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Hope for the best …but expect the worst: A qualitative study to explore how women with recurrent miscarriage experience the early 'waiting period' of a new pregnancy

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Hope for the best …but expect the worst: A qualitative study to explore how women with recurrent miscarriage experience the early 'waiting period' of a new pregnancy

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Abstract

Objective: To investigate how women experience the initial period of a new pregnancy after suffering recurrent miscarriage.

Design: A qualitative study, nested within a randomised controlled feasibility study of a coping intervention for recurrent miscarriage, used semi-structured face-to-face interviews. Interviews were audio-recorded, transcribed verbatim and analyzed utilizing a thematic network approach.

Setting: Participants were recruited from the Recurrent Miscarriage Clinic and Early Pregnancy Unit in two tertiary referral hospitals in the United Kingdom.

Participants: 14 women with recurrent miscarriages and who had previously participated in the RCT feasibility component of the study, were recruited.

Results: Seven organising themes emerged from the data: (1) turmoil of emotions; (2) preparing for the worst; (3) setting of personal milestones; (4) hypervigilance; (5) social isolation; (6) adoption of pragmatic approaches; (7) need for professional affirmation.

Conclusions: The study established that for women with a history of recurrent miscarriage, the waiting period of a new pregnancy is a traumatic time of great uncertainty and emotional turmoil and one in which they express a need for emotional support. Consideration should be given to the manner in which supportive care is best delivered within the constraints of current health service provision.

Trial registration: This study is registered with the ISCTRN registry. Registration number: ISRCTN43571276

Strengths and limitations of this study

- This qualitative study addresses a gap in the literature, providing new and detailed data on how women experience the initial period of a new pregnancy following recurrent miscarriage.
- Qualitative face-to-face interviews enabled the exploration of this sensitive time period, giving participants the opportunity to convey their personal experiences
- While every effort was made to support the recruitment of a diverse sample to this study, the UK setting may limit extrapolation to other national and cultural contexts.

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- The purposive sampling strategy enabled an inclusive approach to data collection from the ethnicities represented in the main feasibility study sample.

Introduction

Miscarriage is the most common adverse outcome of pregnancy [1] and recurrent miscarriage (RM), defined as the loss of three or more consecutive pregnancies, affects approximately 2% of all women trying to conceive [2]. This repeated and unintentional loss of pregnancy has been described as a distinct disease entity [3-5] given that the observed incidence of RM is much higher than would be expected to occur by chance alone. The recently published guidance from European Society of Human Reproduction and Embryology (ESHRE) on the recommended treatment and investigation of recurrent miscarriage highlights the lack of evidence based investigations and treatments available for this condition [2]. Consistent with other guidelines [6] it highlights the need to ensure care is tailored to the psychological needs of couples. Whilst the loss of any desired pregnancy ending in miscarriage is a profound and negative life event, recurrent miscarriage represents an extremely distressing condition that can be both physically and emotionally traumatising. The repetitive nature of recurrent pregnancy loss may intensify the grief and distress experienced, delivering a significant emotional impact on those affected [2]. The experience can evoke intense feelings surrounding a lost baby, a lost future child and a lost motherhood [7].

Numerous studies have investigated emotional morbidity in women in the time period immediately following miscarriage [8-10] and a more recent study concluded that increased levels of psychological distress and major depression are significantly more common among women with recurrent miscarriage compared to women trying to achieve pregnancy who had not experienced this [11]. Furthermore, previous studies, investigating emotional morbidity in women with recurrent pregnancy loss, have indicated that increased levels of anxiety and depression are often experienced throughout subsequent pregnancies [12 13].

The early stages of a new pregnancy when confirmation by ultrasound scan of an ongoing and viable pregnancy is awaited, represent a particularly challenging and difficult time-period for women affected by RM. However, published research data assessing the psychological morbidity associated with the difficult waiting period of a new pregnancy is scarce. One study has suggested that instead of experiencing this period as a time of 'joyful anticipation,' couples who have previously experienced recurrent pregnancy loss frequently experience increased levels of anxiety and worry [14].

The limited data available make it difficult to promote and target the development of therapeutic support for women with RM during the early waiting stages of a new pregnancy. To improve psychological wellbeing during this challenging time, there is a need to develop a deeper and more extensive understanding of lived experiences.

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This study had two main aims. The first was to explore in-depth women's subjective experiences of the study intervention and research methods used in the randomised controlled trial (RCT) for feasibility purposes and the second investigated the lived experience of women with repeated pregnancy loss during the early 'waiting' stages of a new pregnancy. This paper presents the findings from this second element of the study aims.

Methods

Design

This qualitative study was nested within a two-centre RCT feasibility study of a novel self-help intervention designed to support women with a history of RM coping with the waiting period before confirmation of a new ongoing pregnancy [15] . The Positive Reappraisal Coping Intervention (PRCI) [16] is aimed at building coping resources to improve psychological well-being during the waiting period of a new pregnancy following RM. Figure 1 illustrates the context of the present study within the design of the feasibility RCT.

Patient and Public Involvement

A Patient and Public Involvement (PPI) advisory group supported this research and met on a regular basis for the duration of this study. The group were involved with the design of the study and commented on any potential burden of participating in the study from a patient's perspective. The group were involved with data interpretation, and at the end of the study commented on the findings and contributed to the dissemination plan.

Participants

The study population consisted of patients attending the Recurrent Miscarriage Clinic and the Early Pregnancy Unit in two tertiary referral hospitals in the South of England.

Between February 2014 and May 2016, 107 eligible women were invited to take part in the main feasibility RCT component of the study and 75 of these agreed to participate. In total 47 women were randomised at the point of a positive pregnancy test to either the intervention (n=24) or control (n=23) arm of the study. Participants became eligible to take part in the qualitative part of the study once they had completed the initial RCT component. This included participants who had reached twelve weeks of pregnancy and those who had unfortunately experienced a further miscarriage. Care was taken to allow a suitable time-period to elapse before participants were approached and invited to take part in an interview following a miscarriage. The aim of sampling was to collect perspectives from as diverse a group as possible. Selection characteristics considered in the purposive sampling strategy included study group in the RCT (control or intervention), ongoing pregnancy or

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miscarriage, ethnicity of participant, education level of participant and clinically important demographics such as age, comorbidity/medical conditions and previous live births. Of the 15 participants invited to take part in the qualitative element of the study, only one declined participation. Figure 2 illustrates the key demographic information of study participants

Data Collection

Data were collected face-to-face, during semi-structured interviews and took place at a convenient time and place for the participant. Recruitment was stopped when data saturation was achieved. All participants signed a consent form and were interviewed on an individual basis by the primary author. A topic guide was utilised to steer the general direction of the data collection, but participants were encouraged to speak freely about their perceptions and experiences of the waiting period of a new pregnancy. The interviews lasted between thirty and sixty minutes and were audio recorded then transcribed verbatim.

Analysis

Evidence of reliability and validity in qualitative research methods is important to ensure the process of analysis is clear, transparent and trustworthy [17]. 'Thematic Network Analysis' [18] was used as an analytic tool in this study to provide a robust and highly sensitive means of supporting thematic analysis and it facilitated an open and systematic approach. This method of analysis enabled the development of thematic networks that summarised the main themes apparent in the interview transcripts. The method simply provided a technique for breaking up the text into 'Basic Themes' (the most basic theme or lowest order theme), 'Organising Themes' (a middle-order theme that organises the Basic Themes into clusters of similar issues) and 'Global Themes' (which are macro themes that summarise and make sense of the clusters of lower-order themes). Figure 3 illustrates how transcribed data from this study were developed from basic themes into a single global theme.

Thematic network analysis shares the key features of any hermeneutic analysis and is not a new method of analysis. However, the use of its web-like network as an organising principle and representational means, helped to make explicit the procedures utilised in moving from text to interpretation of data [18].

Transparency of data analysis was aided by the use of field notes and memos and by discussing the emerging themes with co-authors proficient in qualitative research analysis. Finally, basic and organising themes were grouped and refined following further analysis and discussion with co-authors.

Results

Analysis of the data identified seven 'Organising Themes.' These themes form the basis for the presentation of the results of this qualitative study.

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Organising Theme 1: Turmoil of emotions

The organising theme of 'turmoil of emotions' brings together the numerous reactions and feelings experienced by women with RM during the early stages of a new pregnancy while they are waiting for confirmation by ultrasound scan that it is ongoing. As outlined in Box 1, the women experienced a plethora of emotions whereby any initial excitement caused by the positive pregnancy test was quickly over-taken, by worry and fear that they would miscarry again. The uncertainty of this situation appeared to compound the experience and the women's distress as they continually ruminated upon the outcome of their pregnancy.

