

Economic evaluation of a randomised controlled trial - An online bereavement support program for parents following perinatal death

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ABSTRACT

Background: Delivering timely, accessible, and cost-effective perinatal bereavement support to parents is essential to support their emotional and mental wellbeing. However, there is limited evidence on the economic impact of online-based support programs.

Objective: This study conducted a cost-utility analysis of parents who participated in a randomised controlled trial – comparing the *Living with Loss* program (LWL; eight-week online program for parents following perinatal death) with care-as-usual (CAU), from the perspective of the healthcare system.

Methods: A health service utilisation survey was designed to collect the hospital and out-of-hospital health services, and prescription medications accessed by participants during the study period. Total costs included costs to the governments and individuals (AUD 2023/24) over time. Utility was measured using quality-adjusted life years (QALYs) calculated based on the Assessment of Quality of Life (AQoL)-8D.

Findings: Among the 95 randomised parents, 52 (20 LWL, 32 CAU) completed economic assessments at baseline (week 0) and post-program (week 9). Of these 52 participants, 39 (16 LWL, 23 CAU) further completed the three-month follow up assessment (week 21).

Compared with CAU, the LWL program showed trends towards costs savings in primary care and maintained similar health outcomes at post-program (-\$264.59 per participant, $p = 0.47$; QALY gained = -0.001, $p = 0.9$) and three-month follow up (-\$531.52 per participant, $p = 0.3$; QALY gained = -0.002, $p = 0.94$).

Conclusion: This study provides preliminary evidence of potential economic benefits of the LWL Program. Future studies with larger sample sizes and adequate power are needed to fully assess the cost-effectiveness of online perinatal bereavement support services.

Statement of Significance

Problem or Issue

There is limited evidence on the economic impact of online-based

perinatal bereavement support programs.

What is Already Known

Living with Loss, an eight-week, online, self-guided program was associated with reduced psychological distress at post-program, compared with care-as-usual.

ABBREVIATIONS: AQoL-8D, The Assessment of Quality of Life 8 Dimensions; AUC, Area Under the Curve; CAU, Care-as-usual; CHEERS, Consolidated Health Economic Evaluation Reporting Standards; GLM, Generalised Linear Model; HRQoL, Health-Related Quality of Life; ISPOR, International Society for Pharmacoeconomics and Outcomes Research; LWL, Living with Loss; MBS, Medicare Benefits Schedule; PBS, Pharmaceutical Benefits Scheme; QALYs, Quality-Adjusted Life Years; RCT, Randomised Controlled Trial; RCT-CEA, Randomised-Controlled Trial Cost-Effectiveness Analysis; USA, United States of America.

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What this Paper Adds

Our economic analysis showed that the Living with Loss program showed trends towards cost savings in primary care and maintained comparable health outcomes at post-program and three-month follow-up, compared with care-as-usual. While these results are not statistically significant, they suggest potential economic benefits that warrant further investigation in larger studies.

1. Introduction

Psychological distress and enduring psychosocial impacts are part of the tragic reality for bereaved families that experience the death of a baby during pregnancy or soon after birth [1]. Globally, the annual rate of perinatal death (i.e. stillbirth and neonatal death) was 6.3 million, with less developed countries in Africa and South-central Asia reporting the highest rates of neonatal death [2]. Despite being one of the safest countries to be born into, there were still 3016 perinatal deaths in Australia in 2021 (9.6 per 1000 births); 76 % of which were stillbirths [3].

The most significant impacts in both the short- and longer-term after perinatal death are those experienced by families. It is well documented that perinatal death can often result in intense feelings of grief, and is linked with increased risk for anxiety, depression, post-traumatic stress and sleeping disorders [1, 4–13]. Perinatal death is also linked to relationship breakdowns and dysfunction [1, 4, 14] with longer-term impacts for subsequent pregnancies including difficulties in early parenting and attachment [15,16]. Moreover, care providers also report psychological effects associated with providing care to families following perinatal death, which lead to compassion fatigue and burnout [4,17].

