

An information app (e-TOP) to support parents' information needs during the first year at home after preterm birth: Development and usability study

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Abstract

Background: Parents of premature infants often face challenges in transitioning from hospital to home, requiring reliable and accessible information to support their caregiving. In the Netherlands, a post-discharge, responsive parenting intervention (TOP program) is standard care for very preterm born infants and their parents. However, parents still indicate unmet information needs. Mobile health (mHealth) interventions have the potential to supplement post-discharge education and empower parents by providing tailored, evidence-based information.

Objective: The primary objectives of this study were: (1) to develop an information app (e-TOP) for parents of preterm infants and (2) to evaluate its usability.

Methods: An exploratory two-phase mixed-method design was employed. In Phase 1, the app was developed through iterative focus group discussions with parents of premature infants and TOP interventionists (pediatric physiotherapists). The content of the app was developed through co-creation by professionals and was subsequently refined and adapted to improve its practical use. In Phase 2, parents with a preterm born infant who participated in the TOP-program received access to the e-TOP app for six months. During and after six months, usability was assessed with a range of quantitative and qualitative measurements, including thinking aloud sessions, online analytics, questionnaires including the System Usability Scale (SUS) and semi-structured interviews.

Results: The collaborative approach with end-users and experts for the development led to a fully functional e-TOP app. Expert review and content validation ensured that information was accurate, accessible, and relevant for parents. For the usability testing, 58 families (116 participants) were recruited, and 69 participants actively used the app. The cumulative e-TOP median (IQR) usage per participant for 26 weeks was 39 minutes (IQR: Q1 8.8 - Q3 53.0). The median number of actions was 64.0 (IQR: 33.5-88.0). The eTOP app received a median SUS score of 75 (IQR: 67.5-80.0), indicating good usability. Participants rated their overall satisfaction with the app with a median of 7.0 (IQR: 7.0-8.0) out of 10. While the app was perceived as useful for finding information on prematurity-specific topics, engagement declined over time. The interviews highlighted a need for improved navigation (e.g., search function), expanded content (e.g. practical exercises, sensory processing), and more interactive features (e.g., chat support, parental community forums).

Conclusions: The e-TOP app is a valuable, digital resource that can supplement post-discharge care by providing tailored, evidence-based, and accessible information for parents of premature infants. While usability scores were high, engagement trends and retrieved feedback suggested the need for enhanced retention strategies, such as push notifications, time-line based navigation structure, interactive tools, and adding (practical) content. Clinical Trial: ISRCTN65709138

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Original Manuscript

An information app (e-TOP) to support parents' information needs during the first year at home after preterm birth: Development and usability study



1 Introduction

Giving birth to a premature infant is a disruptive start in parenthood [1]. The dependency on medical and health professionals can challenge the formation of a secure infant-parent relationship and parents' self-efficacy in their ability to independently care for their infant [2]. The transition to home following discharge is known as challenging. Without the 24/7 access to healthcare professionals, parents of premature infants (PT) often feel unprepared for this new situation and lack confidence in their capacity to care for their infant [3]. Despite efforts to improve parents' readiness for discharge and the availability of follow-up services, many PT parents continue to experience unmet needs for support and practical information after leaving the hospital [4][5]. As the infant's care needs and developmental milestones evolve during the first year, PT parents' informational needs also shift accordingly. Providing tailored information about the consequences of prematurity and the specific health, behavioral and developmental needs of premature infants can strengthen parental self-efficacy, enhance their sense of security in caring for their infant, and potentially reduce healthcare utilization [6][7].

Search for information

After returning home, parents of PT infants search online for information on topics such as infant crying, choice of formula, common illnesses, and developmental stages. While they use search engines, social media, or mobile health (mHealth) apps, finding appropriate and reliable information on the unique challenges of caring for a preterm infant at home remains difficult [8][9]. The use of mHealth could support a shift from time- and professional-dependent access to information toward a more autonomous approach, empowering parents to obtain information whenever and wherever they need it. However, for mHealth apps to be useful and effective, they must address the specific information needs of PT parents [8]. In addition, the application must be user-friendly [10] and the information accessible and easy to understand for parents across varying levels of education and health literacy [11].

mHealth applications

MHealth education interventions for parents of premature infants were developed over the last decades. However, Richardson's evaluation of mobile apps targeting parents of infants in the Neonatal Intensive Care Unit (NICU) revealed that many apps are lacking quality and credibility or do not contain content identified by parents as important [12]. In contrast, the study on the NICU2HOME app provides high quality information on infant and self-care during and after the NICU stay and showed promising results in enhancing parental self-efficacy and discharge preparedness [13]. Despite the rich body of literature regarding parental needs for information after discharge [4], available apps targeting the post-discharge period are limited. A systematic app review of mobile information applications for parents of preterm infants after hospital discharge found that, while the overall quality of the identified apps was acceptable, they insufficiently addressed key post-discharge concerns, such as information on transitions in nutrition, sleep patterns, or developmental stages [14]. This lack of targeted content may contribute to the limited usage and adoption of these apps, a common pitfall when end-users and stakeholders are not adequately involved in the design process [15]. Participatory design approaches, such as the design thinking method, ensure that user requirements are accurately captured from the perspective of the end-users thereby enhancing usability and facilitating effective implementation [16-19].