All of the interviewees provided extremely powerful examples of the turmoil of emotions they had experienced during the waiting period with the majority of participants referring to the significant levels of anxiety and worry they experienced during this time. This was often overwhelming for them, affecting every aspect of their life and an emotion they were unable to escape from or forget. Accompanying the extremes levels of anxiety and the worry, several of the interviewees described emotions of fear and even terror at the situation they were in and the potential outcome of their pregnancy.

A number of participants remarked that a further notable emotion present throughout the waiting period was guilt, with the women blaming themselves entirely for their miscarriages. They spent time contemplating the lifestyle choices they had made in the past (for example previous smoking/alcohol consumption or previous terminations of pregnancy), but they also felt guilty for letting down their partner and family at their inability to have a successful pregnancy.

Participants commonly expressed their shame at experiencing the emotions of jealousy and envy when they encountered other pregnant women or those with small babies, acknowledging the negative connotations of this emotion. They were, however, keen to point out that it was not a personal thing against the pregnant woman or new mother, rather that they wished it was them in that situation.

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BOX 1

Sometimes you will be happy, sometimes you will be sad, sometimes you will be angry. To me it always feels like a fire has been put out inside you, so you can smile, do whatever you want to, but your eyes just feel blank - Participant 6 (4 miscarriages)

Because of how anxious I was, it was affecting everything. I was really anxious. I wasn't sleeping properly, you worry about everything you eat, everything you drink. You just criticize and analyse everything you do all day long, all night long … Being anxious makes you anxious so it's a real vicious circle - Participant 8 (3 miscarriages)

The more you know what can go wrong, it becomes even more frightening … It is terrifying really, literally terrifying and that is how I feel - Participant 7 (4 miscarriages)

Organising Theme 2: Preparing for the worst

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This organising theme conveys the emotional strategies utilised by the women to try to remain emotionally detached from the pregnancy, keeping themselves 'in check' because they did not want to let themselves become excited about the pregnancy (as outlined in Box 2).

A positive pregnancy test was met with feelings of anxiety, trepidation and negativity. It was a moment of realisation and the women described this as being back on the 'rollercoaster' of pregnancy and its associated worry. Women were reluctant to share news of the pregnancy with family and friends because they were certain another miscarriage would occur. Interviewees also suggested that they suppressed any hope of a successful pregnancy and avoided thinking about a future with their unborn child. This appeared to be linked to a notion of self-preservation/protection. By attempting to prepare for the worst outcome (i.e. a further miscarriage) they would be less upset if another miscarriage occurred.

BOX 2

It's the not knowing and it's the being unable to believe anything except the worst. I find I'm baffled by how pregnancies work these days, I'm kind of constantly surprised that people are having babies because my experience is so different … so now it's impossible to believe that it's going to be okay… I just came to the conclusion that the kindest thing I could do for myself was not to hope. The most likely outcome is that you are not going to have that addition to your family and so actually there's no point picturing what life is going to be like because picturing it is exciting and it's hoping for a future that probably isn't going to be there. Hope just feels utterly naïve now - Participant 13 (4 miscarriages)

I was very detached from the whole pregnancy …it was self-preservation kind of mode - Participant 11 (4 miscarriages)

I think it's a self-preservation because of what you've been through, but I was never like that with my daughter. It's a learnt behaviour definitely … it's almost like you can't let yourself dream this might happen after wanting it so long – Participant 10 (3 miscarriages)

I think me and my husband ended up trying not to think about it too much … you don't want to get your hopes up so we'd be very cautious about even really talking about the positives in case it was bad news – Participant 14 (3 miscarriages)

I need to be real and I prepare for the worst, but hope for the best and that's almost like a protective shield around me – Participant 8 (3 miscarriages)

Organising Theme 3: Setting of Personal milestones

The interviewees placed huge importance on the need to attain personal milestones, using this as a method of navigating their way through the uncertainty of the waiting period (Box 3). This was frequently achieved by breaking the pregnancy up in to smaller time chunks, thinking of the first trimester in individual weeks, or even days, rather than as a whole period of time. In addition, the participants frequently recalled how they tried to live the early stages of a new pregnancy day-by-day, trying not to think too far ahead, living in the moment.

The women's personal milestones often consisted of reaching and going past the gestation of their previous miscarriages, or achieving midwife or scan appointments.

During the interviews, participants were asked if anything had helped them cope with the waiting period and everyone referred to the value of reassurance from ultrasound scans and

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how they broke up this time into more manageable time chunks. Interestingly, however, all women commented that any optimism they felt after a positive scan was short-lived and feelings of anxiety soon started to re-emerge.

BOX 3

It's one day at a time, that's how we live one day at a time and that's how we've lived since June and I don't think it's a bad thing because we are appreciating that emotions can change from day to day …rather than think about the birth we think about little hurdles … I try not to think too far ahead because I get overwhelmed with things – Participant 12 (3 miscarriages)

It's kind of like you are trying to climb a ladder and the first rung up is the twelve week scan, but at least if you have a seven week scan and things are okay then you can stand on that rung and you know you've got that far - Participant 13 (4 miscarriages)

As soon as I confirmed the pregnancy they told me that they would get me in for scans at 6,8 and 10 weeks which helps because you've then got a 2 week marker to break up the 12 weeks. But I would say the anxiety massively increases up towards the scan … it build, builds, builds and then you have a scan and it drops so by the time I would go to a scan, especially the 6 week scan I was a complete mess and really struggling to hold it together, crying a lot and incredibly nervous, body full of adrenaline and really, really anxious - Participant 3 (6 miscarriages)

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Organising Theme 4: Hypervigilance

Study participants frequently reported using observing strategies and hypervigilance to help them monitor their pregnancy symptoms, considering symptoms such as nausea, tiredness and breast tenderness as signs of an ongoing pregnancy (Box 4). Many of the participants detailed checking as an obsession and something they could not help doing, wanting constantly to seek reassurance that their pregnancy was ongoing.

One of the most common early signs of miscarriage is the onset of vaginal bleeding or spotting. Many were so convinced that they were going to experience a further miscarriage that they frequently reported repeated visits to the toilet to check for the onset of vaginal bleeding. This could often amount to numerous toilet visits every hour.

Participants expressed that when pregnancy symptoms were more intense then they felt more certain of an ongoing pregnancy, however any fluctuation in symptoms increased their feelings of uncertainty and caused added emotional distress.

BOX 4

Knicker checking is a big obsession - Participant 5 (4 miscarriages)

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You are constantly monitoring your pregnancy symptoms, constantly. Do I feel the same as I did yesterday, are my 'boobs' still sore, do I need to go to the toilet more often or am I just drinking more? And you are constantly questioning every single twinge you feel and you are dying to get morning sickness so that you know you are pregnant – it's just all consuming - Participant 3 (6 miscarriages)

I was just constantly nauseous and if I wasn't thinking about it I probably wouldn't have realised that I was nauseous, because it wasn't that bad. But I felt myself thinking about it and I wanted to feel that feeling sickness just so I know that something is happening. Until now every single time I go to the bathroom I have to check that I'm not bleeding and I've been doing it since the beginning of my pregnancy. I also spent quite a bit of money on pregnancy tests just to see … I did them almost everyday, but I couldn't help it - Participant 9 (3 miscarriages)

Organising Theme 5: Social isolation

This organising theme brings together the participants' views on social interaction during the waiting period (Box 5). Many reported that they felt isolated and lonely during this time. This was compounded by the fact that the women often isolated themselves from friends and family, reluctant to share the news of their pregnancy because they felt certain a further miscarriage would occur, therefore, there was no point in telling people. There was also an innate fear for several participants that sharing the news of their pregnancy in the early stages pregnancy would tempt fate and as a result, they would experience a further miscarriage.

There appeared to be a general withdrawal from social situations and social media, mainly due to the fear of forced social interaction with other pregnant women or those announcing news of a pregnancy. Compounding the degree of isolation was the fact that the women also appeared to feel safer and protected at home as they felt this environment might reduce the risk of miscarriage.

