

Women's Experiences of a Specialist Antenatal Service for Pregnancies After a Stillbirth or Neonatal Death: A Qualitative Interview Study and Social Return on Investment Analysis

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Abstract

Background Pregnancy after the death of a baby is associated with a series of emotional and psychological challenges for pregnant women and their families. Specialist antenatal services have been proposed to address the increased biomedical and psychological risks in pregnancies after perinatal death. This study aimed to explore the pregnancy and postnatal experiences of women in a pregnancy after a perinatal death who were attending a specialist antenatal service and to evaluate the economic impact of the service.

Methods To explore women's views and experiences of care during their pregnancy this study used face-to-face semi-structured interviews following a topic guide comprising of four sections (history leading to care pathway, their experience of coping with new pregnancy after loss, support and advice for others). Following inductive thematic analysis, a deductive approach was taken to map themes to Stroebe and Schutt's Dual Process Model of Grief.

A Social Return on Investment (SROI) analysis informed by contributions from a subgroup of women and staff participants. Information was obtained from focus groups discussions, questionnaires and interviews. The SROI was reported as the ratio of the value generated by the clinic and the costs of providing the service.

Results Thematic analysis of interviews (n=20) described how perinatal death was a *quiet, unspoken subject* and that navigating subsequent pregnancies relied on *expecting the worst and hoping for the best*. Mapping these themes onto the Dual Process Model of Grief found being pregnant complicated the grieving process, as increased awareness of the risk of stillbirth drew parents' focus back to loss. Attendance at a specialist service was valued; SROI analysis found that for £1 invested, £6.10 of value was generated, mostly relating to the birth of a live baby, reduced negative psychological symptoms and fewer focussed contacts with health professionals.

Conclusions Specialist antenatal care in pregnancies after perinatal death was viewed favourably by parents. Women's experiences can be used to synthesise and develop models of care that aim to meet their needs but comparative studies are required to determine whether these models are superior to routine high-risk care and to identify which components are most valued.

Background

A pregnancy following a stillbirth or neonatal death in a prior pregnancy is associated with a series of emotional and psychological challenges for pregnant women and their families; these pregnancies are characterised by increased anxiety, depression and perceived stress, emotional vulnerability and decreased confidence that the next pregnancy will have a healthy outcome [1–3]. In a subsequent pregnancy, many mothers and fathers report the loss of 'normal' positive feelings they expected and have described how their subsequent pregnancies were characterised by heightened anxiety and fear [2]. These emotions are compounded by common societal misconceptions, such as the new pregnancy helps

parents to 'get over' grief for a dead child which isolates parents from social support networks, increasing their reliance on professionals or other parents with similar experiences.

Qualitative studies of women's experiences of subsequent pregnancies highlight the value placed on regular interaction with health professionals [4, 5]. This has led to the suggestion that specialist antenatal support might reduce anxiety, improve experiences of pregnancy, support relationships and positively impact on future parenthood [6]. To address the need for increased support and specialist care in subsequent pregnancies, dedicated "pregnancy after loss" services have developed. An evaluation of 10 women attending such a clinic in a tertiary maternity unit in Australia described seven themes from semi-structured interviews relating to respondent's experiences of the pregnancy after loss clinic and other services and recommendations for improvement [7]. This study recommended further evaluation of such antenatal services with larger, representative samples. Furthermore, evaluation of specialist services for pregnancy after loss was ranked as urgent and important by 73% of respondents participating in a research priority setting exercise regarding pregnancy after stillbirth [8]. However, only 39% of respondents agreed that a randomised controlled trial (RCT) was the best way to evaluate different forms of psychosocial support, with fewer than 50% believing that such a study was feasible [8]. Care in pregnancies after loss could be improved by a better understanding of parents' experiences [9, 10], as this approach has been successfully employed for bereavement care after stillbirth [11] (which has also not been evaluated by RCTs [12]).

A specialist pregnancy after loss service (the Rainbow Clinic) was established at Saint Mary's Hospital, a tertiary maternity unit in Manchester, UK in 2014. This was expanded to a neighbouring maternity unit in Wythenshawe, South Manchester in 2016. The model of care provided by the clinic has been described in detail elsewhere [13], but focuses on continuity of care provided by an experienced multidisciplinary team consisting of obstetricians, midwives, bereavement midwives and administrative staff with access to specialist perinatal bereavement counselling if required. Care follows the international consensus statement for care in pregnancies after stillbirth [14] and is individualised based upon prior history of loss, maternal medical disorders and findings on ultrasound scans performed throughout the pregnancy. This study aimed to explore the pregnancy and postnatal experiences of women attending a specialist antenatal service for women with a history of previous perinatal death and to assess the economic value of the specialist service.

