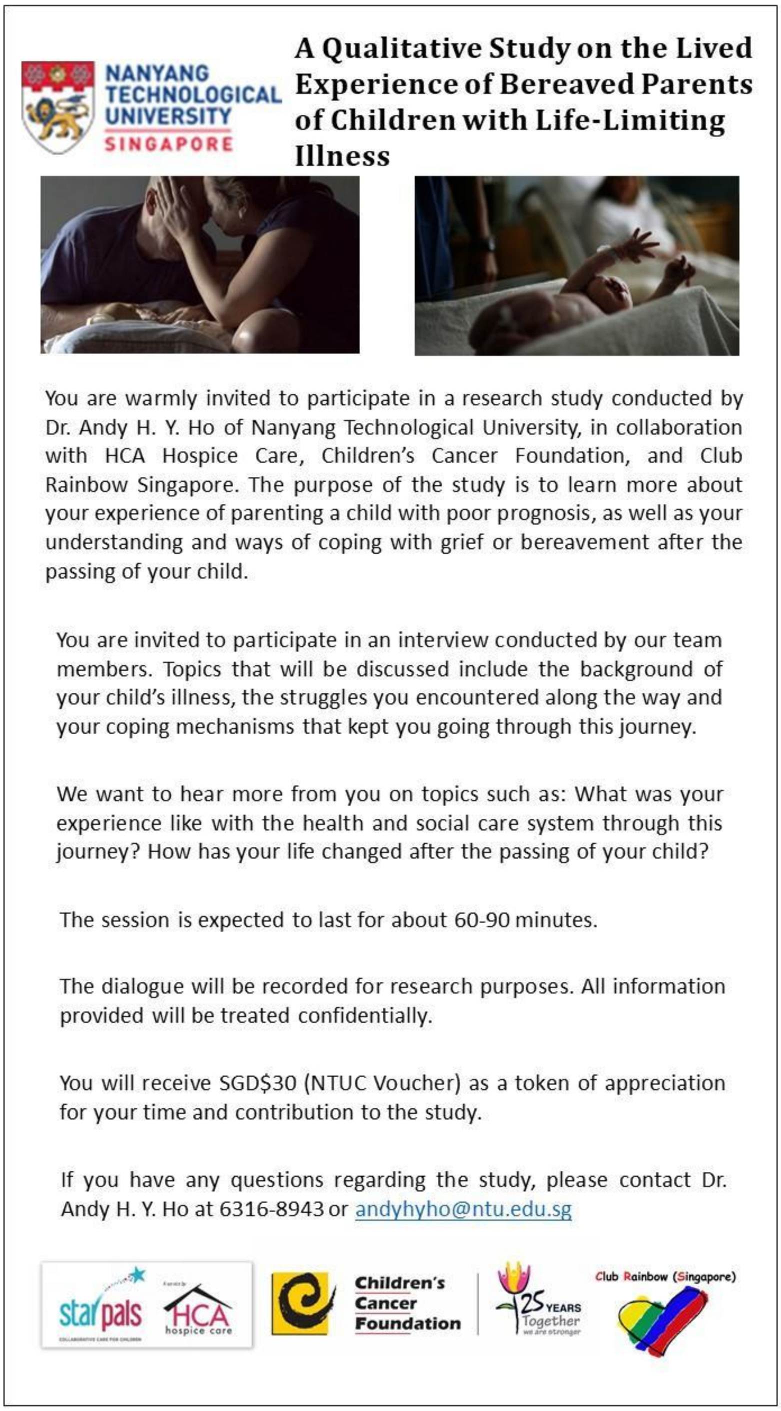
End of Interview

The interviewer will give a conclusion to end the discussion:

- Give thanks to participants for their time and contribution and reassure confidentiality;
- Provide contact details for any further enquiries;
- Ask permission for follow-up members checking meetings.

APPENDIX 4

Flyer for Research Advertisement and Participant Recruitment for Study 2



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A Qualitative Study on the Lived Experience of Bereaved Parents of Children with Life-Limiting Illness

You are warmly invited to participate in a research study conducted by Dr. Andy H. Y. Ho of Nanyang Technological University, in collaboration with HCA Hospice Care, Children's Cancer Foundation, and Club Rainbow Singapore. The purpose of the study is to learn more about your experience of parenting a child with poor prognosis, as well as your understanding and ways of coping with grief or bereavement after the passing of your child.

You are invited to participate in an interview conducted by our team members. Topics that will be discussed include the background of your child's illness, the struggles you encountered along the way and your coping mechanisms that kept you going through this journey.

We want to hear more from you on topics such as: What was your experience like with the health and social care system through this journey? How has your life changed after the passing of your child?

The session is expected to last for about 60-90 minutes.

The dialogue will be recorded for research purposes. All information provided will be treated confidentially.

