



Follow-up: maternal perception on child monitoring

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ABSTRACT. Maternal perception on follow-up monitoring towards the improvement of children's care is investigated. Current descriptive qualitative study was performed at the outpatient clinic of a secondary care hospital in Fortaleza, Ceará State, Brazil, from July to September 2010. Half-structured interviews were undertaken with 16 mothers who accompanied their children in the follow-up. Minayo thematic analysis enabled data categorization in Child Development, Continuing Care, Importance of Follow-up. The monitoring of children discharged from intensive care units is relevant for the prevention of injuries in neuropsychomotor development. The exchange of information and guidance received during follow-up visits provided support to mothers devoted to child care and promoted trust and confidence for care continuation. Health professionals have a role beyond the care itself, or rather, the provision of educational support through the interactive process, including family-provided assistance which becomes part of the method of caring.

Keywords: care, child health, health education.

Follow-up: percepção materna no monitoramento da criança

RESUMO. Objetivou-se investigar a percepção materna frente ao acompanhamento de *follow-up*, bem como contribuir na melhoria da assistência de crianças do programa. Estudo descritivo, com abordagem qualitativa, realizado no ambulatório de um hospital de atenção secundária em Fortaleza, Estado do Ceará, Brasil, no período de julho a setembro de 2010. Utilizou-se entrevista semiestruturada com 16 mães de crianças que acompanham o filho no *follow-up*. A análise temática de Minayo possibilitou a categorização dos dados em: Desenvolvimento do filho, Assistência Contínua, Relevância do *follow-up*. O acompanhamento de crianças egressas de Unidades de Terapia Intensiva é relevante, visto a prevenção de agravos no desenvolvimento neuropsicomotor. A troca de informações e orientações recebidas durante a consulta de *follow-up* ajuda e facilita as mães para o cuidado com a criança, a qual promove confiança e segurança para o cuidado continuado. Evidencia-se que os profissionais de saúde têm papel além da assistência propriamente dita, o oferecimento de suporte educativo por meio do processo interativo, incluindo o cuidado prestado pela família, tornando-o parte do método de cuidar.

Palavras-chave: cuidado, saúde da criança, educação em Saúde.

Introduction

Great progress has occurred in neonatal care in recent decades with the introduction of more effective therapeutic resources, specialized technological and human resources, culminating with the 1999 introduction of the follow-up system to meet the specific needs of groups of children and families (LOPES; LOPES, 1999).

Follow-up is indicated for neonates that received perinatal intensive care or were at risk, so that further changes in the area could be undertaken. There is a consensus that extreme preterm (before 29 weeks) and low birth weight (LBW) (less than 1000 g) are the characteristics that make children most vulnerable to develop disabilities (DORLING; FIELD, 2006). The Brazilian experience featuring a humanization policy

for premature newborns is also based on the reception of the baby and the mother even after hospital discharge, with a follow-up program that includes regular consultations and home visits, if necessary. Ophthalmologic and auditory reevaluation as well as the verification of the vaccination schedule for premature infants have also been included (BRASIL, 2011).

There is also a consensus on the importance of monitoring differentiated neonates, or rather, infants and children with risk factors for changes during development. In fact, the World Health Organization has recently established protocols for conducting a monitoring study in Brazil. Data from countries with similar population revealed that up to 52.0% of all children, between three months and eight years old, showed some developmental

abnormality diagnosed during follow-up (RESEGUE et al., 2008).

Dropouts are expected in follow-up programs and they are more frequent the longer the monitoring period. The success of the return of the child to this service depends on team intervention with regard to the awareness of parents on the program (SALT; REDSHAW, 2006). Studies have demonstrated that the difficulty in follow-up is linked to low socioeconomic status and to mother's schooling level, with a higher incidence in infants with severe disabilities (HILLE et al., 2001; MARLOW et al., 2005).

According to Ferecini et al (2009), assistance to parents and family participation in hospital care for newborns have become a priority in neonatal services. The long hospitalization period and deprivation of the home environment increase the stress of the mother, which may affect bonding and attachment. Early contacts with NB in neonatal units are indispensable and the nursing professionals have a facilitating role. It is actually a highly propitious moment for training care skills after discharge.

