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# Neonatal end-of-life care in Sweden

Anita Lundqvist, Tore Nilstun and Anna-Karin Dykes

## SUMMARY

- A survey was carried out of Swedish neonatal end-of-life regarding practice before birth, at birth, during dying and after death using a descriptive questionnaire with close-ended questions and individual comments
- The practice in 32 of 38 neonatal units, as described by the head nurse or the registered nurses, was largely similar. Respectful treatment of both the neonate and the parents during neonatal end-of-life care was indicated
- Differences were found in pre-natal care concerning the information about the risks of pre-term birth, the opportunity for parents to view a pre-term neonate and meet its family, as well as a social worker
- Practice directly after birth was also different. A little less than half of the units answered that they gave a description of the seriously ill neonate to the parents before the first visit to the ward
- Practice during dying indicated that only a few units permitted the neonate to die at home

**Key words:** Decision making • Dying • End-of-life-care • Fetus • Neonate • Practice

## INTRODUCTION

There are three levels of neonatal care: full intensive care, partial intensive care with ventilator treatment for shorter periods and no intensive care (National Board of Health and Welfare, 1997). Paediatric departments at 38 Swedish hospitals provided neonatal care during the year 2002. Six university hospitals and an additional five more hospitals carried out full intensive care. The facilities were similar at each of these hospitals, but paediatric surgeons were available in only three of them. Twenty hospitals provided partial intensive care, while seven did not provide neonatal intensive care (Statistics in Sweden, 2000). At the two latter levels of care, neonatal death seldom occurred. It occurred when the neonate was seriously ill and a transfer to another hospital was impossible. Decisions not to transfer were mostly made after contact with a university hospital.

In total there were 550 beds for neonatal care, of which 130 were equipped for full intensive care. About 90000 neonates are born each year in Sweden and approximately 5.5/1000 new-born die yearly at birth or in the perinatal period (Statistics in Sweden, 2000).

The loss of a neonate is one of the most devastating events that can happen to a parent (Leon, 1996; Engler and Lasker, 2000; Ujda and Bendiksen, 2002). Only recently have professionals begun to understand and respect the impact this loss can have on the parents and on any subsequent pregnancy and birth (Rosenfeldt, 1991; Brost and Kenney, 1992; Leon, 1992). Various authors (Brown, 1991; Leon, 1992; Calhoun, 1994; Rajan, 1994) have commented on the clinical interventions being used to facilitate the identification and attachment process and to reinforce the reality of the loss. Clinical practice such as seeing and holding the neonate, spending time with the neonate, taking photographs and collecting memories (a piece of clothing, a snip of hair) are used to validate the parents' sense of loss, help them relive the experience and attach meaning to the loss. Not all mothers feel comfortable with such treatment (Malacrida, 1997; Skene, 1999; Hughes *et al.*, 2002). There are variations in the acceptance of participation by parents in ethical decision making concerning life-sustaining treatment. However, decisions to hasten death or to refrain from prolonging life are mostly made after discussion with the parents (Campbell and McHaffie, 1995; Van der Heide *et al.*, 1998).

From a Swedish perspective, an interview study was performed to illuminate how women who had lost a neonate experienced the threat and the reality of loss and the care they had received. The conclusion was that the health-care providers should identify the women's desires and be open for and react to their discomfort, impart a sense of solidarity to them and

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co-operate with them through verbal and practical handling (Lundqvist *et al.*, 2002a, b). The above result also indicated that when the parents, after an ultrasound examination, were informed about a positive diagnosis, especially heart malformation, or when having a high-risk pregnancy concerning pre-term birth, they were at that time asked to decide whether or not to withhold medical treatment. Accordingly, end-of-life care starts during pregnancy for the parents and the parents are prepared for the risk of death of the neonate and decisions about life-sustaining treatment (Lundqvist *et al.*, 2002a). Women may have difficulties in developing a mother-child relationship when the new-born is seriously ill, and the staff feel dissatisfaction when they are not able to influence the parents to see, touch and hold the neonate (Lundqvist and Nilstun, 1998). Despite the large body of published papers about neonatal end-of-life care, empirical data on the actual policies of neonatal units are scarce in many countries, especially in Sweden. Therefore, the aim of this survey was to elucidate clinical practice in Swedish neonatal end-of-life care regarding practice before birth, at birth, during dying and after death of the neonate.

## METHODOLOGY

### Questionnaire

A questionnaire had to be used because of the geographics of the study, but as the topic is sensitive we wanted to gain more than just numerical data. Therefore, we used a mixed methodology, using quantitative measures and categories but also allowing for additional comments (both in writing and by telephone) that gave broader and deeper data.

