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Giving Voice to Parents in the Development of the Preemie Prep for Parents (P3) Mobile App

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Abstract

Background:

Parents at risk for preterm birth frequently receive prematurity education when the mother is hospitalized for premature labor. Parental ability to learn and consider the information is limited because of the stress of the hospitalization. A promising approach is dissemination of information to at-risk parents before the birth hospitalization.

Purpose:

This article describes formative research used to develop smartphone-based prematurity education app for parents at-risk for preterm birth.

Methods:

Stakeholders were parents with a prior preterm birth. Using stakeholder meeting transcripts, constant comparative analysis was used to reflect upon the parental voice.

Results:

The parents named the app, *Preemie Prep for Parents (P3)*. Parent perspectives revealed desire for information in the following 5 categories. (1) *Power in knowledge and control*: parents want autonomy when learning information that may influence medical decision-making. (2) *Content and framing of information*: they desire information from a trusted resource that helps promote prenatal health and provides neonatal intensive care information. (3) *Displaying content*: parents want personalization, push notifications, photographs displaying fetal development, and easy-to-understand statistics. (4) *Providing information without causing harm*: they desire non-value-laden information, and they do not support “gamifying” the app to enhance utilization. (5) *Decision making*: parents want information that would benefit their decision making without assuming that parents have a certain outlook on life or particular values.

Implications for Practice:

These findings support the need for the P3 App to aid in decision making when parents experience preterm birth.

Implications for Research:

The findings highlight the need to study the effects of smartphone-based prematurity education on medical decision-making.

BACKGROUND, SIGNIFICANCE, AND LITERATURE REVIEW

Preterm birth (<37 weeks' gestational age) affects 1 in every 10 children born in the United States.¹ Many mothers who deliver prematurely have risk factors for preterm birth diagnosed earlier in their pregnancies. For parents at risk for preterm birth, antenatal consultation about infant health outcomes frequently occurs while the mother is in labor.² In these instances, parents usually experience significant anxiety, feelings of being overwhelmed, and utter exhaustion.³ Consequently, the parents' ability to understand and utilize information to

make medical decisions may be decreased because of the physical and emotional aspects associated with the birthing process.^{4,5} Research findings suggest that while involving parents in complex medical decision-making is best practice, mothers at risk for preterm birth generally do not receive information at a time when they can utilize it to make informed medical decisions that are consistent with their values and beliefs.⁶ Consultation with clinicians during the prenatal period using mobile health (mHealth) technology may enhance the parents' ability to understand and apply complex medical information in the event of preterm labor and delivery.

Educational information provided to parents through mHealth technology is on the rise.⁷ While mHealth technology is touted as a convenient and quick method to deliver information to targeted groups, evidence of its effectiveness is just beginning to emerge. Delivering information through mHealth technology during prenatal care may provide a flexible and reliable means of educating parents about prematurity. Davis and colleagues⁷ provide a list of recommendations in the design and development of mHealth apps that may promote their effectiveness. These recommendations are as follows: (1) inclusion of the individuals who represent the population for which the app is intended during the early development phases; (2) consideration of health literacy principles and strategies to enhance overall understanding of the content; and (3) inclusion of a family-centered, personalized approach when designing apps.

Formative research is appropriate for mHealth intervention development as it is grounded in understanding and empathy for the affected population.⁸ The purpose of this article is to describe the formative research process used to develop and refine a smartphone-based personalized prenatal educational app designed to be given to expectant mothers who are at risk for preterm birth but not yet in labor. Specifically, we asked parents who experienced preterm birth to identify information that would be helpful for parents at risk for preterm birth.

What This Study Adds

- Multimedia mobile health technology offers the opportunity to enhance antenatal education.
- Because of the unique properties of this medium, the educational materials require thoughtful design.
- This study provides the parental perspective regarding the design of a mobile app to enhance antenatal preterm birth education.

METHODS

Design

Including diverse stakeholders is key to app development, and stakeholders may include designers, developers, users, and customers. Three types of stakeholder groups (early-phase development team of perinatal experts, parents of preterm infants, and the research team) participated in the development and design of the P3 App. This article focuses on the contributions of parent stakeholders as they represent future users of the app. Parent stakeholder group meetings were convened⁸ to develop content and provide preliminary feedback on the P3 App.

Qualitative analysis⁹ was used to incorporate parents' thoughts, reactions, and comments in the development of the P3 App. Five stakeholder group meetings were conducted to allow parents who had a prior preterm birth to share their experiences and provide input on the content of the P3 mHealth App. The stakeholder group meetings were held between May and September 2015. The first group meeting consisted of a semistructured interview designed to promote group discussion and cohesiveness. Between meetings 1 and 2, parent participants were sent "preparatory questions" to reflect upon. Meetings 2 and 3 were characterized by identifying content for and organization of the app. Meetings 4 and 5 were devoted to content and app review (see Table 1).