The Dutch context: TOP program

In the Netherlands, a 1-year home-based responsive parenting intervention (TOP program), is standard care for very preterm born (VP) infants and their parents and currently expanded for moderate to late preterm born infants. Pediatric physical therapists with an additional 1-year TOP training and affiliated with the Dutch Expertise Center for Premature Infants (EOP) carry out the TOP program. The strength-based and process-oriented intervention consists of seven key strategies to enhance parental understanding of the infants behavioral and developmental needs [20]. An important key strategy is to provide parents with information about their PT infant's behavioral and developmental needs. To enhance parents' knowledge and understanding of their infants' needs TOP interventionists provide verbal information transfer and an individualized written parental report with strength based recommendations accompanied by photos taken during the home-visit. Despite the benefits of face-to-face care, there is a need for a complementary mHealth intervention that enhances information retention, supports parental confidence in managing their infant's care, and potentially reduces their reliance on healthcare professionals [4,8]. Before conducting more extensive research to measure its effectiveness, developing an information application that ensures that user requirements are effectively incorporated and is tailored to the specific needs of PT parents is crucial.

The aim of this study was twofold: 1) to develop a post-discharge information app (e-TOP) for parents of premature infants and 2) to evaluate its usability.

2 Methods

A two-phase, mixed method design was employed for this study. In Phase 1, the development of the e-TOP app followed a co-creative, stepwise approach. Focus group meetings were conducted to evaluate user needs and to test prototypes. Subsequently, professionals, including pediatricians, dieticians, occupational and speech therapists, contributed their expertise to develop the app's content. The research team then refined and adapted the content to enhance practicality and relevance. For the evaluation of the usability of the app (Phase 2), PT parents used the e-TOP app for a period of 6 months. Quantitative and qualitative data were gathered, combined, and integrated to provide a comprehensive evaluation of the usability [21].

Setting

The study was performed between October 2021 and November 2023 by the Dutch Expertise Centre for Premature infants (EOP), affiliated with the Amsterdam University Medical Center (AUMC), in collaboration with the Amsterdam University of Applied Sciences. All participants received an information letter detailing the study's objectives, timeline, content, target group, data management practices, and privacy considerations. Subsequently, informed consent forms were obtained. Participants were officially enrolled in the study upon providing written consent. The study was approved by the Medical Ethical Committee of the Stichting Amsterdam UMC (NL78996.018.21).

3. Phase one: Development of the e-TOP app

3.1 Participants

The user centered design approach for the development of the prototype started with three focus groups, one with TOP interventionists and two with parents of VP infants. For focus group 1, TOP interventionists with more than 5 years of experience, representing different geographic and socio-economic regions were approached. For the parent focus groups, participating TOP interventionists approached potential eligible and interested families. Parents were included if they 1) participated in the TOP program for at least three months, and 2) were able to understand and speak the Dutch language. Focus group 3 specifically involved PT parents with limited health literacy (LHL). These

parents were identified and recruited by the TOP interventionist by using the following additional two criteria: 1) parents struggle with understanding and applying the information provided during the intervention or in the parent report, and 2) fulfill the criteria for LHL according to the Dutch checklist to recognize LHL [22].

3.2 Focus group meetings

We conducted three focus group sessions. In the first meeting, eight female TOP interventionists participated. Five interventionists worked in an urban setting, with a diverse population in a challenging socio-economic environment.

In the second focus group, nine parents (5 mothers and 4 fathers) participated. Their mean age was 35.6 years (SD 5.8). For five parents it was their firstborn, and for the other four parents it was their second child. Their infants mean gestational age was 30 weeks and 2 days (SD 19.0). In the third focus group meeting, six mothers with LHL participated with a mean age of 31.6 years (SD 2.2). For five mothers it was their firstborn infant, for 1 mother her third child. Their infants mean gestational age was 29 weeks and 1 day (SD 21.8).

The three 2-hour online focus group meetings were organized in the evenings, which was indicated as the most convenient time. The focus groups were facilitated by an independent female researcher, MM, who has over 20 years of experience in conducting interviews and group discussions. MM was not involved in the study design or analysis. First author (MF) attended the focus groups to take field notes but did not lead the discussions. The three focus group meetings were audio-recorded, re-listened, and summarized by the independent researcher MM. Findings were discussed within the research team.

The goal of the focus groups was two-fold. First, we aimed to verify the identified need for information on the ten found topics in our prior qualitative research [8]. We accomplished this by asking the following questions: What's your association with an online e-TOP app? Do you recognize the topics parents identified earlier? What are the topics you search for on the internet? Where do you search for information? What support do you need?

Second, the aim was to retrieve preferences regarding content, topics, design, and navigation. For this purpose, screens of existing parenting apps, information cards, mock-ups, and text examples were used to identify and discuss preferences such as tone of voice and depth of information. See Figure 1; information cards and 2; mock ups.

3.3 Results

The results of the focus group discussions with TOP interventionists and parents provided valuable insights that shaped the development of the e-TOP app, directly influencing its content and design refinements. TOP interventionists recommended not to use the age-based developmental norms strictly, as individual variation among preterm infants is substantial. Instead of providing medical guidance, the app should direct parents to contact their general practitioner or pediatrician when necessary. Additional topics identified by participants were the digestive system, reflux, constipation, medication management, sensory overload and stimulation, parent-infant attachment, and bonding. Parents expressed preference for clear, supportive, and actionable information. Information should have a layered content structure, allowing simplified messages and scientifically substantiated information. A summary of these findings is provided in Table 2. We used them as a guideline for the further development of the e-TOP app.