A preliminary questionnaire was developed in three steps. Firstly, recently produced recommendations concerning neonatal end-of-life care at a University hospital in Sweden were used. These were inspired by the protocol about neonatal end-of-life palliative care developed by Catlin and Carter (2002) and adapted to Swedish neonatal end-of-life care. At the time of the study, these recommendations had yet not been introduced in the neonatal intensive care unit. Secondly, some questions were added based on the findings of a questionnaire survey concerning how registered nurses in Swedish Neonatal Intensive Care Units performed the care when parents refused to see, touch and hold their dying and dead neonate (Lundqvist and Nilstun, 1998). Thirdly, the questionnaire was modified and further questions were added based on the findings from the qualitative interview study, where 16 Swedish women narrated their lived experiences after having lost a neonate about 2 years earlier (Lundqvist *et al.*, 2002a, b). Fourthly, the questionnaire was tested,

concerning face validity, on five registered nurses on duty in a neonatal unit. This resulted in some minor modifications of the questionnaire.

The final questionnaire was, besides some demographic data, divided into four sections:

- *practice before birth* (information about a positive diagnosis in connection to an ultrasound examination or a high-risk pregnancy, the opportunity to visit a neonatal unit, meet the staff, see a pre-term neonate as well as meet a social worker),
- *practice directly after birth* (the registered nurse's information to the parents before seeing the neonate in the neonatal unit, the care given when the parents visit the seriously ill neonate, the parent's participation in the care, name-giving, visiting hours, the practice in withdrawing of medical treatment, and parents participation in the decision making),
- *practice when the neonate was dying* (the procedure when the withdrawing of medical treatment is decided, and the parents' and the staff's role during the neonates dying)
- *practice after the neonate's death* (collecting memories, taking care of the dead neonate, parents' possibility of staying with the dead neonate, informed consent to an autopsy, and the practice of follow-up visits).

The questions were close-ended and the respondents were given fixed responses from which to choose: always, usually, sometimes, seldom, never and do not know. After each question, they were encouraged to comment on their answers.

### Sample

In January and February 2002, the neonatologist responsible for the neonatal care at each participating hospital received information about the ongoing study. The head nurse at each of the 38 neonatal units in Sweden received a letter informing them about the study and the questionnaire. Voluntary participation and the impossibility to identify individual neonatal units in the published text were emphasized. The head nurse or the registered nurse responsible for the neonatal end-of-life care answered the questionnaire. The neonatal units that had not answered within two weeks were reminded by telephone.

Permission to undertake the study was obtained from the Research Ethics Committee of the Medical Faculty, Lund University, Sweden.

## RESULTS

Each question in the questionnaire described a clinical practice, and the answers indicated the occurrence of

**Table 1** Answers regarding practice before birth and practice directly after birth in Swedish neonatal clinics (%) (n=32)

Questions	4	3	2	1	0	?	Missing
<i>Practice before birth</i>							
Are the parents invited to visit the unit where the neonate will be placed after birth, when fetal impairment is discovered during pregnancy?	44	32	6	3	3	6	6
Are the parents invited to see a pre-term neonate at the unit and meet its parents when there is a risk of pre-term birth?	22	28	3	22	19	0	6
Are the parents offered a consultation with a social worker after receiving information that the unborn child will be affected with a malformation at the birth?	23	31	6	6	0	31	3
Are the parents offered a consultation with a social worker after information about the risk of a pre-term birth?	13	13	31	13	2	28	0
<i>Practice directly after birth</i>							
Are the parents given a description of the seriously ill neonate's appearance before their first visit of the neonate in the neonatal unit.	22	22	16	13	6	13	9
Does the staff try to lighten the parent's feelings by pointing out positive things about their neonate?	38	44	6	0	0	3	9
Does the staff actively influence the parents to caress or touch the seriously ill neonate if the parents do not do it spontaneously?	91	6	0	0	0	0	3
Does the staff influence the parents to hold the seriously ill neonate if the parents do not do it spontaneously?	62	31	3	0	0	0	3
Does the physician, in connection with the information concerning the diagnosis and prognosis, also inform the parents about the medical treatment available?	75	22	0	0	0	0	3
Do the parents participate in discussions with the physician, before making their decision about withdrawing treatment (shut off the ventilator) when the neonate's condition is incompatible with life?	88	3	0	0	0	6	3
Is the seriously ill neonate permitted to die (by withdrawing medical treatment) when there is a risk that treatment would prolong the suffering as the neonate was anyway certain to die?	31	25	16	3	0	6	19
Does the staff instruct and encourage the parents to participate in technical care, such as tube feeding and taking the neonates temperature?	78	13	9	0	0	0	0
Does the staff offer the parents the chance to baptize or in some other ways name the neonate before death?	94	6	0	0	0	0	0
Does the staff cancel the ban of visiting at the unit with regard to relatives, friends and siblings?	72	13	0	0	3	0	12

4, always; 3, usually; 2, sometimes; 1, seldom; 0, never; ?, do not know.

such clinical practice in the neonatal unit. The answers Always or Usually were interpreted as clinical practice, while Seldom and Never as no such practice. The response rate was stated in percentages. The comments made by the respondents were added in italics and reported for each section. The questions and the frequencies of answers are presented in Tables 1 and 2.

