



Blakeley, C., Smith, D. M., Johnston, E. D., & Wittkowski, A. (2019). Women's lived experiences of a prenatal diagnosis of fetal growth restriction at the limits of viability: an interpretative phenomenological study. *Midwifery*, 76, 110-117.

Document version

Peer reviewed version

Licence

CC BY-NC-ND

Copyright information

This document is made available in accordance with publisher policies. Please cite only the published version using the reference above.

Unless a licence is specified above, all rights (including copyright and moral rights) in this document are retained by the authors and/or the copyright holders. The express permission of the copyright holder must be obtained for any use of this material other than for purposes permitted by law.

Takedown policy

Any individual, whether within or external to the University, has the right to request the removal of content from the Leeds Trinity University Repository, on the grounds that it breaches copyright, is in any other way unlawful, or represents research misconduct.

Complaints can be submitted via the Repository Complaints Form at <https://www.leedstrinity.ac.uk/media/site-assets/documents/key-documents/pdfs/repository-complaints-form.pdf>

**Women's lived experiences of a prenatal diagnosis of fetal growth restriction at the
limits of viability: An interpretative phenomenological study**

Manuscript revised for Midwifery

Word count:

7,365(complete text including refs and tables), abstract (217 words), main text (5,082)

Abstract

Objectives

The research team aimed to understand women's lived experiences during pregnancies with poor prognosis following prenatal detection of Fetal Growth Restriction at the limits of viability (FGRLV).

Methods

Qualitative interviews with six women who had attended a specialist service following a prenatal diagnosis of FGRLV were conducted. The interview data were analysed using interpretative phenomenological analysis.

Findings

Three superordinate themes alongside thirteen subthemes were identified. Theme 1 described 'a fine line between supportive and unhelpful' care experiences. A second theme of 'understanding the situation and decisions to be made' described how women faced many uncertainties. The final theme of 'parental responsibility' reflected how women imagined their futures to have been, exploring their embodied parental role and connection to their unborn or young child.

Key Conclusions and Implications for Practice

Women highlighted the importance of maternal healthcare teams providing clear information and reassurance to them. They also reported that prior experiences were important to them in influencing their perception of that pregnancy. Furthermore, women reflected on their desperation for a positive outcome. Understanding these factors can enable maternal healthcare teams to facilitate informed decision-making and provide individualised emotional

support for women. Our findings will enable maternal care teams to better support women in similar clinical situations.

Keywords: FGR; Birth; Continuation; Decision-making; Disorder; Pregnancy; Termination of pregnancy.

Introduction

Fetal growth restriction (FGR) occurs when a fetus fails to reach their genetically predetermined potential growth in ~8% of all pregnancies (Junaid et al., 2014). The majority of FGR occurs near term, but when it occurs prior to 34 weeks it may result in a poor outcome for the fetus (Miller et al., 2008). In the most severe cases, when fetal growth restriction occurs at the limits of viability (FGRLV) women are faced with difficult decisions about ongoing progress of their pregnancies. Some women choose to continue with their pregnancies, aware that stillbirth may occur, others may opt for premature delivery by caesarean with a high chance of neonatal death (Smith, 2018) and some may consider termination (Vayssiere et al., 2015).

Qualitative researchers explored the psychological needs of parents informed of other fetal disorders or illnesses prenatally (Marteau, 1993; Redlinger-Grosse et al., 2002; Leithner 2004; Georgsson Ohman et al., 2006; Miquel-Verges et al., 2009 & Bratt et al., 2015). In addition, researchers examined factors influencing parental decisions about treatment choices (Guon et al., 2014; France et al., 2012 & Benute et al., 2012) and physical care provision (RCOG, 2013). The importance of assessing women's psychological response following diagnosis of FGRLV (Kehl et al., 2017; Vayssiere et al., 2015) has been highlighted in existing guidelines (RCOG, 2013 & RCOG 2011), but these largely focus on the physical management of FGRLV (Kehl et al., 2017; Vayssiere et al., 2015; Lausman et al., 2013 & ACOG, 2013). Thus, further insights into how best to assist women in making decisions about their ongoing pregnancy management, whilst supporting their psychological wellbeing, would be welcome.

Researchers have examined the psychological construct of decision-making (e.g., Classical Decision-Making Theory) and generated descriptive models (e.g., Prospect Theory)

to provide an understanding of real-life choices (Beach & Lipshitz, 2017; Tversky & Kahneman, 1992). It is important to explore how these frameworks may be applied to parental decision-making during pregnancy, especially considering that parents often view the maternal healthcare team as a primary source of decision-making support (Mills et al., 2014).

When considering choices regarding pregnancy management, previous researchers explored parental decision-making in relation to continuation of pregnancy following diagnosis of prenatal disorders (Sandelowski & Barroso, 2005), including pregnancies which were potentially lethal, life-limiting, or had serious long-term implications' (Blakeley et al., under review). Reviews identified that parents considered the importance of their unborn child's life, and the potential quality of life which might be anticipated for both themselves and their unborn child hoping for a more positive outcome when making choices regarding the continuation of their pregnancy, and considering moral and fatalistic views throughout an affected pregnancy (Sandelowski & Barroso, 2005; Blakeley et al., under review). Whilst this is suggestive of decision-making for parents following a lethal, life-limiting diagnosis with serious long-term implications, it may not specifically relate to those whose fetus was diagnosed with FGRLV. For this reason, the research team aimed to explore the lived experiences of women who received a diagnosis of FGRLV, exploring how women reached decisions about the management of their pregnancies after this diagnosis was made.