Methods

Following ethical approval (Ref 16/NW/0258) the study was conducted between 22/09/2016 and 21/12/2018 at St Mary's Hospital and Wythenshawe Hospital, Manchester, UK. Pregnant women were eligible for inclusion if they were attending the specialist antenatal service for care in a pregnancy after perinatal death. Women were excluded if they were less than 16 years of age, lacked capacity to consent or who had been diagnosed with pregnancy complications or received treatment for an acute mental health issue in this pregnancy.

Semi-structured interviews and qualitative analysis

Face-to-face semi-structured interviews were conducted with a sub-group of women from a larger study to explore their views and experiences of care during their pregnancy [3]. The interview topic guide was designed by research team with input from a patient panel who had attended the research clinics at St Mary's Hospital. It comprised four sections (history leading to care pathway, their experience of coping with new pregnancy after loss, support and advice for others). Two interviews were planned, one in the antenatal period and one in the postnatal period. Interviews were conducted by one of two researchers (postgraduate students) with training and support from the research team, interviews were digitally audio-recorded and transcribed verbatim by the researcher.

Two steps to analysing the qualitative data were undertaken; the focus of the analysis was on the current pregnancy and the experience of health care in this pregnancy. The six-stages of thematic analysis as described by Braun and Clarke (2006) were used as a template to analyse qualitative data from the interviews and identify semantic level themes [15]. The initial stages of thematic analysis (Stage 1–4) were conducted by one author (DS), a psychologist with expertise of research methodologies but no personal experience of stillbirth or neonatal death and who had not been involved in conducting the interviews. The experiences of two further authors (AH and ST) were introduced at stage 5 and 6 to allow for theme discussion and contextualisation.

The second step of analysis was undertaken once the themes had been constructed through the steps described above. The aim of this step was to understand the women's current pregnancy experience with the lens of an established model of bereavement to help further explain their care needs. A deductive approach was taken and one researcher (DS) mapped the themes and subthemes onto the Dual Process Model of Coping with Bereavement (Stroebe & Schut, 1999 [16]) and through discussions with authors AH and ST some suggested edits were made to the model to fully encompass the experiences of women pregnant after previous losses.

Social Return on Investment Analysis

A Social Return on Investment (SROI) approach was selected as it attempts to capture the intangible, hard to measure social and environmental value of an intervention in financial units, i.e. £ of value delivered per £ spent. As the intangible costs of stillbirth are considerable [17] and are likely larger than direct costs, this methodology was employed to evaluate the impact of Rainbow Clinic [18]. The SROI analysis employed a six-stage approach: i) establishing scope and identification of stakeholders, ii) mapping outcomes via focus groups with patients, partners and staff, iii) evidencing the outcomes and giving them a value, iv) establishing the impact and the degree to which this was attributable to the Rainbow Clinic, v) calculating the SROI and vi) reporting and embedding the information. In total, 18 women, 3 partners, 4 Rainbow Clinic staff, 2 stakeholders from other maternity units and one representative each from St Mary's Hospital and Tommy's charity contributed to determining the scope of the analysis and relevant stakeholders. Two focus groups of 21 participants and a service user survey (n = 14) were used to measure outcomes and correct for deadweight (the service user and wider outcomes

in the absence of Rainbow Clinic), attribution (the proportion of benefit that could be attributed to the Rainbow Clinic) and displacement (benefits borrowed from elsewhere in the healthcare system). Indicators and proxy variables were identified from currently available secondary data including NHS reference costs [19]. The SROI was reported as the ratio of the value generated by the clinic and the costs of providing the service. Sensitivity analyses were conducted to determine the effect of changing input costs and the value of outputs.

Results

Qualitative Study

Twenty women were interviewed during pregnancy with six of these being interviewed for a second time after birth. The antenatal interviews had a mean length of 38 minutes and the postnatal interviews had mean duration of 25 minutes. Of these 20 women, 13 reported one previous stillbirth, three reported two stillbirths, three reported one neonatal death and one reported both a neonatal death and stillbirth. The number of children that women had given birth to ranged from one to eight. All women had a live born infant, the gestation at birth ranged from 29 weeks to 39 weeks of pregnancy. Fourteen women were White British, one was White European, one was Indian, one was Black African and three did not disclose their ethnicity. Eleven women were married or in a civil partnership, six were single and three did not record their marital status. Thirteen women were employed, one was a homemaker and two were unemployed, three did not disclose their employment status.

Following the inductive analysis, two themes were identified in the antenatal interviews to encapsulate the women's experiences of their current pregnancy following previous loss(es): *'It's just such a quiet and unspoken subject'* and *'Expect the worst, hope for the best'*. Both themes included two subthemes each which are outlined below with excerpts from the interview transcripts to provide context. Within the themes, a number of expressed emotions were evident, these are presented below in the words used by the women in the interviews and thus are in italics.

