



Review article

Support interventions to reduce psychological distress in families experiencing stillbirth in high income countries: A systematic review

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ABSTRACT

Background: Previous research indicates disparities in the care of bereaved parents and siblings following a stillbirth in the family. The aim of this systematic review was to assess the effects of interventions aimed at reducing psychological distress among parents or siblings in high-income countries after experiencing a stillbirth. **Methods:** The databases CINAHL, Medline, PsycInfo, Cochrane Library, and EMBASE were searched in August 2022.

Results: Four intervention studies from the United States (US), the United Kingdom (UK), Finland, and Australia, met the inclusion criteria. The interventions comprised a perinatal grief support team; a perinatal counselling service; a grief support program; and a support package including contacts with peer supporters and health care staff. No studies of interventions for siblings were found. The results could not be synthesised due to disparities in interventions and outcome measures. The risk of bias was assessed as high in all four studies and the certainty for all outcomes was rated as very low.

Conclusion: More controlled trials with rigorous methods are needed to evaluate the effect of bereavement support interventions in parents and siblings after stillbirth. Future studies should include a core outcome set to make them more comparable. Most of the studies in this review were assessed to have an overall high risk of bias, mainly due to problems with missing outcome data; thus, future studies could specifically target this problem.

Statement of significance

Problem or issue

Despite care standards implemented when a baby is stillborn there is sparse literature on interventions measuring the psychosocial consequences following stillbirth.

What is already known

Previous research shows disparities in the care of bereaved parents and siblings after experiencing a stillbirth in the family.

What this paper adds

More controlled trials are needed to evaluate the effect of bereavement support interventions in parents and siblings after stillbirth.

Abbreviations: GRADE, Grading of Recommendations Assessment, Development and Evaluation; US, United States; UK, United Kingdom; RR, Relative risk; CI, Confidence Intervals.

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Background

Most parents anticipate that their pregnancy will culminate in the joyful birth of a new life. Conversely, parents of stillborn babies are confronted with the unimaginable: the birth of a baby who unexpectedly died before they were even born; leaving the parents shocked and entirely unprepared for the loss.

Stillbirth is estimated to occur two million times worldwide yearly, with the majority happening in low- and middle-income countries [1]. In high-income countries the prevalence of stillbirth is 3–4/1000 births [2]. There is a disparity in the definitions of gestational length in the classification of stillbirth, ranging from 20 to 28 gestational weeks [3]. A recent study revealed that the majority of European countries currently use 22 completed gestational weeks as a cut-off for the classification of stillbirths [4]. In Europe, the median stillbirth rate has been estimated to be 2.7 per 1000 births, based on 28 completed gestational weeks, and 3.3 per 1000 when the lower threshold (22 weeks) was used [4]. Based on scientific reviews and priorities set by professionals from 26 countries, an international consensus on care after stillbirth was reached in 2020 [5].

The consortium identified eight major principles considered essential for high quality care after stillbirth: These include offering health professionals extensive education and support in caring for grieving parents, investigating reasons for stillbirth, providing information and participation regarding birth options, treating parents, family, and the baby with respect, encouraging public education to increase knowledge about stillbirth, offering sufficient information and postnatal care based on physical and emotional needs, ensuring continuity of care with a named person, and raising awareness among professionals that grief reactions might vary and could be long-lasting, thus requiring emotional support. Additionally, parents should be given information about their reproductive health and support in pregnancy planning. National guidelines aligning with the international consensus [5] have been developed in collaboration with clinicians and user organisations in countries such as Australia and New Zealand [6,7], England and Scotland [8,9] and Ireland [10].

The initial bereavement care have evolved over time [11,12]. Historically, there was a perception that there was no emotional connection between the pregnant woman and the unborn baby, so stillbirth was viewed as a non-event that the parents should forget. For example, healthcare staff often shielded parents from seeing or holding their deceased baby [12]. It was later shown that maternal-foetal attachment is already formed during pregnancy [13]. This change in knowledge and attitudes has had a significant impact on the care of bereaved parents after stillbirth. In most labour wards, parents are attended to by the same staff during labour and birth in the case of stillbirth [11,12]. The confirmation of the baby's death is typically conducted using ultrasound examination. It is common to induce labour shortly after confirming the baby's death. Labour and birth are managed as usual, with available support, information, and pain relief [11,12]. Today, health professionals encourage the recognition and attachment of families to their stillborn baby and support them in grieving. At birth and postnatally, parents are encouraged to hold and spend time with their baby, creating memories and mementos (lock of hair, hand, footprints, and photos) [11,12].

