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Keywords

Doula; cell phone technology; smartphone app; storytelling; information design; maternal and child health; eHealth; mobile health care; developing countries

Abstract

Postpartum depression (PPD) affects approximately 10-15% of women worldwide. Postpartum doulas provide mothers and their families with non-medical emotional and practical support through the post-birth (postpartum) period. This paper discusses the importance of storytelling in the design and use of a cell phone application developed in the USA for postpartum doulas to help mothers identify PPD symptoms, break their sense of isolation, and get help. This paper then explores how the use of this cell phone app, with its focus on storytelling, could be adapted for use with women in developing countries.

Article

Introduction

Approximately 10-15% of mothers worldwide suffer from postpartum depression (PPD) with some evidence that its incidence could be even higher (Almond, 2009; Chandran 2002). One of the risk factors for PPD is lack of social support, which is not having sufficient or adequate help in integrating a new baby into the family (Beeber & Canuso, 2005). The lack of social support can be aggravated by other risk factors including low-income or poverty and a lack of education. In modern industrialized societies, where the birth experience has become more medicalized, and where people are often separated from family and close friends, doulas – non-medical individuals who provide emotional, physical, and tangible support for women during labor, birth, and the period following birth (called postpartum) – can provide this kind of supportive care that may otherwise be missing. Postpartum doulas specifically can help a new mother sort out her postpartum needs, gather additional support to address those needs, and create networks for support. In a study that documented the "domains of postpartum doula care" (McComish & Visger, 2009), "emotional support emerged as the most frequently used domain of care and focused on the mother. The predominant feature of this domain was client-directed discussion with the doula actively listening to the mother and her needs… the doula would encourage her to express feelings, process her birth story, and take care of herself by building support networks" (McComish & Visger, 2009, p. 151). Thus conversational storytelling – the give and take of talking, listening and responding to feelings, thoughts, and experiences – is at the heart of the doula/mother relationship and of the nature of social support in general. It is also at the heart of the design of our mobile-based materials for postpartum doulas to use with their clients to help reduce the effects of PPD by recognizing the symptoms and getting treatment early. This article will discuss the design of our cell phone app and how the app could be adapted for use in maternal and child health programs of developing countries to help postpartum mothers tell their stories and minimize the effects of PPD in their lives.

Stories and Themes

The nurturing, trusting relationship between doula and mother prompted the research team to think that doulas may be one of the best resources for helping address PPD in new mothers, especially among low-income women in Detroit. PPD often goes undetected or untreated because mothers do not know the symptoms for PPD, associate "depression" with mental illness and do not want to be labeled as "crazy," or do not have the resources or access to resources to get help. We conducted focus groups with doula trainers, doulas, and mothers regarding postpartum care. Their stories – especially their emotional,

intellectual, and physical experiences regarding anxiety and depression, and their insights into those experiences – were the foundation for the verbal content and visual design of our materials. Two major, and inter-related themes arose from our discussions. The first theme was, "How do I [the mother] feel?" As one doula trainer put it, "it all goes back to where the mother is at that moment." That is, how a mother feels at any given time. She may feel differently from day to day or even hour-to-hour, but the point is to address how she feels – and her needs – at the moment. The second theme was "Who can I talk to?" Having the opportunity to express her feelings, get advice, and be taken seriously validates the way a mother feels, breaks her sense of isolation, and puts her on track to cope with her feelings and "go on." In a worldwide study of PPD, the overwhelming answer of women to the question of how to treat PPD was to "be able to talk with someone" (Oates et al, p. s14).

Two additional themes from the focus groups influenced the design of the app: flexibility and interactivity. The design needed to be flexible in responding to the emotional changes and needs that a mother could feel. And the design needed to be interactive so that it provides a format that allows for exchanges between doula and mother, and that a mother could easily work with it on her own. The doula would initially take the mother through the app and help her decide whom to contact for what purpose (developing her network of support). In this way, the doula could explain the symptoms, annotate the range of social agency resources available, and help the mother decide which tasks she needs help with during the postpartum period. The app is then ready for the mother when she needs it, and she knows how to edit her list of contacts and tasks as needed.

