Guided Family-Centred Care

Effect and experiences of structured communication in NICU
GFCC-studiet

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Background

- Having a preterm birth is stressful and a considerable challenge for parents.
- Stress related to NICU admission may last for months or years after discharge.
- Parents risk developing post-natal reactions such as birth-related depression or post-traumatic stress.
- Effective nurse-parent communication is important to provide support tailored to meet parent values, needs and concerns.
The study

Study 1: a pragmatic randomized controlled study (RCT) to determine the effect of the GFCC in a real-life setting.

Study 2: a qualitative study to determine the clinical significance of the GFCC using semi-structured interviews.

Study 3: a feasibility study evaluating a systematic implementation framework for nurse GFCC training, generating qualitative and quantitative data to assess delivery as intended and describe significant factors of importance to successful implementation.
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Purpose of GFCC

- ensure expansion of parents’ person-specific perspectives in order to support their handling of emotional reactions;
- support parent managing of the parental role in the NICU;
- solving current problems;
- negotiating care plans throughout admission.
Mechanisms of GFCC

Nurse-parent communication intervention

- Structured dialogue
- Reflection
- Person-centred communication.
Structured dialogue

- Dialogues held regularly during admission.
- Lasting for up to one hour, conducted in a private room.
- Scheduling dialogues was new to the nurses. In standard care, dialogues were mostly performed ad hoc when the nurse attended to infant care.
Reflection

- Parent preparation using semi-structured reflection sheets:
  - Admission dialogue
  - Values-clarifying dialogue
  - Discharge or transfer dialogue

- Supportive sheets:
  - Invitation to collaborate
  - Negotiating plans
## GFCC reflection sheets

<table>
<thead>
<tr>
<th>Phase</th>
<th>Reflection sheets</th>
<th>Content of reflection sheets</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Acute Critical Phase</strong></td>
<td></td>
<td></td>
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<tr>
<td>Invitation to collaborate</td>
<td>Clarification of roles, collaboration, and use of reflection sheets</td>
<td>&quot;We will collaborate on...&quot; &quot;We have different roles...&quot; &quot;It is important that we understand each other's views...&quot;</td>
<td></td>
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<tr>
<td>Admission dialogue</td>
<td>Six questions on parents' experiences and current issues</td>
<td>&quot;How did you experience pregnancy, giving birth, and admission to NICU?&quot; &quot;Do you experience any particular issues causing you problems?&quot; &quot;Do you need more information regarding your baby's care?&quot;</td>
<td></td>
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<tr>
<td><strong>Stable Phase</strong></td>
<td>Values Clarifying dialogue</td>
<td>17 unfinished sentences for both parents to accomplish reflection on values, experiences and needs</td>
<td>&quot;The worst about premature labor was...&quot; &quot;I wish I could...&quot; &quot;I feel like a parent when...&quot; &quot;I experience collaboration with the healthcare-professionals....&quot;</td>
</tr>
<tr>
<td>Transfer or Discharge dialogue</td>
<td>Six questions on parents' experiences of the NICU stay, positive and negative views of discharge, and need for further information</td>
<td>&quot;How did you experience admission to NICU?&quot; &quot;What are your positive or negative expectations?&quot; &quot;Do you need more information before discharge?&quot;</td>
<td></td>
</tr>
<tr>
<td><strong>Discharge Phase</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Negotiated plan (used in all dialogues)</td>
<td>Space provided for summarizing current issues discussed in the dialogue, and noting negotiated plans.</td>
<td>Parent perspective: Nurse perspective: Plans:</td>
<td></td>
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Person-centred communication

- promote shared decisions on care through exploration of parent perspectives.

- adjust information and discuss plans accommodating the specific family needs.

- sharing the nurses’ professional knowledge and the parents’ private knowledge to benefit the infant and the family.

- Communication strategies: mirroring, active listening and values clarifying responses.
Aim of study

- To explore how parents of premature infants experience GFCC and

- To compare how parents receiving GFCC versus standard care (SC) describe nurse-parent communication in the NICU
Interview study

12 interviews conducted 3-6 months after discharge.
10 dyad interviews with both parents and two individual interviews with mothers

Participants:
- 22 parents of infants born before or at 34 weeks of gestation
- 13 parents received the GFCC; 9 parents received SC
- Mean age of mothers was 31 years (24–38), fathers 33 years (26–38);
- Mean NICU stay 41 days (6–86)
- Mean infant gestational age 28+4 weeks (24+0 to 33+1)
## Interview participant characteristics

