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Citation for published version:

Kresnye, KC, Alqassim, M, Hollins, B, Wolters, M & Siek, KA 2020, What to Expect When You are No Longer Expecting: Information Needs of Women who Experienced a Miscarriage. in *Proceedings of the 14th EAI International Conference on Pervasive Computing Technologies for Healthcare 2020*. Association for Computing Machinery (ACM), pp. 85-96, 14th EAI International Conference on Pervasive Computing Technologies for Healthcare, Online, Georgia, United States, 6/10/20.
<https://doi.org/10.1145/3421937.3421995>

Digital Object Identifier (DOI):

[10.1145/3421937.3421995](https://doi.org/10.1145/3421937.3421995)

Link:

[Link to publication record in Edinburgh Research Explorer](#)

Document Version:

Peer reviewed version

Published In:

Proceedings of the 14th EAI International Conference on Pervasive Computing Technologies for Healthcare 2020

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What to Expect When You are No Longer Expecting: Information Needs of Women who Experienced a Miscarriage

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ABSTRACT

Even though miscarriages are a common experience, there remains a discrepancy between the information needed after a pregnancy is lost and the information received. We explored the reasons for this gap as part of an eight-week online study with 42 participants who experienced a miscarriage. Common online sources of information were forums, blogs, and Facebook. Participants were interested in general information about miscarriage, counselling resources, others' experiences, and information from health care providers. Barriers to information access were both external (e.g., difficulty locating resources) and internal (e.g., self-blame or stigma). We map these information needs and barriers to a generalized miscarriage timeline crafted from participants' individual experiences and discuss implications for the design of sociotechnical systems to support people through miscarriage and beyond.

CCS CONCEPTS

• **Human-centered computing** → **Human computer interaction (HCI)**; • **Applied computing** → *Consumer health*.

KEYWORDS

miscarriage; resource needs; sociotechnical systems

ACM Reference Format:

K. Cassie Kresnye, Mona Y. Alqassim, Briana Hollins, Lucia Guerra-Reyes, Maria K. Wolters, and Katie A. Siek. 2020. What to Expect When You are No Longer Expecting: Information Needs of Women who Experienced a Miscarriage. In *PervasiveHealth '20: EAI International Conference on Pervasive Computing Technologies for Healthcare*, May 18–20, 2020, Atlanta, United States. ACM, New York, NY, USA, 12 pages. <https://doi.org/10.1145/1122445.1122456>

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PervasiveHealth '20, May 18–20, 2020, Atlanta, United States

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ACM ISBN 978-1-4503-9999-9/18/06...\$15.00

<https://doi.org/10.1145/1122445.1122456>

1 INTRODUCTION

Miscarriage, also known as Early Pregnancy Loss [49], is the primary reported form of pregnancy loss [1, 37]. It is common—about 1 in 5 pregnancies (20%) end in miscarriage [7, 18]. Regardless of the stage of pregnancy in which it occurs, miscarriage is a traumatic emotional time for the person who physically loses the pregnancy and people close to them [1].¹

While there is an existing body of work on designing technology to support new and expectant parents (e.g. [26, 52, 58, 66]), only a few solutions have been proposed to support people who have experienced a miscarriage, with notable exceptions [5, 8, 33]. Useful and usable sociotechnical systems need to take into account the context in which women go through the miscarriage experience, which includes the miscarriage journey itself, the health care provisions available, and women's use of and access to technology.

In this study, we examine *what* information women who experience miscarriage need at *which* stage of the process, and *how* it should be delivered. Specifically, our research questions are:

- (1) What is the physical and emotional timeline of pregnancy loss that our designs need to be aligned to?
- (2) How can technology deliver information to support women during pregnancy loss?

We engaged 42 women, who had experienced a miscarriage, to participate in 16 activities over 8 weeks in two online, asynchronous focus groups. To ensure variation in healthcare systems, we invited participants from the United States and the United Kingdom, which have substantially different healthcare systems (UK: single payer; US: insurance).

Overall, participants reported five main stages of their miscarriage journey: (1) pregnancy acknowledgement, (2) early pregnancy journey, (3) trigger event, (4) medical decision making and grieving, and (5) recovery. Information needs depended on a person's stage in the journey: participants wanted information about possible miscarriage outcomes earlier in their pregnancies, guidance on what to expect once they miscarried, and continued support throughout the grieving and recovery process. Blogs, Facebook, and online forums were useful social media information sources. Participants

¹In the rest of this paper, we will refer to the person who physically goes through a miscarriage as a woman. We recognise that this term excludes non-cisgender people who physically experience miscarriage [55]. Following [34], we use the term "women" to signpost that no participants explicitly identified as trans or non-binary in this study.

also greatly benefited from contact with others who had experienced miscarriage. Educating peer support networks may assist in reduced stigma for participants.

2 MISCARRIAGE & HEALTH BACKGROUND

Miscarriage is defined as pregnancy loss before 20-weeks gestation or at a fetal weight of less than 500g [42], and typically happens in the first trimester [64]; only 1% of miscarriages happen after 12 weeks of gestation [53].

Miscarriage affects a person's emotional and physical health [1]. Experiencing miscarriage can be a traumatic event and is usually accompanied by emotional distress [36]. Feelings of anger, guilt, prolonged grief, lowered self-esteem, depression, and anxiety following miscarriage [20, 25, 35, 48] and during subsequent pregnancies [16, 57, 63] are common. The grief following miscarriage can be as intense as that felt after a perinatal death [7, 31].

Traditional interventions for miscarriage include medication, lifestyle changes, and "watchful waiting" with medical monitoring [17, 19, 65]. Within standard medical care, those who discuss their miscarriage while attending follow-up appointments are less likely to suffer from mental health problems than those without this opportunity [30]. Hence, improvements to hospital and community-based care and sensitive after-care services have the potential to enhance mental health after miscarriage [54, 60].

Services sometimes fall short of this ideal. For example, Baird et al. [7] found women² who went to the Emergency Department in the United States after a miscarriage were confused, fearful, and did not receive information or emotional support. Participants were overall unclear of what to expect next.

Providing practical assistance, counselling, psychotherapy and supportive listening can decrease grief and symptoms of depression after pregnancy loss [47, 61]. Unfortunately, only a small percentage of those who have miscarried receive psychological treatment [8]. In-person support groups have also been shown to be successful during and after pregnancy loss [15].