Parental separation caused by the neonate's hospitalization in the Neonatal Intensive Care Unit (NICU) makes them feel sad since they are fragile and insecure about the children's life. They feel guilt because of the children's suffering and, at the same time, express hope and resignation. These feelings may be minimized if the mothers chance to somehow participate in the caring for their infants (MORAIS et al., 2009).

Current study investigates the maternal perception prior to follow-up monitoring and aims at contributing towards the improvement in children during follow-up.

Material and methods

Current descriptive and qualitative study responds to specific issues which comprise, within the Social Sciences, a level of reality that cannot or should not be quantified. Qualitative studies have their greatest strength in the criterion validity, which is a strong attribute that places the subject within a condition of high respectability. They feature most relevant characteristics from the point of view of the construction of knowledge and present themselves more relevant both to the subjects and to the research field (MINAYO, 2010; TURATO 2010). The qualitative approach related to social research is always applied to understand the maternal perception of the query follow-up since it unveils the human experience.

Current research was developed in a follow-up outpatient clinic of a secondary care hospital in Fortaleza, Ceará State, Brazil. The service consists of monitoring children discharged from intensive care units, in extended hospitalizations, or with growth and development risks. All children were born in the institution and were accompanied by the program since birth, for the improvement of their psychomotor conditions.

Sixteen mothers who accompanied their children in the follow-up have participated in this study, meeting the following criteria: mothers over 18 years who enjoyed mental health and complied with monitoring. Relatives and/or caregivers who were not the mother were excluded. It is important to note that the study did not distinguish the participants with regard to color, race, creed or financial situation.

Data were collected between July and September 2010 through non-participant observation and semi-structured interviews, with the following guiding questions: What do you understand by follow-up program? How do you perceive the follow-up monitoring for your child? Do you think it is important that your child is accompanied by the follow-up system? Why?

The thematic analysis of Minayo (2010) was employed for analysis. It is characterized by the description and documentation of responses, with the identification and categorization of the discourses, by finding out the saturation of ideas coupled to similar and different meanings. Finally, thought synthesis, configuration analysis, interpretation and creative formulation of the findings are provided.

The ethical stance was present throughout the research, as recommended by the Ministry of Health through the Resolution 196/96 (BRASIL, 1996). Current study was approved by the Ethics Committee in Research (Coética) of the University of Fortaleza (Unifor), no. 113/2010. The informants' anonymity was observed by using the letter M to designate participating mothers.

Results and discussion

Mothers were between 18 and 35 years old. Five were married; nine in common-law marriage; two were single. As for their occupation, eight were dedicated to house chores, eight were housemaids, two were supermarket tellers, three were salespersons, two were desk clerks and one was a seamstress. After the analysis of data validation and prior to the careful description of the interviews, the following empirical categories were identified: Child

development, Continuing Care, Importance of Follow-up.

Child development

Health professionals of the NICU are in a crucial position to provide support to neurobehavioral development by changes in the environment and strategies for caring, which promote and integrate the principles of child care (ROLIM et al., 2009). The mothers have assigned their children's improvement in growth and neuropsychomotor development to medical guidance and monitoring provided by the follow-up program, which directly affects care quality.

Actually it is a very good accompaniment because it helps in the development of my kid, since she [the nurse] explains how to care for him and stimulate him...to know what the kid is developing, what he has (M 3,11).

[...] [They] monitor the baby from the moment he comes out of our belly; every month we need to come over here for tests, to check his growth, to know whether he is healthy [...] (M 6).

The child who at birth does not have any serious sequelae may eventually present some impairment in intellectual functioning, a recurrent concern of professionals involved in the monitoring and care of infants discharged from the NICU. Despite discussions in the literature on the social and familial factors on premature development, the infant has alterations in the nervous system that continue to exist even when the effects of social factors are taken into consideration (MEIO et al., 2003).

Mancini et al. (2002) reported that the neuropsychomotor development is essential for the growth of the child. Acquisitions during the first year of life, considered a critical period, provide an overall prognosis of the child. The motor function undergoes rapid changes that result in mobility, through the acquisition of crawling and independent gait, respectively on the ninth and twelfth months.

