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User Persona of Mother of Preterm Neonate

Ganesh Bhutkar¹[0000-0002-3044-6471], Aditya Dongre¹, Shahaji Deshmukh²,
Lene Nielsen³[0000-0003-1768-7147] and Jaydeep Joshi¹

¹Centre of Excellence in HCI, Vishwakarma Institute of Technology, Pune, India

²Bharati Hospital, Bharati Vidyapeeth Deemed University, Pune, India

³Business IT Department, IT University of Copenhagen, Denmark
ganesh.bhutkar@vit.edu

Abstract. This research paper presents the design process of creating a user persona of Indian mothers of preterm neonates. Many of these preterm neonates require hospitalization in Neonatal Intensive Care Units (NICUs), leading to mental stress for mothers and their families. The main objective of mother's persona is to understand the mother behavior and preferences for designing app for these mothers. The mother's persona is proposed based on hypothesis, user interviews and data analysis. The result shows that the participant mothers of preterm neonates are graduates and homemakers from semi-urban areas around Pune, India. These mothers prefer non-vegetarian diet, they visit a pediatrician more frequently and presently. Moreover, the mothers have challenges with care and anxieties related to their neonate they do not use any mobile healthcare app or YouTube videos for information about neonatal care. In the future, a mobile app will be developed for these mothers with due consideration to their user persona.

Keywords: User Persona, Mother, Preterm Neonate, Neonatal ICU, Mother's Persona

1 Introduction

India is the second-most populated country in the world, with about 1365 million people [16], including about 653 million women [4]. Its population is growing, recently with a crude birth rate of 18.6 births per thousand population [2]. The effective population growth is about 1.1% per year, adding more than 15 million people to the Indian population [3]. Such high population growth results into national issues like unemployment, increased poverty level, unequal distribution of income, over-strained infrastructure, over-stretched health and educational services [12]. The challenging environment has led to deteriorating health conditions of women inflicting their pregnancies. It also results in too early, too late or too frequent pregnancies, creating complications at the time of childbirth. There is a need to use Information and Communication Technology (ICT) for advising and guiding these mothers on their health condition, along with growth tracking of their neonates, who are infants with an age of upto four weeks.

For usefulness of ICT to women in challenging healthcare conditions, the development process needs to take into account the work conditions of both the clinical staff and the mothers. The developers or researchers working with ICT do not have enough exposure to work environments such as Intensive Care Units (ICU). It generates a vital gap in the understanding of mothers of preterm neonates and their hospitalization in Neonatal Intensive Care Units (NICU). Lack of information may include understanding about the mothers' requirements, preferences, day-to-day activities and the stress generated during hospitalization. This paper presents a case that aims at reducing the gap of knowledge through fieldwork in NICU and a proposed mother's persona.

2 Related Work

In this section, we present a few papers that are helpful in the understanding of the work environment in the NICU, the psychology of parents of preterm neonates and the use of personas in health-related ICT. The papers have created a foundation for forming a hypothesis; especially related to the healthcare domain.

In an Italian study, Bouwstra et al. [1] examine the parent-to-neonate bonding experience in NICU. This research paper reveals that the parents of the hospitalized neonate are insecure about whether their neonate responds differently to them than to the medical staff. The mother is always eager to be together with her neonate, especially for breastfeeding and may not be able to meet the neonate frequently throughout the day, which will be depicted in the hypothesis. The Indian research paper by Patil et al. reveals that mothers of a preterm neonate experience significant psychological distress, with elevated anxiety [12]. This study also points out the emotional problems of the mothers and their need for support. Thus, these mothers face an increased mental stress, which will be highlighted in the hypothesis.

A study from the USA, by Heidari et al. [6] states that due to a busy occupational schedule most of the fathers find it challenging to attend all the time to the mothers during hospitalization as well as follow-up hospital visits. Thus, most of the mothers are accompanied by their mothers or relatives. This is similar to our case and will be reflected in the hypothesis. Finally, a study conducted in South Africa by Mburu et al. [7] aims to use technology to support mothers of preterm infants. In this case, the mothers get to know the neonatal status information via text message, over the phone or through digital video. Similarly, Indian mothers get appointment reminders over a phone call or via text message, which is reflected in the hypothesis.