TABLE 1. - Topics, Questions, and Probes—Stakeholder Meetings

Group	General Topics, Questions With Probes
Questions asked at stakeholder group 1	Introduce yourself and tell us about your family and the experience you had with the premature birth of your child. What information would you have liked to know before you presented in premature labor?
Preparatory questions for stakeholder group 2	Think about your favorite app. What features of the app were most appealing? Tell us about how you might use the app to learn about certain topics. Would you like if the app has 3- to 5-min videos with a “mini-consult” with an OB or NICU physician? If there were 2-3 words to brand the app what might they be? Should we “gamify” the app or make it appealing? If so, how? How would you use push notifications? Which notifications would you be most likely to use? Reminders? Informative? What other considerations can you think of when receiving push notifications? Frequency of the notifications (1× per week); time of day they are received; integration of the notifications with physician visits. What would be the best way to get feedback from parents about what worked well and what could have worked better?
Topics discussed during stakeholder group 2	Push notifications and information about decision making
Topics discussed during stakeholder group 3	Push notifications, bookmarking, levels of NICU care, terms, and language
Topics discussed during stakeholder group 4	Use of images and videos, terms and language, use of audio and video
Topics discussed during stakeholder group 5	Critique of a draft of the Premie Prep for Parents (P3) App

Abbreviations: NICU, neonatal intensive care unit; OB, obstetric.

Sample

The parent participants were recruited from an academic Children's Hospital with an active March of Dimes parent group in the Midwest. The parent participants were predominantly White (100%) and their children were born between the gestational ages of 23 to 28 weeks. The children were between the ages of 1 and 10 years at the time of the stakeholder meetings. A total of 5 stakeholder group meetings (of 3-6 parents) were held on Sunday afternoons at a research building close to the hospital. This location was chosen for the convenience of parents. The building had free parking, was easily accessible, and was not otherwise occupied on Sundays. Eligibility criteria included having a child or children (a) born preterm and (b) who was/were hospitalized in the neonatal intensive care unit (NICU). All parents had to be (c) older than 18 years and (d) fluent in English. Parents received an incentive to offset childcare costs, mileage, and additional cost incurred for participation.

In addition, a research team (research stakeholders) made up of a parent advocate, 3 computer software engineers, 2 neonatologists, and an occupational therapist was also present during the group discussions. Consistent with best practice in mHealth app development, we partnered with early design phase stakeholders (obstetricians, nurses, and pediatric residents) to create an interprofessional team with expertise in neonatal and prenatal care.⁷

Procedure

The study center institutional review board approved the study protocol (#PRO00023645). Oral and written consent to participate in both stakeholder groups (parents and professionals) was obtained immediately before the first stakeholder group meeting. All of the stakeholder group meetings were audio recorded, and the recordings were transcribed verbatim. All participants were assigned pseudonyms and were assured their identities would remain confidential. They were informed that only the approved researchers would have access to identifying information (such as last names) and would be able to use the digital recordings and transcripts for research and dissemination purposes. The participants were assured that no identifying information would appear on any tapes, transcripts, or summaries.

Three members of the research team (2 neonatologists and 1 occupational therapist) facilitated the groups. Researchers followed a semistructured, flexible interview guide informed by the study aims (see Table 1). Each stakeholder group meeting began with a brief check-in, followed by questions regarding app content and design. The stakeholder group meeting facilitator began the first group with a question about the parents' experiences with labor and delivery. This was done so that the participants felt a sense of cohesion due to the sensitive nature of the topic. The stakeholder group meetings lasted about 90 minutes and were characterized by a lively discussion with some debate. The parents seemed genuinely appreciative and willing to share their stories. They offered support to each other, and there was a sense of camaraderie and a willingness to openly share thoughts and opinions.

Data Analysis

The digitally recorded stakeholder group meetings were shared with an approved transcriber, who typed verbatim all of the comments. The transcribed documents were reviewed for clarity and accuracy and subsequently analyzed using the qualitative methodological approach of content analysis. Constant comparative analysis was used to help the research analysis team better identify categories related to the parents' experiences and perceptions that contributed to the development of the app.

