



Parents' information needs during the first year at home with their very premature born child; a qualitative study

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ARTICLE INFO

Keywords:

Very preterm infant
parents' experiences
Information needs
Discharge to home
Post-discharge intervention

ABSTRACT

Objective: To obtain insights into parents' information needs during the first year at home with their very preterm (VP) born infant.

Methods: We conducted semi-structured interviews with parents of VP infants participating in a post-discharge responsive parenting intervention (TOP program). Online interviews were audiotaped and transcribed verbatim. Inductive thematic analysis was performed by two independent coders.

Results: Ten participants were interviewed and had various and changing information needs during the developmental trajectory of their infant. Three main themes emerged; (1) Help me understand and cope, (2) Be fully responsible for my baby, and (3) Teach me to do it myself. Available and used sources, such as the Internet, did not meet their information needs. Participants preferred their available and knowledgeable healthcare professionals for reassurance, tailored information, and practical guidance.

Conclusion: This study identified parents' information needs during the first year at home with their VP infant and uncovered underlying re-appearing needs to gain confidence in child-caring abilities and autonomy in decision-making about their infants' care.

Innovation: This study provides valuable information for healthcare professionals and eHealth developers to support parental self-efficacy during the first year after preterm birth.

1. Introduction

In the Netherlands, very preterm (VP) births before 32 weeks of gestational age (GA) account for 1.3% of live births and represent a proportion of 6,9% of all preterm births (<37 weeks GA) [1]. Unanticipated preterm birth and admission to the high-tech Neonatal Intensive Care Unit (NICU) are very stressful for parents and have a lasting impact [2-5]. Parents have to cope with the emotional impact and consequences of preterm birth while trying to process information provided by medical staff about the infant's condition, treatment options, risks of complications, and uncertain long-term outcomes. Providing information is a key strategy since it generates a sense of control and facilitates the coping process [6]. This in turn can improve self-efficacy, affection, and infant bonding, all of which are linked to positive parenting- and long-

term child developmental outcomes [7-9].

Different factors such as individual learning style, stress coping, the complexity of information, and communication skills of the health care professionals contribute to what extent patients can process and retain information [7]. If VP parents have unmet information needs, they frequently use the internet to seek parenting- and health-related information. However, research has shown that the internet often lacks appropriate information for their situation [8,12-18]. Recent comprehensive literature searches revealed unaddressed information- and support needs before and after discharge from the hospital [9-11]. More promising results were found when using novel technologies such as smartphone applications designed around the needs of VP parents for the NICU and discharge period [19-22].

The Dutch healthcare system provides standardized and insurance-

Abbreviations: CA, corrected age; GA, gestational age; VP, very preterm; TOP program, Transmural developmental support for very preterm infants and their parents; FCC, family-centered care.

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<https://doi.org/10.1016/j.pecinn.2024.100270>

Received 11 October 2023; Received in revised form 16 February 2024; Accepted 28 February 2024

Available online 1 March 2024

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covered follow-up programs for all VP infants. A responsive parenting intervention, the TOP program, is part of the standardized post-discharge care for infants born before 32 weeks of gestation and/or with a birth weight below 1500 g in the Netherlands [23] and is provided by trained pediatric physical therapists (TOP interventionists). The TOP program aims to enhance the developmental opportunities for VP infants at a critical time of their life by targeting parental responsiveness toward their child. A key strategy within the TOP program is to provide parents with information about their child's care and development and psycho-education regarding the impact of premature birth (Fig. 1: Theory of Change). Most of this information is verbally provided by TOP interventionists during home visits and through an individualized written parental report. In our previous care evaluations, parents in the TOP program described difficulties in interpreting their VP infants' behavioral responses, managing wake-sleep patterns, and consoling their infants. In addition, daily activities such as feeding, handling, and engaging were described as challenging. Consequently, parents sought confirmation about specific care decisions and other health and development related topics. We were interested in the possibility of using additional e-health technology to meet the information needs of VP parents. The aim of this study was therefore to gain insights into the VP parents' needs for information during the first year at home.