Methods

Design

As part of this qualitative study, we conducted semi-structured interviews with women who had attended a specialist maternal healthcare service following prenatal diagnosis of FGRLV. Interpretative phenomenological analysis (IPA; Smith, 1996) was chosen to enable the

consideration of a high level of personal detail and lived experience (Smith & Osborn, 2003). This methodology enabled the research team to explore the experiences of a small group of women (Smith & Osborn, 2003), establishing thematic patterns to describe their lived experiences (Larkin et al., 2006), whilst acknowledging and reflecting on the range of presentations within the sample (Tuffour, 2017). IPA has been used in comparable studies with similar sample sizes and healthcare settings (Shaw et al., 2008; Smith, 2004; Nordbo et al., 2006; Smith & Osborn, 2007). Unlike other qualitative methods, IPA enabled the research team to explore how women had understood the phenomenon they had experienced, attempting to make sense of their relationship with the diagnosis and processes which followed and allowed them to reach a decision (Shaw et al., 2008). Ethical approval for this study was granted (ref [REDACTED]), and the authors consulted American Psychological Association guidelines when considering methodological approaches (Levitt et al., 2018).

Participants, Setting and Recruitment

Women were recruited from a single specialist NHS clinic if they were proficient in English and had experienced the loss of a fetus or child due to FGRLV within the previous 6 to 48 months. The clinical care team screened a list of eligible patients, who had all continued with their pregnancy following the diagnosis. Participants were excluded for any contraindications (e.g., a recent miscarriage).

Convenience sampling was used to facilitate the recruitment of an unbiased sample of participants (Ajay & Micah, 2014). The clinical care team contacted eligible women via telephone. Following this initial contact, the first author then contacted interested participants to discuss the study and offered them a participant information sheet. The first author interviewed women who consented to the study.

Development of the Interview Topic Guide

A topic guide was developed based on the literature and expertise of the research team. This guide consisted of open-ended questions and prompts to enable the women to lead the discussion, and describe their understanding of their experiences. A pilot interview was conducted with a woman who had lost her young child following a diagnosis of FGRLV, which assisted in the refinement of the topic guide. A copy of the topic guide can be found in Table 2.

Qualitative Analysis

Following transcription of each interview, data were analysed using IPA guidelines (Smith & Osborn, 2003). Initially, two authors independently identified themes present within each interview transcript, after reading through each transcript several times to immerse themselves in the data. Following immersion in the transcript being read, these authors considered what each participant had portrayed in their interview, through their word choices, periods of distress and emotions presented in the interview, bracketing these within the transcript prior to further analysis. Sub-ordinate themes were developed after grouping codes within the text into themes which described the processes identified. Following this, the authors developed super-ordinate themes which embodied sub-ordinate themes within their wider arching definition. All identified themes were discussed by the research team and agreed.

Reflexivity

The first author is a Clinical Psychologist, with experience of a close relative struggling with fertility difficulties and seeking medical assistance in her journey of becoming a mother. All other authors are parents. The second author, a Health Psychologist and Senior Lecturer with

experience in exploring pregnancy and behaviour change, was pregnant during the study. The third author is a Consultant Obstetrician and Senior Lecturer caring for women following a diagnosis of fetal growth restriction. The final author, a Clinical Psychologist and Senior Lecturer, has an interest in parenting research and she also works with mothers with severe mental health difficulties.

Three of the authors were women who were familiar with psychological theory, whilst one of the authors was a man with clinical expertise of FGRLV; this combination of expertise enabled a wider interpretation of the women's experiences. All but one of the authors were parents and reflected on their own experiences of pregnancy during the study, with discussions held within the team to consider potential bias or difference in interpretation held. Memos relating to the interviewer's observations, and own reflections during the interview process were also considered by the study team when interpreting transcripts and perceived meaning within each participant's responses.

Results

Participants and Setting

Thirty-two eligible women were initially approached for the study, with eleven consenting to contact from the research team. Six women consented to take part in the study and were interviewed by the first author. Except for one, all women were White British and predominantly in full time work at time of pregnancy (see Table 1 for demographic information). The interviews lasted between 55-106 minutes (M=86 minutes). All interviews were audio-recorded, with memos made following interviews. Interviews were then transcribed verbatim and pseudo-anonymised.

Findings

Three super-ordinate themes, underpinned by thirteen subthemes, were identified: 1) ‘a fine line between being supportive and unhelpful’, 2) ‘understanding the situation and decisions to be made’ and 3) ‘parental responsibility’. These are visually presented in Figure 1. Short and embedded quotes, as advised by Creswell (2007), are cited in the text, whereas long quotes are presented in Table 3.

Super-ordinate theme 1: A fine line between being supportive and unhelpful

Women described several types of support, including support from their healthcare teams, family, partner, friends and social media groups. This support was not always sought by women and sometimes was given without them asking. Support was not always perceived as helpful, but there were no clear differences in what women reported as helpful and as unhelpful. Five sub-ordinate themes are used to explain this theme.

Sub-ordinate theme 1.1: Perception of care

Three women attended their local hospitals for ultrasound assessment and maternity care prior to connecting with the specialist centre, with two of the women returning to their local hospital to give birth. These women perceived the care at their local hospital as “cold” and not “very personal” (P3), with no “individual touch” (P5) and an understanding that they were “there to do the job and just get onto the next patient” (P3). The women believed that the care within local facilities was not adapted to their individual needs. Whilst there were some instances of good quality care, they often felt “like a number” (P3), and at times ignored.

All three women, who had attended local services, also experienced care from the specialist team and reported that the specialist care was more attentive, providing

“consistency” (P5) and an “individual touch” (P5). Women reported an affinity to their specialist care team, with a belief that they “fought (their) corner” (P3) and were a “gold standard” (P5) ‘...of care’.