To complete the analysis, 2 members of the original team (1 neonatologist and 1 occupational therapist) and 3 other individuals (1 neonatologist and medical ethicist, 1 neonatal fellow, and 1 research assistant) met to review the transcripts. Respective categories were identified regarding stakeholder perspectives about the type of information that would be beneficial to the design of the app. Specifically, we read the transcripts independently and identified key concepts for discussion. We met consistently (every 1-2 weeks) over a period of 3 months to review the key categories. The meetings were used to cross-check biases of the research team. For example, there was significant discussion about how to present the content in a realistic but hopeful manner. The coinvestigator organized the quotes and categories into a spreadsheet, and the team reviewed and analyzed the appropriateness of the categories, given individual perspectives. In addition, a research assistant developed a table that included stakeholder member suggestions and whether the information was included in the P3 App. These suggestions are woven into the analysis.

Strategies to Achieve Trustworthiness

We employed strategies to ensure aspects of trustworthiness (credibility) of the research team members and the findings. During the stakeholder group meeting process, the research team members included 2 neonatologists, 1 occupational therapist, and at least 1 software engineer, who were present at all group meetings. The research team shared responsibility for pursuing lines of discussion and asking probing questions as appropriate. Each stakeholder group meeting was followed by a debriefing session with the neonatologists and the occupational therapist to reflect upon the discussion, to ensure that key concepts were included in the app development, and to plan for the next stakeholder meeting.

Trustworthiness of the findings was achieved as each member of the research analysis team coded the transcripts independently, took notes, and then convened to compare categories and reach consensus.¹⁰ We reviewed related literature using search terms including “neonatology,” “prenatal consultation,” “preterm birth,” and “decision-making” to identify studies relevant to the topic and to integrate the literature into the discussion. During the analysis, members of the analysis team openly discussed their perspectives and biases about providing counseling to parents at risk for preterm birth. The notion that parents should make informed decisions about their child's care was viewed as paramount.

RESULTS AND DISCUSSION

Since engaging stakeholders is recommended as best practice when developing health communication materials,⁸ we included a purposive sample of 5 mothers and 1 father, all of whom had children who were born preterm (<28 weeks) and had received care in an NICU.

The results from the study revealed that parents provided information about the format and intent of the information in the following topics: (a) *power in knowledge and control or having choice*; (b) *content and framing of information*; (c) *displaying content*; (d) *providing information without causing harm*; and (e) *decision making*. The categories represent a collection of quotes that are fluent and not mutually exclusive. Parents who deliver preterm infants face medical decisions about the care of their child. Parents of infants born during the periviable period (broadly defined as 20⁰/₇ through 25⁶/₇ weeks of gestation)¹¹ are frequently confronted with choosing lifesaving measures versus palliative care. The following discussion represents the views of the parent participants about the content, the flow of information, and medical decision-making. The parents named the app, *Preemie Prep for Parents (P3) App*, and a logo (see Figure 1) was developed with parent input.

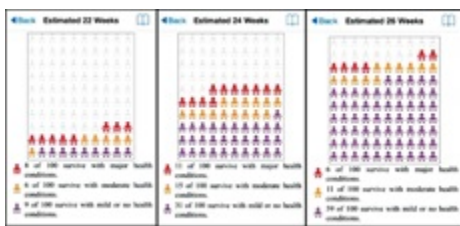


FIGURE 1: Pictograph of survival rates. This figure illustrates the number of infants who will survive with various health conditions if born at the 22nd, 24th, or 26th weeks of gestation.

Power in Knowledge and Having Control

The category of *power in knowledge and having control* refers to the parents' wishes to have access to information related to prematurity. As one parent stated, “There's power in having knowledge and feeling like you have a choice, even if you wouldn't change anything.” The parents also described a need for autonomy when learning information that may influence their medical decision-making. This sense of autonomy had a temporal component as parent participants discussed the timing and access to information. For example, the parent participants identified that having control over the flow of the information they receive was important. One parent stated:

And ... I was just overwhelmed in general, so I guess having the information to look back on would have (helped). I know they (the doctors) left us with papers and that kind of thing, but having that information just to look at on our own time when we're feeling up to, when I was feeling up to it, would be nice.

Parent participants also expressed the need to flag information and come back to it. As one parent participant commented,

You know one thing I don't know if we talked about is ... if you're looking in this app and you flag a topic you want to come back to, is there a way to do that in the app?

This is consistent with previous findings by Logsdon et al,¹² who found that many parents may not remember information provided to them and consequently return to Web sites to retrieve information when possible. In addition, these views are consistent with the findings of Rosenthal and Nolan,¹³ who identified that parents differed in their preferences about the amount of information they were provided. Specifically, they found that some parents wanted to know everything whereas other parents wanted to be spared the details. Similarly, a parent participant in our stakeholder group meeting verbalized what many parents struggle with: “And, how much (information) do you want to know or not want to know, and would you make the wrong decision (based on the information conveyed)?”

