

XXVIII CICLO - Anno Accademico 2016/2017

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Titolo tesi: Family centred care and parents satisfaction in neonatology

ABSTRACT

Background

This thesis presents an overview of the main issues of Family-Centred Care (FCC) in neonatal intensive care unit (NICU). Providing FCC is a shared responsibility among all NICU HCPs. Still FCC needs to be considered a common value and framework of the care and treatment of the infants for all the staff.

The main question of this thesis was: How is the FCC provided in the Italian NICUs? This is an important issue considering the extent of the phenomenon of the infants admitted into NICUs in Italy and the organization of the NICUs. In NICUs, parent satisfaction and their experiences are fundamental to assess clinical practice and improve the quality of care delivered to infants and parents. In Italy, no rigorous instruments were available to evaluate parent satisfaction and experiences in NICUs with FCC.

Aim of the thesis

The overall objective of this research is to evaluate FCC in Italian NICUs, using the quality performance indicator of parent experience and satisfaction, and explore the relationship between this and the level of FCC expressed both by professionals and the organizations of the NICUs. The thesis presents three main studies:

Study 1.

A systematic review that synthesised and described instruments that measure parent satisfaction with the increasing standard practice of family-centred care (FCC) in NICUs. We evaluated 11 studies published from January 2006 to March 2016: two studies validated a parent satisfaction questionnaire, and nine developed or modified previous questionnaires to use as outcome measures in their local settings. Most instruments were not tested for reliability and validity. Only two validated instruments included all of the six FCC principles and could assess parent satisfaction with FCC in neonatal intensive care units, and be considered as outcome indicators for further research. Of these two, EMpowerment of PArEnts in THE Intensive Care-Neonatology (EMPATHIC-N) had fewer items and some open-ended questions.

Study 2

A validation study aimed to translate and validate the Italian version of EMPATHIC- N. The instrument investigated different domains of care in NICUs from a FCC perspective. A psychometric study was conducted in nine Italian NICUs. Parents whose infants were discharged from the units were enrolled. Back-forward translation and cultural adaptation was conducted. A total of 186 parents of infants who were discharged from nine NICUs were invited to participate and 162 parents responded and returned the questionnaire (87%). The mean scores of the individual items varied between 4.3 and 5.9. Confirmatory factor analysis was performed, and all the factor loadings were statistically significant with the exception of the item 'Our cultural background was taken into account'. Cronbach's alpha's at the domain level (0.73-0.92) revealed high reliability. Thus, the Italian EMPATHIC-N confirmed to be a valid and reliable instrument for measuring parent satisfaction in NICUs from a FCC perspective.

Study 3

The third study explored FCC practices in Italian NICUs and described areas for improvement.

A cross-sectional, multicentre, survey was conducted using the Italian version of “Advancing family-centred new-born intensive care: a self-assessment inventory”. The instrument is divided into 10 sections rating the status of family-centred care (1 = not at all, 5 = very well) and ranking the perceived priority for change/improvement (1 = low, 3 = high). A representative group of staff and parents for each unit were invited to complete the survey. Data were collected between January and June 2015.

Forty-six (43.8%) of the 105 NICUs in Italy returned the survey. The “Leadership” section scored highest in status of family-centred care (mean = 3.45; SD 0.78) and scored highest in priority for change (mean = 2.44; SD 0.49). The section “Families as Advisors and Leaders” scored lowest both in status (mean = 1.66; SD 0.67) and in priority for change (mean = 2.09; SD 0.59). The number of discharged infants was positively correlated with many sections in priority for change (r 0.402–0.421; $p < .01$).

Conclusions

The literature review highlighted the characteristics of an instrument aimed to assess parent experience and satisfaction with FCC in NICUs. The Italian version of EMPATHIC-N was developed and showed good psychometric properties, validity, and reliability. This instrument

is fundamental for further research and international benchmarking. The survey across Italian NICUs, showed great variability in the organization of FCC practices and the need to involve parents as partners in the care team. Moreover, a higher priority for change resulted in the “Leadership” section. Innovative leadership at a hospital and unit level are key elements to develop and support institutional policies consistent with international FCC standards. Continuing education and training programmes for neonatal intensive care staff must be provided to implement and support high quality family-centred care practices. Although FCC is considered important by Italian neonatology healthcare professionals, much remains to be done to improve FCC practices in neonatal intensive care units in Italy.