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Parents' experiences of communication with neonatal intensive-care unit staff: an interview study

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Is it important to have a good communication with the staff in NICU?

- Parents need to discuss their experiences and emotions with staff members.
- When parents feel dissatisfied with their communication with staff, their stress increases and it is difficult to establish a close relationship to their child.

Purpose

To describe parents' experiences of communication with NICU staff.



Methods

Interviews in parent's home

Please tell me about your experiences of
communication with the staff when your child
was treated in the NICU

Analysis: Hermeneutic lifeworld approach

Setting and participants

NICU

- Level III in a university hospital in Sweden
- 1,000 newborns per year
- 22 beds
- 120, doctors, reg. nurses, nursing assistants
- Family-centred care

Parent and child

- 27 parents (11 fathers, 16 mothers) in 18 families
- 22 infants, 17 prematurely born
- Stay in NICU 11-120 days (mean 46)
- Respiratory distress, cerebral haemorrhage, neonatal stroke and congenital anomaly
- Less than 12 months since discharge from NICU

Study findings

The parents' experience of communication with the staff when their infant was treated in the NICU can be described by the main theme,
'being given attention or ignored in their emotional situation'.

Meeting a fellow human being

“The doctor listened, the doctor was also a person ... she showed that she was also a fellow human being in the whole thing; she said, ‘but God, here I am, saying horrible things to you, but of course I have to say what I say now’.” (Father)

Meeting a fellow human being

“We noticed that they were keeping an eye on the situation ... They were hanging around, they were there and started talking a bit and could tell if you wanted to talk.” (Mother)

“Communicating, talking about other things, being allowed to forget reality for a while ... there is so much focus on the child. Sometimes it’s like you have no life outside.” (Mother)

Being included or excluded as a parent

“There is a communication together with us, [they] answer questions, provide support, tell us what we can do and what they will help with.” (Father)



Being included or excluded as a parent

“Then there was this doctor who just came in for a few minutes, really stressed out, and burst out with, ‘Yes, these three brain injuries and this one at the back are of course very dangerous and blah, blah, blah’ and then he went out. We were completely devastated and just cried and wondered, ‘Were you talking about our child, has he got another brain injury?’” (Mother)

“I have not told this to anyone because whenever I talk about that time, I say we’ve been treated very well ... but now that we are discussing communication and staff, I can’t hide it.” (Mother)

Bearing unwanted responsibility

“Communication between the maternity ward and Neonatal could be improved. They had failed to schedule the hearing test. They didn’t know if it was the maternity ward or Neonatal that booked it, so I had to check it myself. It was several weeks after we had arrived home.... Then I got worried that there might be more things they had missed.” (Mother)



Bearing unwanted responsibility

“Vague communication, should we remember when the child needs feeding or should the staff do it, and sometimes in case we forgot ... it was as if we were supposed to take on the responsibility.”(Mother)



What are the key findings?

Parents in the NICU experience communication with staff to be essential for them to manage their situation in the unit.

Attentive communication offers the opportunity for a respite from reality, for compassion and relief.

A lack of communication contributes to feelings of loneliness and being abandoned, as well as unwanted responsibility, which adds to the burden of an already difficult situation.



Take home message

The staff should be reminded and remain aware of their unique position to help parents process emotional difficulties and therefore through communication share the parents' situation, respond to their emotions and encourage conversation.

The organization should also facilitate opportunities for good communication between parents and staff through training, staffing and the physical healthcare environment.

Thank You for listening!

