Parents' experiences of VOICE: a novel support programme in the NICU

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Patient consent statement: Written informed consent was obtained from all parents included in the study.

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Author Contributions

AvdH, RE, and JML designed the study and protocol. HDLO, FJ, SMOM, MJJ, LV, JvdN provided support to the study team. RE and AvdH contributed to the data collection. RE, AvdH, HDLO, FJ and JML performed data analysis and interpretation. RE and AvdH drafted the first manuscript. All authors provided comments and approved the final manuscript.

ABSTRACT

Background: Admission of an infant to a Neonatal Intensive Care Unit (NICU) is often a stressful experience for parents and can be associated with feelings of inadequacy to fulfil the desirable parental role. The VOICE (Values, Opportunities, Integration, Control, and Evaluation) program was developed to engage parents in care, decrease stress and to increase empowerment.

Aim: To explore the experiences of parents regarding the involvement in the VOICE program during admission of their infant to the NICU.

Design: The VOICE program includes at least five personal structured meetings between parents, nurses, and other healthcare professionals throughout the pathway from birth, NICU and follow-up. A qualitative design was adopted using semi-structured interviews. Interviews with 13 parents of 11 infants born <27 weeks gestational age were conducted: nine mothers and two couples of father and mother. Thematic analysis was deployed.

Results: The findings have been described in one overarching theme: 'Parental Empowerment'. Parents felt strengthened and were empowered in the development of their role as primary caretaker by the VOICE program. The Parental Empowerment theme emerged from four related interpretive themes were derived: 1) Involvement in care, 2) Personalized information and communication, 3) Transition to a parental role and 4) Emotional support.

Conclusion: The VOICE program can be a structured approach of implementing family support in a NICU to empower parents becoming a partner in the care of their infant and feel confident.

Relevance to Clinical Practice: This study encourages healthcare professionals to provide parental support through a structured intervention program, which contributes to the empowerment of parents in the NICU and encouraged them to participate in care and decision-making.

Keywords: Parents; empowerment, family support program, preterm infants, neonatal care; Family-centred care.

What is known

- Admission of an infant to a Neonatal Intensive Care Unit is a stressful experience for parents.
- Parents experience feelings of inadequacy to fulfil their parental role.

What is new

- Participation and involvement in care and personalized meetings are important factors to support parents in a NICU.
- Parents feel empowered in their parental role, when they are informed and encouraged to participate in care and decision-making.
- The VOICE program as a parent support intervention contributes to the empowerment of parents in the NICU.

INTRODUCTION

Admission of an infant to a Neonatal Intensive Care Unit (NICU) is often a stressful experience for parents and can be associated with feelings of inadequacy to fulfil the desirable parental role (1;2). Worries about the infant's health, the unfamiliar setting, technology and monitoring can interrupt normal family functioning and bonding (2).

To support parent-infant interaction and the parental role during NICU admission, different programs have been developed (3;4;5;6;7). Complementary to the well-known Newborn Individualized Development Care en Assessment Program (NIDCAP) and Kangaroo care interventions, these programs support parents based on the principles of family centred care (FCC) and family integrated care (FIC), with an emphasis on family support and facilitating parents' understanding of their child's developmental and physical care. Melnyk et al describes the COPE program (Creating Opportunities for Parent Empowerment) as standard practice including parents of premature infants, while O'Brien et al developed the Family Integrated Care model in neonatal intensive care (3;5;6;8). The programs often include parents of premature infants born < 37 weeks of gestational age (GA) and extremely premature infants < 27 weeks of GA (8;9;10;11;12;13). Evaluations of these programs have demonstrated a reduction in parental depression, anxiety and stress, as well as improved parental empowerment, confidence and competence (5;8;13). However, the previously developed parent support interventions mainly concentrate on the clinical admission period and lack an evaluation component after discharge.

A structured VOICE (Values, Opportunities, Integration, Control and Evaluation) program was developed to empower parents of extreme premature infants. The VOICE

program is inclusive throughout the pathways of an extreme premature infant from prenatal to the follow-up period after NICU admission. The VOICE program is specifically developed to empower parents of extreme premature born infants < 27 weeks of gestation as they might benefit most of this program due to their extended length of stay in the NICU.