Three women within the study had attended the hospital where the specialist clinic was based from the start of their pregnancy. They described a sense of feeling “blessed” (P2) that their care was immediately provided within this setting. They felt confident that they were “looked after well” (P6) by the team and described a sense of “affinity” (P2) towards staff for the care they received. However, some women did report a shock at the abrupt loss of this connection, once their care was passed over to other teams within the hospital or local services. Women reported feeling as though their care “wasn’t (the specialist team’s) ... issue anymore” (P4), and interpreted a discharge as being “sent back to our hospital” (P5) and abandoned at a vulnerable time. Women reported a loss, and enquired as to why further connection could not be facilitated, perhaps in the form a “check-up, every couple of months” (P2).

Sub-ordinate theme 1.2: Provision of detail

Women appeared to want to be informed of all potential outcomes for their situation. They appeared to value honesty and clarity, presented in a sensitive way, and felt that whilst the clarity was greater within the specialist service, there were still confusing aspects. Whilst some women felt confident asking staff questions, they described how this was only after a length of time when they had built a relationship with staff. One woman described how, after becoming aware of her inability in understanding the complex information being provided, a doctor “drew diagrams” (P4), which she found very helpful.

Women reported feeling unclear around their diagnosis throughout the pregnancy and “didn’t really understand” (P1) the prognosis, with a sense that at times, staff were unable to

provide information appropriately. Women reported they sensed doctors “knew that this wasn’t good, but wasn’t very forthcoming with information” (P5), reporting that advice or information provided “wasn’t clear” (P5) and that at times “no information was given” (P3). This was a theme that was particularly prevalent for mothers who experienced local maternal healthcare, or those who entered the neonatal setting. They described leaving their local facility feeling as though there was “nothing to worry about” (P3), and feeling unsure as to what to expect from an appointment at the specialist placenta clinic. They also sensed that staff within neonatal settings were “really hard” (P6) to contact for updates or information about the care of their baby. The majority of women valued a clear and calm method of explaining the diagnosis and options available, praising staff who had delivered news in “a matter of fact way, but sensitively” (P5). Women felt this was mostly facilitated within the specialist maternal healthcare clinic, in a confident manner which promoted trust and understanding. However, areas of improvement within the specialist healthcare team were highlighted by women, including feeling that some junior staff were unprepared to break bad news, whilst others felt they were not provided with thorough information about the choices they were making, and a sense that information “wasn’t always explained in lay-man’s terms” (P4). Finally, others reported an expectation to undertake research studies, with researchers attending consultations “almost like they were already waiting” (P3) for women to consent, and a sense that more consideration around these aspects of care could be beneficial.

Sub-ordinate theme 1.3: Seeking isolation

Women reported appreciating measures to isolate them somewhat from other mothers with far less complicated pregnancies. Separate waiting rooms within the specialist service were highly valued because women described their worries of being sat with women “just coming

for normal appointments” (P5). However, these measures were not often found in relation to “normal” (P6) pregnancy or post-birth experience with one woman reporting “not having your baby with you and other people around you having their babies” (P4) as a particularly difficult moment following her delivery leading to feelings of isolation.

Women also reported seeking isolation with their partners, because they “didn’t want anybody (else) there” (P6) and wanted to grieve with someone who shared their pain, in their own “little bubble” (P5). However, whilst women reported seeking solace in moments of isolation, they also reported an unwanted feeling of being “the only one” (P6) to have experienced this loss.

Sub-ordinate theme 1.4: Other’s understanding

Women reported seeking understanding from their partner during their experience, relying on them for emotional and practical support at a time when they felt “too fragile... to, to deal with those, that practical side of things” (P3). Women described how they trusted their partner to make the right choices for their family and lost baby and to “do a nice job” (P3) of tasks (e.g., funeral arrangements). Women also reflected on the understanding of wider family throughout their experience, with parents in particular being “very encouraging” (P3) and providing “emotional support” (P2) and solidarity to their daughters, foster daughters and daughters-in-law during this difficult time.

However, women also described distancing themselves from family input to protect them; one woman explained how she delayed the date of her delivery to prevent it coinciding with her nephew’s birthday, so as to prevent his special day being “tarnished with... the sadness” (P2). The need to protect others within the family unit was also particularly salient for the women who had other children. Women “struggled with how much” (P4) to tell their children beforehand, not wanting to “worry them” (P4), but not wanting “it all to come as a

big shock either” (P4). They described how younger children struggled to “understand why” (P1) the sibling they had anticipated was not brought home, with one woman describing how professionals “really helped” (P4) by providing advice.

Whilst women discussed connecting with support networks, and a reliance on them for emotional and practical assistance throughout and after their pregnancy, they also discussed a fear of judgement from others. Women reported that others were “so naïve” (P1) as to what had happened, that they were unable to understand or appreciate their experience, within what women described as a “taboo” (P2) and poorly understood situation.

Sub-ordinate theme 1.5: Helpful strategies for coping

Women described finding comfort in discovering similarities in their experience to that of other women. They explained how this reduced their feelings of being “the only person” (P6) who had ever lost a child to FGRLV. Women reflected on connecting with others via social media outlets, charities, and seeking solace with family friends. They again described finding comfort in understanding that other families had “gone through it” (P5).

Most women described sharing their experience and talking with others as being cathartic, and particularly beneficial after the loss of their baby, with one woman describing talking as her “therapy” (P2). Other women accessed counselling, and also used other homeopathic methods to “deal with grief” (P1). One woman explained that therapy had been beneficial in increasing the “communicating and understanding” (P4) between her and her partner following the loss of their child.

Super-ordinate theme 2: Understanding the situation and decisions to be made

Difficulties making decisions were reported by women, who discussed how they “didn’t really understand” (P1) the potential outcomes, but maintained hope, considering the precious

life of their baby, and the quality of life they would experience. Women reported the unknown outcomes of prognosis and treatment seeking, and their desperation to find answers or reassurance from multiple sources that their decisions were correct. They described periods of realisation of the poor prognosis when they knew “all the information” (P5), and the likelihood that they would not have a successful pregnancy or neonatal experience.