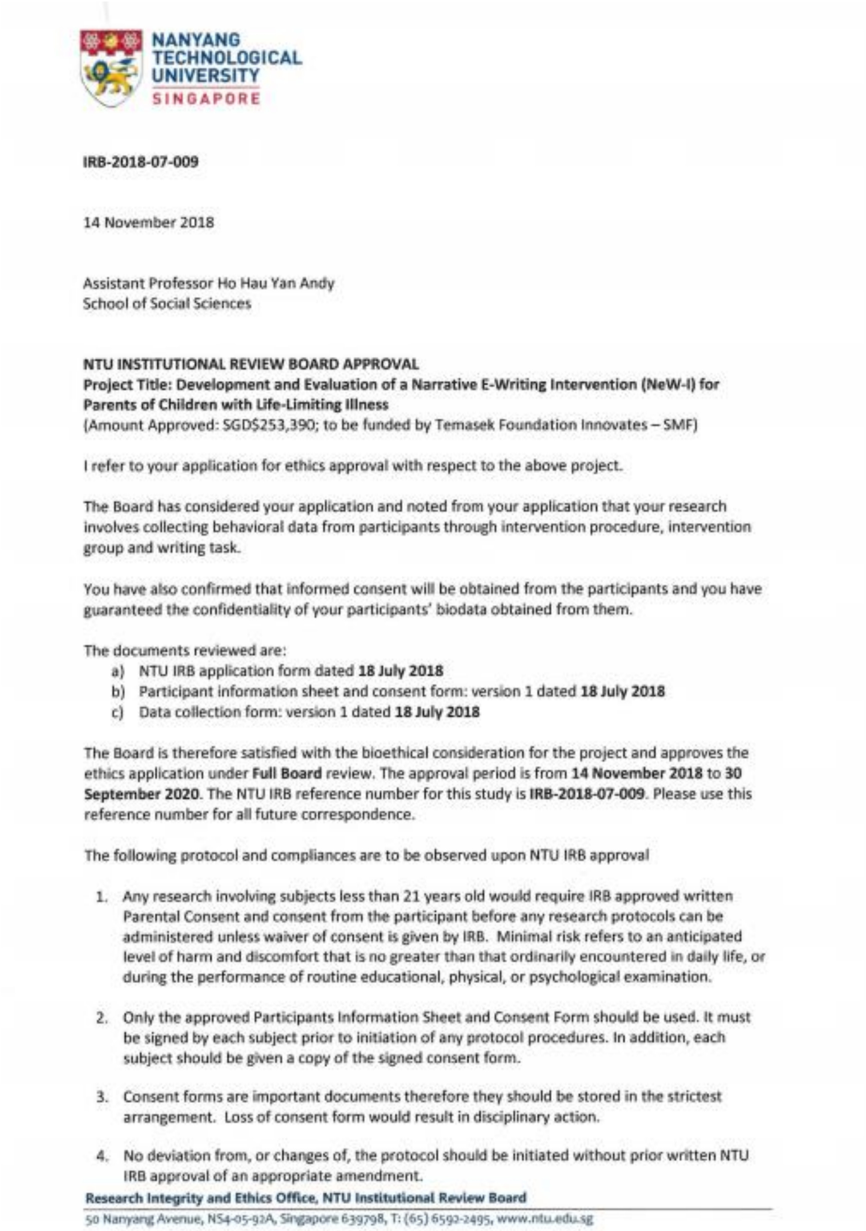
You will receive SGD$30 (NTUC Voucher) as a token of appreciation for your time and contribution to the study.

If you have any questions regarding the study, please contact Dr. Andy H. Y. Ho at 6316-8943 or andyhyho@ntu.edu.sg

star pals
HCA hospice care
Children's Cancer Foundation
25 YEARS Together
Club Rainbow (Singapore)

APPENDIX 5

NTU-IRB Letter of Approval for Study 3



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SINGAPORE

IRB-2018-07-009

14 November 2018

Assistant Professor Ho Hau Yan Andy
School of Social Sciences

NTU INSTITUTIONAL REVIEW BOARD APPROVAL
Project Title: Development and Evaluation of a Narrative E-Writing Intervention (NeW-I) for Parents of Children with Life-Limiting Illness
(Amount Approved: SGD$253,390; to be funded by Temasek Foundation Innovates – SMF)

I refer to your application for ethics approval with respect to the above project.

The Board has considered your application and noted from your application that your research involves collecting behavioral data from participants through intervention procedure, intervention group and writing task.

You have also confirmed that informed consent will be obtained from the participants and you have guaranteed the confidentiality of your participants' biodata obtained from them.