Theme 1: 'It's just such a quiet, unspoken subject' (Alice)

The women's increased awareness of the risks in pregnancy due to their previous loss(es) of a baby influenced their experience in this pregnancy and as one woman called it *'my reality'* (Hazel). Several of the women had experienced the death of more than one baby. Women reflected that as the death of a baby was not openly talked about in society they previously had low awareness. The resulting shock and guilt felt following their previous loss(es) carried through into this pregnancy and the women talked about the ways they protected themselves and their baby to attempt to create a state of normality. Their experience in subsequent pregnancies was noted to be different *'I don't really feel like a normal expectant parent'* (Sarah). Two subthemes described navigating their subsequent pregnancy: protective environment of clinic and a need to protect others.

Protective environment of clinic: A number of women described that attending the Rainbow Clinic in this pregnancy was reassuring as it offered a protected environment. Women felt protected in several ways.

Firstly, they felt relief at not having to repeat their pregnancy story at each appointment and the negative emotions associated with talking through the details with different health professionals. Secondly, they felt they could trust the staff as they were being cared for by the same team of health professionals who had time for them and did not rush their appointment. It was acknowledged by all women that the Rainbow Clinic staff were experts, who could provide personal care to them, the link to the stillbirth research programme also increased confidence in the team. Being cared for by the same health professionals throughout their pregnancy was emphasised by a number of women as something that felt familiar and reduced stress. Thirdly, they felt they were not alone as they knew the other women at the clinic were in the same situation as them and they could relate to them. This also made them feel a ‘... *sense of validation...*’ (Jessie) as their situation was recognised by the staff and peers. However, this also felt daunting to some women due to an awareness of the sadness felt by all of the patients. Finally, the increased frequency of the appointments and the flexibility to arrange additional appointments if desired was valued by the women as it made them feel more relaxed. Being under the care of the Rainbow Clinic and in this protected environment led women to feel less anxiety and was referred to after birth as a ‘... *security blanket...*’ (Cassie).

‘It feels like with the Rainbow Clinic, the anxiety is cut out before it even has a chance to exist. It’s just more personalised care...’ (Hope)

‘It feels like we’re protected and we’ve realised that we are different, but it’s like our own personal space...’ (Chloe).

Conversely, women expressed general disappointment with postnatal care after hospital discharge and many highlighted a lack of any postnatal follow up from the specialist clinic. The necessity of focus on antenatal monitoring and support in subsequent pregnancy was recognised, but the lack of contact in the postnatal period left women feeling abandoned.

‘...I feel like you have built up a closer relationship...it was a bit weird never hearing or seeing them again after that...’ (Sarah).

Some of the women talked about the birth of their baby and milestones after this, reminding them of what they did not have with the child that they lost and they reported a negative impact on their wellbeing.

A need to protect others: The women acknowledged that their awareness of baby loss was not shared by others and they frequently mentioned wanting to protect other people who did not have this experience. They felt it was their responsibility to protect other people, especially partners, family and friends, from the negative emotions that they experienced.

‘It’s not just me that’s worried...it’s that ripple effect of this one thing affecting so many other people as well’ (Geordie Mama)

Women talked about their partners having little support and finding it difficult to express their feelings and the impact of these on their mental wellbeing '*...men don't speak about emotions really, he's just like one of these everything will be fine and if it's not, he's one of these that deals with it when it does happen*' (Natalia). To protect close friends and family, women delayed telling them about their current pregnancy as they feared how they would cope with the new situation. Likewise, women avoided mixing with other pregnant women (such as standard antenatal classes) as they did not want to share experiences and expose them to the reality of loss and did not want them to feel uncomfortable if asked about their pregnancy story. Finally, some women wanted to protect the child they lost as they did not want their current pregnancy or baby to replace them, this led to feels of guilt,

'I just felt guilty every time I got pregnant like I was betraying him, kinda thing' (Natalie).

Theme 2: 'Expect the worst, hope for the best' (Alice)

As stated above, women were more aware of the risks due to their previous experiences and entered their current pregnancies with trepidation. This increased awareness of risks led to heightened levels of anxiety and fear at certain points in pregnancy including the period immediately before scans or appointments and the end of the pregnancy. Women felt responsible for their baby and felt mixed emotions about their pregnancy as a result of the fear of another loss. Many spoke of the desire to stop being led by fear and to stop feeling angry as this was disruptive to their wellbeing, to do this women engaged two approaches which are summarised in these subthemes: Control and hope.

'I feel bad about it because like I'm so grateful to be in this position, but yeah I feel so bad because I'm so scared and so worried and upset' (Lauren)

'I want to move on and move forward' (Geordie Mamma)

Control: Women felt responsible for their baby and they felt they had little control over their previous loss(es) so they attempted to exert control over their emotions and their behaviours in their current pregnancy. A few women outlined that they did not let themselves form a psychological and physical attachment with their baby, seeing them not give the baby a name or buy any items for their baby. The Rainbow Clinic offered them control as they were given more appointments and scans when they needed them which offered reassurance.

'...all the reassurance that you do get has been fabulous. Knowing that if I need extra scans, if I need to come in and speak to someone, all I have to do is ring up...' (Julia)

'I can't let myself get excited about it because you know, I don't know you almost become disassociated with it because I think because you don't really want to let yourself get too excited about it' (Michelle).

