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Original Article

Construction of a Questionnaire to Assess Parental Stress in Neonatal Intensive Care Unit

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ABSTRACT

Background: Once an infant is hospitalized in the Neonatal Intensive Care Unit (NICU), the entire family dynamics is disrupted due to stressors such as interruption in maternal-infant bonding, abandonment of other siblings and financial burdens. Combination of multiple stressors often ends in divorce or other devastating results. In this study, a novel survey questionnaire has been developed to assess the level of parental stress in NICU and identify the warning signs, in order to provide assistance to young couples in need of help.

Methods: Qualitative content analysis was performed to survey 13couplesrecruited from various teaching hospitals in Isfahan, Iran.

Results: The initial part of the questionnaire was designed to assess parents' stress level with an expected content validity index of 0.78 or above and to measure face validity of the questionnaire, all the items received a mean impact score of 1.5 or above, and the Cronbach's alpha reliability of the 12-item questionnaire equaled to 0.904.Based on the factor analysis, the items with a correlation coefficient of less than 0.4 were excluded (one item was omitted).

Conclusion: Most survey questionnaires found in the existing literature have investigated the types of stressors experienced by parents with an infant in NICU. In this study, researchers offer a novel 11-item questionnaire designed to assess the level of stress among parents with a hospitalized infant in NICU.

Keywords: Neonatal Intensive Care Unit, Parents, Scale Development, Stress

Introduction

Stress is a state of physical and psychological disturbance generated by internal or environmental stimuli (1). Mothers of low birth weight (LBW) infants admitted to NICU experience a great deal of stress due to interruption in the maternal-infant bonding process, often without being aware of the source of their emotional anguish (2). The entire family experiences a major disruption in their daily routines due to their frequent visits to NICU, and long periods of absence from home with lack of attention to their other children.

Most parents with an infant in NICU suffer from physical exhaustion and face financial difficulties. Impaired maternal-infant bonding poses a threat to maternal rejection, especially for infants with deformities. Stress associated with a hospitalized infant in NICU has multidimensional effects on families prone to separation and divorce (3). This study aims to highlight the stress level

among parents of infants in NICU in order to find a way to assist the families at risk of the aforementioned threats.

Most infants in NICU are diagnosed with asphyxia, respiratory distress syndrome (RDS), premature birth, congenital anomalies or iatrogenic birth (4), which are known as contributing factors to infant mortality (5). Apart from infants with low gestational age or birth-weight (BW), other vulnerable infants in NICU are overly susceptible to disease or mortality, as well (6). After birth, infant adjustment to the extrauterine environment requires careful attention, especially for the infants susceptible to infection and disease (7).

In fact, NICU is designed to protect vulnerable infants and reduce infant mortality, but parents of infants in NICU spend long hours in the hospital waiting rooms and experience immense feelings of anxiety and fear. Such emotions affect their

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physical, psychological, social and spiritual health, particularly parents of infants with anomalies requiring multiple surgeries and medical procedures to survive (8).

During the last decades, there has been a decrease in the infant mortality due to medical technology advancements and improvements in neonatal care (9, 10). However, the psychological needs of families in distress and their desire to care for their infants have not been adequately addressed (11). Every year, 7.5% of the infants born in the United States are premature with low birth-weight (LBW). One of the national health objectives in 2010, was to reduce infant mortality to 4.5 deaths per 1000 live births; however, the rate of LBW (<2500 grams) continues to fluctuate between 7.29 and 10.15% (12).

In Iran, vital statistics show a decline in infant mortality rate from 19.1/1000 deaths in 1992 to 15.6/1000 deaths in 2004; and in the city of Isfahan (Iran) infant mortality rate decreased from 19/1000 deaths in 1992 to 13.11/1000 in 2006 (13).

Given the increase in the survival rate of premature infants and the growing rate of admission to NICU, there is a significant need for an instrument to assess the level of stress among parents of infants admitted to NICU. The existing inventories shed light on various stressors; however, none of them measure the stress level of parents with infants in NICU. Thus, this study provides an 11-item instrument constructed through the use of qualitative data to assess the stress level of parents with infants in NICU.

