Women's Experiences of a pregnancy whilst attending a Specialist Antenatal Service for Pregnancies After Stillbirth or Neonatal Death: A Qualitative Interview Study.

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Background

Pregnancy following a prior stillbirth or neonatal death is associated with a series of emotional and psychological challenges for women and their families; these pregnancies are characterised by increased anxiety, depression, perceived stress and decreased confidence that the pregnancy will have a healthy outcome [1-3]. Likewise, many mothers and fathers report the loss of 'normal' positive feelings that they expected, such as joy [2].

Qualitative studies of women's experiences of subsequent pregnancies after a stillbirth or neonatal death highlight the value placed on regular interaction with health professionals [4, 5] and social support [2]. 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]. Dedicated "pregnancy after loss" services have developed, although evaluation of such services is rare. An interview study of 10 women attending such a specialist pregnancy after loss clinic in a tertiary maternity unit in Australia made recommendations for future studies including the need for larger, representative samples [7]. Furthermore, the urgent need for evaluations of specialist services for pregnancy after loss was suggested by 73% of respondents (n=79) when being asked to prioritise pregnancy after loss research [8]. Women's experiences of a stillbirth have informed care [9, 10], however a study is yet to be conducted in the UK to explore women's experiences of pregnancy whilst attending a specialist antenatal clinic in a subsequent pregnancy following loss.

A specialist pregnancy after loss service (the Rainbow Clinic) was established in 2014 at a tertiary maternity unit in Saint Mary's Hospital in Manchester, UK. In 2016, this model of care was expanded to Wythenshawe Hospital, Manchester, UK. The model of care provided by the clinic has been described in detail elsewhere [11], but focuses on continuity of care provided

by an experienced multidisciplinary team with access to specialist perinatal bereavement counselling. Care follows the international consensus statement for care in pregnancies after stillbirth [12] and is individualised based upon prior history of loss, maternal medical disorders and findings on ultrasound scans performed throughout the pregnancy. The current study aimed to explore women's experiences of pregnancy whilst attending this specialist antenatal service for pregnancy after loss.

Methods

Following ethical approval (Ref 16/NW/0258) the study was conducted between 22/09/2016 and 21/12/2018 at Saint 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 a stillbirth or neonatal death. Women were excluded if they were less than 16 years of age, lacked capacity to consent, had been diagnosed with pregnancy complications, or were receiving treatment for an acute mental health issue in this pregnancy. Prior to participation women received information about the study from leaflets and verbally from clinic staff, all participants gave written informed consent prior to participation.

Semi-structured interviews and qualitative analysis

Semi-structured interviews were conducted with a sub-group of women who volunteered to take part in an interview after being recruited to a larger quantitative study [3]. An interview topic guide designed by the research team, with input from a patient panel, guided the interviews through four sections: (i) history leading to care pathway, (ii) the experience of coping with new pregnancy after loss, (iii) support received in pregnancy, and (iv) advice for others. Interviews were undertaken in person or by telephone depending on participant

preference. They were digitally audio-recorded and transcribed verbatim. Pseudonyms protected participants' identity.

The focus of the analysis was on the participant's experience of health care in the current pregnancy. The six-stages of thematic analysis (Braun & Clarke, 2006) were used as a template to identify semantic level themes [13]. The initial stages of analysis (1-4) were conducted by one author (DS), and a psychologist with expertise of research methodologies but no personal experience of stillbirth. Two further authors with clinical experience of stillbirth (AH, a consultant Obstetrician; ST, a research midwife) were introduced at stages 5/6 to allow for theme discussion and contextualisation.

Results

Twenty women were interviewed between 23 and 35 weeks' gestation; the mean interview length was 38 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. Demographic characteristics of the participants are summarised in Table 1.

One theme with two subthemes was identified to encapsulate the women's experiences of their current pregnancy following previous loss(es). Awareness of risk in pregnancy due to their experience of pregnancy loss was central to all the women's current maternity experiences. Critically, this increased awareness was not shared by other people (sub-theme 1; *Awareness of risk: 'It's just such a quiet and unspoken subject'*) and had a negative impact on their psychological experience of pregnancy (sub-theme 2; *Awareness of risk: 'Expect the*

worst, hope for the best'). A number of expressed emotions were evident in the interviews and are underlined for emphasis.

Sub-theme 1. Awareness of risk: 'It's just such a quiet, unspoken subject' (Alice)

The women's previous loss(es) heightened their awareness of risk and altered their pregnancy experience as they felt more alone and anxious. Women reflected that the death of a baby is not acknowledged and discussed in society; this contributed to their previous low awareness of the risk of stillbirth (before the death of their baby) and current feelings of isolation. The shock felt following their loss(es) carried through into their current pregnancy and the women talked about the ways they protected themselves to feel less isolated in a society that did not openly recognise stillbirth. A number of women described that attending the specialist clinic during their pregnancy was reassuring as it offered a protected environment where baby loss was acknowledged and discussed, which helped them to feel less alone. Being in this protective environment during their antenatal care meant women felt less anxiety and as it was a *'…security blanket…' (Cassie).*

> *'…having lost, I know how real that possibility is…'* (Lauren)

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

Women's reported several benefits of a specialized antenatal service on their experience of pregnancy. Firstly, continuity of care and building relationships with health professionals who acknowledged their previous loss meant they did not have to repeat their pregnancy story at each appointment, and the negative emotions associated with talking through the details

with different health professionals did not develop. Feeling familiar within these relationships reduced feelings of stress.