BOX 5

You want to tell people of course you do, but it makes you very private, very keep yourself to yourself - Participant 12 (3 miscarriages)

It's really difficult I think these days with Facebook, it's really hard. I had to block a few people who put scan photos up or bump pictures. I found bump photos really hard because you think am I ever going to get there? Is that ever going to be me? - Participant 3 (6 miscarriages)

I've never been so scared to go outside my front door because I might just bump in to someone who is pregnant. Pregnancy just seemed to be everywhere. It's just one of those things where you become really heightened to it … and it was just awful, absolutely awful - Participant 8 (3 miscarriages)

I didn't want to speak to anybody, I didn't want to face anybody – Participant 9 (3 miscarriages)

Organising Theme 6: Adoption of pragmatic approaches

This organising theme brings together some of the pragmatic and practical approaches participants utilised to try to manage the stress and uncertainty of the waiting period (Box

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6). The women referred to the fact that these practical approaches appeared to give them back some control in a situation where they had none.

Pragmatic approaches to coping with the anxiety often consisted of simple distraction techniques and keeping busy. This was particularly evident in participants who already had children, however work often provided a big distraction for employed participants. Other participants used avoidance (namely not allowing themselves to think about the pregnancy and blocking it out of their thought processes).

Commonly, the women tried to adapt their lifestyle to eliminate factors they felt could increase the risk of miscarriage such as reducing strenuous exercise or improving nutritional intake. Lifestyle adaptations could be more extreme with women giving examples of never opening the window on a car journey to avoid pollution from other cars or avoiding taking baths or showers in pregnancy.

Many of the participants referred to the value of accessing peer support as one of the most useful practical approaches they could adopt during this time. They believed only women who had experienced their situation truly understood the anxieties and challenges they faced. In most cases peer support was accessed via on-line miscarriage support groups and forums.

BOX 6

The only thing that would help is my work … It took my mind away so I didn't have time to think or dwell on think, so I think that was helpful - Participant 1 – (3 miscarriages)

I couldn't just dwell in my own self-pity about how hard it all was. So yes distraction did help, so if work hadn't given me distraction I would have gone and sought it. What made it better? Trying to be grateful, being distracted, really seriously just trying not to think about it - Participants 13 (4 miscarriages)

You stop more and more things. So you'll stop doing extra work, you'll start relaxing more. You'll stop doing some parts of your exercise, you'll stop eating different foods. You go through the most illogical things in your head – if I stay calm it will be alright, if I just do walking it will be fine - Participant 6 (4 miscarriages)

Organising Theme 7: Need for professional affirmation

In the final organising theme, interviewees described the need for health professionals' acknowledgement of the challenges they faced and the stress they experienced during the waiting period of a new pregnancy (Box 7).

A recurrent theme in the interviews was a sense that health service provision was both limited and unsupportive and the women felt that this demonstrated a lack of understanding of their needs during this testing time. Often the first health professional the woman accessed for support was their General Practitioner (GP). Whilst the degree of support offered by individual GPs varied, interviewees frequently spoke of the lack of

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support and understanding shown by them. Lack of empathy was considered one of the most upsetting aspects of their situation. All participants expressed the need to be cared for in a sensitive and understanding manner.

When an individual did receive empathetic care from a health professional, whether that was a GP or a nurse working in the Early Pregnancy Unit, then it made a positive difference to their emotional well-being.

BOX 7

There is sometimes an absolute lack of understanding….I think generally the thing I would say to medical professionals is that they need to acknowledge that this person is probably going to be slightly damaged. Massive things don't have to change just some realisation of what a new pregnancy means to a woman who has been through all those lost pregnancies - Participant 10 (3 miscarriages)

It's the whole if you've got no pain and you've got no blood you are fine, that's what the GP would say - Participant 7 (4 miscarriages)

The EPU (Early Pregnancy Unit) staff were more gutted than I was I think, they were lovely… they were all just rooting for me and it was really nice - Participant 13 (4 miscarriages)

Discussion

Awaiting confirmation of an ongoing, viable pregnancy after having experienced recurrent miscarriage is a traumatic period marked by an intense struggle between hope and despair, hypervigilance of pregnancy symptoms and bracing for another miscarriage all occurring in a context of social isolation and feeling relatively unsupported by health professionals. Nevertheless, women were shown to adopt diverse coping strategies aimed at achieving a state of cautious optimism that served to maintain hope while bracing for the possibility of failure.

The findings from this study provide further evidence that there is a need for provision of psychological support to women during the difficult waiting period of a new pregnancy following recurrent miscarriage. It also offers new and previously unexplored insights in to how women experience this challenging time.

The global theme identified in this study was that waiting is traumatic and a time in which the women hope for the best, but expect the worst. This global theme supports and expands on those reported by others. Previous research has demonstrated that women with a past history of repeated pregnancy losses utilise coping strategies to 'brace for the future,' as a means of attempting to control their emotions and future emotions as much as possible

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to prepare for the worst outcome [19]. This involved anticipating the negative feelings that a further miscarriage would cause and utilising bracing strategies such as not allowing themselves to think about a future with their unborn child and attempting to remain emotionally detached from the pregnancy. Behaviours similar to 'bracing for the worst' [19] have been reported in other studies that investigated pregnancy after previous perinatal loss, including 'holding back emotions' [20] and 'emotional cushioning' [21] which involves 'compartmentalising the pregnancy and avoiding its emotional aspects for as long as possible' [21]. The compelling evidence from this study provides further evidence of bracing adding to suggestions from previous studies [19] that propose the need for further research to investigate the impact of bracing strategies on long-term bonding and attachment between child and parents.

All participants concurred that the uncertainty of the situation compounded their emotional upset. The uncontrollability and unpredictability of the waiting period seemed a particularly difficult aspect for them to cope with. The formative work of Lazarus and Folkman [22] examined the processes of stress, appraisal and coping and identified the fact that both a lack of control over a situation and an inability to predict its outcome are potential stress inducing factors. If the demands of a situation exceed the level of coping resources available to the person then the affected individual is likely to experience stress, namely psychological (e.g. anxiety, worry), physiological (e.g. racing heart, tension) and behavioural responses (e.g. insomnia) responses [22]. The participants in this study consistently commented that the uncertainty of the waiting period was itself a stressor eliciting emotional turmoil, some even commenting on the relief they felt when a further miscarriage occurred as they felt better able to cope with the grief of miscarriage than the uncertainty of the waiting period. Positive reappraisal coping has been shown to be useful and valuable coping strategy and a helpful tool to help sustain coping during periods of uncertainty [23 24]. This type of coping might provide some respite from the prolonged and unrelenting stress that women with recurrent miscarriage experience during the early stages of a new pregnancy and help to sustain their ability to cope during this challenging time. The RCT component of this study has investigated the use of a novel self-help coping intervention, the Positive Reappraisal Coping Intervention [16]. Findings from this component of the study will be reported separately. Further research is planned to explore the role of the Positive Reappraisal Coping Intervention and how it appears to generate resilience in its users.

One organising theme described the strong 'need for professional affirmation' and perceptions of the level of care patients would like to receive. In a pioneering piece of work Bradshaw [25] presented a taxonomy of social need in which he acknowledged that the concept of need was both complex and imprecise. Furthermore he emphasised the fact that need was relative and therefore needs identified by professional experts often differed from those felt by the individual. Certainly, a recurrent theme during the interviews was a sense that current health service provision for women with recurrent miscarriage during the waiting period of a new pregnancy was both limited and unsupportive. Participants felt

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these gaps in support demonstrated a lack of understanding of their needs during this challenging time. The need for professional support and reassurance was generated at the actual moment of realisation that they were pregnant again, following the positive pregnancy test and in general was experienced toward the first health professional they would contact for support and advice (i.e. their GP). Whilst the degree of support offered by GPs varied individually, many women spoke of their disappointment at the lack of understanding and compassion shown to them. There was a general feeling that any health professional interaction that took place within a dedicated Early Pregnancy Unit environment was more sensitive to their needs, but that there was still room for improvement.

Whilst this study builds on the results of other studies that have identified the importance of understanding and compassion from health professionals around the time of miscarriage [26 27], it specifically highlights the need for health professional support during the early stages of a new pregnancy following recurrent miscarriage.