3 RELATED WORK

Pregnancy is a frequent topic in sociotechnical system design. Existing research recognizes the critical role played by women's interaction with technology and the benefits that technology provides for self monitoring [14, 58, 62], information sharing [9, 22], and accessing social support [27, 46]. Indeed, Gui et al. [27] emphasizes not only how technology facilitates support for pregnant women when health services are inadequate, but also how women's experiences in themselves are vital information sources. Petyon et al. [50] encouraged the community to consider creating tailored, self-guided information that could incorporate a subset of a pregnant woman's social circle. Almalik et al. [2] identified learning needs during pregnancy that could be met through technology, while Prabhakar et al. showed that support needs change depending on the stage of pregnancy and the number of children women already have [52]. In addition, Prabhakar et al. found that participants were reluctant to share their online search histories, even though past research has shown that pregnancy journeys can be identified through women's online searches [22].

²We note participant gender based on how they were defined in the publication.

Although tracking fertility is one way women use technology when they are trying to become pregnant, these applications are less useful once women become pregnant [21]. Technology has also been used by those who have struggled with infertility to access information about available forms of treatment and other people's experiences in the same situation [9, 13, 32].

One of the earliest studies of technology for miscarriage is that by Kersting et al. [33]. They designed an internet-based, Cognitive Behavioral Therapy program to help coping after experiencing pregnancy loss for five weeks. They found the levels of grief decreased immediately after the treatment and depression symptoms decreased by the 3-month follow-up.

More recently, attention has focused on the effects of internet-based services, such as information seeking, support groups, and self-expression, which offer advantages such as constant accessibility and anonymous disclosure [4, 8, 24, 56] for miscarriage and other areas of women's health [69]. Similar to Gui et al. [27] for pregnant women, Betts et al. [8] found that those who had experienced miscarriages used online forums to seek support that they were not receiving from healthcare providers. Andalibi and Forte [4] conducted semi-structured interviews with 27 women in the US who had experienced pregnancy loss and found that an individual is motivated to disclose within one's network once they have observed others' disclosure - referred to as "network-level reciprocal disclosure" (NLRD). Building from this work, Andalibi et al. [5] designed a prototype mobile application which embodies the NLRD concept to better assist people who experience distress after pregnancy loss by enabling social support and disclosure with others who have had the same experience.

In this literature, we see that women seek personalized information on their reproductive journeys based on their individual experiences and that women's experiences in themselves are important sources of information and support. In this study, we bridge this gap by engaging with 42 women who have experienced miscarriage to identify the *timescale* of their miscarriage journeys and the *information systems they prefer* so that the pervasive health community can design contextually aware, personalized systems.

4 METHOD

We utilized the Asynchronous Remote Community (ARC) method to engage 42 participants from the US and UK in 16 activities about their miscarriage experiences over eight weeks. The study was approved by Indiana University's Institutional Review Board (IRB), the main study sponsor. University of Edinburgh researchers established a reliance agreement with Indiana University, thus all researchers followed the decision of the Indiana University IRB.

4.1 Asynchronous Remote Community Method

In an Asynchronous Remote Community (ARC) study, participants complete various activities and discussions in closed, secret social media groups in their own time [39, 40]. ARC allows researchers to adapt activities during the study based on participants' prior answers to better triangulate data. Prior work successfully utilized ARC to identify the needs of pregnant women and new mothers based on triangulation [51, 52]. Since we recruited women in the United States (US) and United Kingdom (UK) to broaden our sample,

we utilized best practices for engaging participants around the globe [38, 43].

We designed 16 activities for two closed Facebook groups. We used Facebook because communities for miscarriage support are common on the platform. We recruited only existing Facebook users, since they would be familiar with the different interaction mechanisms (e.g., Posts, Likes). The two groups were divided based on if participants had a live birth after their last miscarriage (Live Birth (LB) group) or not (No Live Birth (NoLB) group).

4.2 Recruitment

Both the US and UK groups recruited participants via Facebook. This included advertising in established miscarriage support groups and posting on the researchers' personal pages. The UK group also distributed leaflets in public places, such as libraries, and recruited through personal networks. The US group posted the participation call on twitter and on online miscarriage support forums.

Once potential participants contacted a researcher, they were sent an email with an attached digital copy of the informed consent. Participants were asked to review the informed consent and inquire about any questions or concerns they had. After we answered questions, potential participants could consent by replying to the email with a text statement including their name and the date. Once informed consent was received, participants were sent a link to an intake survey and placed into the appropriate group. A total of 66 people contacted us with interest in the study; 44 people completed the informed consent procedure and joined their respective study FB group. Two participants from the LB group dropped out in the beginning of the study – one without giving a reason, the other due to family concerns. Forty-two participants remained, and of these, 41 completed a post-study follow up survey about their well-being which also included demographic data. Participants received a gift card equivalent to \$50 USD for their participation, regardless of their level of engagement.

4.3 Demographics

All participants identified as women, except for one (2%) who preferred not to answer the question. The only significant difference between the demographic composition of the groups is location: LB were predominantly from the US (χ^2 test, $\chi^2(1) = 30.136, p < 0.0001$). Indeed, 43% of participants were from UK and 57% were from the US. Participants were predominantly white, over half had a graduate or postgraduate degree, and most were in full or part-time employment. All participants regularly used Facebook, but over half report posting less than once a week. Table 1 summarizes the study sample demographics in more detail.