The economic consequences of perinatal death are also widely recognised. A review in the Lancet's *Ending Preventable Stillbirths* series indicated that 10 % of bereaved parents do not return to work for six months, and of those that do return, 38 % of women and 21 % of partners returned at reduced work hours [4]. Evidence from the USA suggests that the productivity loss following perinatal death were estimated at US\$21,332 per household during the first six months [13]. The societal costs can be much more significant. One Australian study estimated that average government healthcare costs (including government-subsidised medicines) were 42 % higher for women who experienced a stillbirth compared to women who had a live birth [18].

Despite the wide-ranging psychosocial and economic implications of perinatal death, interventions aimed at supporting the emotional and mental wellbeing of bereaved families have largely been overlooked by the research community [19–21]. This study aimed to conduct a cost-utility analysis alongside a randomised controlled trial (RCT) conducted in Australia, comparing Living with Loss (LWL) program with care-as-usual (CAU) control group.

The LWL is an online, self-guided program designed to provide evidence-based strategies to support parents navigating perinatal grief and loss in the short and longer-term. It consists of six flexible modules featuring interactive activities, information, and an illustrated parent storyline. The trial protocol including economic analysis plan [22] and clinical outcomes of the trial [23] were published separately. Briefly, the LWL program reduced psychological distress at post-program compared with CAU, but this effect was not sustained at three-month follow-up. No differences were found for perinatal grief intensity, anxiety, and depression.

2. Methods

2.1. Study design

This study is an economic evaluation alongside a randomised

controlled trial – comparing the LWL program with CAU in improving the psychosocial and emotional wellbeing of parents following perinatal death. A cost utility analysis was performed to compare the costs (from the healthcare system perspective) and outcomes (measured in quality adjusted life years (QALYs)) between the LWL program and CAU control groups. The design of the economic evaluation followed the recommendations of the International Society for Pharmacoeconomics and Outcomes Research Randomised Controlled Trial Cost-Effectiveness Analysis (ISPOR RCT-CEA) Task Force [24] and ISPOR Consolidated Health Economic Evaluation Reporting Standards (CHEERS) [25]. The completed CHEERS 2022 checklist was provided in Appendix A.

2.1.1. Participants and recruitment

Bereaved parents were recruited and enrolled to the study between June 2021 and May 2022. Individuals interested in participating in the study were able to self-enrol via the study website, where their eligibility was assessed by the research team. Individuals were eligible to participate if they were 18 years of age or older; had 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 two years and more than eight weeks ago; were Australian residents; were willing to provide their contact details; were able to comprehend, speak and write in English; had access to a reliable computer and internet access; and provided informed consent online.

Individuals were not eligible to participate if they were less than 18 years of age; were pregnant at the time of recruitment; had experienced a stillbirth or neonatal death less than eight weeks prior to self-enrolling; self-reported symptoms of a severely depressed mood or suicidality indicating a severe mental health condition (assessed using the Kessler Psychological Distress Scale [K10] (score ≥ 30) [26] the Edinburgh Postnatal Depression Scale [EPDS] (score ≥ 14) [27], and/or Item 10 of the EPDS (score of 1, 2, or 3); self-reported a diagnosis of psychotic disorder (including psychosis, bipolar disorder or schizophrenia etc.); self-reported substance abuse or dependency; or if they recently (less than eight weeks prior to self-enrolling) started psychological treatment elsewhere. Individuals who screened positive for severe mental health conditions underwent a telephone risk assessment interview to determine whether participation in the RCT would provide sufficient support based on their individual circumstances.

2.1.2. Study processes

After recruitment, study participants were randomised to the LWL or CAU Group. Both groups completed baseline economic assessments (T1, week 0) via online questionnaires for health service utilisation and quality of life measures. During the active study period (weeks 1–8), the LWL group was encouraged to complete one module per week and the CAU group continued to undergo standard care (i.e. continue with any course of treatment already specified to take, such as accessing peer support services). Participants in both groups were invited to complete economic assessments at the end of the active study period (T2, week 9) and three months after the program completion (T3, week 21).