2. Methods

2.1. Design and setting

This qualitative study consisted of semi-structured individual interviews with VP parents. All participants were included in the Dutch follow-up program and received the TOP program and therefore had access to healthcare professionals such as a pediatrician and a TOP

interventionist. Methods and results are reported according to the Consolidated Criteria for Reporting Qualitative Studies (COREQ) checklist [24].

2.2. Participants

This study was performed among Dutch parents. The inclusion criteria were parents who (1) received or just finished the TOP program, (2) had a VP infant with the corrected age (CA) between 6 and 12 months, and (3) were Dutch-speaking. The criteria of CA > 6 months were set to cover sufficient time at home, and also reduce recall bias. The research team informed the TOP interventionists about the aim and method of the study and asked them to approach families they were supporting with the TOP program. The purposive sampling was based on child characteristics: gestational age, first-born, multiple births, and parental factors such as gender, educational level, and family status (Table 1). The number of participants ($n = 10$) was expected to be sufficient to reach saturation and if necessary, could be expanded.

2.3. Data collection

An information letter was sent to parents who indicated interest in the study. Parents who consented to participate were contacted by telephone to schedule the interviews, the short online demographic questionnaire was subsequently sent by e-mail. The interviews were conducted by two interviewers (MF, RB) between April–June 2020, and lasted between 45 and 75 min. Due to the COVID-19 restrictions, participants were offered two options: by phone or virtual meeting. After verbal authorization, interviews were audiotaped. Interviewer MF, (female, nine years of experience working as a TOP interventionist) was involved as the main researcher in this study. Interviewer RB (female,