The group discussion is consistent with the recommendations published in a systematic review conducted by De Rouck and Leys,¹⁴ which found that prenatal counseling frequently does not adapt information in timing and content with respect to parental needs. They recommend that information be provided in a flexible manner. The design of the P3 App includes the ability to view information in an idiosyncratic manner or at a time when the parent is ready to read and process the content (see Table 2). This design is intended to respect parental autonomy and their desire to control the flow or timing of the information, thereby maximizing learning.

TABLE 2. - Parent Stakeholder Suggestions Incorporated Into the Premie Prep for Parents App by Category

Category	Premie Prep App Characteristics
Power in knowledge and control or having choice	Being able to bookmark items and return to the content at a later date User selects the time of day to receive push notifications The ability to flip between gestational weeks
Content and framing of information	Included comments that the father is equally important Added statements that acknowledge a lack of control; that even if the mother did everything she could, she still may deliver early Added language in push notifications that was motivating and comforting (ie, “you've made it another week and here is how your baby has developed”)
Displaying content	Utilized photographs (ultrasound scans of the infant in womb) Present statistics regarding survival rates using pictographs Personalization of push notifications to include the mother's name
Providing information without causing harm	Avoided using terms such as “challenging,” “problems,” or “scary” Limit the use of exclamation marks Did not gamify the app
Decision making	Provided information about levels of NICU care Recommended that parents tour NICUs Described resuscitation and medications Described palliative care vs medical intervention

Abbreviation: NICU, neonatal intensive care unit.

Content and Framing of Information

The importance of the actual content and framing of information was another category found in our analysis. Parents were seeking content that conveyed information about what to expect in the NICU. One stakeholder group member asked for, “Just seeing ... and knowing what those first hours (in the NICU) would be like (would be helpful).” In addition, parent participants wanted to know terms commonly used in the NICU, members of the NICU care team, parents' role in the NICU, and information that would promote health and well-being during the prenatal period. The P3 App includes this information, so parents know what to expect if they deliver early.

When discussing content, stakeholder group members unanimously agreed that information for the father and/or partner needed to be included.

The ways that dads help, and making sure that that's clear to everyone (doctors, nurses and parents)....

My husband was very torn. He didn't know where to go ... my husband didn't know what his role should be....

While the parent participants in our stakeholder group were of higher socioeconomic status and primarily white, including content for fathers during the prenatal period is viewed as best practice to prevent infant mortality in populations where health disparities in birth outcomes continue to exist.¹⁵ Second, stakeholder group members recommended presenting information that validated the emotions of expectant parents and information that was educational and positive. Parents often feel guilty if they are not able to carry an infant to term. For example, one stakeholder group member commented,

I think that guilt, that mom guilt and dad guilt, that happens the second you're pregnant.... We have to entice that guilt into this is a way to educate, and a way to boost your confidence, and a way ... to help you learn, even though it is scary and frightening and the more you kind of know you can prepare yourself a little bit for. So just little doses of the education along with the, "this is a fun time to be pregnant and this is what you should be doing and this is what baby is doing."

Our stakeholder group members' views were consistent with research findings of parents engaged in making decisions while their child was hospitalized in the NICU. On the basis of their findings, Rosenthal and Nolan¹³ and von Hauff et al¹⁶ suggested that information be provided in a hopeful, compassionate, yet realistic fashion. Communicating in this manner helps parents trust their provider and the information given. One stakeholder echoed this sentiment by saying,

Their anxiety is just through the roof, and (it's helpful to) try to get them back down to a reliable resource, such as you guys (the doctors).... That (contributes to a) trust between providers and what's really, truly sound information.

Displaying the Content

The stakeholder group members also discussed how the information should be displayed and whether certain aspects of the app could be personalized. Personalizing content may increase the sensitivity to the parents' experiences, values, and culture and is a recommended practice.¹⁶ We personalized the P3 App by having the push notifications address the mother by her name. Another method of personalization was allowing the mother to select the time of day she should receive the push notifications. An example of a push notification found in the P3 App is a general statement about fetal development with respect to gestational age. This type of information was regularly and automatically sent to the mother. Push notifications were also saved to a library, and the mother was reminded about the saved notifications. Other methods to personalize the app included the infant's gender-specific pronouns, individualized due date and count down, and the ability to add photographs of the parent's choosing.

The stakeholder group members also requested that the app include photographs illustrating fetal development. One parent participant stated, "...when I was pregnant, I had a(n) app where it showed really good pictures of the ... infant in the womb, It was ... very (helpful)."

