

Roser Porta*, Beatriz Ibáñez*, Cristina Berenguer**, Montserrat Roca***, Clara González****, Ma Teresa Gomez*****, Vicente Molina*****

Is the Privacy of Information Protected in a Neonatal Intensive Care Unit? An Observational Study

SUMMARY

Respecting patients' intimacy and confidentiality can be a challenge in the neonatal intensive care units (NICUs) designed according to traditional standards (e.g. a single big room with a number of cots and incubators located close one to another). Concerned about this topic, two members of the team designed a study to check the quality of the confidentiality in the NICU area, and identify opportunities for improvement. This is an observational study performed for a period of one month. The observed team was not aware of being observed. During observation time, a total of 147 hours, 25 confidentiality violation situations were encountered. Twelve (48%) were comments, spoken with a loud voice, about the patients in the NICU area or in adjacent areas, 24% (6/25) were related to the privacy issues due to leaving medical documentation or computer screens available for anybody to see or informing parents in a way that could be heard by parents of other babies, 12% (3/25) were phone conversations about patients in a loud voice, 4% (1/25) were answering questions to parents or relatives about other babies. The medical and personal information of the patients in the NICU is often exposed and shared with parents of other patients and non-related professionals. The architectural design of the traditional NICUs, some socio-cultural

* Neonatal Intensive Care Unit, Hospital Quiron Dexeus, Barcelona, Spain.

** Clinical Bioethics Committee of Quiron Hospitals, Barcelona, Spain.

*** Assisted Reproduction Unit, Hospital Teknon, Barcelona, Spain.

**** Department of Reproductive Medicine, Hospital Quiron Dexeus, Barcelona, Spain.

***** Clínica Ginecológica, Hospital Teknon, Barcelona, Spain.

***** Pediatric departmen, Hospital Quiron Dexeus, Barcelona, Spain.

Correspondence Address: Roser Porta Neonatal Intensive Care Unit, Hospital Quiron Dexeus, C/Sabino d'Arana 5-19, 08028 Barcelona, Spain. E-mail: rosier.porta@quironosalud.es.

issues in South European countries, and the difficulties in changing attitudes are the critical points to focus on to start a quality educational project to protect the right to intimacy and confidentiality of vulnerable children and parents admitted to the NICUs.

Keywords: privacy, confidentiality, NICU, family centred care.

1. INTRODUCTION

The ethical issue of information confidentiality shared in the physician-patient relationship is a central topic in professionalism and quality of care, while permanently at risk in various ways. The intensive care units (ICU) are unique areas in hospitals where a variable number of patients are looked after together in an open ward. In newly built hospitals, there is a trend towards a novel design of the ICUs, neonatal (NICUs) and paediatric (PICUs) ICUs that offers a more intimate and respectful atmosphere for individual patients. Meanwhile, most of the hospitals designed before the 21st century, continue caring for patients in the old standard way. The traditional architectural designs often pose a real challenge for intimacy and confidentiality.

The Clinical Ethics Committee (CEC) in our institution has recently set a quality improvement project to improve the clinical practices and knowledge about patient confidentiality, addressed to all clinical staff members. The Working Group on Confidentiality has published a written guideline and is performing role-play simulations to teach and implement it.¹ A growing number of physicians, nurses and auxiliary staff are attending these sessions.

Two members of the CEC working in the NICU, concerned about the difficulties in preserving intimacy and privacy of information in this area, decided to conduct an observational study. The objectives were to check the quality of the patient confidentiality in the NICU area, and to find out opportunities for education and improvement.

The NICU is designed according to traditional standards: one single room with twelve incubators and a variable number of cots. Parents are allowed to enter 24 hours a day, and grandparents and siblings can also visit the unit for short periods of time. Parental participation in medical rounds next to their infants is a routine practice. Identification of people entering the NICU is not regularly assessed at the entrance. Doctors, nurses, auxiliary nurses, technicians, cleaning staff, consultant specialists, and parents and relatives share the NICU room. The doors are automatically opened without security codes. Prior to discharge, some babies are accommodated in family

1 Berenguer C, Gómez T, González C, Roca de Bes M, (2018). *The value of confidentiality as an ethical indicator in the health system. Document of position statement.* Clinical Bioethics Committee of Quiron Hospitals in Barcelona.

rooms next to the NICU, from where they are carried to the main area to check weight or vital signs, once or twice a day.

