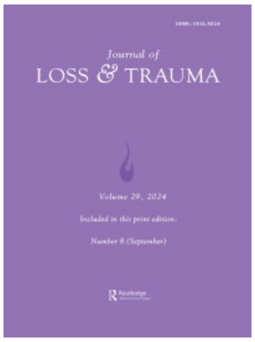

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Journal of Loss and Trauma
International Perspectives on Stress & Coping

ISSN: (Print) (Online) Journal homepage: www.tandfonline.com/journals/upil20

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To cite this article: Siobhan A. Loughnan, Ann Lancaster, Sara Crocker, Chrissie Astell, Alison Griffin, Aleena M. Wojcieszek, Frances M. Boyle, David Ellwood, Julie Dean, Dell Horey, Emily Callander, Claire Jackson, Sean Seeho, Antonia Shand & Vicki Flenady (22 Oct 2024): Living with Loss: Evaluating an Internet-Based Program for Parents Following Perinatal Death, Journal of Loss and Trauma, DOI: 10.1080/15325024.2024.2415708

To link to this article: https://doi.org/10.1080/15325024.2024.2415708

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JOURNAL OF LOSS AND TRAUMA
https://doi.org/10.1080/15325024.2024.2415708

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Living with Loss: Evaluating an Internet-Based Program for Parents Following Perinatal Death

Siobhan A. Loughnan[a], Ann Lancaster[a], Sara Crocker[a], Chrissie Astell[a], Alison Griffin[b], Aleena M. Wojcieszek[a], Frances M. Boyle[a,c], David Ellwood[a,d], Julie Dean[a,c], Dell Horey[a,e], Emily Callander[f,g], Claire Jackson[h], Sean Seeho[i], Antonia Shand[j] and Vicki Flenady[a]

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ABSTRACT

Stillbirth and neonatal death are devastating pregnancy outcomes with enduring psychosocial and emotional effects on parents and families. Families need appropriate support, yet access to services is often limited. In a randomized controlled trial, we evaluated the efficacy and acceptability of a self-guided internet-based perinatal grief program, Living with Loss (LWL), to support coping and wellbeing among bereaved parents following perinatal death. Eligible parents, largely mothers, were recruited online and randomized to the intervention arm (n = 48) or a care-as-usual (CAU) control arm (n = 47). The LWL program comprised six internet-based modules completed over 8 weeks. The primary outcome was psychological distress; secondary outcomes were perinatal grief intensity, anxiety, depression, and program satisfaction and acceptability. The LWL program reduced psychological distress at post-program compared with CAU. The program had moderate adherence rates and high program satisfaction. There were no differences in the secondary outcomes, and the effect on psychological distress was not sustained at 3-month follow-up. This study provides preliminary evidence for the utility of an internet-based perinatal grief support program to reduce psychological distress in the shorter term among bereaved parents. Further research is needed to determine how psychological distress can be minimized in the longer term, and whether self-guided internet-based

ARTICLE HISTORY
Received 1 April 2024
Accepted 4 October 2024

KEYWORDS
Stillbirth; neonatal death; perinatal loss; Internet; bereavement

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Supplemental data for this article can be accessed online at https://doi.org/10.1080/15325024.2024.2415708.

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support is effective for bereaved fathers and extended family members. Further research is also needed to investigate the effectiveness of the program in real-world settings.

Trial Registration: Australian New Zealand Clinical Trials Registry, ACTRN12621000631808, registered prospectively on 27/05/2021; https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=381231&isReview=true

Introduction

More than 3000 babies died in the perinatal period in Australia in the year 2021; three quarters were stillborn and one quarter died in the neonatal period (Australian Institute of Health & Welfare, 2023). The death of a baby during pregnancy or soon after birth is devastating for families, with enduring psychosocial and emotional effects (Ellis et al., 2016; Heazell et al., 2016). Bereavement impacts all family members. Many report feelings of guilt, anger, stigma, shame, social isolation, relationship difficulties, and disenfranchized grief (Ellis et al., 2016; Heazell et al., 2016; Pollock et al., 2021). Perinatal bereavement is also linked to an increased risk of psychological disorders including anxiety, posttraumatic stress disorder, major depressive disorder, and prolonged grief disorder (Christiansen, 2017; Heazell et al., 2016; Kishimoto et al., 2021).

The quality of care that families receive around the time their baby dies and the ongoing support provided in community settings are major contributors to immediate and long-term wellbeing (Berry et al., 2021; Helps et al., 2020). While grief, distress, and other multifaceted emotions are natural responses following perinatal death (Flenady et al., 2020), some people face significant and prolonged distress, particularly for bereavement of a baby (Aoun et al., 2015; Kersting et al., 2011). Bereaved parents and families need appropriate support, yet access to services is often limited and little is known about which types of supports are beneficial (Koopmans et al., 2013). In addition, bereaved parents face a range of social, geographical, and logistical barriers, such as lack of awareness of available support, reluctance to seek help due to perceived stigma, and long waiting periods that can limit access and engagement with support services (Harrop et al., 2020).

The rise of digital resources and internet-based interventions for grief and bereavement (Beaunoyer et al., 2020) has provided accessible and flexible alternatives to traditional forms of support, offering options with or without therapist guidance or coaching. These interventions allow for private and convenient access, fostering a greater sense of anonymity (Andrews et al., 2018; Etzelmueller et al., 2020). Such interventions may be particularly valuable to those experiencing perinatal bereavement, as many such parents hesitate to seek help and share their emotional struggles following their loss, which is often misunderstood and stigmatized within society (Pollock et al., 2020). Internet-based interventions for mental and physical health (e.g. anxiety, depression, insomnia, chronic pain, diabetes) are now well-established and used in routine care in many countries, either as stand-alone services (i.e. low-intensity support) or in conjunction with face-to-face care services (i.e. high-intensity support) (Andersson et al., 2019; Etzelmueller et al., 2020). Familiarity with digital healthcare platforms, such as telehealth, has also become more commonplace in maternity and primary care, particularly since the COVID–19 pandemic (Palmer et al., 2021).