2.1.3. Costs measure

The costs were measured from a healthcare system perspective (including costs to the governments and individuals).

2.1.3.1. LWL program costs. Design and development costs, as well as recurrent costs associated with delivering the LWL program were included in this analysis (detailed in Appendix B). These costs were allocated across Australia's estimated annual perinatal death cases ($n = 3016$ in 2021, the latest available data at the time of publication [3]). This population-based cost allocation approach assumes the online program could potentially reach all parents who experienced perinatal death without marginal cost increases, though actual implementation would require separate evaluation of scaling costs.

2.1.3.2. Health service utilisation. A health service utilisation survey (Appendix C) was specifically developed for the LWL program to collect self-reported data. This survey was designed by combining elements from existing resource utilisation measures [28–30]. It comprises eight sections, covering general practitioners/nurse practitioners, psychologists, specialists, emergency department, inpatient, outpatient, other, and prescription medications; and out-of-pocket fees incurred for any above services.

2.1.3.3. Cost assignment of health service utilisation. Costs were assigned to health service usage based on the 2021/22 average costs reported in the National Hospital Cost Data Collection Public Sector for inpatient, outpatient, and emergency department services, the latest available data at the time of publication. Costs for out-of-hospital care were sourced from the 2023/24 Medicare Benefits Schedule (MBS) and prescription medication costs were obtained from the 2023/24 Pharmaceutical Benefits Scheme (PBS). Unit costs for these services are detailed in Appendix D.

All costs were inflated to 2023/24 Australian dollars based on the Reserve Bank of Australia Inflation Calculator [31]. Australian dollars are presented throughout. The discount factor was not applied as the time horizon was three months.

For participants who completed the health service utilisation survey but did not specify the exact out-of-pocket fees for the MBS services, we estimated these missing amounts using the gap expense, which is the difference between the 'schedule fee' and the 'benefit amount' as set in the MBS.

The 'schedule fee' is the recommended fee set by the Australian Federal Government for a medical service, while the 'benefit amount' is the portion of the fee covered by Medicare. Of note, the service provider's charge is the actual fee billed by the healthcare provider, which may exceed the 'schedule fee'.

2.1.4. Health outcome measure

Quality-adjusted life years (QALYs) were used to measure health outcomes. Changes in QALYs between LWL and CAU groups were determined using the 'Area Under the Curve' (AUC) method, which assumes a linear relationship between health-related quality of life (HRQoL) measured at different time points [32].

The Assessment of Quality of Life (AQoL)-8D was collected to assess the HRQoL. This generic, self-reported instrument comprised 35 items, loaded onto eight dimensions representing different aspects of HRQoL: independent living, pain, senses, mental health, happiness, coping, relationships and self-worth [33]. The AQoL-8D was developed in response to omissions in existing measures, which were not sufficiently sensitive to psychosocial elements of health (e.g. mental health and relationships) [33]. It has been shown to have robust validity, reliability and sensitivity to changes in health states [33–36], and is recommended by the ISPOR RCT-CEA Task Force [24].

2.1.5. Analysis

In our analysis, we employed a complete case analysis approach by focusing on participants who provided complete cost and utility data across all time points, given the substantial proportion lost to follow-up. To assess potential selection bias, we compared baseline characteristics between participants who completed the economic data collection and those who did not. The baseline characteristics between participants in the LWL and CAU groups were also compared. The Fisher exact test was used due to small frequencies and categorical variables. P-values less than 0.05 were considered statistically significant. If significant differences were identified, these variables were considered as confounding factors and adjusted accordingly.

A generalised linear model (GLM), where cost is the dependent variable, was constructed using a negative binomial distribution and log link function to account for the skewness of the data as suggested by the

ISPOR CEA-RCT Task Force [24]. Both total costs and its categories (primary, inpatient, outpatient, emergency care and prescription medication costs) were analysed to identify key drivers of cost differences between groups. A GLM where QALYs were the dependent variable was then constructed using a gamma distribution and log link. The incremental cost and utility were calculated by comparing the LWL to the CAU group.