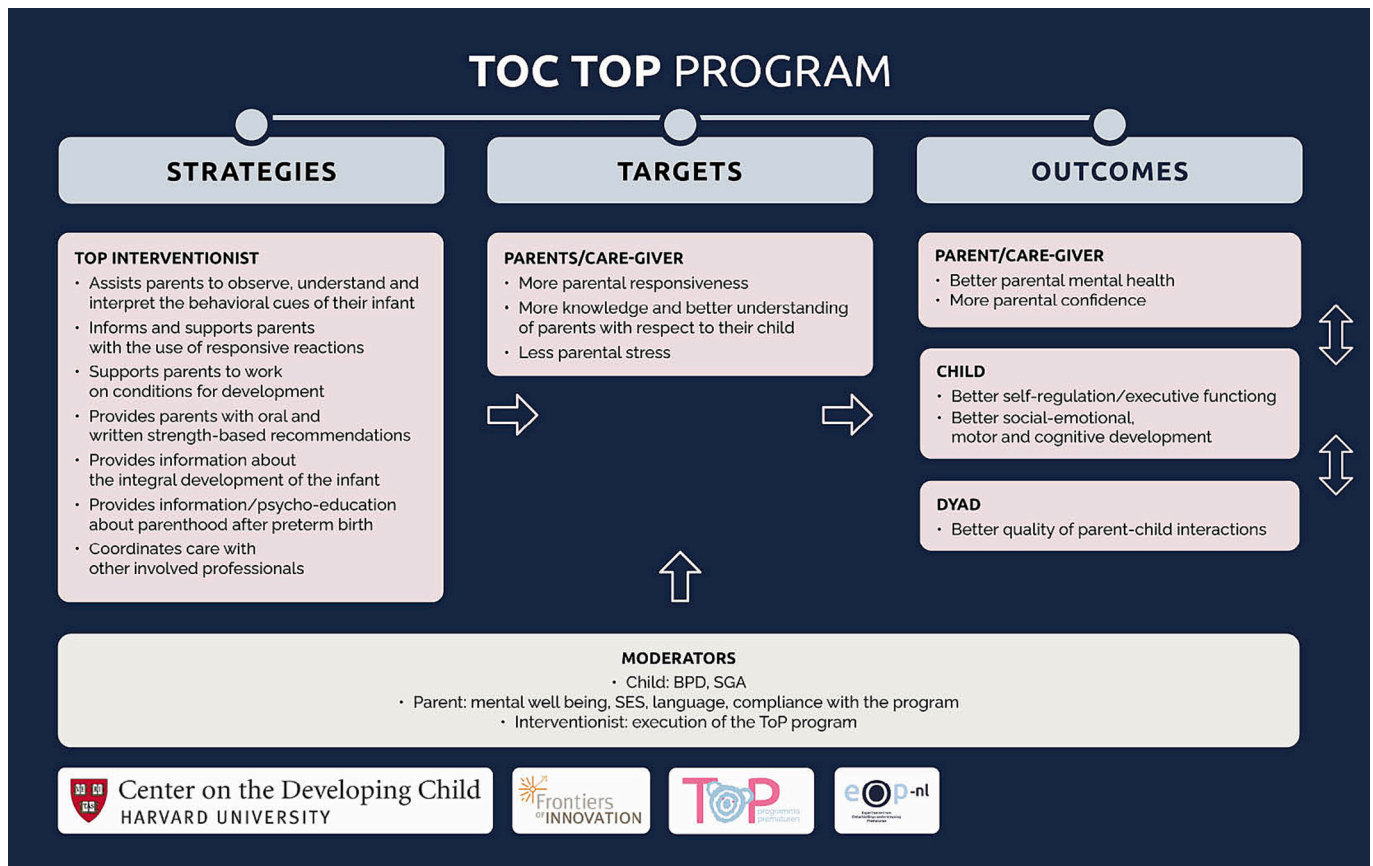


Fig. 1. Theory of change of the TOP program

Table 1
Participants characteristics.

	Relationship to infant	Age	Marital status	Parental education*	Employment	First born	Infant GA	Singleton/twin	Infant CA **	TOP home visits
1	Mother	28	Married	High	Paid job	First	26/0	Twin	12	12
2	Mother	27	Single	Middle	Paid job	Second	25/5	Singleton	8	10
3	Mother	25	Single	Middle	Sick leave	First	29/1	Twin	13	12
4	Father	41	Married	High	Paid job	First	24/6	Singleton	7	8
5	Mother	31	Married	High	Paid job	Second	31/3	Singleton	9	11
6	Mother	40	Married	High	Paid job	Second	26/0	Singleton	8	10
7	Father	30	Married	High	Paid job	First	31/1	Singleton	8	7
8	Mother	30	Married	Middle	Paid job	First	30/0	Singleton	8	9
9	Father	29	Married	Middle	Paid job	First	29/1	Twin	9	10
10	Mother	30	Married	High	Unemployed	First	25/1	Singleton	10	10

* Parental education; Low: no education/primary school—4 years after primary school. Middle: 5–8 years after primary school. High: bachelor/master level (CA).

** Infants' corrected age (months) during the interview.

pediatric physical therapist and clinical epidemiologist) had no pre-existing relationship with care for VP infants or their parents. The interview guide was developed in 4 phases (1) aligning interview questions with research questions, (2) constructing an inquiry-based conversation, (3) receiving feedback on the interview protocol, (4) piloting the interview protocol as described by Castillo-Montoya (2016) [25]. The topics of the interview guide were based on a pragmatic literature search focusing on information for VP parents after discharge, promising e-health applications, and the use and preferences for information sources. Interviews were listened, to reflect on the interview style. The two interviewers had regular meetings to discuss the interview technique. Interview questions were open-ended regarding parents' personal experience. Only for topic 6 (requirements and preferences for online sources) the interviewers used more structured questions or provided examples. Asking about their current use of existing information apps, exploring what they liked or not liked helped participants to articulate their ideas and define their requirements.

The interview guide entailed six topics: (1) experiences with the transition to home and received- or desired support, (2) needs for information regarding childcare and development during the first year at home, (3) information needs regarding parenthood, (4) perceptions of the provided information by TOP interventionists, (5) perceptions of using online resources, and (6) requirements and preferences for online resources.

