Original Article

Perceptions of mothers of premature babies regarding their experience with a health educational program*

Percepções de mães de prematuros acerca da vivência em um programa educativo

Percepciones de madres de prematuros acerca de la vivencia en un programa de educación en salud

Geovana Magalhães Ferecini[1], Luciana Mara Monti Fonseca[2], Adriana Moraes Leite[3], Mariana Firmino Daré[4], Carolina Souza Assis[4], Carmen Gracinda Silvan Scochi[5]

ABSTRACT

Objective: To identify the perceptions of mothers of premature babies regarding their experience with a health educational program using participant observation methodology. **Methods:** Thirty-eight mothers of inpatient premature babies of a neonatal unit participated in the health educational program. The goal of the educational program was to provide mothers with the knowledge and skills to care for their premature babies. Paulo Freire's theory of education served as the framework for the study. An educational booklet and group activities were used to stimulate mothers' perceptions regarding the educational program. A thematic analysis was used to identify the perceptions of mothers regarding the educational program through participants' talk. **Results:** Four themes emerged: The development of mothers' knowledge by participating in the educational program; the potential for mothers to share the acquired knowledge with family members; the education program as a medium and place for relaxing and listening; and the development of an affective bond with other mothers and the nurse. **Conclusion:** Given the positive results of this study, it is recommended that such educational programs in neonatal units expand to include the participation of other family members or premature babies as well.

Keywords: Infant, newborn; Infant, premature; Health education; Neonatal nursing, Mothers/education

RESUMO

Objetivo: Analisar a percepção de mães de prematuros sobre a vivência em um Programa de Educação em Saúde utilizando metodologia participativa. **Métodos:** Participaram 38 mães de prematuros internados em uma unidade neonatal. O Programa, visando construir conhecimentos sobre os cuidados com o prematuro, consistiu na entrega de uma cartilha educativa às mães para leitura e posterior participação em atividades grupais, fundamentadas no referencial da problematização de Paulo Freire, com estímulo à expressão das percepções acerca da vivência no Programa. Foi realizada a análise temática das falas das mães. **Resultados:** Apreenderam-se quatro núcleos temáticos: o aprendizado proporcionado pelo Programa; a criação de possibilidades de socializar o conhecimento com a família; o Programa como espaço para descontração e escuta; e desenvolvendo o vínculo afetivo com outras mães e com a enfermeira. **Conclusão:** Diante dos resultados positivos deste estudo, recomenda-se que programas educativos dessa natureza e ampliados com a participação de outros membros da família do prematuro sejam implantados em outras unidades neonatais.

Descritores: Recém-nascido; Prematuro; Educação em saúde; Enfermagem neonatal; Mães/educação

RESUMEN

Objetivo: Analizar la percepción de madres de prematuros sobre la vivencia en un Programa de Educación en Salud utilizando metodología participativa. **Métodos:** Participaron 38 madres de prematuros internados en una unidad neonatal. El Programa, visando construir conocimientos sobre los cuidados con el prematuro, consistió en la entrega de una cartilla educativa a las madres para la lectura y posterior participación en actividades grupales, fundamentadas en el referencial de la problematización de Paulo Freire, con estímulo a la expresión de las percepciones respecto a la vivencia en el Programa. Se llevó a cabo el análisis temático de los discursos de las madres. **Resultados:** Se construyeron cuatro núcleos temáticos: el aprendizaje proporcionado por el Programa; la creación de posibilidades de socializar el conocimiento con la familia; el Programa como espacio para la relajación y la escucha; y desarrollando el vínculo afectivo con otras madres y con la enfermera. **Conclusión:** Frente a los resultados positivos de este estudio, se recomienda que los programas educativos de esa naturaleza y ampliados con la participación de otros miembros de la familia del prematuro sean implantados en otras unidades neonatales.

Descriptores: Recién Nacido; Prematuro; Educación en salud; Enfermería neonatal; Madres/educación

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[1] *Graduate student at the Post-Graduation Program Public Health Nursing at Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo – USP-Ribeirão Preto (SP), Brasil; Fellowship holder CNPq 2006/2008.*

[2] *PhD at the Post-Graduate Program on Public Health Nursing, Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo – USP- Ribeirão Preto (SP), Brasil.*

[3] *Ph.D, Professor at the Maternal Child and Public Health Department at the Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo – USP- Ribeirão Preto (SP), Brasil.*

[4] *Nursing Scholar at the Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo – USP- Ribeirão Preto (SP), Brasil; Fellowship holder PIBIC/CNPq 2007/2010.*