While studies show that internet-based interventions can be as effective as face-to-face therapy (Hermes et al., 2021; Kambeitz-Ilankovic et al., 2022), evidence for their efficacy and acceptability in bereavement contexts is limited (Zuelke et al., 2021). A systematic review and meta-analysis found therapist-guided internet-based interventions for grief to be effective in reducing symptoms of grief, posttraumatic stress and depression with the largest effect sizes observed for posttraumatic stress (Zuelke et al., 2021). Overall satisfaction with this type of intervention was moderate to high. Notably, only one RCT has evaluated an internet-based intervention for parents after pregnancy loss (Kersting et al., 2013). Kersting et al. (2013) evaluated a 5-week therapist-guided program in German for parents who had experienced miscarriage, termination of pregnancy for medical reasons, or stillbirth. This structured intervention, based on treatment for posttraumatic stress disorder (PTSD), was adapted for prolonged grief and included CBT techniques such as exposure, cognitive restructuring, and social sharing. Personalized writing assignments were developed and reviewed by an online therapist for each participant. Participants who completed the intervention showed significant reductions in symptoms of grief, posttraumatic stress, and depression compared to a wait-list control group. The program also demonstrated a low attrition rate (14%), with sustained improvements observed at 3-month and 12-month follow-ups.

Further research is needed to explore how internet-based interventions can address gaps in the availability of bereavement support for parents following the death of a baby. This is especially important in Australia, where support services can be limited or non-existent in regional and rural areas, and many national support organizations have long wait lists. It is crucial to investigate whether a universal (i.e. available to all regardless of prolonged grief or posttraumatic stress symptoms) and self-guided digital support option, without online therapist involvement, is effective and acceptable for bereaved parents. Evaluating digital support services is vital, particularly considering the shift toward digital healthcare prompted by the COVID-19 pandemic.internet-based interventions

Australia's Center of Research Excellence in Stillbirth (Stillbirth CRE) led the development and evaluation of a parent-centered internet-based program called Living with Loss (LWL) to support the coping and well-being of bereaved parents following perinatal death (Loughnan et al., 2022). The present study evaluated the efficacy and acceptability of the LWL program compared with a care-as-usual (CAU) control group. We hypothesized that, compared with CAU, the LWL program would: (1) reduce symptoms of general psychological distress; (2) reduce grief intensity, anxiety and depressive symptoms, and decisional regret; and (3) be perceived as a helpful and acceptable support option. Our fourth hypothesis was that the LWL program would be cost-effective; these data will be reported separately.

Materials and methods

Design and setting

We conducted a CONSORT-EHEALTH compliant (Eysenbach, 2013) two-arm, parallel group, superiority randomized controlled trial (RCT) in Australia. Recruitment occurred between June 2021 and May 2022. Trial participation spanned 21 weeks, with three assessment timepoints: (T1) baseline; (T2) post-intervention; and (T3) 3-month follow-up. The trial was registered with the Australian New Zealand Clinical Trials Registry (ACTRN12621000631808) and protocol published in 2022 (Loughnan et al., 2022). The study was approved by the Mater Misericordiae Ltd Human Research Ethics Committee (HREC/MML/70343).

Intervention

The LWL program was designed to address the cognitive, behavioral, emotional, relational and motivational impacts of bereavement (Schut & Stroebe, 2010), normalizing and validating individual grief experiences while avoiding the pathologization of grief. Developed by clinicians, researchers, parent support and advocacy organizations, and bereaved parents, the program incorporated specialized knowledge of perinatal bereavement care, mental health, and lived experiences of perinatal loss. The development process emphasized co-design principles, engaging end-users and lay perspectives.

Qualitative interviews with parents and healthcare professionals identified barriers, enablers, and preferences for internet-based bereavement support. The program included six modules covering topics highlighted by bereaved parents and healthcare professionals as important (Table 1) (Boyle et al., 2020; Shakespeare et al., 2020). In the absence of a Core Outcome Set (COS) for stillbirth and neonatal death, the six modules were aligned with the COS for coping and wellbeing in adult bereavement within palliative care settings. Content incorporated cognitive and behavioral approaches including mindfulness and compassion-focused therapy. For more detail, refer to the trial protocol (Loughnan et al., 2022).

The program was designed to be flexible, self-paced, and adaptable to parents' needs in both the short and long term. Each module, designed to be stand-alone, included illustrated fictional parent stories, information addressing key topics and strategies, and 1–2 exercises to consolidate key points, including a grounding mindfulness or compassion-focused mediation. The program was delivered via a custom-built online learning system viewable on any computer, tablet, or smartphone with Internet connection. For more detail, please refer to the trial protocol (Loughnan et al., 2022).

Participants and recruitment

Participants were recruited primarily by social media advertising and word of mouth (e.g. via bereavement midwives). Inclusion criteria were: experienced a stillbirth (defined as a baby of 20 or more weeks' gestation who dies before birth) or neonatal death (defined as a baby who dies after birth and within 28 days) in the past 2 years; aged 18 years and older;

Table 1. The Living with Loss program description.

Module description
Module 1: Understanding Grief. Introduces the structure and design of the program. This module aims to support parents in understanding perinatal grief and loss (including co-occurring mental health considerations such as anxiety, depression, and trauma). Strategies such as mindfulness meditation and activity planning to support coping with the behavioral, motivational, and physical aspects of bereavement (e.g. tension, sleep quality) are provided.
Module 2: Managing Intense Feelings. Focuses on understanding the emotional impact of grief and loss (e.g. overwhelming feelings of grief, anger, blame, regret) and aims to improve coping with negative and challenging emotional states. The module includes mindfulness and self-compassion strategies and activities (e.g. exploring creative practices such as self-compassion through writing).
Module 3: Balancing Thoughts. Focuses on understanding the potential cognitive impact of grief and loss, such as overwhelming thoughts of grief, to improve coping with negative or challenging thoughts. Mindfulness meditation and grounding activities are included to support management of worry and anxiety.
Module 4: Facing Hard Situations and Conversations. Focuses on understanding how grief affects social and psychological functioning and uses practical strategies including mindfulness and self-compassion to manage worry, repetitive thoughts, and reengagement with work and social activities. A focus on identifying and planning for difficult situations and times ahead (e.g. memories, anniversaries) is also included.
Module 5: Strengthening Relationships and Communication. Focuses on understanding the impact of grief on relationships, including differences between partners and family members in the way grief is experienced. Provides strategies for enhancing communication and connectedness with others such as identifying types of support (practical, emotional), setting boundaries, and practising mindfulness and self-compassion.
Module 6: The Future. Acts as the concluding module of the program and focuses on understanding how grief changes over time. Explores ways to find balance and meaning in grief including renewed sense of purpose in life. Includes mindfulness and self-compassion-focused strategies and ways to plan for the future including accessing emotional support when needed.

living in Australia; access to a device with Internet connection; fluent in English language; willingness to provide personal contact details; and informed consent. Exclusion criteria were: current pregnancy; pregnancy loss was prior to 20 weeks' gestation; experienced a stillbirth or neonatal death less than 8 weeks ago or more than 2 years ago; diagnosis of psychosis, bipolar disorder, or schizophrenia within the last 2 years; and/or severe symptoms of distress, depression, and/or suicidal ideation indicating a severe mental health condition.

