

A Novel Narrative E-Writing Intervention (NeW-I) for Parents of Children with Chronic Life-Threatening Illnesses: Protocol for an Open-Label Randomized Controlled Trial

Andy Hau Yan Ho (✉ andyhyho@ntu.edu.sg)

<https://orcid.org/0000-0003-0373-7043>

Oindrila Dutta

Nanyang Technological University <https://orcid.org/0000-0002-2925-2477>

Geraldine Tan-Ho

Nanyang Technological University

Toh Hsiang Benny Tan

Nanyang Technological University

Casuarine Low Xinyi

Nanyang Technological University

Sashikumar Ganapathy

Club Rainbow Singapore

Lee Beng Ang

KK Women's and Children's Hospital

Josip Car

Nanyang Technological University

Ringo Moon-Ho Ho

Nanyang Technological University

Chun Yan Miao

Nanyang Technological University

Study protocol

Keywords: Narrative Therapy, Psychotherapy, Pediatric Palliative Care, End-of-Life Care, Randomized Controlled Trial, Cyber-Counselling

Posted Date: July 31st, 2019

DOI: <https://doi.org/10.21203/rs.2.12263/v1>

License:  This work is licensed under a Creative Commons Attribution 4.0 International License.

[Read Full License](#)

Abstract

Background: Conventionally, psycho-socio-emotional interventions for parents of children with chronic life-threatening illness begin post child loss. Evidence indicates pre-loss interventions addressing anticipatory grief can improve psycho-socio-emotional well-being and grief outcomes among family caregivers of dying patients, but no known intervention addresses the unique psycho-socio-emotional needs of Asian parents facing their child's chronic life-threatening illness. Globally, palliative care strives to holistically support patients and their caregivers at the end-of-life, but inadequacies exist both globally and locally in pediatric palliative care and parental bereavement support services. Aim: A novel evidence-based Narrative e-Writing Intervention (NeW-I) is developed to address this gap. NeW-I is a strength-focused, meaning-oriented and therapist-facilitated mobile app and web-based counseling platform that aims to enhance quality of life, spiritual well-being, hope and perceived social support, and reduce depressive symptoms, caregiver burden and risk of complicated grief among parents facing their child's chronic life-threatening illness. Methods: The design of NeW-I is informed by an international systematic review and a Singapore-based qualitative inquiry on the lived experience of bereaved parents of children with chronic life-threatening illness. Together with four major local pediatric palliative care providers, NeW-I is implemented in Singapore as an open-label pilot randomized controlled trial with 66 parents and supplemented with a built-in accessibility and feasibility study. Discussion: NeW-I aspires to improve psycho-socio-emotional well-being of parents facing their child's chronic life-threatening illness through a structured cyber-counseling platform, thereby enhancing holistic pediatric palliative care and parental bereavement support services. Findings from this pilot study can inform large-scale implementation and evaluation of NeW-I in Singapore and globally.

Background

In 2016, over 6.6 million children died globally [1] with chronic illnesses being a prevalent cause of child mortality [2]. For Singapore specifically, the number of child deaths (age < 19) increased from 204 in 2014 to 245 in 2016 [3, 4]. The cause of this 20% rise is primarily child death due to chronic conditions, which climbed from 120 in 2014 to 152 in 2016 [5]. A child's death shatters the assumption that children do not die before their parents, thus invalidating parents' self-concept and social roles [6]. Furthermore, the experience of child loss is associated with disenfranchised grief [7] and greater risk of physical, psychological and social health problems among bereaved parents, especially in the initial months of bereavement [8].

Parental Bereavement Trajectories of Child Loss

Our research team recently conducted a qualitative systematic review of 25 high-quality research articles published between 2000 and 2017, exploring the lived experience of parental bereavement due to a child's chronic life-threatening illness; a four-phase parental bereavement trajectory of child loss was developed, highlighting appropriate interventions that help parents identify care needs, elicit caregiving strengths,

enhance death preparedness, and foster meaning-making throughout the illness trajectory in order to reduce psycho-emotional distress during end-of-life and into bereavement [9]. Our research team conducted a second study to examine the Asian experience of parental bereavement, via meaning-oriented strength-focused interviews with 25 parental units who lost their child to chronic life-threatening illness in Singapore [10]. Analysis using grounded theory approach revealed 7 themes and 25 sub-themes which further illuminate the need to enhance support for parents caring for children with chronic life-threatening illness early in the illness trajectory (see Table 1).

[Insert Table 1 here]

These findings echo previous literature that parents facing potential child loss could benefit from psychosocial and therapeutic interventions as early as prognosis and throughout the illness trajectory, which could ease the transition from caregiving, through mortality and bereavement [9, 11–13], thus mitigating adverse grief outcomes [14]. However, most supportive interventions for parents caring for children with chronic life-threatening illness only occur after bereavement [15–17], and a recent systematic review found negligible evidence to support their effectiveness [18]. As such, there is a need to develop a pre-loss intervention to augment pediatric palliative care and parental bereavement support service - one that empowers 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.