4.4 Study Activities

We prepared 16 activities inspired by [51]. We posted two activities per week over a span of eight weeks, summarised in Table 2. These activities involved three major categories: Free-Text, Media, and Survey. Free-text activities involved open discussions based on a written prompt to the group. This allowed for participants to explore, develop, and react to ideas together, through the use of replies and reactions (e.g., Liking, Loving). The media activities involved a physical medium that the participant created. We advised using

Table 1: Demographics (Follow Up Survey). No LB = No Live Birth. LB = LiveBirth. * indicated fields where multiple options could be selected, resulting in totals greater than participant count.. 1 participant in No LB chose not to complete the survey.**

	No LB (n=20) N (%)	LB (n=21) N (%)	Total
Currently Based			
United Kingdom	9 (45)	8 (38)	17
United States	11 (52)	13 (61)	24
Age Group			
25-29	2 (10)	3 (14)	5
30-34	6 (30)	5 (24)	11
35-39	6 (30)	9 (42)	15
40-44	3 (10)	3 (14)	6
45+	3 (15)	1 (5)	4
Ethnicity*			
White	14 (90)	18 (76)	32
Asian	1 (5)	1 (5)	2
Arab	3 (14)	1 (5)	4
Hispanic	1 (5)	0	1
Native American	1 (5)	0	1
Black	0	1 (5)	1
Other	1 (5)	0	1
Education			
Postgraduate	6 (30)	6 (19)	12
Graduate	6 (30)	7 (22)	13
Other	8 (40)	8 (40)	16
Employment*			
Full time	10 (45)	10 (45)	20
Part time	4 (35)	3 (14)	7
Other	7 (35)	8 (38)	15
Self-Reported Facebook Log In frequency			
Daily	18 (90)	20 (95)	38
4-6 times per week	1 (5)	1 (5)	2
Once a week	1(5)	0	1
Self-Reported Facebook Posting frequency			
Daily	1 (5)	3 (14)	4
4-6 times per week	2 (10)	2 (10)	4
2-4 times per week	2 (14)	3 (14)	5
Once a week	5 (24)	2 (10)	7
Rarely	10 (47)	11 (52)	21

pen and paper for our media activities, and requested participants to post images of the resulting product in a group thread to spark discussion. Lastly, we used surveys that were sent privately to each participant's email. Full documentation of all activities can be found in [68].

The study began with an icebreaker activity to introduce participants before asking questions about their miscarriage experience. We utilized an open prompt of what was the participants' preferred superpower. At the end of the study, both groups remained open to avoid harm to participants by ending supportive relationships they may have formed throughout the study. We encouraged participants to review Facebook's privacy policy for how their information would continue to be used in the beginning of the study and at the end, when data collection was complete.

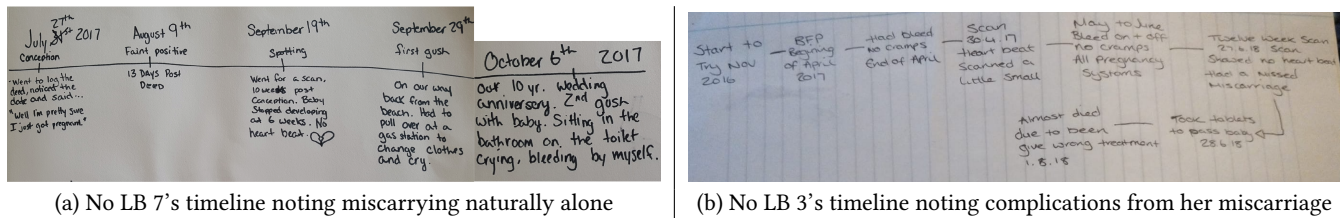


Figure 1: Examples of miscarriage timelines participants provided for A3 activity

Table 2: Activities Used in the Study. Bolded activities indicate where most study data came from. Column acronyms: W=Week; Type= Type of Activity (FT= Free Text, M=Media, S=Survey); RQ = Research Question (Info: Information Needs, Soc: Social Support, Time: Timeline, Tech= Technology Needs, Org: Group Organization / Icebreaker); N= Number of participants who completed the activity

W	Activity	Type	RQ	N (%)	LB N (%)	No LB (%)
1	A1: Meet and Great: Participants shared what super power they wanted.	FT	Org	37 (88)	19 (90)	18 (85.7)
	A2: Facebook Availability: Participants voted what day posts should be made.	Poll	Org	38 (90)	18 (85.7)	20 (95)
2	A3: Timeline: Participants created a timeline of their miscarriage experience.	M/FT	Time	36 (86)	19 (90)	17 (81)
	A4: Emotional Well-being: Participants completed a survey on their well-being.	S	Soc	40 (95)	21 (100)	19 (90)
3	A5: Dear Abby: Participants responded to a fictitious request for advice on what comes next in a miscarriage and how to deal with feelings of guilt.	FT	Time	28 (66)	15 (71)	13 (62)
	A6: My Miscarriage: Participants wrote about their miscarriage focusing on who was present, what was missing, and what happened.	FT	Time	32 (76)	18 (85.7)	14 (66)
4	A7: Circle Diagram: Participants drew a circle diagram with themselves at the center showing their miscarriage support structure.	M	Soc	22 (52)	13 (62)	9 (42.8)
	A8: Coping Mechanisms: Participants noted how they coped with miscarriage.	S	Soc	36 (86)	20 (95)	16 (76)
5	A9: Social Support Network: Participants discussed what information participants received and what they would share with their support network.	FT	Soc	22 (52)	13 (62)	9 (42.8)
	A10: Social Support: Participants completed a survey about what information they would share with whom about their miscarriage.	S	Soc	35 (83)	19 (90)	16 (76)
6	A11: Coping Mechanisms: Participants shared tips for coping with a miscarriage.	FT	Soc	25 (60)	14 (66)	11 (52)
	A12: Missing Information: Participants discussed what information they wished they had known and how they wanted to receive it.	FT	Info	21 (50)	13 (62)	8 (38)
7	A13: Important Information: Participants rated information by importance.	S	Info	30 (71)	17 (81)	13 (6)
	A14: Technology Use: Participants noted technology they use to access information.	S	Tech	33 (79)	18 (85.7)	15 (71)
8	A15: Future Technology: Participants considered future interactions with technology.	S	Tech	34 (81)	19 (90)	15 (71)
	A16: Goodbye: Researchers concluded the study with plans for disseminating findings.	FT	Org	4 (10)	2 (9.5)	2 (9.5)

The activities we focus on in this paper are highlighted in bold in Table 2. The *Timeline* (A3) activity required participants to write or draw a timeline of their miscarriage experience(s). In the *Dear Abby* (A5) activity, named after an agony aunt famous in the US, participants gave advice to a fictional woman who had experienced a miscarriage. In *My Miscarriage Experience* (A6), participants were invited to share the story of one or more of their miscarriage experiences, including a discussion of who was present and supported them through it. The *Missing Information* (A12) and *Important Information* (A13) activities allowed participants to share what kinds of information was important to them, what information they would have liked to receive after the miscarriage, and how they would

have liked to receive it. Finally, *Technology Usage* (A14) focused on the technology and social media used for obtaining information about miscarriage, which could be leveraged for solutions.

