Women from diverse minority ethnic or religious backgrounds desire more infertility education and more culturally and personally sensitive fertility care

Running title: Care needs of minority ethnic or religious women

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Abstract

Study question: What are the views, experiences and healthcare needs of infertile women from a minority ethnic or religious background living in Wales?

Summary answer: Women from ethnic and religious minority backgrounds consider that their communities have highly pronatalistic attitudes and stigmatize infertility, and express the need for more infertility education (for themselves and their communities), as well as more socio-culturally and interpersonally sensitive fertility care.

What is already known: Some people from minority ethnic or religious groups perceive pressure to conceive from their communities, experience social costs when they are unable to have children, and stressful interactions with the fertility healthcare system while attempting to conceive.

Study design, size, duration: This study was based on a one-day drawing workshop to collect visual (artwork produced by participants) and textual (all conversations and discussions during the workshop) data about the participants' views and experiences of infertility and their fertility care needs.

Participants/materials, setting and method: Participants were nine adult women with a minority ethnic or religious status living in Wales, UK, who were experiencing or had experienced infertility in the past. The workshop comprised five activities: 1) small and large group discussion of infertility-related drawings, 2) Slide-based lecture consisting of an introduction to the basics of drawing objects and people and 3) thoughts and feelings, 4) free drawing session, and 5) group sharing. Audio recordings of the workshop were transcribed verbatim. Textual data was analysed with thematic analysis. Risk for bias was addressed via individual coding by two authors followed by joint presentation and discussion of results with the research team and participants.

Main results and the role of chance: Forty-one themes were identified and grouped into 8 distinct higher order themes. These themes described the emotional, relational and social burden of infertility experienced by women, which they perceived to result from their communities' highly pronatalistic attitudes and stigmatization of infertility. Themes also captured women's adaptive coping strategies and critical attitude towards pronatalist ideologies. Lastly, themes captured their overall positive evaluation of their fertility health care, their desire for more infertility education (for themselves and their communities), and for culturally competent and interpersonally sensitive care.

Limitations, reasons for caution: Our participants were a small, non-random sample recruited in collaboration with a local charity, which may mean that all participants were well integrated in their communities. Analysis focused on capturing commonalities in participants' experiences and this may sometimes result in homogenising diverse experiences.

Wider implications of the findings: More education about the infertility experiences of minority ethnic and religious groups at the community and healthcare delivery level may translate into lessened negative attitudes towards infertility and more culturally competent care, which can be beneficial for women.

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Key words: Infertility, ethnicity, religion, healthcare needs, visual research methods, drawing, arts-based research, culturally competent care

Introduction

Infertility can affect any woman or man in their reproductive years. The most recent statistics show that in the UK 8% of infertile people are non-white, with 51% of these being Asian or Asian British, 26% Black or Black British, 12% Chinese or other ethnic groups, and 11% Mixed (HFEA, 2006). Ethnic and religious minority groups are underrepresented in European infertility psychosocial research (Culley et al., 2009a), despite research showing that ethnicity is associated with some reproductive health problems (e.g., miscarriage, Harb et al., 2014) and worse treatment outcomes (Dhillon et al., 2016). The consequences are a lack of understanding of these patients' infertility and treatment experiences and a lack of available guidance about how to meet their specific support needs. In this study we used a participatory drawing-based method, *DrawingOut* (Gameiro et al., 2018), to explore the views, experiences and healthcare needs of a group of infertile women from a minority ethnic or religious background living in Wales, UK; and to co-develop an engaging booklet that minority groups can use to share their infertility experiences and advocate for support with their communities and health professionals.

It has been claimed that the need for fertility care of ethnic and religious minority groups has received little political and academic attention (Culley et al., 2009a). This is certainly the case for European research focusing on psychosocial adjustment to infertility and its treatment. Most psychosocial research has been conducted with white middle-class heterosexual infertile couples undergoing fertility treatment (Greil et al., 2010b), and very few studies have investigated how ethnicity and religion (compared to other socio-demographic factors such as gender and education) influence adjustment to infertility and associated support needs. Stated reasons for the inadequate representation of minority ethnic

and religious groups in research include these groups' lack of access to healthcare settings where research tends to be conducted; language and socio-cultural barriers, for instance stigma around infertility, that make it harder for minority groups to participate; and self-exclusion, for instance, due to lack of experience with or distrust in health research (Johnstone et al., 2009).

Some researchers were able to overcome language and socio-cultural barriers to research participation by using community facilitators (Culley et al., 2007), or by conducting qualitative research with specific minority groups. In the Netherlands and Germany, the focus has been on Turkish immigrant communities (van Rooij et al., 2009;Vanderlinden, 2009, 2011); in the UK, on British South Asian - Indian, Pakistani and Bangladeshi (Culley and Hudson, 2009;Culley et al., 2009a), British Turkish (Gürtin-Broadbent, 2009), and British Pakistani Muslim groups (Blell, 2017;Hampshire et al., 2012;Simpson et al., 2014).

All these minority groups have distinctive histories within Europe, as well as specific sociocultural and religious beliefs that shape the way infertility is experienced at an individual and social level. However, there are also some commonalities of their experiences. For example, within these communities, most people are expected to marry early, sometimes in the context of arranged marriages, and to have their first child within one year of marriage.

According to participants, their cultures share a strong investment in children, and male children are of special importance to ensure the continuation of the family lineage. In the study of South Asian and Pakistani communities in the UK, some individuals talked about a generational 'gap', whereby younger people were starting to delay parenthood for a short while to pursue other goals, and highlighted individual motivations to have children (e.g., desire to develop an emotional bond) beyond the need to meet family expectations (Culley and Hudson, 2009;Hampshire et al., 2012;Simpson et al., 2014).