2.4. Data analysis

An inductive thematic approach was based on the six-step process by Braun and Clarke (2006) [26]. First (1), the transcribed interviews were checked individually (against the recorded interviews) and read by the first author to familiarize with the data. For the next step (2), data were coded and organized using MAXQDA-Analytics Pro 2020. Two researchers independently coded the first two interview transcripts and discussed differences in their coding. A preliminary codebook was made by EV and MF to code the remaining transcripts. The codebook was refined by MF as the analysis progressed and new codes emerged in the interviews. In the third phase (3), the initial codebook identified specific information needs as well as patterns, meaning, and essential elements underlying parental information needs. Codes were then collated into potential sub-themes. In phase 4, two researchers (MF and FN) reviewed, interpreted, and discussed the themes by analyzing the underlying latent meaning of the initial themes. Phase 5 identified the main three themes from the subthemes through ongoing reflective dialogue. The findings were then presented and discussed with the research team. In the report writing phase (6), the analysis and themes were related to the research question and current literature. Quotes were in this last phase translated by an official translator to contribute to the best possible representation [27].

3. Results

3.1. Participant characteristics

Seven mothers and three fathers were interviewed. All approached families expressed interest in participating and responded positively. Subsequently, they were scheduled for the interview. All ten participants received at least seven TOP intervention sessions (Mean (SD) = 10 (1.6) / range: 7–12), and all infants were > 7 months CA. The socio-economic background varied although parents without education or < 4 years after primary school were not represented (Table 1).

3.2. The trajectory of information needs

On the first more general question; “How are you and [name infant] doing?”, all parents immediately started with the conversation by looking back at the NICU experience and the period after discharge. When the interview questions guided them toward the preceding months, additional experiences and new information needs emerged. The main themes in their information needs were; (1) Help me understand and cope, (2) Be fully responsible for my baby, (3) Teach me to do it myself. These themes re-appear during the first year at home (Table 2).

3.2.1. Help me understand and cope

The theme ‘help me understand and cope’ appeared initially within the context of the NICU when participants sought information to regulate their distress and manage their uncertainties about their infants' well-being. As one parent described:

“Yes, and in one of those first weeks, eh...it became clear that my child had had a minor stroke, eh...so, well you go and look that up too, while it applies to, in fact, 1 out of 3 or 1 out of 4 children have a stroke during the pregnancy but you don't know that” [P9].

Although the information from NICU professionals was generally perceived as adequate and prompt, all our participants used the internet as an additional information source to familiarize themselves with the NICU environment and their infant's medical condition. The search for information on the internet was described as: difficult to find, not

Table 2
Themes and subthemes.

Themes	Subthemes		
Help me understand and cope	Making sense of the experience	Struggling to feel confident	Seeking information to comprehend
Be fully responsible for my baby	Ambivalent feelings	Loss of professional support	Seeking information for caregiving
Teach me to do it myself	Reassuring and regaining agency	Feeling competent and trusting own parenting skills.	Needing personalized and specific information

helpful, and too many horror stories. These first negative experiences with internet search influenced further use of online sources and often led to the avoidance of the internet during the first year at home.

“Yes, well every child is different. You can Google things, but I have to say it didn't help me much at all, it was extremely difficult for us to find information on the Internet, so, in fact, at one point we simply stopped trying” [P10].

Participants expressed increased feelings of insecurity in anticipation of being discharged home. They all expressed mixed feelings of joy and readiness to go home while simultaneously having the awareness and fear of being fully responsible for their vulnerable child.

“You're pleased to be home again, but we also found it extremely tiring to be back home” [P1].

Once at home, parents encountered new challenges such as poor feeding intake, sleeping problems, and regulating their infant and expressed their insecurity and need for information for baby care.

“How could I know if there are too many stimuli? So, when do I give a bath, what can my baby handle, that is what I needed to know” [P1].

After the first few months, parents became more aware of the ongoing risks of prematurity and neurodevelopmental delays and sought information to compare their VP-born children with existing norms for full-term infants.

“With a premature baby, of course, you use their corrected age, uh..... so you can do that for the first two/three months because you know that they're nine weeks behind schedule, but will they catch up?” [P10].