Table 1 Results focus group meetings.

Topics	Focus group 1 ^a	Focus group 2 ^b	Focus group 3 ^c
Associations participants have with a digital information source.	Reliable and user-friendly digital source aligns well with the needs of young parents.	An app can offer practical guidance supporting in everyday care. Given the limited experience of general practitioners and Dutch health services with prematurity, the app could also be a valuable source.	Participants expressed curiosity and recognized the usefulness of an app in addressing their concerns
What questions do parents have?	Ten topics most frequently searched align with participants concerns, validating the app's content. In addition, practical information on adequate sensory input and use of slings is needed.	Different experiences with gavage feeding at home, a need for more tailored information. What can I do with my premature infant?	Participants sought information on baby positioning, especially with preferred head position. In addition to the showed topics: reflux and gavage feeding tips. Information about constipation.
About which topics do parents seek additional information?	Information about constipation, intestinal cramps, reflux, or medication.	Feeding, sleep patterns, sensory overexcitability	Inconsolable crying. Psychological support for anxiety. Premature clothes. Information about long term effects of oxygen.
Which support do parents need?	Finding psychological support for themselves.	Need for a readily accessible professional after discharge.	Information on available services, particularly for single moms.
Where do they look	Online communities	Parents shared their	Online forums such as

for information?	including Facebook group and consumer association websites.	favorite websites but they are often not specific for premature infants.	baby 24 are used. Other parents with experiences serve as key sources of information.
Presentation of information	Adaptability to literacy levels. Videos and animations in multiple languages for less literate parents.	Varied content preferences. Different preferences, some participants liked text-based information, others favored videos.	Preference for animation (visual oriented). Practical demonstrations with videos for e.g., making the crib. Interactive features like chat box for quick response. Peer-experiences. Some valued real-life success stories, others were not interested in fellow sufferers.
Navigation	A structured topic design, with a FAQ chapter.	Search button to improve content discoverability.	Clicking through for more detailed information.
Information cards	Reassuring and supportive tone is essential. Normalizing and comforting tone of voice is important.	Concise messages can raise questions. The messages should not oversimplify.	Informative, necessity to be able to search further for more extensive information.
Text validation	Be aware of tone of voice, clarity of the information.	Comforting information is important. Informal tone of voice is nice, it related to parents and feels personal.	Easy-to-read text, supplemented by practical examples on what to do. Information can be brought more casual, like you talk to a trusted friend or relative. It needs to be valid information.
Depth of information	Layered information structure. Parents need to be able to explore in-depth details or stay at a simpler level.	Different headings/titles can help to make content more accessible.	Information should clearly explain differences in care for premature infants.
Scope of information	Coverage for the first year, aligning with the TOP program.	Guidance on more complex cases, should refer parents to the health care professionals. Potential integration with a hospital app could enhance usability.	Developmental milestones per week/updates about what your baby is doing in relation to other infants (corrected for prematurity)

^aTOP interventionists. ^b PT parents. ^c PT parents with LHL.

3.4 From prototype to a functional e-TOP app

To create content for the app, experts were recruited through the researchers' network. Healthcare

experts were selected based on their expertise regarding prematurity or related topics such as feeding, sleep, or motor development. To address user needs, the following four steps were taken. First, the topics parents indicated in our prior research [8] were complemented with the findings of the focus group meetings. Experts drafted comprehensive information on these topics. Two members of the research team (MF, EM) finalized the content in three rounds of review and refinement. Second, The Dutch Expertise Centre for reducing health inequities provided support to improve the readability whereafter the text was simplified by the first two authors (MF, EM) to that of the reading ability to understand everyday health information (level 2). Key messages for each topic were formulated at reading level 1 for parents who prefer to read short pieces of information [23]. In addition to text, a read out loud function was added. Third, the first two authors (MF, EM) included images, picture stories,. Fourth, video content, either developed by health care experts from different fields or retrieved from the EOP library, was added. Videos consisted of interviews, demonstrations of parent-infant interaction, and explanations of infant behavioral signs. To clarify the content, videos had voice-overs and subtitles.

Simultaneously with creating content, we collaborated with a design company (ZIGT, Amsterdam) to build a functional prototype of a web app accessible on smartphone, tablet, and desktop devices. The research team organized and posted all content leading to the final functional e-TOP app. See Figure 3.

4. Phase two: Evaluation

4.1 Participants

For the evaluation of the e-TOP app, the purpose sample was composed of parents with a VP born infant (below 32^{0/7} gestation) and moderate preterm (MP) born infants (32^{0/7}-34^{6/7} weeks gestation). VP parents received the TOP program (routine care, reimbursed by basic package of insurers) and MP parents received a shortened TOP program in a study context [24]. In addition to the home visits by the TOP interventionists, all participants received access to the e-TOP app.

4.2 Procedure

Fifteen TOP interventionists from different geographic- and socio-economic regions received a one-day training in the intervention and research protocol including the informed consent procedure. The enrollment took place between November 2022 and March 2023. TOP interventionists introduced

the study to eligible parents. When interested, parents received an information letter from the study center. If they agreed to participate, an informed consent visit was scheduled. Upon signing the informed consent, both parents received a unique access code and an animation video explaining how to install the e-TOP app. Additionally, at the start (T0) parents were invited via email to complete an online questionnaire on sociodemographic information including age, educational level, employment status, and family structure. Parents had continuous access to the app for the duration of six months. During this period, Matomo analytics was used to collect user data and thinking aloud tests were performed. At the end of this period (T1), parents received a follow-up invitation to complete online questionnaires assessing their experiences and ten participants were invited for the interview.