Personas [11] is a popular UX method to understand the involved users. e.g. within healthcare ICT products. As mentioned by van Velsen et al. [13], it has the potential to be a useful tool for designing usable eHealth services. Looking at the field, most personas are related to self-monitoring and tracking such as a public website with cancer-related information [5], a handheld device to monitor chronic heart failure [15] or well-being [14].

3 Field Work

The research has been conducted in two local hospitals located in Pune, India. The larger hospital is housed in huge multi-story buildings with a capacity of more than 500 beds. Multispecialty departments have various units like Emergency, ICU, Burn centre and NICU. Preterm neonates who need intensive medical attention are often admitted into a special area of the hospital called the Neonatal Intensive Care Unit (NICU). This unit combines advanced technology and trained healthcare professionals to provide specialized care for the tiniest patients as seen in Fig. 1. It has continuing care areas for neonates who have health issues and need skilled nursing care. Such NICUs are categorized in different levels [8]. NICU at Level I, looks after neonates who need more care than healthy neonates and require regular monitoring assistance. NICU at Level II provides special care where nurses are assigned to 3-4 neonates for constant attention and care. NICU at Level III take care of very sick neonates providing prolonged lung ventilation-support. **A neonatologist typically leads NICU and staffed with intensivists, nurses, therapists and dietitians.** Neonatologists are pediatricians with additional training in the care of sick and preterm neonates [8] [9].



Fig. 1. A typical work environment in Neonatal ICU (NICU)

The research in NICU has started with the design of hypothesis about mothers of preterm neonates mainly focused on their personal traits, the medical context and mobile usage in practice. A questionnaire, designed on the basis of the hypothesis, has been used for interviews of selected mothers. To facilitate the active participation of mothers, the questions for the interviews are also provided in the local regional language - Marathi along with English. The field work started with interviews of physicians and nurses working with NICUs while forming the hypothesis. The main participants of these interviews have been 19 mothers of preterm neonates. Initially, about 15 mothers of preterm neonates have been interviewed and for further clarifications on related doubts, the interviews of 4 more mothers have been conducted. In all these interviews, the aim has been to get the details about demographic information, sources of information for mothers, their preferences, related facts, challenges and issues in the work environment of NICUs. The participating mothers of preterm neonates have been in the age group of 18-32 years. Most of these mothers are graduates from semi-urban areas around Pune. They were married between the age of 18 to 25 years and are housewives / home-makers. Most neonates are their first child.

The interviews have been conducted three days over a fortnight. Each interview lasted for 15-20 minutes. The research team had limited medical knowledge despite putting sufficient effort into an understanding of the neonatal context. **The all-male team in Pune has faced difficulties during the initial interviewing process of mothers due to gender incompatibility and therefore, a female intern from one of the hospitals is included as an interviewer of the mothers.** This intern has been there to help in sharing expectations, priorities and experiences of these mothers.

4 Construction of Proposed User Persona

In this qualitative research, the user is the mother of a preterm neonate. A related user persona of a mother is proposed to analyze the maternal experience in NICUs. This study aims to understand a typical Indian mother, her experience and challenges in NICU. The process of creating the neonate mother personas started with formation of a hypothesis [10]. **The hypothesis is mainly focused on their personality, medical traits and active mobile usage.** The assumptions include demographic information such as age, education, marriage age, area, occupation and others as depicted in Fig. 2.

The health and medical science traits include - personal Body Mass Index (BMI), diet, medication schedule, knowledge of medical terms/equipment, mental/physical stress and others. The mobile usage section includes factors such as internet access, use of messenger app, local language support, m-Health app usage, social media groups and so on. Based on all these factors, the hypothesis of mother of preterm neonate is created with more than 30 statements.

Topic: User Persona of Mother of Preterm Neonate

Hypothesis for Mother of Preterm Neonate

[A] Mother's Personality:

1. Mother belongs to the age group of 18-25 years.
2. She has completed her education till 12th Std.
3. She got married at 18 years or more of her age.
4. She stays in or belongs to rural area.
5. She is a housewife / homemaker.
6. She travels at least 3-5 KM daily using public transport.

