

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

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4 **Running title:** Care needs of minority ethnic or religious women

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21 **Abstract**

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

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

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

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

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

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

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

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

61 **Study funding/competing interest(s):** This research was funded by Welsh Crucible. The
62 authors have no conflict of interests to declare.

63 **Key words:** Infertility, ethnicity, religion, healthcare needs, visual research methods,
64 drawing, arts-based research, culturally competent care
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66 **Introduction**

67 Infertility can affect any woman or man in their reproductive years. The most recent
68 statistics show that in the UK 8% of infertile people are non-white, with 51% of these being
69 Asian or Asian British, 26% Black or Black British, 12% Chinese or other ethnic groups, and
70 11% Mixed (HFEA, 2006). Ethnic and religious minority groups are underrepresented in
71 European infertility psychosocial research (Culley et al., 2009a), despite research showing
72 that ethnicity is associated with some reproductive health problems (e.g., miscarriage, Harb et
73 al., 2014) and worse treatment outcomes (Dhillon et al., 2016). The consequences are a lack
74 of understanding of these patients' infertility and treatment experiences and a lack of
75 available guidance about how to meet their specific support needs. In this study we used a
76 participatory drawing-based method, *DrawingOut* (Gameiro et al., 2018), to explore the
77 views, experiences and healthcare needs of a group of infertile women from a minority ethnic
78 or religious background living in Wales, UK; and to co-develop an engaging booklet that
79 minority groups can use to share their infertility experiences and advocate for support with
80 their communities and health professionals.

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

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

94 Some researchers were able to overcome language and socio-cultural barriers to
95 research participation by using community facilitators (Culley et al., 2007), or by conducting
96 qualitative research with specific minority groups. In the Netherlands and Germany, the focus
97 has been on Turkish immigrant communities (van Rooij et al., 2009;Vanderlinden, 2009,
98 2011); in the UK, on British South Asian - Indian, Pakistani and Bangladeshi (Culley and
99 Hudson, 2009;Culley et al., 2009a), British Turkish (Gürtin-Broadbent, 2009), and British
100 Pakistani Muslim groups (Blell, 2017;Hampshire et al., 2012;Simpson et al., 2014).

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

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

113 Nonetheless, having no children at all or only one child is still negatively perceived in
114 many of the researched ethnic minority communities in Europe, especially if the only child is
115 a girl (Culley et al., 2009b;Simpson et al., 2014). Consistently, infertility tends to be highly
116 stigmatized and seen almost exclusively as the woman’s fault. Its social consequences are
117 more severe for women than for men; they can include being gossiped about, ostracized, and
118 sometimes even ill-treated by family members. Some male respondents also reported that
119 they were being put under pressure to divorce their wives and remarry because their marriage
120 had not produced any children (e.g., Culley and Hudson, 2009). These data suggest that
121 minority groups experience higher social burden of infertility. However, infertility social
122 distress is also commonly reported by non-minority groups (Gameiro and Finnigan, 2017),
123 and quantitative studies using US samples have not shown that ethnicity, religion and high
124 social value placed on motherhood are associated with higher infertility distress (Greil et al.,
125 2011;Jacob et al., 2007), which suggests that distress may depend on how individuals
126 perceive their circumstances. As shown by McQuillan et al. (2012), it may also be that social
127 expectations about parenthood are only distressing when internalised by individuals. Another
128 explanation is that these qualitative studies’ samples are not representative of the full
129 heterogeneity of experiences and socio-cultural attitudes present in ethnic and religious
130 minority groups.

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

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

152 In sum, evidence suggests that at least some people from minority ethnic or religious
153 groups perceive increased pressure to conceive from their communities, higher social costs
154 when they are unable to have children, and stressful interactions with the fertility healthcare
155 system while attempting to conceive. The current study used *DrawingOut* (Gameiro et al.,
156 2018) to explore the views, experiences and healthcare needs of nine infertile women from a
157 minority ethnic or religious background living in Wales, UK. *DrawingOut* is a participatory
158 visual research method that consists of a one-day metaphor-centred drawing workshop to
159 collect visual and textual data about a particular health related topic, in this case infertility.
160 We hypothesised that *DrawingOut* would be successful in engaging participants from diverse
161 cultural and religious backgrounds and with varying levels of language proficiency. Its non-
162 directive (using activities instead of questions) and group character should also empower

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

168

169

Materials and Methods

Design

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

174

Participants

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

188

189 **Procedures**

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

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

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

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

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

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

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

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

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

232

233 **Data Analysis**

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

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

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

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

265

266 **Results**

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

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

282

283 **Table 1 around here.**

284

285 **The emotional burden of infertility**

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

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

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

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

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

300

301 **Figure 1.near here**

302

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

308 *“Those who have infertility, who are infertile they, they lack confidence, they have*
309 *low self-esteem and they’ve poor mental health, some not all of them.”* (A, 39, childless)