4.3 Usability

For a comprehensive evaluation of the usability of the app, we used qualitative and quantitative measurements. User data provided insights into objective usage engagement, while qualitative data highlighted usability needs and identified issues for further improvement [25].

Usability testing: Thinking aloud.

Thinking aloud tests were used to gain insights into the ease of use and navigation experiences with the app [26][27]. While navigating the app, parents were encouraged to express their thoughts, frustrations, questions, and feedback in real-time. The tests were conducted by two students from the faculty of health of the University of Applied Sciences Amsterdam, supervised by a researcher [VV]. Five parents were asked to complete the following three tasks: (1) Determine when your infant can pick up a small object; (2) Identify what actions you can take as a parent when your child is anxious about touch; and (3) Calculate your infant's corrected age. After completing each task, participants rated the difficulty using the Single Ease Question (SEQ), which scores task performance on a scale from 1 (very difficult) to 7 (very easy). Afterwards, parents were asked questions regarding the content (e.g., "Are there any topics you would like to add?"), usability (e.g., "How was your experience with the e-TOP app?"), and comprehension (e.g., "Did you understand the answers you found when searching for information?"). These sessions were screen-recorded, and audio transcripts were generated.

User data

User data was monitored and analyzed with the web analytics tool Matomo [28]. Users were defined

as those who accessed the e-TOP app more than once. The main metrics of interest were installs, visits, visit duration and change of usage over time, and visited topics.

To allow participants to provide immediate feedback on the app, the e-TOP app included a prompt at the end of each page asking, “was this information helpful?” with two response options: yes or no. After selecting an option, a comment box appeared, allowing users to provide additional feedback.

Usability Questionnaires

The Dutch version of the System Usability Scale (SUS) was used [29]. The SUS is an easy to use, valid, and reliable questionnaire for usability assessment of mHealth applications. The scale consists of 10 statements, which can be completed within 10 minutes. All items are scored on a five-point Likert scale from “strongly disagree” to “strongly agree.” Scores per item are converted to an overall SUS score, which ranges from 0 to 100, with higher scores indicating better usability. Overall scores from 0 to 50 indicate “not acceptable,” scores from 51 to 67 indicate marginal level of usability, and scores from 68 to 100 indicate “acceptable to excellent” levels of usability [30].

To measure user experience and appropriateness of the content, a customized 10 item questionnaire was used. Seven statements were scored on a five-point Likert scale from “strongly disagree” to “strongly agree.” Two statement examples are: ‘The e-TOP app helps me to find information about premature birth’ and ‘The pictures and videos help me to understand the information’. Overall satisfaction with the app was scored on a numeric scale from 1 to 10 with 1 indicating very dissatisfied to 10 indicating extremely satisfied. Two open-response questions allowed participants to provide unrestricted and more subjective answers: ‘What information did you miss when using the e-TOP app?’ and ‘Do you have suggestions to improve the e-TOP app?’

Interviews

A subgroup of participants (n=10) was invited for a semi-structured interview with the first author (MF) to discuss their experiences with the e-TOP app in more detail. Interviews were scheduled at a time convenient for the parents (by phone or an online meeting). The interview guide was set up to elicit direct, actionable feedback on app usage and contained the following questions: How was your overall experience with the e-TOP app? Follow-up questions were: What were the reasons why you did not use the app and at what moments did you use the app? Did the app provide the information you wanted to know or read? Can you tell me if and which information or topics you felt were missing? Did the information align and/or complement with the guidance you received from the

TOP-interventionist. What suggestions do you have to better meet your information needs. Do you have tips for us to make the app easier to use?

4.4 Data analysis

Questionnaire data were collected using Castor database (Electronic Data Capture, Ciwit BV, Amsterdam, the Netherlands, 2021). Descriptive statistics were used to describe the participants and the user data (installs, visits, visit duration and change of usage over time, and visited topics). Questionnaires data were checked for normal distributions using a graphical summary of data and descriptive statistics. The median score with interquartile range (IQR) was used in case of skewed distributions.

For the qualitative data collected through thinking-aloud sessions and interviews, a pragmatic thematic analysis approach was used. For the thinking aloud analysis initial open coding was analyzed and discussed within the project group and subsequently categorized into themes. Subthemes were then developed under each main theme to capture more specific insights. In addition, user comments and open questions from the questionnaires were evaluated and categorized by MF. Ultimately, the qualitative analysis resulted in four overarching themes, user experience, content, navigation, and functionality.

4.5 Results

4.5.1 Participants

A total of 69 families with a PT born infant were assessed for eligibility by fifteen TOP interventionists. Of these, 58 eligible families, consisting of 58 fathers and 58 mothers, agreed to participate, signed informed consent, and received the access code for the e-TOP app. Five families (10 participants) withdrew from the study after signing informed consent and receiving the first questionnaires. At T0, 61 participants completed the demographic questionnaire (Figure 3 Flow diagram). For participant characteristics see Table 2

Table 2 Participant characteristics.