> *'Once you've mentioned it once, then that should be kind of it unless you want to bring it up or unless that have to, but when it's something that keeps having to be asked, it's not ideal'* (Ania)

> *'Fantastic [Rainbow Clinic], coz you see the same people all the time, they already know my history'* (Natalie).

Secondly, they felt they could trust the staff who made the time for them to express their concerns, and they were reassured that the Rainbow Clinic staff were *'…experts in the field…'* (Julia) of baby loss, who could provide personal care to them; this interaction provided ongoing reassurance for women making them feel heard and not alone.

> *'…I do enjoy coming as well to this clinic [Rainbow]. Up here, you feel like a person rather than just a number…so I kind of save everything I want to talk about for when I come to the Rainbow clinic'* (Natalia)

> *'…I never feel like its [Rainbow clinic] rushed'* Cassie.

Thirdly, women wanted to avoid pregnant women without experience of loss as they knew their awareness would be low; they wanted to avoid exposing them to the reality of loss and did not want to feel the guilt associated with increasing their awareness of risk. Attending the specialist clinic, women felt they were not alone as they knew the other women there were in the same situation as them. This induced a *'…sense of validation…' (Jessie)* as their situation was recognised. However, the awareness that other women had also experienced loss felt daunting to some women.

'…I had a thing about pregnant people…just meeting the normal ones coz they're always like oh I've got ages left, and you just think how lucky you are, you're pregnant you know. So if I did see people who have had losses its different coz I know they're so appreciative that they're pregnant.' (Natalie)

''I just burst into tears because I knew they were there because they'd had a similar experience to me and it was just so sad to me…' (Hazel).

Finally, women felt it was their responsibility to protect others including friends, family, their partner and their baby, from the *'ripple effect…'* (Geordie Mama) of the negative emotions (e.g., anxiety, worry) that were associated with increased awareness of risk. To protect close friends and family, some women delayed telling them about their pregnancy as they feared how they would cope. Women expressed concern for their partners as they had little or no support outside of their relationship. Some women wanted to protect their feelings about the child they lost as they did not want people to think that their current baby would replace them, this led to feelings of guilt.

'But the problem was that nobody was there for him [partner], coz he had to be there for me…' (Issy).

'…people who've not been through my experience kinda think they are just a replacement and they're not… it's always important not to forget them' (Michelle).

Sub-theme 2: Awareness of risk: 'Expect the worst, hope for the best' (Alice)

As stated above, women were more aware of the risks and loss due to their previous experiences. As such, they entered their pregnancies with trepidation. This led to *'a rollercoaster'* (Cassie) of heightened anxiety and fear at certain points in pregnancy including

the period immediately before scans or appointments, and at the end of the pregnancy. Women spoke of their desire to stop feeling fear and anger, and instead wished to focus on the positive aspects of pregnancy particularly their hopes for a healthy baby. The Rainbow clinic had a central role in this experience, as outlined above, because it made them feel less alone and supported which increased their feelings of 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).

Women also felt they had little control over their previous loss(es) so they attempted to exert control over their current pregnancy, particularly their emotions and behaviours. A few women outlined that they controlled their psychological and physical attachment to their baby by not giving the baby a name or buying any items for their baby. Several also delayed telling others about the pregnancy to prevent them from the sadness they may feel.

> *'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).*

Likewise, the increased number of appointments and scans at Rainbow Clinic meant women felt increasingly reassured and hopeful, and more in control of their pregnancy, which reduced their anxiety . Women valued the increased frequency of the appointments and the flexibility to arrange additional appointments as it gave them some ownership over their care, and they felt more relaxed and less anxious following these appointments.

'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)

'Coming into the Rainbow Clinic, all the reassurance that you do get has been fabulous. Knowing that if I need extra scans, if I need to speak to somebody, all I have to do is ring up and they'll make an appointment for me to come in' (Julia).

Women expressed feeling mixed feelings in pregnancy due to the increased awareness of risk and many reported supressing feelings of excitement. Women wanted to feel hope and to enjoy the pregnancy, however, these positive emotions were constantly challenged by increased awareness of risk which was accompanied by negative feelings such as worry. As their pregnancies progressed, some women felt more anxiety as they reached the gestation of their previous loss(es) with one comparing this feeling to *'..walking a tightrope everyday..' (Judith)*. However, some felt more confident and hopeful as time progressed. Feeling fetal movements for many women increased feelings of hope and the absence of movement made them more anxious, particularly during the early stages of the pregnancy. Knowing that the expert staff at the Rainbow clinic were available for reassurance at any point was vital to the women.

'…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)

'You have to enjoy it, you can't think that its gonna happen again because otherwise what's the point?' (Ania).