<table>
<thead>
<tr>
<th>Parent number</th>
<th>Study allocation</th>
<th>Mother’s age, years</th>
<th>Father’s age, years</th>
<th>Infant GA, weeks</th>
<th>NICU stay, days</th>
<th>Transfer to local hospital</th>
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</thead>
<tbody>
<tr>
<td>M1, F1</td>
<td>GFCC</td>
<td>32</td>
<td>37</td>
<td>26 + 0</td>
<td>61</td>
<td>No</td>
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<tr>
<td>M2, F2</td>
<td>GFCC</td>
<td>28</td>
<td>31</td>
<td>29+6</td>
<td>36</td>
<td>No</td>
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<tr>
<td>M3, F3</td>
<td>GFCC</td>
<td>38</td>
<td>38</td>
<td>24+4 triplets</td>
<td>73</td>
<td>Yes</td>
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<tr>
<td>M4, F4</td>
<td>GFCC</td>
<td>24</td>
<td>30</td>
<td>30+4</td>
<td>6</td>
<td>Yes</td>
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<tr>
<td>M5, F5</td>
<td>GFCC</td>
<td>36</td>
<td>38</td>
<td>33+0 twins</td>
<td>23</td>
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<tr>
<td>M6</td>
<td>GFCC</td>
<td>31</td>
<td></td>
<td>30 + 4</td>
<td>14</td>
<td>Yes</td>
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<tr>
<td>M7, F7</td>
<td>GFCC</td>
<td>26</td>
<td>26</td>
<td>29+3</td>
<td>6</td>
<td>Yes</td>
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<tr>
<td>M8, F8</td>
<td>SC</td>
<td>38</td>
<td>35</td>
<td>24+0</td>
<td>29</td>
<td>Yes</td>
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<tr>
<td>M9, F9</td>
<td>SC</td>
<td>38</td>
<td>32</td>
<td>25+2</td>
<td>86</td>
<td>Yes</td>
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<tr>
<td>M10, F10</td>
<td>SC</td>
<td>26</td>
<td>32</td>
<td>33 +1</td>
<td>15</td>
<td>No</td>
</tr>
<tr>
<td>M11</td>
<td>SC</td>
<td>32</td>
<td></td>
<td>31+4</td>
<td>86</td>
<td>No</td>
</tr>
<tr>
<td>M12, F12</td>
<td>SC</td>
<td>27</td>
<td>28</td>
<td>24 + 3 triplets</td>
<td>59</td>
<td>Yes</td>
</tr>
</tbody>
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Data analysis

- Thematic analysis (Braun & Clarke 2006)
- Inductive and deductive analysis combined

- Six phases of analysis
  - Getting acquainted with the data
  - Extracting and gathering data in meaningful groups, creating initial codes
  - Re-focusing the analysis at the broader level of themes, sorting initial codes into potential themes
  - Reviewing and refining themes, creating a satisfactory thematic map of the data
  - Defining and naming themes
  - Producing the report
Findings

Overarching theme:

- Parents coping as persons, parents, and couples through empowering relationships with nurses
Three interrelated themes in GFCC communication

- Discovering and expressing emotions
- Reaching a deeper level of communication
- Obtaining mutual understanding
Discovering and expressing emotions

- Parent recognition of emotions and concerns was facilitated by use of reflection sheets.

- Scheduled dialogues helped parents prioritize time for preparation.
Discovering and expressing emotions

- **GFCC-M1**: You are so engaged with your baby - you are not dealing with your own situation. I’m so glad we were invited to participate and had the chance to fill in these sheets.

- **GFCC-M5**: It was a bit difficult finding the time but it felt good going through the sentences having time to reflect on the situation because things were often fast paced in the unit. It was nice having these questions to help me think things over.
Discovering and expressing emotions

- **SC-M10**: We didn’t quite understand why we had to do one thing rather than another. It was not until after discharge I realized that we actually needed more explanations.

- **SC-F12**: There are many things you need to think about as a parent – also practical things such as the right way to arrange sick leave and you just don’t have the energy. Maybe you don’t realize this until you come home and then it may be too late.
Reaching a deeper level of communication

- Scheduled dialogues were experienced as meaningful

- Dialogues expanded the parent perspective

- Important issues were remembered when parents were prepared
Reaching a deeper level of communication

- **GFCC-M4**: It just meant a lot to me to talk things through. Because you can always discuss things with family and friends, but a nurse knows something about it and also knows about stuff that might bother you.

- **GFCC-F5**: We talked all the time [in the unit], but that was different. We discussed subjects at a deeper level [in the dialogues]. Yes; we discussed totally different things than in the unit everyday life.

- **GFCC-F5**: [Having filled in reflection sheets] made it easier to remember stuff in the dialogue – in contrast to just discussing matters in the dialogue thoughts had been made in advance.
Reaching a deeper level of communication

- **SC-M9:** I found it [skin-to-skin contact with my baby] so distressing ... I could not see that it benefitted her. When she was most fragile I found it far less distressing to sit and hold her in the incubator but I never discussed my thoughts with the nurses.

- **SC-F8:** They also did it [nurses stayed and talked] because they liked us. It was obvious that it was not everybody ... there were some [parents] they had quite different relationships with.
Obtaining mutual understanding

- Nurses gained insight into the lives of the parents
- Increased insight enabled tailoring of information in response to parent concerns and preferences
- Parents gained insight into each other's perspectives
- Shared decision-making was facilitated between parents and nurses
Obtaining mutual understanding

- **GFCC-M1**: She met us where we were and listened to us. But she also prepared us for the next step.

- **GFCC-F2**: It was a process for us to talk through the questions in the reflection sheets. I think we were totally unaware of some of our differences...we knew there were differences in our views, but being forced to reflect on it, put it into words, that was what I experienced as most valuable afterwards.

- **GFCC-M5**: [Having explicit plans] made it possible for me to keep control of the situation – also knowing when it would be okay for me to go for a walk as this was important to my own recovery.
Obtaining mutual understanding

- **SC-F10**: You may get into a negative spiral when you are overwhelmed by all the general information available. We needed somebody who sat down and discussed our personal situation.

- **SC-M11**: I don’t think I actually told anybody that I was very upset. I just made a big deal out of saying how I wanted things to be done and what I wanted to do myself.

- **SC-F12**: Everything was so chaotic – we did not ask for more information – we just existed… and tried to tag along.
Conclusion

- The results of the study contributes to existing knowledge on parental stress and the importance of communication between parents and healthcare professionals.

- GFCC provides structured delivery of supportive communication between nurses and parents, and this was experienced as beneficial by the parents.

- This kind of intervention has the potential to increase nurses’ sensitivity to person-specific issues.
Papers on GFCC


- Weis J, Zoffmann V, Egerod I **Improved nurse-parent communication in NICU: Evaluation and adjustment of an implementation strategy.** *Journal of Clinical Nursing.* Accepted for publication February 2014.