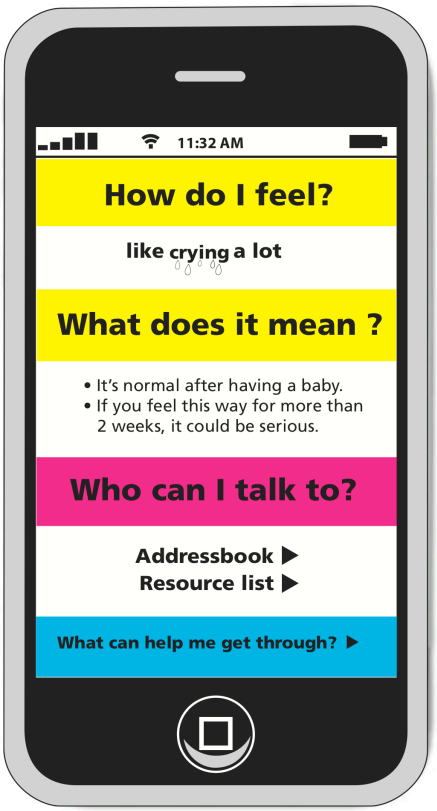
Thus, storytelling is central to the design of the app and to its use. Storytelling as a research and design methodology (Moldenhauer, 2008) informs the question-and-answer structure of the navigational sequence, and is the platform for the interaction between doula and mother. The app personalizes the mother's experiences and personalizes the information, advice, and support provided by the doula. In this dialogue, storytelling enables the give- and- take of information sharing at a personal level that builds a trusting relationship between doula and mother. The doula is then able to provide support for the mother's needs based on how the mother is feeling (Beeber & Canuso, 2005).

It is important to note that the doula cell phone app does not use the term PPD but rather use terms that the mothers used to describe their feelings. We found that mothers did not like the term "postpartum depression" because of its association with – and stigma of – mental illness and because they often did not know what it really was. Often their first thought about PPD was that of postpartum psychosis, the extreme end of PPD – stories of women killing their babies or harming themselves. They often did not associate their feelings of crying a lot, sadness, not wanting to leave the house, being overly protective of their babies, anxiety, or being uninterested in doing day-to-day things as possible signs of PPD. They just knew that "something wasn't right."

The Doula Cell Phone App

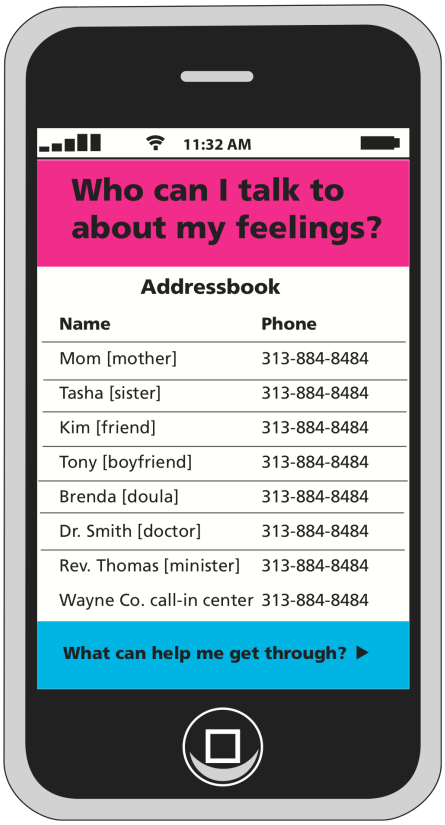
Doula cell phone app: Screen 1

The cell phone app begins with the screen that says, "How do I feel?" It is the starting point for the app; everything else in the app responds to that question. The list of "feelings" runs from common feelings that mothers may experience during the first couple of weeks of postpartum – feelings often associated with the "baby blues" – to serious symptoms of PPD. The naming of the feelings came from the words used by the mothers during the focus groups to describe their feelings. Each feeling was designed as a typographic icon – a visual interpretation of the description – that works as a mnemonic device and, through its animated quality, picks up on the emotional content of the words. The typographic icon modifies the abstraction of the printed word to make the description of the feeling more tangible and, thus, more personal.