General recommendations suggest that parents need clear, easily understood, and structured information, continuity of dedicated midwives and obstetricians and acknowledgement of the inclusion of the partner [11]. The family's psychological distress can be exacerbated by feelings of blame and shame, and the stigma that often accompanies stillbirth [14]. Marginalisation, and the standard of care can also influence how the family reacts to grief [15,16]. People around the bereaved families may lack an understanding of the significance of the loss, which may increase the feeling of being alone and not receiving the social support the parents need [17].

Grief following stillbirth is similar to bereavement following the

death of any other loved ones (e.g. death of child, spouse). Although grief is a normal reaction after a loved one dies, the psychosocial consequences of stillbirth can be long-lasting, with an increased risk of mental health problems such as depression and anxiety [18,19] as well as posttraumatic stress [19]. Furthermore, considering the psychological, as well as economic, consequences of stillbirth, bereavement support for the families is essential [20].

Siblings are often referred to as the “forgotten grievers”. Children's grief reactions manifest differently based on their age and cognitive skills [21]. Siblings, in general, are deeply affected by losing a brother or sister. For instance, siblings can often feel lonely and without support as they want to avoid burdening their grieving parents [21].

Despite the existing care standards implemented in high-income countries when a baby is born without signs of life, it is important to examine the effect of interventions measuring the psychosocial consequences following stillbirth. The aim of this study was to assess the effects of interventions aimed at reducing psychological distress among parents or siblings after experiencing a stillbirth in the family.

Method

Protocol and registration

The work presented in this paper was part of a report including a systematic review conducted at The Swedish Agency for Health Technology Assessment and Assessment of Social Services (SBU) [22]. This systematic review adhered to the guidelines outlined in the Cochrane handbook [23]. A protocol encompassing both qualitative and quantitative reviews was preregistered in PROSPERO (CRD42022306655). The report is written in Swedish and aimed to inform managers and health care professionals on the evidence regarding stillbirth care. To reach an international audience it crucial also to disseminate the research in English. This paper reports only on the quantitative findings from that review and that the qualitative findings have been published elsewhere [24].

Selection criteria

Input was initially sought from representatives of non-profit organisations supporting and advocating for families who have experienced stillbirth, as well as clinicians actively working or conducting research in the field, during the formulation of our study question. This ensured that our study question would be as relevant as possible to these stakeholders (inclusion and exclusion criteria). Studies comprising parents and siblings of stillborn babies were incorporated. Studies with mixed populations, such as intervention studies on miscarriage or other types of perinatal loss, were included if at least 50 % of the study participants matched our selection criteria or if the results were reported separately for our selection group. To be included, studies should have been conducted in high-income contexts/countries with a stillbirth rate below 5 per 1000 live births (Additional file 1). Another criterion was a defined gestational age of 22 or more completed weeks at stillbirth, reflecting European definitions [4].

Intervention

Studies investigating any intervention or program provided to parents or siblings of a stillborn baby, intended to offer support, were included. For the parents, the intervention had to be initiated from when the parents were informed of the baby's death, up to six months after birth. For the siblings the intervention should be initiated within one year of the stillbirth.

Control

Studies in which the control group received treatment as usual or any

other interventions were included.

Outcome

Studies with parents' and siblings' mental health and quality of life as outcomes were included.

Study design

Both randomised and non-randomised controlled trials were included.

Setting

Studies from developed countries with a prevalence of stillbirths under 5 per 1000 live births in 2019 (see Additional file 1) were included.

Information sources and search strategies

The search strategy was collaboratively developed by an information specialist in consultation with the experts in the review team. A second information specialist reviewed the search strategy using the PRESS Checklist. Electronic literature searches were conducted on the following databases: CINAHL (EBSCO), Cochrane Library (Wiley), EMBASE (embase.com), Medline (Ovid) and PsycINFO (EBSCO). The initial search took place in December 2021 with an update conducted in August 2022. Additionally, citation searching of key articles in Scopus and examination of reference lists from published articles supplemented the search. Records in English, Swedish, Danish, or Norwegian were included. Deduplication of records was performed using the reference management program EndNote. The complete search strategy is available as an additional file (see Additional file 2).