In addition, they wanted to include the statistics regarding survival rates and associated health risks at the various gestational ages. One parent participant commented,

Then, you know (for example) the survival rate if it was born at 24 weeks (is) 50% ... or whatever, just the percentage of survival rate. And maybe just some ... of the risks or health issues the child could have for ... each week.

Statistics depicting survival rates associated with gestational age were conveyed using pictographs (see Table 2). Pictographs represent numeric health information¹⁷ and are used to convey information in a manner that facilitates accurate perception and timely processing of health-related information, in addition to enhancing shared decision-making.¹⁸ These graphical representations can take the form of icon arrays, pie charts, or bar graphs, and they are designed to help individuals make informed decisions about screening, diagnostics, and interventions.¹⁹ Pictographs may be particularly useful when communicating numerical information to individuals who have low literacy and low educational attainment.¹⁹ The P3 App included icon arrays as a pictograph to convey the probability of survival versus death and the likelihood of impairment for various gestational ages (see Figure 1).

Balancing Provision of Information Without Causing Harm

Because the P3 App includes statistics about survival, death, and potential impairments, there was significant discussion about how to frame this type of information in a manner that was clear and not value-laden.^{13,16,20} Research has shown that parents of preterm infants are “guided by hope and spiritual values” whereas neonatologists make decisions based on the best evidence available.²¹ A key goal of the neonatologists on the research team was to provide information that was suitable and usable by parents without imparting the neonatologists' values and beliefs on the parents. The parent participants discussed the importance of providing information that is specific in content but general in nature and does not cause harm.

So how do we get to that without it being so specific that is only applies to one person because, as we've all witnessed with our stories, we've all had preterm deliveries and not a single one was the same, so....

In addition to provision of content, the stakeholder group discussed using care in choosing or adding certain terms and avoiding those that may have negative connotations. For example, one parent preferred the word “overwhelming” to “scary.”

The parent participants were not in favor of “gamifying” the app. Gamifying, or making something more game-like, is frequently employed to enhance utilization of an app by increasing the user's motivation.²² Gamification includes giving badges or other type of recognition to participants who have reviewed certain proportion of the app. The parent participants felt that app utilization could be evaluated through conversations with the obstetric provider and that gamification may impose harm.

I think a topic that's serious like this, I wouldn't want it to be ... a game. And if we're concerned that the parents aren't potentially reading it (the app), then I think that needs to be (in) the conversation with that provider when they come in. “Hey, ok, so you're at 20 weeks, was there anything in that app that we talked about at 20 weeks?”

Decision Making

The P3 App includes statistics about the probability of survival versus death and the likelihood of impairment. This type of information is included in the app so that parents of infants born during the periviable period can make decisions about their child's/children's care that are suitable to their values and beliefs (see Table 2). Research has shown that provision of information for medical decision-making is not straightforward. Rosenthal and Nolan¹³ found some parents believe that a physician will withhold certain information or will share only the information that is consistent with the physician's values. This implies that for some parents, the information they receive is dependent upon the physician's preferences. While these negative experiences were not

necessarily echoed in our parent stakeholder group, the parent participants did express the desire to receive complete information that would benefit their decision making without assuming that parents have a certain outlook on life or particular values.

Parents who choose any of these treatment options love their child the same. Because I think any parent, they probably have the same outlook on life. If they knew their baby was going to be living great, their decision would probably be unanimous. But, it's not necessarily their outlook on life as it is how they are taking the statistics....

The P3 App included information about levels of NICU care. This information was included to encourage decision making about options to receive care. The following quote illustrates the importance of decision making in regard to service delivery: "But I think giving the woman that power to make that decision, if they can... through their insurance...."

CONCLUSIONS

The development and design of the P3 App was an iterative process that included parent participants (stakeholder group members) who experienced a preterm birth that was followed by NICU hospitalization. The app development process included formative research and was part of a larger study that pilot tested the app. The P3 App was designed to prepare parents for the overall birthing experience, let them decide how they will manage the infant's care after giving birth, and help them find resources to enhance their caregiving. The findings from the stakeholder group meetings suggested that parents prefer to have information before the time of labor. They want factual information that helps them know what to expect from NICU care, that comes from a trusted resource, and that aids in complex medical decision-making. The P3 App provides this by capturing the parental voice in the development process. The app was pilot tested showing benefits of increasing parent knowledge about preterm birth and the findings are reported in the journal of *Patient Education and Counseling*.²³ Future research will test the revised P3 App on a larger, diverse, and more robust sample to determine its efficacy in facilitating shared decision-making when mothers are at risk for preterm birth.

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