4.5 Analysis

R was used for descriptive statistics and non-parametric tests of differences between groups. The timelines from A3 were qualitatively distilled into sequences of key events. A ranking of important information needs was derived from A13. The analysis of A14 established where participants obtained information online.

Qualitative analysis was conducted on the free text activities A5, A6, and A12 and the free text responses to A13. Qualitative data

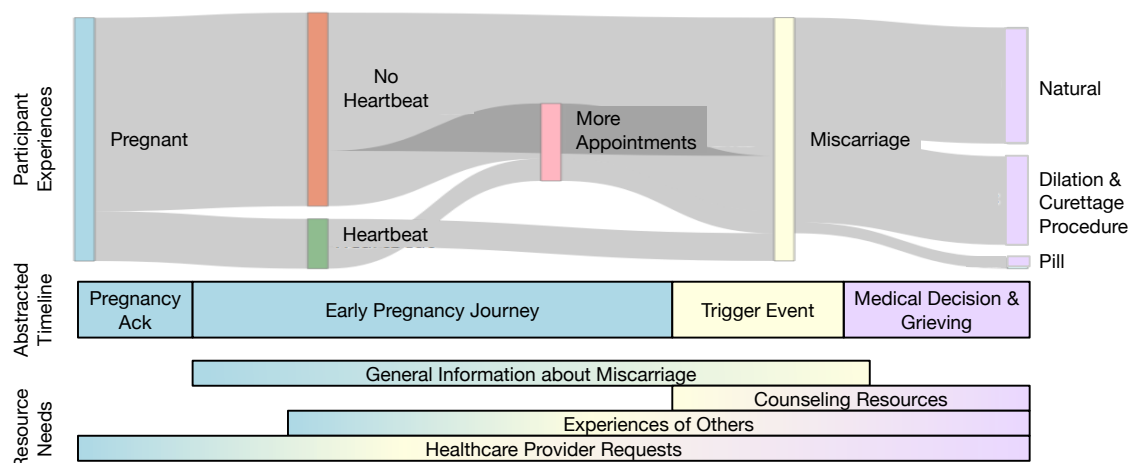


Figure 2: A Sankey diagram showing how many of the 42 participants learned about their miscarriage and the medical decisions to complete their miscarriage. Based on participants' experiences, we abstracted their miscarriage journeys and identified the resources they needed throughout this time frame (Early Pregnancy Journey (blue), Trigger Event (yellow), and Medical Decision & Grieving (purple)).

were first coded by two researchers (KCK and MYA) independently using a combination of content analysis and open coding. Top-down codes for the content analysis were derived from the research questions, and open coding supplemented the top-down codes. Based on the initial codes, the two coders agreed on a code book, and re-coded the data. Coding was coordinated using Dedoose. We used affinity diagramming to identify broader themes.

5 RESULTS

5.1 The Physical and Emotional Timeline

Participants provided us with a total of 50 individual miscarriage timelines (No LB : 23, LB : 27) - examples are shown in Figure 1. Most participants only talked about one miscarriage experience. The amount of detail varied greatly.

When looking at the progression of symptoms leading up to miscarriage, we found each miscarriage was unique in the frequency, length, and severity of symptoms. Using the participants' timelines, we constructed an abstracted timeline based on commonalities throughout the timelines using affinity diagramming, as shown in Figure 2. This timeline breaks down into five stages: Pregnancy Acknowledgment, Early Pregnancy Journey, Trigger Event, Grieving and Medical Decision, and Recovery.

Pregnancy Acknowledgement. The first stage is the acknowledgement of pregnancy - 67% of the participants discussed this stage. These first moments of understanding the new possibility were shared with a close circle - most only including a partner at first. This event was shared by both those participants who were trying to get pregnant and those who were not. LB 19 related, "the day my period was supposed to come, I told my husband I might be pregnant because nothing was normal. Several tests proved it" [A3]³.

Early Pregnancy Journey. Once participants learned they were pregnant, they transitioned to a new phase of scheduling medical appointments and mentally adjusting to this new reality. This second stage is filled with emotional energy, which can be channeled as excitement or anxiety about the future. Participants with positive feelings about their pregnancy expressed excitement for the future to come. Participants shared their activities, such as pregnancy celebrations, family reveals, and imagining how their futures were evolving to include a new family member. No LB 04 described, "So excited, take [pictures] of daughter in 'promoted to big sister' shirt, start thinking about names, converting office to nursery, and how life will change in the fall" [A3]. Some participants who had experienced prior losses shared similar feelings: "Actually, I think it was because we were so excited to be pregnant again and we thought, well, we already had the bad experience so here we are, finally having a baby." [LB 16, A3].

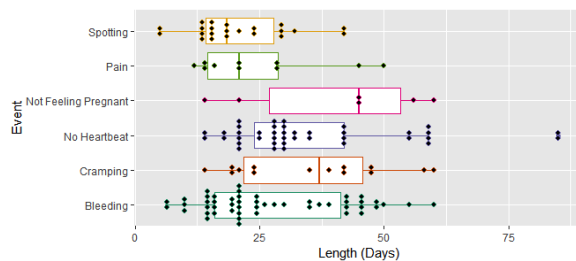
Others experienced uncertainty and anxiety due to an unplanned pregnancy or a previous miscarriage. LB 01 shared, "I did not want to have a baby and had a whole bunch of mixed feelings about the pregnancy. I felt like a complete basket case with feelings of anxiety and depression. I had a few panic attacks as well. . . I wasn't able to get into a doctor's office for a check up until 13 weeks. Around that time, I started feeling more settled and adjusted to the idea of having a child. Picked a name and started envisioning my new life with a baby." [A3]⁴. Participants who experienced anxiety described keeping expectations in check as to ensure emotional stability. Behaviors such as avoiding pregnancy disclosure with the family and opting to keep the pregnancy out of mind were prevalent as explained by No LB 04, "Very anxious, hard to muster any excitement for this pregnancy, and try not to think about/do not talk about names, nursery, etc" [A3].

³Participants are labeled based on the group they were in (LB or No LB), participant number, and the activity data the quote came from (A#).

⁴All quotes preserve original spelling.

Table 3: Prevalence of pre-miscarriage symptoms reported by participants in the timeline activity (A3).