Participant characteristics	N (%)

Sex	
Mother	42 (69%)
Father	19 (31%)
Family status	
Firstborn child	37 (61%)
Family status of 2 parents	61 (100%)
Language	
Dutch language for health care information	60 (98 %)
Education^a	
Lower	2 (3%)
Intermediate	22 (36%)
High	37 (61%)
Employment	
Fulltime	35 (57%)
Part time	25 (41%)
No employment	1 (2%)

^a Highest educational level completed: Low level education refers to primary school, vocational education, lower of middle general secondary education. Intermediate: refers to higher secondary general education, pre-university education. High; Higher vocational or university.

4.5.2 Usability results

Thinking aloud

Five participants (three fathers, two mothers) were visited at home, where they performed the Thinking Aloud tasks. The ease of use was rated as follows: Task 1 had a mean score of 6.4 (SD 0.55), Task 2 a mean of 6.0 (SD 0.89), and Task 3 a mean of 6.0 (SD 1.22) on a scale from 1 to 7, indicating these that all three tasks were easy to perform. Participants appreciated the app, the used tone of voice and understandability of the information. Participants provided explicit and actionable

recommendations regarding content and functionality. For example, regarding content, participants expressed a desire for more information on health issues and medication. They also expressed interest in instructional videos on techniques, such as holding and carrying their baby. Regarding functionality, a home button, a scroll arrow, and search function was missed.

User data

In total, 69 participants (47 mothers and 22 fathers) used the personal access code to log in. Due to ad blockers, tracking data was available for 63 participants. The median cumulative e-TOP usage per participant during six months (26 weeks) was 39 minutes (IQR 8.8-53.0). The median number of actions was 64.0 (IQR 33.5-88.0). Most actions and largest time spent on the app were registered during two weeks after receiving the access code. See figure 5 and 6 for further details. Multiple participants visited all 10 topics during the first 2 weeks. The total amount of visits per topic declined after this period with another peak in visits between week 11 and 17. The most visited topics in the app were nutrition, sleep, and correcting age for prematurity (Table 3).

Table 3 Visited Topics e-TOP app

Topic	Total # visits	Peak visits (week)
Nutrition	81	17
Sleep	79	6
Correcting age	54	3
Understanding your baby	49	4
Long term consequences	44	14
Motor development	42	11
Returning to work	33	4
Parenting	25	4

Infant Health	23	4
Follow up	21	9

Usability Questionnaires

A total of 55 participants completed the SUS, yielding a median total SUS score of 75.0 (IQR 67.5–80.0), indicating generally good usability. The app was rated positively for its ease of use, functional integration, and user confidence.

Participants gave the app an overall satisfaction of 7.0 (IQR 7.0–8.0), on a scale of 1-10. Content satisfaction was rated with a mean score of 3.7 (SD .89) and the app's appearance was considered attractive, with a mean score of 3.6 (SD .83) on a scale from 1-5. Participants found the pictures and videos being particularly helpful. (M 4.0, SD .56) and expressed that the app was helpful in addition to face-to-face care from the TOP interventionist (M 3.5, SD .99)

Qualitative data

Data collected through thinking-aloud sessions, interviews, and written comments from the app's comment box were categorized in four themes: user experience, content, navigation, and functionality.

User Experience

Participants appreciated the specific and depth of information provided yet expressed concerns about retrieving tailored answers to specific situations. As a participant in the interview stated, "*The only thing I couldn't find was whether it's possible to swim with a premature baby and at what age that is safe*". The app facilitated users' understanding of infant behavioral cues and sleep patterns. However, parents also preferred direct interaction with a TOP interventionist, indicating a desire for more personalized and human support. For example, a mother stated in the interview that "*The TOP interventionist explained it to me personally, so I found that easier and more comfortable*." Suggestions were given to incorporate interactive features, such as chat support or a parent community, indicating a preference for increased interactivity and social connection within the app.

Content:

The content was generally deemed useful and relevant to the specific needs of parents with premature infants. As one participant noted in the comment box "*It gives information you cannot find on the internet, all content is related to premature birth*." Suggestions for improvement emerged

from both the interviews and the comment box. Requests for additional practical tips, along with more in-depth information on motor development and health-related concerns, highlighted opportunities to expand the scope of information. As a participant stated during the interview: *"More information about motor development, like crawling, creeping, and sitting, would be helpful"*. Another parent expressed during the interview *"I would like there to be more concrete information, such as a chart with a baby weighing this much should drink this much."* Videos were highlighted as particularly effective for conveying complex concepts, such as sleep patterns and infant signals.

Navigation:

While users found the landing pages clear and well-organized, they reported difficulties with lengthy chapters and locating specific information. As a participant during the interview reported: *"Searching for specific information is more difficult if you don't know under which chapter to search"*. Another participant reported in the comment box: *"The sub-chapters contain too much information and not so easy to find answers to your questions."* The need for enhanced navigation design, such as the inclusion of a search function, a home button, and scroll arrows was suggested and could enhance information retrieval. A participant explained during the thinking aloud session: *"If there was an arrow next to the app indicating that there's more room to scroll down, you might have looked further"*.

Functionality:

A timeline-based structure reflecting the developmental stages of premature infants was suggested as a potential solution to improve content organization. One participant stated in the comment box: *"It would also be helpful if there was a timeline showing what a child /should do at each (corrected) age."* The ability to share information easily with family members, particularly regarding hygiene practices for visits, emerged as a key functional improvement.

5. Discussion

This study aimed to develop and evaluate a digital information source (e-TOP) to address the specific information needs of parents caring for preterm infants during the first year post-discharge.