Clearly, consideration needs to be given to the most effective and appropriate ways in which health professionals can meet this demand for support, given the limited time constraints within which they work. GPs have time-limited consultations, often of less than ten minutes per patient and similarly secondary care health professionals work within restricted clinic appointment times. It is not always feasible to address every aspect of the woman's psychological needs during this time. For example, some women with recurrent miscarriage would prefer at least weekly reassurance ultrasound scans and others individual regular counselling sessions. However, the data from this study highlighted that in all cases, there was a sense amongst participants of the need to raise awareness within the health professional community of the potential emotional impact of the waiting period and the need for empathetic care. The participants acknowledged that they understood that the involvement of health professionals would not make a difference to the outcome of their pregnancy. Furthermore the women understood that their emotional needs fluctuated during the waiting period and therefore it was difficult for GPs and other health professionals to address these needs specifically. However, similar to the findings of a study by Musters, et al. [10] that investigated supportive care for women with recurrent miscarriage, women in this study noted that when health professionals took their emotional concerns seriously by listening to them and showing them understanding and empathy then it made a positive difference to their emotional wellbeing. The 'soft' skills of compassion, empathy and understanding appeared to meet the need for support during the uncertainty of the waiting period.

The main strength of this study is that it addresses a gap in the literature and provides new and detailed qualitative data on how women experience the initial waiting period of a new pregnancy following recurrent miscarriage. However, one of the study limitations is that the majority of participants who took part in this study were of White British ethnicity, mainly

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due to the study sites in the South of England. A more varied ethnicity sample may have provided a more diverse and richer insight in to the cultural effects of recurrent miscarriage.

Conclusion

This study demonstrates that for many women with recurrent miscarriage, the waiting period of a new pregnancy is a time of great uncertainty and emotional turmoil and one in which they are likely to require emotional support.

Recurrent pregnancy loss has the potential to cause serious psychological effects including grief, anxiety and depression, and these emotional symptoms can affect every aspect of the woman's life. Recurrent miscarriage is therefore much more than just a medical condition; its consequences are more profound and life changing and the provision of supportive care should be central to the management of women who experience this distressing and frustrating condition.

This study reveals the thoughts and perceptions of women with a history of recurrent miscarriage during the waiting period of a new pregnancy; the challenge remains for both clinicians and service providers to develop a service that meets the needs of these women given the complex and challenging times that the NHS is experiencing. Recent NHS policy [28] advocates the need to ensure health services are designed around patients, but on a more sustainable footing. This includes the use of technology and innovation to enable patients to take a more active role in their health. The next stage of this programme of research plans to investigate the potential utilisation of technical innovation strategies as a method of providing much needed support to this vulnerable patient population.

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Contributors

SB contributed to the design of the study, was responsible for obtaining ethical approval and liaised with the PPI group for this study. NM, CB, JB, EKR and YC contributed to the design of the study. SB and EKR coded and analysed all the transcripts. All authors were involved in interpretation of the data. SB wrote the first draft of the manuscript and all authors were involved in subsequent revision. All authors approved the final manuscript.

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Competing interests

None declared

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Ethical approval

A favourable opinion was received from National Research Ethics committee, South Central – Hampshire A (13/SC/0506)

Provenance and peer review

Not commissioned; peer reviewed for ethical and funding approval prior to submission

Data sharing statement

This research is part of a PhD study by SB. The PhD will be available via the University of Southampton depository

Figure legend/ captions

Figure 1 – RCT feasibility study of a coping intervention for recurrent miscarriage

Figure 2 – Demographic information of study participants

Figure 3 – Development of basic, organising and global themes using thematic network analysis

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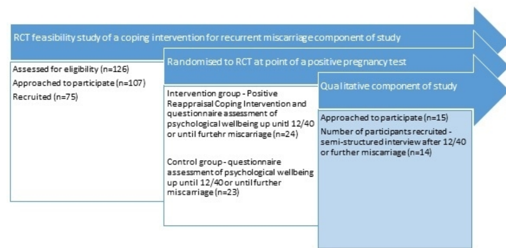

Figure 1 - RCT feasibility study of a coping intervention for recurrent miscarriage

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1. From Basic to Organising to Global Themes		
Themes as Basic Themes	*Organising Themes*	*Global Themes*
1. Uncertainty and fear of unknown	1.Turmoil of emotions	1.Hope for the best ... but expect the wors
2. Extreme feelings of anxiety		
3. Betrayed by body - theft of expectations		
4. Envy of other pregnant women		
5. Guilt - must be to blame		
6. Increased superstitious tendancies		
7. Mixed emotions after positive pregnancy test	2. Preparing for the worst	
8. Lost expectations		
9. Lack of hope		
10. Expecting the worst		
11. Denial of pregnancy		
12. Efforts to remain 'detached' from pregnancy		
13.Waiting period divided up into 'bite sized chunks'	3. Setting of personal milestones	
14.Take it day-by-day		
15. Checking for pregnancy symptoms	4.Hypervigilance	
16. 'Knicker checking'		
17. Heightened intuition		
18. Social withdrawal	5. Social isolation	
19. Effect on relationship with family and friends		
20. Reluctance to announce news of pregnancy		
21. Views on personal social media use		
22. Views on on-line support groups		
23. Value of peer support		
24. Getting used to RM	6. Adoption of pragmatic approaches	
25. How to deal with RM		
26. Controlling behaviour		
27. What helped?		
28. What didn't help?		
29. Ultra sound scans	7. Need for professional affirmation	
30. Investigations in to RM		
31. Views on health professionals		
32. Importance of sensitivity of health professionals		

Figure 3 - Development of basic, organising and global themes using thematic network analysis

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Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQR reporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245-1251.

		Reporting Item	Page Number
	#1	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1
	#2	Summary of the key elements of the study using the abstract format of the intended publication; typically	1

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		includes background, purpose, methods, results and conclusions	
Problem formulation	#3	Description and signifcance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	2
Purpose or research question	#4	Purpose of the study and specific objectives or questions	3
Qualitative approach and research paradigm	#5	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenolgy, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together.	3
Researcher characteristics and reflexivity	#6	Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research	4

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		questions, approach, methods, results and / or transferability	
Context	#7	Setting / site and salient contextual factors; rationale	4
Sampling strategy	#8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	4
Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	12
Data collection methods	#10	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of procedures in response to evolving study findings; rationale	4
Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	4
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	4

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Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	5
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	5
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	5
Syntheses and interpretation	#16	Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	5-8
Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	5-8
Intergration with prior work, implications, transferability and contribution(s) to the field	#18	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	9-11

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Limitations	#19	Trustworthiness and limitations of findings	2
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	12
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	12

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Hope for the best ...but expect the worst: A qualitative study to explore how women with recurrent miscarriage experience the early waiting period of a new pregnancy

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Primary Subject Heading:	Reproductive medicine
Secondary Subject Heading:	Obstetrics and gynaecology
Keywords:	recurrent miscarriage, adaptation, psychological, anxiety, pregnancy

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Hope for the best …but expect the worst: A qualitative study to explore how women with recurrent miscarriage experience the early waiting period of a new pregnancy

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Word count:

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Key words:

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Abstract

Objective: To investigate how women experience the initial period of a new pregnancy after suffering recurrent miscarriage.

Design: A qualitative study, nested within a randomised controlled feasibility study of a coping intervention for recurrent miscarriage, used semi-structured face-to-face interviews. Interviews were audio-recorded, transcribed verbatim and analyzed utilizing a thematic network approach.

Setting: Participants were recruited from the Recurrent Miscarriage Clinic and Early Pregnancy Unit in two tertiary referral hospitals in the United Kingdom.

Participants: 14 women with recurrent miscarriages and who had previously participated in the RCT feasibility component of the study, were recruited.

Results: Seven organising themes emerged from the data: (1) turmoil of emotions; (2) preparing for the worst; (3) setting of personal milestones; (4) hypervigilance; (5) social isolation; (6) adoption of pragmatic approaches; (7) need for professional affirmation.

Conclusions: The study established that for women with a history of recurrent miscarriage, the waiting period of a new pregnancy is a traumatic time of great uncertainty and emotional turmoil and one in which they express a need for emotional support. Consideration should be given to the manner in which supportive care is best delivered within the constraints of current health service provision.

Trial registration: This study is registered with the ISCTRN registry. Registration number: ISRCTN43571276

Strengths and limitations of this study

- This qualitative study addresses a gap in the literature, providing new and detailed data on how women experience the initial period of a new pregnancy following recurrent miscarriage.
- Qualitative face-to-face interviews enabled the exploration of this sensitive time period, giving participants the opportunity to convey their personal experiences
- While every effort was made to support the recruitment of a diverse sample to this study, the UK setting may limit extrapolation to other national and cultural contexts.