The aim of this study was to explore the experiences of parents regarding their involvement in the VOICE program, specifically during the period the infants were admitted to the NICU.

METHODS

Design*:* A qualitative research method was adopted with face-to-face semi-structured interviews. The guideline 'Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups' has been used to report this study (14).

Setting: The study was conducted in a 24-bed tertiary NICU in The Netherlands with around 650 annual admissions.

Sample and Recruitment: A convenience sampling was used to gain insights in different perspectives. The inclusion criteria were being a parent of an infant born <27 weeks gestational age admitted to the NICU and participating in the VOICE program. Parents were excluded if they were unable to speak Dutch or if their infant had a prognosis of imminent death. Parents were informed about the study by an independent researcher and at that time they received both oral and written information. Parents were approached and asked to participate in order of admission of their infant. When

parents were willing to participate and gave consent, an appointment for an interview was made.

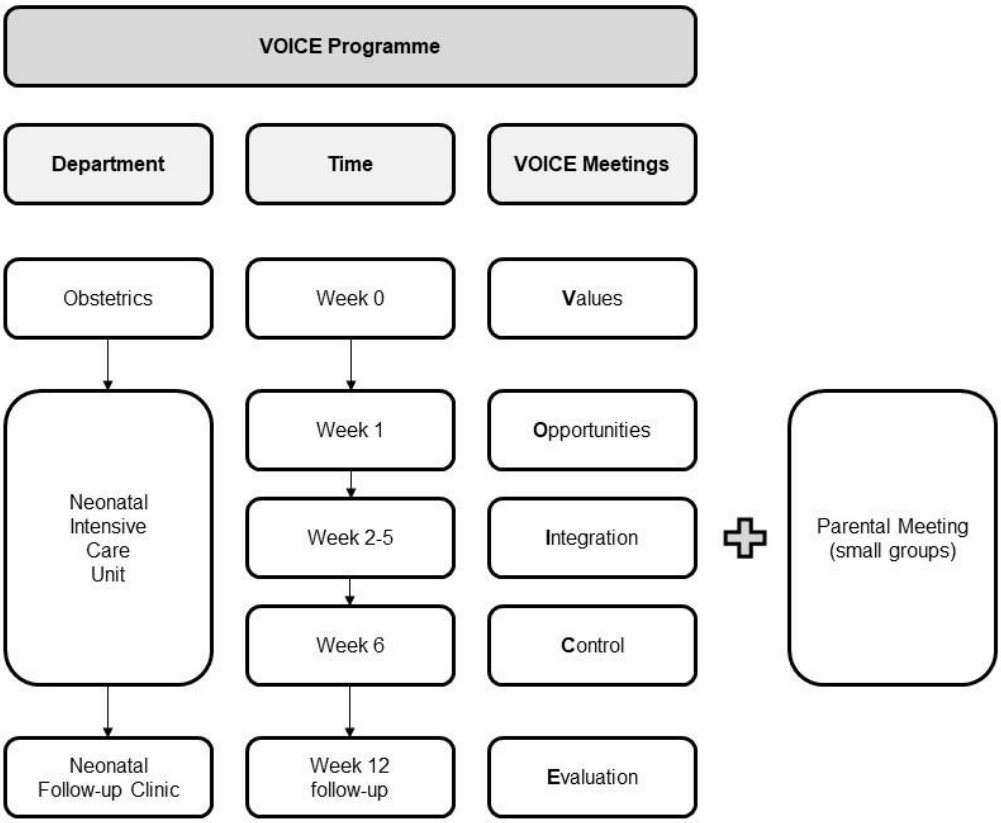
VOICE Program

To support and empower parents of preterm infants, a program was developed called VOICE: Values, Opportunities, Integration, Control and Evaluation. The VOICE program is based on previous research indicating the need for a structured support program that meet the needs and wishes of parents in the NICU (15;16;17). Compared to previously developed FCC interventions to support parents, the novelty of the VOICE program is that it is designed to support parents throughout the full pathway from prenatal, birth, NICU, and follow-up care.

