
***Not Alone*: Designing for Self-Disclosure and Social Support Exchange After Pregnancy Loss**

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Abstract

Pregnancy loss is a common complication in pregnancy. Yet those who experience it can find it challenging to disclose this loss and feelings associated with it, and to seek support for psychological and physical recovery. We describe our process for interleaving interviews, theoretical development, speculative design, and prototyping *Not Alone* to explore the design space for online disclosures and support seeking in the pregnancy loss context. Interviews with 27 women who had experienced pregnancy loss resulted in theoretical concepts such as “network-level reciprocal disclosure” (NLRD). In this paper, we focus on how interview findings informed the design of the *Not Alone* prototype, a mobile application aimed at enabling disclosure and social support exchange among those with pregnancy loss experience. The *Not Alone* prototype embodies concepts that facilitate NLRD: perceptions of homophily, anonymity levels, and self-disclosure by talking about one’s experience and engaging with others’ disclosures. In future work, we will use *Not Alone* as a technology probe for exploring and evaluating NLRD as a design principle.

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Our design process includes three main activities:

1. In-depth interviews to understand the lived experiences of those who have gone through pregnancy loss and the perceived role of existing social technologies in this experience for them. We refer readers interested in the details of these interviews and findings to [2]. Participants' average age was 33.6 (range: 27-42). Participants were not screened based on gestational stage of loss, as the grief experience is not dependent on it [7]. Interviews directly informed requirements and experimental prototype designs. In this paper, we solely focus on the resulting *design* process.
2. Speculative design that explores a fanciful idea that challenges norms and expectations.
3. An iterative process of design thinking that yielded a prototype of a realistic mobile application that we will use as a technology probe in future research.

Author Keywords

Pregnancy loss; miscarriage; perinatal; grief; social support; design; social media; reproductive health; maternal health; network-level reciprocal disclosure

ACM Classification Keywords

H.5.2 Information Interfaces and Representation: User Interfaces – User-centered design. K.4.2 Social Issues

Introduction

When people experience stressful life events or trauma, being able to talk about these events and access to social support is key to recovery and linked to improved wellbeing [9]. One such event is pregnancy loss, which is a common pregnancy complication; Pregnancy loss occurs in at least 20% of recognized pregnancies in the U.S., yet 55% of Americans perceive it as rare [12]. For those who experience it, feelings of isolation, guilt, shame, unworthiness, stigma, and trauma are common and can contribute to not disclosing the loss or seeking support [15]. Finding helpful support can be beneficial to those affected by pregnancy loss; for instance, participation in in-person support groups after stillbirth leads to significantly fewer traumatic stress symptoms, compared to non-participation [3].

Disclosure of sensitive personal information and support seeking in the face of stigma and distress is a challenging design context. Pregnancy loss support in particular is largely unexplored in HCI, in spite of its prevalence and potential to help many people. HCI research and interventions exist for new parents and mothers (e.g., [10,11]), tracking pregnancies (e.g., [6]), or tracking health data for preterm babies [5]. With few exceptions (e.g., [5]), prior work largely focuses on pregnancy journeys that progress as

planned, and none address pregnancy loss. We investigate online support seeking after pregnancy loss as a context for designing for vulnerable populations experiencing distress and stigma, with the goal of fostering wellbeing through facilitating disclosure and social support exchange mechanisms. As outlined in the sidebar, here we focus on the design contribution and process of a prototype we call *Not Alone*.

Design Process

Our initial design process included the goals of empathizing with potential users, defining their goals, and ideation/speculative design, which led to development of an interactive prototype.

Empathize. Empathy for potential users began with interviews conducted by the first author to investigate disclosure and support seeking after pregnancy loss as discussed in prior work [2]. Participants were 27 women who had experienced pregnancy loss within two years and reported using social media in daily life. This interview study directly informed requirements and experimental prototype designs. Overall, knowing similar others who had experienced pregnancy loss was an important need for participants. Often, when they disclosed online or offline that they experienced a pregnancy loss, others reciprocated with their own loss experiences. However, the initial disclosure was often necessary to prompt further disclosures in the network. When reciprocal disclosures happened, they were often helpful in the healing process, made participants feel less alone and isolated or more “normal.”

The interview analysis generated support for a concept that Andalibi and Forte term “Network-Level Reciprocal Disclosure” (NLRD) [2], which we used to inform design explorations in the ideation phase. NLRD refers to