Enrollment, screening, and baseline assessment

All applicants completed a registration form via the LWL website which included eligibility questions, informed consent, and personal account details. Applicants who did not meet study criteria were notified on-screen and provided with information on parent support organizations. Applicants then proceeded to the baseline assessment (T1) which included screening for severe symptoms of distress, depression and/or suicidal ideation; indicated by a score of 30 or greater on the Kessler Psychological Distress Scale [K10] (Kessler et al., 2002) and/or a score of 14 or greater on the Edinburgh Postnatal Depression Scale [EPDS] (Cox et al., 1987) and/or a score of 1, 2, or 3 on Item 10 of the EPDS. Consistent with most efficacy studies of internet-based mental health interventions, individuals who screened positive received a telephone interview (risk assessment) to assess whether inclusion in an RCT would provide sufficient support to the applicant based on their individual circumstances. Applicants deemed unsuitable for the study were excluded and referred to more appropriate support services. Those deemed suitable were instructed to log back into their account to complete the T1 assessment.

Randomization and group allocation

Following completion of T1, participants were allocated to the LWL or CAU group using 1:1 ratio random permuted block randomization (block sizes of 2, 4, 6). Participants were stratified by their relationship to baby and distress severity at baseline (low vs moderate-to-high distress). Following allocation, participants were notified on-screen and given instructions for their group. Participants and research personnel were not involved in randomization sequencing nor were they blinded to group allocation.

Procedure

Throughout the study period, participants received two automated email notifications to login to their participant portal to complete each primary timepoint as they became available. If participants had not completed the timepoint, a follow-up phone call was provided. After 2 weeks, participants were automatically moved into the next phase and that timepoint was marked as not completed. Participants in both study arms were able to access their usual care or support during the 21-week trial period. Contact between participants and research personnel occurred in response to participant request for technical support or was initiated by the trial clinician for safety monitoring.

LWL group

Once T1 was completed, participants were provided with immediate access to the LWL program via their participant portal. Parents were asked to complete up to six modules over the 8-week intervention period. Participants were required to complete the introductory Module 1 before remaining modules became available. Modules 2–6 could be completed in any order and timeframe, and there was no requirement for participants to complete all 6 modules. All participants were encouraged, but not forced, to complete Module 6 last as a conclusion to the program. After the 8-week period, participants were automatically moved from the active intervention period to the post-program phase to complete T2 assessments.

CAU group

Once T1 was completed, participants were sent an automated email to login to their participant portal when subsequent assessments became available at Week 9 (T2) and Week 21 (T3). At completion of T3, participants were notified that the study had concluded and were provided access to the LWL program.

Safety monitoring

Participant progress was monitored throughout the study by the trial clinician (AL), a registered psychologist in Australia with expertise in perinatal mental health. If severe symptoms of distress (i.e., total score ≥30 on the K10), depression (i.e., total score ≥13 on the EPDS), or thoughts of self-harm (i.e., item 10 on the EPDS, item 8 on the PGS-SF) were indicated at each primary timepoint, and/or during weekly assessments for participants in the intervention group, an automated notification email was sent to both the participant and the trial clinician. This email encouraged participants to seek support from their personal network (e.g., partner, family) and healthcare professionals (e.g., General Practitioner). If feeling unsafe, participants were advised to contact emergency or crisis support services. The trial clinician then contacted participants within 72 hours to conduct a telephone risk assessment and determine if the study provided adequate support. Additional assistance in finding appropriate support and clinical care was provided as needed.

Measures

Primary outcome

Psychological distress. Symptoms of nonspecific psychological distress were assessed using the Kessler Psychological Distress 10-item scale (K10) (Kessler et al., 2002) at T1, T2 and T3. Total scores range from 10 (indicating no distress) to 50 (indicating severe distress) (Andrews & Slade, 2001). For safety monitoring, participants in the intervention arm completed the K10 once per week or each time they logged in to their portal. Internal reliabilities for the current sample at each timepoint were acceptable (Cronbach's α = .89, .84, .84). For more information on all measures, see the trial protocol (Loughnan et al., 2022).

Secondary outcomes

Perinatal grief intensity. The Perinatal Grief Scale—Short Form (PGS-SF) (Potvin et al., 1989) assessed behavioral and affective symptoms of grief specific to perinatal loss at T1, T2 and T3. The PGS-SF consists of 33 items under three subscales: active grief, difficulty coping, and despair. Total scores range from 33 to 165, with a score over 91 indicative of greater vulnerability to the loss (Setubal et al., 2021) (current sample α for total scale = .90, .93, .93; subscale α's ranged from .71 − .89).

Anxiety. The Generalized Anxiety Disorder Scale, 7-Item (GAD-7) (Spitzer et al., 2006) assessed generalized anxiety symptoms at T1, T2 and T3. Total scores range from 0 to 21, with a score of 8 or more indicative of a likely anxiety disorder (current sample α = .85, .85, .86).

Depression. The Edinburgh Postnatal Depression Scale (EPDS) (Cox et al., 1987) assessed postnatal depression at T1, T2 and T3. The EPDS consists of 10 items with total scores ranging from 0 to 33. A total score of 12 or greater indicates possible depression (current sample α = .84, .85, .86).

Decisional regret about a healthcare decision. The Decisional Regret Scale (DRS) (Brehaut et al., 2003) assessed whether participants were experiencing distress or remorse after a health care decision at T1, T2 and T3. In this study, such decisions related to the death of their baby. Total scores range from 0 to 100, with higher scores indicating high regret (Brehaut et al., 2003) (current sample α = .85, .85, .87).