The documents reviewed are:
- a) NTU IRB application form dated **18 July 2018**
- b) Participant information sheet and consent form: version 1 dated **18 July 2018**
- c) Data collection form: version 1 dated **18 July 2018**

The Board is therefore satisfied with the bioethical consideration for the project and approves the ethics application under **Full Board** review. The approval period is from **14 November 2018** to **30 September 2020**. The NTU IRB reference number for this study is **IRB-2018-07-009**. Please use this reference number for all future correspondence.

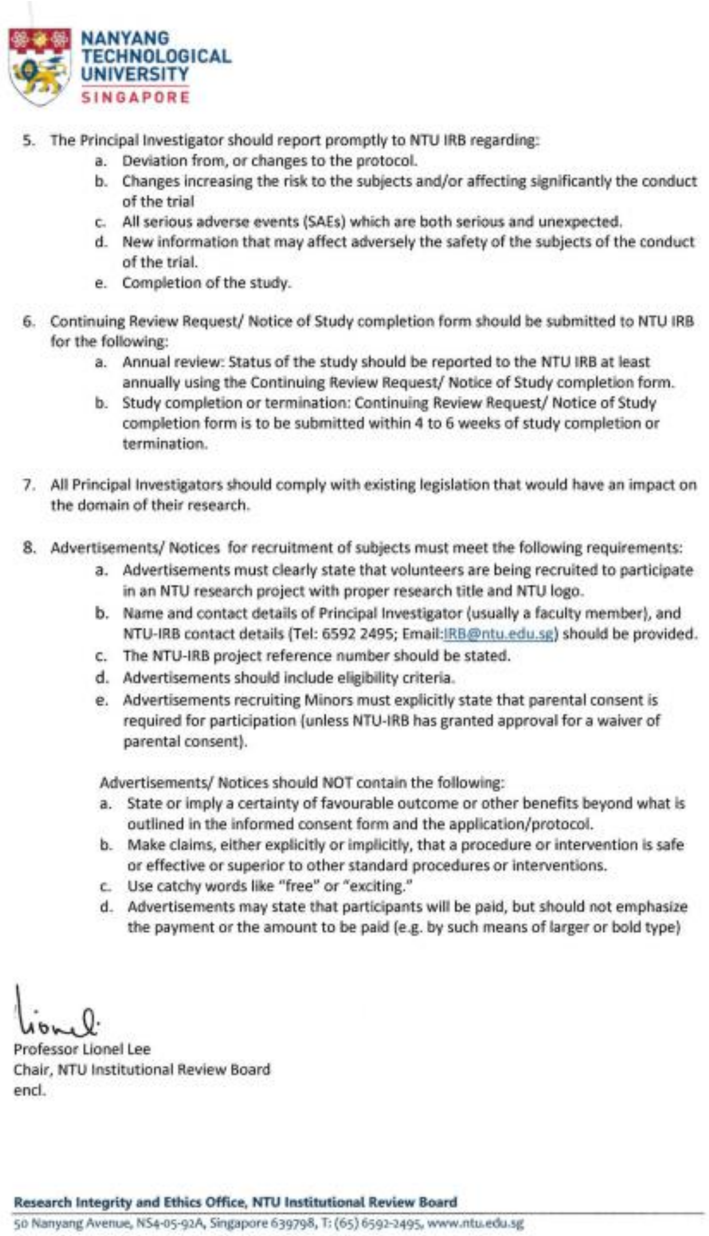
The following protocol and compliances are to be observed upon NTU IRB approval

1. Any research involving subjects less than 21 years old would require IRB approved written Parental Consent and consent from the participant before any research protocols can be administered unless waiver of consent is given by IRB. Minimal risk refers to an anticipated level of harm and discomfort that is no greater than that ordinarily encountered in daily life, or during the performance of routine educational, physical, or psychological examination.

2. Only the approved Participants Information Sheet and Consent Form should be used. It must be signed by each subject prior to initiation of any protocol procedures. In addition, each subject should be given a copy of the signed consent form.

3. Consent forms are important documents therefore they should be stored in the strictest arrangement. Loss of consent form would result in disciplinary action.

4. No deviation from, or changes of, the protocol should be initiated without prior written NTU IRB approval of an appropriate amendment.



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SINGAPORE

5. The Principal Investigator should report promptly to NTU IRB regarding:
    a. Deviation from, or changes to the protocol.
    b. Changes increasing the risk to the subjects and/or affecting significantly the conduct of the trial
    c. All serious adverse events (SAEs) which are both serious and unexpected.
    d. New information that may affect adversely the safety of the subjects of the conduct of the trial.
    e. Completion of the study.

6. Continuing Review Request/ Notice of Study completion form should be submitted to NTU IRB for the following:
    a. Annual review: Status of the study should be reported to the NTU IRB at least annually using the Continuing Review Request/ Notice of Study completion form.
    b. Study completion or termination: Continuing Review Request/ Notice of Study completion form is to be submitted within 4 to 6 weeks of study completion or termination.