Nonetheless, having no children at all or only one child is still negatively perceived in many of the researched ethnic minority communities in Europe, especially if the only child is a girl (Culley et al., 2009b;Simpson et al., 2014). Consistently, infertility tends to be highly stigmatized and seen almost exclusively as the woman's fault. Its social consequences are more severe for women than for men; they can include being gossiped about, ostracized, and sometimes even ill-treated by family members. Some male respondents also reported that they were being put under pressure to divorce their wives and remarry because their marriage had not produced any children (e.g., Culley and Hudson, 2009). These data suggest that minority groups experience higher social burden of infertility. However, infertility social distress is also commonly reported by non-minority groups (Gameiro and Finnigan, 2017), and quantitative studies using US samples have not shown that ethnicity, religion and high social value placed on motherhood are associated with higher infertility distress (Greil et al., 2011;Jacob et al., 2007), which suggests that distress may depend on how individuals perceive their circumstances. As shown by McQuillan et al. (2012), it may also be that social expectations about parenthood are only distressing when internalised by individuals. Another explanation is that these qualitative studies' samples are not representative of the full heterogeneity of experiences and socio-cultural attitudes present in ethnic and religious minority groups.

All the studies mentioned above found that some of their respondents had experienced difficulties when seeking fertility healthcare. These were related to a range of issues, including a lack of language proficiency that led to problems understanding doctors or relying on a family member's translation; being exposed to information that contradicts religious beliefs; having to undergo potentially humiliating or demasculinizing procedures (e.g., testing for male infertility); and a lack of cultural sensitivity and prevalence of cultural stereotypes on the part of healthcare providers. These data suggest that minority groups may

experience a high burden of treatment. One study showed that Turkish migrant infertile patients reported higher depression, self-blame and guilt, and more sexual problems due to infertility than Dutch patients (van Rooij et al., 2007), but it did not identify the sources of burden. Dissatisfaction with treatment can also lead to dropout. For instance, many of the Turkish patients who travel home for fertility treatment are critical of the Dutch healthcare system (Gürtin-Broadbent, 2009). Despite this negative portrayal of fertility treatment experiences, little research has been conducted to understand what these patients' support needs and preferences might be. One research team tried to address the lack of guidance for healthcare practitioners by developing educational materials (Culley and Hudson, 2004). However, systematic reviews of patients' preferences (Dancet et al., 2010) and European and UK national (NICE) evidence-based guidelines (Gameiro et al., 2015;National Institute for Clinical Excellence, 2013) give no information on how to address ethnic, cultural and religious specificities in care, with both guidelines calling for further research to address this research gap.

In sum, evidence suggests that at least some people from minority ethnic or religious groups perceive increased pressure to conceive from their communities, higher social costs when they are unable to have children, and stressful interactions with the fertility healthcare system while attempting to conceive. The current study used *DrawingOut* (Gameiro et al., 2018) to explore the views, experiences and healthcare needs of nine infertile women from a minority ethnic or religious background living in Wales, UK. DrawingOut is a participatory visual research method that consists of a one-day metaphor-centred drawing workshop to collect visual and textual data about a particular health related topic, in this case infertility. We hypothesised that DrawingOut would be successful in engaging participants from diverse cultural and religious backgrounds and with varying levels of language proficiency. Its non-directive (using activities instead of questions) and group character should also empower

participants to bring their own agendas into the research setting and to construct meaning about their experiences and needs both individually and collectively, through group-negotiation (Guillemin, 2004;McNicol, 2014). Finally, DrawingOut was expected to enable the creation of engaging outputs for dissemination that communicate individual experiences in an immediate and striking way (Hodgins and Boydell, 2013).

Materials and Methods

Design

This study was based on a one-day drawing workshop to collect visual (artwork produced by participants) and textual (all conversations and discussions during the workshop) data about the participants' experiences and views of infertility and their fertility care needs.

Participants

Participants were nine adult women with a minority ethnic or religious background living in Wales, UK, who were currently experiencing or had experienced infertility in the past. The average age was 42 (range 30-59). Five women were South Asian Muslims, two were Sub-Saharan African Christians, one was a North African Muslim, and one a British Muslim married to a North African Muslim man. Seven women had migrated to and two had grown up in the UK; all had transnational extended families. Six women reported that they had experienced fertility problems in the past. Of these, five had managed to conceive, but one had not and was still childless when she entered menopause. In addition, one of these women was trying to conceive again and experiencing secondary infertility. The remaining three women were childless and currently experiencing fertility problems. In total, of the nine participants, five already had at least one child. The participants had different levels of English proficiency, ranging from native- and near-native to very limited skills only.

Procedures

The study received ethical approval from the Ethics Committee of the School of Psychology, Cardiff University. A convenience sample was recruited in partnership with a local charity, Women Connect First (womenconnectfirst.org.uk). Potential participants were contacted by phone by a staff member of the charity and informed about the general aim of the project. Those women who provided oral consent were asked about their fertility status, to ascertain if they were eligible participants. All the women who attended the workshop were asked to sign an illustrated consent form and given a debrief form at the end; we also invited participants back for a second session to share the research findings and give feedback. As a token for their participation, women were offered a £50 voucher.