Elements of a Pre-Loss Intervention for Parents Facing their Child's Chronic Life-Threatening Illness

In developing a pre-loss intervention that could meaningfully impact families throughout their child's illness trajectory and leading to the final days of their child's life, a number of important therapeutic elements need to be considered and incorporated. First, *Anticipatory Grief* (AG), defined as the process of mourning the loss of a loved one prior to actual loss that enables caregivers to experience and adjust to various grief responses, must be central to such an intervention [13, 19]. AG can smoothen the process of coping with death, since the individual has scope to come to terms with the loss in advance [20]. Studies have found that strength-based end-of-life interventions with elements that address AG can improve adult patients' quality of life and mitigate poor bereavement outcomes among family caregivers [21]. It is therefore possible that an AG-based psychotherapeutic intervention for parents facing their child's chronic life-threatening illness could aid parents in understanding and regulating emotions, enhancing death preparedness, and thereby building resilience.

Second, it would be useful for a pre-loss intervention for parents facing their child's chronic life-threatening illness to adopt a *Meaning-Reconstruction Approach* [22–24], with each individual actively constructing a phenomenological world of his/her own experiences in relation to various familial and socio-cultural contexts, and supporting their sense of loss and grief accordingly. Such a meaning-

reconstruction approach empowers griever to choose whether to direct their attention to the loss and process turbulent feelings, or to focus on practical adjustments to re-engage with their everyday life. Third, a pre-loss intervention would benefit from a *Narrative Approach* [25, 26], which could help individuals connect with emotions that are challenging to accept, generate new meaningful stories about life and loss, and restructure negative emotional appraisal of situations such as end-of-life caregiving into more positive ones, thereby generating a sense of hope.

Two effective examples of applying the meaning-reconstruction approach and the narrative approach in supporting holistic end-of-life care are *Dignity Therapy* [21, 27, 28] and *Family Dignity Intervention* [29], both of which are evidence-based psychotherapies that addresses the physical, psychosocial and existential issues pertaining to one's dignity at end-of-life. Specifically, Family dignity intervention is designed to support the collective experience of grief and loss for Asian families facing mortality, and it could add great value to a pre-loss intervention for parents of children with chronic life-threatening illness. In practice, family dignity intervention comprises a meaning-focused interview with the patient-and-family caregiver dyad that fosters the expression of appreciation and emotional connection through the retelling of important life narratives; the interview is recorded, transcribed and edited into a legacy document, and returned to the dyad for sharing with their loved ones for healing and remembrance

Finally, a pre-loss intervention for parents facing their child's chronic life-threatening illness must be mindful of the caregiving responsibilities and limitations that serve as barriers for parents to engage in sit-and-talk therapy [9]. It is possible that an internet-based platform which is cost-effective and time-efficient [30] can deliver psychotherapy to such parents. Such *therapist-facilitated e-platforms* are increasingly used for brief and effective psychotherapy for a range of conditions including depression, anxiety, and stress [31–34]. Moreover, when internet-based platforms use writing as the modality for emotional expression and reflection, efficacy is superior, as compared to audio/video mediums [35]. Finally, the anonymity of an e-writing channel can encourage greater willingness to self-disclose [36, 37].

Present Study

Globally, pediatric palliative care interventions predominantly emphasize the stages of grief and psychological tasks that grieving parents must accomplish after their child's death [18], and in Singapore, there is no known empirically-tested intervention to provide psycho-emotional support and psychoeducational resources to parents of children with chronic life-threatening illness. Given that Singapore is a leading nation in digital readiness, and smartphone utilization for communication is ingrained into the everyday life of its people [38], internet-based solutions can be vital in enhancing pediatric palliative care and parental bereavement support services. The Medical Research Council Framework for the Development and Evaluation of Complex Interventions is widely recognized for designing and evaluating complex interventions which could improve health outcomes [39, 40].

The present research team has integrated the aforementioned elements necessary for a pre-loss intervention for parents of children with chronic life-threatening illness and conceived Narrative e-Writing

Intervention (NeW-I) to address the gap in pediatric palliative care delivery and research in the local context. Specifically, NeW-I is a novel internet-based, therapist-facilitated, strength-focused, and meaning-oriented intervention designed to provide direct service to parents facing their child's chronic life-threatening illness.

Methodology

The NeW-I study protocol is guided by the SPIRIT 2013 checklist for reporting of clinical trial protocols [41] (see Figure 1 for the corresponding Standard Protocol Items: Recommendations for Interventional Trials (SPIRIT) Figure).

[Insert Figure 1 here]

Aims, Objectives and Hypothesis

The development and evaluation of NeW-I is informed by the medical research council framework for the development and evaluation of complex interventions [39, 40], the meaning-reconstruction model [42], the narrative approach to anticipatory grief [43], dignity therapy [27, 28], and family dignity intervention for holistic end-of-life care [29], and guided by the findings of a recent investigation on Asian parental bereavement experience of child loss by our research team [10]. The objectives of this study are:

- a. to develop a detailed protocol for a culture-specific and meaning-oriented Narrative e-Writing Intervention (NeW-I) for anticipatory grief and bereavement support for parents facing their child's chronic life-threatening illness and impending death;
- b. to evaluate the efficacy of NeW-I in enhancing quality of life, spiritual well-being, hope and perceived social support, and decreasing depressive symptoms, caregiver burden and risk of complicated grief among participants; and
- c. to examine positives and challenges in the design and implementation of NeW-I through a built-in accessibility and feasibility study for establishing a solid foundation towards full-scale implementation.

It is hypothesized that intervention group participants who successfully complete NeW-I will experience enhanced quality of life, spiritual well-being, sense of hope and perceived social support, and decreased depressive symptoms, subjective caregiver burden and risk of complicated grief as compared to control group participants. It is also hypothesized that NeW-I is deemed an accessible and user-friendly service by participants.