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

312 *from society, and sometimes phone calls from back home to see whether you have children.”*

313 (C, 38, childless)

314

315 **The relational burden of infertility**

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

321 *“A division, it creates a division between that the husband and wife or the woman*
322 *with the, with the husband’s family.”* (A, 39, childless)

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

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

329

330 **The social burden of infertility**

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

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

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

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

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

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

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

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

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

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

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

370 *“Mmm, the extended family members should mind their business, they shouldn’t*
371 *intrude.”* (E, 39, children)

372

373

374 **The community**

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

381 *“I think our community is just like a spider, like a net. [...] I am here, the very small*
382 *thing and the spider...the spider net is very big.”* (I, 52, children)

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

387 *“Their mind-set is that women should have children, stay at home, and the man*
388 *works.”* (D, 43, children)
389 *“There’s a culture of being interrogated and not knowing the boundaries of personal privacy*
390 *issues. And that’s higher in our community rather than in the British community.”* (B, 38,
391 children)

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

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

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

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

406

407 **Views and concerns about infertility**

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

412 goals. Most participants expressed the belief that women could be fulfilled in life even
413 without having their own children, particularly through education and a professional career.
414 This journey metaphor was also present in many of the drawings. For instance, one woman
415 drew her experience of infertility in terms of climbing up a mountain, while others
416 represented themselves as ducks swimming on a river or birds flying into the sky (see Figure
417 2).

418

419 **Figure 2. Near here**

420

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

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

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

430 *“Yeah, I would agree with that, just relax and go with the flow and, ah, it will*
431 *happen.” (D, 43, children)*

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

437 *“Don’t worry. As long as the period continues...”* (I, 52, children)

438 *“Oh no you are young! You are young, you still ovulate, that’s fine.”* (C, 38, childless)

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

441

442 **Coping strategies**

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

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

452 *“That’s why I have, just need to thinking about the good things. [...] Not easy, yeah,*
453 *it’s not easy but we need to think the good things, be positive.”* (I, 52, children)

454

455 **Figure 3. near here**

456

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

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

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

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

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

474

475 **Healthcare experiences**

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

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

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

493

494 **Support needs**

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

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

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

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

516

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

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

530

531 **Participants’ evaluation of the booklet**

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

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

537

538 **Discussion**

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

555 Our study replicates previous findings regarding the perception of highly pronatalist
556 attitudes among some minority ethnic communities (Culley and Hudson, 2009;Gürtin-
557 Broadbent, 2009;Simpson et al., 2014). All the women in our study agreed that their
558 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).

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

602 Putting their own agenda forward, women explicitly expressed a desire to know more
603 about infertility and its biological causes. A lack of (in)fertility education has been reported
604 in previous research with minority groups, regarding infertility itself (Culley and Hudson,
605 2009;Culley et al., 2004;Inhorn, 1996), its treatments, and the way specific aspects of
606 treatment (e.g., gametes storage) are handled by clinics (Simpson et al., 2014). Some research
607 suggests that Muslim communities may be suspicious regarding (in)fertility information
608 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-

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

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

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

659 precisely to ensure that patients' views and preferences are taken into account (Dancet et al.,
660 2010). However, we recognise that our results are unable to adequately represent the full
661 scope of some of the emergent themes (e.g. , how religious beliefs shape infertility
662 experiences, how infertility experiences may change as a function of participants'
663 immigration status or generation, or according to the family and community ties they
664 established in the UK) and that these would benefit from more in-depth exploration. Another
665 limitation resulted from our recruitment strategy. Our decision to work with Women Connect
666 First to recruit participants meant that our sample was composed of women who were well
667 integrated and active members of their communities, which may have contributed both to
668 their resilience and to their skilled analysis of the social and systemic issues affecting their
669 infertility experience. This may have resulted in a too optimistic characterisation of general
670 infertility experiences and low criticism of Western/Welsh cultures. Criticism may also have
671 been dampened by the fact that the four researchers are white, secular women. Finally,
672 although the DrawingOut method allows participants without language proficiency to express
673 their views through drawing, they still have to explain their drawings verbally. Although we
674 took this into consideration when determining the prevalence of themes across participants,
675 some views may have been voiced more frequently and eloquently than others.