Prolonged grief. The Brief Grief Questionnaire (BGQ) (Shear et al., 2006) assessed symptoms of prolonged grief at T1 only. A total score of five or more indicates prolonged grief symptomology (Ito et al., 2012) (current sample α = .66).

Resilience. The Resilience Scale (RS-25) (Wagnild & Young, 1993) assessed participants' personal resilience at T1 only. Each item is scored from 1 to 7 with total scores ranging from 25 to 175. A total score below 115 is indicative of low resilience, while scores above 165 are indicative of greater resilience (current sample α = .88).

Support and/or other treatment. Participants' use of other supports and/or treatments, such as informal (e.g. family, spiritual advisor) and formal (e.g. mental health professional), was assessed at T1, T2, and T3.

Acceptability outcomes—LWL group only

Perceived expectancy of benefit was assessed by two questions rated on a 5-point scale at completion of Module 1. Program engagement and completion adherence were assessed by the mean number of modules sessions completed by each participant.

Module satisfaction was assessed at the end of each module via five statements rated on a 5-point Likert scale (from strongly agree to strongly disagree). Program satisfaction and experience was assessed at the end of the intervention period (T2). Twelve questions assessed participant's overall experience and included a range of open-ended, brief rating scales, and multiple-choice responses. All acceptability measures were developed specifically for this study and were based on similar internet-based intervention satisfaction measures (e.g. treatment satisfaction questionnaire; Cox et al., 1994). For more detail, please refer to the trial protocol (Loughnan et al., 2022).

Survey completion

For T2 and T3, participants were categorized as completed if they completed the primary outcome (K10).

Analyses

Data were analyzed using Stata v17.0 (Stata Corp, College Station, TX). Baseline characteristics and psychometric scales at T1 were compared between those who completed T3 (3-month follow-up) and those who did not using Pearson's chi-square test or Fisher's exact test for categorical data and the two-sample t-test for continuous data. The primary outcome was K10; additional outcomes were GAD-7, EPDS, DRS, PGS-SF and its three subscales. Analysis was intention to treat. Mixed effects linear regression using restricted maximum likelihood estimation—treating participant ID as a random effect and study group (LWL or CAU), time, and an interaction between treatment group and time, as fixed effects—was used to estimate the effect of treatment group on the outcomes. Sensitivity analysis excluding males (partners) was completed for the primary outcome. P-values <0.05 were considered significant.

Results

A total of 99 parents enrolled in the study and 98 started T1. Of these, 10 received an enrollment telephone interview (risk assessment) following self-reported severe symptoms of distress with one applicant excluded and referred to support services. One participant was withdrawn at request, and two did not complete all T1 questionnaires. For safety monitoring purposes, 166 risk assessment interviews were conducted across 66 participants throughout the study period. One participant was excluded for current severe mental health condition. A total of 95 participants completed T1 and were randomly allocated to the LWL group (n = 48) or CAU group (n = 47) and included in baseline analyses (Figure 1).

Baseline characteristics

Participant characteristics are shown in Table 2. Most participants were mothers (94%) with just over half having experienced a stillbirth within the preceding 12 months. Most participants were aged between 30 and 44 years (76%), were born in Australia (74%), resided in major cities (71%), lived with a partner (93%), had a university degree (85%), and were employed full-time or part-time (72%). Two (2%) participants identified as Aboriginal or Torres Strait Islander. Almost half (44–49%) reported a history of anxiety or depressive disorder diagnosis and/or treatment, 21% reported taking medication, and 43% reported receiving professional therapy for their mental health. The most common source of support at baseline was family or friends (92%) (Supplementary Table 1).

More than half of participants (69%) met the clinical cutoff score on the K10, with 26% experiencing severe levels of psychological distress (Table 3). Most (62%) also exceeded the clinical cutoff score on the perinatal grief scale, and 64% met the clinical cutoff score on a prolonged grief screening scale. Participants self-reported significant symptoms of depression (M = 13.3) and minimal symptoms of anxiety (M = 6.1).

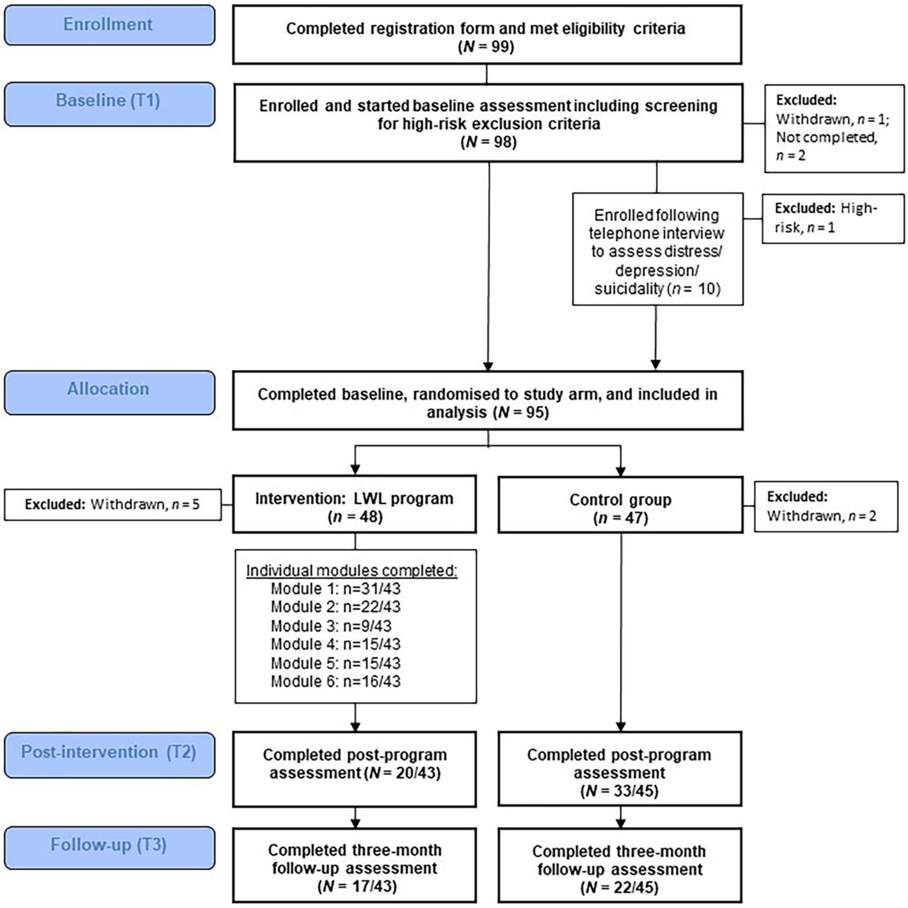

Figure 1. Participant flow diagram.