[B] Health / Medical Science:

1. She has BMI less than 18.5 or more than 25.
2. She has delivered a preterm neonate within 18 months of her marriage.
3. She has delivered a preterm neonate as a first neonate.
4. Her preterm neonate is delivered before 37 weeks.
5. She is hospitalized for a longer duration along with her neonate than that of mothers with normal deliveries.

Fig. 2. A section of hypothesis of mother of preterm neonate

आईसाठी प्रश्नावली

1. आईचे वय काय आहे?
 - a. 18-25 वर्षे
 - b. 25-32 वर्षे
 - c. 32 वर्षे किंवा त्यापेक्षा जास्त
 - d. इतर
2. मुदतपूर्व प्रसूत बाळाच्या आईचे शिक्षण काय आहे?
 - a. 12 वी पर्यंत
 - b. पदवी पर्यंत
 - c. पोस्ट ग्रेज्युएशन पर्यंत
 - d. इतर
3. आईचे लग्न कित्तव्या वर्षी झाले?
 - a. 18+ वर्षे
 - b. 20+ वर्षे
 - c. 25+ वर्षे
 - d. इतर
4. आई कुठल्या भागात राहते?
 - a. शहरी भागात
 - b. अर्ध-शहरी
 - c. ग्रामीण
 - d. इतर

Fig.3. A section of questionnaire in local language for mothers

After proposing the hypothesis, a questionnaire has been prepared for conduction of interviews of selected mothers in hospitals, during the field work. A questionnaire seen in Fig. 3, is in Marathi, the local language to facilitate active participation of mothers in the interviews. It has more than 30 objective questions with upto 4 options.

More than one-third questions are of YES / NO type. Using this questionnaire, interviews of mothers of preterm neonates have been conducted in NICUs. The interviews of main participant mothers have been conducted to get the details about demographic information, sources of information for mothers, their preferences, related facts, challenges and issues in work environment of NICUs. The more details of interviews and data collection process are elaborated in the section about Field Work.

The collected interview data has been analyzed to get vital findings / insights, capturing mother's experience in NICU. The related detailed user persona and interesting observations made on the basis of hypothesis are presented in the next section – The Mother Persona.

5 The Mother Persona

The results of interviews mainly consist of accepted and rejected statements in proposed hypothesis as well as the user persona of mother of preterm neonate. Participant mothers of preterm neonates have been mainly in the age group of 18-32 years. Most of these mothers are graduates from semi-urban areas around Pune, India. Most of them were married within 18 to 25 years range and are housewives / homemakers, as depicted in a graph on mother's occupation in Fig. 4. Most of the mothers prefer non-vegetarian diet and visit more frequently a pediatrician than gynecologist, as seen in a graph related with visits to physicians in Fig. 5.

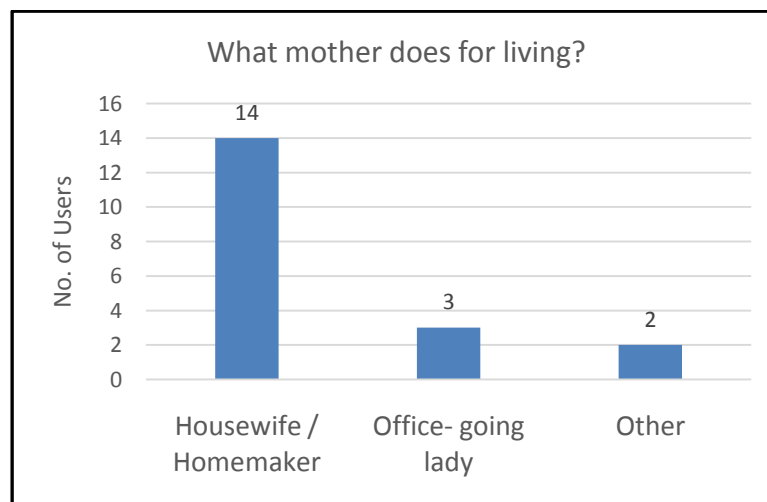


Fig. 4. A graph depicting occupation of mothers

Most neonates are their first child and spontaneous preterm infants. These mothers are always eager to be with their neonates especially for breast-feeding, but are not able to meet the neonates frequently; especially during nights. Most of them do not use any m-Health app, as seen in a Fig. 6. They do not join any user group related with neonate / pregnancy care on social media, but read related blogs. These mothers communicate with physician in person and also, take appointments in person or over a phone. Most of them do not use YouTube videos for information about neonate / pregnancy care, as seen in Fig. 7.