The DrawingOut method is described in detail elsewhere (Gameiro et al., 2018). In short, the workshop started with an ice-breaking activity, followed by the presentation of the workshop structure and discussion of rules of good conduct to ensure consideration and confidentiality during and after the workshop. The workshop itself consisted of five carefully structured activities:

(1) Discussion of infertility-related drawings. Women were asked to 'choose the drawing they most identified or connected with' among a set of infertility-related illustrations and comic strips by illustrator Paula Knight (available online https://paulaknight.wordpress.com/comics-3/), to describe the chosen drawing, and explain to the group why they had selected it. These strips covered the main themes relating to our research questions (impact of infertility, relationship with others, healthcare experiences and needs).

(2) How to draw things and people. Participants were introduced to the basics of drawing objects and people in a slide-based lecture and guided through some simple drawing

exercises. This session ended with the request to ‘Draw yourself thinking or talking about infertility’ (self-portrait exercise).

(3) How to draw thoughts and feelings. Participants were introduced to the concept of visual metaphor, defined as the use of something visible to show something that is invisible. Examples of visual metaphors were presented and their meaning was discussed. This section ended with four drawing activities, in which the participants were asked to produce visual metaphors for their infertility experience, using the following instructions: ‘If infertility was a creature or animal, what would it be?’; ‘If it was a place or situation, what would it be?’; ‘If it was weather, what would it be?’; and ‘Draw how infertility affects your relationship with other people’.

(4) Free drawing session. The women were given one hour to produce a large-scale drawing about any aspect of their infertility experience.

(5) Group sharing. The workshop ended with a group session, in which the women were invited to present their artwork and comment on the different emerging views.

Multiple simultaneous audio recordings captured the small- and large-group discussions. One researcher took notes to support the transcription process. The audio recordings were transcribed verbatim. Occasionally some of the women would have brief interactions in other languages, often explained as helping to translate for each other, but only conversations held in English were transcribed.

Data Analysis

Thematic analysis was implemented by two of the authors (SG and BBG), following the procedures recommended by Braun and Clarke (2006). Thematic analysis was chosen because data gathering was complete at the time of the analysis, the data consisted of textual material, and there was no strong theoretical perspective driving the analysis (Howitt, 2010).

Although participants came from different minority groups, we were interested in identifying common views and experiences of infertility and healthcare. Therefore, we worked to identify themes that captured a patterned response or meaning within the data, defined as something that was mentioned by at least two participants (Braun and Clarke, 2006). A bottom-up approach to the data was adopted: first, SG and BBG familiarised themselves with the full workshop transcript; second, they individually assigned textual descriptors to relevant passages in a line-by-line coding; and third, they discussed the descriptors and grouped them into themes. Finally, the themes were grouped into higher-order themes, which were to a certain extent led by the research questions (e.g., emotional burden of infertility, relational burden of infertility) but also set by participants' own agendas (e.g., coping strategies). Each participant was allocated a random letter to ensure anonymity, and that is how they are represented in the results section.

SG has expertise in the topic of infertility and assisted reproduction, having researched the topic for over 10 years. Although this was the first time she conducted research with minority groups, she was familiar with the existing literature. Due to her expertise, she was able to differentiate general experiences of infertility from the specifics of these women's experiences, but this might have made her biased towards identifying themes that had emerged in previous research. BBG has no expertise in infertility, but biases in her analysis may have arisen from everyday knowledge about infertility (newspaper reports, friends' experiences). Separate individual coding, followed by joint discussion, was adopted to counterbalance these potential individual biases. Finally, to ensure triangulation, SG and BBG presented their coding to the other members of the research team (LER and AP, who had attended the full workshop) for a final review. LER is an expert in visual and health metaphors and AP had been developing academic work with minority ethnic women in Wales for 4 years. At a later stage, a booklet was produced on the basis of the results obtained

and was presented to the workshop participants, who were asked to comment on whether they felt the booklet represented their views and experiences accurately.

Results

We identified a total of 41 themes that we grouped into eight higher-order themes. Six of them concerned the women's wellbeing and relationship with others, and two their fertility healthcare views and experiences. All themes are presented in Table 1. They are also represented in a co-produced comic booklet using the women's own drawings and words that is available online (Thorns and Flowers – Infertility experiences of Black and Minority Ethnic women, https://www.cardiff.ac.uk/psychology/about-us/engagement/thorns-and-flowers). This 16-page A5 booklet, produced in English and Welsh, aims to increase awareness about the infertility experiences of women from a minority ethnic or religious background and can be easily printed and used by anyone for their own purposes. The booklet was posted to more than 100 relevant stakeholders, including health charities and professionals and policy makers. It was also presented at a community event organized by Women Connect First and at several national and international academic and health conferences.

In the text below we first describe the higher-order themes identified in our analysis and then the women's evaluation of the booklet.

Table 1 around here.

The emotional burden of infertility

All participants expressed a range of negative emotions caused by their infertility, especially when they were asked to draw infertility as an animal or creature, weather or place

(activity 3: how to draw thoughts and feelings). They tended to use dangerous animals to represent feeling frightened, confused or overwhelmed. The following participant, for instance, explained:

"*I have put like a monster hippopotamus ape, because the moment you are told, the moment you are infertile you become so scared, it's something scary, something that can cause you to be depressed or to have poor mental health*." (A, 39 years old, childless)

Another participant drew what she described as a 'shadow monster' (Figure 1), in order to show how infertility affects all areas of her life and to emphasize the need for more education and awareness:

"*Infertility is always there, wherever you go, like a shadow. If we educate people the shadow will still be there but much smaller. We can be bigger than our fears*." (B, 38, children)

Figure 1.near here

Participants also drew different types of weather to represent their emotions, mostly drawing gloomy weather to represent negative emotions such as sadness, anger, loss of hope and uncertainty about the future. In this context, participants stated that infertility causes low mood and poor mental health, and that these mental states are exacerbated by the social burden associated with infertility. Participants referred to this as a 'double pressure':

"Those who have infertility, who are infertile they, they lack confidence, they have low self-esteem and they've poor mental health, some not all of them." (A, 39, childless)

"[…] when a woman cannot have children, I did experience this, you are always in low mood. […] You are living in double pressure. Pressure inside yourself, and pressure

from society, and sometimes phone calls from back home to see whether you have children." (C, 38, childless)

The relational burden of infertility

Several of the participants agreed that men were generally less affected by infertility and could sometimes be dismissive of their partner's suffering. They thought that infertility could either damage or strengthen a marriage, depending on the couple's relationship and coping strategies. However, they all held that it was likely for the partnership to be negatively affected by the social pressure placed on the couple.