Health professionals use such methods as child health card, with graphs of growth in height and weight, and guide the family in case of delays or lack of appropriate development, vaccination, anthropometric data and the scheduling of the next visit.

Continuing care

The follow-up of the preterm child's health, with special focus on the family, highlights behavioral and development aspects. Genealogy is the support and the follow-up is evaluated from the influence of the environment (DORLING; FIELD,

2006; VIERA; MELO, 2009). The continuity of care after the visits increases the mother's confidence in the service provided, which reduces the physical and economic burnout to move frequently to the outpatient clinic for attendance. Therefore, the longer the follow-up, the more detailed the assessment on the consequences in neuropsychological functioning, educational gain and motor coordination difficulties.

[...] It brought me a lot of things, because without this follow-up I didn't know how it was to be monitored, because where I live there isn't this kind of service, and it's being great (M9).

[...] Here is great because if we need to do some further test, we can do [it] right here, all is accompanied here [...] (M14).

In fact, continuing care provides security on the health service after prenatal visits, monitoring at and after delivery, and assistance to the newborn at risk in developing neuropsychomotor disabilities. It increases the survival of these infants since it prevents possible alterations.

According to Frota et al. (2011), in the first year of life, children experience changes that include issues involving physical growth to emotional development, highlighting language as a skill to be learned. These changes affect the maternal feelings in relation to the child and the new abilities are a challenge to the mother who needs to acquire knowledge and adapt herself to the requirements.

Child assistance has to be increased aiming at follow-up and for an adequate support to children discharged from NICU and to their families. In fact, care during the neonatal period cannot be restricted to the moment of hospitalization or as a preparation for discharge. It should especially comprise the extra-hospital period with quality guidelines for the survival of the infants. The visits provide the perspective for what care means since the performance of clinical tests in the health unit strengthens the bond with the unit and its personnel. The exchange of information and orientation received during the visit promotes trust and security to continuing care.

It is very good, because it takes away our doubts, and in any emergence we can count on a skilled professional to attend us (M 8).

It is good because we know what is happening with him, what we need to take a good care of him... things that I didn't know before, I now know (M 5,10).

According to Santos and Penna (2009), health education may promote practical apprenticeship and

contributes to prepare people to deal with situations that are part of life and health-, related. It produces knowledge that supports the subjects autonomy and emancipation. The mothers referred to feeling of anguish by experiencing a constant struggle as being stuck within an exhaustive routine full of responsibilities. This reality matches the daily experience of challenges related to child health.

Importance of follow-up

Responses showed that the mothers acknowledged the importance of the follow-up visit and contributed by the return of their children to the outpatient clinic and thus to the program's success. They referred to improvement in the child's growth and development due to the monitoring developed and to the guidelines received from health professionals.

[...] We always achieve a good result, at every visit he is better... without the visits, he wouldn't be so good (M16 and 2).

[...] It's helping a lot, he started just now, and it's the second visit, he couldn't move the neck, but now he can. He has recovered well; we thought he wouldn't, but each day he is better and better (M 1,7).

[...] As his problem is anemia and weight, I think he will get better, because he will gain weight, and develop better, and the doctor said that he doesn't have the first movements, I think he will get better (M 4).

Improvement in motor reflexes is due to the maturation of the Central Nervous System (CNS), an evolution correlated with stimuli provided by the mother or caregiver. When children do not develop the reflexes prior to the stimuli, they must be accompanied by a multidisciplinary staff. Mariano et al. (2011) reported that care practice assisted the professionals involved in a pediatric unit to guide the strategies of humanization and welcome the child and family. The team needs to be aware of the peculiar ways of the infant's feeling and perceiving and should set an authentic relationship which values the individuality and intersubjectivity of each.

Visits scheduled with shorter intervals allow a stricter control. If they do not, the problems should be investigated and solutions and guidance provided to the mothers. According to Del Ciampo et al. (2006), monitoring during the first years of life is important to prevent diseases. The onset of visit appointments occurs in the first month of life, with at least nine visits, emphasizing health instead of disease and aiming at promoting health and education of the family by orientation with regard to health risks and by offering effective preventive measures.