2.1.5.1. Primary analysis. The primary analysis included participants who completed both health service use and AQoL-8D questionnaires at T1 and T2. Total mean cost covered health service use from one month prior to randomisation to week 9.

2.1.5.2. Secondary analysis. The secondary analysis included participants who completed both health service use and AQoL-8D questionnaires at T1, T2, and T3. Total mean cost covered health service use from one month prior to randomisation to week 21.

2.1.5.3. Sensitivity analysis. A sensitivity analysis was conducted by assigning gap expenses to all participants who reported paying out-of-pocket fees for the MBS services.

All analyses were performed using SAS V9.4 and Stata SE18.

3. Results

Fig. 1 shows the flow diagram of participants. A total of 99 parents enrolled in the trial, with 95 randomised. In our economic evaluation, we analysed data from 52 participants in the primary analysis (20 in LWL and 32 in CAU) and 39 participants in the secondary analysis (16 in LWL and 23 in CAU). There were no significant differences in baseline characteristics for participants who completed the economic data collection and those who did not (Table S1).

Table 1 presents the baseline demographic and clinical characteristics of participants in the LWL and CAU groups. Notably, no significant baseline differences were observed between two groups during the primary analysis. The majority of participants resided in major Australian cities, identified as women, fell within the 30–44-year age range, were either married or living with a partner, employed, and had tertiary education qualifications.

The analysis of participants who completed economic data at both baseline and post-program showed that the LWL program yielded non-significant costs saving of \$885.39 per participant ($p = 0.09$) and maintained comparable health outcomes (QALYs gained = -0.001 , $p = 0.9$), compared with the CAU (Table 2). The observed cost savings were primarily driven by reductions in inpatient admissions ($-\$609.95$, $p = 0.99$) and primary care visits ($-\$264.59$, $p = 0.47$) among LWL participants. In the CAU control group, three participants were admitted from one-month prior to randomisation to post-program follow-up. Two of these participants reported their reasons for admission, which were childbirth and laparoscopic gallbladder removal; both appear unrelated to the intervention. In contrast, no participants in the LWL program reported inpatient admissions during the study period.

For analysis of participants who completed economic data across baseline, post-program, and three-month follow up, compared with CAU, the cost savings to the healthcare system increased to \$1085.67 per participant ($p = 0.11$) while maintaining similar health outcomes (QALYs gained = -0.002 , $p = 0.94$) (Table 2). The observed cost savings were primarily attributable to reductions in primary care visits among LWL participants ($-\$531.52$, $p = 0.3$).

All sensitivity analyses yielded similar non-significant cost savings in primary care among LWL participants (Table S2).