"A division, it creates a division between that the husband and wife or the woman with the, with the husband's family." (A, 39, childless)

In this context, the women agreed that their partner's support was essential. For instance, one childless woman described how support from her partner was important to both herself and her family:

"You can see, that's my husband and that's me and he says - Be happy, don't worry. […] So my family is also happy, so he's happy with me […] In the future I will conceive baby… Inshallah…" (H, 30, childless)

The social burden of infertility

Most women related that they often experienced a burden stemming from multiple difficult and stressful social interactions around the theme of parenthood, especially with their partner's close family:

"Every time we would go home to, I say home, this is my home, but back to my husband's, they'd say to me so where's your children? Why have you only got one? What's going on with you?" (D, 43, children)

"You are, your in-laws are so hard, in fact life becomes really hell." (E, 38, children)

Interactions with friends or other members of the community can also be stressful because children are a central topic in everyday conversations. These interactions included transnational family and friends visiting or calling from 'back home'. The women reported that they were constantly asked about their parenthood status, a difficult experience that could make them feel isolated from their partner, family and community, and likely to withdraw in order to avoid painful situations. They said that members of the older generation, in particular, were often confrontational, making insensitive comments:

"I don't have children, so it has been a very difficult question for me everywhere I go. You know it's like, you get to meet with other ladies and they start talking about their children." (A, 39, childless)

Most women identified with an image that represented strained social interactions resulting from infertility by means of a rift metaphor (activity 1). Some of the participants used this and other similar metaphors such as a rift, a valley, a wall or a prison to express their own sense of social isolation. One participant described her deeply painful sense of being separated from her family and community:

"This is the community […] and there's like family, friends, schoolmates, in-laws. So this is me here, […] there is this unconscious divide, this rift valley existing in terms of the stereotypes that they think about you, the stigma that they think you have, a problem. […] So in a way it affects your love because when they influence your husband to be against you somehow, it might not be obvious, but somehow there is an indirect influence, especially from the in-laws." (E, 39, children)

Some of the women said that their partners were also subjected to family and/or community pressure, which typically took the form of advice to leave their childless partner. Several participants knew of couples that had got divorced due to family pressure to have

children, either because they were infertile or because the woman did not want to have children immediately. One older participant reported her own experience:

"Some people, ah, say to my husband, why don't you marry again? Because your wife doesn't bring for you children. Because in our culture you can marry again, yes? And take a new wife to bring, ah, children." (F, 59, childless)

Several participants expressed a desire for other people to be more sensitive when discussing parenthood, and to stop asking questions when it was clear that someone was feeling uncomfortable:

"Mmm, the extended family members should mind their business, they shouldn't intrude." (E, 39, children)

The community

The specific ways in which women's communities perceive and react to childlessness and infertility was one of the most prevalent topics of the workshop. We did not ascertain what exactly participants meant by 'community', or if it meant the same for everyone. Some participants referred to 'our community', the 'BME community' or 'BME communities' and some referred to it as being distinct from the 'British community'. One participant represented her community as a spider and its web:

"I think our community is just like a spider, like a net. […] I am here, the very small thing and the spider…the spider net is very big." (I, 52, children)

The women considered the social burden they experience (described in the previous section) to be the result of socio-cultural norms and traditionalist views of family and parenthood, whereby children are highly valued and women perceived almost exclusively as caregivers.

"Their mind-set is that women should have children, stay at home, and the man works." (D, 43, children)

"There's a culture of being interrogated and not knowing the boundaries of personal privacy issues. And that's higher in our community rather than in the British community." (B, 38, children)

According to the participants, the expected norm in their communities is for couples to have children soon after marriage. When this does not happen, women are put under pressure to have (more) children, especially if they do not have boys. When there is suspicion or evidence of infertility, women tend to be blamed, in part because male infertility is taboo, so the possibility that infertility may be due to a male factor cannot be discussed, as expressed in the following quotes:

"And, and so there was this, ahm, every monthly cycle my mother in law used to check whether, you know, I've come on [menstruated], […] and I used to feel really bad, and I used to hate telling my husband at the time that I've come on." (G, 40, children)

"Even if the male is the one who has the problem, maybe low sperm count, they always see the woman as the problem." (E, 39 years, children)

Most women agreed that the described attitudes and social norms were not related to their community's religious beliefs and that, in fact, they derived a great sense of comfort from their religious faith.

Views and concerns about infertility

Several participants discussed their infertility experience in terms of a journey: at the start there is the hope of becoming a mother, and difficulties conceiving are imagined as impediments on a long, arduous journey. At the end of the journey there is either the longed-for child, or, in some cases, a sense of having achieved contentment by focusing on other

goals. Most participants expressed the belief that women could be fulfilled in life even without having their own children, particularly through education and a professional career. This journey metaphor was also present in many of the drawings. For instance, one woman drew her experience of infertility in terms of climbing up a mountain, while others represented themselves as ducks swimming on a river or birds flying into the sky (see Figure 2).