All titles and abstracts underwent independent screening by two authors. Potentially relevant articles were then read in full text and independently screened by two authors who are experts in the field. Discrepancies regarding the inclusion of an article were resolved

through discussions between authors. A flow chart detailing the review process is presented in Fig. 1.

Data collection process

Data were extracted from each included study using a template specifically constructed for this purpose and organised into tables. Extracted information included names, publication year, country, study design, setting, recruitment, population, drop-outs, inclusion criteria, intervention, time of measurement, and outcome (type of outcome and measures). One author conducted the data extraction, which was subsequently reviewed by a second author.

Study risk of bias assessment

Risk of bias was independently assessed by three authors using the Cochrane Risk-of-Bias tool for randomised trials, RoB 2, and for non-randomised trials, the ROBINS-I [25,26]. Disagreements regarding the risk of bias in a study were resolved through discussion.

Certainty assessment

Certainty of evidence for each outcome was evaluated using the Grading of Recommendations Assessment, Development, and Evaluation (GRADE) [27].

Results

Study selection

The search resulted in 15,072 records (titles and abstracts) and after deduplication, 10,671 records were screened. Following a detailed examination, 90 full-text articles were reviewed, with four studies published in five scientific reports [28–32] meeting the inclusion criteria (refer to Fig. 1). Additional information detailing the reasons for exclusion after full-text review is available in (Additional file 3).

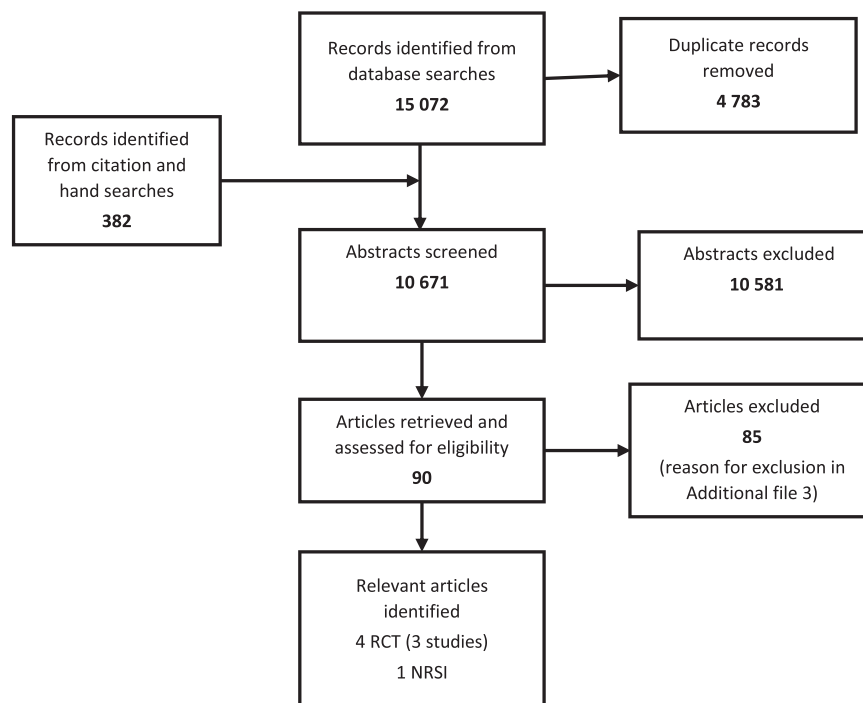


Fig. 1. Flow chart of study selection. Note: Flow chart was adopted from PRISMA.

Study characteristics

Among the included studies, two were randomised [28,29], one study was cluster randomised presented in two reports [30,31] and one was a non-randomised longitudinal experimental study with a control group [32]. All studies were unblinded and three studies reported a high drop-out rate (56 % [28], 30–40 % [29], 17–18 % [32]). In two reports from one study, the dropout was not clearly described [30,31]. Table 1 provides a summary of study characteristics, while additional detailed descriptions are available in supplemental information (Additional file 4).