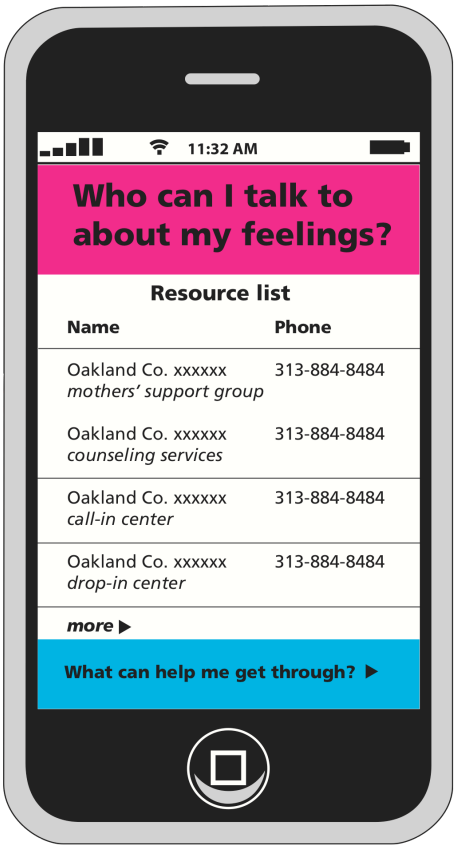


Doula cell phone app: Screen 2

The second screen shows only the implications for the "feeling" selected initially by the mother followed by "What does it mean?" "Who can I talk to?" and "What can help me get through?" The phrase "What does it mean?" serves as a way to help mothers learn the symptoms of PPD, know the difference between signs of "baby blues" and PPD. It serves as an initial gauge to the severity of their experiences, as well as to help them figure out whom to call. Navigation buttons to the mother's address book with a list of her contacts and their phone numbers or to an extensive resource list of agencies and social services and their phone numbers are under "Who can I talk to?" The mother can choose to import any of these agency numbers into her address book. "What can help me get through?" is a list of activities and tasks that the mother can annotate with the names of people she can call to help her with those specific items. She can also add items to fit her particular needs. "What can help me get through?" also shows up at the bottom of the screens for her address book and the list of resources.