Development of the app

To develop the e-TOP app, a user-centered design approach was used. The feedback from the three focus groups with TOP interventionists and parents of premature infants, including LHL parents,

directly influenced the app's content and design. The co-creation and iterative process between experts, design company and research team was highly successful in shaping the app's functionality and refining its design and content. This collaborative approach ensured that the final prototype of the e-TOP app was both user-friendly and rich in relevant, evidence-based information, tailored to meet the diverse needs of its users. This methodology aligns with established practices in mHealth app development, emphasizing the importance of participatory design including health professionals to meet user needs [16-19].

Parents with limited health literacy were actively engaged during the focus group meetings in the developmental phase of the e-TOP app. They expressed a need for clear, actionable information, preferably content in multiple formats, with an accessible tone and simplified messages. The app therefore incorporated features like simplified language (Level 1), multimedia content, and "read-out-loud" functionality to accommodate LHL parents with videos and text at different reading levels. This preference is supported by research indicating that visual-based interventions, particularly videos, are effective in improving health literacy and comprehension of health-related information [31].

Usage and usability

Participants engaged with the app for a median total of 39 minutes during the six-month study period. The number of recorded actions per participant had a median of 64.0, but usage varied significantly between participants. Differences in purpose, target groups and the lack of user engagement metrics makes comparison to other parenting apps challenging, as also described in Li's systematic review of commercial mHealth parenting apps [32]. The e-TOP app is designed as an additional information source and if we compare the results to educational health apps longer, but less frequent sessions are found [33]. This found gap calls for established standardized benchmarks for digital engagement in neonatal mHealth interventions.

While the app was perceived as useful for finding information on prematurity-specific topics, user data revealed a decline in engagement after the initial two weeks. These differences in intent to use versus lower non usage attrition is found in other web-based parenting interventions [10]. The e-TOP engagement peaked at week 11 and week 16, parents revisited the app at key developmental milestones such as rolling over, reaching for toys and the transition to solid foods. Integrating features such as search functionality, interactive (push notifications, chat function) and time-line based navigation could enhance the e-TOP app's long-term utility [34][35].

SUS distribution with a mean SUS score of 68 is considered a suitable usability for Digital Health apps [36]. The e-TOP app demonstrated acceptable-to-good usability with a SUS score of 75.0. By complementing the SUS with a customized satisfaction survey and data collected through thinking-aloud sessions, interviews, and written comments from the app's comment box, this study followed best practices of combining quantitative ratings with rich qualitative findings for the usability testing [25]. Participants provided actionable feedback across key areas and by integrating these improvements, the e-TOP app can enhance usability ensuring it remains a valuable long-term resource for parents of preterm infants.

Limitations and opportunities for future research

The total study period of two years and restricted finances necessitated pragmatic approaches to the evaluation of the usability. We used several qualitative and quantitative methods, but we had to make compromises impacting the study methodology such as the reliance on a single author for qualitative data analysis which may introduce bias. Integrating multiple researchers into the thematic analysis process not only enriches the analysis through diverse perspectives but also enhances the credibility and trustworthiness of the research findings [37].

Although LHL parents contributed to the development of the app, the study faced challenges in recruiting LHL parents for the evaluation phase. Their limited representation in the evaluation phase underscores a broader challenge in engaging these parents in research [38]. Barriers such as complex consent processes and digital questionnaires have hindered participation in our study. Allowing parents to first establish a connection with the researchers or interventionists and using postponed consent is expected to promote inclusivity. Also, verbal consent or simplified forms could foster inclusivity. Although improved comprehension and trust may have positive effects on study enrollment, we emphasize the active involvement of the target group in the early stages of research projects when developing the study design, procedures, and the selection of measurements [39].

This study had a low attrition of the fathers, only 32% of the fathers used the app and 25% completed the usability questionnaires. In general, retaining participants in studies using mHealth apps has been described as challenging [40]. The found low attrition among fathers aligns with the results on the study on the NICU2HOME app, in which high usability scores were similarly observed among mothers, but lower engagement among fathers was noted [10]. Xie (2023) also found in her

systematic review of digital interventions for fathers of infants from conception to 12 months postpartum that fathers have expressed the need and desire for access to relevant, accurate, and up-to-date information on infant care and challenges associated with new parenthood and called for interventions that target father-identified priorities [41]. These studies and our findings highlight the importance of gaining a deeper understanding of perceived barriers to engage fathers.

The usability evaluation confirms that the app was responsive to the needs of parents with a premature infant. Given the evidence supporting user-centered iterative development, we strongly advocate for proceeding with the implementation of the e-TOP app ensuring it remains a valuable and available resource while integrating continuous user feedback by using real-time analytics e.g. engagement metrics [42][43]. Future research should focus on assessing the effectiveness by evaluating how app usage translates into improved parental confidence and decision-making in caregiving with the goal to reduce dependency on healthcare professionals and fostering parental autonomy.

6. Conclusion

The e-TOP app has demonstrated strong potential to complement information transfer to the face-to-face care after discharge and bridging the information gap for parents when they leave the hospital. While usability findings are promising, continued development, customization, and integration of the app with healthcare systems are necessary to maximize its long-term impact. By addressing user engagement, content expansion, accessibility, and healthcare integration, future versions of e-TOP can become an essential tool for empowering parents of preterm born infants and improving neonatal post-discharge care.

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Abbreviations

EOP: Expertisecentrum Ontwikkelingsondersteuning Prematuren.

IC: Informed Consent.