Symptom	No LB	LB	Total
Bleeding	18(78%)	13(48%)	31 (62%)
No Fetal Heartbeat	13(56%)	10 (37%)	23(46%)
Spotting	11(47%)	6 (22%)	17(34%)
Cramping	6(26%)	1(3%)	7(14%)
Pain	2 (8%)	4(14%)	6(12%)
Not Feeling Pregnant	2(8%)	1(3%)	3(6%)

**Figure 3: Length of miscarriage symptoms. Horizontal axis is in days, with respect to the pregnancy confirmation being day 0.**

Trigger Event The third stage was a trigger event that was the first indicator of something wrong - 74% of participants noted these events, more detail in Table 3. A majority of participants noted when they started bleeding (62%) or spotting (34%) - distinctions between bleeding and spotting were at the participants' discretion - on their timelines, as shown in Figure 1. Bleeding was typically described as sudden, "All went well until mid-April (around 8 weeks) when I suddenly started bleeding (on my birthday.) Every few days I had a small gush of blood, with some spotting in between." [LB05, A3] When time was mentioned related to bleeding, participants noted it lasted from 6 to over 50 days, as shown in Figure 3. Participants textual descriptions often alluded to the difficulty they felt emotionally and physically during this time, "Over the next few days bad cramping and bleeding getting worse and worse. Three days after coil removed it 'all fell out'. I still struggle with phrasing that but won't forget seeing it there." [No LB 01, A3] After participants experienced bleeding or spotting, they sought medical attention - which sometimes did not provide much assistance: "I woke up with horrible bleeding..I ran to the hospital and they couldn't decide whether it's a miscarriage or just bleeding." [LB 03, A3]

Less than half of participants (46%) learned about their miscarriage by finding out their was no fetal heartbeat. Some participants found out at the initial scan, "I had had some spotting and low progesterone, and when I went for the ultrasound to confirm they didn't see anything but a gestational sac. Except they should have seen something at that time in the pregnancy." [LB 17, A3] Whereas others found out at a subsequent scan: "The technician asked if a heartbeat had been found, I said yes, she responded with 'oh thats strange because there is only debris in there now'. I cried, the technician fled the room." [LB 13, A3] Trigger events do not have to be when the

miscarriage officially occurs, as this can be difficult to pinpoint, but it was the first time the individual learned of a potential serious issue with their pregnancy.

Medical Decision and Grieving The miscarriage events and their medical management were diverse - 19 were natural miscarriages (No LB : 10, LB : 9); 13 required removal by dilation and curettage (D&C) (No LB : 6, LB : 7); and in 3 cases, women were given a pill (No LB : 2, LB : 1). For the remaining 15 miscarriages, this information was not specified (No LB : 5, LB : 10).

Medical decision making and grieving is interleaved for miscarriage due to how quickly it transpires. Participants documented their decision making processes, as No LB 16 shared on her pictorial timeline, "Decision how to proceed - confusing? - Decided to let nature take it's course - pass teeny tiny baby at home mid-Sept." Whereas LB 16 disclosed a different course of action, "I didn't want to force bleeding and I didn't want to wait for it to happen naturally so we opted for a D&C." [A3]. Participant LB 13 agreed with LB 16 responding to her, "I opted for a D&C as well. Couldn't cope with the idea of it happening slowly." Participants also considered how their miscarriage would impact their work - "I would have a really hard time managing things if I let things happen naturally. I was worried that I might be at a client's home when I lost the baby. So we opted for the D&C." [LB 17, A3].

Sometimes, this stage is drawn out when a potential miscarriage needs to be confirmed further - "There wasn't any way to have a confirmation ultrasound done until Monday. So all weekend long I was in a mourning process, trying to have hope but realizing that the doctor was probably right." [LB 17, A3] For participants who learned of their loss during a scheduled pregnancy visit, this complex decision was usually prompted at the same visit they learned of the loss, meaning that they were required to decide in a raw emotional state. As No LB 8 explained, she "Spent hours waiting about for someone to come tell me what my options were when finally I got a photocopied leaflet and asked to make a decision. I opted for an op and waited a few more hours only for a really young doctor to come along, filling the form and ticking 'yes' to agreeing to experiment with the remains. He was rather embarrassed when I challenged him but didn't apologize." [A3] Several participants noted that the medical management of their miscarriage focused on procedures and processes, but not on supporting them and their partners through the experience of loss. Participants often related feeling alone - whether in a medical facility or at home - "Our 10 yr. wedding anniversary. 2nd gush with baby. Sitting in the bathroom on the toilet crying, bleeding by myself." [No LB 07, A3]

Recovery. The final and least discussed stage at 36% was recovery. This is when the physical aspects of the miscarriage have passed and mentally the individual navigates how to move on. Many participants were unsure to what extent they had recovered themselves and considered themselves still in the grieving stage: "Now debating how or even IF to move forward. Do we really want another baby anymore or do we not know how to stop trying after all this time? Is it just easier to continue to hope/try than to deal with grieving for our 'dream' family?" [No LB 04, A3]

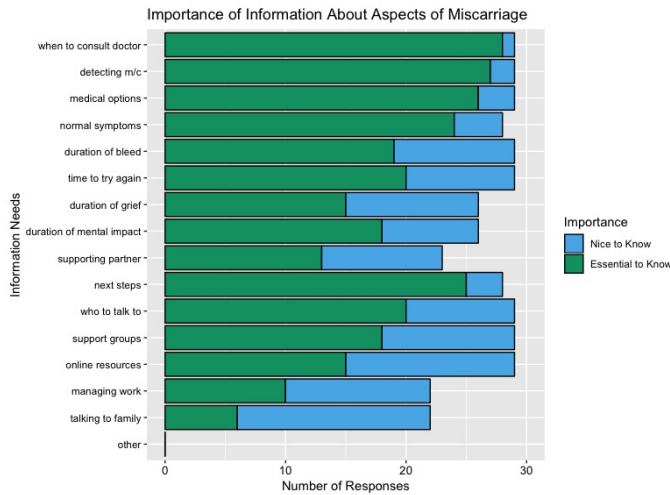


Figure 4: Importance of each type of information about aspects of miscarriage that had been raised by the literature or participants, from the survey in Activity A13. 30 participants engaged with the activity.