Redefining concepts and actions in educational practice on health, owing to the relevance of experiences in Health Promotion, is evident. Thus, professionals will be able to reverse the care practice and to enhance public awareness on determinant factors, self-care, relationship with the environment, as a means to promote life quality (FROTA et al., 2009).

The follow-up programs give support to the child and family and are a contribution to the mother to note the child's growth and development and to feel insecure to execute care-giving and prevent future complications.

[...] I think it's very important because we, as mothers, never realize what the child is developing, but in front of the doctor we note how much the child had already achieved (M13).

[...] I do, because if she hadn't being monitored, I wouldn't know about her problem [...] (M12).

Children's health care policy demands that every newborn should be accompanied during the growth and development process, from birth. The vulnerable newborn baby living in adverse conditions should be focused upon and looked upon by a constant and effective follow-up to detect damages and promote specific actions so that the hardships these children are subjected to could be minimized (VIERA; MELLO, 2009). Visits are important to explain to the family about the stimuli that should be offered to children, aiming at adequate development.

Final considerations

The monitoring of infants discharged from NICU is relevant for the prevention of serious and dangerous delays in neuropsychomotor development. Clinical visits start soon after hospital discharge and extend to the discharge of the follow-up service, when child care should be continued in outpatient clinics in health care units.

The lack of a multidisciplinary health team for the rehabilitation of impaired children may be detected. Its presence would minimize transference to other specialized services involving interruptions in care, waste of time and money for the mother and child. Although problems are rife, the follow-up program has been evaluated by the mothers as satisfactory for child monitoring. In fact, it is essential and stimulating for the hospital to maintain the service through the improvement in child assistance and consequently in life quality.

The above shows that health professionals have a role in contributing towards the building of mother's

perception for follow-up monitoring. This function includes providing educational support, taking into account the individual aspects that differentiate the needs, and the care provided by the family and/or relatives who, albeit lacking scientific knowledge, have strong cultural values. The latter may be easily transformed as part of the care method.

Current research demands further studies related to the theme, especially on health professionals becoming disseminators of information on neonatology and health promoters to guide these children towards full citizenship beside their family and to develop healthy and happy citizens. Health Education should be linked to health promotion and should provide appropriate conditions of life to mothers to promote a quality care to their children.

