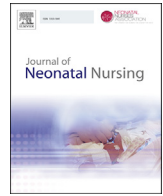




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Information to parents in the neonatal unit



Björn Lantz

Department of Technology Management and Economics, Chalmers University of Technology, Gothenburg, Sweden

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ABSTRACT

We aimed to identify the principal components during neonatal care regarding parents' views of the information received, and to analyse the relationships between these variables and parental characteristics. We surveyed a convenience sample of 141 parents with infants in the neonatal intensive care unit, based on the EMPATHIC-N questionnaire. Principal component analysis revealed that parents viewed the information provided as either critical or general. The importance of critical information was not significantly dependent on any demographic variable, but the rating for general information was significantly related to parental educational level and the infant's gestational age. Hence, the results suggest no need to discriminate among parents regarding the way critical information is presented, but parents with a lower educational level and/or a more premature infant should receive more thorough general information. The value of these results is limited by the fact that the questionnaire was not validated for the Swedish context.

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Introduction

Parents with premature or sick infants admitted to a neonatal intensive care unit (NICU) have a great need for information. The desire to receive accurate and understandable information is one of the primary needs of parents in the NICU; it may even be their most important need (De Rouck and Leys, 2009; Cleveland, 2008). Parents desire information about their infant and their infant's progress during NICU hospitalization as a way of engaging in the care of their infant and to gain control over the situation. Receiving inaccurate and/or insufficient information pertaining to their premature or sick infant's condition is often a source of stress, and may also hinder parental attachment with the child (Hurst, 2001).

Parents receive different types of information for different purposes during their time in the NICU. Research has shown that regular communication with caregivers, adapted to different needs at different times, helps parents to interact and bond with their premature neonate (Guillaume et al., 2013). For example, Smith et al. (2012) found that the staff can support parents' coping strategies by providing accurate and consistent clinical information. Parents often appreciate getting regular information and being informed by both nurses and physicians (Ignell Modé et al., 2014; Wigert et al., 2013). In particular, parents seem to appreciate information about planned procedures (Edéll-Gustafsson et al., 2015).

Some parents prefer to get complicated or technical information from physicians, even though they may need additional information from nurses for more guidance (Smith et al., 2012). On the other hand, information regarding routines and practicalities in the NICU is often made available in brochures (Ignell Modé et al., 2014).

When information is given to parents depends on its seriousness or significance. Cuttini et al. (1999) found that routine information is usually given when time is available, but acute information regarding, for example, substantial deterioration in the child's condition, is typically given immediately or as soon as the health care professionals have a clear picture of the child's condition. It is also important to fine-tune the provision of information with parental readiness; either too little or too much information at an unsuitable moment can induce anxiety and fear (Arockiasamy et al., 2008; Shellabarger and Thompson, 1993).

More specific studies related to the provision of information to parents in the NICU can also be found in the recent literature. For example, the benefits of using smartphone applications to provide parents with information have been evaluated (Garfield et al., 2016). The effects of clinical staffs' communication on parental stress have been explored (Enke et al., 2016). The effect of a course in communication for nurses (Bry et al., 2016) or of an internet-based education program for mothers (Kadivar et al., 2016) on the interaction between professionals and parents has been analysed. The information and communication needs of families in neonatal end-of-life and bereavement in the NICU have been explored (Sadeghi et al., 2016; Xafis et al., 2015). Furthermore, the

E-mail address: bjorn.lantz@chalmers.se.

information needs of fathers in the NICU have been specifically reviewed (Ireland et al., 2016).

The fact that specific pieces of information given to parents in the NICU can be classified in terms of categories as well as in terms of seriousness or significance implies that parents may value different types of information differently (Cuttini et al., 1999). Managing the flow and content of information given to parents might also be problematic because all parents are different. What works well for some parents might not work for others. In particular, parental characteristics, such as gender, age, and previous parental experience, should be considered in this context (De Rouck and Leys, 2009; Lantz, 2013a; Wigert et al., 2014; Ireland et al., 2016). However, there are essentially no prior quantitative studies with generalizable results in this particular area. Therefore, the purpose of this study was to identify the principal components of neonatal care with respect to the parental view of the information provided to them, and to analyse the relation between these principal components and parental characteristics.