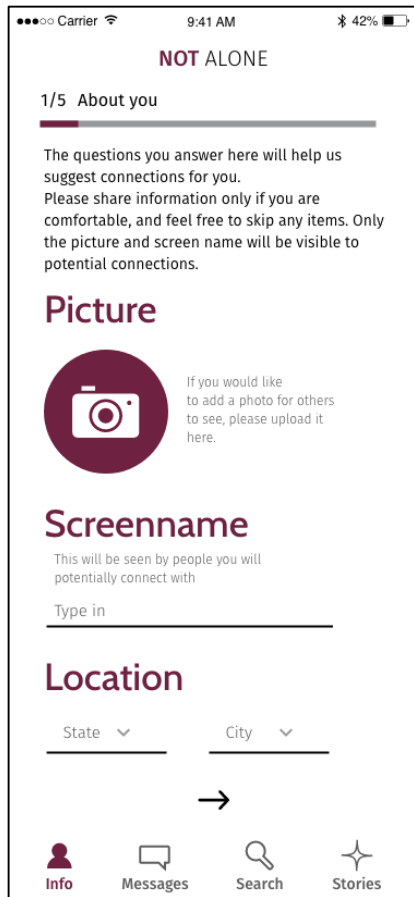


Figure 1. One of the several screens where users can enter their personal information. Users can choose their screen name and picture. Other fields include age, gender, race and ethnicity, sexual orientation, religion, pregnancy history, etc.

disclosures on social media inspired by observing others’ disclosures but not directly in response to a specific individual, generally as a result of reduced perception of stigma. Perceptions of similarity with one’s network (e.g., homophily), options for anonymity and identifiability, and self-disclosure by talking about one’s experience and engaging with others’ disclosures are concepts related to NLRD. We examine NLRD as an example of how findings from qualitative studies can produce theoretical constructions that can inform design-based experimentation and research.

Define, ideate, and speculate. We defined the problem space and goals with the question, “How might we design technology that helps those experiencing pregnancy loss to find the support they need?” Components of this need included: identifying similar others who had experienced loss, reducing perception of stigma and rarity, and empowering safe disclosures and supportive interactions.

Speculation: augmented reality (AR). Initial ideation included a speculative AR design that discounted technological feasibility and social norms and sparked discussions related to privacy, anonymity, and the role of embodiment in self-presentation. We envisioned an AR system that would surface pregnancy loss as a common and visible identity facet. Everyday users of AR glasses would use a location-based filter to reveal invisible identity characteristics of the people around them to identify potential sympathetic others. For example, if a user wants to reveal the prevalence of pregnancy loss in the first trimester, they set their filters to see this identity feature of the people around them, either as a label or other user-defined visual augmentation. To address loss of information control, we imagine permissions systems could be used to

restrict use of specific filters to those who themselves possess those identity characteristics and choose make themselves visible. Additional functionality could help users remember found connections, identify geographic “sympathy” zones where sympathetic others are likely to be encountered, or use a beacon to reach out to the similar strangers around them in a moment of need. This speculative design almost certainly violates expectations of privacy and safety that may help facilitate disclosure of stigmatized identity facets, yet it provides a canvas for thinking about the relationship between stigma and concealment. Moving forward, we imagined a system that creates porous boundaries between one’s articulated network on social media sites and a larger potential support network: *Not Alone*.

Prototype Design: *Not Alone*

Our prototype design is a mobile app called *Not Alone* that helps users find others with similar experiences within and outside of their existing social media connections. Users can choose to connect *Not Alone* to one or more social media accounts or can search for connections outside these networks. The interface consists of search and messaging functions that facilitate reaching out to others who have entered identity characteristics of interest. Users can also share stories and engage with others’ stories. We have created detailed prototypes of *Not Alone*, which embodies concepts that facilitate NLRD: Perceptions of similarity (e.g., homophily), levels of anonymity and identifiability, and self-disclosure by talking about one’s experience and engaging with others’ disclosures. We will use it in future studies as a technology probe for exploring NLRD as a design principle and to better understand people’s reactions to reciprocal sharing of stigmatized information (e.g., depression, illness, loss).

Sample Interview Data

Quote 1: *It's been helpful in general just to see that someone else, my age, that I knew experienced a loss and has been brave enough to talk about it.* (woman, 28)

Quote 2: *It's easier when there's strength in numbers, but if you don't know for certain that there's people out there who have been through it, it's a very vulnerable thing to put yourself out there by yourself and hope that someone reads it and responds and says, "Hey, me too."* (woman, 34)

Quote 3: *When you're on the anonymous forum, you're just there talking about the miscarriage or the pregnancy. It doesn't give you the sense of the wholeness of their life. When you know somebody, I think that might be more comforting to know that it's a piece that fits into their life, but it doesn't necessarily define their life.* (woman, 37)

Personal information. Users can upload a profile picture and enter screen names, location, age, gender, race and ethnicity, sexual orientation, religion, and relationship status. They can also share details such as current number of children, number of pregnancy losses, medical condition(s), and more (Figure 1). Interviews [2] suggested these information pieces likely matter to people when they consider seeking support from others after pregnancy loss. We will evaluate which of these features are important to people at a larger scale, why, and what we may be missing.

Search connections and connect. Once users enter their own information, they can search for connections in social media platforms they already use or simply search all *Not Alone* users, and can filter potential connections based on the aforementioned personal information fields. Two concepts guided our choices with the search: homophily and degree of anonymity.