5.2 Resource Needs

Throughout the activities, participants described situations where they wanted or sought various resources, summarized in Figure 4, to help them throughout their miscarriage experience. In some instances, after identifying resources, they encountered barriers to obtain them. We contextualize when these resources are needed with the miscarriage timeline in Figure 2.

5.2.1 Identifying Resources. The four primary resources sought by participants were: (1) general information about miscarriage; (2) information about counselling resources; (3) information about the experiences of others, and (4) health care provider requests.

Theme 1: General Information about Miscarriage. Participants were frustrated by the lack of awareness of miscarriages. Limited, if any, information was given at the beginning of their pregnancy, and participants wanted to know more about miscarriages from a trusted source early on. Specifically, participants wanted information about biomedical aspects of miscarriage (Figure 4) - when to consult a doctor, detecting miscarriage, medical options for miscarriage management, degree to which symptoms are normal, and when to try to conceive again. Participants shared, "we hadn't really heard of a missed miscarriage." [No LB 16, A3] and "I wish I would have known how common miscarriage was, how even though it's common a lot of women still find it extreme difficult physically and emotionally" [LB 07, A12]. After they miscarried, they also received little information - especially about what to expect, as LB 09 said, "I would have liked to know more about what to expect from my body after a miscarriage. What kinds of hormonal, and biological changes to expect." [A12] Pregnancy has a set care path, however once this path is taken away, participants expressed feeling alone and unsure what to do next.

Information about miscarriages should be presented during the *Early Pregnancy Journey*, so that it is readily available during the

Trigger Event and can be consulted as needed during the *Medical Decision and Grieving* stage. In addition, sociotechnical pregnancy systems could better capture symptoms, as outlined in Table 3 and Figure 3, to identify when someone may need more miscarriage information (e.g., how long has one been spotting or bleeding with cramping).

This was especially the case for home miscarriages, where people faced difficulty determining what to do with the fetus once passed. Participants talked about a limited awareness of options and the impact it may have on their grieving process. No LB 10 recalled, "I remember not really knowing what to do. It was very painful physically and the doctor has prepared me for what I'd see, but I didn't think to ask what I should do with the sac and no one thought to talk to me about it. I regret having not buried it or even having a conversation about what to do. I also bled so much I was very scared." [A3]

Participants also wanted to know why they experienced a miscarriage, although clinical research shows it is difficult to identify reasons [3, 41]. Participants discussed a potential cause of their loss for only 9 out of 50 miscarriages. Several participants noted the financial difficulties of genetic testing, and some pointed out that insurance would only cover genetic testing after three confirmed miscarriages.

Theme 2: Counseling Resources. Although some participants discussed finding counseling or informal online groups, they wished they could have been directed to resources at the time the miscarriage was diagnosed. LB 04 expressed "I also sought counselling myself but it could have been useful to receive guidance as to where to find this." [A12] Similarly LB 11 shared, "Information about support groups would have been very beneficial. In the end I found my own through an online forum but something concrete would have helped." There was a clear need for professional emotional support for the grief and recovery journey from those who are skilled to give such support, because as No LB 10 explained, "I think we [...] haven't taught people how to grieve well at all. It makes it more difficult for people who haven't miscarried to understand grief is very difficult emotionally and physically." [A9] We note that skillfully communicating uncertainty may be more important than providing answers. As LB 05 shared, "I also appreciated acknowledgement of the information that wasn't available, such as the when/why/would it happen again stuff - the ability of people to say 'I don't know' in a compassionate and validating way." [A12]

Referring back to our timeline, information about counseling resources needs to be available at the very latest at the beginning of the *Medical Decision and Grieving* phase. If sociotechnical systems do provide counseling, then they should be able to sympathetically note when no information or answers are available.

Theme 3: Experiences of Others. Participants desired hearing others' stories to come to terms with their own experience, especially when sharing was difficult. Indeed, most participants used online forums ($n = 28$, 87.5%), Facebook ($n = 23$, 71%), and blogs ($n = 17$, 53%) for information seeking to know that they were not alone, while keeping their anonymity as shown in Figure 5. The experiences of others would be particularly valuable during the *Trigger Event*, *Medical Decision and Grieving*, and *Recovery* stages.

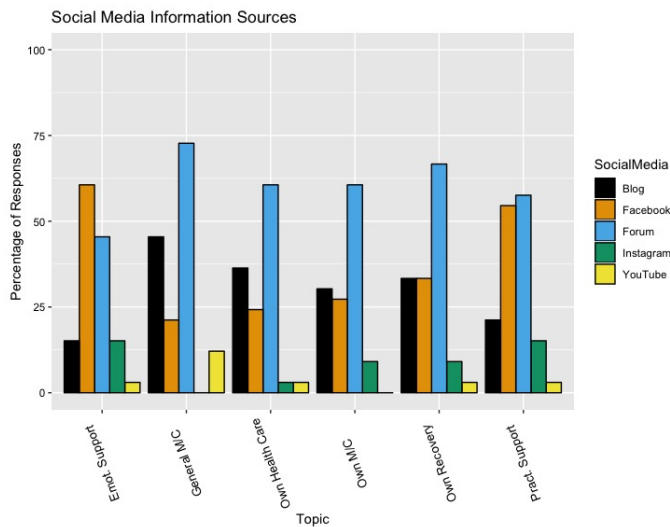


Figure 5: Use of Social Media (A14) to get information on: emotional support; general miscarriage information; participant's own healthcare, miscarriage, and recovery; practical support. 32 participants completed the activity

No LB 02 explained, "It might make you feel better to think that you are not alone and that there are numerous women out there who are experiencing the same." [A6]. Indeed, during the timeline activity, participants often responded via Facebook reactions (e.g., love, like, sadness) and replies (e.g., "Thanks for sharing," and "Same:").

This desire to connect with others usually warranted a one way connection, where the individual can read others' experiences without revealing their own. No LB 21 discussed how challenging it was to share earlier on, "I wish I could have been more open about my miscarriages [...] but my emotional state combined with the stigma of talking about it kept me from doing so." [A8] A tension arose in knowing there were groups that could support them, but with the acknowledgment of how difficult it would be to participate - "In retrospect, I would have liked information about a local support group, though I don't know if I would have gone" [LB 05, A12].