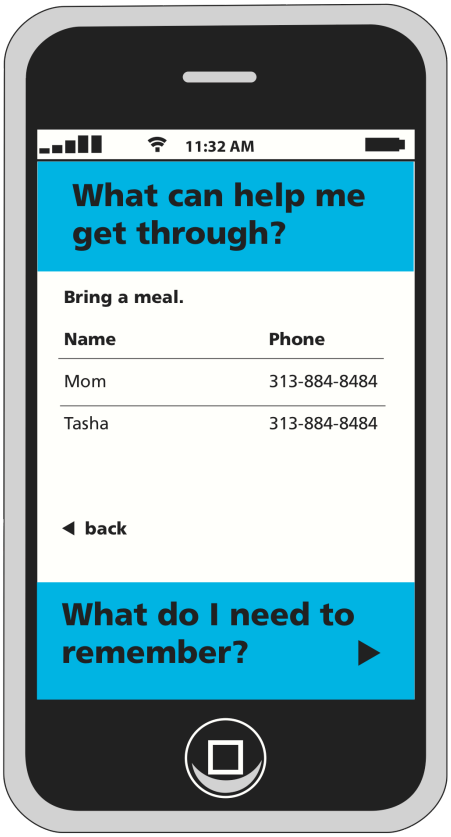


Doula cell phone app: Screen 3

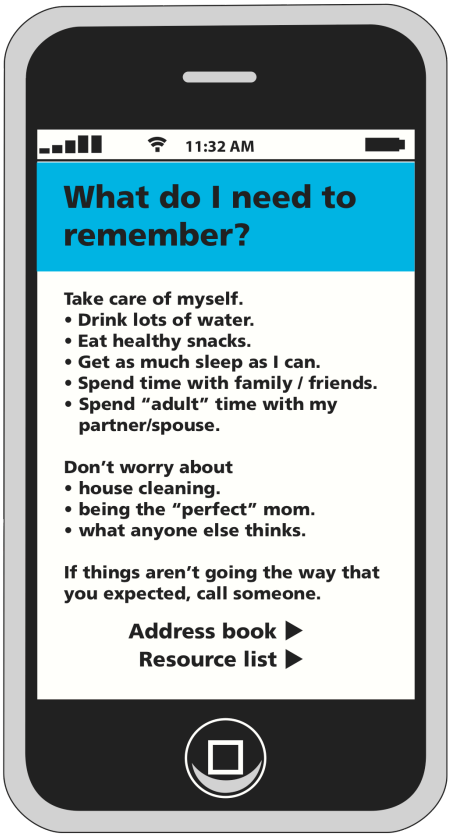


Doula cell phone app: Screen 4

Doula cell phone app: Screen 5



Doula cell phone app: Screen 6



Doula cell phone app: Screen 7

The key to using this app is setting up the names and numbers in the mother's contact list – who to talk to and who to call for help with such things as grocery shopping and looking after her children while she runs errands. The doula would help the mother set up the app, discuss various symptoms (feelings) with the mother, help her decide whom she can talk to – especially advise her on the service agencies – and what kinds of tasks would relieve her of some responsibilities, and increase her time for rest and restoration while adjusting to life with a newborn. The mother's story is central to how she will shape the specifics of the app to her needs and contacts. And, setting up the app will facilitate storytelling between doula and mother, allowing the doula to tell the mother about PPD and its symptoms, set up the contacts for the mother to use if she feels those symptoms. Support received from the doula during this process may have the potential to shorten an episode of PPD or at least lessen its effects. If a mother uses this app when she feels any of these symptoms, she is may be more likely to get the help she needs, and, thus, feel "better" sooner. The app is designed to quickly connect a mother to her support network, to help her figure out her needs and who to contact. The first screen is the point of entry to the app and does not waste time getting to the heart the matter – how a mother is feeling at that moment. The second screen is the point from which the mother can get access to the people who can help her at that moment. With three clicks, she can be talking with someone.

While the app is intended for use on a "smart phone" such as the iPhone, the information can be adjusted to a non-smart phone simply by setting up a "my support" contact list with names and numbers, and a "help with tasks" list, annotating the listings as much as is possible through the cell phone brand and provider.

Adapting the Doula Cell Phone App to Developing Countries

Adapting our cell phone doula PPD app to the needs of new mothers in developing countries could address an important gap in their maternal and child health programs. PPD is not just a phenomenon of industrialized Western societies. The experience of PPD is worldwide but is often thought of as something that is a part of motherhood and that women just have to be tough and get through it (Ramachanran et al, 2010; Chandran et al, 2002). PPD (and maternal mental health in general) is often overlooked by many public health programs in developing countries, which usually concentrate on preventing maternal death during childbirth, child nutrition, and disease prevention. Even in developed countries that provide good and readily available medical coverage for all its citizens, such as Chile, maternal and child care includes little care for mental health and even less information or follow-up about PPD (Rojas et al, 2007). PPD is not "on the radar" of health initiatives of many developing countries because of social customs or because the sheer physical act of survival of mother and child in the face of rampant disease and scarce medical resources is a hard enough task. Yet there are studies that demonstrate that addressing the mental health of a mother, specifically regarding PPD, helps increase the likelihood that the child will survive and thrive (Beeber et al, 2004).

Two studies looked at PPD in India, one among the poor in the city of Goa (Patel et al, 2002) and one in a rural area of Tamil Nadu province near the town of Vellore (Chandran et al, 2002). The Goa study concluded that "economic deprivation and poor marital relationships were important risk factors" for PPD, (Patel et al, 2002, p.46) as was gender-bias (wanting a boy baby but giving birth to a girl), which is a common risk factor in societies that value male children over female children. "The implications of the findings of this study for policy and practice is that mental health must be integrated into maternal health care in low-income countries," and that "improving marital communication and reducing gender preference should be important components of any such interventions" (Patel et al, 2002, p.46).