4. Discussion

To the best of our knowledge, this study represents the first

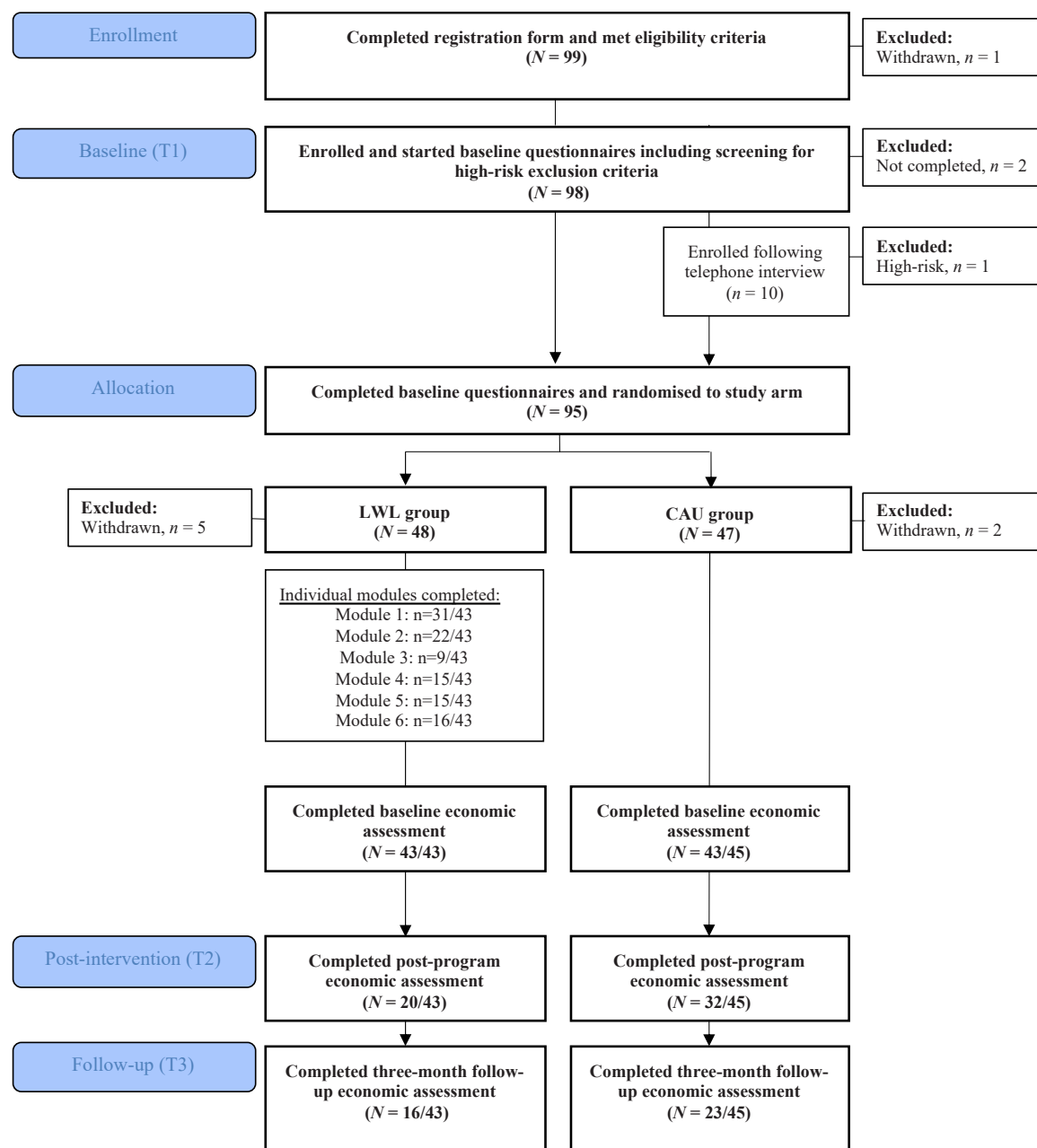


Fig. 1. A flow diagram of participants who completed economic assessment. Abbreviations: LWL=Living with Loss; CAU=Care-as-usual.

evaluation of the cost-utility of an online, self-guided program designed to support parents navigate and cope with the short and long-term impacts of perinatal death. Our economic analysis showed that the LWL program yielded non-significant cost savings in primary care and maintained similar health outcomes at post-program and three-month follow up, compared with CAU. While these results are not statistically significant, they suggest potential economic benefits that warrant further investigation in larger studies. This economic evaluation, alongside findings from the LWL trial, provides preliminary evidence supporting the value of online-based program for parents following perinatal death.

Traditional support mechanisms often pose significant barriers for bereaved parents, including lengthy waitlists and limited availability, which can prevent timely access to necessary resources. In contrast, the LWL program offers a flexible and accessible alternative, allowing parents to engage with support materials at their own pace and in the comfort of their own homes. Further research is needed to evaluate the

potential for scaling the LWL program to a population level as it presents an opportunity to address the increasing demand for evidence-based support options for parents experiencing perinatal death. By providing a readily accessible online platform, the LWL program may reach a broader audience, particularly those who may feel isolated or underserved by conventional support systems. Integrating this intervention into standard care pathways may enhance access to timely support while simultaneously generating significant savings for the healthcare system.

