Continuity and coordination of care during and after neonatal intensive care

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Abstract
To assess parental experiences regarding the continuity and coordination of care in children suffering from long-lasting health problems during and after treatment at a Neonatal Intensive Care Unit (NICU), a cross-sectional survey was performed, using a validated tool to obtain continuity and coordination scores. Scores were collected among parents of four age groups: newborns at the NICU (n = 51), ex-NICU preschool children (n = 50), ex-NICU children in primary school (n = 53), and ex-NICU children in secondary school (n = 57). Overall, parents are least satisfied with the consistency of care concerning the specific needs of their children. Parents of children in primary school experience most problems, followed by parents of children in secondary school. Furthermore, parents had a positive opinion towards other continuity and coordination aspects. Our findings implicate that regular neonatal follow-up care should not be restricted to the first years of life, but should be extended to both primary school age, and secondary school age. In particular, health care providers have to be attentive to the changing needs of children during their development.

Keywords
child health, continuity of care, coordination of care, neonatology, quality of health care

Introduction
In the last decades, the number of newborns requiring intensive care has increased, due to several factors. Advances in medical technology result in advances in neonatal care. Therefore, a vast improvement of the survival rate of premature and low birthweight infants or severely ill neonates
has been achieved (Horbar et al., 2002). In addition, women in western countries tend to have children at a later stage in life, which has led to more childbirth complications (Usta and Nassar, 2008). As a consequence of these technological and societal changes, there has been an increasing need of neonatal intensive care treatment (Anthony et al., 2004).

A minority of these children treated in a NICU are left with severe disability or chronic disease. Many others suffer from less severe conditions. Studies show that prematurity and low birthweight are associated with an increased risk of impairments, disabilities and handicaps (Veen et al., 1991). Compared to children in a general population, prevalence rates of long-lasting health problems, especially lung and gastrointestinal problems (Moster et al., 2008; Robertson et al., 2009), or hearing and vision loss (Christobal and Oghalai, 2008; O’Connor et al., 2007), are higher among very preterm and very low birthweight children. Furthermore, they are at risk of developing neurologic, cognitive and behavioral problems (de Kleine et al., 2003; Hille et al., 2001; Wood et al., 2000). Hence, some of these children experience problems at school with regard to their motivation, attention and performance (Hille et al., 1994; Saigal et al., 2003; Weisglas-Kuperus et al., 2009).

Most research into this group of ex-NICU children focuses on medical outcomes, while research investigating the quality of care these children receive is rare (Pritchard et al., 2008; Ygge and Arnetz, 2001). This is surprising, because continuity of care, which in the case of complex chronic conditions should be seen as ‘the delivery of services by different providers in a coherent, logical and timely fashion’ (Shepperd and Richards, 2002), may be affected for multiple reasons. First, the needs of ex-NICU children may fluctuate over the years, as changes can occur in both their health status, and personal development, which alters rapidly during childhood and adolescence. These fluctuations bring along the risk of gaps between their health care needs and the actual supply of services. Secondly, these children might need different types of care, due to the complexity of their health problems. Consulted professionals vary from pediatrician to general practitioner (GP), and from physical therapist to psychiatrist. Thirdly, they often need care for a longer period, as a consequence of the long-term character of many of these problems. Finally, as a result of the sometimes complex chronic conditions, these children receive help from several health care providers, over the years and at the same time. When several care providers are involved successively or simultaneously, patient care may be subjected to omissions and duplications.

In adults, lack of continuity may reduce compliance and patient satisfaction (Alazri and Neal, 2003; Hjortdal and Lærum, 1992). The few existing studies in children found that continuity of care was associated with higher quality of care, as reported by parents, with less emergency department use, and with fewer hospitalizations (Brousseau et al., 2004; Christakis et al., 2001, 2002). Furthermore, lack of continuity may, in time, lead to feelings of anger, grief and anxiety (Haggerty et al., 2003). Esbjørn and colleagues (2008) found that parents of prematurely born children indeed needed professional care, besides social support of family and friends.

Most of the studies regarding continuity of care adopted a provider point of view, defining and measuring this concept as the degree to which children always see one and the same health care provider. However, due to the serious and intensive character of the health problems children are suffering from as a consequence of neonatal health problems, this is not a realistic view. Adoption of a provider-defined definition also excludes a patient perspective on continuity. This can be regarded as an omission in a time in which this perspective is becoming increasingly important.
**Study aim**

The aim of this explorative study was to assess, from a parental perspective, the continuity and coordination of care in children suffering from long-lasting health problems during and after neonatal intensive care. An additional aim was to provide insight into the extent to which these parents make use of professional care as a consequence of the health problems of their children.