Methods

Participants

We asked all parents of children admitted for more than 48 h to any of the five NICUs in the Västra Götaland region of Sweden during the spring of 2013 to participate in the study at the time of discharge. Parents whose children passed away during their NICU stay were excluded from the survey. We provided the parents with verbal and detailed written information about the study, and informed them that declining to participate would not affect their future interactions with the healthcare system in any way. The parents who agreed to participate received questionnaires and return envelopes. In order to ensure the anonymity of all participants, only the contact persons in the NICUs were provided information to could match the respondents' identities to the respondent numbers, and only the author could match the respondent numbers to specific answers. After one reminder was sent to the parents who had agreed to participate but had not returned their questionnaires within three weeks, a total of 141 of 173 (80.5%) completed questionnaires were received.

Questionnaire

The instrument used in the study was a Swedish version of the EMpowerment of PARENTS in THE Intensive Care-Neonatology (EMPATHIC-N) questionnaire, which was developed and validated by Latour et al. (2010). In addition to demographic questions, it consists of 92 items that assess general neonatal care issues that are rated on a 6-point scale ranging from 1, 'completely unimportant' to 6, 'extremely important'. The 92 items are distributed over five independent domains: information to parents, treatment and care, organisation of work, parental participation, and professional attitude. This study used only the items related to the domain of information to parents (see Table 3). In order to use the questionnaire in a Swedish context, a professional translator was employed to convert the questionnaire into Swedish. The author modified the translated version for specific terminology used in Swedish NICUs, which was verified by the professional translator. Hence, unlike some other recent studies in this field (Gomez et al., 2016; Dall'Oglio et al., 2014), the tool was never formally validated for a different language and a different cultural setting than the original Dutch context, and the results should of course be viewed in light of this limitation.

The regional research ethics committee approved the present study.

Data analysis

Data were analysed using principal component analysis (PCA) and multiple regression analysis with SPSS software, version 22.0. The level of statistical significance was set at $p < 0.05$. A power analysis showed that the minimum sample size for a multiple linear regression analysis with 5 explanatory variables was 139, given a medium effect size of $f^2 = 0.15$, a nominal significance level of $\alpha = 0.05$, and a power level of $1 - \beta = 0.95$ (Faul et al., 2009). Hence, the study was considered to have sufficient power with an actual sample size of $n = 141$.

Results

Table 1 presents the characteristics of the 141 respondents. The observed values are in line with official statistics in Sweden; for example, the majority of younger Swedish women attend university, whereas the majority of younger Swedish men do not (SCB, 2017). Hence, we proceeded under the assumption that the data were not characterised by nonresponse bias. The gestational age of the infants ranged from 24 weeks to 42 weeks.

Table 2 displays the Pearson's correlations between item ratings. Many pairs of item ratings exhibited substantial correlations, indicating that there might be a few common underlying factors (note that all table values above 0.16 are significant at the 0.05 level). Hence, a principal component analysis (PCA) was considered a suitable way to proceed in order to clarify those factors.

A PCA was conducted on the 20 items using Varimax rotation and Kaiser Normalization. Bartlett's test of sphericity was significant ($p < 0.001$) and the Kaiser-Meyer-Olkin measure of sampling adequacy was 0.74, indicating that the data were suitable for a PCA. A solution where seven factors had eigenvalues over Kaiser's criterion of 1 was found, which in combination explained 66.5% of the variance. The scree plot was somewhat ambiguous and showed an inflexion point that justified retaining two rather than seven factors. Because the sample size was not large, a conservative approach was used and the PCA was rerun in order to extract two factors. Table 3 shows the results in terms of factor loadings after rotation. The items that cluster on the same factor suggest that factor 1 represents critical information, and that factor 2 represents general information. Both factors exhibit relatively high values on Cronbach's α , indicating a reliable solution.

Multiple regression was used to analyse the relation between the explanatory variables (parental gender, parental age, parental educational level, the infant's gestational age, and whether the parent had previous parental experience) and each of the two factors above. The final results of these two procedures are presented in Tables 4 and 5. The results of the first regression model indicate that neither explanatory variable was significantly associated with the parental rating of critical information. In the second regression model, the parental educational level and the infant's gestational age were found to be significantly associated with the parents' rating of general information ($\beta = -0.29$, $p = 0.033$, and $\beta = -0.03$, $p = 0.039$). Hence, a lower parental educational level and

Table 1
Characteristics of the participating parents.

	Female (n = 81)	Male (n = 58)
Age (mean)	31.2 years	33.5 years
University education	61.7%	41.4%
Infants' gestational age (mean)	33.4 weeks	33.6 weeks
Previous parental experience	28.4%	31.0%
Pearson's correlation between parental and gestational age	0.01	0.12

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