7. All Principal Investigators should comply with existing legislation that would have an impact on the domain of their research.

8. Advertisements/ Notices for recruitment of subjects must meet the following requirements:
    a. Advertisements must clearly state that volunteers are being recruited to participate in an NTU research project with proper research title and NTU logo.
    b. Name and contact details of Principal Investigator (usually a faculty member), and NTU-IRB contact details (Tel: 6592 2495; Email:IRB@ntu.edu.sg) should be provided.
    c. The NTU-IRB project reference number should be stated.
    d. Advertisements should include eligibility criteria.
    e. Advertisements recruiting Minors must explicitly state that parental consent is required for participation (unless NTU-IRB has granted approval for a waiver of parental consent).

    Advertisements/ Notices should NOT contain the following:
    a. State or imply a certainty of favourable outcome or other benefits beyond what is outlined in the informed consent form and the application/protocol.
    b. Make claims, either explicitly or implicitly, that a procedure or intervention is safe or effective or superior to other standard procedures or interventions.
    c. Use catchy words like "free" or "exciting."
    d. Advertisements may state that participants will be paid, but should not emphasize the payment or the amount to be paid (e.g. by such means of larger or bold type)

Lionel
Professor Lionel Lee
Chair, NTU Institutional Review Board
encl.

Research Integrity and Ethics Office, NTU Institutional Review Board
50 Nanyang Avenue, NS4-05-92A, Singapore 639798, T: (65) 6592-2495, www.ntu.edu.sg

APPENDIX 6

Participants’ Informed Consent Form and Information Sheet for Study 3

Participant Information Sheet For Research Subjects

Study Information

IRB reference number

Protocol Title

Development and Evaluation of a novel Narrative E-Writing Intervention (NeW-I) for Parents of Children with Chronic Life-Threatening Illnesses

Principal Investigator & Contact Details

Dr. Andy H. Y. Ho, Assistant Professor of Psychology,
Nanyang Technological University [14 Nanyang Drive, HSS-04-03, Singapore 637332; Telephone: (65) 6316 8943; Email: andyhyho@ntu.edu.sg]

Study Sponsor

This study is funded by Temasek Foundation Innovates Singapore Millennium Foundation 8th Grant Call.

Purpose of the Research Study

You are invited to participate in a research study. It is important to us that you first take time to read through and understand the information provided in this sheet. Before you take part in this research study, the study will be explained to you and you will be given the chance to ask questions. After you are properly satisfied that you understand this study, and that you wish to take part in the study, you must sign the accompanying consent form. You will be given a copy of this consent form to take home with you.

The purpose of this study is to develop and test a novel therapist-facilitated, online, narrative writing intervention protocol and platform (a mobile app that is both iOS and android compatible as well as a web-browser based version) for parents who are caring for their child with a chronic life-threatening illness. We hope to learn about the challenges and pitfalls of the intervention platform so that we can propose recommendations for its large-scale implementation.

This study will recruit 66 participants from KK Women and Children’s Hospital, Club Rainbow Singapore as well as from the public over a period of two years.

Are there any exclusion criteria?

This study will be undertaken with mothers and fathers who are currently providing care to their child who is diagnosed with a chronic life-threatening illness between the ages of 0 to19 years with a prognosis of more than 3 months. Participants who do not fall within this category will be excluded from this study.

What procedures will be followed in this study
If you agree to take part in this study, you will randomly be allocated to either the intervention or the control group. Randomisation means assigning you to one of two groups by chance, like tossing a coin or rolling dice.

If you agree to take part in this study, your participation in this study will span across four consecutive weeks, with an additional audio call in the fifth week. Working with an experienced therapist, you will be provided with the opportunity to create and review a 'legacy document' of your child, through reflecting on your experience of caregiving, exploration of avenues where you can seek more information about your child's illness and resources for caregiving, acknowledging the pillars of support within your family and network of friends, and celebrating your child's life by assisting them to rise above the challenges posed by the illness. You will also be required to complete a set of standardized questionnaires at the start of the intervention, immediately after completion of the intervention, one month after completion of the intervention, three months after completion of the intervention and six months after completion of the intervention. In addition, you are requested to participate in a written interview so that we may know more about what your experience with the intervention has been like.

During the first four weeks of the intervention, you will engage in a weekly structured writing task and receive subsequent feedback and affirmation from the therapist. Each writing task will last for approximately 15-30 minutes. Your personal information will be anonymized, and the content of your writing task will be kept confidential. In the fifth week, you will receive a 'legacy document', which is a consolidated and edited version of your four weekly writing tasks. In the fifth week, an appointment will be set up with the therapist for an audio call, which will be recorded and transcribed verbatim for analysis.