The program exists of at least five structural interdisciplinary focussed meetings with parents, before, during and after an NICU admission, to inform and discuss with parents their role in how to care for their infant and building a partnership between parents and caregivers. The five VOICE meetings, lasting around 20-30 minutes each meeting, are designed with a specific focus (Fig. 1). The first meeting is focused on Values (V): During an antenatal conversation at the obstetric ward, the focus of this meeting is on preparing the parents for NICU admission and building mutual trust and confidence between parents and health care professionals (nurses, neonatologists and social workers). The second meeting is centred around Opportunities (O): In the first week of NICU admission, consultation regarding the wishes and needs of parents are explored and discussed (by a neonatal nurse and social worker). The third meeting is about Integration (I): During the NICU admission period the focus is on integration of the parents' wishes and needs, including their involvement in care and treatment of their

infant (by neonatal nurse, physiotherapists and occupational therapists). This meeting is repeated on a weekly basis till the last week of the expected discharge. The forth meeting is held in the week of expected discharge and is focused on Control (C): At the end of the NICU admission the focus is on knowledge of parents regarding the transition towards discharge and the care at home (by neonatal nurse). The final meeting is Evaluation (E): During the follow-up visit (6 weeks after term date) the focus is on evaluating the experiences of the parents regarding the NICU admission and discuss emerging questions regarding care of their infant in their home situation (by social worker and neonatal nurse).

In addition to these series of VOICE meetings, parents are invited to visit the weekly parental classroom meetings (Fig 1). During these meetings, parents are educated by physiotherapists, occupational therapists, lactation specialists and nurses on several subjects such as breastfeeding, developmental care, learning to know your infant and transition to another department or another hospital. In these weekly parental meetings, an exchange of thoughts and feelings of parents are discussed with the emphasis on positive support for the parents.



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194 Fig 1. VOICE program and Parent Meetings

195 **Data collection:** *S*emi-structured interviews were conducted between February 2017
196 and October 2017. The interviews were audio-taped and transcribed ad verbatim.
197 Interviews were conducted in Dutch and held in a quiet room in the hospital prior to
198 discharge of the infant. Due to the nature of data collection in this study, by organising
199 the interviews before discharge, we were not able to evaluate the E (Evaluation meeting
200 at follow-up) of the VOICE program. However, this evaluation will be performed at the
201 follow-up clinic in another study. The researcher (MJE) who performed the interviews
202 was trained in interview techniques and pilot interviews were performed (14). The
203 interview-guide was based on recent literature and expert opinion (Electronic

Supplement Material 1). Demographic characteristics of the study participants as sex, age, education level of the parents and gestational age, birthweight and admission time of the infants were collected during the interviews. Data were collected until data saturation was obtained. Data saturation means that no new information is collected regarding the selected research topic.

Data analysis: Thematic analysis was performed with an inductive approach; data coding was performed without using a pre-existing framework. Thematic analysis involves the searching and coding across a data set to find repeated patterns of meaning, so called themes. We adopted the thematic analysis described by Braun and Clarke (18). This involves six phases to explore meaningful repeated patterns in the data: Step 1 was familiarising with the data: The manuscripts were read several times. To ensure rigour and trustworthiness, each transcript was read and coded separately by two researchers (ME and FJ) independently. In step 2, generating initial codes, the individual narratives of parents were coded. Step 3, searching for themes, was performed by collating codes into sub-themes. If uncertainty appeared in this process, the linked narratives belonging to the codes were reviewed back to better understand the underlying meaning of the code and the sub-theme. Step 4, reviewing themes, was performed by combining sub-themes to themes if appropriate. If sub-themes were clearly indicating a specific meaningful theme, this was kept as an individual theme. Step 5, defining and naming themes, was the ongoing analysis of reviewing the codes and generated (sub)themes. Refinement of the themes was considered to improve the clarity and relevance of the themes. This process was performed with a third researcher

(AvdH). Any disagreement of the codes, sub-themes and themes was solved by discussion. Step 6, producing the report, the findings are reported in this paper.

Consensus among the researchers was reached after each step.

Furthermore, member checking was performed by sending the participating parents a resume of the analysis asking if they agreed with the findings and if there were missing determinants. The used quotations in the results section are anonymized by codes: M=mother and F=father added with the number of the study interview.

Ethical considerations: Verbal and written information was provided to eligible parents. All participating parents provided written informed consent. The Medical Research Ethics Committee of the University Medical Centre Utrecht approved the study (Protocol number: 17-059/C).