Sub-ordinate theme 2.1: The unknown

Women reported feeling uncertain about the prognosis for their pregnancy and the limitations of treatment pathways. They described knowing there was a problem, but not knowing “exactly what the problem was” (P4) which make them feel unclear as to what decisions they should be making, having “never been through it before” (P5).

Women reported being desperate to know why this had happened and reported a sense of despair at “not having any concrete answers” (P4) around causality, both during pregnancy and following their loss. One woman, who had questioned whether her prior health condition and “what else?” (P6) had caused the FGRLV, found no comfort in reassurances.

Sub-ordinate theme 2.2: Hope

Hope was important to women from the very start of their pregnancy and was stressed at the early stages of initial scans, through to diagnosis and during the participation in a research trial. Mothers described themselves as desperate to protect and nurture. Women explained that they were willing to try “anything” (P1) to “save” (P4) their child, and described hope as being key in their decision to continue with their pregnancy when offered the chance to terminate. Women described the fear of making the “wrong” (P2) choice for their pregnancy as “just too much” (P2). Even when all chance of a positive outcome had been removed, they described a lingering hope in the form of “wishing” (P5).

Hoping for a positive outcome, women described how they “Googled and researched” (P6) information related to FGRLV. Women reported holding on to professionals’ indications of safer thresholds of weight and gestation, focussing on there being “more chance of (baby) surviving than there would have been a couple of weeks earlier” (P6), whilst those who experienced neonatal care focussed on aspects of their baby’s presentation that challenged the poor prognosis they had been provided with. Women reported that sometimes they were provided with “false hope” (P1) by staff who advised that there was “nothing to worry about” (P3), particularly prior to diagnosis and during recruitment to the research trial.

Sub-ordinate theme 2.3: Precious life

Most of the women in the study reflected on the pregnancy being precious, with previous experiences of FGRLV, miscarriage, advanced age or difficulty in conceiving influencing their hopes for future pregnancies. These women described a willingness to try anything to ensure the survival of their fetus, with a sense that this could be their “last chance of... having a child.” (P3)

Sub-ordinate theme 2.4: Quality of life

The women described considering the quality of life which a baby surviving this pregnancy might face when considering options to terminate. Women explained how they wanted to continue their pregnancy so long as their baby would experience a quality of life acceptable to them, something that differed due their personal situations. Some women felt termination to be “the most sensible thing to do” (P5), and preferable than birth with potentially life impacting disabilities or “suffering” (P5). One woman described how she “might have terminated” (P1) had she known the severity of the condition earlier in her pregnancy.

Sub-ordinate theme 2.5: Reassurance

Women spoke about their need to seek reassurance about their fetus. They spoke of attachment to staff and medical devices which could provide that reassurance, and highlighted specialist staff support in enabling reassurance by offering further scans whenever they were “worried” (P6). Women reported a sense of guilt and self-blame for their loss, and sought reassurance through medical professionals and the internet to try and appease that feeling. Women described their internet-based reassurance-seeking as “dangerous sometimes” (P6), but seemingly necessary to alleviate the fear that they “might have killed” their baby. They valued reassurance that they were not at fault “from a professional” (P1) and found that this reassurance alleviated some feelings of guilt.

Super-ordinate theme 3: Parental responsibility

Women reported a sense of responsibility in the situation, including the need to act in a maternal way. Previous experiences also influenced women’s choices and sense of parental responsibility. Women described their need to protect their unborn or young child, reflecting on maternal instincts and an established connection.

Sub-ordinate theme 3.1: Imagined futures

Women discussed their imagined future as a mother, considering “normal labour” (P1), and how their previous experience had also impacted their experience (“we’d had a miscarriage before” (P5)). They described their lost futures, “mourning the future” (P2) that was taken when discovering that their unborn child had passed away. They described a sense of losing a connection that had never fully developed, and uncertainly related to their role and identity during a time that “should have been filled” (P5) with parenting tasks, not quite knowing

“what to expect” (P3).

Sub-ordinate theme 3.2: Parental role

Women described how they connected with their perception of being a parent, and giving “a mother’s love” (P2), even prior to meeting their child. They had an urge to protect and nurture their unborn child, and do everything in their power to “love and protect” (P1) them. This protective role and sense of “being that mothership” (P2) influenced their choices, with some mothers describing how they were unable to terminate, unable to allow doctors to “physically have to... stop baby’s heart” (P5) because they would see it as a failing of their duty. Some women described a sense of relief and gratefulness when decisions regarding the ongoing progress of their pregnancies were “taken out of (their) hands” (P4), figuratively speaking, when staff advised them that fetal death in utero had occurred. They were able to continue protecting their child, whilst no longer seeing or imagining them in pain, and described how it had made the process “so much easier” (P5).

Sub-ordinate theme 3.3: Connection

Women discussed how their connection to their unborn child began before birth, often through ultrasound appointments where mothers reflected on being able to “see (their) baby on the screen” (P3) and “listen to the heart beat” (P3). Some women described the birthing process as a traumatic detachment from this connection, with the sense that inside the womb, their unborn child “was safe” (P2).

Women often spent time bonding with their child following the birth, reflecting on the positive experience of “finally” (P3) being able to hold their child. However, most women found the experience very “bittersweet” (P3), with the understanding that “you can hold them, and give your love to them, but you’re getting nothing back” (P1). One woman had

pre-empted this emotional anguish, and attempted to sever the connection with her unborn child prior to birth. She described how she had been “angry” (P2) with her unborn child, and at times didn’t “want to meet him” (P2) to prevent attachment.

Discussion

To the authors’ knowledge, this is the first in-depth study exploring women’s lived experiences following the loss of an unborn or young child due to FGRLV. Women described a shift between helpful and unhelpful care provided by professionals, generally discussing a more beneficial approach to care and information provision within the specialist maternal healthcare clinic, valuing honest and realistic information, and both seeking and resenting isolation at different stages. Women, needing support in adjusting to lost roles and imagined futures, described seeking further emotional and psychological support whilst struggling with the unknown outcomes of their pregnancy, specifically within the early stages whilst investigations were ongoing. Reassurance from professionals alongside their own private research influenced their choices, with women highlighting the importance of staff maintaining realistic levels of hope.