Homophily. This refers to the extent to which individuals have similar attributes such as age, gender, wealth, beliefs, and attitudes and influences the effectiveness of online health communities [14]. Prior research emphasizes homophily's impact on *perceived empathy* in online health communities, suggesting that designs could connect those with similar health backgrounds [8]. Interviews showed that while sometimes only generic loss experience was a criterion for a helpful connection, other times people had more specific needs to enable disclosures (e.g., someone within an age range – see Quote 1 in sidebar). In order to support the development of meaningful homophilous connections, *Not Alone* search uses characteristics mentioned by interviewees. We will evaluate this concept and explore other potential relevant factors.

Anonymity and identifiability. Anonymity can be important when people want to share about experiences that are highly personal, painful, and potentially stigmatized [13]. Some of the interviewed women described how disclosures in anonymous online spaces helped them feel safe enough to eventually disclose their loss and grief on Facebook [2]. NLRD may be enhanced by the potential to signal about an experience to members of one's social network without identifying oneself and creates a context in which others may feel comfortable doing the same. For example, knowing that five friends have experienced a pregnancy loss may be helpful for someone enduring the grief of a pregnancy loss and may allow them to begin the process of sharing, seeking support, and recovery, but finding the "strength in numbers" described in Quote 2 may require a degree of anonymity. In *Not Alone*, users can remain pseudonymous to their known connections if they wish. Still, the power of knowing a friend or acquaintance had experienced a loss was mentioned more than once, as illustrated in Quote 3. We are interested in discovering when, how, to whom, and why *Not Alone* users choose to reveal their identities.

Self-expression via stories and reactions. Sharing personal narratives in dedicated or ad-hoc online support spaces and mainstream social media (e.g., Facebook) helps with meaning creation and healing in contexts like pregnancy loss [2,4]. *Not Alone* users can create stories using text and pictures with different levels of privacy. Users can view their own stories and others'. They can privately message story writers and interact with the story in several ways: like, love, hug, "I feel you", and comment. We borrowed "hug" from Scary Mommy forum design and Ahmadi et al. [1]; who

Carrier 9:41 AM 42%

NOT ALONE

Search my connections within:
(You can choose multiple options)

f p i t t

Location:

State City

Age range:

18 100

Gender:

Woman Custom

Sexual Orientation:

Heterosexual Homosexual

Bisexual Custom

Religion:

Christian Muslim

Buddhist Jewish

Atheist Agnostic

Custom

Relationship Status:

Single In a monogamous relationship

In a polyamorous relationship Married

Separated Engaged

Have children:

Yes No

Have experienced multiple pregnancy losses:

Yes No

Period(s) in which the loss(es) happened:

1st trimester 2nd trimester

3rd trimester Live birth

Have a child prior to pregnancy loss(es)

Yes No

Have medical conditions that may have impacted the pregnancy experience:

Yes No

See my potential connections

Info Messages Search Stories

Carrier 9:41 AM 42%

NOT ALONE

OTHERS' STORIES MY STORIES

EVERYONE ON NOT ALONE		
Ente2b	You are not alone	Aug 30th
BB1965	My family's reactions	Aug 11th
EmmaRele	One year later	Aug 5th
Ashley2	My loss experience	Aug 1st
xAnGe	My family's reactions	Jul 31st
EmmaRele	One year later	Jul 25th
GloRia	My loss experience	Jul 23rd

Info Messages Search Stories

Figure 2. The two images on the left partially depict how users can search for connections based on the criteria that matters to them. The third image shows how users can see others' stories (i.e., everyone's, saved connections', their own). The image below shows how users can interact with other's stories. These and other screens (not depicted due to space constraints) are designed to uncover behaviors, reactions, preferences, and needs at a large scale and details are not finalized.



suggest paralinguistic digital affordances like “hugs” are a useful alternative to “likes” for communicating support. We experiment with “I feel you” to see if it communicates brief reciprocity. “Like,” “love,” and comments are common on social media platforms such as Facebook. We will explore the roles stories play on *Not Alone*, for example with respect to helping with the initiation of private messages, assessing whether a connection would be helpful, or feeling less alone when people connect *Not Alone* to their existing networks and when they do not. Future work could also explore how to combat potential unwanted use such as trolling.

Conclusion and Future Directions

By focusing on an important reproductive health experience that is underexplored and with the potential and ultimate goal of benefiting many people, we have

started to design for helpful social support, sensitive self-disclosures, and reduced stigma. Grounded in in-depth interviews and design explorations, we have shown how findings from qualitative investigations can produce theoretical constructs (e.g., NLRD) that can inform design-based experimentation and research. The resulting *Not Alone* prototype embodies concepts that facilitate NLRD: homophily, anonymity levels, and self-disclosure by talking about one's experience and engaging with others' disclosures. These concepts help meet the needs interviews identified: identifying similar others who had experienced loss, reducing perception of stigma and rarity, and empowering safe disclosures and supportive interactions. Our next step is to evaluate these concepts and designs with potential users by using *Not Alone* as a technology probe for exploring NLRD as a design principle.

Acknowledgments

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