Method

Qualitative content analysis method was employed to collect data. Subsequently, the collected data went through a three-step analysis comprising of open coding, category development and abstraction (14). The participants were parents of infants admitted to NICU at teaching (governmental) and private hospitals in Isfahan, Iran.

The parents with infants in NICU for a minimum of 24 hours who consented to participate in the study were included. Additionally, the parents excluded from the study were as follows: to refuse to participate, mothers with a medical condition after delivery and those suffering from psychological disorders such as anxiety, depression, obsessive compulsive or psychosis. In total, the participants consisted of seven mothers and six fathers.

Institutional research ethics committee approved a risk-free informed consent form

detailing assurance for participants' anonymity, the right to withdraw from the study at any time and preservation of privacy and confidentiality of the data from interviews on a password-secured computer file. Parents signed an informed consent after the researchers explained the study's aims and objectives. Moreover, purposive sampling method was applied to gather a diverse group from different regions of Isfahan.

The interviews took place in hospitals, or participants' home for their convenience. They started with open-ended questions e.g. "please tell me about your baby's condition and your visits to NICU". During each interview, research objectives were reviewed and at the same time it was tried to earn participants' trust by refraining from thought manipulation. Each recorded interview lasted between 30 and 60 minutes at different settings, after transcription, raw data were translated from Persian to English and back translated for accuracy. Data collection continued until saturation was reached, that is, until no new information was added.

Raw data were reviewed several times before application of coding procedures to develop categories, they were also evaluated for coding validity and accuracy of each category. A number of interviews were returned to the participants to ensure they agree with codes and to prevent any kind of misunderstandings on the part of the researchers.

Results

Qualitative content analysis of the data resulted in development of a preliminary questionnaire with four domains, i.e., 1) the nature of stress (5 items), 2) parental reaction (7 items), 3) consequences of parental stress (12 items) and 4) stress management (10 items).

The questionnaire items were drawn from the body of literature and the coded data. Items with the highest rate of frequency were prioritized and reviewed by 8-12 experts to suggest any necessary revisions (15). Lastly, the content validity of the questionnaire was evaluated by 12 experts who reviewed all the questions and provided feedback on whether each question represents a single element of each item.

The experts were from four groups: Nursing Department at the Isfahan University of Medical Sciences, Nursing and Midwifery Faculty of Shahid Beheshti University of Medical Sciences in Tehran, two neonatologists from the Isfahan University of Medical Sciences; one neonatologist from Tehran University of Medical Sciences; two statisticians

with expertise in instrument development and two psychologists.

At first, 80 items were developed using main categories and subcategories that were deduced from the results of this qualitative study. Content validity of the questionnaire was evaluated by applying Likert-type scale criteria; the relevance, clarity and simplicity of each question were examined as described below:

A. Content Validity Ratio (CVR)

For calculating CVR of each item, experts responded to the following questions concerning how essential a particular item was and determined whether the knowledge gauged by this item was essential, useful, not essential, or not necessary for evaluation of the construct.

A formula for *CVR (CVR= $(n_e$-N/2)/ (N/2))* estimated CVR with n_e= number of experts indicating 'essential' and N= total number of panelists. Given the 12 panel experts assessment, items with more than 56% agreement (p< 0.05), were considered essential (16).

B. Content Validity Index (CVI)

To ensure the items reflecting the knowledge of a given topic area, the panel of experts determined a set of three criteria including simplicity, relevance and clarity. For evaluating each criterion, a four-point Likert scale was applied as follows: Simplicity (1. complex, 2. requiring revision, 3. simple, though requiring revision and 4. very simple), relevance (1. irrelevant, 2. requiring revision, 3. relevant, though requiring revision and 4. relevant), and clarity (1. unclear, 2. requiring some revision, 3. clear, though requires some revision and 4. clear).

In this study, content validity index was estimated to be 0.78 or above (15) and was calculated through dividing the number of experts who chose number 3 or 4 for each item by the number of whole panelists.

$$CVI = \frac{number\ of\ experts\ choosing\ each\ item, number\ 3\ or\ 4}{Number\ of\ whole\ panelists}$$

C. Face Validity

Face validity is defined as how a test measures the target construct. In fact, to evaluate face validity, the elements of reasonableness, suitability for a given purpose, interestingness, logical sequence of items, understandability and adequacy are taken into account.