[5] *Full Professor at the Maternal Child and Public Health Department, Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo – USP-Ribeirão Preto (SP), Brasil; Fellowdhip holder, CNPq.*

Corresponding Author: **Carmen Gracinda Silvan Scochi**
Av.: Bandeirantes, 3900 - Monte Alegre - Ribeirão Preto - SP
Cep: 14040-902. E-mail: cscochi@usp.br

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INTRODUCTION

In the last 15 years, prenatal and neonatal mortality has decreased, especially among premature newborns, thus enabling greater survival of these high risk newborns. More modern neonate intensive care units are among the factors that have resulted in this greater survival, with human resources, complex and specialized technologies[1-2].

Premature newborns run twice as many risks. A biological risk due to physiological immaturity and an environmental risk due to a poor environment associated with low income common to most families[3]. In this context, the result is a greater harm to the growth and development of these babies[2].

Thus, prematurity as a public health problem has results not only in the high economic and social costs, but also in the suffering to families[2]. Pregnancy and the birth of a baby change the whole family context, creating expectations and anxieties and, in the case of a premature newborn, these are expressed in a different and unique way. Feelings such as incompetence, frustration, anger, guilt, and anguish are sometimes present when parents lose hope of having a baby that is completely healthy and when the one they have is not their ideal[4-5].

Early contact of parents with babies in the neonate units is important to foster a bond and to support care, it is also an adequate time for training mothers' the care skills they will need after discharge and the nursing professionals play a facilitating role[6-7].

Some interventions can be performed to encourage a connection between parents and children and favor the adjustment of parents to high complexity neonatal units, these interventions are: free access and presence of parents in the unit, encouraging physical contact and early care of newborns; introducing and structuring support groups and networks for parents and relatives with the cooperation of multi professional teams, and sharing decision-making on the care provided to premature[2,6].

These measures are for quality of life and total development of the human beings involved, using new therapies related with psychological features, taking human rights into account and using holism as a paradigm[2,6]. In this new perspective, the care provided focus on individual and developmental care, to provide quality of life, fostering health, empowerment and families' capacity building[2,8].

Therefore, it is relevant to provide activities for health education, preparing parents for care, and developing skills to take care of newborns at home. To meet this need and optimize education activities, authors have developed textbooks and didactic material, and some of them are described next.

Especially dealing with premature newborns, the educational game *"Mamãe e o pequeno bebê"* (Mommy and the little baby) was developed to be used in activities of guided education to prepare mothers for hospital discharge. From the evaluation of its use, it was seen that it makes learners interested, and it helps building, developing personality, and learning. Health professionals become learning mentors, fomenters, and evaluators[9].

Didactic-teaching material "Caring for premature babies: an education booklet for maternal guidance" was developed using a participative methodology with mothers and the nursing team at the neonatal intermediate care unit of a university hospital. In the assessment of participants, the booklet was appropriate to its purpose, easy to understand and use[10-11]. In its second edition called "Caring for premature babies: a family guide", the content was updated and more things were included because users, parents and health professionals, suggested support to parents and growth follow-up charts[12].

The introduction of health programs that are creative and participative is extremely important to prepare parents for hospital discharged due to the incidence and the result of the birth of a premature newborn to the health system, to babies and families, as well as to the importance of the participation of parents in child care, in the hospital. That is where the motivation for the present study comes from, focusing on assessing maternal perspective since they are more present in the neonatal unit.

OBJECTIVE

To assess the perception of mothers from premature newborns on the experience they had in a Health Education Program using a participative methodology.

METHODS

The present study is a qualitative education intervention survey performed at the neonatal intermediate care unit of the university hospital of Ribeirão Preto-SP. Thirty-eight mothers took part in the survey (m1, m2... m38) they had premature newborns staying in the unit from June to November 2007 and met the following inclusion criteria: babies with gestational age below 37 weeks, with no contraindication to breastfeeding, being able to read the education booklet and verbalize it, and agree to take part in all the stages of the study.

The Health Education Program was a set of activities to build mothers' knowledge on care for premature newborns, to prepare them for hospital discharge. It includes the distribution of the educational booklet "Caring for premature babies: a family guide"[12], for each mother to read and to take home. In this first contact with the material, we encouraged participants to become familiar with it, to raise questions and other issues, and to discuss it with the family and friends.

The booklet was a didactic-education material with illustrations and organized as questions and answers in issues that are considered necessary by premature mothers to prepare them for their infants' discharge, they are: family relationship, diet, hygiene, daily and special care, support to parents, and growth chart[12].