Other participants started processing the impact of preterm birth on their well-being and sought support from professionals (psychologists) or found support from the parents' association Facebook group.

“How do you keep yourself upright and not get buried under the weight of taking care of your baby? This can be hard on your relationship as well, how do you share the responsibilities?” [P1].

“The Facebook group is made up of parents with premature babies or babies who were ill at birth. It's a nice group” [P4].

3.2.2. Be fully responsible for my baby

Participants perceived the transition to becoming a parent in an institutional context as complex. Feelings of insecurity and challenges associated with their parental role continue to be present in the transition phase of going home and throughout the first year. All of our interviewed parents described the fragile sense of parental agency and insecurity about being fully responsible for their vulnerable child.

“Yes, because after all, you're suddenly responsible for everything, whereas in the hospital you always had a safety net. You don't have that at home. Suddenly, find yourself without that safety net, in a different environment where you suddenly have to do everything yourself; well that is simply a whole new ball game” [P6].

Participants expressed conflicting feelings about holding on to prescribed schedules and protocols and starting to trust their parenting skills.

“The same goes for growth, they have to grow. We had weighing scales at home for a time. But after a while, we got rid of that too. We decided we had to let it go and keep a close eye on the baby, decide if it was feeling comfortable” [P3].

Engagement in their infant's hospital care improved their practical skills such as diaper change and provided them with insights about their infant's health issues. Some parents used the possibility of a 24-h presence (rooming-in), to prepare for discharge. For other parents, the transition to home came unexpectedly fast. Despite the preparation,

parents experienced a knowledge gap between hospital- and care at home.

“I found that really quite overwhelming. And then you're back home, and of course, before you go home the nurse does give you information, but it's more the basics, like how to get a bottle ready and test the temperature and so on, but very little else. Of course, in the end, you have to work it out for yourself. You have to get to know your child. But in general, I received very little support during that period” [P4].

In the hospital, information on the growth and body functions of the infant is collected daily by highly sophisticated equipment or health care professionals. The absence of a healthcare team to rely on, feeling responsible, and making caregiving decisions was challenging. Parents expressed difficulties in transferring their acquired skills and knowledge into their new situation and described new emerging information needs about practical topics, such as diapering, bed making, feeding, recognizing their preterm infant's needs, and sleep and wake patterns for the first days at home.

3.2.3. Teach me to do it myself

To achieve the desired confidence, parents require experienced, knowledgeable professionals who interact sensitively with the parent's needs and can reassure them.

“Like with postnatal maternity care, for example. The midwife was really good, it was just that she didn't know much about premature babies. I think it must be great if you have someone with experience in this field” [P1].

Parents appreciated the accurate timing and dosage of information provided by the TOP interventionist. This practical and deployable information was described as transferable and seemed to enhance their independence.

“If I needed advice about sleeping, for example, I was given information about sleeping. I didn't get too much information that wasn't relevant. The program was very much tailor-made. And that's what you want, that it suits your baby's needs. That you can use it in your situation” [P1].

During the course of the first year, participants' information needs changed to a need for specific and personalized information. Depending on the infants' developmental trajectory and own path of processing, participants identified their concerns and formulated their ideas for an additional information source. The ten most relevant topics, which parents sought more information about, are outlined in Table 3. There was a high agreement about these topics between parents. Parents indicated either had searched for this information on the internet or had missed it. Participants desired knowledge on how they can contribute to their infants' development, this was sometimes reinforced by concerns about the long-term impact of the premature birth.

“But I'm starting to get just a bit worried about things like, hmm, what about if my child is not doing so well when it starts school? I want her to have a problem-free life as possible. What can we do to make sure that happens?” [P7].

During the interviews, parents reflected on which additional information they would have liked to have and in which period or situation. All parents first and foremost seem to benefit from a comprehensive and tailored source accessible at desired times.

“You don't need all the information upfront, but you need to know more about where you can run into and who can I then ask for advice or where can find the information” [P1].