In the Tamil Nadu study of women recruited from village antenatal clinics, "low income, birth of a daughter when a son was desired, relationship difficulties with mother-in-law and parents, adverse life events during pregnancy and lack of physical help were risk factors for the onset of post-partum depression" (Chandran et al, 2002, p. 503). The study found that "both antepartum and post-partum depression are significant public health problems in terms of frequency" (Chandran et al, 2002, p.502). Most significantly, " none of these mothers sought help for their symptoms, although many were functionally impaired and were barely coping with their responsibilities. One possible reason for this low utilization of health services could be the belief held by mothers, family members and even the area health workers that this state was a normal part of pregnancy and the post-partum period, or a temporary maladjustment that would remit. A screening programme to detect post-partum depression and identify mothers in need of help certainly seems warranted" (Chandran et al, 2002 p. 502). The study concludes that,

> antepartum and post-partum depression are common, heterogeneous and largely undetected public health problems. Screening for depression in the last trimester and in the post-partum period… is a service that needs to be incorporated into maternal and child health programmes. There is a paucity of research from developing countries addressing the consequences of post-partum depression on the cognitive, emotional and physical health of infants born to women with this disorder. Research aimed at measures to prevent post-partum depression and to elucidate what

> treatments work best – and are practical in low-income countries – is also urgently required (Chandran et al, 2002, pp. 503-504).

As with the US doulas and the cell phone app, the interaction and storytelling between healthcare worker and mother should be at the heart of adapting the app to developing countries. That would mean adjusting the use of the cell phone app to the cultural and communication contexts of each country. The paper, "Mobile-izing Health Workers in Rural India," (Ramachandran et al, 2010) describes the use of mobile phones by village ASHAs in Orissa. (An ASHA is an Accredited Social Health Activist; the Indian National Rural Health Mission mandates that one woman from each village serve as an ASHA to promote health services among pregnant women.) ASHAs used the phones to show their clients seven short videos (each less than one minute long) on "danger signs that could occur during pregnancy and immediate actions to take" and on the importance of taking iron pills during pregnancy. The researchers "coached them [ASHAs] on pausing, asking questions and ensuring that their clients understood" (Ramachandran et al, 2010, p. 1894). One example of an ASHA visit describes the ASHA "pausing and repeating the points shown in the video" (Ramachandran et al, 2010, p. 1894) when the mother-in-law and the husband joined the conversation with the ASHA and the pregnant woman. The ASHAs also made videos of their interaction with clients, and in many of them "pregnant women related their experiences" (Ramachandran et al, 2010, p. 1895) of pregnancy and spoke of their appreciation for what the ASHA has done for them.

An ASHA using a cell phone with a family in Orissa, India

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The doula app could, for example, be adapted for use in India with an ASHA or other health care workers. The Orissa study (Ramachandran et al, 2010), though not about PPD per se, recognizes the vital importance of how the design of the media and the structuring (i.e., pacing, sequencing) of the health information can encourage conversational storytelling between healthcare worker and client in order to personalize the information and make it meaningful to that individual. This is exactly the function of our doula app. The Orissa study also recommends an interface that "eliminates the need to navigate through heavily text-based menus;" our doula app uses typographic icons and short, jargon-free phrases. If the mother had a "smart" cell phone, the healthcare worker could show the mother the information on the phone, and help her set up her contact list and list of tasks. The healthcare worker could also show her websites where she could listen to other women tell their experiences, and record her own account of PPD. If the mother's cell phone is not a smart phone, then a contact list of people with whom she could talk about her feelings or ask for help with chores could be created. If the mother did not have a cell phone, the healthcare worker could bring her own smart phone to show videos and visit websites as a means to begin conversations and help the mother feel less isolated. In countries where a cell phone is shared among the people of the village, and each person has a SIM card containing his/her contacts, a mother could simply insert her SIM card – complete with her contact list – into the cell phone body when it was her time to use the phone. The main point of the app and use of a cell phone is to connect a mother to others, to be able to talk with someone, and share the story of how she is feeling, and break her sense of isolation and helplessness. A study (Oates et al, 2004) that found PPD is experienced worldwide regardless of culture. The authors concluded that for women suffering from PPD, "social support from family (and in Europe friends), practical and emotional support from partners and having somebody to talk to were universally expressed as the remedy for postnatal depression" (Oates et al, 2004, p. s13).