Figure 2. Near here

Some women expressed a desire to know more about the biological causes of infertility and took advantage of the workshop to ask questions on the topic.

"This [comic] appeals to me because what I am thinking is that […] the person who drew this image is that maybe she had problems with her fallopian tube, the problem I have? So I have a really keen interest on it […] and I am a bit curious about it, what could be done to flow them out to get clearer and to open the fertilization." (E, 39, children)

Their comments also reflected some common myths and misconceptions about infertility. For instance, many believed that relaxing and trying not to worry too much might, in itself, be enough to facilitate conception:

"Yeah, I would agree with that, just relax and go with the flow and, ah, it will happen." (D, 43, children)

Their comments also revealed a lack of awareness of the detrimental effect of age on fertility; for instance, some seemed to agree that up to the age of 45 there is no need to worry about decreasing fertility. When one woman (H, 30,) expressed concerns about being childless at the age of thirty, other women reassured her by stating that as long as she ovulated and had a regular period it meant she was able to conceive:

"Don't worry. As long as the period continues…" (I, 52, children)

"*Oh no you are young! You are young, you still ovulate, that's fine."* (C, 38, childless)

Finally, the women also expressed some concerns regarding fertility treatment, focusing in particular on its low success rates and high costs.

Coping strategies

Individual strategies to cope with infertility emerged in the flow of the conversation, particularly when participants were asked to draw themselves thinking about infertility (activity 2). One of the most prevalent strategies involved taking comfort in prayer and in accepting God's will. Other participants coped by 'thinking positively' or 'focusing on the good things'. Commenting on her drawing (see Figure 3), one participant said:

"One of the, like my solution was to have to trust God and put your faith in it, in your, you know, what you're destined to have, pray, there's hope, um, if you're blessed then you'll get a child, but if you're not then I think this is, like, just be happy with whether you have a child or not, relax and enjoy life." (C, 38, childless)

"That's why I have, just need to thinking about the good things. […] Not easy, yeah, it's not easy but we need to think the good things, be positive." (I, 52, children)

Figure 3. near here

Women also considered that it was important to be persistent and keep trying to get pregnant, either by continuing to have unprotected sex or by undergoing fertility treatment. Indeed, the women in our study did not express any ethical reservations about using assisted reproduction as long as they could use their own gametes.

"Fail one time, second…Try again. It is not the end… if it is from the first time that is ok, try again and again and you will get pregnant. [Laughter]" (F, 59, childless)

Other coping strategies included taking good care of one's physical appearance, both as a form of self-care and as a way of not revealing distress and suffering to others, and keeping busy and focusing on other life goals. In general women agreed that one can have a fulfilled life with or without children. Describing her drawing, one childless participant said:

"These are glasses, this is a book, and this the moon. This is me. I am very happy with children or without children. […] that is the river, my new life with my husband." (F, 59, childless)

"Having a baby for a woman is not the core, you know, one, what you call it, goal in life because she is, we are forgetting that she is an individual human being as well. […] You know. Educate yourself. There are millions of ways of shining, other ways, not… You know, having baby is not the ultimate goal in life." (B, 38, children)

Healthcare experiences

In the first activity (discussion of infertility-related comic strips) a few women chose a picture depicting a healthcare interaction, which triggered a long discussion about healthcare experiences. The women agreed that they were not the object of discrimination within the British (universal) National Healthcare System (NHS) and that they had experienced a lot of good care, although some also reported being ignored or misunderstood by individual care professionals, who, for example, showed a lack of appreciation of the women's desire to have more than one child or their reservations about using donated sperm. Participants also commented on a perceived lack of interpersonal skills, particularly among younger doctors.

"Because I had a daughter, a baby girl before that, and she was, she was about eight years old at that time, I felt that they [health professionals] kind of looked down at me? You know. Why are you even thinking of another one? You know if it's not working, there are people who don't even have one, kind of thing?" (B, 38, children)

"I also think that health professionals should listen more because at times they miss out on what the patient is saying and they, they, they give advice that is not appropriate because they didn't listen, they should listen more than talking because some of them they like talking a lot [laughter]." (A,39, children)

Support needs

When asked about the type of support they wanted for themselves and other infertile women from their community, many stated that healthcare professionals should be more sensitive to socio-cultural issues and could benefit from training on this and on interpersonal skills. In addition, some also advocated counselling for women and men, including before the start of fertility treatment. Overall, it was felt that women needed more support to cope with the stigma associated with childlessness and the abuse to which they are sometimes subjected. Limited sexual knowledge was also thought to contribute to some couples' inability to conceive, so sexual education was seen as beneficial. Finally, there were comments about the inability of GPs to detect infertility cases properly and refer them for specialist assessment.