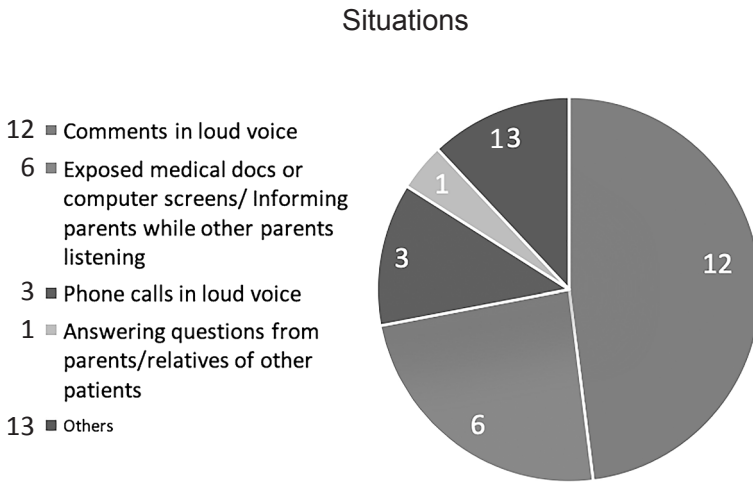
2. METHODS

This is an observational study performed during one month period (1-30 June 2018), during the morning shift, from Mondays to Fridays. A nurse and a neonatologist observed and collected the data of any confidentiality violation situations that were predefined, for instance: to comment patient's medical or personal conditions in a level of voice that could be heard by the parents of other patients, phone conversations giving data about patients in a loud voice, to leave documentation or computer screens (clinical comments, laboratory results, radiological exams) unprotected. The professional roles of the staff involved in the study were also collected. The observed team was not aware of being observed.

3. RESULTS

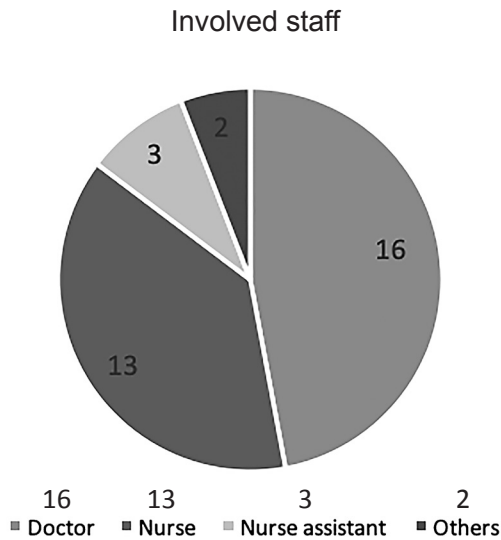
During a total observation time of 147 hours, 25 situations of confidentiality violation were encountered, as showed in Figure 1. 48% (12/25) were comments spoken in a loud voice about patients in the NICU area or in adjacent areas, 24% (6/25) were related to privacy issues, due to leaving medical documentation or computer screens available for anybody to see or to inform parents in a way that could be heard by parents of other babies, 12% (3/25) were phone conversations about patients in a loud voice, 4% (1/25) were answering questions to parents or relatives about other babies, and 12% (3/25) other situations (to give parents names and examples of babies experiencing a similar pathology in the past, to answer medical requirements from the insurance company about infants condition, etc.).

Figure 1



Doctors and nurses were involved in a similar number of confidentiality violation cases (see Figure 2).

Figure 2



4. DISCUSSION

The medical and personal information of the patients in the NICU is often exposed and shared with parents of other patients and non-related professionals. The arising question is, whether parents have a choice to participate in this or not. Commonly, parents of babies admitted to a NICU tend to share information between them, as a spontaneous and first-line aid to cope with their infants' situation. They do it by oral conversations, social networks or phone messaging. As primary caregivers, they have the right to decide which information is shared. Besides the reflexions about the right amount of information that parents spread out and the right of the child to keep his medical condition private, the staff caring for those patients should not assume that *if parents do not mind to share information about their children, it can be done*.

Since now, the guidelines about standards of care in NICUs published by the local scientific society have paid little attention to the topic of confidentiality. In the document of the SENEo (Spanish Society of Neonatology) about design of NICU², the authors admit that a single room for all patients can offer less intimacy for patients but allows a better optimization of human resources (mainly nurse-patient ratio). The Family Centered Care (FCC) is a goal in all NICUs in the developed countries. Besides a large number of concepts related to the protection of infants' future neurodevelopment, involving parental presence and humanization of care, FCC suggests to care for critical or semi-critical patients in the so-called 'single family rooms'. That design requires a higher amount of economical and human resources, but is better in all ethical senses and helps to preserve confidentiality. Another aspect of FCC is enhancing participation of parents in bedside medical rounds. This is strongly supported by staff and caregivers³ but, if the rounds took part in the common area of the NICU, an additional effort to preserve intimacy has to be done. The promotion of low voice in the conversations between parents and staff or between the staff members is a useful tool, not only to protect infants' natural sleep and neurodevelopment⁴, but also their intimacy.