FINDINGS

Eleven semi-structured interviews with parents were completed with 13 participants: nine interviews with mothers and two interviews with both mothers and fathers (Table 1). The interviews lasted between 30-45 minutes. Mean age of the parents was 33 years (range 28-43). Gestational age of the infants was between 24-27 (mean 25.8) weeks and birthweight between 700-1070 (mean 899) grams (Table 1).

Table 1: Characteristics of Parents (n = 13) and infant (n = 11)

Interviews mother (M) father (F)	Parents Age	Parent education h=high m=moderate	Siblings No/Yes	Infant Sex (M / F)	Infant GA (weeks)	Infant Birthweight (gr)	Infant LoS NICU (days)
M1/F1	30/30	h/h	No	F	$26^{5/7}$	955	80
M2/F2	28/30	h/h	No	M	$25^{4/7}$	930	121
M3	38	m	Yes	M	26	950	128
M4	43	h	Yes	M	25	710	94
M5	34	h	No	M	$24^{3/7}$	700	126
M6	30	h	No	M	$26^{6/7}$	1025	43
M7	37	h	Yes	M	$26^{1/7}$	900	43
M8	33	h	No	M	$26^{5/7}$	1030	40
M9	35	m	Yes	M	$26^{4/7}$	800	104
M10	28	h	No	F	24	710	79
M11	34	h	No	F	$26^{1/7}$	1070	105

gr=grams; M/F= Male / Female; LoS=Length of Stay

The findings have been described in one overarching theme: 'Parental empowerment' (Table 2). Parents felt strengthened and were empowered by their involvement in care and the VOICE program. This is reflected by four related interpretive themes: 1) Involvement in care, 2) Personalized information and communication, 3) Transition to a parental role and 4) Emotional support (Table 2).

257 **Table 2.** Summary of Overarching and Interpretive-themes and Quotations

Overarching Theme	Interpretive themes	Quotations
Parental Empowerment	1. Involvement in care	Involved as a partner in healthcare by caring myself for my baby made me strong (M8)
		Involved in care gave confidence (F2)
		The webcam made it possible to be involved and it helped me even while pumping breastmilk (M10)
		The possibility to be more connected by caring is appreciated very much (M6)
	2. Personalized information and communication	Parental meetings were very informative in education about the principles of developmental care (M5)
		Other parents asked questions, which contributed to knowledge (M5)
		Motivating to get information and to learn to observe the behaviour of my infant together (M6)
		A huge amount of written and oral information during NICU admission and difficult to remember all of it (M9)
	3. Transition to a parental role	We did the care all by ourselves. It was our own process and very meaningful for us to feel complete as a parent (M5)
		Being involved as a partner in healthcare contributes to my parental feelings (M8)
		As a father, I have the full responsibility for my infant. In order to fulfill my role as a father, I need to know about all the daily choices and considerations of the doctors (F1)
		Information about handling and positioning are not only useful in the NICU period but also in the period after admission (M5)
	4. Emotional support	Nurses and doctors were very friendly and always asking how we were doing, this was very supporting (M9)
		We were surviving in the NICU and without the social worker we hadn't discussed feelings of mourning and anxiety. It helped us to reflect on our situation (M5)
		It was nice to tell them my story to nurses and to have somebody who was just listening and who understood the situation on the NICU (M9)
		We had a lot of contact with our relatives but everyone liked to hear good news. It helped to talk with other parents from the NICU (F1)

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Involvement in care

The VOICE meetings helped parents to express their needs and wishes and how they wish to participate in caring for their infant in a way that they wanted. Parents valued active participation in care of their infants and having skin-to-skin contact stimulated. It empowered the parental role: "*To hold him and to care for him gave me warm feelings and contributed to stronger feelings of being a mother" (M7)*. The possibilities of being 24/7 present at the ward, and to be engaged in caring for the infant was very important for parents. In addition, getting confidence by the NICU staff during the VOICE meetings and being connected is important for parents: "*A very experienced nurse, involved us in care of our infant and gave us a lot of confidence"(F2)*. In summary, participation in VOICE and involvement in care are important factors to support and empower parents in the NICU.