4. Discussion and conclusion

4.1. Discussion

This study was set up to obtain insight into VP parents' needs for

Table 3

Topics and subtopics.

TOPIC	Subtopics and concerns identified by participants
General health issues	Common pediatric health issues such as fever, a cold, getting teeth. How to decide if I need to visit the pediatrician or a general practitioner?
Motor development	Information about motor milestones (small steps), sequences in motor development. And how is this different for premature infants?
Regulation	What can I do to help my baby to regulate? What stimulus can my premature baby handle? How do I avoid sensory overload?
Feeding	Basic information about formula. When can I let go the tight feeding schedules. How and when can I transition to solid foods? Digestion-related questions.
Sleeping	How do I recognize the patterns of sleep and my baby's fatigue? Is it bad to let my premature baby cry? Suggestions for how to put your baby to sleep.
Prematurity	Why and until when use the corrected age? What are the anticipated problems for premature infants?
Long term outcomes	What are the increased risks for long term problems and what to expect for my baby? What can we do right now to prevent adverse outcomes?
Parenthood	Impact of premature birth and intensive caregiving on partner- and family relationships and our own wellbeing. How do you keep balance?
Going back to work	What if my baby is not ready for daycare? How do I inform my manager?
Professionals	What kind of help is available? Where do I find a knowledgeable professional?

information during the first year at home. Family-centered care (FCC) and the European standards for newborn health are extensively implemented in the Netherlands [28]. The participants in this study appreciated the efforts to involve them in hospital care and prepare them for discharge. However, this study clearly showed that despite these efforts, parents need personalized and specific support and information for new emerging developmental phases of their infant. Participants expressed the need for practical and confirming information to be confident in taking care of their baby at home. Knowledgeable and specialized healthcare professionals, such as the TOP interventionist and the pediatrician, were considered the most important source of information. Parents stated that reliable and tailored online sources can complement post-discharge care, but should not replace the professional. This is in line with a scoping review from David-Strauss and colleagues (2020) who highlighted the need for in-person support, such as a specialized home visitor, in addition to online sources [9].

The NICU period appeared to have a notable negative lasting impact on gaining self-confidence, making autonomous decisions, and trusting their parenting skills. Our participants seemed to benefit from the practical guidance to learn about their infants' behavior and needs, positive appraisal, and confirmation of their capabilities. Our findings correspond with Bandura's self-efficacy theory (1977) which describes the development of a strong sense of efficacy as influenced by four resources; mastery experiences, vicarious experiences, social persuasion, and somatic and emotional states [29,30].

The three ultimate themes, namely (1) Help me understand and cope, (2) Be fully responsible for my baby, and (3) Teach me to do it myself, are strongly interconnected to each other and re-appear during the first year after preterm birth at three distinctive periods; hospital, discharge, at home. These identified underlying needs are in line with the parental experiences after discharge described in the meta-synthesis by Adama et al. (2016) and the phenomenological study by Murdoch and Franck (2011) [31,32]. This qualitative study adds new insights into underlying requirements for reassurance, trajectory-dependent topics, and changing practical information needs. These insights could improve not only existing discharge programs, but should also be considered as foundations for creating new intervention programs.

Overall, participants perceived the available information about the impact and consequences of VP birth as insufficient or not appropriate

for their situation and indicated ten important topics for the first year at home corresponding with the priority topics found by Alderdice (2018) [33]. Parents were less likely to use online sources after hospital discharge, shaped by their negative experience of retrieving helpful information. This lack of written (discharge) information to complement interpersonal exchanges was also described by Lorie (2021) in a qualitative study with Dutch (NICU) parents [34]. This underlines the need for the joint development of an online information source for VP parents, growing with them during the different phases of their trajectory.