Theme 4: Healthcare Provider Requests. Participants wanted to be guided and supported through the miscarriage experience by trusted, reliable health care providers who could provide accurate information. They talked about wanting a follow up after the miscarriage where they could ensure they were okay, ask questions, and received trusted resources. No LB 08 explained, "In terms of Medical staff I was offered no support, no follow up no informational handouts or here is where you may go for further support, no follow up from the doctor." [A9] Some participants expressed feeling abandoned - "I always thought it was weird how the hospital was quick to let me go/didn't much care for a follow up and just let me deal with everything on my own [...] I would have liked to have received more support from the hospital staff and not be kicked out which is how I felt." [No LB 01, A3] When participants did have follow-ups, they sometimes felt like "particularly doctors and nurses, just brushed it off." [LB 06, A12] Follow-up information delivered without healthcare provider

follow-up was equally not well received - "I received a letter 3 weeks ago to say I have tested positive for [condition] and just take aspirin when I find out I'm pregnant again until 34 weeks and that no follow up appointment was needed. I had to do my own research to find out what this meant." [No LB 03, A3] In particular, they wanted more time with a trusted, compassionate provider to explore their future options. When healthcare provider support was absent, participants primarily turned to forums, and occasionally blogs, to learn about healthcare, miscarriage, and recovery (Figure 5).

Overall, participants were interested in having more access to general information throughout their experience with *all* of their providers. This means that health care providers should be ready to provide continuity of care throughout the entire miscarriage process, from *Early Pregnancy Journey* when they start experiencing symptoms to *Recovery*.

5.2.2 Barriers for Accessing Resources. Participants encountered problems with meeting their individual resource needs that were due to internal and external barriers. All of these barriers were linked to the perceived taboo nature of miscarriage.

Internal Barriers. Predominately in our advice prompts, *Dear Abby* [A5], participants acknowledged the difficulty of talking about miscarriage. Sometimes, this was caused by the internal stigma they perceived which affected both medical and family relationships. No LB 04 advised the fictional mother, "It is also is tricky because, while fairly common, it's not something many women talk about. This secrecy can feed the feelings of shame and guilt, but you are not to blame and you do not need to keep it a secret." [A5] Although participants wanted more people to talk about miscarriage, they acknowledged that in practice talking in-person was hard and they often used technology to circumvent the difficulty and seek support. LB 12 shared, "Personally, I found it easier to open up about my experiences to people I knew online, in a relatively anonymous 'safe' space..."[A5]. They also utilized technology to communicate during their miscarriage experience - "I would text but couldn't really say it aloud without dissolving into a puddle" [No LB 09, A3]

Without having a guiding hand, many talked about being alone in this experience. They were not given a starting point to find resources, and felt isolated in their attempts to gather accurate information in solitude.

External Causes. Throughout the study, participants revealed how family and friends who were uncomfortable with miscarriage sometimes did more harm than good. Indeed, LB 19 noticed "Everyone else tries to change the subject and begins to act uncomfortable." [A8] Participants talked about not reaching out due to unwanted responses. As No LB 09 shared, "I would love to talk about anything miscarriage [...] with my family but won't. I don't think the response would be what I need." [A8]

Women also felt that that their voices were not heard. When No LB 03 requested guidance from medical professionals, she recalled, "...Was told that was fine and just to carry on with life for the next [few] weeks I was getting little pains and very strange discharge. Kept calling EP and they kept saying this was normal. I was eventually told to stop calling as there was nothing more [they] can do." [A3]. A lack of acknowledgement was also found in their family relationships, with participants feeling unable to move on as their families had: "Last time it was clear we would try again, but after two loses, our

path forward is not as clear. Our family and close friends still care, but they have moved on and we haven't yet." [No LB 04, A3]. Participants felt that others "moved on" faster than themselves. This sparked participants to shift from focusing on their own grief and recovery to proving to others their loss was real. Some participants continued to speak up with positive results - as LB 07 recounted, *"I let my doctor know my frustration and he was very receptive to it."* [A9]

6 DISCUSSION

Overall, participants had complex information needs about topics which ranged from medical aspects (e.g., physical symptoms in Table 3) to self care and coping with grief. A core problem in meeting those needs was that participants often only had limited knowledge of what a miscarriage was before experiencing one themselves. This left many overwhelmed, with complex information to absorb and difficult decisions to make while in a raw emotional state. To make matters worse, informational and emotional support at the time was often insufficient. This can be mitigated by sharing general, trusted, information sources about miscarriage with women towards the beginning of pregnancy, which can be explored at their own pace.

Having clear next steps was particularly important. As we saw in our discussion of Theme 1: General Information about Miscarriage, most uncomplicated pregnancies follow a clear timeline, and there is plenty of information about "what to expect when you are expecting." This structure is ripped away once the miscarriage occurs and replaced with after care advice [67], ideally for both mind and body [12]. In particular, women need reassurance around what is normal after miscarriage. A drastic shift like this leaves many with questions on what to do next, which is intrinsically tied to the reason behind the miscarriage and the motivation of the pregnancy. The former can be difficult to identify medically. In most cases our participants were given no specific answer. This is not surprising, given that 50% of recurrent miscarriages are still medically unexplained [23]. Reflecting on motivations for pregnancy may involve a substantial shift in a person's view of themselves and their goals in life, especially if they decide to not try to get pregnant again.

We found that participants felt particularly unsupported when it came to their journey of grief and eventual recovery of a new normal. While there are resources, such as books [10], web sites, and leaflets, finding and accessing them at the right time is difficult.

6.1 Connecting People with Technology

Participants' experiences highlighted substantial problems in the delivery of antenatal services and miscarriage care. While technology can link women to communities and sites that provide much of the needed information, it cannot plug the support gap left by the reality of service delivery [7]. For participants, searching for information online is often a lonely activity, and only half of the respondents (Figure 4) regarded online resources as an essential piece of information. In particular, online resources, such as blogs or forums, may make it difficult to determine what symptoms fall within the normal range, because users share their individual, unique experiences.

In line with recent initiatives for better, evidence-based, interdisciplinary miscarriage care [12], *we encourage researchers to develop new mechanisms to collect larger scale data about miscarriages related*

to the symptoms and time frames so that clinicians and patients can better identify "is this normal?" Since participants are focusing on their physical and emotional health, information capture may not be in a simple application (e.g., menstruation trackers [21] or trackers for chronic illness [44]) and may need data fusion through multiple streams, such as forums, web searches, wearable sensors (e.g., smart watches), and experience documentation media. In addition, any data fusion needs to respect women's privacy and ensure that anonymised identities that they may use for online activities related to miscarriage are protected. This makes pervasive solutions challenging to design.