An ASHA using a cell phone with a woman in Orissa, India
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Issues in Adapting the Doula Cell Phone App for Developing Countries

While the use of cell phones to help reduce or prevent PPD could be very helpful, some important infrastructure and cultural issues need to be addressed. The biggest problem for the Orissa study (Ramachandran et al, 2010) was the amount of training needed for the AHSAs to use the device and the software effectively. This will continue to be a major issue when depending on local health care workers with low-literacy skills. The study also recognized the constraints of providing care to women within more traditional societies with strong social and familial structures that define women's roles and limit their personal interactions. The authors stressed the need to address those structures when employing new technologies and communicating new information.

The study of cell phone use by the ASHAs of India (Ramachandran et al, 2010), clearly recognized that just the availability of a cell phone was not enough to make an impact on the lives of pregnant women in a village. The researchers realized that while "interventions often focus on immediate affordances of ICTs [information and communication technologies], like information or knowledge transfer… ICTs for development can instead directly address barriers to change… to *persuade* targets of an intervention in favor of change, and *motivate* key community members who act as agents of change" (Ramachandran et al, 2010, p.1889). Researchers therefore addressed the power dynamics of the village – such as the low status of women in general, the dominance of the mother-in-law and the husband in the daily life and decision-making of young married women, and the influence of the "headman" of the village whose support (or lack of) could make or break the efforts of any health worker – and the inadequate level of consultation/education provided by the ASHAs. To motivate the headman and the ASHAs, both made brief testimonial videos: one by the headman stating his support of the ASHAs and others recorded by the ASHAs as their clients stated the value of their ASHA sessions. The approval of the headman for the work of the ASHAs helped persuade a woman and her husband's family of the value of the information presented by the ASHAs. With this endorsement and coaching by the researchers on how to present the videos and elicit interaction with the woman and her family, the ASHAs – through the storytelling exchange – could more effectively persuade women (and their families) of the importance of the information.

The United Nations Foundation and Vodafone Foundation Technology Partnership in collaboration with the mHealth Alliance published a discussion paper (Ranck, 2011) that clearly lays out the technological, logistical, and bureaucratic problems that interfere with providing health care in developing countries via wireless networks and mobile devices. The incompatibility of software used by different agencies, the fragmentation of data flow (that is, the lack of coordination of data collection and management between local and national levels), complexity of supply chains, need for adequately trained and qualified health care workers, and lack of governmental infrastructure are some of the difficulties described in the paper.

Conclusion

While the United Nations Foundation's discussion paper presents the obstacles to efficient wireless health services, it also contains recommendations for maximizing the promise of mobile devices to improve health care in developing countries. Two of the paper's recommendations for maximizing the promise of mobile devices to improve health care in developing countries were at work in the development of our doula cell phone app: "design thinking for data collection" and "building systems from the ground up" (Ranck, 2011, p.45). "Insights taken from the design field could be useful in the context of eHealth systems…Designers might be able to develop creative 'work arounds' or forms more friendly to health workers or platforms that are more clearly integrated into workflows and clinical contexts… A sound design approach begins with the end users and then structures incentives and rewards for collecting and transmitting accurate data – for making good decisions at all levels" (Ranck, 2011, p.45). It is this kind of collaborative engagement that

will be needed to adapt our app and address the cultural and technological realities of women suffering from PPD in developing countries. Decreasing the incidence and impact of PPD can make a difference in the well-being of women and children around the world – and mobile cell phone technology can help make that happen.

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