Hope: Women wanted to have hope as they wanted to enjoy the pregnancy and this baby, however, this was challenged by their increased awareness of risk. Women expressed a mixture of feelings as their pregnancies progressed, some women felt more anxiety as they reached the gestation of their previous loss(es) and one mentioned feeling like they were '*..walking a tight rope everyday..'* (Judith) until the end

of pregnancy. Whereas, some felt more confident and hopeful in their pregnancy outcome. These mixed feelings in pregnancy saw many women suppress feelings of excitement for the current pregnancy. Feeling movements of their baby for many women felt reassuring and gave them hope and the absence of movement was something that women reported as being anxiety provoking during the early stages of the pregnancy. When discussing partner's feelings about hope, women outlined similar attitudes expressed by their partners.

'...the first part you are anxious but...you don't know what's happening inside you...rely on the baby's movements...' (Sophia)

'he's [partner] warming up now but he's always waiting for something to go wrong' (Julia).

These mixed feelings led to many women not preparing psychologically and physically for their baby. The postnatal interviews saw participants reflect that they have not accepted what it would be like if they gave birth to a live baby which they took home with them. A few women reported seeking support from healthcare providers and also charities to support their postnatal preparation, but the rest of the women did not have any support and felt this was needed to enable them to both prepare psychologically and manage their emotions. Several women reported feeling anxious and panic about how to care for their baby as they had not allowed themselves to feel emotional attachment to a baby and had not attended any antenatal education groups.

'...it was very, very difficult bringing him home and S [husband] and I cried a lot on the way home because we just got upset that we hadn't had the opportunity to bring J home...' (Geordie Mama)

'...it [speaking to the counsellor] was more about talking through the emotions of what it would meant to hopefully bring home a, you know a baby, a health baby at the end of this given that had happened last time, how that was going to affect me, how it was going to bring things back...' (Sarah)

Using a deductive approach, the themes and subthemes were mapped onto the Dual Process Model of Coping with Bereavement according to women's expressed emotions and experiences of coping during their subsequent pregnancies. Since their loss, the women had been coping with their bereavement through their 'everyday life experiences'. However, during these interviews the women were experiencing their bereavement during pregnancy, the life experience that was directly related to their loss and bereavement, this complicated the oscillation process between loss-orientation and restoration-orientation. Furthermore, they had an increased awareness of the risk of pregnancy loss which drew focus back to loss. This added element to the model sees women reliving the psychological and physiological state of pregnancy and all the time-specific events associated with this such as scans and baby movements (Fig. 1).

The emotions associated with theme 1 (It's such a quiet unspoken subject) of shock and guilt were associated with the loss-orientation state. Whereas, the coping strategies used by the women across both

themes (four subthemes) were located in the restoration-orientation. Theme one (expect the worst, hope the best) showed the journey of women from the loss-orientation state to the restoration-orientation state.

Social Return on Investment Analysis

The focus group discussions and interviews with parents, staff and stakeholders identified 14 outcomes of the clinic for quantification. The patient-related outcomes were: reduced healthcare costs, reduced experience of depression and anxiety during pregnancy, greater connection with baby, reduced isolation and a greater sense of control and ability to plan and reduced post-natal depression. The proportion of change related to attendance at the specialist clinic ranged from 64% for reduced postnatal depression through to 100% for reduced use of ultrasound or attendance with other health professionals (Fig. 2A). The social return on investment was calculated to be £1,358,400 compared to the cost of running the service of £223,958, giving a ratio of 6.10 (i.e. for every £1 invested £6.10 of benefit was derived). This was dominated by the value attached to the birth of a live baby (£499,944), if this value were subtracted, the total social return on investment was £858,456 giving a ratio of 3.81 (Fig. 2B).

Discussion

This study provides a holistic view of women's experiences in the antenatal and immediate postnatal period in a pregnancy following a stillbirth. Using a thematic analysis approach, two themes were developed: *'It's just such a quiet and unspoken subject'* and *'Expect the worst, hope for the best'*. The findings also describe the impact of attending a specialist antenatal service by reducing participant's negative psychological symptoms and consequent health behaviours e.g. attending additional focussed appointments.

Strengths and Limitations

This study is strengthened by the combination of qualitative interviews and social return on investment methodology to describe women's experiences of pregnancy after stillbirth and capture the associated intangible costs. However, this study did not employ a comparative design so conclusions cannot be drawn about whether this model of care achieves better outcomes than standard care. As not all women participated there may be a selection bias which could impact upon the responses; it is plausible that non-participants may have had more negative experiences of a subsequent pregnancy or the model of care.