For the development of the education activity, we have used critical consciousness that is based on Paulo Freire's theories, aiming at the critical and reflexive insertion of men in reality, so that there is social transformation, exchange of experiences, questioning, individualization, and humanization. To that end, the everyday experiences of learners are used in a dialogical and participative way[13].

After a relaxing activity with music and introduction of mothers, the contents of the booklet, and other contents raised by participants were dealt with and all participants, divided into groups and coordinated by the author, took part with the purpose of building knowledge on the care of premature infants.

At the end of the education activities, mothers were encouraged to talk about their experiences in the education groups.

All education activities have been filmed and the speeches have been fully transcribed. Data were obtained through organized and systematized education groups using the thematic analysis that best fit qualitative studies. The "theme" is connected with a statement regarding a certain issue, with a set of relationships that can be graphically expressed by a word, a sentence or an abstract. This analysis, which deals with meanings rather than with statistical inferences, is to find out "units of meaning" in a communication, since their presence can show reference values and behavior models in the speech, and their frequency may show the type of speech[14].

From the qualitative sample, the empirical picture of the research was concluded when theoretical saturation was assessed with repetition, absence of new data and increased understanding of the concepts identified[14].

The project was approved by the Ethical Research Committee of the hospital. Mothers of premature babies that were interested in taking part of the study gave their written consent and got a copy from the agreement term, after previous contact with the researcher and being informed about the study's objectives. Parents or guardian of adolescent mothers had to give their written agreement.

RESULTS

All participants from the study considered the experience in the Health Education Program important. Through mothers' statements four thematic groups presented next were formed.

Learning enabled by the Health Education Program

Mothers highlighted that the Program is a place for learning where they can pose questions in a light way with freedom, favoring the development of confidence for child care both in the hospital and at home.

... there was nothing to help me understand (at ICU)*, then, here* (neonatal unit) *I learned. (...), the leaflet, it explains very well... I helps a lot and so does the meeting...* m7

... I thought it was very good. (...)... we settle a lot of questions, and learn more. (...) There are many things we do not know, we talk and learn here... m1

We discuss a lot of things, no embarrassment! We learn more! m11

Yes, I liked the group a lot, I settle the questions we are afraid to ask, I liked it a lot. m33

I liked it because we learn how we can do things at home, even taking care of it here... We feel more confident... (...) these meetings are important...we learn a lot... m4

Among the care learned from the group discussions and reading of the booklet, participants highlighted those related to prematurity as opposed to term birth, expressing milk, feeding, body and clothes hygiene, preventing diaper rash and sun baths.

Sometimes we do not know how to take care, because they are premature, it is not the same as the term babies... We have to be more careful... (...) But here (booklet)*, they say we are not supposed to put the baby... in a bubble!* m12

I liked most to learn about baby care, how to express milk. (...) Also, we have the other (kids)*, but it is different! They are smaller; we have to be more careful... I like to learn what to do after he is breastfed, how to do it right!* m5

I was curious, and here (booklet) *you are even taught how to bathe the child! First you have to get everything, all things before hands, then you wash the head, then the eyes, and then you take off the clothes and wash the body! Then you wrap it up and put the clothes on! m12*

Using coconut washing powder (to wash babies clothes)*, right? This one I've read. (...) Use as little as you can of fabric softener... If possible add a bit of vinegar, right? (...) I did not know that, I learned on the booklet. m20*

And when the sun is nice, we take out all the baby's clothes put it on the sun... then I have to know for how long he can be there! I don't know that... I don't know if I have read that, but I think it is on the book (booklet) *at home, I can read it right. You can put it when it has a diaper rash... The skin gets stronger...* m3

Creating possibilities of sharing knowledge with the family

Mothers mentioned that the Health Education

Program is also important for family learning, stressing the relevance of having a written material (booklet) that helps the relationship with relatives and visitors and in the approach of some issues related with health promotion and disease prevention, such as mothers and children resting, smoking around the baby, excessive number of visitors, and washing the hands before holding the baby.