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- The purposive sampling strategy enabled an inclusive approach to data collection from the ethnicities represented in the main feasibility study sample.

Introduction

Miscarriage is the most common adverse outcome of pregnancy [1]. It has been defined as the spontaneous demise of a pregnancy before the fetus reaches viability, therefore the term includes all pregnancy losses from the time of conception until 24 weeks of gestation [2]. Recurrent miscarriage (RM) is currently defined as the loss of three or more consecutive pregnancies within the UK [3]. However, other countries have adopted different definitions and the recently published European Society Human Reproduction and Embryology (ESHRE) guideline concludes that a diagnosis of RM could be considered after the loss of two or more pregnancies [2]. The prevalence of RM is significantly lower than sporadic miscarriage, but the exact occurrence is difficult to estimate [2]. When defined as the loss of three or more consecutive pregnancies then it is proposed that 1 % of couples who are trying to conceive are affected [3]. However, the recently published ESHRE guidelines suggest that at least 1-2% of couples experience recurrent pregnancy loss [2].

This repeated and unintentional loss of pregnancy has been described as a distinct disease entity [4-6] given that the observed incidence of RM is much higher than would be expected to occur by chance alone. The ESHRE guideline on the recommended treatment and investigation of recurrent miscarriage highlights the lack of evidence based investigations and treatments available for this condition [2]. Consistent with other guidelines [3] it highlights the need to ensure care is tailored to the psychological needs of couples. Whilst the loss of any desired pregnancy ending in miscarriage is a profound and negative life event, recurrent miscarriage represents an extremely distressing condition that can be both physically and emotionally traumatising. The repetitive nature of recurrent pregnancy loss may intensify the grief and distress experienced, delivering a significant emotional impact on those affected [2]. The experience can evoke intense feelings surrounding a lost baby, a lost future child and a lost motherhood [7].

Numerous studies have investigated emotional morbidity in women in the period immediately following miscarriage [8-10]. More recently, a study by Kolte, et al. [11] concluded that increased levels of psychological distress and major depression are significantly more common among women with recurrent miscarriage compared to women trying to achieve pregnancy who had not experienced this. This corresponds with the findings from previous studies, investigating emotional morbidity in women with recurrent pregnancy loss, which indicated that increased levels of anxiety and depression are often experienced throughout subsequent pregnancies [12 13].

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The early stages of a new pregnancy when confirmation by ultrasound scan of an ongoing and viable pregnancy is awaited, represent a particularly challenging period for women affected by RM due to their anxiety that they will experience a further miscarriage [14].

Medical waiting periods have been defined as those during which patients wait for test results that could be potentially threatening to their wellbeing [15]. These waiting periods appear to have a distinct emotional signature. Psychological stress reactions are present and build from the start of any waiting period whereby anticipation of loss leads to further anxiety and prolonged psychological distress [16]. Lazarus and Folkman [17] have proposed that the conditions that create stressful situations are particularly applicable to medical waiting periods. These characteristics include waiting for an outcome that can have negative consequences of significant impact consequences for the individual, and the fact that it is not possible to change, control or predict the outcome. These stressors are uniquely characteristic of the waiting period of a new pregnancy following RM.

In the context of pregnancy after RM, the waiting period generally refers to the first 12 weeks of a pregnancy, although the actual length can vary between women and is often dependent on the timing of their previous miscarriages. However, a scan at 12 weeks gestation confirming viability is associated with a greater than 95% chance [18] of an ongoing pregnancy and this reassurance can be considered to mark the end of the waiting period.

Published research data assessing the psychological morbidity associated with the difficult waiting period of a new pregnancy are scarce, however a qualitative study exploring the experiences and coping strategies of women during the initial waiting period (weeks 1-12) of pregnancy after miscarriage revealed extreme anxiety about pregnancy outcome [14]. As the number of previous miscarriages increased women with RM felt extremely anxious about the pregnancy outcome, proposing that this uncertainty grew after each miscarriage and their coping was orientated towards presumed failure (a further miscarriage). Another study by Hutti, et al. [19], has suggested that instead of experiencing this period as a time of 'joyful anticipation,' couples who have previously experienced recurrent pregnancy loss frequently experience increased levels of anxiety and worry.

Despite the emotional morbidity associated with the waiting period, many women who have experienced RM are not provided with support during this time and are left to cope alone with their anxiety. This is mainly because existing supportive interventions are labour intensive and expensive to provide and as urgency is almost immediate, it may be difficult to provide support quickly. The limited data available make it difficult to promote and target the development of therapeutic support for women with RM during the early waiting stages of a new pregnancy. To improve psychological wellbeing during this challenging time, there is a need to develop a deeper and more extensive understanding of lived experiences.

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3 The qualitative study presented in this paper was nested within a two-centre RCT feasibility
4 study of a novel self-help intervention designed to support women with a history of RM to
5 cope with the waiting period before confirmation of a new ongoing pregnancy [20 21] . The
6 design and methodology of this paper have been published elsewhere [20] and the results will
7 be reported separately.

The aim of the presented paper was to develop a deeper understanding and detailed insight in to the lived experience of women with repeated pregnancy loss during the early 'waiting' stages of a new pregnancy.

Methods

Design

This qualitative study was designed to develop a deeper understanding of the types of emotional reaction to the waiting period to target the development of psychological therapeutic support for this group of women.

Patient and Public Involvement

A Patient and Public Involvement (PPI) advisory group supported this research and met on a regular basis for the duration of this study. The group were involved with the design of the study and commented on any potential burden of participating in the study from a patient's perspective. The group were involved with data interpretation, and at the end of the study commented on the findings and contributed to the dissemination plan.

Participants

The study population consisted of patients attending the Recurrent Miscarriage Clinic and the Early Pregnancy Unit in two tertiary referral hospitals in the South of England.

Between February 2014 and May 2016, 107 eligible women were invited to take part in a feasibility RCT testing a self-administered psychological support [20 21]. Participants became eligible to take part in this qualitative study once they had completed the intervention. This included participants who had reached twelve weeks of pregnancy and those who had unfortunately experienced a further miscarriage. Care was taken to allow a suitable time-period to elapse before participants were approached and invited to take part in an interview following a miscarriage. The aim of sampling was to collect perspectives from as diverse a group as possible. Selection characteristics considered in the purposive sampling strategy included study group in the RCT (control or intervention), ongoing pregnancy or miscarriage, ethnicity of participant, education level of participant and clinically important demographics such as age, comorbidity/medical conditions and previous live births. Of the 15 participants invited to take part in the qualitative element of the study, only one declined participation. Figure 1 illustrates the key demographic information of study participants

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Data Collection

Data were collected face-to-face, during semi-structured interviews and took place at a convenient time and place for the participant. Recruitment was stopped when data saturation was achieved. All participants signed a consent form and were interviewed on an individual basis by the primary author. A topic guide was utilised to steer the general direction of the data collection, but participants were encouraged to speak freely about their perceptions and experiences of the waiting period of a new pregnancy to increase the understanding of the emotional reactions experienced during this time. The interviews lasted between thirty and sixty minutes and were audio recorded then transcribed verbatim.

Analysis

Evidence of reliability and validity in qualitative research methods is important to ensure the process of analysis is clear, transparent and trustworthy [22]. 'Thematic Network Analysis' [23] was used as an analytic tool in this study to provide a robust and highly sensitive means of supporting thematic analysis and it facilitated an open and systematic approach. This method of analysis enabled the development of thematic networks that summarised the main themes apparent in the interview transcripts. As demonstrated in Figure 2, the method simply provided a technique for breaking up the text into 'Basic Themes' (the most basic theme or lowest order theme), 'Organising Themes' (a middle-order theme that organises the Basic Themes into clusters of similar issues) and 'Global Themes' (which are macro themes that summarise and make sense of the clusters of lower-order themes).

Thematic network analysis shares the key features of any hermeneutic analysis and is not a new method of analysis. However, the use of its web-like network as an organising principle and representational means, helped to make explicit the procedures utilised in moving from text to interpretation of data [23]. Figure 3 illustrates how transcribed data from this study were developed from basic themes into a single global theme.

Transparency of data analysis was aided by the use of field notes and memos and by discussing the emerging themes with co-authors proficient in qualitative research analysis. Finally, basic and organising themes were grouped and refined following further analysis and discussion with co-authors.

Results

Analysis of the data identified seven 'Organising Themes.' These middle order themes were the principles on which the global theme of 'Hope for the best, but expect the worst,' was based and form the basis for the presentation of the results of this qualitative study.