Contextualising the findings

Although there is a wealth of evidence that pregnancy after loss requires additional antenatal care in terms of support from professionals and investigations to identify recurrent or related conditions to help parents navigate the increased risk of psychological and medical complications [2], there are few studies that evaluate the impact of specialist antenatal services [14]. Furthermore, there is limited research looking at the impact of attending specialist services on long term parenting behaviours. Warland et al., interviewed 13 parents about their experiences of parenting following a previous loss and attendance at a specialist service and found that the loss influenced their parenting in that they talked about every

aspect of parenting in two extreme forms e.g., 'in control/out of control' [20]." They concluded that more research needed to look at the long term impact on parenting and namely the mental health of parents and emotional development of their children. The importance of research into care in pregnancies after loss was emphasised by its inclusion into stillbirth research priorities identified by over 1,000 parents and professionals [21].

The findings presented here provide a detailed insight into the experiences of women attending a specialist antenatal service for perinatal loss. Whilst this study was carried out in the North-West of the UK its findings are similar to those reported elsewhere, indicating the transferability of some of the recommendations for care. The themes derived from the qualitative interviews showed similarities with previous research such as Meredith et al.'s thematic analysis of ten parents attending a pregnancy after loss clinic (PALC) in Brisbane [7]. In both studies, women describe the mixture of emotions felt in their pregnancy including the guilt of having another child, while not wanting to forget their stillborn baby. Also, women viewed a specialist service positively, giving security, understanding and reassurance that their emotional responses were normal. Meredith et al. also noted the important effects on the wider family unit which were not assessed here [7]. Further research is needed to investigate whether a specialist antenatal service for pregnancy after loss improves partner's and other family member's experience. Likewise, more work is needed to understand the emotional and psychological experiences of parents following birth as this study demonstrated that women try to protect themselves emotionally, in case of another loss. The impact of these experiences on parenthood and mother-child attachment are not well understood, although disorganized attachment has been described [22].

In their seminal papers on the Dual Process Model of Grief, Stroebe and Schutt described grief as something personal that is experienced in an iterative manner [16]. When the themes derived from the qualitative interviews were mapped to the Dual Process Model, it was evident that although restoration-orientation behaviours were commonly reported, navigating pregnancy after loss saw parents relive events that led to the loss of their baby which in turn leads to increased oscillation between loss- and restoration- oriented behaviours. Individuals who have greater restoration oriented behaviour have better adjustment after the death of a child, and these behaviours to some extent buffered the negative effects of loss oriented experiences [23]. The current findings suggest that pregnancy-related events hinder the bereavement as they evoke memories and emotions leading to loss-orientation behaviours. This analysis increases our theoretical understanding of the process of bereavement and provides a cogent reminder that professional or lay support may be required to allow parents to develop more restoration-oriented behaviours in pregnancies following a stillbirth or neonatal death. Early intervention at this stage may have long term impacts on parenting and thus the mental wellbeing and development of parents and children [20]. Further research is needed to determine how this can be best provided and to understand how being in the same physiological state with physical reminders (e.g., scan appointments for pregnancy) can influence the bereavement process.

Pregnancies after loss are associated with increased resource use [24], Hutti et al. described that resource use was associated with increased maternal anxiety and depressive symptoms [25]. One potential reason

for this is that women whose care needs are not being met, may have increased anxiety and depression and also seek additional appointments from healthcare professionals. As many costs associated with stillbirth are “intangible” [17], we adopted a SROI analysis. In agreement with the hypothesis outlined above, parents reported that attendance at the specialist antenatal service reduced their anxiety and depressive symptoms and reduced the number of consultations during pregnancy. After the birth of a live baby, these were the largest areas of benefit derived from the specialist clinic. Our analysis suggests that the specialist clinic provides a significant social return on investment in keeping with other reported interventions in reproductive health (range 1.73–21.20) [26]. Thus, wider implementation of a specialist antenatal service would be viewed as providing social value and would address current efforts to personalise maternity care (e.g. UK Maternity Transformation Programme).

Conclusions

This study provides a detailed view of women’s experience in pregnancies after perinatal death. As previously described, provision of specialist care in a dedicated clinical service was viewed favourably, but comparative studies are required to determine whether this model is superior to routine high-risk care and to identify which components of the dedicated service are valued. A recent prioritisation study found 73% of respondents indicated that this was an urgent and important research question to be addressed [8], but that participants stated that RCTs were not perceived as the best means to evaluate psychological and social support. Therefore, thought needs to be given to how best care in pregnancy loss can be discerned so that evidence-based care can be introduced to address the wide variation in the quality of care women receive in pregnancies after perinatal death [27]. Further studies are also needed to understand partners’ and other family member’s experiences of pregnancy/ies after stillbirth to appreciate which aspects of care and support are beneficial to them in a future pregnancy.

List Of Abbreviations

PALC Pregnancy After Loss Clinic

RCT Randomised Controlled Trial

SROI Social Return on Investment

UK United Kingdom

Declarations

Ethics approval and consent to participate

All experimental protocols were approved by Greater Manchester East Research Ethics Committee (Ref 16/NW/0258). All participants gave written informed consent prior to participation; all methods were performed in accordance with the relevant guidelines and regulations.