According to inclusion criteria, in all reports at least 50 % of cases were stillbirths. While all studies included parents who lost a baby before birth, some also included parents whose children died up to two hours after birth [28], during the neonatal period [29,32] or later [30–32]. One study included only women [28] and the other studies included both women and men [29–32]. The sample size of the included studies ranged from 50 [29] to 144 [32].

The interventions varied across studies: One study evaluated a perinatal grief support team [28], one study evaluated a perinatal counselling service [29], one study evaluated a grief support program including a meeting with a grief worker and resource material [32] and a bereavement follow-up intervention including with a support package, peer supporters' contact and health care personnel's contact for fathers [30] and mothers [31].

All studies measured changes in symptoms using self-assessment scales, including assessments grief reactions [28,30,31], symptoms of depression and anxiety [29,32] and general mental health [29]. None of the studies included measures of quality of life. The follow-up period for all studies was six months, with some also reporting longer follow-up periods of 14 [29] and 15 months [32].

Risk of bias in studies

Concerns about risk of bias were present in all studies. The overall risk of bias was deemed high in all four studies, with missing outcome

Table 1
Summary of study characteristic.

Reference	Population	Intervention	Control	Outcome
Forrest et al. (1982), UK	Mothers, Fathers; stillbirth (50 %)	Perinatal counselling service	Routine hospital care	Psychiatric disorders (General health questionnaire) Depressive and Anxiety symptoms (Leeds scales) Grief reactions
Lake et al. (1987), USA	Mothers of stillborn or died withing 2 h of birth	Perinatal grief support team	No intervention from the grief support team.	(Grief experience inventory)
Murray et al. (2000), Australia	Mothers, Fathers; perinatal death (81 %)	Contact with a trained grief worker and receiving resource materials	Routine community care	Depressive and Anxiety symptoms (Personal Disturbance Scale: Delusions-Symptoms-States Inventory)
Aho et al. (2011)/ Raitio et al. (2015), Finland	Mothers, fathers; stillbirth (66 % interventions; 39 % control)	Peer contact, resource packet, health care personnel contact	Care as usual	Grief reactions (the Hogan Grief Reactions Checklist)

data being a prevalent factor leading to a high-risk assessment. The studies by Aho /Raitio, [30,31] was evaluated as a high risk of bias overall due to issues with the randomisation process and a high number of missing data. The studies by Forrest et al. [29] and Lake et al. [28], were assessed as including high risk of bias, primarily due to high levels of missing data. In the non-randomised trial by Murray et al. [32] the overall risk of bias was high, with confounding assessed as a major concern.

Results of individual studies

No results from the studies could be synthesised due to the evaluation of different complex interventions and the reporting of various outcome measures (Table 2).

Forrest et al. [29] found that mothers who received support immediately after the stillbirth had a lower rate of psychological wellbeing than the control group (RR: 0.24; CI: 0.06 to 0.93), but no difference in the rate of pronounced symptoms of depression and anxiety (RR: 0.59; CI: 0.26 to 1.38). The study included 50 mothers and their partners with follow-ups at 6 and 14 months after the death. The support intervention (n = 25) encouraged the parents to see and hold the baby and making mementos, and both parents were offered bereavement counselling. There was no difference between groups of fathers on either rate of psychiatric disorders (RR: 1.17; CI: 0.19 to 7.07) or depression and anxiety (RR: 1.17; CI: 0.19 to 7.07).

The study by Lake et al. [28] evaluated a perinatal grief support team in a group of mothers experiencing a perinatal death (n = 78) with a follow-up at 6 months after birth (intervention n = 18; control n = 16). The results showed no statistically significant difference in grief reaction scores between the intervention (mean=240.17) and the control group (mean=259.60).

Murray et al. [32] reported that their intervention, that included contact with a grief worker and resource materials, reduced symptoms of psychological distress in both mothers and fathers. The results from the 6-month follow-up indicated that the interventions reduced symptoms of depression in mothers (mean difference, intervention vs control: -3.00; CI: -4.24 to -1.77) and fathers (mean difference: -1.64; CI: -3.12 to -0.16). There were no differences in symptoms of anxiety in mothers (mean difference: 1.13; CI: -0.21 to 2.47) or fathers (mean difference: -0.38; CI: -1.86 to 1.09), as compared to the control group.