Participants noted that miscarriage still carries considerable stigma. Many reported unwanted responses and belittlement of the loss, which made them more hesitant to reach out. On the other hand, hearing other people's stories helped them reframe their experience without the self-blame. Similar to Gui et al. [27], we see women experiencing a miscarriage continue to utilize technology for support when other options fail them. Interventions such as Not Alone [5] create a safe space for people to reach out to one another after miscarriage that protects against stigma. It is important to design solutions that work across multiple platforms given the strong individual preferences for information and support sources evidenced in Figures 4 and 5. Since miscarriage is a trying time, particularly for face-to-face communication, people should be able to choose their desired level and modality of interaction (e.g., reading, messaging, calling).

6.2 Implications for Designing to Meet Resource Needs

People who experience miscarriages may benefit from having information proactively provided to them based on where they are in their timeline. Ideally, such a system would be *integrated into a pregnancy system where experiences, support, and symptoms could be monitored and a seamless transition could be provided to miscarriage resources and support* if needed. While similar systems already exist for relatively standardised procedures, such as recovery from coronary bypass surgery (e.g., HeartCare [11]), creating such a guide for miscarriage is substantially more complex due to the diversity of symptoms and individual timelines. Large scale data collection as discussed above could be leveraged for dashboards that show shared experiences.

Where health care systems provide for follow up care and appointments, such a *personalised information system should also allow women to connect with the practitioners who provide compassionate services*. This would allow the individual to connect with an expert to discuss physical and emotional recovery, and receive information about trustworthy online and offline resources, including counselling options. While information may be provided during the trigger event or at the start of the medical decision stage [12], not all women may be ready for it at this stage, and may need more time to come to terms with the loss that is happening first. Ambient displays that can give care practitioners information about non-verbal patient cues, such as Hartzler et al.'s visual system [29], could improve empathetic communication during this difficult time.

In particular, the question of dealing with the remains post-miscarriage emerged as an important issue during the recovery

phase of the timeline. Information can be difficult to supply in a sensitive manner, because a person's beliefs, values, and reproductive history may affect both how they will view the different options (e.g., burial, flushing, testing) and how they would like to refer to the remains. Although researchers have investigated how people navigate loss and grieving [6, 45], more work must be done on how we can capture this rich contextual information before the miscarriage to provide empathetic, personalized advice.

Similar to [4] we reiterate the *need to identify how we can help people navigate loss that is not well recognized by society and help society understand stigmatized losses*. As Theme 3: Experiences of Others shows, the human aspect aids with this process, as our participants discussed the isolation they felt when searching online for their own answers, particularly for physical recovery, and when the loss is still new. Similar to Peyton et al.'s call for social network integration into pregnancy sociotechnical systems [50] and Andalibi et al.'s Not Alone system [5], the system should connect individuals to others who share similar experiences, so that they can seek emotional social support at a level of disclosure with which they are comfortable. The system might also be useful for providing information to people in an individual's care and support network to inform them of how to provide effective support; guidelines for providing a listening, nonjudgmental ear; and how to navigate their own discomfort. This is similar to the vision MacLeod et al. [38] developed to help people understand the experiences of rare diseases.

A first step would be to diversify current women's health information sources and expertise, in particular apps and websites targeted at pregnancy, to include miscarriage information. Online resources should at a minimum cover the essential issues identified by our participants, such as navigating the health care system (which continues to be a struggle after one has a child [28]), detecting miscarriage, common miscarriage symptoms, and next steps. In addition, the sociotechnical systems should be aware of relevant pregnancy context (e.g., infertility; unexpected pregnancy) to further personalize information. Since people are often unsure about what to expect when they are no longer expecting, information should be structured to match possible timelines of miscarriage, so that it becomes easier to know what to expect, and information should be delivered asynchronously, so that users can choose to access it when they are ready to process it. We acknowledge that there are government resources available to participants in both countries⁵, however these resources are lists of links that informally launch participants into a labyrinth of information. The US MedlinePlus site is more procedure oriented - which reflects the experiences of participants receiving information only about procedures and options to complete their miscarriages. While the UK National Health Services site discusses both procedures and aspects such as remembrance, the only relevant "what next" question answered is when someone can have sex again.

Even though charities, such as the UK Miscarriage Association (www.miscarriageassociation.org.uk) and the UK Stillbirth and Neonatal Death Society (www.sands.org.uk), have dedicated

web portals that already incorporate most of the design implications that emerged from our study, people are most likely to find these resources after their first loss, during their lonely search for information about an event that may have hit them unexpectedly. We encourage researchers to investigate *appropriate ways to provide timely information proactively, but without stressing people experiencing healthy pregnancies*.

6.3 Limitations

Our study was limited to a predominantly white, well educated population of Facebook users, which might explain the dominance of Facebook as a resource for information and support. Even though the ARC method allowed us to reach 42 people from two different countries, it still proved difficult to reach people from different ethnic backgrounds and people from lower socioeconomic strata. Our recruitment criteria also used the terms "women who experience miscarriages," which may have excluded individuals who experienced a miscarriage, but do not identify as women [55]. Along with this, our demographics survey only included 3 options for gender ("male," "female," "other") which may not fully capture the genders of the participants. In future iterations, we will use more inclusive recruitment and surveying mechanisms (e.g., [59]).

7 CONCLUSION

Our findings reiterate a clear need for technology that lets people know what to expect when they are no longer expecting, and helps them navigate the complex and varied landscape of loss. Such technology should proactively provide access to relevant information about miscarriage, and access to people who can help, many of whom will have lived through the socially stigmatised loss of miscarriage themselves. In future work, we will investigate how such safe spaces can be integrated into apps that are already provided or recommended by health care providers.

8 ACKNOWLEDGEMENTS

We would like to thank the women who participated in our study. Funding for this research was provided in part by the National Science Foundation (IIS-1560276, IIS-1852294), Indiana University Precision Health, Ministry of Education (Government of the Kingdom of Saudi Arabia) and the Alan Turing Institute (EPSRC, EP/N510129/1). Any opinions, findings, and conclusions or recommendations expressed in this material are those of the author(s) and do not necessarily reflect the views of the funders.

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