Data return and intervention completion

Of the 95 participants randomized and eligible for analyses, seven withdrew during the trial. Of the 43 parents in the LWL group, 30% completed most of the program (5–6 modules), 14% completed 3–4 modules, 28% completed 1–2, with a further 28% not commencing. Attrition was moderate across the timepoints. At T2 assessment, data were provided by a higher percentage of participants in the CAU group (73%) than the LWL group (47%) ($\chi^2(1)$ = 6.6, p = 0.01), while T3 data were provided by a similar percentage of participants in the CAU group (49%) and the LWL group (40%) ($\chi^2(1)$ =0.78, p = 0.38). There were no differences in baseline characteristics and psychometric scales between participants who completed the primary outcome (K10) at T3 and those who did not (Supplementary Table 2).

Table 2. Demographic and obstetric participant characteristics at baseline.

	Total	CAU	LWL
	N = 95	N = 47	N = 48
Relationship to baby			
Mother	89 (94%)	44 (94%)	45 (94%)
Father/partner	6 (6%)	3 (6%)	3 (6%)
Age group (years)			
Less than 25 years	4 (4%)	2 (4%)	2 (4%)
25–29 years	18 (19%)	9 (19%)	9 (19%)
30–34 years	37 (39%)	15 (32%)	22 (46%)
35–44 years	35 (37%)	21 (45%)	14 (29%)
More than 44 years	1 (1%)	0 (0%)	1 (2%)
Type of loss			
Stillbirth	41 (55%)	20 (51%)	21 (58%)
Termination of pregnancy	14 (19%)	9 (23%)	5 (14%)
Neonatal death	20 (27%)	10 (26%)	10 (28%)
Time since loss (months, median (IQR))	9 (4–15)	10 (5–15)	8 (4–11)
Less than three months	12 (16%)	4 (11%)	8 (22%)
3–6 months	13 (18%)	7 (19%)	6 (17%)
7–12 months	28 (38%)	14 (38%)	14 (39%)
13–18 months	8 (11%)	5 (14%)	3 (8%)
19–24 months	7 (10%)	5 (14%)	2 (6%)
More than 24 months	5 (7%)	2 (5%)	3 (8%)
Gestation at loss (weeks, median (IQR))	30 (23–36)	27 (23–37)	32 (23–36)
History of perinatal loss	67 (71%)	39 (83%)	28 (58%)
Quality of follow-up care following loss (median (IQR); possible range 1 [very poor] – 10 [excellent])	7 (5–9)	7 (5–9)	7 (3–9)
Rurality[a]			
Major cities	67 (71%)	33 (70%)	34 (71%)
Inner regional	20 (21%)	10 (21%)	10 (21%)
Outer regional	7 (7%)	3 (6%)	4 (8%)
Very remote	1 (1%)	1 (2%)	0 (0%)
Country of birth			
Australia	70 (74%)	34 (72%)	36 (75%)
Other	25 (26%)	13 (28%)	12 (25%)
Aboriginal or Torres Strait Islander status	2 (2%)	1 (2%)	1 (2%)
First language is English	86 (93%)	45 (98%)	41 (89%)
Relationship status			
Living together	87 (93%)	43 (91%)	44 (94%)
Living apart	4 (4%)	3 (6%)	1 (2%)
Single or separated	3 (3%)	1 (2%)	2 (4%)
Highest level of education			
Postgraduate	27 (28%)	12 (26%)	15 (31%)
Undergraduate	54 (57%)	23 (49%)	31 (65%)
Secondary	13 (14%)	11 (23%)	2 (4%)
Prefer not to say	1 (1%)	1 (2%)	0 (0%)
Employment status			
Employed full time	41 (43%)	22 (47%)	19 (40%)
Employed part time	28 (29%)	11 (23%)	17 (35%)
On leave	17 (18%)	9 (19%)	8 (17%)
Student (full time)	2 (2%)	2 (4%)	0 (0%)
Not employed	7 (7%)	3 (6%)	4 (8%)
History of mental health diagnosis and/or treatment			
Anxiety	46 (49%)	23 (49%)	23 (49%)
Depression	41 (44%)	23 (49%)	18 (38%)
Posttraumatic stress	10 (11%)	5 (11%)	5 (11%)
Other (e.g. eating disorder; bipolar disorder)	9 (10%)	2 (4%)	7 (15%)
None (of the listed conditions)	39 (41%)	20 (43%)	19 (40%)
Currently taking prescribed medication(s) for mental health	20 (21%)	8 (17%)	12 (26%)
Currently receiving mental health therapy with a health professional	40 (43%)	20 (43%)	20 (43%)

Note. For demographics, variable data were not available for: Type of loss (n = 20); Time since loss (n = 22); Gestation at loss (n = 25); First pregnancy (n = 1); Quality of follow-up care (n = 1); First language is English (n = 3); History of mental health diagnosis and/or treatment (n = 1–2); Medications or therapy for mental health conditions (n = 1); Referral (n = 26).

[a] Rurality based on the 2016 Australian Statistical Geography Standard (ASGS) remoteness areas); no participants resided in remote Australia.

Table 3. Psychometric scales at baseline.