**Methods**

**Study population**

We performed a cross-sectional study consisting of parents of children in four consecutive age groups: parents of newborns, hospitalized at the NICU during the time of the study, parents of ex-NICU preschool children (2–5 years old), parents of ex-NICU children in primary school (6–11 years old), and parents of ex-NICU children in secondary school (12–18 years old).

All respondents were derived from the Sophia Children’s Hospital, a part of the Erasmus MC, University Medical Center in Rotterdam. This hospital offers neonatal intensive care to the South West region of the Netherlands and is one of the 10 perinatal centers in the Netherlands, with approximately 550 admissions a year.

Regarding the youngest age group, we selected newborns that, at the time of the study, were hospitalized at the NICU for at least 10 days. Our purpose was to select children with an increased chance of long-lasting health problems. Length of hospitalization is related to birthweight and gestational age, which are two risk factors of developing chronic disease in the future. Furthermore, when the duration of the hospitalization on a neonatal ward is longer, for example, when the newborn is suffering from a congenital disease or serious handicap, chances of long-term damage are assumed to increase.

Regarding the other age groups (2–18 years old), children were selected from the hospital’s computer information system. At the time of the study, complete information on the health status of the children was not registered in this system. Therefore, children with both the longest stay at the NICU, and the most consultations or admissions afterwards were included. We presumed that these children were experiencing chronic health problems (Doyle et al., 2003). No further inclusion or exclusion criteria were applied.

We sent questionnaires to the parents of 100 children within each age group. Parents received questionnaires at their home address. We informed them about the study by means of a letter in which the research aim and relevance were explained. They were of course free to decide whether or not to participate. The mother or the father of the child was asked to fill out the questionnaire anonymously. Participation in the study was on the basis of informed consent.

**Assessment**

The first part of our questionnaire included questions concerning health care use of the child, as a consequence of neonatal health problems, and concerning health care use of the parent, as far as this use was related to the health problems of their (ex-)NICU child. Except for the newborns, health care use during the year previous to the study was measured. Also included, were general questions, such as gender, gestation duration and birthweight. To describe the health status of the children, as perceived by the parent, we included a single item question on perceived health, including five answering categories, from excellent (1) to poor (5).
In the second and central part of the questionnaire, we used a validated instrument, developed in the Netherlands, to assess the perceived continuity and coordination of care by patients (Casparie et al., 1998; Schneider et al., 2000). In order to assure content validity, this instrument was developed on the basis of a literature review, discussions in panel groups composed by patients and care providers, and semi-structured interviews with patients.

The perceived continuity and coordination of care, obtained by this instrument, consisted of a score on four domains: (1) the consistency between the health care provider and the needs of the child; (2) the consistency between health care providers in case of referral; (3) the consistency between health care providers in case of replacement; and (4) the consistency between different health care providers, at a given moment in time (see Appendix for example questionnaire items). We measured experience of (in)consistency and (dis)continuity by using a 5-point Likert scale. The scale ranged from 1 (very negative experiences) to 5 (very positive experiences).

Depending on a specific health care provider, the questionnaire included 12 to 15 statements with regard to the actual experience. Parents only had to complete a set of items concerning this care provider if their child had actually received care from this professional during the last year.

Items in the questionnaire were applied to three health care areas: medical care (medical specialist, child nurse, GP); care from allied health professionals (physical therapist, occupational therapist); and psychosocial care (social worker, pastor, psychologist, educational assistant).

Analysis

First of all, the four groups of children were described by gender, gestational age at birth, birthweight, and, except for the newborns, the length of stay at the NICU, the number of ambulatory consultations, and the number of hospital admissions after children left the NICU (means and standard deviations). Furthermore, we examined in more detail the health care use in the year previous to the study of the children, as reported by their parents, including contacts with health care providers (percentages of the total number of children). Similarly, we computed the percentages of children that did not make any use of health care during the year preceding the study.

A reliability analysis was conducted to examine the internal consistency of the instrument on continuity and coordination of care. Results from this instrument were presented as mean scores and standard deviations on each of the four domains for each age group, and for the total study population. These scores were complemented with the percentage of items receiving scores below 4, which indicate negative evaluations, and where improvement thus is possible. To determine significant differences between the scores of the four age groups, we performed an ANOVA using the SPSS program (version 14.0).