There were notable similarities between past research exploring other prenatally diagnosed conditions and this study’s findings. For example, women felt ill-informed regarding implications of diagnosis and options available to them (Marteau, 1993; Redlinger-Grosee et al., 2002; Bratt et al., 2015) and they highlighted the importance of previous experiences (Redlinger-Grosee et al., 2002). In addition, women sought connection with others who had similar experiences (Bratt et al., 2015) and reflected on the importance of support from care teams (Bratt et al., 2015).

When considering women’s experiences of decision-making in pregnancy, in relation to other prenatally diagnosed disorders, it is important to consider a) attachment processes, b)

the sense of a precious life which they might not create again due to their advanced age or infertility (Redlinger-Grosee et al., 2002) and c) the hope women hold for a more positive outcome following diagnosis (Miquel-Verges et al., 2009). Prior life experiences influencing this perception are likely to influence decision-making in a way concordant with descriptive models of decision-making (Falzer et al., 2004). The similarities found within this study and previous research exploring decision-making and experiences with parents learning of other prenatal disorders suggest that influential factors on parental decision-making may be identified across prenatally diagnosed disorders.

Women within this study, and previous research exploring decision-making following diagnosis of prenatal disorders (e.g., Redlinger-Grosse et al., 2002), emphasised the importance of their perception of the fetus as a much longed for and precious baby. The understanding that women seek further knowledge and are unsettled by aspects of the ‘unknown’ when making decisions about treatment options (Marteau, 1993; Redlinger-Grosse et al., 2002; Bratt et al., 2015) fits within the concept of descriptive models of decision-making. In our study, women reflected that had they been more informed of likely outcomes at an earlier date, they may have made alternative decisions in relation to ending their pregnancy. Therefore, women require all potential outcomes and information prior to making their decision.

Limitations

Whilst IPA is an appropriate methodology to use when exploring phenomena which occur in small populations (Larkin et al., 2006; Tuffour, 2017), the findings require further replication with different methodologies before they can be considered generalizable.

Only two of the participants interviewed went on to experience a successful pregnancy following the loss of their unborn or young child. Both women, who have since

experienced a successful pregnancy, openly discussed their thoughts about termination following diagnosis of FGRLV, and how they may have considered termination had the severity of the prognosis been made clearer to them from earlier in their pregnancy. Other women who have not since experienced a successful pregnancy did not express thoughts of terminating their pregnancy. It is possible that the time lapse of up to three years since their loss, along with changes in circumstance for some of the women, may have influenced their perception of their experience in hindsight. Future studies should consider interviewing women sooner.

Clinical Implications

Current policies and guidelines focus on providing physical care and offering preventative measures for women diagnosed with FGRLV, with the UK government striving to raise awareness and intervene in pregnancies affected pregnancies to reduce preventable stillbirth (NHS England, 2016).

Whilst our findings represent the experiences of a small sample of women affected by prenatal diagnosis of FGRLV, they were reviewed within a framework of the authors' knowledge and experience of prenatal healthcare and the psychological experience of prenatal diagnosis, enabling the consistent messages presented from participants to suggest that future research should explore how best maternity health care professionals can: 1) provide clear and accessible information including likely outcomes to women throughout their experience, facilitating a supportive and reflective space in which women can discuss their thoughts and options, 2) form an understanding of women's personal history and how this may impact their interpretation or experience and decision-making process, 3) assess benefits of facilitating women's connection with other women or support groups with specialist provision or experience within this area, and 4) explore benefits of a distinct

separation of clinical appointments and research recruitment, with researchers only brought into consultations following explicit patient consent.

As well as improving the transparency and clarity of the provision of information, researchers may also wish to explore the benefit of local facilities implementing some aspects of the specialist care which women found particularly comforting and beneficial. These included: 1) the provision of attentive and person-centred care, 2) considering women's previous experience, potential recent loss and emotional needs during all interactions, 3) providing honest and transparent information, and preparing women for appointments with a specialist maternal healthcare clinic.

The indication of emotional distress and uncertainty for women experiencing FGRLV is apparent from initial contact with local services, through to discharge following the loss of their fetus or child. The psychological and emotional impact will vary dependant on the woman presenting. Future research exploring the impact of maternity healthcare teams attending to women's needs by providing primary care level psychological support and assistance during this time may be beneficial. The importance of recognising psychological distress within perinatal settings and alerting staff to the need for an individualised and empathic approach has been highlighted (McKenzie-McHarg et al., 2014), with tiered care models for psychological support have been evidenced as appropriate and beneficial in other health related areas (Steginga et al., 2006; Von Korff, 1999), and may be of benefit within maternal healthcare teams. Specialist perinatal psychologists could also provide interventions for women with more complex needs or difficulties adjusting following diagnosis, and should be provided within all hospitals providing maternal healthcare (BPS; 2016). It may be beneficial to explore the implementation of this within maternal healthcare teams in future research.

Conclusion

Our findings provide valuable and novel insight into the experiences of women following diagnosis of FGRLV and offer further understanding of the possible factors that influence women's decision-making during this time. Maternal healthcare teams working to support women following diagnosis of FGRLV may consider adapting current practice in line with study recommendations, scaffolding women's decision-making and providing adequate emotional and psychological support.