The findings of this study and the illustrated quotes are representative of the perceptions and feelings of both groups of women in the RCT feasibility study (those who received the intervention and those who did not). Furthermore, although at the time of the interviews 8

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of the 14 women interviewed had ongoing pregnancies, they felt well able to reflect back on their experiences of the early waiting period with accuracy and did not feel their ongoing pregnancy affected their recollection of emotions at this time.

Organising Theme 1: Turmoil of emotions

The organising theme of 'turmoil of emotions' brings together the numerous reactions and feelings experienced by women with RM during the early stages of a new pregnancy while they are waiting for confirmation by ultrasound scan that it is ongoing. As outlined in Box 1, the women experienced a plethora of emotions whereby any initial excitement caused by the positive pregnancy test was quickly over-taken, by worry and fear that they would miscarry again.

The acute uncertainty of this situation appeared to compound the experience and the women's distress as they continually ruminated upon the outcome of their pregnancy because they were unable to accurately predict the outcome of the pregnancy. Instead, the women focused on what might happen and this meant it was difficult for them to utilise strategies to cope with the situation they found themselves in, as they had no definite idea of what would actually happen. The interviewees suggested that the situation was made worse by the 'not knowing' of what the outcome of the pregnancy would be. Once the uncertainty of the waiting period was over, because the pregnancy was progressing as expected and they felt confident that their pregnancy would continue or because they unfortunately experienced a further miscarriage, then the negative emotional effects of uncertainty appeared to reduce.

All of the interviewees provided extremely powerful examples of the turmoil of emotions they had experienced during the waiting period with the majority of participants referring to the significant levels of anxiety and worry they experienced during this time. This was often overwhelming for them, affecting every aspect of their life and an emotion they were unable to escape from or forget. Accompanying the extremes levels of anxiety and the worry, several of the interviewees described emotions of fear and even terror at the situation they were in and the potential outcome of their pregnancy.

A number of participants remarked that a further notable emotion present throughout the waiting period was guilt, with the women blaming themselves entirely for their miscarriages. They spent time contemplating the lifestyle choices they had made in the past (for example previous smoking/alcohol consumption or previous terminations of pregnancy), but they also felt guilty for letting down their partner and family at their inability to have a successful pregnancy.

Participants commonly expressed their shame at experiencing the emotions of jealousy and envy when they encountered other pregnant women or those with small babies, acknowledging the negative connotations of this emotion. They were, however, keen to

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point out that it was not a personal thing against the pregnant woman or new mother, rather that they wished it was them in that situation.

BOX 1: Turmoil of emotions

Sometimes you will be happy, sometimes you will be sad, sometimes you will be angry. To me it always feels like a fire has been put out inside you, so you can smile, do whatever you want to, but your eyes just feel blank - Participant 6 (4 miscarriages)

Because of how anxious I was, it was affecting everything. I was really anxious. I wasn't sleeping properly, you worry about everything you eat, everything you drink. You just criticize and analyse everything you do all day long, all night long … Being anxious makes you anxious so it's a real vicious circle - Participant 8 (3 miscarriages)

The more you know what can go wrong, it becomes even more frightening … It is terrifying really, literally terrifying and that is how I feel - Participant 7 (4 miscarriages)

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Organising Theme 2: Preparing for the worst

This organising theme conveys the emotional strategies utilised by the women to try to remain emotionally detached from the pregnancy, keeping themselves 'in check' because they did not want to let themselves become excited about the pregnancy (as outlined in Box 2).

A positive pregnancy test was met with feelings of anxiety, trepidation and negativity. It was a moment of realisation and the women described this as being back on the 'rollercoaster' of pregnancy and its associated worry. Women were reluctant to share news of the pregnancy with family and friends because they were certain another miscarriage would occur. Interviewees also suggested that they suppressed any hope of a successful pregnancy and avoided thinking about a future with their unborn child. This appeared to be linked to a notion of self-preservation/protection. By attempting to prepare for the worst outcome (i.e. a further miscarriage) they would be less upset if another miscarriage occurred.

BOX 2: Preparing for the worst

It's the not knowing and it's the being unable to believe anything except the worst. I find I'm baffled by how pregnancies work these days, I'm kind of constantly surprised that people are having babies because my experience is so different … so now it's impossible to believe that it's going to be okay… I just came to the conclusion that the kindest thing I could do for myself was not to hope. The most likely outcome is that you are not going to have that addition to your family and so actually there's no point picturing what life is going to be like because picturing it is exciting and it's hoping for a future that probably isn't going to be there. Hope just feels utterly naïve now - Participant 13 (4 miscarriages)

I was very detached from the whole pregnancy …it was self-preservation kind of mode - Participant 11 (4 miscarriages)

I think it's a self-preservation because of what you've been through, but I was never like that with my daughter. It's a learnt behaviour definitely … it's almost like you can't let yourself dream this might happen after wanting it so long – Participant 10 (3 miscarriages)

I think me and my husband ended up trying not to think about it too much … you don't want to get your hopes up so we'd be very cautious about even really talking about the positives in case it was bad news – Participant 14 (3 miscarriages)

I need to be real and I prepare for the worst, but hope for the best and that's almost like a protective shield around me – Participant 8 (3 miscarriages)

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Organising Theme 3: Setting of Personal milestones

The interviewees placed huge importance on the need to attain personal milestones, using this as a method of navigating their way through the uncertainty of the waiting period (Box 3). This was frequently achieved by breaking the pregnancy up in to smaller time chunks, thinking of the first trimester in individual weeks, or even days, rather than as a whole period of time. In addition, the participants frequently recalled how they tried to live the early stages of a new pregnancy day-by-day, trying not to think too far ahead, living in the moment.

The women's personal milestones often consisted of reaching and going past the gestation of their previous miscarriages, or achieving midwife or scan appointments.

During the interviews, participants were asked if anything had helped them cope with the waiting period and everyone referred to the value of reassurance from ultrasound scans and how they broke up this time into more manageable time chunks. Interestingly, however, all women commented that any optimism they felt after a positive scan was short-lived and feelings of anxiety soon started to re-emerge.

BOX 3: Setting of personal milestones

It's one day at a time, that's how we live one day at a time and that's how we've lived since June and I don't think it's a bad thing because we are appreciating that emotions can change from day to day …rather than think about the birth we think about little hurdles … I try not to think too far ahead because I get overwhelmed with things – Participant 12 (3 miscarriages)

It's kind of like you are trying to climb a ladder and the first rung up is the twelve week scan, but at least if you have a seven week scan and things are okay then you can stand on that rung and you know you've got that far - Participant 13 (4 miscarriages)

As soon as I confirmed the pregnancy they told me that they would get me in for scans at 6,8 and 10 weeks which helps because you've then got a 2 week marker to break up the 12 weeks. But I would say the anxiety massively increases up towards the scan … it build, builds, builds and then you have a scan and it drops so by the time I would go to a scan, especially the 6 week scan I was a complete mess and really struggling to hold it together, crying a lot and incredibly nervous, body full of adrenaline and really, really anxious - Participant 3 (6 miscarriages)

Organising Theme 4: Hypervigilance

Study participants frequently reported using observing strategies and hypervigilance to help them monitor their pregnancy symptoms, considering symptoms such as nausea, tiredness and breast tenderness as signs of an ongoing pregnancy (Box 4). Many of the participants detailed checking as an obsession and something they could not help doing, wanting constantly to seek reassurance that their pregnancy was ongoing.

One of the most common early signs of miscarriage is the onset of vaginal bleeding or spotting. Many were so convinced that they were going to experience a further miscarriage

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that they frequently reported repeated visits to the toilet to check for the onset of vaginal bleeding. This could often amount to numerous toilet visits every hour.

Participants expressed that when pregnancy symptoms were more intense then they felt more certain of an ongoing pregnancy, however any fluctuation in symptoms increased their feelings of uncertainty and caused added emotional distress.