4.1. Limitations

The interpretation of our results is limited by the small sample size and the resulting lack of statistical power. Future studies with larger sample sizes and adequate power are needed to fully assess the cost-effectiveness of online perinatal bereavement support services. In addition, our analysed sample overrepresented non-Indigenous female participants with high educational attainment and English as their first

Table 1
Demographic and clinical characteristics of included participants.

	Primary analysis		Secondary analysis	
	LWL Group	CAU Group	LWL Group	CAU Group
Characteristics	20 (38.46 %)	32 (61.54 %)	16 (41.03 %)	23 (58.97 %)
Rurality^a				
Major cities of Australia	15 (75 %)	23 (71.88 %)	14 (87.5 %)	18 (78.26 %)
Inner regional Australia	4 (20 %)	6 (18.75 %)	2 (12.5 %)	4 (17.39 %)
Outer regional Australia	1 (5 %)	2 (6.25 %)	-	1 (4.35 %)
Very remote Australia	-	1 (3.13 %)	-	-
Initial risk level (measured in Kessler Psychological Distress Scale (K10))				
High distress symptoms at baseline (0–19)	11 (55 %)	18 (56.25 %)	11 (68.75 %)	13 (56.52 %)
Low distress symptoms at baseline (20–50)	9 (45 %)	14 (43.75 %)	5 (31.25 %)	10 (43.48 %)
Gender				
Female	18 (90 %)	30 (93.75 %)	14 (87.5 %)	22 (95.65 %)
Male	2 (10 %)	2 (6.25 %)	2 (12.5 %)	1 (4.35 %)
Age group*				
25–29 years	2 (10 %)	7 (21.88 %)	1 (6.25 %)	5 (21.74 %)
30–34 years	12 (60 %)	10 (31.25 %)	11 (68.75 %)	6 (26.09 %)
35–44 years	6 (30 %)	15 (46.88 %)	4 (25 %)	12 (52.17 %)
English first language				
Yes	17 (85 %)	31 (96.88 %)	13 (81.25 %)	22 (95.65 %)
No	3 (15 %)	1 (3.13 %)	3 (18.75 %)	1 (4.35 %)
Indigenous (Aboriginal or Torres Strait Islander origin)				
No	20 (100 %)	32 (100 %)	16 (100 %)	23 (100 %)
Current relationship status				
In a relationship but living separately	-	1 (3.13 %)	-	1 (4.35 %)
Married or living with a partner	19 (95 %)	30 (93.75 %)	15 (93.75 %)	21 (91.3 %)
Separated or divorced	1 (5 %)	-	1 (6.25 %)	-
Single	-	1 (3.13 %)	-	1 (4.35 %)
Highest level of education				
Secondary	1 (5 %)	4 (12.5 %)	1 (6.25 %)	3 (13.04 %)
Tertiary/undergraduate university degree	12 (60 %)	18 (56.25 %)	8 (50 %)	11 (47.83 %)
Postgraduate university degree	7 (35 %)	9 (28.13 %)	7 (43.75 %)	8 (34.78 %)
Not stated	-	1 (3.13 %)	-	1 (4.35 %)
Employed				
Yes	19 (95 %)	31 (96.88 %)	15 (93.75 %)	22 (95.65 %)
No	1 (5 %)	1 (3.13 %)	1 (6.25 %)	1 (4.35 %)
First pregnancy				
Yes	7 (35 %)	15 (46.88 %)	5 (31.25 %)	8 (34.78 %)
No	13 (65 %)	17 (53.13 %)	11 (68.75 %)	15 (65.22 %)
Number of previous stillbirth (defined as a baby of 20 or more weeks' gestation who dies before birth)				
0	17 (85 %)	27 (84.38 %)	13 (81.25 %)	18 (78.26 %)
1	3 (15 %)	5 (15.63 %)	3 (18.75 %)	5 (21.74 %)

*There was a significant difference in age between the groups in the secondary analysis ($p = 0.0311$); all other comparisons were non-significant.

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

Table 2
Cost-utility analysis.