References

- Ajay, S.S., & Micah, M.M., 2014. Sampling techniques and determination of sample size in applied statistics research: An overview. *International Journal of Economics, Commerce and Management*, 2(11), 1-22.
- American College of Obstetricians and Gynecologists, 2013. Practice Bulletin, Clinical Management Guidelines for Obstetrician-Gynecologists. *American College of Obstetricians and Gynecologists*, 121(5)
- Beach, L.,R., Lipshitz, R, 2017. Why classical decision theory is an inappropriate standard for evaluating and aiding most human decision-making. *Decision-Making in Aviation*, 85
- Benute, G.R.G., Nomura, R.M.Y., Liao, A.W., de Lourdes Brizot, M., Lucia, M.C.S., Zugaib, M., 2012. Feelings of women regarding end-of-life decision-making after ultrasound diagnosis of a lethal malformation. *Journal of Midwifery*, 18:472-475
- Blakeley, C., Smith, D.M., Johnstone, E., Wittkowski, A., pending publication. Parental decision-making following lethal or life-limiting prenatal diagnosis: a meta-synthesis
- Bratt, E., Jarvholm, S., Ekman-Joelsson, B., Mattson, L., Mellander, M., 2015. Parent's experiences of counselling and their need for support following a prenatal diagnosis of congenital heart disease - a qualitative study in a Swedish context. *BMC Pregnancy Childbirth*, 15(1):171 DOI 10.1186/s12884-015-0610-4
- British Psychological Society, 2016. Briefing paper No. 8 Update, Perinatal Service Provision: The Role of Perinatal Clinical Psychology.
- Creswell, J.W., 2007. *Qualitative Inquiry & Research Design: Choosing among five approaches*. Sage Publications, 2nd edition, Thousand Oaks, California.
- Falzer, P.R., 2004. Cognitive schema and naturalistic decision-making in evidence- based practices. *Journal of Biomedical Informatics*, 37(2):86-98 DOI 10.1016/j.jbi.2004.02.002

- France, E.F., Locock, L., Hunt, K., Ziebland, S., Field, K., Wyke, S., 2012. Imagined Futures: how experiential knowledge of disability affects parents' decision-making about fetal abnormality. *Health Expectations*, 15(2):139-156 DOI 10.1111/j.1369-7625.2011.00672.x
- Georgsson Öhman, S., Saltvedt, S., Waldenström, U., Grunewald, C., Olin-Lauritzen, S., 2006. Pregnant women's responses to information about an increased risk of carrying a baby with Down syndrome. *Birth*, 33(1):64-73 DOI 10.1111/j.0730-7659.2006.00075.x
- Guon, J., Wilfond, B.S., Farlow, B., Brazg, T., Janvier, A., 2014. Our children are not a diagnosis: the experience of parents who continue their pregnancy after prenatal diagnosis of trisomy 13 or 18. *American Journal of Medical Genetics*, 164(2):308-318 DOI 10.1002/ajmg.a.36298
- Junaid, T.O., Brownbill, P., Chalmers, N., Johnstone, E.D., Aplin, J.D., 2014. Fetoplacental vascular alterations associated with fetal growth restriction. *Placenta*, 35(10):808-815
- Kehl, S., Dotsch, J., Hecher, K., Schlembacj, D., Schmitz, D., Stephan, H., Gembruch, U., 2017. Intrauterine Growth Restriction. Guideline of the German Society of Gynecology and Obstetrics (S2k-Level, AWMF Registry No. 015/080, October 2016. *Geburtshilfe Frauenheilkd*, 77(11):1157–1173
- Larkin, M., Watts, S., Clifton, E., 2006. Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, 3(2):102-120 DOI 10.1191/1478088706qp062oa
- Lausman, A., Kingdom, M.D., Gagnon, R., Basso, M., Bos, H., Crane, J., Davies, G., Delisle, M., Hudon, L., Menticoglou, S., Mundle, W., Ouellet, A., Pressey, T., Pylypjuk, C., Roggensack, A., Sanderson, F., 2013. SOGC Clinical Practice Guideline: Intrauterine Growth Restriction: Screening, Diagnosis, and Management. *Journal of Obstetrics and Gynaecology Canada*, 35(8): 741-748

- Leithner, K., Maar, A., Fischer-Kern, M., Hilger, E., Löffler-Stastka, H., Ponocny-Seliger, E.,
2004. Affective state of women following a prenatal diagnosis: predictors of a negative
psychological outcome. *Ultrasound in Obstetrics & Gynaecology*, 23(3):240-246 DOI
10.1002/uog.978
- Levitt, H.M., Bamberg, M., Creswell, J.W., Frost, D.M., Josselson, R. Suarez-Orozco, C.,
2018. Journal article reporting standards for qualitative primary, qualitative meta-
analytic, and mixed methods research in Psychology: The APA publications and
communications board task force report. *American Psychologist*, 73(1), 26-46 DOI
<http://dx.doi.org/10.1037/amp0000151>
- Marteau, T.M., 1993. Psychological consequences of screening for Down's syndrome. *BMJ:
British Medical Journal*, 307(6897):146 DOI 10.1136/bmj.307.6897.146
- McKenzie-McHarg, K., Crockett, M., Olander, E.K., Ayers, S., 2014. Think Pink!
A Pink Sticker Alert System for Women with Psychological Distress or Vulnerability
During Pregnancy. *British Journal of Midwifery*, 22(8);590-595.
- Mills, T.A., Ricklesford, C., Cooke, A., Heazell, A.E.P., Whitworth, M., Lavender, T., 2014.
Parents' experiences and expectations of care in pregnancy after stillbirth or neonatal
death: a metasynthesis. *International Journal of Obstetrics and Gynaecology*, 121(8):943-
950 DOI 10.1111/1471-0528.12656
- Miller, J., Turan, S., Baschat, A.A, 2008. Fetal Growth Restriction. *Seminars in
Perinatology*, 32(4):274-280. DOI 10.1053/j.semperi.2008.04.010
- Miquel-Verges, F., Woods, S.L., Aucott, S.W., Boss, R.D., Sulpar, L.J., Donohue, P.K.,
2009. Prenatal consultation with a neonatologist for congenital anomalies: parental
perceptions. *Pediatrics*, 124(4):573-579 DOI 10.1542/peds.2008-2865
- NHS England, 2016. Saving babies' lives, a care bundle for reducing stillbirth.