	Total	CAU	LWL
	N = 95	N = 47	N = 48
Psychological distress (K10), mean (SD)	23.9 (7.4)	23.9 (7.7)	23.9 (7.2)
Nonclinical (0–19)	29 (31%)	15 (32%)	14 (29%)
Minimal distress (0–19)	29 (31%)	15 (32%)	14 (29%)
Clinical (20–50)	66 (69%)	32 (68%)	34 (71%)
Mild distress (20–24)	23 (24%)	10 (21%)	13 (27%)
Moderate distress (25–29)	18 (19%)	11 (23%)	7 (15%)
Severe distress (30–50)	25 (26%)	11 (23%)	14 (29%)
Perinatal grief intensity (PGS), mean (SD)	94.4 (16.6)	92.1 (17.5)	96.6 (15.7)
Nonclinical (33–90)	34 (38%)	20 (45%)	14 (31%)
Clinical (91–165)	55 (62%)	24 (55%)	31 (69%)
PGS subscale: Active grief, mean (SD)	37.9 (5.4)	37.1 (5.9)	38.7 (4.7)
Low (11–33)	19 (21%)	11 (25%)	8 (18%)
High (34–55)	70 (79%)	33 (75%)	37 (82%)
PGS subscale: Difficulty coping, mean (SD)	30.5 (7.1)	30.0 (7.4)	31.0 (6.9)
Low (11–29)	38 (43%)	20 (45%)	18 (40%)
High (30–55)	51 (57%)	24 (55%)	27 (60%)
PGS subscale: Despair, mean (SD)	26.0 (6.6)	25.0 (6.5)	26.9 (6.5)
Low (11–26)	49 (55%)	29 (66%)	20 (44%)
High (27–55)	40 (45%)	15 (34%)	25 (56%)
Perinatal depression (EPDS), mean (SD)	13.3 (4.9)	13.6 (4.9)	13.0 (4.9)
Nonclinical (0–12)	39 (41%)	20 (43%)	19 (40%)
Clinical (13–30)	56 (59%)	27 (57%)	29 (60%)
Generalized anxiety (GAD-7), mean (SD)	6.1 (4.3)	5.4 (3.4)	6.8 (4.9)
Nonclinical (0–9)	74 (83%)	39 (89%)	35 (78%)
Clinical (10–21)	15 (17%)	5 (11%)	10 (22%)
Decisional regret (DRS), mean (SD)	31.4 (20.7)	33.2 (18.9)	29.7 (22.3)
Prolonged grief (BGQ), mean (SD)[a]	4.1 (2.1)	4.1 (2.2)	4.2 (2.0)
Nonclinical (0–3)	24 (36%)	14 (40%)	10 (32%)
Clinical (4–10)	42 (64%)	21 (60%)	21 (68%)
Resilience (RSA), mean (SD)	129.9 (17.4)	131.6 (16.0)	128.2 (18.6)

Note. Results presented as mean (standard deviation) when scales treated as continuous and number (%) when treated as categorical. K10 = Kessler Psychological Distress Scale (possible range 10–50, actual range 10–40); PGS = Perinatal Grief Scale (possible range 33–165, actual range 49–134); GAD-7 = Generalized Anxiety Disorder Scale (possible range 0–21, actual range 0–21); EPDS = Edinburgh Postnatal Depression Scale (possible range 0–30, actual range 1–23); BGQ = Brief Grief Questionnaire (possible range 0–10, actual range 0–9); RS = The Resilience Scale (possible range 25–175, actual range 86–168); DRS = Decisional Regret Scale (possible range 0–100, actual range 0–90). For psychometric scales, variable data not available for: BGQ (n = 29), DRS (n = 6), GAD-7 (n = 6), PGS (n = 7), RSA (n = 5).

[a] BGQ calculated only for participants 7 months or more post-loss (n = 66) to align with screening criteria for prolonged grief disorder (i.e. greater than 6 months).

Effects of the LWL program

Table 4 presents the estimated marginal means and linear mixed model results of participants' symptom severity at each timepoint.

Symptoms of general psychological distress

There was a reduction in psychological distress between T1 and T2, and between T1 and T3 for both the CAU group and LWL group. There was a significant group by time interaction ($p = 0.016$) for the primary outcome (K10), indicating the K10 trajectory was different for each group. There was a difference between groups at T2, but this difference was no longer present at T3. Results were similar when sensitivity analyses excluding

Table 4. Estimated marginal means for the intervention arm (LWL group) and control arm (CAU group) on primary and secondary outcome measures, and within- and between-group differences at post-treatment and three-month follow-up.

	Estimated marginal means (SE)						Within-group difference (95%CI), p-value				Between- group difference (95%CI), p-value			
	Baseline	*N*	Post-program	*N*	Follow-up	*N*	Baseline to post-program (T2)		Baseline to follow-up (T3)		Post-program (T2)		Follow-up (T3)	
Psychological distress (K10)														
Control	23.87 (0.94)	47	21.60 (1.07)	33	20.44 (1.23)	22	**−2.27 (−4.29, −0.26)**	**0.027**	**−3.44 (−5.79, −1.09)**	**0.004**	**−4.66 (−7.96, −1.35)**	**0.006**	−2.17 (−5.81, 1.46)	0.241
Intervention	23.92 (0.93)	48	16.94 (1.30)	20	18.26 (1.39)	17	**−6.97 (−9.46, −4.48)**	**<0.001**	**−5.66 (−8.31, −3.00)**	**<0.001**				
Perinatal grief intensity (PGS)														
Control	92.12 (2.66)	44	94.55 (2.86)	33	93.38 (3.07)	25	2.43 (−2.12, 6.97)	0.295	1.26 (−3.76, 6.27)	0.624	2.64 (−6.00, 11.28)	0.549	−3.42 (−12.58, 5.73)	0.464
Intervention	96.62 (2.64)	48	97.19 (3.35)	20	89.96 (3.52)	17	0.57 (−5.08, 6.22)	0.843	**−6.67 (−12.69, −0.64)**	**0.03**				
PGS subscale: Active grief														
Control	37.07 (0.82)	44	37.08 (0.91)	33	36.83 (0.99)	25	0.01 (−1.64, 1.67)	0.988	−0.24 (−2.06, 1.59)	0.798	0.84 (−1.95, 3.63)	0.553	−1.12 (−4.12, 1.87)	0.463
Intervention	38.71 (0.82)	45	37.92 (1.10)	20	35.71 (1.16)	17	−0.79 (−2.83, 1.25)	0.448	−3.00 (−5.18, −0.83)	0.007				
PGS subscale: Difficulty coping														
Control	29.98 (1.12)	44	30.60 (1.21)	33	29.97 (1.29)	25	0.62 (−1.27, 2.52)	0.52	−0.01 (−2.10, 2.08)	0.992	1.04 (−2.60, 4.67)	0.576	−0.79 (−4.64, 3.07)	0.689
Intervention	31.00 (1.12)	45	31.64 (1.41)	20	29.18 (1.48)	17	0.64 (−1.72, 2.99)	0.596	−1.82 (−4.33, 0.69)	0.156				
PGS subscale: Despair														
Control	25.08 (1.05)	44	26.86 (1.12)	33	26.62 (1.20)	25	1.78 (0.03, 3.52)	0.046	1.54 (−0.39, 3.46)	0.118	0.79 (−2.59, 4.18)	0.645	−1.55 (−5.13, 2.02)	0.395
Intervention	26.91 (1.04)	45	27.65 (1.31)	20	25.06 (1.37)	17	0.74 (−1.43, 2.91)	0.505	−1.85 (−4.16, 0.47)	0.118				
Anxiety (GAD-7)														
Control	5.41 (0.63)	44	5.66 (0.70)	33	5.20 (0.76)	25	0.25 (−1.02, 1.52)	0.699	−0.20 (−1.61, 1.20)	0.775	1.15 (−1.00, 3.30)	0.294	0.22 (−2.08, 2.53)	0.849
Intervention	6.82 (0.63)	48	6.81 (0.85)	20	5.43 (0.90)	17	−0.01 (−1.58, 1.55)	0.988	−1.39 (−3.07, 0.28)	0.102				
Depression (EPDS)														
Control	13.55 (0.69)	47	10.91 (0.79)	33	9.80 (0.92)	22	**−2.64 (−4.16, −1.13)**	**0.001**	**−3.76 (−5.53, −1.99)**	<0.001	−0.47 (−2.95, 2.00)	0.708	−1.32 (−4.02, 1.38)	0.339
Intervention	12.96 (0.68)	48	10.44 (0.99)	19	8.48 (1.03)	17	**−2.52 (−4.43, −0.61)**	**0.01**	**−4.48 (−6.48, −2.48)**	<0.001				
Decisional regret (DRS)														
Control	33.48 (3.18)	44	33.22 (3.37)	33	32.36 (3.56)	25	−0.26 (-4.96, 4.43)	0.912	−1.12 (6.30, 4.05)	0.671	−2.08 (12.08, 7.92)	0.683	−2.51 (12.99, 7.97)	0.639
Intervention	29.67 (3.16)	48	31.14 (3.83)	20	29.85 (3.99)	17	1.47 (-4.39, 7.33)	0.623	0.18 (6.06, 6.43)	0.954				