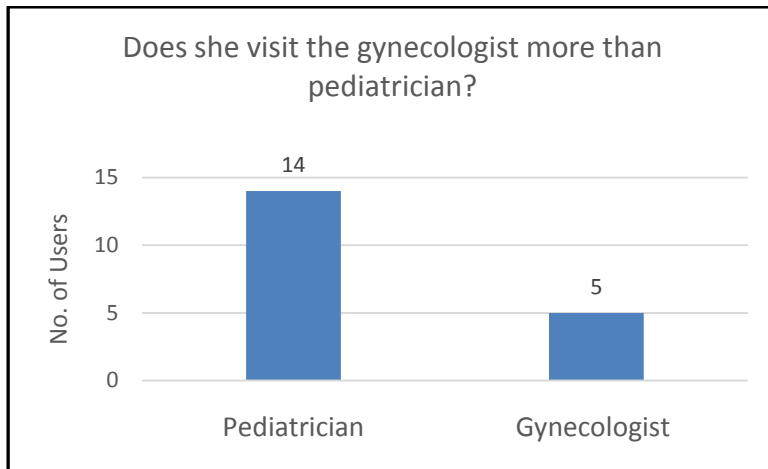


Fig. 5. A graph depicting preference of visits to physician

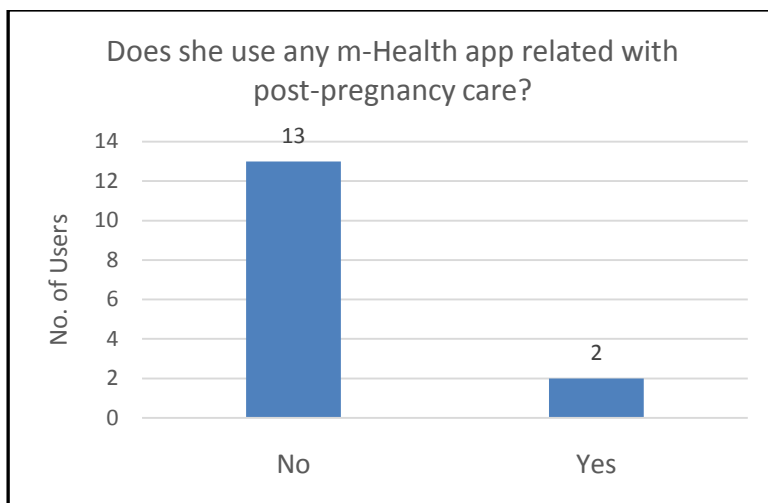


Fig. 6. A graph depicting usage of m-Health apps

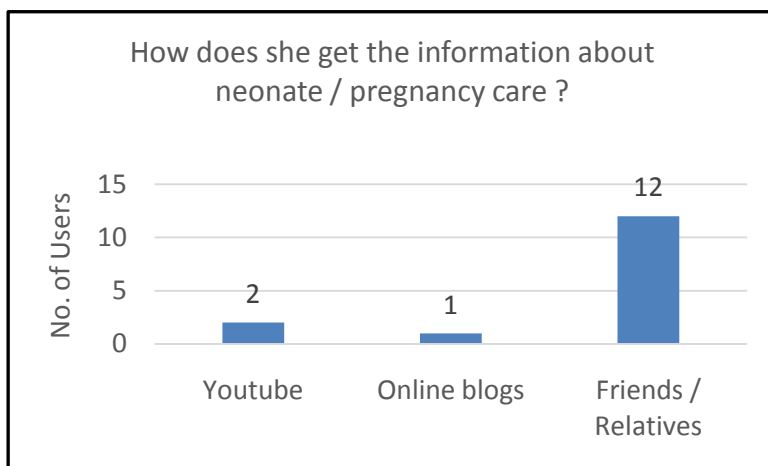


Fig. 7. A graph depicting use of YouTube videos

Fig. 8 depicts the user persona of mother of preterm neonate and is proposed based on accepted / corrected statements in proposed hypothesis. This mother persona depicts the details about demographic information, sources of information for mothers, their preferences, related facts, challenges and issues in the work environment of NICUs.