"She mentioned good point about, ah, counselling taking into consideration religion and culture. What happened, like for me and my husband, when we were filling forms for having IVF there was one question, if you like to, ah, have the sperm of another man, and this is not, uhm, allowed in, ah, Islam. It is like, is it the same as adoption." (C, 38, childless)

"One advice I'd have for health professionals is to look out for other signs of psychological or emotional abuse, because if they've got to that stage where they are being referred it's in the majority of the cases they're more likely to have been victimized, belittled, you know, emotional abuse, psychological abuse." (G, 40, children)

"There's another area, it's sex education, because a lot of our couples, especially from Muslim backgrounds, they're sexually inexperienced, so often the infertility is due to their lack of knowledge and skills." (G, 40, children)

Finally, throughout the workshop the women repeatedly stressed the importance of education as a way of achieving greater autonomy and gender equality, overcoming traditionalist views of women and parenthood, and increasing awareness about the impact of infertility and thereby encouraging men and the community to be more supportive. They referred specifically to the need to increase awareness of male infertility and to encourage men to seek treatment. In this context, one participant suggested that initiatives should try to liaise with religious leaders or institutions, as men would be more receptive in those contexts:

"I have noted that all these, you know, social and general things from the health board they kind of ignore the religious places? And men are usually more, ah, you know, functional at religious places, for example temples and mosques […], and all the people who run these places they are educated and they can, they've got religious education as well as the other, they can better reach them there rather than, you know, us women getting together and dragging them ourselves [laughter]." (B, 38, children)

Participants' evaluation of the booklet

A preliminary version of the booklet was presented to six of the workshop participants. Overall they were very pleased with it and suggested only two minor changes,

namely increasing the font size and adding colour to one drawing that included a verse in Arabic stating “women bring colour to the world”. These changes were incorporated before the final production of the booklet.

Discussion

Results from this study support the view that women from ethnic and religious minority backgrounds consider that their communities have highly pronatalistic attitudes and stigmatize infertility,, to which they attribute (most of) their infertility-related stress. Our results advance current knowledge showing that women were critical of such cultural attitudes, considered that fertility education was needed to overcome these, and put forward concrete proposals on how to implement change. In addition, women distinguished between cultural attitudes and religion, which they found comforting. Women’s overall evaluation of their fertility health care was positive. Nonetheless, they desired more culturally competent and interpersonally sensitive fertility care and recommended for fertility staff to be trained in these areas of practice. Women also desired more infertility education (e.g., on the biological causes of infertility). Overall results suggest that these women present high levels of resilience and effective coping strategies (with religious coping being highly prevalent) in the face of infertility and the personal and social adversity it creates. Finally, the DrawingOut method proved suitable to work with this group of women, whose levels of English proficiency ranged from native- and near-native to very limited skills only, and they felt well represented in the booklet produced.

Our study replicates previous findings regarding the perception of highly pronatalist attitudes among some minority ethnic communities (Culley and Hudson, 2009;Gürtin-Broadbent, 2009;Simpson et al., 2014). All the women in our study agreed that their communities placed more pressure on young couples to procreate than what they perceived to

559 be the norm in the British majority population. All could recall at least one instance when
560 they had felt ostracised or blamed for their childlessness and/or pressurised to have (more
561 and/or male) children. Specific themes mentioned were the exacerbation of personal suffering
562 by an adverse social context, intense feelings of isolation, having to cope with stressful
563 interactions around childlessness on a regular basis, the existing taboo around male infertility
564 and how this results in directing the blame of infertility towards women, as well as the
565 pressure put on men to leave their wives when the couple is not able to conceive.

566 The study results advance current knowledge by showing that the women in this study
567 also showed a critical attitude towards these socio-cultural pressures, emphasizing that it was
568 not acceptable for women to be blamed for infertility and criticizing members of their
569 communities for defining women's lives and value too narrowly in terms of marriage and
570 children. Several women were assertive in expressing a need for further education within
571 their communities, which, they argued, should focus both on gender equality and women's
572 rights in general, and, more specifically, on the causes and treatments of infertility. They
573 were assertive about the need to involve men in such initiatives and to tackle the taboo
574 around male factor infertility, and suggested that a possible productive way to do so could be
575 by engaging with religious leaders. These findings suggest that women do not passively
576 accept their communities' views, but are active agents in negotiating their reproductive
577 desires and co-constructing social meanings of infertility with their families and
578 communities. Previous research has shown that women are more likely to experience
579 infertility distress when they internalise the need to become mothers (McQuillan et al., 2012);
580 therefore these women's conviction that one can be happy with or without children, may be
581 contributing to their apparent resilience. Such conviction has also been found to be conducive
582 to better psychosocial adjustment in people who did not manage to conceive with fertility
583 treatment (Gameiro and Finnigan, 2017).

None of the women in our study felt they had been subjected to discrimination in the NHS system. Indeed, women perceived their fertility care experiences to be more positive than negative and expressed a balanced view between what they know to be the pressures and demands put on the NHS and what they could reasonably expect from the professionals they interact with. However, some of the care experiences reported, for instance a perceived lack of empathy for seeking treatment to have a second child, suggest that institutionalised racism and/or stratified reproduction may condition women's access to optimal care (Ginsburg and Rapp, 1995), as observed in previous studies with minority groups (Blell, 2017;Gürtin-Broadbent, 2009). Consistent with these experiences, women expressed the need to receive more culturally competent care. Research shows that fertility staff struggle with communicating with patients from different socio-cultural backgrounds or beliefs, for instance, when a patient's religious beliefs conflict with the clinic's policies or when one of the partners is unwilling to cooperate with treatment (Boivin et al., 2017). In sum, both our participants and fertility staff agree that there is a need for staff training on these issues (Boivin et al., 2017) in order to ensure optimal care and prevent stressful patient-staff interactions, which are known to be detrimental to both parties. Another care need participants expressed is one all infertile patients report (Dancet et al., 2010): better interpersonal and communication skills from staff.

