

ORAL EXAMINATION

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

OINDRILA DUTTA, PSYCHOLOGY

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 intervention for parents facing their child's chronic life-threatening illness and potential death was

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8.45am

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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-

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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 wellbeing 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-sociospiritual 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

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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-sociospiritual well-being of parent-caregivers facing anticipatory grief. The work is discussed in the light of previous literature.

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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.

Proceedings

Duration	Session
5 mins	Chairperson Welcome & Introduction of Panel
30-45mins	Presentation by Student
15 mins	Q&A (by audience – faculty / students)
Break	Audience to leave the meeting
30 mins	Q&A by Panel
15 mins	Chairperson to ask candidate to leave the meeting Private Panel Discussion and Decision on the Oral Examination
15 mins	Candidate invited back by Chairperson Feedback and Outcome of Oral Examination

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