Consent for publication

Not applicable

Availability of data and materials

The datasets generated and/or analysed during the current study are not publicly available as ethical approval was not sought for their dissemination but are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests

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Authors' contributions

Contribution of Authorship: Conception (AEPH, ST, TAM, DMS), planning (AEPH, ST, TAM, DMS, AMA), carrying out (LS, ST, CH), analysing (AEPH, ST, DMS), writing up (AEPH, ST, DMS, AMA). All authors have seen and approved the final draft of the manuscript.

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References

1. Hunter A, Tussis L, MacBeth A: **The presence of anxiety, depression and stress in women and their partners during pregnancies following perinatal loss: A meta-analysis.** *J Affect Disord* 2017, **223**:153-164.
2. Mills TA, Ricklesford C, Cooke A, Heazell AE, Whitworth M, Lavender T: **Parents' experiences and expectations of care in pregnancy after stillbirth or neonatal death: a metasynthesis.** *BJOG* 2014, **121**(8):943-950.
3. Thomas S, Stephens L, Mills TA, Hughes C, Kerby A, Smith DM, Heazell AE: **Measures of anxiety, depression and stress in the antenatal and perinatal period following a stillbirth or neonatal death: a multicentre cohort study.** *BMC pregnancy and childbirth* 2021, **Submitted**.

4. Cote-Arsenault D, Donato KL, Earl SS: **Watching & worrying: early pregnancy after loss experiences.** *MCN Am J Matern Child Nurs* 2006, **31**(6):356-363.
5. Cote-Arsenault D, Donato KL: **Restrained expectations in late pregnancy following loss.** *J Obstet Gynecol Neonatal Nurs* 2007, **36**(6):550-557.
6. Caelli K, Downie J, Letendre A: **Parents' experiences of midwife-managed care following the loss of a baby in a previous pregnancy.** *Journal of advanced nursing* 2002, **39**(2):127-136.
7. Meredith P, Wilson T, Branjerdporn G, Strong J, Desha L: **"Not just a normal mum": a qualitative investigation of a support service for women who are pregnant subsequent to perinatal loss.** *BMC pregnancy and childbirth* 2017, **17**(1):6.
8. Wojcieszek AM, Heazell AE, Middleton P, Ellwood D, Silver RM, Flenady V: **Research priorities and potential methodologies to inform care in subsequent pregnancies following stillbirth: a web-based survey of healthcare professionals, researchers and advocates.** *BMJ Open* 2019, **9**(6):e028735.
9. Downe S, Schmidt E, Kingdon C, Heazell AE: **Bereaved parents' experience of stillbirth in UK hospitals: a qualitative interview study.** *BMJ Open* 2013, **3**(2).
10. Kingdon C, Givens JL, O'Donnell E, Turner M: **Seeing and Holding Baby: Systematic Review of Clinical Management and Parental Outcomes After Stillbirth.** *Birth* 2015, **42**(3):206-218.
11. Ellis A, Chebsey C, Storey C, Bradley S, Jackson S, Flenady V, Heazell A, Siassakos D: **Systematic review to understand and improve care after stillbirth: a review of parents' and healthcare professionals' experiences.** *BMC pregnancy and childbirth* 2016, **16**:16.
12. Koopmans L, Wilson T, Cacciatore J, Flenady V: **Support for mothers, fathers and families after perinatal death.** *Cochrane Database Syst Rev* 2013(6):CD000452.
13. Heazell AE, Wojcieszek AM, Graham N, Stephens L: **Care in pregnancies after stillbirth and perinatal death.** *International Journal of Birth and Parent Education* 2018, **6**(2):23-28.
14. Ladhani NNN, Fockler ME, Stephens L, Barrett JFR, Heazell AEP: **No. 369-Management of Pregnancy Subsequent to Stillbirth.** *J Obstet Gynaecol Can* 2018, **40**(12):1669-1683.
15. Braun V, Clarke V: **Using thematic analysis in psychology.** *Qual Res Psychol* 2006 **3**(2):77-101.
16. Stroebe M, Schut H: **The dual process model of coping with bereavement: rationale and description.** *Death Stud* 1999, **23**(3):197-224.
17. Ogwulu CB, Jackson LJ, Heazell AE, Roberts TE: **Exploring the intangible economic costs of stillbirth.** *BMC pregnancy and childbirth* 2015, **15**:188.
18. Nicholls J, Lawlor E, Neitzert E, T. G: **A guide to social return on investment.** In., 2nd edition edn. London: The Cabinet Office; 2012.
19. England. N: **National Schedule of Reference Costs 2018/19 [Internet].** In.; 2019.
20. Warland J, O'Leary J, McCutcheon H, Williamson V: **Parenting paradox: parenting after infant loss.** *Midwifery* 2011, **27**(5):e163-169.
21. Heazell AE, Whitworth MK, Whitcombe J, Glover SW, Bevan C, Brewin J, Calderwood C, Canter A, Jessop F, Johnson G *et al*: **Research priorities for stillbirth: process overview and results from UK**