Study Design

This study adopts an open-label randomized controlled trial design comprising two groups: (1) an intervention group (structured NeW-I protocol) and (2) a control group (unstructured journaling activity).

Sample

The sample comprises 66 parents of varying ethnicity in Singapore (N = 66). To be eligible for participation in this study, the individual must be a parent whose child has been diagnosed with a chronic life-threatening illness between the ages of 0–19 years and has a prognosis of more than 3 months at the time of study registration. The individual must be able to speak, read, and write in English and provide informed consent. Individuals are excluded from this study if they cannot provide informed consent and are 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 do not meet the stated cut-off scores of Patient Health Questionnaire–9 (>19) and Kessler Psychological Distress Scale (>29) are excluded as formal treatment and therapy would be more beneficial [44, 45]. Additionally, if participants cease to meet the inclusion criteria during the study (such as, due to their child's untimely death), they are excluded from the study and provided alternative resources for psychosocial support.

Sample Size Calculation

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 [46]. In fact, many high quality psychotherapy studies (as defined by proficiently trained therapist, treatment integrity, $N \geq 50$) for the treatment of depression have a mean effect size of $d = 0.22$ [47]. Allowing for an attrition rate of 30% at follow-up (a larger estimate due to end-of-life context), the minimal sample size required for this study is 66, or 33 in each group.

Study Sites and Recruitment Procedures

In collaboration with leading pediatric palliative care providers in Singapore including KK Women's and Children's Hospital, Club Rainbow Singapore, Muscular Dystrophy Association Singapore and Rare Disorders Society Singapore, purposive sampling is adopted to achieve the target sample size of 66. Potential participants are identified and contacted by the relevant collaborating organization to introduce the study. If verbal consent is obtained from potential participants, their contact details are passed to the NTU research team who subsequently establish telephone contact, explain study procedures and introduce the NeW-I online platform. All personal information pertaining to potential participants is kept confidential and only the responsible researchers have access to such information.

Open recruitment is also carried out, so that all parents of children with chronic life-threatening illness have equal opportunity to participate in a potentially beneficial study, and to examine the feasibility of implementing this free and easily accessible intervention in the community. Posters are placed in strategic locations across Singapore providing information regarding the study. When interested participants contact the research team, study procedures are explained, the NeW-I platform is introduced, and registration information is provided.

App and Intervention Procedure

The NeW-I therapist-facilitated online platform comprises a mobile app and a website. When participants initially log on to the app or website, they are directed to a study participation and informed consent page that provides details about study procedures, rights of research participants and protection of confidentiality. After participants endorse this online informed consent form on the NeW-I platform, they are directed to a demographic information page. This is followed by a screening page where participants complete the PHQ-9 and the K-10. Those who pass the screening assessments receive confirmation of study participation and are requested to wait for a phone call from the research team. Those who do not pass the screening assessments are thanked for their time and provided resources for psychosocial support. Individuals who pass the screening assessments receive a phone call from the NeW-I team as a means of identity-checking. This is followed by random allocation of participants to either the intervention or the control group which is done via the NeW-I platform by using computer-generated random numbers. Following this, participants complete baseline measures (T1 assessment) and are then directed to the first writing session. Participants may choose to begin the T1 assessment and first writing session immediately, or delay for a maximum of 3 days. The day on which participants begin the writing session is day 1 of week 1. Study procedures are described in detail in Figure 2.

[Insert Figure 2 here]

Intervention and Control Group

Both intervention and control group participants follow the procedures described in Table 2. There are 4 weekly sessions of writing. A template is provided to ensure that participants' writings are structured and tie in with the session objectives. To improve participants' adherence to the study protocol, they receive an automated notification on their phone app and email each time a fresh writing session becomes available to them. Participants are assured of anonymity and confidentiality of their writing to encourage open and honest self-expression. The structured writing for each session requires 15 to 30 minutes, since exposure and time to process ideas through written disclosure over at least 3 sessions of 15 minutes each can produce effective outcomes [48].

[Insert Table 2 here]

For intervention group participants, each weekly session has a unique objective (see Table 3). Briefly, in week 1, participants reflect on the demands of caring for a child with chronic life-threatening illness, and the means to cope with these challenges. In week 2, participants consider avenues where they can seek more information about their child's illness and resources for caregiving. In week 3, participants examine the sources of support which they have within their network of family and friends. In week 4, participants explore how they (and their children) can rise above illness-related challenges and live their lives as fully as possible.

[Insert Table 3 here]

For control group participants, the objective is consistent across the 4 weeks, that is, participants engage in a weekly unstructured writing session which allows them to experience the therapeutic benefits of unstructured narrative writing (see Table 4).

[Insert Table 4 here]

Evaluation of Outcomes

Quantitative assessments. Via the NeW-I platform, both intervention and control group participants fill out a socio-demographic form at baseline, and are then assessed on a battery of standardized and validated measures across 5 time-points. This includes: (i) Kemp Quality of Life Scale [49], (ii) a modified version of the Functional Assessment of Chronic Illness Therapy- Spiritual Well-Being [51], (iii) Herth Hope Index [50], (iv) Patient Health Questionnaire–9 [44], (v) Burden Scale for Family Caregivers-Short [51], (vi) Inventory of Social Support [52] and (vi) a modified version of the Brief Grief Questionnaire [53] (see Table 5).

