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Designing eHealth with Muslim Women who Have Experienced Miscarriage

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ABSTRACT

Lack of social support greatly affects women's well-being after miscarriage. In this paper, we report a pilot analysis of three co-design workshops with Muslim women who had experienced at least one miscarriage that focus on leveraging technology to seek social support. While all types of support were valued by Muslim women after miscarriage, informational support was challenging to obtain. We suggest that technology should provide more timely information, support women's spiritual coping, and help educate women's support network about miscarriage.

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KEYWORDS

Social support, Miscarriage, Muslim Women, Technology, Interaction Design



Figure 1: Example of generated miscarriage Journey Mapping showing technology use and needs throughout miscarriage timeline

Table 1: Key themes of coping with miscarriage

Themes	Quotes
1. Trusting Allah	<i>I have a strong belief in Allah [God] and I am satisfied with what happened to me. (P1)</i>
2. Pray and Supplicate	<i>Keep saying zikr (Subhan Allah) and listening to Qura'an thorough the day helping me a lot to cope emotionally. (P3)"</i>
3. Receiving Support	<i>My husband's mum was very kind and took care of me a lot [...] I was telling my mum more than dad [...], but dad knew my news and keep checking on me. Even though my sisters were busy and had duties, they checked on everyday morning and visited me a lot, not little. (P2).</i>

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INTRODUCTION

About 1 in 5 women who know they are pregnant miscarry before 20 weeks [4], which can be profoundly distressing [5]. Appropriate social support can provide a much-needed boost for women after a pregnancy is lost [2, 6]. The main categories of social support are emotional (consolation, comfort, validation, community), tangible support (practical and assistance), and informational support (advice and information) [3]. Given the limited research that specifically looks at the situation of Muslim women who have miscarried, in this study, we investigate the potential of leveraging technology to provide appropriate support for this target group.

METHOD

Recruitment. We recruited women through two Facebook groups created for a previous study [1], a Facebook group for charity and support group partners, the researchers' social media network, and leaflets in libraries and charity shops in central Edinburgh. The study was approved by the PPLS Research Ethics Committee, The University of Edinburgh.

Participants. Three Muslim women consented to participate. All had a smartphone, and two of them reported the smartphone to be their favourite piece of technology. All participants actively used and communicated with their social network through WhatsApp, while only one of them used Facebook regularly.

Study Design. We chose a 1:1 workshop to offer a comfortable environment for women to talk about her miscarriage experience. In order to visualise women's experience over a miscarriage timeline, we used **Journey Mapping** as a stimulus for discussing support needs and the potential of technology to help address those needs [7], with the aim of trying to expand on technology usage and needs. We provided the participant with a few questions to aid mapping and cards to indicate key people and types of support. Participants provided feedback in a post-workshop survey.

Data Analysis. Thematic analysis was used to analyse qualitative data. The first author coded the data using a combination of bottom-up (inductive) codes with top-down (deductive) codes derived from the research questions and discussed her findings with the third author. Nvivo software was used to coordinate the coding.

Table 2: Keys themes of requirements for better support

Themes	Quotes
4. Information needs	<i>My mental health has been destroyed, and I wished there was someone probably a therapist who could explain to me what's going on with me? (P1)</i>
5. Educate People	<i>Thank God that I am good for now, but I want to tell everyone that what happened for me was not easy either physically or mentally. It is like actual delivery but without having the baby. (P1)</i>
6. Gender Barrier	<i>Delivering the news of miscarriage from a doctor man was uncomfortable for me. I could not express my feelings. I tried to not react properly or display my feelings. If the doctor was female I think I would react differently. (P3)</i>

FINDINGS AND DISCUSSIONS

How do Muslim women cope with miscarriage?

The three main themes are summarised in Table 1. During miscarriage, participants' faith in Allah and trusting Him was the most important strategy that brings them comfort. The sense of surrender to God's will, and accepting what happened brought them the strength that they needed to cope with their loss (**Theme 1**). Participants' relationship with Allah and Islam was redefined after miscarriage. Participants extensively describe the level of comfort that prayer and supplication provides them. They listened to the Qura'an throughout the day, and that was the ultimate source of support to recover emotionally (**Theme 2**). The social support received from their husband and family (including the in-law family) helped them cope well with the perceived nature of miscarriage. Their family members were so supportive to the extent that they did not feel the need to turn to their friends for additional support (**Theme 3**).

What was required to better support Muslim women?

The three relevant themes are summarised in Table 2. Overall, there was a substantial lack of informational support about miscarriage. Appropriate informational support was seen as important for navigating this emotional journey (**Theme 4**). Information also needed to be delivered to the people in participants' network to educate them on how to provide effective support. Participants' extended family and friends sometimes asked a lot of questions concerning their pregnancy and miscarriage, which participants found annoying and uncomfortable. Therefore, we also need to raise the overall community's awareness on how miscarriage affects women emotionally and physically (**Theme 5**). One participant, whose doctor was a male, stating that she would have preferred a female doctor. Services providers should be aware of Muslim women's religious and cultural perspectives to ensure an environment where women can openly share their feelings (**Theme 6**).

How Muslim women leverage technology to seek more support?

Trusted and recommended website and online forums were the only common platform that participants turned to for information about their symptoms, other women's experiences of miscarriage, and the latest research about miscarriage. Contrary to previous findings [1], participants did not use Facebook as a source for information and support for their miscarriage experience, even P2 who is a regular Facebook user. None of Muslim women participated in this study joined an online support group after they experienced miscarriage. They reported that they were satisfied with the support received from their close family members and their husband.

Table 3: Participants' use of technology and social platforms for seeking informational support during the miscarriage journey

	P1	P2	P3
Smartphone	✓	✓	✓
Desktop	✓	✓	-
Laptop	✓	-	-
Website Information	✓	✓	✓
Online Forums	✓	✓	✓
Phone Helpline	✓	✓	-
Blogs	✓	-	-
YouTube	✓	-	-
Guidance and Advice	-	-	✓
Facebook	-	-	-
Podcast	-	-	-
Instagram	-	-	-

IMPLICATION FOR DESIGN

Our findings suggest two main roles for technology: providing timely information on miscarriage and its physical and emotional effects on women, and accessing spiritual resources. While women were generally happy with the level of support received by family and friends, they felt that better information about miscarriage, such as a list of resources to their network with guidelines on how to provide effective support, would help reduce potentially hurtful comments. Access to spiritual resources is important given that religion is crucial to participants' recovery. Resources might include a discussion of what miscarriage in Islam means, stories about Prophet Muhammad's (peace be upon him) companions who had experienced miscarriage, and information about the reward from Allah to women who have lost her pregnancy. This spiritual dimension, which is so important for Muslim women, is often neglected in the Western literature on miscarriage. We are currently designing a solution that addresses those needs, and plan to iteratively test them with women before consulting a range of stakeholders the findings of our qualitative work.

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