Your Responsibilities in This Study
If you agree to participate in this study, you should:

- Engage in the narrative writing activity and follow the instructions as given to you by the research team.
- Complete the questionnaires and assessments as per the instructions given to you by the research team.
- If it is not possible for you to keep to the study schedule, please contact the research staff to reschedule as soon as you know you will be unable to keep to the schedule.

- Inform the research team as soon as possible if you experience any discomfort as a result of your participation in this study.

What Is Not Standard Care or is Experimental in This Study
The study is being conducted to test the newly developed therapist-facilitated, online, narrative writing intervention protocol for parents facing their child's chronic life-threatening illness. We hope that your participation will help us to determine the challenges and pitfalls of the intervention platform so that we can propose recommendations for its large-scale implementation.

Possible Risks and Side-Effects
There is minimal risk for engaging in a narrative writing activity. An experienced therapist will be available to offer online support, in the event that some aspects of the intervention cause you distress or discomfort. If you need further support, a referral can be made to the psychosocial team of your healthcare provider, and they will be able to provide you with follow-up assistance and consultations.

Possible Benefits from Participating in the Study
Your participation in this intervention will bring about the opportunity for you to experience enhanced quality of life, spiritual well-being, sense of hope and meaning in social relationships. We hope that you will experience satisfaction from being a part of this intervention, while helping us to develop and assess the efficacy of this intervention in providing psychosocial support to parents of children with life-limiting illness in Asia.

Costs & Payments if Participating in the Study
If you take part in this study, you will have the opportunity to engage with the newly developed therapist-facilitated, online, narrative writing intervention protocol for parents facing their child's chronic life-threatening illness at no charge to you.

You will be reimbursed for your time and inconvenience. For each completed set of questionnaires, you will receive a $30 cash voucher as a token of appreciation, totally up to $150 per completed study participation.

Voluntary Participation and Participant's Rights
Your participation in this study is entirely voluntary. You may stop participating in this study at any time without any obligation or need to explain your decision and without any adverse consequences. Your decision not to take part in this study or to stop your participation will not affect you and/or your child's medical care or any benefits to which you and/or your child are entitled. If you decide to stop taking part in this study, you should tell the Principal Investigator.

However, the data / research information that has been collected until the time of your withdrawal will be kept and analyzed. The reason is to enable a complete and comprehensive evaluation of the study.

The Principal Investigator of this study may stop your participation in the study at any time if they decide that it is in your best interests. They may also do this if you do not follow instructions required to complete the study adequately or you no longer meet the inclusion criteria for this study. If you have other medical problems, the Principal Investigator will decide if you may continue in the research study.

In the event of any new information becoming available (including but not limited to occurrences of serious adverse events, and changes in proposed research) that may be relevant to your willingness to continue in this study, you will be informed in a timely manner by the Principal Investigator (or his or her representative) and will be contacted for further consent if required.

Compensation for Injury

There is no known risk of engaging in an internet-based narrative writing activity. The researchers do not reasonably foresee any side-effects that could arise as an outcome of study participation. However, in the event that some aspects of the intervention do in fact cause distress or discomfort to participants, an experienced therapist will be available to offer online support. If participants need further support, a referral can be made to the psychosocial team of their healthcare provider, who will then be able to provide participants with follow-up assistance and consultations.

Confidentiality of Study

Your participation in this study will involve the collection of data in an individually-identifiable form (or “Personal Data”). “Personal Data” means data about you / your child / your ward, which makes you identifiable (i) from such data or (ii) from that data and other information which an organization has or likely to have access. This includes medical conditions, medications, investigations and treatment history.

Information collected for this study will be kept confidential and stored for a minimum of 10 years in a secure environment with restricted access within NTU. Your records, to the extent of the applicable laws and regulations, will not be made publicly available.

However, the Sponsoring company (Temasek Foundation Innovates Singapore Millennium Foundation), Regulatory Agencies, NTU Institutional Review Board and Ministry of Health will be granted direct access to your original medical records or “Personal Data” to check study procedures and data, without making any of your information public.

By signing the Informed Consent Form attached, you are authorizing (i) collection, access to, use and storage of your “Personal Data”, and (ii) disclosure to, and use and storage by, authorized service providers and relevant third parties, whether located in Singapore or overseas, for the purposes of this study or future research studies.

Data collected are the property of Nanyang Technological University. In the event of any publication regarding this study, only aggregated research data without identifiable personal details will be used, and your identity will remain confidential. Research arising in the future, based on this “Personal Data”, will be subject to review by the relevant institutional review board.