[Insert Table 5 here]

Assessment for both intervention and control group takes place at five time-points: baseline (T1), immediately after completion of the intervention or control protocol (T2), one month after completion of the intervention or control protocol (T3), three months after completion of the intervention or control protocol (T4), and a final follow-up six months after completion of the intervention or control protocol (T5) (described in both Figure 1 and Figure 2). Participants receive an automated notification on their phone app and email each time an assessment set becomes available to them. For each completed assessment, participants receive a 30 SGD voucher.

Accessibility study. To evaluate the accessibility and effectiveness of NeW-I, all intervention group participants are invited to participate in a written interview at the completion of all intervention components at T2, which explores the impact of the intervention, aspects of the intervention found to be helpful, aspects of the intervention found to be unhelpful and how they could be improved, challenges encountered in completing the intervention, and scope for enhancing intervention usability.

Feasibility study. To maintain a detailed audit trail and to assess the implementation and delivery of NeW-I, the research team records 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, intervention delivery, observations of participants' experiences and responses, and difficult or deviant cases. All feedback provided to participants is vetted by at least two members of the research team for data monitoring, quality and safety assurance.

Data Analysis

Quantitative data. All quantitative data are stored and analyzed using the SPSS computer software. Reliability tests are reported for all scales with the sample population. Between-and within-participant comparison of outcomes are conducted, and appropriate effect size estimates are reported. Further, comparisons are done at T3, T4 and T5 follow-up with baseline for both groups to assess longitudinal outcomes and potential maintenance effects. To characterize and predict changes in outcome variables, multilevel analyses are conducted. The intervention and control group are also compared on demographic characteristics and baseline measures. If necessary, these are controlled in the analyses. Deviant cases which could impact intervention outcomes, recruitment rates, comparison of drop-out rates and missing data in the two groups are reported.

Qualitative data. All qualitative data are stored and analyzed using the QSR NVivo computer software. Phenomenological analysis is used to obtain an in-depth and comprehensive view of the dataset from an insider perspective [56]. Unique or minority voices are elicited to illuminate counterpoints to the stated views. Throughout the data analysis process, strategies to maximize research rigor and trustworthiness are prioritized. The use of such a method of data analysis has been demonstrated in previous research involving grief therapy with bereaved parents [54].

Discussion

NeW-I is a first-of-its-kind internet-based, therapist-facilitated, strength-focused, and meaning-oriented intervention designed to provide direct service to parents facing their child's chronic life-threatening illness, filling in a critical service gap in local pediatric palliative care. Through an open-label randomized control trial, the efficacy of NeW-I for improving such parents' quality of life, spiritual well-being, hope, depressive symptoms, caregiver burden, social support and risk of complicated grief is investigated across five time-points. This study further allows for: (1) a longitudinal assessment of the mental states of 33 parents (i.e. control group) to obtain a naturalistic trajectory of anticipatory grief; (2) an evaluation of the extent to which the intervention is successful in improving 33 parents' mental well-being (i.e. intervention group); and (3) an evaluation of the extent to which these potential positive effects are sustained over time. The findings will be disseminated via research articles and presentations, so that they can inform large-scale implementation and evaluation of NeW-I in Singapore, which in turn can

enable NeW-I to be further implemented and tested globally with parents of children with chronic life-threatening illness, thereby meaningfully impacting population health.

The internet-based narrative writing model of NeW-I supports the unique needs of Asian family caregivers who are uncomfortable with emotional expression even during times of loss and separation [55]. It is hoped that NeW-I is perceived by parents to be a safe platform for engaging in intimate dialogue regarding their child's caregiving, thereby enhancing parents' experience of their child's illness trajectory, empowering them to harness available resources to provide the best possible care to their child, while simultaneously reducing psychosocial distress and caregiver burden. Finally, although the current format of NeW-I is tailored for parents facing their child's chronic life-threatening illness, the online therapeutic protocol can be adapted to deliver psychotherapy to diverse populations. The intervention protocol is inherently cost-effective, convenient-to-access, allows expression of disenfranchised emotions and promotes meaning-ascription to traumatic experiences.

Limitations, Future Directions And Conclusion

Presently, NeW-I can only be implemented with participants who speak, read, and write English. Singapore is a multi-cultural and multi-linguistic nation [56], and future research should expand the delivery language of NeW-I and assess its acceptability and effectiveness among different linguistic and ethnic groups in Singapore and globally. Despite this limitation, NeW-I could enhance participants' wellness by drawing attention away from their illness narrative and instead emphasize areas that research has demonstrated to be most meaningful at the end-of-life. Expected study outcomes can generate new knowledge to inform research and practice in pediatric palliative care and parental bereavement support locally and globally.

Trial status

Protocol version number: 1; date: 1 May 2019

Participant recruitment starting date: 1 February 2019; participant recruitment expected completion date: June 2020.

List Of Abbreviations

NeW-I: Narrative e-Writing Intervention

Declarations

Ethics approval and consent to participate

This study has been approved by the Institutional Review Board of Nanyang Technological University Singapore (IRB–2018–07–009). Online endorsed informed consent is obtained from all participants before study participation. Participants’ confidentiality, safety from unintended outcomes and right to withdraw without any adverse consequences is safeguarded under the ethical provisions of HBRA studies reviewed by NTU-IRB.

Consent for publication

Not Applicable

Availability of data and material

No additional data is available.

Competing interests

The authors declare that they have no competing interests.

Funding

This work is supported by the Temasek Foundation Innovates’ Singapore Millennium Foundation Grant (Ref no. M4062472.SS0). The funder played no role in the study design, collection, analysis or interpretation of data, or preparation of manuscript.