- Nordbø, R.H., Espeset, E., Gulliksen, K.S., Skårderud., F., Holte, A., 2006. The meaning of self-starvation: Qualitative study of patients' perception of anorexia nervosa. *International Journal of Eating Disorders*, 39(7):556-564
- Redlinger-Grosse, K., Bernhardt, B.A., Berg, K., Muenke, M., Biesecker, B.B., 2002. The decision to continue: the experiences and needs of parents who receive a prenatal diagnosis of holoprosencephaly. *American Journal of Medical Genetics Part A*, 112(4):369-378 DOI 10.1002/ajmg.10657
- Royal College of Obstetricians & Gynaecologists (RCOG), 2011. Reduced fetal movements, (green-top guidelines no.57
- Royal College of Obstetricians & Gynaecologists (RCOG), 2013. Small-for-Gestational-Age Fetus, Investigation and Management (Green-top Guideline No. 31), 2nd Edition.
- Sandelowski, M., Barroso, J., 2005. The travesty of choosing after positive prenatal diagnosis. *Journal of Obstetric Gynaecological Neonatal Nursing*, 34(3):307-18 DOI 10.1177/0884217505276291
- Shaw, R.L., Senior, C., Peel, E., Cooke, R., Donnelly, L.S., 2008. Ethical issues in neuroimaging health research: an IPA study with research participants. *Journal of Health Psychology*, 13(8):1051-1059
- Smith, G.C.S., 2018. The STRIDER trial: one step forward, one step back. *The Lancet*, 2(12):80-81
- Smith, J.A., 1996. Beyond the divide between cognition and discourse: using interpretative phenomenological analysis in health psychology. *Psychology and Health*, 11(2):261-271 DOI 10.1080/08870449608400256
- Smith, J.A., 2004. Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, 1(1):39-54

- Smith, J.A., Osborn, M., 2003. Interpretative phenomenological analysis. In *Qualitative psychology: A practical guide to methods*, Edited by: Smith, J. A., London: Sage Publications
- Smith, J.A., Osborn, M., 2007. Pain as an assault on the self: An interpretative phenomenological analysis of the psychological impact of chronic benign low back pain. *Psychology and Health*, 22(5):517-534
- Steginga, S.K., Hutchison, S.D., Turner, J., Dunn, J., 2006. Translating psychosocial care: guidelines into action. *Cancer Forum*, 30(1):28
- Tuffour, I., 2017. A Critical Overview of Interpretative Phenomenological Analysis: A Contemporary Qualitative Research Approach. *Journal of Healthcare Communication*, 2:52 DOI: 10.4172/2472-1654.100093
- Tversky, A., Kahneman, D., 1992. Advances in prospect theory: cumulative representation of uncertainty. *Journal of risk and uncertainty*, 5(4):297-323 DOI [10.1007/BF00122574](https://doi.org/10.1007/BF00122574)
- Vayssiere, C., Sentilhes, L., Ego, A., Bernard, C., Cambourieu, D., Flamant, C., Gascoin, G., Gaudineau, A., Grange, G., Houfflin-Debarge, V., Langer, B., Malan, V., Marcorelles, P., Nizard, J., Perrotin, F., Salomon, L., Senat, M.V., Serry, A., Carbonne, B., 2015. Fetal Growth Restriction and Intra-Uterine Growth Restriction: Guidelines for clinical practice from the French College of Gynaecologists and Obstetricians. *European Journal of Obstetrics and Gynaecology and Reproductive Biology*, 193:10-18. DOI 10.1016/j.ejogrb.2015.06.021
- Von Korff, M., 1999. Pain management in Primary Care: An individualised stepped care approach. In Gatchel, R., Turk, D., eds. *Psychological factors in pain: evolution and revolutions*. New York: Guildford Press.

Figure 1: Diagrammatic representation of women's experience following diagnosis of FGRLV

Theme 1) A fine line between being supportive and being unhelpful
Sub-theme 1) Perception of care
Sub-theme 2) Provision of detail
Sub-theme 3) Seeking isolation
Sub-theme 4) Other's understanding
Sub-theme 5) Helpful strategies for coping

Women's lived experiences of and decisions in relation to a prenatal diagnosis of FGRLV

Theme 2) Understanding the situation and decision to be made
Sub-theme 1) The unknown
Sub-theme 2) Hope
Sub-theme 3) Precious life
Sub-theme 4) Quality of life
Sub-theme 5) Reassurance

Theme 3) Parental responsibility
Sub-theme 1) Imagined Futures
Sub-theme 2) Parental role
Sub-theme 3) Connection