Who to Contact if You Have Questions
If you have any questions, complaints or feedback about this research study, you may contact the Principal Investigator, as follows:

Dr. Andy H. Y. Ho, Assistant Professor of Psychology,
Nanyang Technological University [14 Nanyang Drive, HSS-04-03, Singapore 637332; Telephone: (65) 6316 8943; Email: andyhyho@ntu.edu.sg]

The study has been reviewed by NTU Institutional Review Board (the central ethics committee) for ethics approval.

If you want an independent opinion to discuss problems and questions (complaints / feedback), obtain information and offer inputs on your rights as a research participant, please contact:

NTU Institutional Review Board
Research Integrity and Ethics Office
50 Nanyang Avenue, North Spine
NS4-05-92A
Singapore 639798
Email: irb@ntu.edu.sg
Tel: 6592 2495

Informed Consent Form

Protocol Title

Development and Evaluation of a novel Narrative E-Writing Intervention (NeW-I) for Parents of Children with Chronic Life-Threatening Illnesses

Principal Investigator & Contact Details

Dr. Andy H. Y. Ho, Assistant Professor of Psychology,
Nanyang Technological University [14 Nanyang Drive, HSS-04-03, Singapore 637332; Telephone: (65) 6316 8943; Email: andyhyho@ntu.edu.sg]

Consent to Take Part in the Study

I voluntarily consent to take part in this research study. I have fully read, discussed and understood the purpose and procedures of this study as noted in the Participant Information Sheet attached to this consent form. This study, including its nature, risks and benefits, has been explained to me directly by the investigator or through a translator, in a language that I understand. I have been given enough time to ask any questions that I have about the study, and all my questions have been answered to my satisfaction. I have also been informed and understood the alternative treatments or procedures available and their possible benefits and risks.

I understand that I may withdraw my consent and stop participating in the study at any time. By participating in this research study, I confirm that I consent to the collection, use and disclosure of my "Personal Data" for the purposes set out in the Participant Information Sheet.

I agree that I will be contacted for further consent, including but not limited to changes in the proposed research, serious adverse events that would lead to a change in the proposed research, the development of capacity by minors to make decisions, and any other circumstances which are specific to this research study or future research study.

Consent to be Re-Identified and Notified in the Case of an Incidental Finding

☐ Yes, I want to be contacted for any incidental findings that may be uncovered by the study.

☐ No, I do not want to be contacted for any incidental findings that may be uncovered by the study.

Notwithstanding the above, I agree that I may be contacted should incidental findings that are of serious clinical significance (for example, life-threatening) be uncovered during the course of this study.

Name of Participant	Signature	Date

Investigator Statement
I, the undersigned, certify that I explained the study to the participant and to the best of my knowledge the participant signing this informed consent form clearly understands the nature, risks and benefits of his / her participation in the study.

Name of Investigator	Signature	Date

APPENDIX 7

Flyer for Research Advertisement and Participant Recruitment for Study 3

New-i

Narrative e-Writing Intervention

Providing psycho-emotional support & resources to parents & caregivers online

Are you caring for a child with a chronic life-threatening illness?

Caring for your sick child can be both a fulfilling and challenging journey, filled with wonderful memories.

We would like to hear about your precious caregiving experiences.

NeW-I is a mobile app that allows you to share your experiences as a parent and caregiver by journaling in a safe and private platform.

Complete 4 journaling sessions of 15 - 30 min each, once a week for four consecutive weeks. Receive support from our friendly NeW-I therapist with personalised responses.

A record of your precious journal entries about your child will be given to you as a memento.

Additionally, you will receive a total of **S$150 cash vouchers** for the completion of 5 surveys in this study.

"[NeW-I] helps me to open up and reflect on the past... how I managed to overcome issues."

- Father of 10 y.o. boy

"It can be a useful platform for parents with chronically ill children to receive support from a professional, whether it is psychological support or recommendations for practical strategies to deal with an individual child's specific medical condition."

- Mother of 6 y.o. girl

NeW-I was found to have improved **overall spiritual well-being**, **sense of peace**, **quality of life**, and reduced the sense of burden for family caregivers.

Reflection 25:26

Tell us what you love best about your child. What quality about him/her makes you proud?

My son has faced a lot of challenges since birth, but he has been very strong throughout. Even when he is in pain, he smiles when he sees us.

My son loves to go out with the family. On weekends, we like to go to a restaurant, eat together and chat. Even though my son cannot talk properly, his smile tells me that he enjoys this very much.

When I kiss him good night before bedtime, he hugs me and that feeling makes all my efforts worth it.

tinyurl.com/newi-ios

tinyurl.com/newi-android

All information will be kept strictly confidential.