Authors’ contributions

AHYH and OD conceived and designed the study, obtained funding, and drafted the manuscript. GTH, THBT and CLX participated in designing the study and operationalizing procedures. GTH also contributed to training and skills development. LBA, JC, RMHH, CYM and SG helped in study planning and study execution. All authors have made substantial contribution to the development and editing of the manuscript and have approved the final version.

Acknowledgements

The authors are deeply grateful to KK Women’s and Children’s Hospital, Club Rainbow Singapore, Muscular Dystrophy Association Singapore, and Rare Disorders Society Singapore for supporting this project.

Access to data

Information collected during this study will be kept confidential. Only the research team will have access to participants' personal data. For any publication arising from this study, only aggregated research data without identifiable personal details will be used.

References

1. Hug L, Sharrow D, You D, et al (2017) Levels & trends in child mortality report 2017: Estimates developed by the UN Inter-agency Group for Child Mortality Estimation. UNICEF, New York
2. Modell B, Berry RJ, Boyle CA, Christianson A, Darlison M, Dolk H, Howson CP, Mastroiacovo P, Mossey P, Rankin J (2012) Global regional and national causes of child mortality. *Lancet* 380:1556–1557
3. Singapore Registry of Births and Deaths (2017) Report on Registration of Births and Deaths 2016. Immigration and Checkpoints Authority, Singapore
4. Singapore Registry of Births and Deaths (2016) Report on Registration of Births and Death 2015. Immigration and Checkpoints Authority, Singapore
5. Committee on the Rights of the Child (2017) Singapore's Fourth and Fifth Periodic Report. United Nations Convention on the Rights of the Child
6. Mun S, Ow R (2017) Death of a child: Perspective of Chinese mothers in Singapore. *Journal of Religion & Spirituality in Social Work: Social Thought* 36:306–325
7. Attig T (2004) Disenfranchised grief revisited: Discounting hope and love. *Omega* 49:197–215
8. Youngblut JM, Brooten D, Cantwell GP, DelMoral T, Totapally B (2013) Parent health and functioning 13 months after infant or child NICU/PICU death. *Pediatrics* 132:e1295–301
9. Dutta O, Tan-Ho G, Choo PY, Ho AHY (2018) Lived experience of a child's chronic illness and death: A qualitative systematic review of the parental bereavement trajectory. *Death Studies* 1–15
10. Dutta O, Tan-Ho G, Choo PY, Chong PH, Ng C, Ganapathy S, Ho AHY (2019) Asian experience of Child Loss to Chronic Life-Threatening Illness.
11. Tan JS, Docherty SL, Barfield R, Brandon DH (2012) Addressing parental bereavement support needs at the end-of-life for infants with complex chronic conditions. *Journal of Palliative Medicine* 15:579–584
12. Rini A, Loriz L (2007) Anticipatory mourning in parents with a child who dies while hospitalized. *Journal of Pediatric Nursing* 22:272–282
13. Al-Gamal E, Long T (2010) Anticipatory grieving among parents living with a child with cancer. *Journal of Advanced Nursing* 66:1980–1990
14. Kreicbergs UC, Lannen P, Onelov E, Wolfe J (2007) Parental grief after losing a child to cancer: Impact of professional and social support on long-term outcomes. *Journal of Clinical Oncology* 25:3307–3312

15. Harvey S, Snowdon C, Elbourne D (2008) Effectiveness of bereavement interventions in neonatal intensive care: a review of the evidence. In: *Seminars in Fetal and Neonatal Medicine*. Elsevier, pp 341–356
16. Contro N, Sourkes BM (2012) Opportunities for Quality Improvement in Bereavement Care at a Children's Hospital: Assessment of interdisciplinary staff perspectives. *Journal of Palliative Care* 28–35:
17. Murray A, Terry DJ, Vance JC, Battistutta D, Connolly Y (2000) Effects of a program of intervention on parental distress following infant death. *Death Studies* 24:275–305
18. Endo K, Yonemoto N, Yamada M (2015) Interventions for bereaved parents following a child's death: A systematic review. *Palliative Medicine* 29:590–604
19. Worden WJ (2003) *Grief counseling and grief therapy: A handbook for the mental health practitioner*, Third. Routledge, London
20. Ivancovich DA (2004) *The Role of Existential Coping and Spiritual Coping in Anticipatory Grief*. Trinity Western University
21. Chochinov HM, Kristjanson LJ, Breitbart W, McClement S, Hack TF, Hassard T, Harlos M (2011) Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: A randomized controlled trial. *The Lancet Oncology* 12:753–762
22. Neimeyer RA, Keesee NJ (1998) Dimensions of diversity in the reconstruction of meaning. *Living with grief: Who we are, how we grieve* 223–237
23. Schut MSH, Schut Margaret Stroebe H (1999) The dual process model of coping with bereavement: Rationale and description. *Death Studies* 23:197–224
24. Gilbert KR (1996) "We've had the same loss, why don't we have the same grief?" Loss and differential grief in families. *Death Studies* 20:269–283
25. Dysvik E, Natvig GK, Furnes B (2013) A narrative approach to explore grief experiences and treatment adherence in people with chronic pain after participation in a pain-management program: a 6-year follow-up study. *Patient Preference and Adherence* 7:751
26. Morris C, Simpson J, Sampson M, Beesley F (2015) Emotion and Self-Cutting: Narratives of Service Users Referred to a Personality Disorder Service. *Clinical Psychology & Psychotherapy* 22:125–132
27. Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M (2005) Dignity therapy: A novel psychotherapeutic intervention for patients near the end of life. *Journal of Clinical Oncology* 23:5520–5525
28. McClement S, Chochinov HM, Hack T, Hassard T, Kristjanson LJ, Harlos M (2007) Dignity Therapy: Family Member Perspectives. *Journal of Palliative Medicine* 10:1076–1082
29. Ho AHY, Car J, Ho M-HR, et al (2017) A novel Family Dignity Intervention (FDI) for enhancing and informing holistic palliative care in Asia: Study protocol for a randomized controlled trial. *Trials* 18:587