Putting their own agenda forward, women explicitly expressed a desire to know more about infertility and its biological causes. A lack of (in)fertility education has been reported in previous research with minority groups, regarding infertility itself (Culley and Hudson, 2009;Culley et al., 2004;Inhorn, 1996), its treatments, and the way specific aspects of treatment (e.g., gametes storage) are handled by clinics (Simpson et al., 2014). Some research suggests that Muslim communities may be suspicious regarding (in)fertility information because it enables couples to better decide if, when and how they want to have children and

609 to fully understand how their reproductive system works (Simpson et al., 2014). It should be
610 noted, however, that multiple surveys have shown that (in)fertility knowledge is modest in
611 the general population too (Bunting et al., 2013), which makes it hard to determine whether
612 or not it is a particular problem in ethnic minority groups. The important issue to note is that
613 women desire to be informed and feel such knowledge would empower them to better
614 address their fertility problems. (Harper et al., 2017)(Harper et al., 2017)
615 Another novel finding referred to how women differentiated between their socio-
616 cultural context and their religious faith, experiencing aspects of the former as stifling and
617 harmful, and the latter mainly as comforting. For these women, their faith was an essential
618 part of what we know to be effective religion-based coping with infertility, for instance,
619 social support, positive reappraisal coping or (re)engagement with other fulfilling life goals
620 (Roudsari et al., 2007). Nonetheless, it is important to say that multiple studies have shown
621 that religious beliefs do influence reproductive and fertility help-seeking attitudes and
622 behaviour in multiple and complex ways (Greil et al., 2010a).
623 The DrawingOut method was successful in engaging this group of minority ethnic and
624 religious women with varied levels of English proficiency, ranging from native- and near-
625 native to very limited skills only. This is evidenced by the amount and richness of the data
626 collected, although only a comparative study would have allowed us to ascertain whether
627 DrawingOut is able to produce more or richer data compared to other qualitative techniques
628 (e.g., interviews, focus groups). Nonetheless, it is fair to say that DrawingOut was very
629 successful in engaging participants in personal disclosure. Participants were very positive
630 about DrawingOut (to access the full data on participants' evaluation of DrawingOut see
631 Gameiro et al., 2018)), in particular, they found drawing very appealing and enjoyable,
632 stating that it made it easier for them to talk about such a distressing topic. Another obvious
633 advantage of DrawingOut concerns the opportunity to use participants' drawings to co-

produce outputs that are appealing to multiple audiences, such as the booklet produced. In addition, many of the graphic elements and visual metaphors in the booklet explicitly capture the participants' socio-cultural and religious background (e.g., drawing of the Quran and prayer mat to represent the comfort brought by religion), facilitating identification by other women from similar backgrounds facing similar challenges.

DrawingOut has since been used to run three additional workshops (one exploring experiences of endometriosis and two exploring fear of infertility). Data suggests DrawingOut has benefits for workshop participants, namely in facilitating the normalization of experiences and empowerment, promoting social support and connectedness in illness, and providing education (Gameiro et al., 2018). Although DrawingOut was developed as a research method, it has been adapted into an online support tool for people affected with socially invisible diseases, where, like in infertility, symptoms are not immediately recognizable to others (see www.drawingout.org). Infertility researchers, clinics, charities and other entities can use DrawingOut to support infertile people, both in a group setting or, if patients struggle to meet (e.g., many women with endometriosis experience too much pain to travel), in an individual (online) setting. They can also use DrawingOut to conduct patient consultation activities or to co-produce tailored information and awareness raising materials.

Our study examined the infertility experiences of a heterogeneous sample of women from different minority ethnic or religious background with links to nine nations, reflecting some of the diversity of the UK (Barnard and Turner 2011). While we focused on capturing commonalities in the participants' experiences of infertility, we recognise the danger of homogenising what are clearly diverse experiences (Hudson et al., 2016). Nonetheless, we are confident that we managed to communicate those messages that our participants wanted to share with their health carers and the general public (as they confirmed in the follow-up feedback session), a precondition for the deliverance of patient-centred care, whose ethos is

precisely to ensure that patients' views and preferences are taken into account (Dancet et al., 2010). However, we recognise that our results are unable to adequately represent the full scope of some of the emergent themes (e.g. , how religious beliefs shape infertility experiences, how infertility experiences may change as a function of participants' immigration status or generation, or according to the family and community ties they established in the UK) and that these would benefit from more in-depth exploration. Another limitation resulted from our recruitment strategy. Our decision to work with Women Connect First to recruit participants meant that our sample was composed of women who were well integrated and active members of their communities, which may have contributed both to their resilience and to their skilled analysis of the social and systemic issues affecting their infertility experience. This may have resulted in a too optimistic characterisation of general infertility experiences and low criticism of Western/Welsh cultures. Criticism may also have been dampened by the fact that the four researchers are white, secular women. Finally, although the DrawingOut method allows participants without language proficiency to express their views through drawing, they still have to explain their drawings verbally. Although we took this into consideration when determining the prevalence of themes across participants, some views may have been voiced more frequently and eloquently than others.

Findings from this study and others highlight the need to increase awareness about the infertility experiences of minority ethnic and religious groups. The booklet Thorns and Flowers (www.cardiff.ac.uk/psychology/about-us/engagement/thorns-and-flowers) is available online and can be used by people experiencing infertility, fertility clinics and other stakeholders to introduce conversations and discussions on this topic. In addition, fertility staff might benefit from having evidence-based guidelines on culturally competent fertility care and accessing skills training on this topic. At the community level, educational initiatives are needed and may be better accepted if they engage with religious (or other

community) leaders. Finally, the integration of fertility education into the academic curriculum, as advocated by many (Harper et al., 2017), would ensure that all young women and men, regardless of their socio-cultural background, are able to access relevant knowledge and information.

Authors' Role

SG, BBdG contributed to conception and design of the study, acquisition and analysis of data, drafting the article and revising it critically. LER contributed to conception and design of the study, acquisition of data, drafting the article and revising it critically. AP contributed to acquisition of data and drafting the article and revising it critically. All authors approved the final version submitted for publication.