Personalized information and communication

All parents indicated that personalized, open, understandable and honest communication from the NICU staff throughout the VOICE meetings was very important to facilitate a positive parent-staff relationship. Important areas of information and support would include information on infant health, both medical and technical, infants' care, and how to be involved. Neonatologists and neonatal nurses are the primary sources of information. Parents appreciated it when the same doctor and nurses were responsible for their infant during the NICU admission. The nurses, physiotherapists and occupational therapists informed and educated the parents about the principles of developmental care such as one mother mentioned: *"The NICU nurse encouraged us to participate in the care. We learned a lot by observing how nurses cared and by copying*

their practice" (M9). Parents who visited the educational parental meetings reported that this program gave them a lot of information and support from other participating parents: "*The parental meetings were very informative and it was very nice to meet other NICU parents to share some feelings and experiences about behavioural cues and because other parents asked questions, which contributed to my knowledge" (M5)*. Also, parents were positive about the VOICE meetings and the personalized training with the physiotherapist or occupational therapist where they received information to look at their infant's behaviour when caring for their infant, like one mother said *"It was very motivating to get information and to learn to observe the behaviour of my infant together. I looked forward to the next round to handle even more sensitive than I already did" (M6)*. Overall, parents feel empowered in their parental role, when they are informed and encouraged to participate in care and decision-making. VOICE contributes to their knowledge.

Transition to a parental role

Parents indicated that the VOICE program changed their role as a parent from feeling powerless and *"can't do anything"* to fully participating in their infants' care and decisions. Parents indicated that it was very important to get control over the care of their infants in order to establish their role as parents. They need confidence to do so, as some mothers indicated: *"We did the care all by ourselves. It was our own process and very meaningful for us to feel complete as a parent" (M5).* Other parents mentioned that they felt it was their responsibility to be involved in the healthcare team as a serious partner. *"As a father, I have the full responsibility for my infant. In order to fulfill my role as a father, I need to know about all the daily choices and considerations of the doctors"*

(F1). Briefly, the VOICE meetings contribute to participating in care and empowerment of parents. Additionally, the program also helps to support and accept their parental role.

Emotional support

Emotional support by neonatal staff was important throughout the VOICE meetings: "*The nurses were so very friendly, and kind and the doctor always asked how we were doing, this was very supporting" (M9)*. Most of the parents experienced the VOICE meetings as valuable in supporting their emotional feelings. Parents mentioned that individual emotional support and confirmation of what they did well was of great value: "*We got a lot of compliments and it supports us to feel positive and to feel more confident with the whole situation" (M9)*. Parents made a distinction between the practical information they received from the social worker and emotional support from others. Practical information such as how to deal with the duration of maternity leave, the possibilities of postponed maternity care was given to all parents and reiterated during the C meeting (Control) in the VOICE program. All parents expressed that this kind of practical information was very useful. Emotional support was targeting the emotional rollercoaster parents faced in the NICU. This was often discussed in the O (Observation) and I (Integration) meetings of the VOICE program with various team members attending, like one mother mentioned: "*We were surviving in the NICU and without the social worker we hadn't discussed feelings of mourning and anxiety. It helped us to reflect on our situation" (M5)*. Some parents indicated that they had no need to share emotional feelings during the VOICE meetings. They preferred to discuss emotions with their partner and other relatives. Other parents indicated that sharing their

story and feelings helped them to process all things that happened around birth and admission to the NICU: "*It was nice to tell them my story and to have somebody who was just listening and who understood the situation on the NICU" (M9)*.

The VOICE meetings have been supporting the parents specifically about the feelings of being in an 'emotional rollercoaster'. However, some parents also want to share their thoughts and emotions with peers.

DISCUSSION

The findings of our study regarding the experiences of parents participating in the VOICE program during NICU admission identified one overarching theme: 'Parental empowerment'. Empowerment reflects on knowledge, capabilities, motivation and opportunities (14). It is a process, however, there is not an unambiguous definition. Instead, a variety of definitions is known and often empowerment refers to a combination of ability, motivation and increase opportunities, including activation, enablement, involvement, and participation (19). Parents indicated that the VOICE meetings empowered them and helped them to gain more knowledge and experiences in caring for their infant which improved their parental role. Our findings highlight the need for support and promote the application of the principles of family centred care (20).