30. Griffiths KM, Christensen H (2006) Review of randomized controlled trials of Internet interventions for mental disorders and related conditions. *The Clinical Psychologist* 10:16–29
31. Newman MG, Szkodny LE, Llera SJ, Przeworski A (2011) A review of technology-assisted self-help and minimal contact therapies for anxiety and depression: Is human contact necessary for therapeutic efficacy? *Clinical Psychology Review* 31:89–103
32. Barak A, Hen L, Boniel-Nissim M, Shapira N 'ama (2008) A comprehensive review and a meta-analysis of the effectiveness of internet-based psychotherapeutic interventions. *Journal of Technology in Human Services* 26:109–160
33. Kaltenthaler E, Parry G, Beverley C (2004) Computerized cognitive behaviour therapy: A systematic review. *Behav Cogn Psychother* 32:31–55
34. Gainsbury S, Blaszczynski A (2011) A systematic review of Internet-based therapy for the treatment of addictions. *Clinical Psychology Review* 31:490–498
35. Williams A, Duggleby W, Eby J, Cooper RD, Hallstrom LK, Holtslander L, Thomas R (2013) Hope against hope: Exploring the hopes and challenges of rural female caregivers of persons with advanced cancer. *BMC Palliative Care* 12:44
36. Perle JG, Langsam LC, Nierenberg B (2011) Controversy clarified: An updated review of clinical psychology and tele-health. *Clinical Psychology Review* 31:1247–1258
37. Suler J (2004) The online disinhibition effect. *Cyberpsychology & Behavior* 7:321–326
38. EY Asia-Pacific: Digital Nations 2016 (2017) Savvy Singapore: Decoding a digital nation.
39. Campbell M, Fitzpatrick R, Haines A, Kinmonth AL, Sandercock P, Spiegelhalter D, Tyrer P (2000) Framework for design and evaluation of complex interventions to improve health. *BMJ: British Medical Journal* 321:694
40. Lakshman R, Griffin S, Hardeman W, Schiff A, Kinmonth AL, Ong KK (2014) Using the Medical Research Council Framework for the Development and Evaluation of Complex Interventions in a Theory-Based Infant Feeding Intervention to Prevent Childhood Obesity: The Baby Milk Intervention and Trial. *Journal of Obesity*. doi: 10.1155/2014/646504
41. Chan A-W, Tetzlaff JM, Altman DG, et al (2013) SPIRIT 2013 statement: Defining standard protocol items for clinical trials. *Annals of Internal Medicine* 158:200–207
42. Neimeyer RA (2006) Bereavement and the quest for meaning: Rewriting stories of loss and grief. *Hellenic Journal of Psychology* 3:181–188
43. Toyama H, Honda A (2016) Using Narrative Approach for Anticipatory Grief among Family Caregivers at Home. *Global qualitative nursing research*. doi: 10.1177/2333393616682549
44. Kroenke K, Spitzer RL, Williams JB (2001) The PHQ–9: Validity of a Brief Depression Severity Measure. *Journal of General Internal Medicine* 16:606–613
45. Andrews G, Slade T (2001) Interpreting scores on the Kessler Psychological Distress Scale (K10). *Aust N Z J Public Health*. doi: 10.1111/j.1467–842X.2001.tb00310.x

46. Whitehead AL, Julious SA, Cooper CL, Campbell MJ (2016) Estimating the sample size for a pilot randomized trial to minimize the overall trial sample size for the external pilot and main trial for a continuous outcome variable. *Statistical Methods in Medical Research* 25:1057–1073
47. Cuijpers P, van Straten A, Bohlmeijer E, Hollon SD, Andersson G (2010) The effects of psychotherapy for adult depression are overestimated: A meta-analysis of study quality and effect size. *Psychological Medicine* 40:211–223
48. Frattaroli J (2006) Experimental disclosure and its moderators: A meta-analysis. *Psychological Bulletin* 132:823
49. Siebens HC, Tsukerman D, Adkins RH, Kahan J, Kemp B (2015) Correlates of a Single-Item Quality-of-Life Measure in People Aging with Disabilities. *American Journal of Physical Medicine & Rehabilitation* 94:1065–1074
50. Herth K (1992) Abbreviated instrument to measure hope: development and psychometric evaluation. *Journal of Advanced Nursing* 17:1251–1259
51. Graessel E, Berth H, Lichte T, Grau H (2014) Subjective caregiver burden: validity of the 10-item short version of the Burden Scale for Family Caregivers BSFC-s. *BMC Geriatrics* 14:23
52. Hogan NS, Schmidt LA (2002) Testing the Grief To Personal Growth Model Using Structural Equation Modeling. *Death Studies* 26:615–634
53. Shear KM, Jackson CT, Essock SM, Donahue SA, Felton CJ (2006) Brief Grief Questionnaire. *PsycTESTS Dataset*. doi: 10.1037/t62516–000
54. Yelvington D (2013) Bereaved parents' perceptions about their participation in an equine assisted grief-group experience. Capella University
55. Ho AHY (2013) Living and dying with dignity: An Interpretive-Systemic Framework in Hong Kong. *HKU Theses Online (HKUTO)*
56. Department of Statistics, Ministry of Trade and Industry, Republic of Singapore (2017) Population Trends. doi: ISSN 1793–2424
57. Bredle JM, Salsman JM, Debb SM, Arnold BJ, Cella D (2011) Spiritual Well-Being as a Component of Health-Related Quality of Life: The Functional Assessment of Chronic Illness Therapy- Spiritual Well-Being Scale (FACIT-Sp). *Religions* 2:77–94
58. Shear KM, Jackson CT, Essock SM, Donahue SA, Felton CJ (2006) Screening for complicated grief among Project Liberty service recipients 18 months after September 11, 2001. *Psychiatric Services* 57:1291–1297