The articles by Aho [30] and Raitio [31], based on the same study, included fathers [29] and mothers [31] immediately after the death of their child with follow-up 6 months after leaving hospital. The Bereavement follow-up intervention included an information package, peer contact and contact with healthcare staff. Intervention fathers reported stronger personal growth on the Hogan Grief Reaction Checklist (n = 62, median 2.75, range 1.50–4.58), than the control fathers (n = 41, median 2.33, range 1.33–4.17) at follow-up (p < 0.03), but there were no statistically significant differences on any of the other dimensions/subscales of grief reactions. The grief reaction checklist tested on mothers [32], showed no statistically significant differences between the intervention group and the control group.

Certainty of evidence

All results were rated as having very low certainty, indicating unclear effects of the interventions (Table 2). The downgrading of certainty was attributed to high risk of bias, imprecision, and indirectness. Further details are available in Table 2.

Discussion

The main finding of the present systematic review was that controlled studies investigating the effect of psychosocial support directed towards parents or siblings after a stillbirth are rare. Furthermore, the published studies exhibited a high risk of bias, and all

Table 2
Summary of findings.

Outcome (Effect measure)	Number of participants (Number of studies) Country Reference	Effect (95 % CI)	Certainty of the results (GRADE)	Reasons for downgrading the evidence
<i>Support programs which focus on care after stillbirth</i>				
Psychiatric disorder (General health questionnaire; over the threshold for psychiatric disorder)	50 mothers	<u>Mothers</u>	Very low	Risk of bias –3 ^a Imprecision –1 ^b Indirectness –1 ^c
	50 fathers (1 RCT) England [Forrest, 1982]	RR (95 % KI) = 0.24 (0.06 to 0.93)		
Depression and anxiety (Leeds scales; threshold for pronounced symptoms)	50 mothers	<u>Mothers</u>	Very low	Risk of bias –3 ^a Imprecision –1 ^b Indirectness –1 ^c
	50 fathers (1 RCT) England [Forrest, 1982]	RR (95 % KI) = 0.59 (0.26 to 1.38)		
		<u>Fathers</u>	Very low	Risk of bias –3 ^a Imprecision –1 ^b Indirectness –1 ^c
		RR (95 % KI) = 1.17 (0.19 to 7.07)		
<i>General support programs</i>				
Grief (Grief experience inventory; min= NA, max= NA)	34 mothers (1 RCT) USA [Lake, 1987]	<u>Mothers</u> No statistically significant differences	Very low	Risk of bias –3 ^a Imprecision –2 ^d Indirectness –1 ^c
		<u>Fathers</u> NA		
<i>Programs that facilitate the grieving process</i>				
Depression (Delusions-Symptoms-States Inventory; min=0, max=21 points; higher = more severe symptoms)	79 mothers	<u>Mothers</u>	Very low	Risk of bias –3 ^e
	65 fathers (1 CT) Australia [Murray, 2000]	MD (95 % CI)* = –3.00 (–4.24 to –1.77)		
Anxiety (Delusions-Symptoms-States Inventory; min=0, max=21 points; higher = more severe symptoms)	79 mothers	<u>Mothers</u>	Very low	Risk of bias –3 ^e
	65 fathers (1 CT) Australia [Murray, 2000]	MD (95 % CI)* = 1.13 (–0.21 to 2.47)		
Grief (Hogan Grief Reactions Checklist; 6 dimensions; min =1, max=5 points; higher = more severe symptoms)	139 mothers	<u>Mothers</u>	Very low	Risk of bias –3 ^f Imprecision –2 ^d
	103 fathers (1 block-RCT) Finland [Aho, 2011; Raitio, 2015]	No statistically significant differences		
		<u>Fathers</u> Statistically significant difference for dimension "Personal Growth" = 0.42	Very low	Risk of bias –3 ^f Imprecision –2 ^d

Table 2 (continued)