These data highlight how women recall their experience of attending a specialist antenatal clinic following a previous stillbirth or neonatal death.

Discussion

This study explores women's experiences of pregnancy after loss while attending a specialist antenatal clinic in the UK. Using a thematic analysis approach, one theme of '*awareness of risk'* and two subthemes were developed to summarise these experiences: *'Awareness of risk: It's just such a quiet and unspoken subject'* and *'Awareness of risk: Expect the worst, hope for the best'*. This study highlights key emotions experienced by women and that specialist care was perceived positively.

Strengths and Limitations

This exploratory study gives us insight into the role of specialist antenatal clinics at two hospitals following a previous stillbirth or neonatal death. The sample was representative of women using the clinical service and participants in a larger quantitative study of service users [3]. However, this study did not employ a comparative design so conclusions cannot be drawn about whether this model of care achieves better outcomes with regard to experience of antenatal care than standard consultant-led care or whether experiences of women differ based on their history (e.g., number of previous stillbirths, gestation at stillbirth). The study initially aimed to interview women twice with an additional interview after birth. However, due to resource constraints we were not able to follow all participants up and collect data in the immediate postnatal period. Thus, the data was not included here as no clear postnatal conclusions or recommendations would have been possible. Future work should include a greater focus on the intrapartum and postnatal experiences of women attending specialist antenatal clinics, and the study design must include a clear plan with adequate resources to

recruit these women as previous studies have found recruitment and follow-up to be low following birth [15].

Contextualising the findings

The best available clinical evidence suggests that pregnancy after loss requires additional antenatal care to identify recurrent or related medical conditions to help parents navigate the increased risk of biomedical and psychological morbidity [2]. However, there are few studies that evaluate the impact of specialist antenatal services on mother's experiences [12]. Furthermore, a Cochrane review was unable to find any randomised controlled trials evaluating psychological or support interventions in pregnancies after loss [14]. The need for further research into care in pregnancies after a stillbirth or neonatal death was identified by over 1,000 parents and professionals and was included in UK stillbirth research priorities [15]. Thus, evaluating the impact of specialist antenatal services for pregnancy after loss to determine optimal care is a cogent need.

The findings presented here provide insight into the experiences of women attending a specialist antenatal service following a previous stillbirth or neonatal death. Whilst this study was carried out in the North-West of the UK, our findings support other research conducted in Australia [7] indicating the likely transferability of some of the recommendations for specialist care in pregnancy after loss. In both this study and Meredith et al's study [7], 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. In both studies, women viewed the specialist service positively as it gave security, understanding and reassurance thus regulating their emotional responses. However, Meredith et al. also noted the important effects on the wider family unit which were not assessed here [7]. Given that (male) partners experience

different challenges after a baby dies [16, 17], further research is needed to investigate whether a specialist antenatal service for pregnancy after loss improves partner's and other family member's experience of subsequent pregnancies as well as the having a positive impact on the parental relationship . Likewise, more work is needed to understand the emotional and psychological experiences of both parents following birth of a live baby. Critically, the impacts of the experience of loss on parenthood and mother-child attachment are not well understood, although disorganized attachment has been described [18]. Thus, moving forwards it is important to build an integrated view regarding the short, medium and longer-term impact of specialist services for pregnancy loss can have on mothers, their partners and their wider family.

The findings of women described here can be used to guide the implementation of perinatal mental health services in the UK and elsewhere. The National Health Service Long Term plan states it will improve access to and the quality of perinatal mental health care for mothers, their partners and children by increasing access to evidence based care provided by specialist teams, including access to psychological services [19]. Perinatal loss is recognised as a specific area in need of psychological support. Key components of care within this area the principles of sensitive, respectful communication, continuity of carer, involvement of other family members and the need for dedicated professionals with sufficient time to provide care. The findings described in qualitative studies to date suggest that these same principles are relevant to pregnancy after loss [20].

Conclusions

This study provides insight into women's experiences of pregnancy whilst attending a specialist antenatal service for pregnancies after a stillbirth or neonatal death. As previously

described, provision of specialist care in a dedicated clinical service was viewed favourably as it helped to control women's anxiety, which was increased due to their awareness of risk. Further studies including comparative studies are required to determine which components of the dedicated service are valued and would benefit from being introduced more widely into care. Therefore, optimal evidence-based care for women experiencing pregnancy after loss needs to be implemented to address the wide variation in the quality of care women currently receive [21]. Further studies need 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. Likewise, specialist postnatal support for women after previous loss needs consideration.

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333 **Table 1 -** Demographic characteristics of the participants.

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Demographic characteristic	**Median (range) for continuous data N (%) for categorical data**
Maternal age (years)	36 (26-41)
Ethnicity	
Black African	1 (5)
Indian	1 (5)
White British	14 (70)
Other White Ethnicity (Irish/European)	1 (5)
Ethnicity not recorded	3 (15)
Marital status	
Single	6 (30)
Married / Cohabiting	11 (55)
Status not recorded	3 (15)
Employment status	
Employed	13 (65)
Not in paid employment	3 (15)
Home maker	1 (5)
Not recorded	3 (15)