References

- BRASIL. Ministério da Saúde. Conselho Nacional de Saúde. Resolução n.º 196/96. Diretrizes e Normas Regulamentadoras de Pesquisa envolvendo Seres Humanos. **Diário Oficial da União**, Brasília, 10 de Outubro de 1996.
- BRASIL. Ministério da Saúde. **Atenção humanizada ao recém-nascido de baixo peso**. Método mãe-canguru. Área de Saúde da Criança. 2. ed. Brasília: Ministério da Saúde, 2011.
- DEL CIAMPO, L. A.; RICCO, R. G.; DANELUZZI, J. C.; DEL CIAMPO, I. R. L.; FERRAZ, I. S.; ALMEIDA, C. A. N. O Programa de Saúde da Família e a Puericultura. **Ciências e Saúde Coletiva**, v. 11, n. 3, p. 739-743, 2006.
- DORLING, J. S.; FIELD, D. J. Follow up of infants following discharge from the neonatal unit: Structure and process. **Early Human Development**, v. 82, n. 3, p. 151-156, 2006.
- FERECINI, G. M.; FONSECA, L. M. M.; LEITE, A. M.; DARÉ, M. F.; ASSIS, C. S.; SCOCHI, C. G. S. Percepções de mães de prematuros acerca da vivência em um programa educativo. **Acta Paulista de Enfermagem**, v. 22, n. 3, p. 250-256, 2009.
- FROTA, M. A.; BEZERRA, J. A.; FÉRRER, M. L. S.; MARTINS, M. C.; SILVEIRA, V. G. Percepção materna em relação ao cuidado e desenvolvimento infantil. **Revista Brasileira em Promoção da Saúde**, v. 24, n. 3, p. 245-250, 2011.
- FROTA, M. A.; MARTINS, M. C.; ALBUQUERQUE, C. M. Aspectos culturais no cuidado familiar à criança com desnutrição. **Acta Scientiarum. Health Sciences**, v. 31, n. 1, p. 9-14, 2009.
- HILLE, E. T. M.; DEN OUDEN, A. L.; SAIGAL, S.; WOLKE, D.; LAMBERT, M.; WHITAKER, A. Behavioral problems in children who weigh 1000 g or less at birth in four countries. **The Lancet**, v. 357, n. 9269, p. 1641-1643, 2001.
- LOPES, S. M. B.; LOPES, J. M. A. **Follow-up do recém-nascido de alto risco**. Rio de Janeiro: Medsi, 1999.
- MANCINI, M. C.; TEIXEIRA, S.; ARAÚJO, L. G.; PAIXÃO, M. L.; MAGALHÃES, L. C.; COELHO, Z. A. C. Estudo do desenvolvimento da função motora aos 8 e 12 meses de idade em crianças pré-termo e a termo. **Arquivos de Neuro-Psiquiatria**, v. 60, n. 4, p. 974-980, 2002.
- MARIANO, L. R. A.; BACKES, D. S.; ILHA, S.; NICOLA, G. D. O.; FREITAS, H. M. B.; FERREIRA, C. L. L. Significado da internação hospitalar pediátrica na perspectiva de profissionais e familiares. **Cogitare Enfermagem**, v. 16, n. 3, p. 511-516, 2011.
- MARLOW, N.; WOLKE, D.; BRACEWELL, M. A.; SAMARA, M. For the Epicure study group. Neurologic and developmental disability at six years of age after extremely preterm birth. **New England Journal of Medicine**, v. 352, n. 1, p. 9-19, 2005.
- MEIO, M. D. B. B.; LOPES, C. S.; MORSCH, D. S. Fatores prognósticos para o desenvolvimento cognitivo de prematuros de muito baixo peso. **Revista de Saúde Pública**, v. 37, n. 3, p. 311-318, 2003.
- MINAYO, M. C. S. **Pesquisa social: teoria, método e criatividade**. 29. ed. Petrópolis: Vozes, 2010.
- MORAIS, A. C.; QUIRINO, M. D.; ALMEIDA, M. S. O cuidado da criança prematura no domicílio. **Acta Paulista de Enfermagem**, v. 22, n. 1, p. 24-30, 2009.
- RESEGUE, R.; PUCCINI, R. F.; SILVA, E. M. K. Risk factors associated with developmental abnormalities among high-risk children attended at a multidisciplinary clinic. **São Paulo Medical Journal**, v. 126, n. 1, p. 4-10, 2008.
- ROLIM, K. M. C.; SILVA, W. C. P.; GURGEL, E. P. P.; ALMEIDA, D. T.; ALBUQUERQUE, V. L. M. Ambiência neonatal no desenvolvimento neurocomportamental do recém-nascido de risco: conhecimento da enfermeira. **Revista Tendência da Enfermagem**, v. 1, n. 2, p. 115-118, 2009.
- SALT, A.; REDSHAW, M. Neurodevelopmental follow-up after preterm birth: follow up after two years. **Early Human Development**, v. 82, n. 3, p. 185-197, 2006.
- SANTOS, R. V.; PENNA, C. M. M. A educação em saúde como estratégia para o cuidado à gestante, puérpera e ao recém-nascido. **Texto e Contexto em Enfermagem**, v. 18, n. 4, p. 652-60, 2009.
- TURATO, E. R. **Tratado da metodologia da pesquisa clínico-qualitativa: construção teórico epistemológica, discussão comparada e aplicação nas áreas da saúde e humanas**. 4. ed. Petrópolis: Vozes, 2010.
- VIERA, C. S.; MELLO, D. F. O seguimento da saúde da criança pré-termo e de baixo peso egressa da terapia intensiva neonatal. **Texto e Contexto em Enfermagem**, v. 18, n. 1, p. 74-82, 2009.

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