- Stillbirth Priority Setting Partnership.** *Ultrasound in obstetrics & gynecology : the official journal of the International Society of Ultrasound in Obstetrics and Gynecology* 2015, **46**(6):641-647.
22. Hughes P, Turton P, Hopper E, McGauley GA, Fonagy P: **Disorganised attachment behaviour among infants born subsequent to stillbirth.** *J Child Psychol Psychiatry* 2001, **42**(6):791-801.
23. Wijngaards-de Meij L, Stroebe M, Schut H, Stroebe W, van den Bout J, van der Heijden PG, Dijkstra I: **Parents grieving the loss of their child: interdependence in coping.** *Br J Clin Psychol* 2008, **47**(Pt 1):31-42.
24. Mistry H, Heazell AE, Vincent O, Roberts T: **A structured review and exploration of the healthcare costs associated with stillbirth and a subsequent pregnancy in England and Wales.** *BMC pregnancy and childbirth* 2013, **13**:236.
25. Hutti MH, Armstrong DS, Myers J: **Healthcare utilization in the pregnancy following a perinatal loss.** *MCN Am J Matern Child Nurs* 2011, **36**(2):104-111.
26. Banke-Thomas AO, Madaj B, Charles A, van den Broek N: **Social Return on Investment (SROI) methodology to account for value for money of public health interventions: a systematic review.** *BMC Public Health* 2015, **15**:582.
27. Mills TA, Ricklesford C, Heazell AE, Cooke A, Lavender T: **Marvellous to mediocre: findings of national survey of UK practice and provision of care in pregnancies after stillbirth or neonatal death.** *BMC pregnancy and childbirth* 2016, **16**:101.

Figures

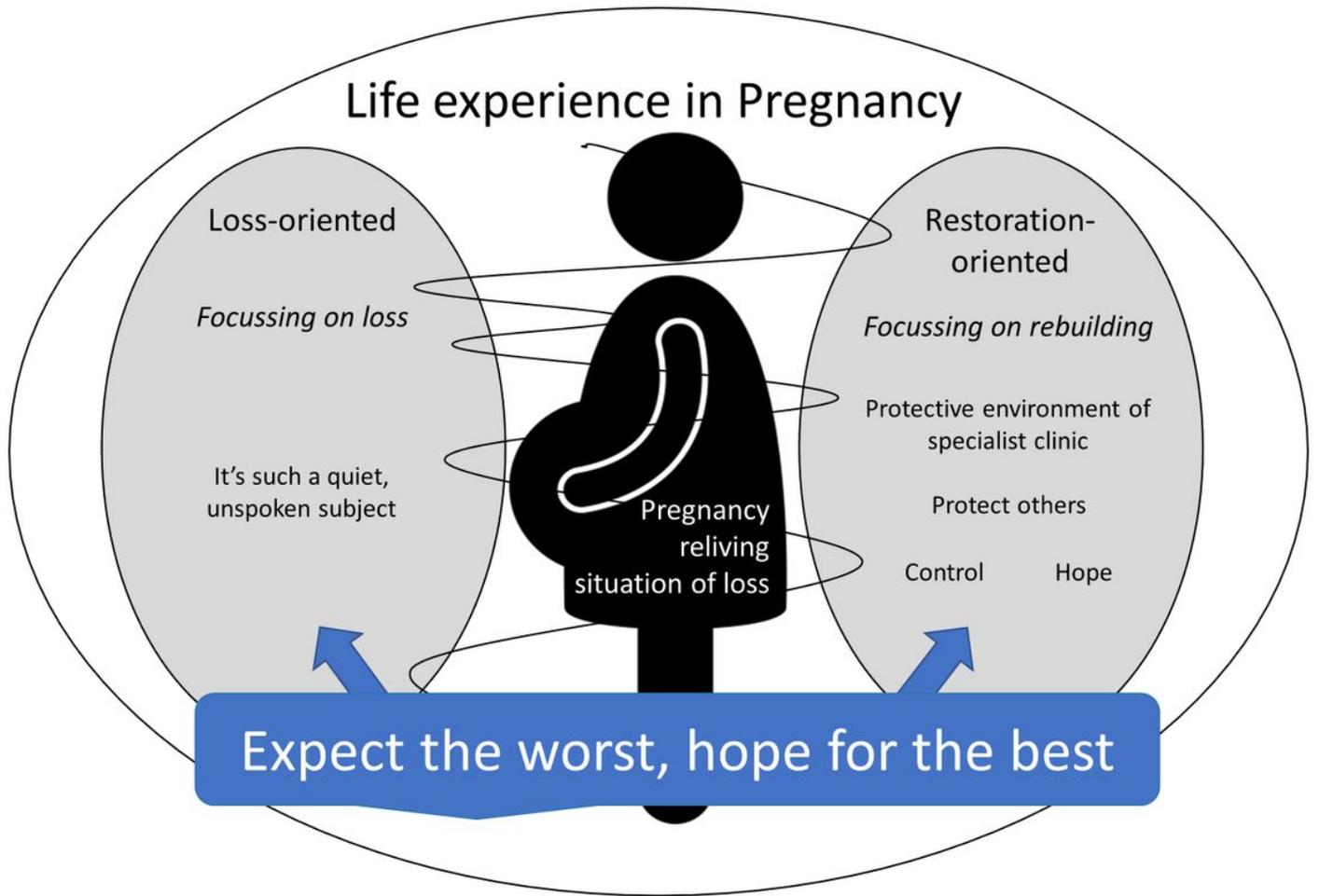
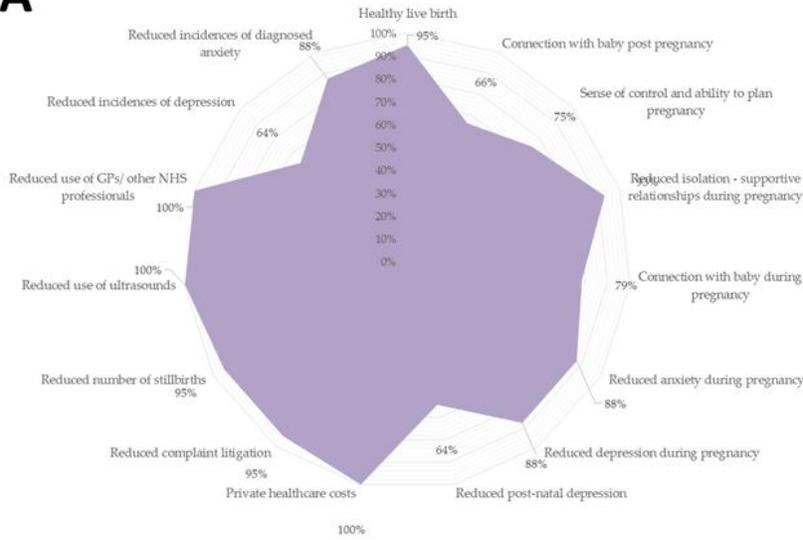