Results

General information about the respondents, including the response rates for each group, is presented in Table 1. Mean response rate was 52.8 percent. In most cases, mothers filled out the questionnaire (83.4%). Altogether, we included 118 boys and 93 girls (n = 211).

Table 1 shows that the mean gestational age is about six to nine weeks less than the average of 40 weeks. Also, mean birthweight of the children in our study population is much lower than the average birthweight in the Netherlands, which is 3500 grams. The number of consultations at the Sophia Children’s Hospital after neonatal treatment was relatively high in our subjects: between 20 and 35 by children in the three oldest age groups. Furthermore, these children had been
Table 1. Characteristics of the study population

<table>
<thead>
<tr>
<th>Age groups</th>
<th>n</th>
<th>Gender child</th>
<th>Gestational age at birth (weeks)</th>
<th>Birthweight (grams)</th>
<th>Length of stay during neonatal intensive care (days)</th>
<th>Number of consultations after neonatal intensive care</th>
<th>Number of admissions after neonatal intensive care</th>
<th>Perceived health status of the child</th>
</tr>
</thead>
<tbody>
<tr>
<td>Newborns</td>
<td>51</td>
<td>male 27 (53)</td>
<td>33.8 ± 8.4</td>
<td>1892 ± 1039</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>female 24 (47)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Preschool children (2–5 years old)</td>
<td>50</td>
<td>male 34 (68)</td>
<td>31.4 ± 5.6</td>
<td>1652 ± 1065</td>
<td>38</td>
<td>5.1</td>
<td>28</td>
<td>3.8</td>
</tr>
<tr>
<td></td>
<td></td>
<td>female 16 (32)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Children in primary school (6–11 years old)</td>
<td>53</td>
<td>male 29 (55)</td>
<td>31.5 ± 5.2</td>
<td>1700 ± 1077</td>
<td>34</td>
<td>4.8</td>
<td>35</td>
<td>4.4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>female 24 (45)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Children in secondary school (12–18 years old)</td>
<td>57</td>
<td>male 28 (49)</td>
<td>31.3 ± 4.3</td>
<td>1645 ± 883</td>
<td>31</td>
<td>4.8</td>
<td>20</td>
<td>4.3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>female 29 (51)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Notes: ¹ not yet known at the time of data collection; ² not applicable, since these newborns had not yet left the Neonatal Intensive Care Unit.
hospitalized up to four times during the last year. Groups did not differ significantly on any of these characteristics ($p > .05$). Indeed, the health status, as perceived by the responding parent, can be considered as far from optimal: in all age groups the mean score is between 4 and 5.

Table 2 presents the health care use of the child. As can be seen, many health care providers are involved during and after neonatal intensive care. Most frequently consulted professionals are medical specialists, especially pediatricians ($n = 93; 64.1\%$), followed by the GP and the physical therapist.

Particularly children between 2 and 5 years of age and children between 6 and 11 years of age consult many other care providers, more specifically: dieticians ($n = 27; 12.8\%$) and speech therapists ($n = 22; 9.9\%$). Except for the children in the youngest age group, who of course all have been seen by health care providers, the other groups of children not consulting any care provider ($15\%–19\%$) did not differ significantly ($p > .05$).

In Table 3 the health care use by the parents of these children is presented. Considering that our figures only refer to health care use in relation to the neonatal health problems and their consequences, health care use among this group is high. They most frequently appeal to the GP, followed by the social worker, for parents of the younger children in primary school (up to 5 years old), and by the psychologist, for parents of the older children and those in secondary school (from 6 years old).

Data on the continuity and coordination of care, as experienced by these groups of parents, are presented in Table 4. Cronbach’s alpha of the continuity and coordination of care scores was varying from .61, which is moderate, to .89, which is very high (see Table 4). Results show that in all age groups parents are least satisfied with the consistency with the needs of their children (1). The scores in this domain are lower compared to the other three domains ($p < .05$). No significant