### Demographic data

The response rate was 32/38. Concerning how many neonates that had died in the 32 units, five units did not answer the questionnaire. Among the remaining 27 neonatal units, a little less than 200 neonates had died in the year 2000 (range 0–40, median 3).

### Practice before birth

After ultrasound examination, some mothers were informed that their fetus was suffering from a severe disease. In such cases, 76% of units invited the parents to visit the neonatal unit. At risk of pre-term birth, 40% of units invited the parents to see a pre-term

neonate and meet its family in the unit, while 41% had no such practice. Eight comments were given. *'The parents are welcome to meet the staff, see the rooms and the resuscitation table to where the baby is at once moved, and also an emergency room. Even the unit for parents is shown.'* *'...Perhaps sometimes, but it is not usually frequent to exhibit other preterm babies.'*

On the question, whether the parents are offered a contact with a social worker after receiving the information about fetal impairment, such a consultation was offered by 54% of units, but 31% of units did not know. As to the risk of pre-term birth, 26% of units offered a consultation, while 28% of units did not know. Nineteen units commented that this consultation was provided by the obstetric clinic.

### Practice directly after birth

Describing the neonate's appearance to the parents before they visit the neonate was performed by 44% of units, while 13% of units did not. Eleven comments were given indicating that it was presumed that the

**Table 2** Answers regarding practice when the neonate is dying and practice after death in Swedish neonatal clinics (%) (n=32)

Questions	4	3	2	1	0	?	Missing
<i>Practice when the neonate is dying</i>							
Is mechanical ventilation withdrawn after a medical prognosis assessing the neonate as dying?	22	53	0	0	0	3	22
Does the physician inform the parents about the withdrawal of the mechanical ventilation before it is done?	66	9	0	0	0	6	19
Are the parents asked to decide a time and possible day for withdrawing mechanical ventilation after having made their decision?	19	22	15	0	9	13	22
Are the parents invited to be present during the withdrawal of the mechanical ventilation?	66	3	3	0	0	6	22
Are the parents asked to stay with their dying neonate?	97	0	0	0	0	0	3
Does the staff actively influence the parents to hold the neonate during the dying process?	71	25	0	0	0	4	0
Is the staff concerned present in the room while the neonate is dying?	78	16	3	0	0	3	0
Is the neonate placed in a private room during the dying process?	53	41	3	3	0	0	0
Are the parents given the possibility to let the neonate die at home?	19	13	30	19	3	13	3
<i>Practice after death</i>							
Does the staff collect mementos of the dead neonate to be given to the parents – a snip of hair, footprints etc?	75	22	0	3	0	0	0
Are the parents asked to nurse and dress the neonate after death	72	25	0	0	0	3	0
Can the parents give their consent to a possible autopsy before a decision is made?	94	3	0	0	0	0	3
Are the parents given a possibility to see the neonate after an autopsy is performed?	78	6	3	0	0	6	6
Are the parents offered to have pictures of the dead neonate taken by the hospital photographer?	76	6	0	0	3	6	9
Are the parents offered the possibility to stay with their dead neonate for a few days?	72	13	6	6	0	3	0
Are the parents offered a follow-up visit about a week after the neonate's death, to review the care their neonate received, with the staff concerned?	73	9	6	6	0	3	3

4, always; 3, usually; 2, sometimes; 1, seldom; 0, never; ?, do not know.

parents had seen the neonate at the delivery room. 'At delivery the baby is shown to the parents'. 'We [the registered nurses] do not participate in this part of the delivery, perhaps our doctors.' The answers indicate that 82% of units called attention to something healthy in the neonate when the parents visit the neonatal unit for the first time. Ten commented: 'We try to call attention to something that gives the parents a feeling that it is their little baby, such as, look at the babies sweet toes, ears or the pretty nose, etc.' They actively influenced the parents to touch (in 97% of units), and hold (in 94% of units), the seriously ill neonate. Five commented about touching the neonate. 'By our touching the baby we show the parents that they can also touch their little baby.' 'We try to pick up the parents' feeling concerning what they can manage to do, giving support and being at hand the whole time.' 'We try again if the parents find it difficult.' Five comments explained how they influenced the parents to hold the neonate. 'It depends on the infant's condition, i.e. some infants have too much equipment connected to their body.' 'We are supporting the parents but it must be their own decision.'