Notes. Negative scores indicate symptom improvement; SE = standard error; CI: confidence interval; Variable data missing for one participant at post-program on EPDS; three participants at follow-up for K10 and EPDS. Bold values indicate statistical significance.

fathers (LWL: n = 3; CAU: n = 3) were completed for the primary outcome (interaction: p = 0.043; data available on request).

Grief intensity, anxiety and depressive symptoms, and decisional regret

There was a reduction in depression between T1 and T2 and between T1 and T3 for both the CAU group and LWL group. For perinatal grief intensity, there was a within-group difference between T1 and T3 for the LWL group only (Table 4; Supplementary Figure 1). There were no significant group by time interactions for the secondary outcomes (Table 4).

For within-group differences, these data indicate that psychological distress and depression lessened over the course of the trial and at follow-up for both the LWL and CAU groups, while perinatal grief intensity lessened between baseline and follow-up only for the LWL group. For between-group differences, participants in the LWL group had lower psychological distress than participants in the CAU group at post-intervention, but the difference was no longer present at 3-month follow-up. There were no other differences between the LWL and CAU groups following the intervention or at follow-up.

Perceptions of the LWL program

Expectancy of benefit

At completion of Module 1, 29 of 48 participants (60%) completed a credibility and expectancy questionnaire. Of these 29 participants, most reported that the information and modules of the LWL program would be very useful (45%) or somewhat useful (45%). Most reported that the program was expected to be very beneficial (48%) or somewhat beneficial (45%) and reported no concerns about the program (69%).

Time spent on modules

Module completion time varied. The median time spent ranged from 10 minutes (e.g. Module 3: median[IQR] = 10.0 [11.0–33.0], R = 1–61) to 30 minutes (e.g. Module 1: median[IQR] = 30.5 [14.0–41.5], R = 1–68).

Satisfaction

At post-program, 21 of 48 participants (44%) completed the satisfaction questionnaire. Of these 21 participants, most rated their experience of the LWL program as excellent (29%) or satisfactory (52%); two (10%) reported that the program was unsatisfactory. Most reported that the strategies in the program were very helpful (n = 7/20, 35%) or helpful (n = 12/20, 60%) and that the parent character stories were very helpful (29%) or helpful

(57%) in understanding the program content. For the end of module satisfaction questions, 29 surveys were completed by 11 of 48 participants (M1: n = 10, M2: n = 5; M3: n = 1, M4: n = 4, M5: n = 4, M6: n = 5). Of these participants, most agreed that each module was helpful (80–100%), the information was useful (95–100%), activities/strategies were useful (95–100%), topics and themes were useful (95–100%), and easy to complete in an online format (95–100%). No participants reported that the module(s) were unhelpful, not useful, or hard to complete in the online format.

Nineteen participants responded to questions about whether they would recommend and refer others to the LWL program. Of these, most were very likely (26%) or likely (47%) to recommend LWL to their healthcare professional (e.g. General Practitioner [GP]) or a bereaved parent following perinatal loss. Most (95%) had not discussed completing the program with their GP prior to starting, and most (68%) reported that they would prefer not to have had their GP or healthcare professional involved in completing the program, with 21% unsure.

Sources of support and contact with research team

At T2 and T3, both groups reported the most common source of help and support received during the RCT was family or friends (T2: 87%; T3: 96%) (Supplementary Table 1). Participants in both groups also reported internet-based support (e.g. discussion forums/groups) and their GP as common sources of support.

Over the course of the RCT, 89% of participants (LWL group: 94%; CAU group: 85%) received email and/or telephone contact with the research team for technical support or safety monitoring.

Discussion

The LWL group had lower psychological distress post-intervention when compared with CAU, however the effect was not sustained at 3-month follow-up. It is unclear whether participants in the LWL group continued to engage with the strategies in-between intervention completion and follow-up; this may partly explain the lack of a sustained reduction in distress. Grief is a natural, adaptive reaction to bereavement and loss-related distress will typically reduce over time (Tseng et al., 2017), as was observed for both groups. Given more than half of participants self-reported moderate-to-high psychological distress and difficulty coping at baseline, it is promising that a flexible, self-guided program produced significant and earlier reductions in distress compared with CAU. Our findings also highlight the importance of screening for distress to ensure appropriate support referrals and networks are activated.