If you are interested to participate, please contact Oindrila Dutta at 82219802 / oindrila001@e.ntu.edu.sg or Casuarine Low at 92425238 / low.casuarine@ntu.edu.sg

For questions regarding the study, please contact Dr. Andy H. Y. Ho at 63168943 / andyhyho@ntu.edu.sg

The study has been reviewed by NTU Institutional Review Board (IRB-2018-07-009). If you want to discuss problems and questions, obtain information and offer inputs on your rights as a research subject, please contact NTU Institutional Review Board at 69047038 / irb@ntu.edu.sg

NANYANG TECHNOLOGICAL UNIVERSITY SINGAPORE

KK Women's and Children's Hospital SingHealth

Club Rainbow (Singapore)

mdas Muscular Dystrophy Association (Singapore)

RDSS

APPENDIX 8

Package for Baseline, Post-Intervention and One-Month Follow-Up Assessments for Study 3

Patient Health Questionnaire - 9 (PHQ-9)

Over the past 2 weeks, how often have you been bothered by any of the following problems?

1. Little interest or pleasure in doing things

Not at all / Several days / More than half the days / Nearly everyday

2. Feeling down, depressed or hopeless

Not at all / Several days / More than half the days / Nearly everyday

3. Trouble falling asleep, staying asleep, sleeping too much

Not at all / Several days / More than half the days / Nearly everyday

4. Feeling tired or having little energy

Not at all / Several days / More than half the days / Nearly everyday

5. Poor appetite or overeating

Not at all / Several days / More than half the days / Nearly everyday

6. Feeling bad about yourself - or that you’re a failure or have let yourself or your family down

Not at all / Several days / More than half the days / Nearly everyday

7. Trouble concentrating on things, such as reading the newspaper or watching television

Not at all / Several days / More than half the days / Nearly everyday

8. Moving or speaking so slowly that other people could have noticed. Or, the opposite - being so fidgety or restless that you have been moving around a lot more than usual

Not at all / Several days / More than half the days / Nearly everyday

9. Thoughts that you would be better off dead or of hurting yourself in some way

Not at all / Several days / More than half the days / Nearly everyday

Kessler Psychological Distress Scale (K10)

These questions concern how you have been feeling over the last 30 days.

1. During the last 30 days, about how often did you feel tired out for no good reason?

None of the time / A little of the time / Some of the time / Most of the time / All of the time

2. During the last 30 days, about how often did you feel nervous?

None of the time / A little of the time / Some of the time / Most of the time / All of the time

3. During the last 30 days, about how often did you feel so nervous that nothing could calm you down?

None of the time / A little of the time / Some of the time / Most of the time / All of the time

4. During the last 30 days, about how often did you feel hopeless?

None of the time / A little of the time / Some of the time / Most of the time / All of the time

5. During the last 30 days, about how often did you feel restless or fidgety?

None of the time / A little of the time / Some of the time / Most of the time / All of the time

6. During the last 30 days, about how often did you feel so restless you could not sit still?

None of the time / A little of the time / Some of the time / Most of the time / All of the time

7. During the last 30 days, about how often did you feel depressed?

None of the time / A little of the time / Some of the time / Most of the time / All of the time

8. During the last 30 days, about how often did you feel that everything was an effort?

None of the time / A little of the time / Some of the time / Most of the time / All of the time

9. During the last 30 days, about how often did you feel so sad that nothing could cheer you up?

None of the time / A little of the time / Some of the time / Most of the time / All of the time

10. During the last 30 days, about how often did you feel worthless?

None of the time / A little of the time / Some of the time / Most of the time / All of the time

Kemp Quality of Life Scale

Taking everything in your life into account, please rate your overall Quality of Life (QOL) on the following 7-point scale. One (1) means life is very distressing, it's hard to imagine how it could get much worse. Seven (7) means life is great, it's hard to imagine how it could get much better. Four (4) means life is so-so, neither good nor bad. (Mark only one option.)

1 (Life is very distressing.)
2
3
4 (Life is so-so.)
5
6
7 (Life is great.)

Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being (adapted version for NeW-I)

Below is a list of statements that other people in your situation have said are important. Please mark the response which applies to you in the past 7 days. (Mark only one option.)

1. I feel peaceful.

Not at all / A little bit / Somewhat / Quite a bit / Very much

2. I have a reason for living.

Not at all / A little bit / Somewhat / Quite a bit / Very much

3. My life has been productive.

Not at all / A little bit / Somewhat / Quite a bit / Very much

4. I have trouble feeling peace of mind.

Not at all / A little bit / Somewhat / Quite a bit / Very much

5. I feel a sense of purpose in my life.

Not at all / A little bit / Somewhat / Quite a bit / Very much

6. I am able to reach down deep into myself for comfort.

Not at all / A little bit / Somewhat / Quite a bit / Very much

7. I feel a sense of harmony within myself.

Not at all / A little bit / Somewhat / Quite a bit / Very much

8. My life lacks meaning and purpose.

Not at all / A little bit / Somewhat / Quite a bit / Very much

9. I find comfort in my faith or spiritual beliefs.

Not at all / A little bit / Somewhat / Quite a bit / Very much

10. I find strength in my faith or spiritual beliefs.

Not at all / A little bit / Somewhat / Quite a bit / Very much

11. My child's illness has strengthened my faith or spiritual beliefs.

Not at all / A little bit / Somewhat / Quite a bit / Very much

12. I know that whatever happens with my child's illness, things will be okay.

Not at all / A little bit / Somewhat / Quite a bit / Very much

Herth Hope Index

Please read each statement carefully and mark the response which best describes how you are feeling.