LHL: Limited Health Literacy

MP: Moderate preterm born infants (32^{0/7} - 34^{6/7} weeks of gestational age)

NICU: Neonatal Intensive Care Unit

PT: preterm birth.

TOP program: Transmural developmental support for preterm children and their parents

VP: Very preterm (<32 weeks of GA).

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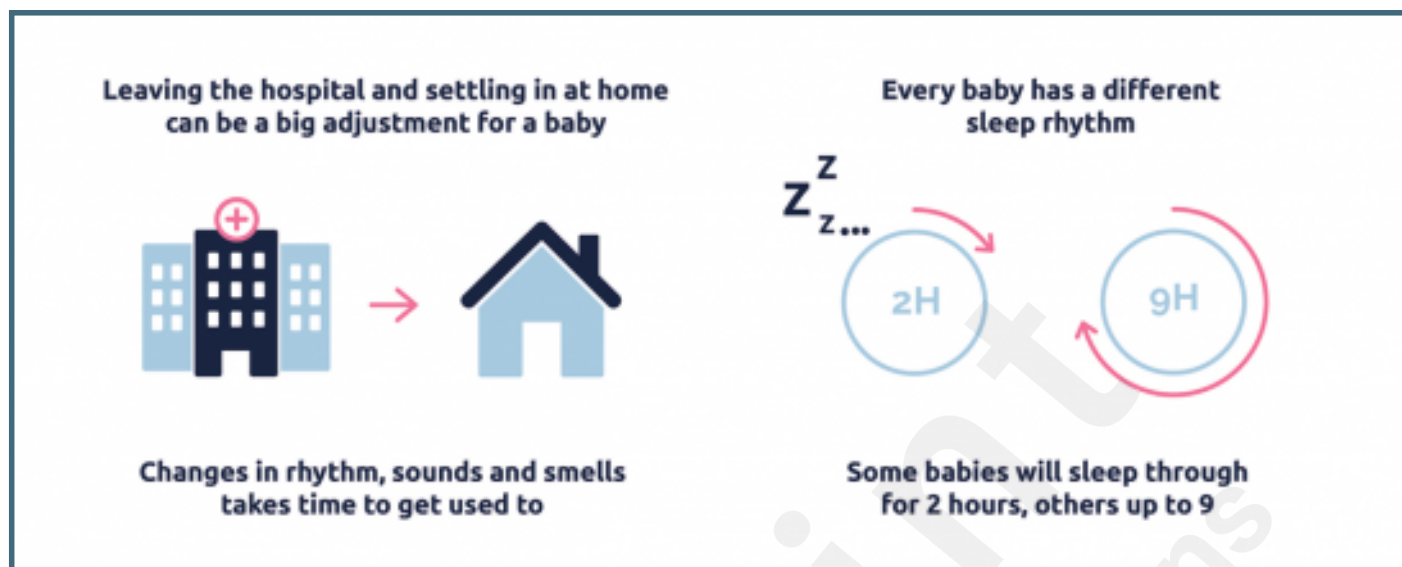
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Supplementary Files

Figures

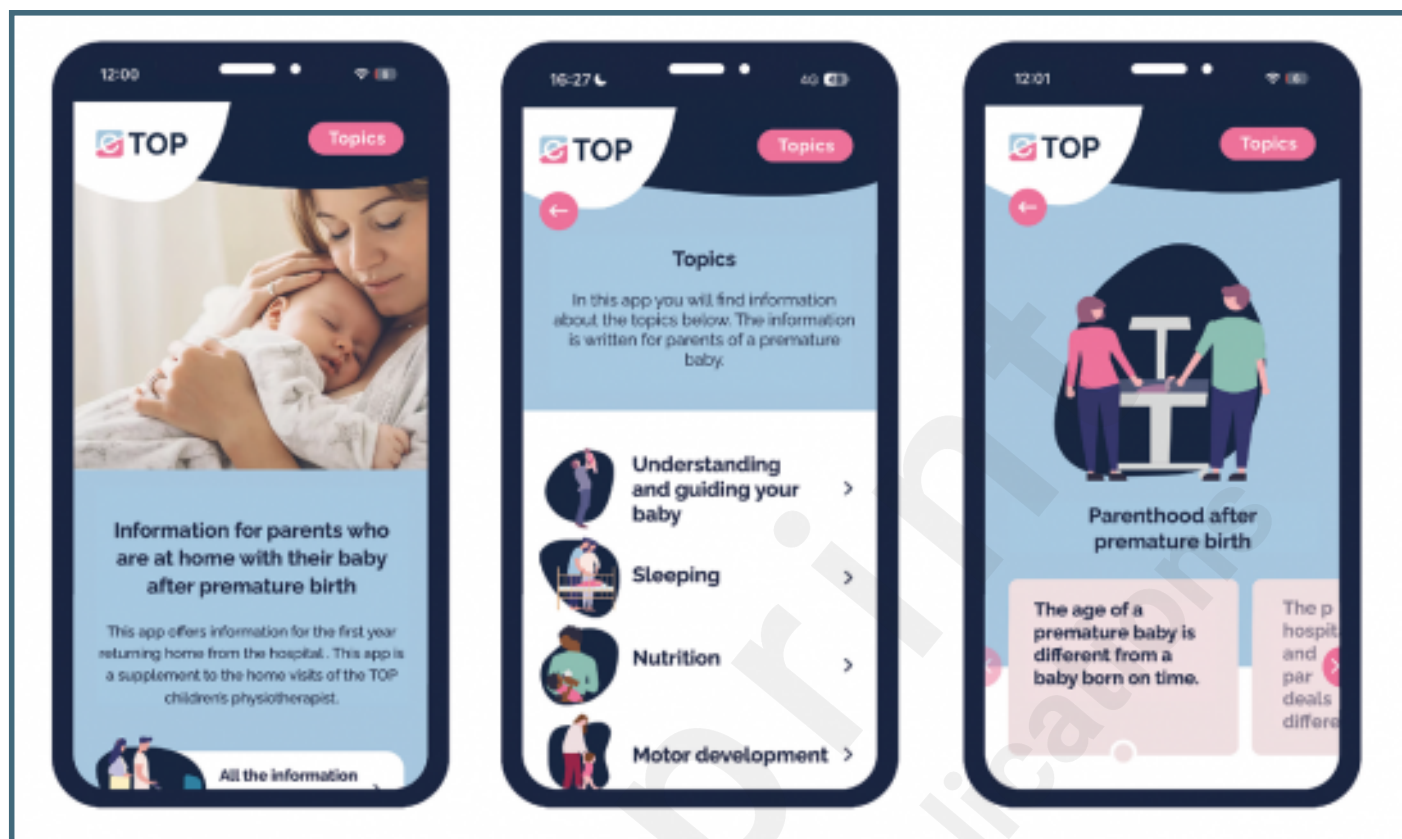
Information cards.