Outcome (Effect measure)	Number of participants (Number of studies) Country Reference	Effect (95 % CI)	Certainty of the results (GRADE)	Reasons for downgrading the evidence
				points (p = 0.02) No statistically significant differences in the other dimensions
RR = risk ratio; RCT = randomised controlled study; CT = controlled study; CI = Confidence interval; P = p-value				
* Calculated in Review Manager based on data reported in the article				
** The confidence interval includes both a positive and negative effect.				
^a Very high risk of bias due to a large loss to follow up and that the outcome measurement was unblinded and self-reported.				
^b Few participants, and the confidence interval ranges from very little to very large effect.				
^c Care after stillbirth has changed significantly since the 1980's when this study was published. It is therefore likely that the care the control group received differs significantly from standard care today.				
^d The confidence interval includes both a positive and negative effect and insufficient information was provided to determine whether the effects measured are clinically meaningful.				
^e Very high risk of bias due lack of randomisation which may result in substantial confounding factors that were not addressed, and that the outcome measurement was unblinded and self-reported.				
^f Very high risk of bias due to issues with randomisation, high loss to follow-up, and that the outcome measurement was unblinded and self-reported.				

outcomes in this review were assessed as having very low certainty of evidence. The interventions and outcomes also varied significantly, making it challenging to pool the results. None of the studies investigated the effect of support interventions directed to siblings. One reason for the lack of studies may be the difficulty in conducting controlled trials in this population soon after a stillbirth. No studies could be synthesised since they evaluated different complex interventions and reported various outcome measures. One study focused on the immediate care after the loss [29], another on more general interventions and expressing grief [28] and a third on making the grief process easier [30, 31]. There is also a notion of time that might affect the interpretation of the results. The oldest study was published in 1982 [28] and care after stillbirth and bereavement care, in general, might have changed since then.

This systematic review was based on controlled studies where participants received an intervention or were in a control condition. The reason for choosing only intervention studies with controls was to avoid a high risk of bias due to confounding. Studies with other research designs have not been included, such as pre-post design.

In 2013 a Cochrane review acknowledged the need for rigorous randomised controlled trials in the field [4]. Still, very few studies have been published since then. Indeed, two of the included studies in the present review [28,29] were published before the Cochrane review [4] were excluded from that review, mainly due to large loss to follow-up rates.

The research field around bereavement care in the case of stillbirth has developed over the last decades [11,15]. In bereavement care, hospital routines and recommendations on how to support parents were established a long time ago, making it challenging to withdraw support already implemented to study the effects of support interventions. Abandoning parents from standard care after stillbirth would be unethical. Caring for families experiencing a stillbirth is a sensitive topic which might explain the lack of controlled studies. Despite this notion of

sensitivity, more controlled studies are needed to evaluate the effect of support interventions for parents and siblings when a baby is stillborn.

Future studies could benefit from additional support interventions exceeding routine care when a stillbirth occurs. In addition, qualitative studies could enlarge the understanding of stillbirth from the parents' perspective and thereby inform healthcare providers of important outcomes to consider when planning the care [24].

None of the included studies investigated the effect of support interventions to siblings of stillborn babies. This should be prioritised in future studies. In addition, studies with particular groups, such as people who don't master the native language or have certain traditions in bereavement, should be encouraged, as it is well known from previous research that people who do not speak the native language of the country they live in, are often excluded from research and more often exposed to stillbirth [33].

Similarly, refugee women and women without a residence permit are more likely to suffer from ill-health, stillbirth, or birth complications [34]. It has also been reported that foreign-born women are more prone to suffer from depressive symptoms, anxiety, and posttraumatic stress [35]. These circumstances might make them more vulnerable in the case of stillbirth. Foreign-born parents could belong to a religion that demands a quick burial and not always agreeing on an autopsy [36]. It is therefore important with culturally sensitive care, as research has shown that parents value respect and knowledge about their culture and religion [37].

A recently published systematic review regarding the development of a core outcome set in stillbirth care concluded that it is a considerable lack of research on specific intervention types in stillbirth care and that a significant variation in outcome measures is currently used [11]. The systematic review supports that a core outcome set is needed to standardise outcome measures in research to be used in intervention studies, which would strengthen the evidence based on effective interventions and thus inform best practice and improve care [11].

Conclusion

To evaluate the effect of bereavement support interventions in parents and siblings after stillbirth more controlled trials with rigorous methods and interventions beyond the existing support and care already implemented in standard care are needed. Future studies should include similar outcome measures, when possible, to make studies more comparable. All of the studies in this review were assessed to have an overall high risk of bias mainly because there were problems with missing outcome data; thus, future studies could specifically target this problem if possible.

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CRediT authorship contribution statement

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Ethical approval

Not applicable.

Conflict of interest

None declared.

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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.2024.01.007.

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