BOX 4: Hypervigilance

Knicker checking is a big obsession - Participant 5 (4 miscarriages)

You are constantly monitoring your pregnancy symptoms, constantly. Do I feel the same as I did yesterday, are my 'boobs' still sore, do I need to go to the toilet more often or am I just drinking more? And you are constantly questioning every single twinge you feel and you are dying to get morning sickness so that you know you are pregnant – it's just all consuming - Participant 3 (6 miscarriages)

I was just constantly nauseous and if I wasn't thinking about it I probably wouldn't have realised that I was nauseous, because it wasn't that bad. But I felt myself thinking about it and I wanted to feel that feeling sickness just so I know that something is happening. Until now every single time I go to the bathroom I have to check that I'm not bleeding and I've been doing it since the beginning of my pregnancy. I also spent quite a bit of money on pregnancy tests just to see … I did them almost everyday, but I couldn't help it - Participant 9 (3 miscarriages)

Organising Theme 5: Social isolation

This organising theme brings together the participants' views on social interaction during the waiting period (Box 5). Many reported that they felt isolated and lonely during this time. This was compounded by the fact that the women often isolated themselves from friends and family, reluctant to share the news of their pregnancy because they felt certain a further miscarriage would occur, therefore, there was no point in telling people. There was also an innate fear for several participants that sharing the news of their pregnancy in the early stages would tempt fate and as a result, they would experience a further miscarriage.

There appeared to be a general withdrawal from social situations and social media, mainly due to the fear of forced social interaction with other pregnant women or those announcing news of a pregnancy. Compounding the degree of isolation was the fact that the women also appeared to feel safer and protected at home as they felt this environment might reduce the risk of miscarriage.

BOX 5: Social isolation

You want to tell people of course you do, but it makes you very private, very keep yourself to yourself - Participant 12 (3 miscarriages)

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It's really difficult I think these days with Facebook, it's really hard. I had to block a few people who put scan photos up or bump pictures. I found bump photos really hard because you think am I ever going to get there? Is that ever going to be me? - Participant 3 (6 miscarriages)

I've never been so scared to go outside my front door because I might just bump in to someone who is pregnant. Pregnancy just seemed to be everywhere. It's just one of those things where you become really heightened to it … and it was just awful, absolutely awful - Participant 8 (3 miscarriages)

I didn't want to speak to anybody, I didn't want to face anybody – Participant 9 (3 miscarriages)

Organising Theme 6: Adoption of pragmatic approaches

This organising theme brings together some of the pragmatic and practical approaches participants utilised to try to manage the stress and uncertainty of the waiting period (Box 6). The women referred to the fact that these practical approaches appeared to give them back some control in a situation where they had none.

Pragmatic approaches to coping with the anxiety often consisted of simple distraction techniques and keeping busy. This was particularly evident in participants who already had children, however work often provided a big distraction for employed participants. Other participants used avoidance (namely not allowing themselves to think about the pregnancy and blocking it out of their thought processes).

Commonly, the women tried to adapt their lifestyle to eliminate factors they felt could increase the risk of miscarriage such as reducing strenuous exercise or improving nutritional intake. Lifestyle adaptations could be more extreme with women giving examples of never opening the window on a car journey to avoid pollution from other cars or avoiding taking baths or showers in pregnancy.

Many of the participants referred to the value of accessing peer support as one of the most useful practical approaches they could adopt during this time. They believed only women who had experienced their situation truly understood the anxieties and challenges they faced. In most cases peer support was accessed via on-line miscarriage support groups and forums.

BOX 6: Adoption of pragmatic approaches

The only thing that would help is my work … It took my mind away so I didn't have time to think or dwell on think, so I think that was helpful - Participant 1 – (3 miscarriages)

I couldn't just dwell in my own self-pity about how hard it all was. So yes distraction did help, so if work hadn't given me distraction I would have gone and sought it. What made it better? Trying to be grateful, being distracted, really seriously just trying not to think about it - Participants 13 (4 miscarriages)

You stop more and more things. So you'll stop doing extra work, you'll start relaxing more. You'll stop doing some parts of your exercise, you'll stop eating different foods. You go through the most illogical things in your head – if I stay calm it will be alright, if I just do walking it will be fine - Participant 6 (4 miscarriages)

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Organising Theme 7: Need for professional affirmation

In the final organising theme, interviewees shared their views on the level of care they actually received from health professionals during the waiting period of their pregnancy and their perceptions of the type of care they would like to have received. Furthermore, they described the need for health professionals' acknowledgement of the challenges they faced and the stress they experienced during the waiting period of a new pregnancy (Box 7).

A recurrent theme in the interviews was a sense that health service provision was both limited and unsupportive and the women felt that this demonstrated a lack of understanding of their needs during this testing time. Often the first health professional the woman accessed for support was their General Practitioner (GP). While the degree of support offered by individual GPs varied, interviewees frequently spoke of the lack of support and understanding shown by them. Lack of empathy was considered one of the most upsetting aspects of their situation. All participants expressed the need to be cared for in a sensitive and understanding manner.

In general, the participants referred to the fact that contact with health professionals during the uncertainty of the waiting period was very important. They understood that the involvement of a health professional would not make a difference to the outcome of their pregnancy, but the contact helped them to feel more supported and they valued being able to share their concerns.

When an individual did receive empathetic care from a health professional, whether that was a GP or a nurse working in the Early Pregnancy Unit, then it made a positive difference to their emotional well-being.

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BOX 7: Need for professional affirmation

There is sometimes an absolute lack of understanding….I think generally the thing I would say to medical professionals is that they need to acknowledge that this person is probably going to be slightly damaged. Massive things don't have to change just some realisation of what a new pregnancy means to a woman who has been through all those lost pregnancies - Participant 10 (3 miscarriages)

It's the whole if you've got no pain and you've got no blood you are fine, that's what the GP would say - Participant 7 (4 miscarriages)

The EPU (Early Pregnancy Unit) staff were more gutted than I was I think, they were lovely… they were all just rooting for me and it was really nice - Participant 13 (4 miscarriages)

Discussion

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Awaiting confirmation of an ongoing, viable pregnancy after having experienced recurrent miscarriage is a traumatic period marked by an intense struggle between hope and despair, hypervigilance of pregnancy symptoms and bracing for another miscarriage. This all occurring in a context of social isolation and feeling relatively unsupported by health professionals. Nevertheless, women were shown to adopt diverse coping strategies aimed at achieving a state of cautious optimism that served to maintain hope while bracing for the possibility of failure.

The findings from this study provide further evidence that there is a need for provision of psychological support to women during the difficult waiting period of a new pregnancy following recurrent miscarriage. It also offers new and previously unexplored insights in to how women experience this challenging time.

The global theme identified in this study was that waiting is traumatic and a time in which the women hope for the best, but expect the worst. This global theme supports and expands on those reported by others. Previous research has demonstrated that women with a past history of repeated pregnancy loss utilise coping strategies to 'brace for the future,' as a means of attempting to control their emotions and future emotions as much as possible to prepare for the worst outcome [14]. This involved anticipating the negative feelings that a further miscarriage would cause and utilising bracing strategies such as not allowing themselves to think about a future with their unborn child and attempting to remain emotionally detached from the pregnancy. Behaviours similar to 'bracing for the worst' [14] have been reported in other studies that investigated pregnancy after previous perinatal loss, including 'holding back emotions' [24] and 'emotional cushioning' [25] which involves 'compartmentalising the pregnancy and avoiding its emotional aspects for as long as possible' [25]. The compelling evidence from this study provides further evidence of bracing adding to suggestions from previous studies [14] that propose the need for further research to investigate the impact of bracing strategies on long-term bonding and attachment between child and parents.

All participants concurred that the uncertainty of the situation compounded their emotional upset. The uncontrollability and unpredictability of the waiting period seemed a particularly difficult aspect for them to cope with. The formative work of Lazarus and Folkman [17] examined the processes of stress, appraisal and coping and identified the fact that both a lack of control over a situation and an inability to predict its outcome are potential stress inducing factors. If the demands of a situation exceed the level of coping resources available to the person then the affected individual is likely to experience stress, namely psychological (e.g. anxiety, worry), physiological (e.g. racing heart, tension) and behavioural responses (e.g. insomnia), [17]. The participants in this study consistently commented that the uncertainty of the waiting period was itself a stressor eliciting emotional turmoil, some even commenting on the relief they felt when a further miscarriage occurred as they felt better able to cope with the grief of miscarriage than the uncertainty of the waiting period. Positive reappraisal coping has been shown to be useful and valuable coping strategy and a

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helpful tool to help sustain coping during periods of uncertainty [26 27]. This type of coping might provide some respite from the prolonged and unrelenting stress that women with recurrent miscarriage experience during the early stages of a new pregnancy and help to sustain their ability to cope during this challenging time. The RCT component of this study has investigated the use of a novel self-help coping intervention, the Positive Reappraisal Coping Intervention [21 28] . Further research is planned to explore the role of the Positive Reappraisal Coping Intervention and how it appears to generate resilience in its users.