Tables

Table 1: Findings from qualitative study on the lived experience of parental bereavement in Asia

Findings from qualitative study on the lived experience of parental bereavement in Asia

Implications for clinical work

Facing their child's impending mortality is a difficult experience which can isolate parents. Societal attitudes towards illness can make it difficult for parents to engage with their previous social networks.

Support parents in gaining a greater sense of control over their lives and strengthening resilience during the period of end-of-life caregiving through empathic support and psychoeducational resources for self-care and healthy coping.

Parents seek to understand the medical terminology associated with their child's illness and prognosis of the condition, so that they can evaluate potential risks and benefits of treatment procedures and make informed care decisions.

Empower parents to provide the best possible care to their child through exploration of resources for seeking information about illness and caregiving.

Parents desire to give their children a chance to rise above the difficulties brought on by the illness and display strength to help their child live as fully as possible.

Facilitate meaningful family experiences that allow parents and their children to move away from the drudgery of illness, suffering and caregiving and focus on building parent-child memories.

Asian parents tend to have a collaborative approach to caregiving for their sick child. They often relied on or family members, relatives and other parents of sick children for support.

Explore sources of support which participants have within their close social network and how they can be harnessed in care provision.

Table 2: NeW-I procedures for intervention and control group

Week 0	Week 1-4	Week 5	
		Intervention group	Control group
Online platform registration	Days 1, 2, 3: Participants engage in 15-30-minute writing session to be completed in 1 seating.	Participants receive their legacy document, ^[29] and have an opportunity to suggest revisions.	Participants receive a consolidated document that includes all unedited journal writings together with a brief statement of appreciation by the therapist.
Informed consent		1-hour live voice call with NeW-I therapist to provide psychosocial support and closure of therapy.	
Screening assessment		Participants prompted to complete T2 outcome assessment and qualitative written evaluation of intervention, and subsequently similar automated prompts are sent to complete T3, T4 and T5 outcome assessments.	Participants prompted to complete T2 outcome assessment, and subsequently similar automated prompts are sent to complete T3, T4 and T5 outcome assessments.
Participation confirmation (if eligible)	Days 4, 5, 6:		
Completion of baseline assessments	Therapist provides written constructive empathetic feedback.	Participation Complete.	Participation Complete.
Confirmation of the participant's identity by the research team			
Random group allocation (via the app)			
Proceed with intervention immediately or choose to postpone start date for up to 3 days			

Table 3: Content and questions for reflective writing for intervention group

	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	<p>1) Tell us a little about your child and what you love about him or her.</p> <p>2) Tell us about the challenges that you have encountered when caring for your child.</p> <p>3) What has been your biggest challenge so far?</p> <p>How have you coped with it?</p> <p>4) What are three things that have helped you cope in your caregiving journey?</p>	<p>1) How satisfied are you with the knowledge and information that you have about your child's condition?</p> <p>What has been helpful in providing you with the knowledge and information?</p> <p>2) What are some forms of support that have been helpful for you in providing quality care to your child?</p> <p>How were these forms of support helpful?</p> <p>3) What would help you to feel more competent as your child's caregiver?</p> <p>What is one thing you could do to make that difference?</p>	<p>1) Tell us about some people who have been helpful or supportive in your caregiving journey.</p> <p>How have they helped you to cope during difficult times?</p> <p>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.)</p> <p>What might make that score a little higher?</p> <p>3) What are some things that others could do for you that could further help you in your caregiving journey?</p>	<p>1) Tell us what you love best about your child.</p> <p>What quality about him/her makes you proud?</p> <p>2) What would a good day for your child look like right now?</p> <p>What makes it a good day?</p> <p>3) Tell us about an enjoyable moment with your child.</p> <p>What are some things you can do to make an enjoyable moment happen?</p>
Counselling goals	<p>1) To affirm the strengths that have helped participants to survive and thrive.</p> <p>2) To provide psychoeducation</p>	<p>1) To acknowledge participants' efforts to seek power and control over their seemingly</p>	<p>1) To reframe that they are indeed blessed to have the support of their spouse/ family and/or friends to help them to cope</p>	<p>1) To assist participants (and their children) in building meaningful and cherished</p>

about local social welfare organizations that can provide them with support.

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.

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.

memories through reflecting on achievements and fulfilment of dreams.

2) To examine ways in which participants can enhance quality of life in their child's final days.