	LWL Group (mean, SE)	CAU Group (mean, SE)	Difference (LWL - CAU) (mean, p-value)
Primary analysis (completers at baseline and post-program)			
Total costs	\$978.91, \$295.27	\$1864.30, \$444.49	-\$885.39, 0.0938
Intervention costs	\$38.77	0	\$38.77
Primary care	\$814.42, \$246.49	\$1079.01, \$258.15	-\$264.59, 0.4659
Inpatient care	0	\$609.95, \$1126.34	-\$609.95, 0.9916
Outpatient care	\$125.71, \$159.35	\$111.76, \$111.99	\$13.95, 0.9420
Emergency care	0	\$62.37, \$129.26	-\$62.37, 0.9978
Prescription medication	0	\$1.33, \$1.96	-\$1.33, 0.9998
Total QALYs	0.1108, 0.0065	0.1118, 0.0052	-0.001, 0.8988
Secondary analysis* (completers at baseline, post-program, and three-month follow up)			
Total costs	\$1139.50, \$357.20	\$2225.17, \$612.05	-\$1085.67, 0.1100
Intervention costs	\$38.77	0	\$38.77
Primary care	\$899.09, \$309.68	\$1430.61, \$404.55	-\$531.52, 0.2989
Inpatient care	0	\$0.21, \$355.52	-\$0.21, 0.7802
Outpatient care	\$202.44, \$272.29	\$111.64, \$129.27	\$90.8, 0.7489
Emergency care	\$1.19, \$1717.20	\$0, \$0.63	\$1.19, 0.3531
Prescription medication	\$0.56, \$3.41	\$32.78, \$107.69	-\$32.22, 0.6482
Total QALYs	0.2545, 0.0204	0.2565, 0.0148	-0.002, 0.9356

Abbreviations: LWL=Living with Loss; CAU=Care-as-usual; SE=standard error; QALYs=quality adjusted life years.

*This analysis was adjusted for age group to account for differences introduced by non-responders at three-month follow up.

language. Fewer LWL participants completed economic data collection during follow-up compared with CAU participants. Participants in the intervention group who did not benefit from the program may have been less likely to complete study assessments, potentially affecting the results.

Furthermore, this study has several methodological limitations to consider. First, we are unable to capture the social opportunity costs arising from the LWL program. This is because we did not capture data regarding LWL group participants' time directly (e.g. screen-time) or indirectly (e.g. offline activities) when completing the LWL program. Similarly, we did not capture time-related data for CAU group participants' participating in health-seeking behaviours (e.g. accessing psychological services, travelling to appointments). However, the opportunity costs associated with utilising health services is inherently an individual decision, where benefits and consequences are weighed up by the individual. Therefore, this limitation should not have a significant impact on our ability to inform a holistic societal perspective. Second, we are using self-reported measures, which may limit accuracy compared to administrative medical and service utilisation records, where data are collected more proximal to the time of events occurring and without the limitation of recall bias (as can occur when using self-reported measures) [24]. However, given the motivation of the target population [37] and the small recall periods, we perceived a low to negligible level of bias introduced into the study by self-reported measures.

5. Conclusion

This study provides preliminary evidence of potential economic benefits of the LWL Program. Future studies with larger sample sizes and

adequate power are needed to fully assess the cost-effectiveness of on-line perinatal bereavement support services.

Ethics Statement

Ethics approval for this trial was obtained from Mater Misericordiae Ltd. Human Research Ethics Committee (HREC) in Australia in December 2020 (HREC/MML/70343). Electronic informed consent was obtained from participants for this study via the study website and registration process. On the consent form, participants were asked for permission for the research team to share relevant data with people from the Universities taking part in the research or from regulatory authorities, where relevant.

Author Contributions

EC and CB led the study design and drafting of the manuscript. YH led the data analyses and drafting of the manuscript. SL, AL, FB, VF and DE contributed to the study design, interpretation of the results, and editing of the final manuscript. All authors read and approved the final manuscript.

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Conflict of Interest

The authors report no conflicts of interest.

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Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.wombi.2025.101933](https://doi.org/10.1016/j.wombi.2025.101933).

Availability of data and materials

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.

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