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

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

688

689

690 **Authors' Role**

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

696

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699

700 **Conflict of Interest**

701 The authors do not have any competing interests,

702

703

704

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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
<ul style="list-style-type: none"> • 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 	<ul style="list-style-type: none"> • 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 	<ul style="list-style-type: none"> • 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	<p style="text-align: center;"><u>Research questions:</u></p> <p style="text-align: center;">How does infertility affect the wellbeing of women and their relationships with their partner, family and community?</p> <p style="text-align: center;">What are women’s views and experiences regarding fertility healthcare?</p>	Views and concerns about infertility
<ul style="list-style-type: none"> • Traditional views of women and parenthood • High pressure for parenthood • Women blamed for childlessness and infertility • Boys preferred over girls • Male infertility is taboo 		<ul style="list-style-type: none"> • 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
<ul style="list-style-type: none"> • 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 	<ul style="list-style-type: none"> • No perceived discrimination • Lack of interpersonal skills • Lack of empathy towards socio-cultural issues • Good care experiences happen • Pressure/demands on NHS 	<ul style="list-style-type: none"> • 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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 811

812 **Figure legends**

813

814 **Figure 1.** Drawing of infertility as a shadow monster.

815

816 **Figure 2.** Drawing containing a journey metaphor.

817

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

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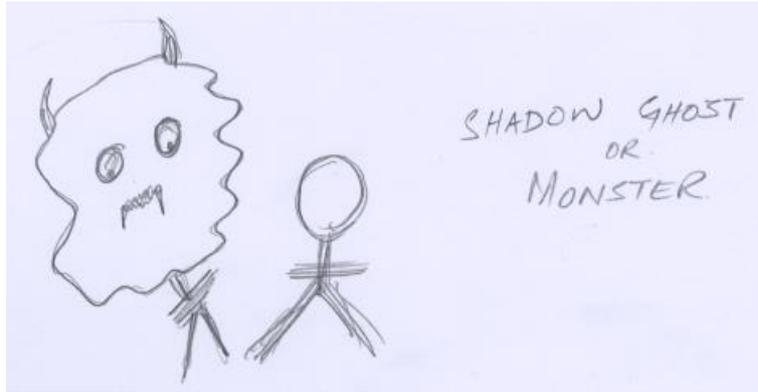


Figure 1. Drawing of infertility as a shadow monster.

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Figure 2. Drawing containing a journey metaphor.

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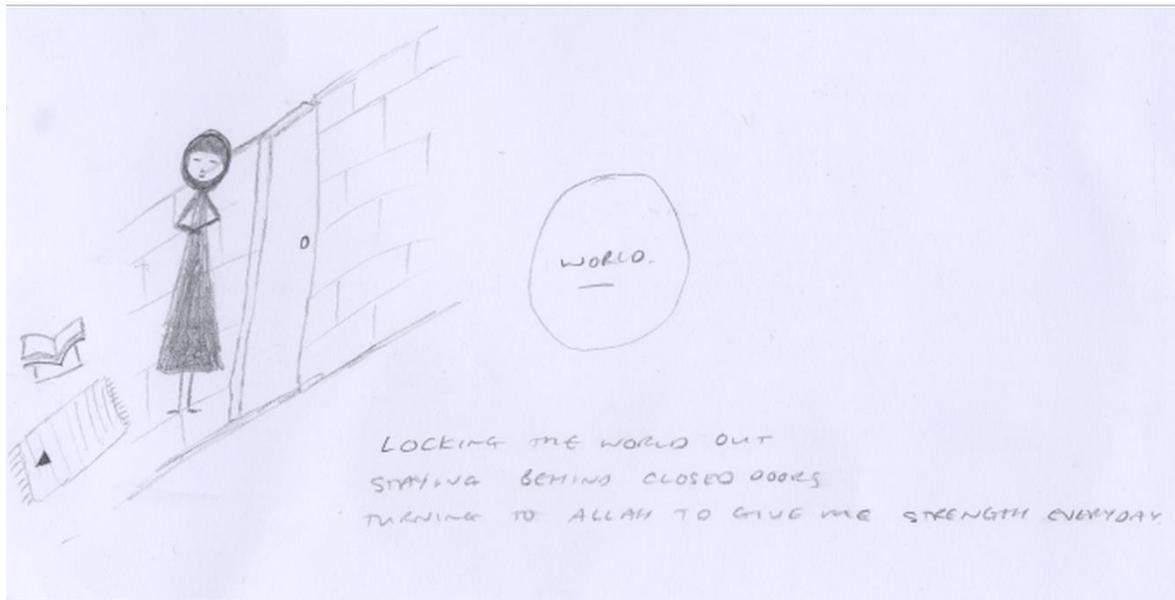


Figure 3. Drawing expressing a sense of social isolation and the comfort found in religion.

825