Table 4: Content and questions for reflective writing for control group

	Week 1	Week 2	Week 3	Week 4
Objective	To engage participants in a weekly unstructured writing session which allows them to experience the therapeutic benefits of unstructured 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 has the past week 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?

Table 5: Quantitative outcome measures

Measure	# of items	Sample items	Rating scale / Factor(s)
Kemp Quality of Life Scale (KQOL)[49]	1	Taking everything in your life into account, please rate your overall quality of life?	7-point Likert scale; 1 factor
Adapted version of the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being (FACIT-Sp-12)[57]	12	I have a reason for living [meaning subscale] I have trouble feeling peace of mind [peace subscale] My child's illness has strengthened my faith or spiritual beliefs [faith subscale]	5-point; 3 factors: meaning, peace, faith
Herth Hope Index (HHI)[50]	12	I believe that each day has potential. I can see possibilities in the midst of difficulties.	4-point; 1 factor
Patient Health Questionnaire-9 (PHQ-9)[44] (also serves as a screening assessment)	9	Little interest or pleasure in doing things Feeling down, depressed, or hopeless	4-point; 1 factor
Burden Scale for Family Caregivers-Short Version (BSFC-s)[51]	10	My life satisfaction has suffered because of the care. From time to time I wish I could "run away" from the situation I am in.	4-point; 1 factor
Inventory of Social Support (ISS)[52]	5	I can express my feelings openly and honestly There is at least one person I can talk to about my feelings.	5-point; 1 factor
Adapted version of the Brief Grief Questionnaire (BGQ)[58]	5	How much are you having trouble accepting the life-threatening illness of your child? 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?	3-point; 1 factor

Figures

	Study period						
	Enrolment	Allocation	Post-allocation		Closeout		
Time point	-t ₁	0	Weeks 1 to 4	Week 5	1 month post study	3 months post study	6 months post study
Enrolment:							
Eligibility screen	X						
Informed consent	X						
Randomization		X					
Interventions:							
Online writing session			X				
Consolidated or legacy document				X			
Assessments:							
Questionnaires		X		X	X	X	X
Qualitative evaluation				X			

Figure 1

Schedule of enrollment, intervention, and assessment

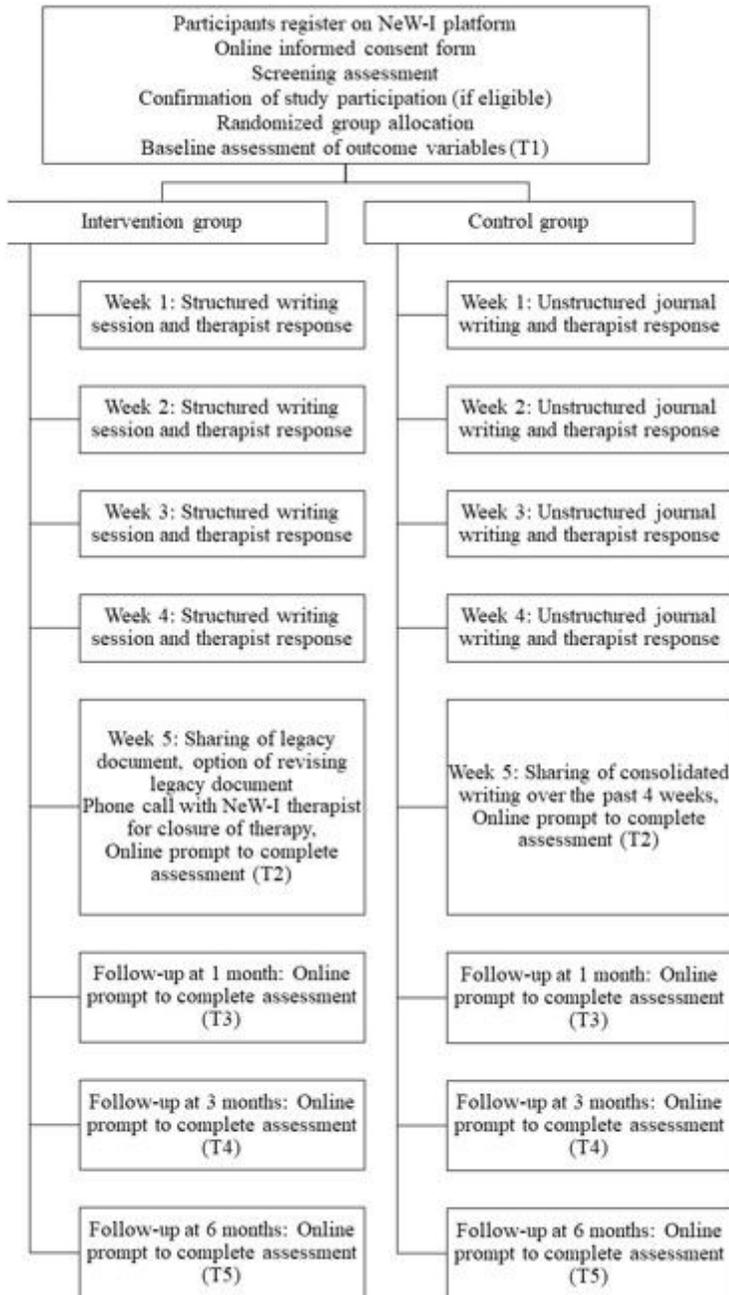


Figure 2

Detailed description of study procedures for intervention and control group

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [supplement1.docx](#)