2 Rite Gracia, S., Fernández Lorenzo, J.R., EchánizUrcelay, I., et al. (2013), Health care levels and minimum recommendations for neonatal care, *An Pediatr (Barc)*, 79(1), 51. doi: <https://doi.org/10.1016/j.anpedi.2012.11.007>

3 Abdel-Latif, Mohamed E, Boswell, Danette, Broom, Margaret, et al. (2015), Parental presence on neonatal intensive care unit bedside rounds: randomized trial and focus group discussion. *Arch Dis Child Fetal Neonatal ed*, 203-9. doi: <http://dx.doi.org/10.1136/archdischild-2014-306724>

4 Roué, Jean-Michel, Kuhn, Pierre, López Maestro, Maria, et al. (2017), Eight principles for patient-centred and family centred-care for newborns in the intensive care neonatal units, *Arch Dis Child Fetal Neonatal ed*, 1-5. doi: <http://dx.doi.org/10.1136/archdischild-2016-312180>

Meanwhile, because of the lack of single family rooms for most critical neonates, the members of the staff have the ethical duty of keeping the level of confidentiality as good as possible. This can be achieved by giving the right amount of information to the right people and in the adequate places, by using a low voice level into the NICU and in all hospital areas, by avoiding the exposition of medical documentation and by limiting the use of communication tools that could disrupt patient's intimacy.

5. CONCLUSIONS

The architectural design of the traditional NICUs, some socio-cultural issues in countries of the Southern Europe, and the difficulties in changing attitudes are the critical points to be addressed to start a quality improvement project to protect the right to intimacy and confidentiality of the patients admitted to the NICUs.

BIBLIOGRAPHY

1. Berenguer, C., Gómez, T., González, C., and Roca de Bes, M. (2018). *The value of confidentiality as an ethical indicator in the health system. Document of position statement.* Clinical Bioethics Committee of Quiron Hospitals in Barcelona.
2. Rite Gracia, S., Fernández Lorenzo, J.R., EchánizUrcelay, I., et al. (2013), Health care levels and minimum recommendations for neonatal care, *An Pediatr (Barc)*, 79(1), 51. doi: <https://doi.org/10.1016/j.anpedi.2012.11.007>.
3. Abdel-Latif, Mohamed E, Boswell, Danette, Broom, Margaret, et al. (2015), Parental presence on neonatal intensive care unit clinical bedside rounds: randomized trial and focus group discussion. *Arch Dis Child Fetal Neonatal ed*, 203-9. doi: <http://dx.doi.org/10.1136/archdischild-2014-306724>.
4. Roué, Jean-Michel, Kuhn, Pierre, López Maestro, Maria, et al. (2017), Eight principles for patient-centred and family centred-care for newborns in the intensive care neonatal units, *Arch Dis Child Fetal Neonatal ed*, 1-5. doi: <http://dx.doi.org/10.1136/archdischild-2016-312180>.

Je li privatnost informacija zaštićena u neonatalnoj jedinici intenzivnog liječenja? Opservacijska studija

SAŽETAK

Poštovanje privatnosti i povjerljivosti pacijenata može biti izazov u neonatalnim jedinicama intenzivnog liječenja (NJIL) koje su dizajnirane prema tradicionalnim standardima (npr. jedna velika soba s određenim brojem krevetića i inkubatora smještenih jedni blizu drugih). Zabrinuti zbog ove teme, dva člana tima osmislila su studiju koja će provjeriti kvalitetu povjerljivosti u neonatalnim jedinicama intenzivnog liječenja i pronaći mogućnosti za poboljšanje. Ova opservacijska studija provodi se tijekom jednog mjeseca. Tim koji je bio promatran nije bio svjestan našeg promatranja. Tijekom vremena promatranja, ukupno 147 sati, primijećeno je ukupno 25 situacija u kojima je prekršena povjerljivost.

Bilo je dvanaest (48 %) komentara koji su bili glasnije izgovoreni o pacijentima u neonatalnim jedinicama intenzivnog liječenja ili u bližoj okolini, 24 % (6/25) situacija odnosilo se na pitanja privatnosti, bilo zbog ostavljanja medicinske dokumentacije ili računala bez nadzora ili zbog informiranja roditelja, tako da su ih mogli čuti i roditelji druge novorođenčadi, 12 % (3/25) su bili telefonski razgovori o pacijentima i to glasnijim tonom glasa, 4 % (1/25) su bili odgovori na pitanja roditelja ili rodbine o drugoj novorođenčadi-pacijentima. Medicinski i osobni podaci pacijenata na odjelu NJIL-a često su izloženi i podijeljeni s roditeljima drugih pacijenata i profesionalcima koji nisu ni u kakvoj vezi s tim pacijentima. Arhitektonski dizajn tradicionalnih jedinica NJIL-a, neka sociokulturna pitanja u južnoeuropskim zemljama i poteškoće u promjeni stavova kritične su točke na koje se treba usredotočiti kako bi se pokrenuo kvalitetan obrazovni projekt za zaštitu prava na intimu i povjerljivost ranjive djece i roditelja koji borave na odjelu NJIL-a.

Ključne riječi: privatnost, povjerljivost, neonatalna jedinica intenzivnog liječenja (NJIL), njega u središtu obitelji.