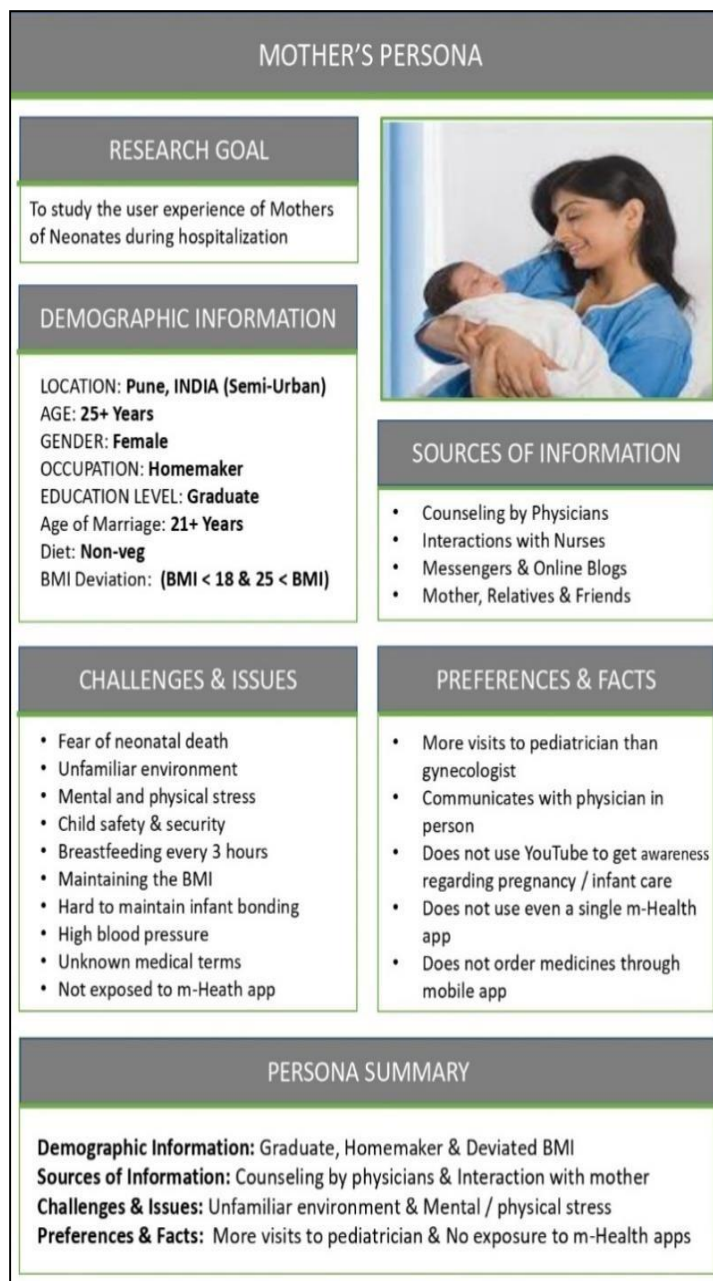


Fig. 8. User persona of mother of preterm neonate

6 Conclusion and Future Work

In this paper, a user persona for Mother of Preterm Neonate has been proposed. This user persona has provided interesting insights into demographic information, sources of information for mothers, their preferences, related facts, challenges and issues in the work environment of NICUs. It will help application developers and usability

professionals in the design of related healthcare applications. In the future, an Android app will be developed for the mothers of preterm neonates with due consideration to their user persona derived during this research work. Furthermore, how the app fits into the work of the healthcare staff in neonatal care, can also be addressed.

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