### Table 2. Health care use as a consequence of neonatal health problems (children)

<table>
<thead>
<tr>
<th>Age groups</th>
<th>Medical specialist $^1$</th>
<th>Child nurse $^1$</th>
<th>General practitioner</th>
<th>Physical therapist</th>
<th>Occupational therapist</th>
<th>Educational assistant</th>
<th>Other</th>
<th>No health care use</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n  %</td>
<td>n  %</td>
<td>n  %</td>
<td>n  %</td>
<td>n  %</td>
<td>n  %</td>
<td>n  %</td>
<td>n  %</td>
</tr>
<tr>
<td>Newborns</td>
<td>51 100.0</td>
<td>51 100.0</td>
<td>2 3.9</td>
<td>16 31.4</td>
<td>0</td>
<td>3 5.9</td>
<td>3 5.9</td>
<td>0</td>
</tr>
<tr>
<td>2–5 years</td>
<td>36 72.0</td>
<td>0</td>
<td>31 62.0</td>
<td>20 40.0</td>
<td>10 20.0</td>
<td>7 14.0</td>
<td>22 44.0</td>
<td>9 18.0</td>
</tr>
<tr>
<td>6–11 years</td>
<td>29 54.7</td>
<td>0</td>
<td>30 56.6</td>
<td>23 43.4</td>
<td>17 32.1</td>
<td>6 11.3</td>
<td>26 49.1</td>
<td>8 15.1</td>
</tr>
<tr>
<td>12–18 years</td>
<td>26 45.6</td>
<td>0</td>
<td>26 52.6</td>
<td>11 19.3</td>
<td>3 5.3</td>
<td>1 1.8</td>
<td>7 12.3</td>
<td>11 19.3</td>
</tr>
</tbody>
</table>

Note: $^1$ all newborns received care from a medical specialist and a child nurse at the Neonatal Intensive Care Unit.

### Table 3. Health care use related to health problems of the child (parents)

<table>
<thead>
<tr>
<th>Age groups</th>
<th>General practitioner</th>
<th>Social worker</th>
<th>Pastor</th>
<th>Psychologist</th>
<th>Other</th>
<th>No health care use</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n  %</td>
<td>n  %</td>
<td>n  %</td>
<td>n  %</td>
<td>n  %</td>
<td>n  %</td>
</tr>
<tr>
<td>Newborns</td>
<td>18 35.3</td>
<td>13 25.5</td>
<td>1 2.0</td>
<td>1 2.0</td>
<td>4 7.8</td>
<td>13 25.5</td>
</tr>
<tr>
<td>2–5 years</td>
<td>17 34.0</td>
<td>6 12.0</td>
<td>3 6.0</td>
<td>1 2.0</td>
<td>11 22.0</td>
<td>19 38.0</td>
</tr>
<tr>
<td>6–11 years</td>
<td>29 54.7</td>
<td>4 7.5</td>
<td>3 5.7</td>
<td>3 5.7</td>
<td>8 15.1</td>
<td>22 41.5</td>
</tr>
<tr>
<td>12–18 years</td>
<td>12 21.1</td>
<td>3 5.3</td>
<td>3 5.3</td>
<td>1 1.8</td>
<td>7 12.3</td>
<td>21 36.8</td>
</tr>
</tbody>
</table>
differences between the four age groups were found. Parents of children in primary school (6–11 years old) seem to experience most problems, resulting in the lowest score (2.6) and the highest percentage below 4 (32.4%), followed by parents of children in secondary school (12–18 years old). The parental opinion towards other consistency of care domains (2, 3, 4) was positive.

**Discussion**

As expected, this study shows that both children suffering from long-lasting health problems during and after neonatal intensive care treatment, and their parents make frequent use of care: medical care, care from allied health professionals, and psychosocial care.

For the general population, little comparable figures are available: in a national representative sample between 36.2 and 41.4 percent of the children between 0–14 years consulted a GP, while in our study between 56.6 and 62 percent of the 2–11 years old did. Between 2 and 4.9 percent of the 0–14 year children consulted a physical therapist, while we found percentages between 31.4 and 43.4 percent. Considering our figures only refer to health care use in relation to the neonatal health problems and their consequences, we may conclude that health care use is high. Also, many parents consulted health care providers: between 21.1 and 54.7 percent consulted a GP in our study. These figures only reflect consultations as a result of the problems they experience with their child. In the general Dutch population between 25 and 64 years, these percentages vary between 14.3 and 15.6
percent, while these figures relate to all reasons for contacting a GP, thus also personal health problems (Temmink et al., 2002; van Lindert et al., 2004).