Secondary outcomes were comparable between the LWL and CAU groups at post-intervention and follow-up. These findings may be partly explained by the program's self-guided nature. A previous evaluation of two internet-based programs for perinatal anxiety and depression in routine care found that, compared with a self-guided approach, those who received clinician guidance reported greater improvements in outcomes (Mahoney et al., 2023). Our moderate adherence rates may also be attributable to the LWL program's flexible, autonomous approach. While this approach enabled participants to prioritize modules based on their immediate needs, it is possible that a more structured approach—such as completing lessons sequentially within a designated timeframe and with frequent reminders or therapist support—would have enhanced program adherence, as shown previously (Loughnan et al., 2019; Milgrom et al., 2016). Indeed, Kersting et al. (2013) showed that, compared with a wait-list control group, a structured, therapist-guided internet-based intervention reduced symptoms of PTSD, prolonged grief, and general psychopathology at post-intervention with reductions maintained at 3- and 12-month follow-ups. The same study demonstrated low attrition rates (14%). Importantly, our program was designed and evaluated as a universal self-guided support option with the aim to introduce parents to evidence-based psychotherapeutic techniques to manage the impacts of perinatal grief and utilized a range of cognitive and behavioral approaches such as mindfulness, acceptance and commitment therapy, and self-compassion therapy. In contrast to the program developed by Kersting et al. (2013), our program was not a treatment program for prolonged grief or posttraumatic stress symptoms and was not adapted from a manualized treatment protocol for PTSD. Given our program was co-developed with a range of stakeholders and end-users, it was promising that satisfaction with the LWL program was high, with most participants reporting that the content was useful and should be recommended to others. Furthermore, participants reported the program effectively addressed their needs, enabling them to engage at their own pace and depth of involvement.

Scaling up and increasing the quality and availability of diverse bereavement support options are priorities identified in the National Stillbirth Action and Implementation Plan (Commonwealth of Australia, 2020) and Care Around Stillbirth and Neonatal Death Clinical Practice Guideline (NHMRC Centre of Research Excellence in Stillbirth & Perinatal Society of Australia & New Zealand, 2024). Like LWL, self-directed interventions that require no specialist clinician support or training can potentially be safely and effectively integrated into routine care within a range of blended or stepped care (Newby et al., 2021) models (e.g. as a stand-alone intervention or adjunct to face-to-face therapy). This could enable parents to access professional resources and clinical support earlier, particularly when experiencing severe distress, prolonged grief, or comorbid conditions, and when faced with long wait times for professional support. Further advantages of self-directed programs include reduced cost and increased accessibility, including to rural and remote populations.

Limitations and future research

Findings are limited by a small sample size. The study was powered to detect moderate to large differences, but not small differences between groups, and there was moderate attrition across trial timepoints. Only a minority of participants completed most of the program (5–6 modules). Lower completion rates are predictable for self-guided programs (as discussed earlier), but we were unable to assess the minimum number of completed modules required to produce a benefit. Future studies should be adequately powered to detect effects against usual care control conditions, such as comparing internet-based support with an active control group (e.g. self-help, psychoeducation) and should describe the components of usual care that contribute to improved outcomes. Additionally, while follow-up assessment was completed by a similar proportion of participants in each group, fewer LWL participants provided data post-assessment when compared with CAU participants. It is possible that participants in the intervention group who did not gain a benefit from the program were less likely to complete modules and study assessments, which may have influenced results.

As there is no standardized measure of distress for perinatal grief and bereavement, the primary outcome was a validated measure of general distress in the general adult population. We are therefore unable to discriminate between clinically significant distress that may necessitate professional support and natural grief reactions which do not (Zisook & Shear, 2009). As only six fathers participated in this study, it is unclear whether this type of support benefits bereaved men. Obst and colleagues have highlighted the importance of responding to men’s unique needs with tailored bereavement support resources (Obst et al., 2020). Although comparable to other self-guided internet-based programs (Loughnan et al., 2019), only 29% of participants resided in regional or rural Australia, and our sample overrepresented socially advantaged bereaved parents with a higher education.

Future research should explore the efficacy of internet-based programs in overcoming differential access to support based on geographical location, cultural and ethnic background, socioeconomic status, health literacy, and other intersecting factors. Finally, our study excluded parents who were within 8 weeks of experiencing perinatal death; future research may investigate whether similar programs are beneficial to parents immediately following their loss.

Conclusion

This study provides preliminary evidence for the short-term efficacy of an internet-based intervention to reduce psychological distress following the death of a baby. The LWL program can provide parents with readily accessible information and evidence-based strategies to support coping and wellbeing following perinatal bereavement, and is delivered in a flexible, self-guided digital format. Understanding how to minimize distress in the longer term and how best to implement such programs in routine care—ideally within blended or stepped models of care with therapist- or peer-support—are important avenues for future studies. Increasing availability and accessibility to appropriate evidence-based grief support, particularly digital or internet-based options which may help increase reach, is an important priority in Australia and internationally.

Acknowledgements

We thank all parents who participated in this study for their willingness to help to better understand and improve care and support for families experiencing the death of a baby. We gratefully acknowledge the healthcare professionals and parent support organizations who shared and promoted the study to parents.

Author contributions

SL conceived the study with VF, AL, SC, CA, FMB, DE, JD, DH, EC, CJ, AS. SL, AL, SC, CA conducted the trial between 2021 and 2023. AG conducted statistical analysis with SL. SL drafted the manuscript with AMW and AL, and all coauthors contributed to the revision of the draft.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

The Living with Loss project is supported by the Australian Government's Medical Research Future Fund (MRFF) Rapid Applied Research Translation program grant awarded to Health Translation Queensland. The funders did not play any role in the study design, collection of data, or in the development of this manuscript. The study also falls within the work program of the Stillbirth CRE. The Stillbirth CRE is funded by the National Health and Medical Research Council (NHMRC, AP2006523). We thank Mater Foundation for its contribution.

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Data availability statement

The participants of this study did not give written consent for their data to be shared publicly, so due to the sensitive nature of the research supporting data is not available. Data for meta-analysis available from the corresponding author (SL), upon reasonable request.

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