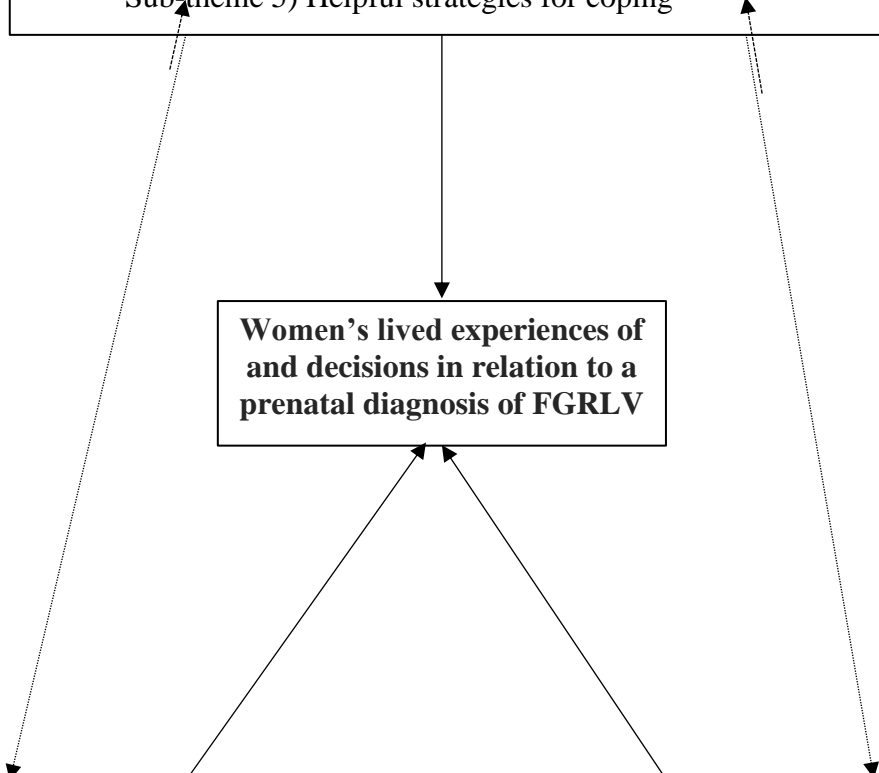


Table 1: Participant demographic information

Participant	Ethnicity	Age (when pregnant)	Number of conceptions prior to pregnancy (successful conceptions)	Number of conceptions post pregnancy (successful conceptions)	Fetal or early neonatal death
1	White British	27 (25)	2 (2)	1 (1)	Fetal death
2	White British	30 (29)	0 (0)	1 (0)	Fetal death
3	White/Black African	41 (39)	1 (0)	0 (0)	Fetal death
4	White British	39 (37)	3 (3)	2 (0)	Early neonatal death
5	White British	32 (29)	1 (0)	3 (1)	Fetal death
6	White British	29 (28)	1 (0)	0 (0)	Early neonatal death

Table 2: Interview topic guide and prompts

Section of Interview	Example Question	Possible Prompts
Experiences	Please could you tell me about your experience of being diagnosed of fetal growth restriction and what this meant for you?	What was your understanding of the risks involved with this diagnosis?
Support	What are your views of the psychological support and guidance you were offered throughout the experience?	What impact did this have on you and your emotional well- being? Could anything have been changed to better support you, if so what?
Decision-making	Please talk me through your decision-making process when deciding to continue with your pregnancy?	What factors influenced your decision-making process? Any psychosocial and emotional factors? What would be helpful if you were ever faced with situation again? Please tell me more? What else can you tell me about that? Please elaborate more on that. In what way?
Other considerations	Is there anything else you would like to add?	

Table 3: Super-ordinate and Sub-ordinate themes with quotations from transcripts

Theme	Title	Quotation
Super-ordinate Theme 1	A fine line between supportive and unhelpful	“We weren’t on the placenta clinic, we were on a maternity ward... and... initially, I wasn’t... it wasn’t a separate bay, we were on a mixed ward... and the nurses obviously don’t know... what’s been going on... you know, they will have been given an idea, but there’s just not that same relationship and the same... connection... erm... and it was scary... really...” (P4)
Sub-ordinate Theme 1.1	Perception of care	“That individual touch, in taking... each couple... each person... and... providing the care that they need.” (P5)
Sub-ordinate Theme 1.2	Provision of detail	“I thought, I would just... the baby would be removed... or I’d have a caesarean... I didn’t realise.” (P2)
Sub-ordinate Theme 1.3	Seeking Isolation	“The room next door was of women giving birth... and you can hear the babies crying... and I’m just stuck there.” (P6)
Sub-ordinate Theme 1.4	Other’s understanding	“My mum would be around and I’d say, “He’s not moved for like, 4 hours”, so then she’d take me back to the hospital.” (P6)
Sub-ordinate Theme 1.5	Helpful strategies for coping	““Cos I did post a few things... I did... like comment on a few things, but now... I’m still there, I’m still friends with people (online).” (P1)
Super-ordinate theme 2	Understanding the situation and decision to be made	“Initially it was... well... that’s the right thing to do... there’s no point carrying on when we don’t know how long this will go on for... our baby could survive another two weeks... they could survive another six weeks... but with such poor blood flow, it just felt cruel to do it... but then when you know all the information... you know how that’s going to be done... that changed it massively... it just flips it around.....” (P5)
Sub-ordinate theme 2.1	The unknown	“I couldn’t process why they couldn’t get him out, why they couldn’t try and do something.” (P1)
Sub-ordinate theme 2.2	Hope	“What we were seeing was... (baby) turning to look at us when he heard our voices, and... putting his hand and gripping your finger.” (P4)
Sub-ordinate theme 2.3	Precious life	“I really want us to have a child together.” (P4)
Sub-ordinate theme 2.4	Quality of life	“As long as he’s fighting, we’ll keep fighting ... Unless you can tell us that he’ll be in a vegetative state.” (P4)

	Sub-ordinate theme 2.5	Reassurance	“There were times where... you wanted them to sugar coat things... but that wasn’t what we needed.” (P3)
	Super-ordinate theme 3	Parental responsibility	“We paid for the... gender scan. We knew he was a little boy. He had an identity, his name was (baby’s name), we had lots of lovely things for him... so he had a real identity when he passed.” (P2)
	Sub-ordinate theme 3.1	Imagined futures	“I think mentally and physically your body is prepared that this time should have been filled... This time should have been, like... You know, parenting.” (P5)
	Sub-ordinate theme 3.2	Parental role	“At that time I was like, “Well, anything. Anything to help”. “Because as a parent, if you know deep down, that you’ve done everything you can to try and help.....” (P1)
	Sub-ordinate theme 3.3	Connection	“I remember getting distressed and screaming “Don’t leave me! I don’t want you to leave me!” (P2)