It is not possible to compare the results on health care use by the youngest age group with the older children, because all children in the youngest group were hospitalized in the NICU. Therefore, all children had contact with health care. This bias was of course inevitable. The results nevertheless inform us on the perceived continuity and coordination of care during the first period of life, which is spent at the NICU. Between the children in the other age groups, there is little difference in the amount of children not making use of health care in the year preceding our study. These percentages vary between 15.1 and 19.3 percent. The health care use of the children between 2 and 5 years and between 6 and 11 years is very similar, but the children aged 12–18 years make use of fewer different services, suggesting that children might outgrow some of their difficulties.

This high utilization pattern makes these children more vulnerable for fragmentation in the care they receive, and it raises questions as to whether the care they receive addresses their needs in a satisfactory way. Results from this study show that parents do not experience many problems regarding consistency between care providers. We did not find significant differences between the four age groups, suggesting that problems do not increase or decrease with the ageing of the children. However, parents do experience a lot of problems with regard to the consistency of the care with the specific needs of their children: the scores, varying between 2.6 and 3.7, are much lower compared to a Dutch reference population, where the mean score for this domain was 4.6 ($n = 3146$; SD = 0.7). Especially among ex-NICU primary school children, problems regarding the consistency of the care to their needs are most prominent, followed by ex-NICU secondary school children. As a possible consequence, parents still struggle with difficulties during the development of their son or daughter, years after treatment at the NICU, for example, due to inadequate coping with the neonatal health problems. Health care use among these parents is high.

In the Netherlands, children in need of neonatal care are routinely offered follow-up in the first one and a half to two years of life (Graafmans et al., 2002). In this study however, parents of children in primary school are experiencing most problems, followed by the parents of children in secondary school. It may well be that, once discharged from neonatal follow-up, parents experience new problems, related to developmental delay, as their children start their school career, while in secondary school these problems may be complemented by emotional problems, due to puberty. Therefore, it is interesting to notice that the problems most often mentioned all relate to the tuning of the health care to the needs of the children. As discussed previously, the need for care may fluctuate over the years. Hence, it is recommended that neonatal follow-up should be extended to both primary school age, and secondary school age. Furthermore, health care providers should be especially attentive to the changing needs of children on the transition from toddler to primary school child, and from primary school child to secondary school pupil.

Our study has some limitations. A first limitation is the way in which the children have been selected, namely on the basis of the longest duration of hospitalization at the NICU and the highest frequency with which they visited the hospital for a consultation or admission after discharge from the NICU. Unfortunately, these criteria were the only available information in the hospital’s computer information system, which does not allow for selecting children with long-lasting health problems directly. Although length of stay at the NICU is associated with birthweight and gestational age, which are considered to be predictors of the occurrence of chronic health problems, our data may underestimate or overestimate the experienced health problems and, consequently, underestimate or overestimate the use of care by both these children, and their parents. Indeed, it may be possible that the included children did not suffer any more from health consequences
related to neonatal health problems. This perhaps is reflected in the finding that between 15 and 19 percent of the children do not make use of any health care during the study. Nevertheless, the poor health status of the children in our study, as perceived by their parents, ultimately supports our assumption and justifies our selection criteria. Also, it does not seriously affect our results with regard to continuity and coordination, since these quality indicators were only assessed if the children actually appealed to this specific health care provider in the past year.

In this study we investigated the perceived continuity and coordination of care from a parent perspective. Choosing this perspective, as a second limitation, implies that some dimensions might be less visible. We found that parents in this study experienced more problems regarding the tuning of the care to the needs of their children, than other consistency of care domains. It is likely that the ongoing tuning of health care supply to the needs of the patients is easier to study from this perspective than the consistency between different health care providers, at a given moment in time. Parents are supposed to score adequately whether or not their children receive the care they need, whether the provided care takes into account changes in health status or in personal situation, and whether help is quickly available when necessary. However, parents can only partly and indirectly experience other problems, as far as they observe incoherence in the received care.

A subsequent qualitative study is to be performed, where health care providers will be interviewed on this subject, to obtain a better insight and a broader perspective of these problems with regard to the continuity and coordination of care in children during and after neonatal intensive care.

Acknowledgements
This research was made possible by a grant of the Netherlands Organization for Health Research and Development (32060123).

References


**Appendix: example questionnaire items**

1. **consistency with needs**
   - When the situation of my child changed, the care provider adapted the care when necessary.

2. **consistency between care providers: transfer (referral)**
   - The care provider referred my child to another care provider, when I considered it necessary.

3. **consistency between care providers: transfer (replacement)**
   - When the care provider was absent, a locum was present.

4. **consistency between different care providers: coordination**
   - The care provider cooperated in harmony with other care providers.