1. I have a positive outlook towards life.

Strongly disagree / Disagree / Agree / Strongly agree

2. I have short, intermediate, and/ or long-range goals.

Strongly disagree / Disagree / Agree / Strongly agree

3. I feel all alone.

Strongly disagree / Disagree / Agree / Strongly agree

4. I can see a light at the end of the tunnel.

Strongly disagree / Disagree / Agree / Strongly agree

5. I have a faith that gives me comfort.

Strongly disagree / Disagree / Agree / Strongly agree

6. I feel scared about my future.

Strongly disagree / Disagree / Agree / Strongly agree

7. I can recall happy/ joyful times.

Strongly disagree / Disagree / Agree / Strongly agree

8. I have deep inner strength.

Strongly disagree / Disagree / Agree / Strongly agree

9. I am able to give and receive caring/ love.

Strongly disagree / Disagree / Agree / Strongly agree

10. I have a sense of direction.

Strongly disagree / Disagree / Agree / Strongly agree

11. I believe that each day has potential.

Strongly disagree / Disagree / Agree / Strongly agree

12. I feel my life has value and worth.

Strongly disagree / Disagree / Agree / Strongly agree

Burden Scale for Family Caregivers - Short Version

We are asking you for information about your present situation. The present situation comprises your caregiving deduced from the illness of your child. The following statements often refer to the type of your assistance. This may be any kind of support up to nursing care. Please indicate the best description of your present situation.

1. My life satisfaction has suffered because of the care.

Strongly agree / Agree / Disagree / Strongly disagree

2. I often feel physically exhausted.

Strongly agree / Agree / Disagree / Strongly disagree

3. From time to time I wish I could “run away” from the situation I am in.

Strongly agree / Agree / Disagree / Strongly disagree

4. Sometimes I don’t really feel like “myself” as before.

Strongly agree / Agree / Disagree / Strongly disagree

5. Since I have been a caregiver my financial situation has decreased.

Strongly agree / Agree / Disagree / Strongly disagree

6. My health is affected by the care situation.

Strongly agree / Agree / Disagree / Strongly disagree

7. The care takes a lot of my own strength.

Strongly agree / Agree / Disagree / Strongly disagree

8. I feel torn between the demands of my environment (such as family) and the demands of the care.

Strongly agree / Agree / Disagree / Strongly disagree

9. I am worried about my future because of the care I give.

Strongly agree / Agree / Disagree / Strongly disagree

10. My relationships with other family members, relatives, friends and acquaintances are suffering as a result of the care.

Strongly agree / Agree / Disagree / Strongly disagree

Inventory of Social Support

Please select the response that best describes the way you have been feeling during the past two weeks, including today.

1. People take the time to listen to how I feel.

Does not describe me very well / Does not quite describe me / Describes me fairly well / Describes me well / Describes me very well

2. I can express my feelings about my grief openly and honestly.

Does not describe me very well / Does not quite describe me / Describes me fairly well / Describes me well / Describes me very well

3. It helps me to talk with someone who is nonjudgmental about how I grieve.

Does not describe me very well / Does not quite describe me / Describes me fairly well / Describes me well / Describes me very well

4. There is at least one person I can talk to about my grief.

Does not describe me very well / Does not quite describe me / Describes me fairly well / Describes me well / Describes me very well

5. I can get help for my grieving when I need it.

Does not describe me very well / Does not quite describe me / Describes me fairly well / Describes me well / Describes me very well

Brief Grief Questionnaire (adapted version for NeW-I)

Please read each question carefully and mark the response which best describes how you are feeling.

1. How much are you having trouble accepting the life-threatening illness of your child?

Not at all / Somewhat / A lot

2. Having a child with a life-threatening illness can result in a sense of sorrow and distress. How much does such negative emotions interfere with your life?

Not at all / Somewhat / A lot

3. How much are you bothered by images and thoughts of your child?

Not at all / Somewhat / A lot

4. Are there things you used to do when your child was well that you don't feel comfortable doing anymore, that you avoid? How much are you avoiding these things?

Not at all / Somewhat / A lot

5. How much are you feeling cut off or distant from other people since your child's illness, even people you used to be close to like family or friends?

Not at all / Somewhat / A lot