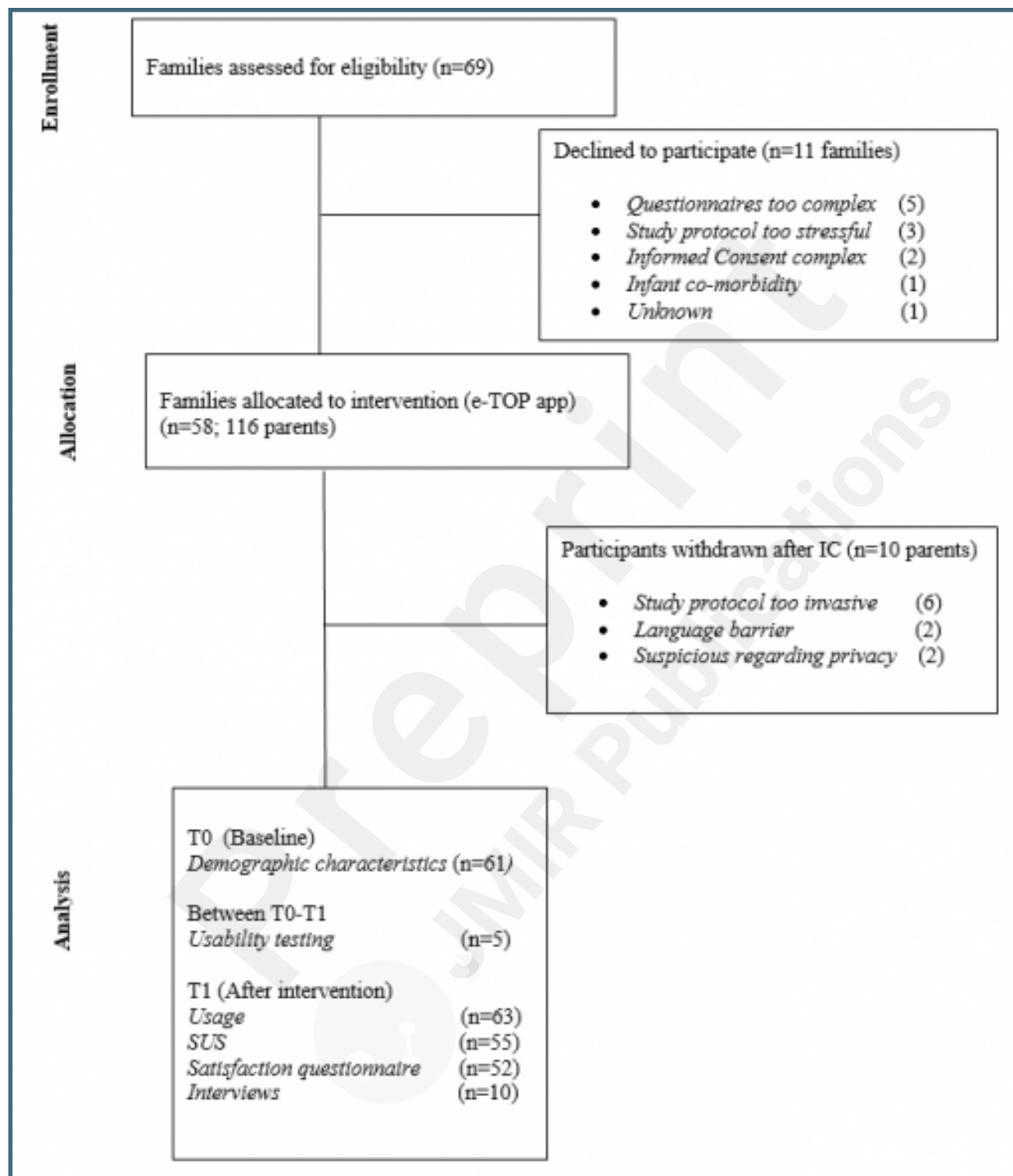
Mock up.



e-TOP app.



Flow of participants.



Time spent per week.



Actions per week.