Thus, ten people were asked to share their opinions on the importance of each item in a format of five-point Likert scale consisting of 'very important', 'important', 'quite important', 'a little

important' and 'not important'.

To calculate mean impact score (MIS) of each item, the percentage of items labeled as very important and important, was multiplied by MIS for those items labeled as very important and important. By means of this method, we expected to have MIS for all items to be 1.5 or above.

$$Mean\ Impact\ Score = \frac{The\ percentage\ of\ items\ labelled\ as\ 4\ and\ 5\ (frequency)}{Mean\ importance\ score\ of\ those\ items\ labelled\ as\ 4\ and\ 5}$$

After evaluation of the content and face validity of the initial questionnaire, a final version was developed. In order to assess the internal consistency, copies of the questionnaire were distributed among 30 individuals (15 fathers and 15 mothers) who met the inclusion criteria.

Both reliability and internal consistency of the questionnaire were measured using Cronbach's alpha and the coefficient of interest for internal consistency, equaled 0.70 or above (15, 17). Additionally, Cronbach's alpha of the 12-item questionnaire reached 0.904. Moreover, based on factor analysis, the items with a correlation coefficient of less than 0.4 were excluded, which included item #8 in this study. Table 1 demonstrates that item #8 had a correlation coefficient of less than 0.4 and was excluded for inappropriateness (18, 19).

Discussion

Upon completion of this study, researchers developed a preliminary questionnaire based on a widely used method devised by Lawshe to measure content validity ratio (16). An expert group of 12 individuals determined how essential each item was and according to Lawshe, the items with more than 56% of panelists' approval were regarded as essential (P< 0.05). Content validity index was also estimated at 0.78 or above.

After determining essentiality of each item, the face validity of the questionnaire was evaluated by 10 people and the importance of each item was assessed, using a five-point Likert scale and the items with the highest percentage of 'very important' and 'important' were selected. The mean importance score of these items were multiplied by mean importance score of those items labelled very important and important. In this manner and the impact scores of all the items were calculated to be 1.5 or above.

The 12-item questionnaire evaluating parental stress level obtained Cronbach's alpha of 0.904. Furthermore, using the factor analysis method, the items with correlation coefficient of less than 0.4 were removed. The final version of the

questionnaire evaluating parental stress level constituted of 11-items.

Frank et al., (2004), measured unit-related parental stress in NICU on a sample from the United Kingdom (UK) to determine the validity and reliability of the Parent Stressor Scale, subsequently, the data were compared with those of another contemporary sample from the United States. Researchers recognized the greatest NICU-related parent stressors and identified demographic or situational factors influencing NICU-related parental stress (20).

However, as Frank et al. (2004) reported, researchers have only focused on the identification of stressors and have not indicated how stress among parents with infants in NICU should be assessed.

In another study, Valizadeh et al., (2004) described stressors affecting 300 mothers with premature newborns in NICU at three teaching hospitals in Tabriz, Iran. The Parent Stressor Scale and its content validity were evaluated by experts from Tabriz and abroad. Researchers estimated Cronbach's alpha of the questionnaire with 20 participants as 0.87 (21). However, parental stress level was not measured in this study.

In this qualitative study researchers developed a questionnaire to measure the parental stress level in NICU and aimed to discover the areas needing improvement in nursing services and to help the parents with infants admitted to NICU. This self-designed instrument determines the parental stress scores as [0-16.1] no stress, [16.2-33.1] slight stress, [33.1-50.1] moderate stress and [50.2 or higher] with severe stress.

Conclusion

Parents of infants admitted to NICU spend long hours awaiting or visiting their newborn in a hospital, where medical policies and procedures takes their sense of control over healthcare decisions related to their infant. In such a situation, the parents experience fear and stress, placing them in physical and psychological conditions disrupting their daily life.

To date, no other instrument has been developed to assess the stress level of the Iranian parents with an infant in NICU, and all the available tools from different countries investigate stressors rather than stress levels. This study provides a novel questionnaire with 11-items to assess the stress levels of the parents with an infant in NICU. Further application of this instrument in other studies will help validate it among other populations.

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