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Conflict of Interest

The authors do not have any competing interests,

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808 **Table 1. Themes identified in the thematic analysis.**

Emotional burden of infertility	**Relational burden of infertility**	**Social burden of infertility**
• Fear, confusion, anger • Uncertainty about the future • Sadness, loss of hope, poor mental-health • Low self-esteem • 'Double pressure': personal suffering exacerbated by social burden of infertility	• Men less affected than women • Men can be dismissive of women's suffering • Infertility hinders versus strengthens the partnership • Social pressure affects the partnership • Support from partner is very important	• Social interactions are difficult and stressful • Childlessness creates a rift from social world • Childless women self-isolate • Men are advised to leave childless/infertile women • People should be sensitive regarding childlessness
The community	**Research questions:** **How does infertility affect the wellbeing of women and their relationships with their partner, family and community?** **What are women's views and experiences regarding fertility healthcare?**	**Views and concerns about infertility**
• Traditional views of women and parenthood • High pressure for parenthood • Women blamed for childlessness and infertility • Boys preferred over girls • Male infertility is taboo		• Infertility is a personal journey • Fulfilment is possible without children • Reservations about adoption as alternative route to parenthood • Desire to know about biological causes of infertility • Myths and misconceptions were common
Coping strategies	**Healthcare experiences**	**Support needs**
• Taking comfort in religion • 'Thinking positively' • Being persistent in trying to get pregnant • Caring for oneself • Being busy and active • Focusing on other life goals	• No perceived discrimination • Lack of interpersonal skills • Lack of empathy towards socio-cultural issues • Good care experiences happen • Pressure/demands on NHS	• Education, fertility education and awareness • Engagement with religious leaders • Counselling • Training in socio-cultural issues and in interpersonal skills (healthcare professionals) • Sexual education

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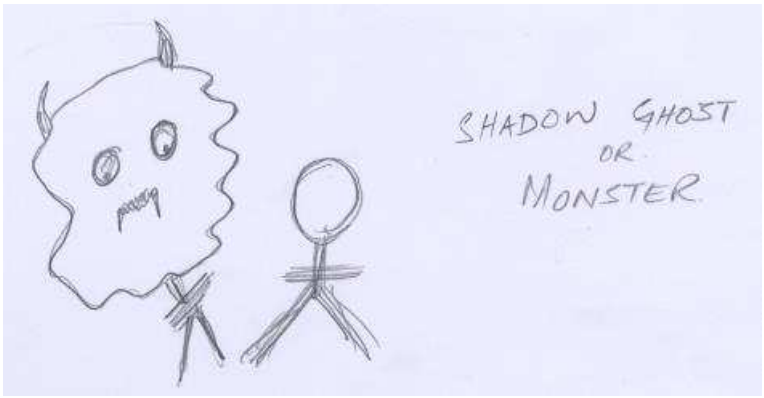
Figure legends

Figure 1. Drawing of infertility as a shadow monster.

Figure 2. Drawing containing a journey metaphor.

Figure 3. Drawing expressing a sense of social isolation and the comfort found in religion.



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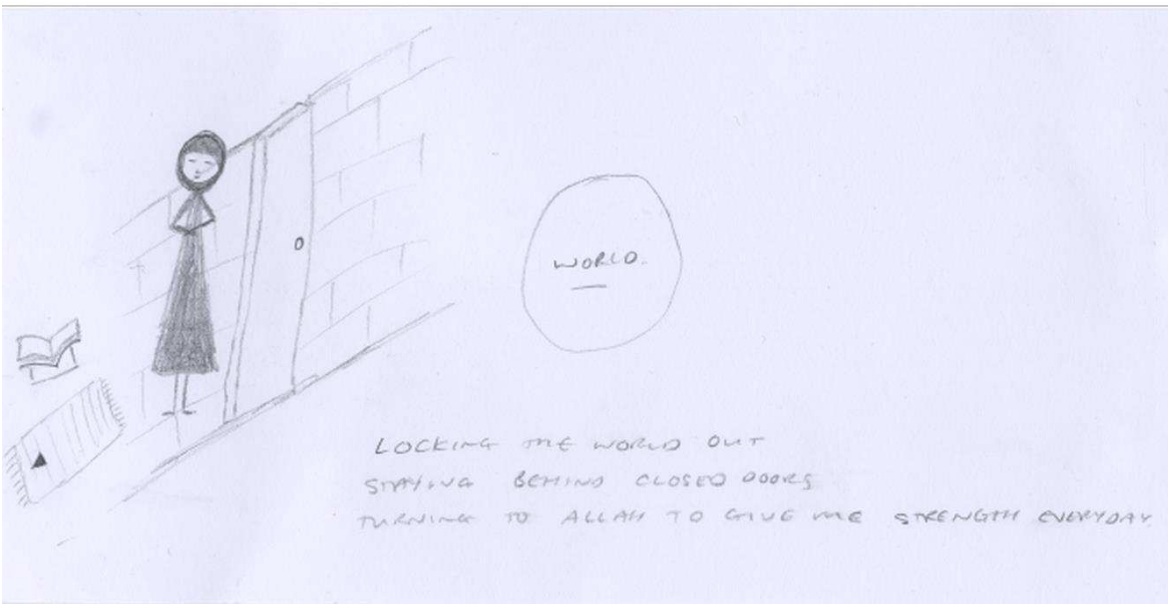

Figure 3. Drawing expressing a sense of social isolation and the comfort found in religion.

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