Family is hard, because there are some things you say that goes one ear and out the other! (...) I think it has to be written! Therefore, the booklet helped me a lot. m12

I read it all (booklet). *My daughter* (eldest daughter) *read it too. She is an expert.* m17

Regarding smoking... You know, there are people at home who smoke a lot... And she (sister in law) *also read the part that mentions visitors having to wash their hands...* m9

... if someone comes to visit us, for example, a bunch of people come, it is useful to limit the amount of people and the time they will spend, so that it is not tiresome neither for the baby nor for the mother, because we also need a break! (...) Also, sometimes you want a break, and there are many people, you ask them to come back the next day! It is enough just to show the booklet, what is written there. m12

When I leave, I am not going to tell anyone that he will be discharged, because if I tell, many people will come (relatives). *They will say we are boring... (...) We have to wash our hands, right? We should not kiss the face. When they arrive, I will leave the book* (booklet) *open...* m29

We must always wash our hands before holding the baby! (...) Sometimes, people come from the streets and want to hold it. (...) We have to ask them to wash their hands! (...) Especially for our premature babies! (...) Ah! I think we must explain to visitors the baby is premature. (...) avoid letting people all over the baby... not being in a stuffy place, always in small number of people, and smoking only outdoors. m1

The Health Education Program as a space for distraction and listening

According to the participants, the Program gave mothers a space where they could relax and find relief for the tensions and also distraction.

It helps a lot because... it takes our mind off! m29

It helps a lot! Because we talk, relax." m28

It was good! I did not close my eyes, but just the song is enough for you to relax! The music is very soft, it enters your mind, it's just a touch and you relax! m8

Relaxation was also very good... you have the problem here (hospital) *and there* (home)*, and then you fell you become loose* (put the hands on the arms and back)*, you relax... I feel lighter! Here* (education group) *the problems are more distant!* m5

The program also fostered greater interaction among participants, creating spaces for listening and talking, meeting their needs of talking, being heard and sharing with other people rather than the relatives, due to the problems they experience.

Ah,the group helps. (...) Because sometimes, I talk to my husband and it doesn't help because he gets nervous and makes me nervous. So I prefer, sometimes, not to talk, I get quiet. She (researcher) *listens to us... We get it out of our chest here. (...) Ah I think it was wonderful... (...) We go to lunch if our mind relaxed. Because some days, I can't even eat.* m31

Developing a connection with other mothers and with the nurse

In the interaction provided by the Health Education Program, mothers share each other's company and the company of the research nurse, developing a connection with them.

Oh! (takes a deep breath) *Relief! It is so good to have someone to explain to us with politeness! We even start to like the person!* m3

Today I was already happy because my baby went to the cradle, and now, in the afternoon, I am happy because I am here with you all! m30

It was very good to have your company. (...) Will we have this again tomorrow? If it were for me, I would use the opportunity, and then, next thing we know, it is evening and we are still here (it was 2 pm). *m17*

In any case, if I have any questions, I will look for you, ok? You will have to tolerate us. m28

DISCUSSION

Mothers pointed out that the Health Education Program is a space for learning, favoring the settling of questions, with freedom and no fear or embarrassment, contributing to the development of infant care both in the hospital and at home.

Such aspect is pointed out by another study (15), showing that in the activities of health education, mothers are more open to express their questions and what they had learned. Mothers who were shy, felt more at ease to talk when they listened to reports of similar experiences by other participants, they approach their questions and exposed fears that they were afraid of expressing.

To meet the learning needs of adults, we must use teaching strategies that use their previous experiences, emphasizing their participation and active involvement. Health learning is raised by the interest they have for new and encouraging situations[15].

The booklet given to participants was important to discuss care to prepare mothers adequately for hospital

discharge, it is a didactic material that, in case of questions, may be referred to and guide care for premature babies. These results are similar to other studies[10,16], which showed, on the speeches, mothers' need for a written material that can be taken home.

This didactic-instructional material, when it is taken home, favored also the family learning, especially when treating issues that conflict with family practices, helping premature babies' mothers approaching the family and visitors regarding some necessary care for health promotion and disease prevention.

Families have their own habits and values and when they have to face care for the premature baby, they face cultural problems related with lack of guidance, many times requiring the help of a professional. The routine of families is affected by the presence of the baby and it can be changed in some aspects, like abandoning bad habits such as smoking, at least inside the house.

As families are inserted into the space of neonatal units, they present the difficulties of having to take routine care of a baby that will need, many times, long term special care, as well as the aspects connected with the socio-cultural conditions[2].

In society, it is up to the family to care for children, to provide opportunities for proper encouragement, relationship and learning. Families may develop these competences as long as they receive the necessary support. Social networks have the role to engage the families in learning processes and also in processes to acquire skills to care for their babies at home, so as to foster development in the physical, emotional, social and, cognitive area[17]. The nursing team is always facing this issue because they remain in contact with the baby and the family longer and there is the need for new intervention strategies such as the support groups[2].