Developing a tailored information source for VP parents at home is a first and essential step before evaluating if e-health technology can be a good strategy to support parental self-efficacy. In this study, we asked participants to reflect on this future scenario and learned it is not easily solved by providing just more information to enhance knowledge. To make the use of (online) information sources successful for VP parents, we must also take into account the complexity of the found underlying emotional needs, all in line with how Lee (2012) described self-efficacy; a person's belief in his or her ability to succeed in a particular situation [30]. Also endorsed by van Gemert-Pijnen (2019) who described the need for a comprehensive and holistic view of supporting health care by e-Health technology addressing the need for recognizing interdependencies between individual characteristics and the ability to use e-Health technology [35,36]. When carefully considering the unique needs of the VP parents, the combination of e-health technology and a healthcare professional can support the shift from time- and healthcare professional-dependent delivery of information to self-management.

4.2. Limitations

The number of participants (10) was set in advance and followed by strategic sampling. The interview number was large enough to reach data saturation. All participants had a good understanding of the Dutch language, which was a pre-condition for the interviews but may have limited the inclusivity of parents with a low educational level. Involving non-native Dutch parents and parents with a lower educational background could have provided an additional layer of understanding. However, the middle and highly-educated participants expressed their information needs, and we expect that the parents with lower education will also require more tailored information. Further research in the development of information sources is essential to not enlarge the already existing disparities between education levels.

4.3. Innovation

This study shows the importance of retrieving in-depth information about parents' needs before designing a useful and parent-empowering e-health application. Our findings target unaddressed needs in existing (digital) information sources for VP parents after discharge. By addressing the underlying themes found in this study, e-health technology solutions can be more tailored for the unique needs of the target group. This study is useful because it gives information that can be directly converted into practical implementation. Participants did not only reflect on their trajectory dependent information needs but also provided ideas for improvement. The underlying need to feel confident and gain autonomy requires strength-based and re-assuring information and tone of voice. Participants identified information needs for a substantial number of topics e.g. infant feeding, sleeping, or motor development. The information needs change over time, requiring specific age- and development related information provision along the trajectory of the first year. The transferability to their own unique situation requires information that is easy to understand and apply. Another important finding was the preferred approach for support from a professional in combination with a digital information source (blended care). Findings of this study can be used as a starting point for development and co-designing an applicable and useful information source to support VP parents.

4.4. Conclusion

The present study shows the pervasive impact of premature birth on parental confidence and identifies parental information needs during the first year at home with their VP infant. The underlying themes further extends the understanding of how to support parental needs for information. Participants expressed a preference for a knowledgeable healthcare professional in combination with a customized information source accessible when needed. These results are relevant for e-health developers in the field of neonatal care since these findings give direction for the (content) development and use of e-health technology to support VP parents' self-efficacy.

Informed consent

All personal identifiers have been removed or disguised, so participants cannot be identified through the story's details. All participants have provided online informed consent.

Funding

This research is co-financed by 'Regie Orgaan SIA', part of the Netherlands Organisation for Scientific Research (NWO) [RAAK. MKB13.004 / 2021]. The funding source had no involvement in the study design, the collection, analyses, and writing of the report, or the decision to submit the article for publication.

Ethical approval

The Medical Ethical Committee of the Amsterdam Medical Center waived the need for ethical approval as the study is not subject to the Medical Research Involving Human Subjects Act [W20_011#20.036].

CRedit authorship contribution statement

Monique Flierman: Writing – review & editing, Writing – original draft, Project administration, Methodology, Formal analysis, Data curation, Conceptualization. **Daniel Bossen:** Writing – review & editing, Writing – original draft, Supervision, Project administration, Methodology, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Rosa de Boer:** Writing – review & editing, Writing – original draft, Formal analysis, Data curation, Conceptualization. **Eline Vriend:** Writing – original draft, Methodology, Formal analysis, Conceptualization. **Fenna van Nes:** Writing – original draft, Supervision, Methodology, Formal analysis, Conceptualization. **Anton van Kaam:** Writing – review & editing, Writing – original draft, Supervision, Methodology, Formal analysis, Conceptualization. **Raoul Engelbert:** Writing – review & editing, Writing – original draft, Supervision, Project administration, Methodology, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Martine Jeukens-Visser:** Writing – review & editing, Writing – original draft, Supervision, Methodology, Formal analysis, Data curation, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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