Figure 1

Schematic diagram mapping life experiences described in pregnancy on to the Dual Process Model of Grief [16]. Themes identified in semi-structured interviews are shown in loss-oriented or restoration oriented domains.

A



B

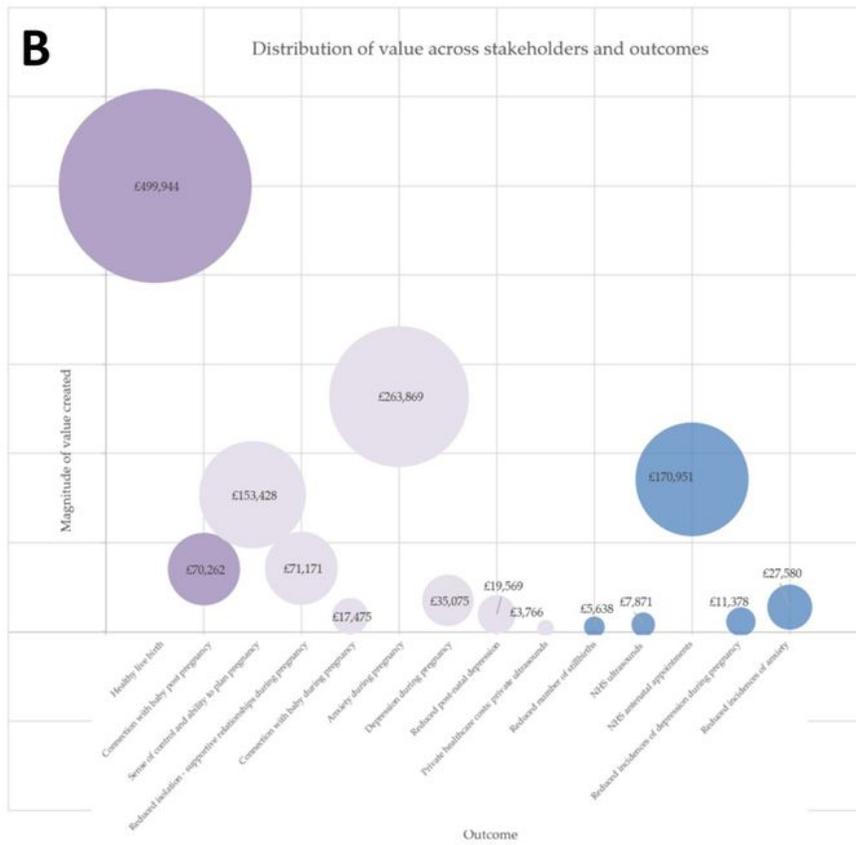


Figure 2

Results of social return on investment analysis showing A) the proportion of change in a given domain attributed to attending the specialist antenatal service and B) the distribution of value generated across different stakeholders and outcomes.