The approach for developmental and individualized care for premature babies includes these aspects and one of its components is care centered on the family[8]. Additionally, one of the guiding principles of care in the Agenda de Compromissos para a Saúde Integral da Criança e Redução da Mortalidade Infantil (*Agenda for commitment to Comprehensive Child Health and Reduction of Infant Mortality)*[18] is the participation of families in care, getting them involved with the information on care and health problems, as well as the proposals in the necessary approach and interventions, understood as a right of each citizen, together with the qualification potential and making care more humane.

Both participant mothers of the Health Education Program and the researcher felt the need for families, in addition to mothers, to be present in the education activities, exchanging experiences, learning and possibly changing their actions. However, in this survey we could not include family members in the education groups.

The tendency to encourage early premature newborn discharge and the technological development that increased survival make these babies, many times, being discharged from hospital dependent on some kind of technology. Thus, the families are responsible for increasingly complex care, requiring insertion of families in hospital care and their efficient preparation for this task. The lack of research on learning and on the learning needs of premature families is pointed out[10].

By taking part on the Program, mothers had a space for distraction and relaxation, this outcome is similar to that of another study where education activities were developed in a relaxed and fun way, using unusual resources for this practice, such as educational materials and encouraging effective participation of mothers and professionals; before hands, guidelines were monotonous, discouraging and repetitive[9].

In the activities of a support group to mothers of premature newborns in a hospital from Recife-PE mothers could smile and play and the hospital was perceived by them as a place for smiling and distraction, where they could disconnect for some time from the difficulties experienced, and from the feelings of guilty, they shared happy and relaxed moments there[19].

To understand the birth problem and hospitalization of premature newborns for families, especially for mothers, listening is an essential part of the educational activities since it can alleviate mothers' suffering. Thus, the Health Education Program is a place for mothers to talk, be heard and let it out.

Also, from mothers' statements, we could see the importance of the Program due to the benefit of company, talks, the time for listening, therefore stressing the need for them to talk and to be heard.

Birth and hospitalization of premature newborns lead to important changes in families, making their members more fragile, and it hinder the dialog between mothers and relatives[19].

In support groups, mothers are initially embarrassed to talk about themselves and their feelings, but then they start trusting the group and can share, express their feelings and thoughts. Strategies, such as listening, can and should be used by professionals in clinical practice during activities with mothers[19].

An affective connection was developed between mothers and the nursing researcher because of the interactions provided by the Health Education Program, in agreement with other findings where this feeling was present even after infants' discharge, verified in the outpatient appointments during follow-up[19].

With birth and premature newborn hospitalization the triad mother-premature newborn-nursing team gets

to know each other, providing care, interacting and getting involved so closely that affective connections are established and they continue after hospital discharge[20].

Freire's thoughts have significantly help building educational nursing practices such as those used in the present and in other studies[9], incorporating a critical and problem-building education, guided by dialog which is a need of human beings, they need to gather in a process of reflection and the actions should be guided by transformation and humanization of the world. This education process values culture and the word which form a type of Pedagogy full of existence and Love, – the freedom Pedagogy – introducing a sympathetic living experience with social and humane relationships[13].

On the other hand, it is still a challenge to meet the more humane sense of care for mothers with children in hospital, creating bonds through dialog and common interests, in the search of care humanization[21].

It is worth mentioning that establishing a bond between the team and health service users is one of the principles and forms of action from the national health public policy which is part of the guidelines from HumanizaSUS. Thus, results from this and other intervention studies have showed the possibility to build a more humane care with the establishment of connections between health professionals and the users to build HumanizaSUS[22].

CONCLUSION

From the participation of women with premature children in the Health Education Program through the use of the booklet and the methodology of problem-building, we have learned that women enjoyed taking part in the activities and mentioned the following regarding their experience: the learn provided by the Health Education Program, ways to share knowledge with the family, the Health Education Program as a space for distraction and listening and the connection developed with other mothers and with the nurse.

The limitations of the present study are the small number of participants and the no-inclusion of other family members in the education program, due to the small participation of family in this institution. With this regard, it is worth mentioning that the education program, although it is valid, it must be increased together with the care focused on the family, strengthening the philosophy of developmental and humanized care in neonatal units and continuous care.

Due to the positive results of the present study, we recommend other education programs such as this one with the participation of other family members that can be introduced in other neonatal units in Brazil, using active learning methodology and didactic-instructional material, leading to the transformation and helping build a quality care that is creative and participative.

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