One organising theme described the strong 'need for professional affirmation' and perceptions of the level of care patients would like to receive. In a pioneering piece of work Bradshaw [29] presented a taxonomy of social need in which he acknowledged that the concept of need was both complex and imprecise. Furthermore he emphasised the fact that need was relative and therefore needs identified by professional experts often differed from those felt by the individual. Certainly, a recurrent theme during the interviews was a sense that current health service provision for women with recurrent miscarriage during the waiting period of a new pregnancy was both limited and unsupportive. Participants felt these gaps in support demonstrated a lack of understanding of their needs during this challenging time. The need for professional support and reassurance was generated at the actual moment of realisation that they were pregnant again, following the positive pregnancy test and in general was experienced toward the first health professional they would contact for support and advice (i.e. their GP). Whilst the degree of support offered by GPs varied individually, many women spoke of their disappointment at the lack of understanding and compassion shown to them. There was a general feeling that any health professional interaction that took place within a dedicated Early Pregnancy Unit environment was more sensitive to their needs, but that there was still room for improvement.

Whilst this study builds on the results of other studies that have identified the importance of understanding and compassion from health professionals around the time of miscarriage [30 31], it specifically highlights the need for health professional support during the early stages of a new pregnancy following recurrent miscarriage.

Clearly, consideration needs to be given to the most effective and appropriate ways in which health professionals can meet this demand for support, given the limited time constraints within which they work. GPs have time-limited consultations, often of less than ten minutes per patient and similarly secondary care health professionals work within restricted clinic appointment times. It is not always feasible to address every aspect of the woman's psychological needs during this time. For example, some women with recurrent miscarriage would prefer at least weekly reassurance ultrasound scans and others individual regular counselling sessions. However, the data from this study highlighted that in all cases, there was a sense amongst participants of the need to raise awareness within the health professional community of the potential emotional impact of the waiting period and the need for empathetic care. The participants acknowledged that they understood that the

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involvement of health professionals would not make a difference to the outcome of their pregnancy. Furthermore the women understood that their emotional needs fluctuated during the waiting period and therefore it was difficult for GPs and other health professionals to address these needs specifically. However, similar to the findings of a study by Musters, et al. [10] that investigated supportive care for women with recurrent miscarriage, women in this study noted that when health professionals took their emotional concerns seriously by listening to them and showing them understanding and empathy then it made a positive difference to their emotional wellbeing. The 'soft' skills of compassion, empathy and understanding appeared to meet the need for support during the uncertainty of the waiting period.

This study has two main strengths; its development and protocol was guided by an active PPI advisory group and this ensured the patient's perspective was central to the study. Secondly, the study addresses a gap in the literature and provides new and detailed qualitative data on how women experience the initial waiting period of a new pregnancy following recurrent miscarriage. Study limitations included the fact that the qualitative study was nested within an RCT feasibility study[20 21] and this was reflected in the choice of research methods selected. Furthermore, the majority of participants who took part in this study were of White British ethnicity, mainly due to the study sites in the South of England. A more varied ethnicity sample may have provided a more diverse and richer insight in to the cultural effects of recurrent miscarriage.

Conclusion

This study demonstrates that for many women with recurrent miscarriage, the waiting period of a new pregnancy is a time of great uncertainty and emotional turmoil and one in which they are likely to require emotional support.

Recurrent pregnancy loss has the potential to cause serious psychological effects including grief, anxiety and depression, and these emotional symptoms can affect every aspect of the woman's life. Recurrent miscarriage is therefore much more than just a medical condition; its consequences are more profound and life changing and the provision of supportive care should be central to the management of women who experience this distressing and frustrating condition.

This study reveals the thoughts and perceptions of women with a history of recurrent miscarriage during the waiting period of a new pregnancy; the challenge remains for both clinicians and service providers to develop a service that meets the needs of these women given the complex and challenging times that the NHS is experiencing. Recent NHS policy [32] advocates the need to ensure health services are designed around patients, but on a more sustainable footing. This includes the use of technology and innovation to enable patients to take a more active role in their health. The next stage of this programme of research plans to investigate the potential utilisation of technical innovation strategies as a method of providing much needed support to this vulnerable patient population.

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Contributors

SB contributed to the design of the study, was responsible for obtaining ethical approval and liaised with the PPI group for this study. NM, CB, JB, EKR and YC contributed to the design of the study. SB and EKR coded and analysed all the transcripts. All authors were involved in interpretation of the data. SB wrote the first draft of the manuscript and all authors were involved in subsequent revision. All authors approved the final manuscript.

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Competing interests

None declared

Ethical approval

A favourable opinion was received from National Research Ethics committee, South Central – Hampshire A (13/SC/0506)

Provenance and peer review

Not commissioned; peer reviewed for ethical and funding approval prior to submission

Data sharing statement

This research is part of a PhD study by SB. The PhD will be available via the University of Southampton depository

Figure legend/ captions

Figure 1 – RCT feasibility study of a coping intervention for recurrent miscarriage

Figure 2 – Demographic information of study participants

Figure 3 – Development of basic, organising and global themes using thematic network analysis

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Participant	Ethnic background	Age	Number of miscarriages	Ongoing pregnancy (OP) /Miscarriage (M) at time of interview
1	White British	38	3	OP
2	White British	37	3	OP
3	White British	42	6	M
4	White British	34	4	M
5	White British	31	4	M
6	White British	39	4	M
7	White British	33	4	M
8	White British	37	3	OP
9	Asian British	29	3	OP
10	White British	38	3	OP
11	White British	34	4	OP
12	White British	36	3	OP
13	White British	40	4	M
14	White British	34	3	OP

Figure 1: Demographic details of study participants

195x109mm (300 x 300 DPI)

Figure 2: A thematic network map (based on Attride Stirling 2001)

219x123mm (300 x 300 DPI)

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1. From Basic to Organising to Global Themes		
Themes as Basic Themes	*Organising Themes*	*Global Themes*
1. Uncertainty and fear of unknown	1.Turmoil of emotions	1.Hope for the best ... but expect the wors
2. Extreme feelings of anxiety		
3. Betrayed by body - theft of expectations		
4. Envy of other pregnant women		
5. Guilt - must be to blame		
6. Increased superstitious tendancies		
7. Mixed emotions after positive pregnancy test	2. Preparing for the worst	
8. Lost expectations		
9. Lack of hope		
10. Expecting the worst		
11. Denial of pregnancy		
12. Efforts to remain 'detached' from pregnancy		
13.Waiting period divided up into 'bite sized chunks'	3. Setting of personal milestones	
14.Take it day-by-day		
15. Checking for pregnancy symptoms	4.Hypervigilance	
16. 'Knicker checking'		
17. Heightened intuition		
18. Social withdrawal	5. Social isolation	
19. Effect on relationship with family and friends		
20. Reluctance to announce news of pregnancy		
21. Views on personal social media use		
22. Views on on-line support groups		
23. Value of peer support		
24. Getting used to RM	6. Adoption of pragmatic approaches	
25. How to deal with RM		
26. Controlling behaviour		
27. What helped?		
28. What didn't help?		
29. Ultra sound scans	7. Need for professional affirmation	
30. Investigations in to RM		
31. Views on health professionals		
32. Importance of sensitivity of health professionals		

Figure 3: Development of basic, organising and global themes utilising thematic network analysis

106x83mm (300 x 300 DPI)

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Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQR reporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245-1251.

		Reporting Item	Page Number
	#1	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1
	#2	Summary of the key elements of the study using the abstract format of the intended publication; typically	1

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		includes background, purpose, methods, results and conclusions	
Problem formulation	#3	Description and signifcance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	2
Purpose or research question	#4	Purpose of the study and specific objectives or questions	3
Qualitative approach and research paradigm	#5	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenolgy, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together.	3
Researcher characteristics and reflexivity	#6	Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research	4

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		questions, approach, methods, results and / or transferability	
Context	#7	Setting / site and salient contextual factors; rationale	4
Sampling strategy	#8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	4
Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	12
Data collection methods	#10	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of procedures in response to evolving study findings; rationale	4
Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	4
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	4

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Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	5
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	5
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	5
Syntheses and interpretation	#16	Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	5-8
Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	5-8
Intergration with prior work, implications, transferability and contribution(s) to the field	#18	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	9-11

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Limitations	#19	Trustworthiness and limitations of findings	2
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	12
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	12

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