All parents indicated that personalized, open, understandable and honest communication in receiving information from NICU staff was very important to facilitate a positive parent-staff relationship. This confirms the results of the study by Friedman et al. who showed that a collaborative open interaction with the neonatal staff is a an

important factor for parents to feel comfortable in NICU settings (21). Parents are supported to discuss their involvement in their infants' care with increasing responsibility during admission till discharge. Support and personal information are important in making parents feel valued and become active partners. As documented in the literature and in our study, neonatal nurses have an important role in guiding parents to become comfortable and autonomous (21;23). Previous research emphasized that giving parents the opportunity to perform care routines by themselves and supervise them in a positive way improves the parent-infant relationship as well as the parent-nurse relationship (24;25).

Parents were positive about the individual support during the VOICE meetings, which contributed to a higher sensitivity and better understanding of their own and infant's needs. A positive approach to meet the individual needs of parents provide confidence in the day-to-day care (24). Parent participation in educational programs providing information and opportunities for sharing has been shown to reduce parental stress and anxiety, and improves confidence and competence (12;23;26). This corresponds to the findings of our study where parents gain more insight in how they could support their infants in an optimal way which empowered them. To increase learning and to meet the needs of parents, studies have indicated that the use of multiple approaches is important (8;27). Different educational programs have been reported that a combination of observation, written information and discussions are preferred methods to support parents (26). This is also shown in our VOICE program where parents receive information and education during the VOICE meetings and the weekly parental educational sessions with experts. In addition, parents receive medical

and technical information from doctors and nurses during daily rounds where parents are invited which they valued as very important.

Providing support to parents is one of the key caring responsibilities of NICU staff, specifically in connection with the family-centred care approach. The VOICE program was initiated to provide a structured approach to support parents throughout the pathway of a NICU admission. The program was initiated to provide a structured support to complement other support that is often provided in unscheduled conversations at the bedside. We acknowledge that our VOICE program complements other interventions to support parents which have been standard practice for some years in the NICU, community. An example is the intervention related to new mothers who received peer support through a "buddy" program. These mothers experienced less anxiety and greater social support than mothers who did not participate in the buddy program (23;28). Perhaps the synergy of various support programs in a NICU can contribute to the empowerment and partnership between parents and staff; the whole is greater than the sum of the parts.

In our study, the VOICE program corresponds with many aspects of family centred care in the NICU and therefore might be considered as a transferable and beneficial program in neonatal care (8;29). Understanding the needs of parents, to empower them and to give them confidence is an important goal of the VOICE program. Active listening to the views of parents is a powerful element to understand the individual needs and to create a fundamental improvement in quality of care based on empowerment of parents. In order to empower parents and support them in their parental role to reduce stress and anxiety before, during and after NICU admission,

parents need to be involved as partners in care in every neonatal ward and NICU globally. However, 'parental empowerment interventions' in the NICU need more robust studies to confirm the effectiveness on parents' health outcomes and infants' clinical outcomes (12).

Strength and limitations

The strengths of our study were that the newly introduced VOICE program was evaluated by interviewing parents (both mothers and fathers) who were involved in the program. Another strength was the rigour and trustworthiness of the qualitative methods by training junior researchers, involving experienced qualitative researchers in the analysis and constant feedback. Limitations were the origin of the different parents included. The participants were mostly Caucasian Dutch mothers and only two fathers participated. Parents with other ethnicity might have different experiences and needs. Further studies need to confirm the impact of these cultural differences. Another limitation could be the small sample size, however after ten interviews saturation of data was reached and no new information was gained. Therefore, after the eleventh interview the recruitment was stopped. Finally, the VOICE program was evaluated with parents who were still present at the NICU. The conversations of the fifth VOICE meeting (Evaluation) have not been explored. Further studies should test the full program including long-term follow-up.

CONCLUSION

Participation and involvement in care with personalized structured and focussed meetings are important initiatives to support parents in the NICU. There is a need for

transparent, clear and respectful communication between parents and healthcare professionals. A multi-disciplinary approach adds value in supporting parents in their role in the NICU. The VOICE program is structured framework of implementing family support in the NICU to support and empower parents. Further studies need to confirm the effect on parental outcomes and infants' health outcomes.

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