Once cognizant of the diagnosis and the prognosis, the parents were informed about possible medical treatment in 97% of units, and 91% of units permitted the parents to participate in discussions about withdrawing medical treatment. Withdrawing of medical treatment when there is a risk of prolonging the suffering

of the neonate is performed by 56% of units and 16% of units sometimes did so. Ten gave comments. 'Such decisions should be made after discussions among the physicians.'

Most, 91% of units, encouraged the parents to perform technical care themselves such as tube feeding and 100% of units offered name giving. The ban of visiting was lifted by 85% of units. Among the 12 comments given, the risk of disease carrying was mentioned. 'Concerning the siblings there are no restrictions if there is no risk for RS-virus.' 'Relatives and friends are welcome after agreement.'

### Practice when the neonate is dying

The practice in 75% of the neonatal units with intensive care was to withdraw mechanical ventilation when the medical diagnosis confirms that the neonate will die independent of treatment. Three of the 10 comments mentioned the importance of shared decision making, between the parents and the physicians. Before treatment is withdrawn, 75% of units informed the parents about the procedure (19% of units did not answer and 6% of units did not know). The parents were offered the opportunity to decide the time for withdrawing mechanical ventilation, the same day or the next day in 41% of units and in 15% sometimes, while 13% did not know. Six of the 10 comments emphasized that it was the physicians' decision, but the parents could

decide if they were waiting for a relative to be present. *'Consultations with the parents require consideration, and [one needs to find out if] relatives are expected to be present.'*

In 69% of units, the parents were invited to be present when the mechanical ventilation was withdrawn and 97% of units expected them to be with their neonate, while 96% influenced the parents to hold the neonate while it was dying. Five comments were given. *'We are respectfully aware of the parents feelings and are not persistent in asking (them) or forcing them.'* The staff were present in the room while the neonate was dying in 94% of units. Ten comments emphasized the parents' right to choose whether to have the staff present. *'If possible, the dying neonate should receive end-of-life care in privacy'*, practised in 94% of units. Five comments indicated exceptions. *'The infant cannot get a private room when the neonatal unit is overcrowded'*.

Permitting the neonate to die at home was practiced by 32% of units, and sometimes by 30% of units. The most frequent of the 14 comments was that the care of the neonate did not allow moving the neonate. *'It is impossible because of NICU care.'*

### The practice after death

The majority of units, 97%, collected mementoes from the dead neonate, and asked the parents to nurse and dress the neonate after death.

When clinical (to be distinguished from forensic) autopsy was required the parents consented in 97% of units, and 84% of units allowed the parents to see the neonate afterwards.

About 82% of units asked the parents if they wanted to have photos of the dead neonate and 85% of units that the parents could say goodbye to the dead neonate up to several days after death. A follow up visit was practiced by 82% of units involving the parents and the attending staff. The 13 comments given varied. The most common was that the time for the follow up differed as well as the persons involved. *'It could be later on.'* *'Not only one follow up, but several.'* *'Generally it is the physician and the social-worker who take part in the follow up visit.'*

## DISCUSSION

The aim was to survey current neonatal end-of-life practice in Sweden using a descriptive questionnaire. No judgements about good or failing practices were made. A questionnaire was the only feasible way to collect data from the neonatal units all over the country. Since no questionnaire existed, one had to be developed. The wording of the questions was assessed in a test study indicating acceptable face validity.

In the comments to the final questionnaire, some of the respondents answered that they did not know or

were hesitant concerning some of the prenatal practices. We admit that a few questions were more directed towards the obstetric clinic and the responsible physicians. However, the findings may suggest that the communication between obstetric clinics and neonatal units is insufficient. One explanation could be that some obstetric clinics deliver perinatal care. This is a question for further research.

Our findings indicate that the health-care providers permit forgoing life-sustaining treatment. Authors have argued that medical education and organizations traditionally have supported, and often continue to be perceived as supporting, the philosophy that all neonates should be resuscitated aggressively ( American Academy of Pediatrics, Committee on Fetus and Newborn, and American College of Obstetricians and Gynecologists, Committee on Obstetric Practice, 1995; Wall and Patridge, 1997). Pierucci *et al.* (2001) found that consultation with the palliative care team occurred at a neonate's median age of 118 days of life and a median of 2.5 days before death. However, the WHO model of palliative care prescribes early involvement for those who are at risk of dying and increasing involvement if therapies are not working (World Health Organisation, 1998). In Sweden, no special palliative care teams exist in the neonatal end-of-life care. However, there are ongoing projects on home care after pre-mature birth. The neonates were not allowed to die at home in less than half of the cases. In a study, 15 of 211 neonates died at home following a palliative care consultation with home hospice services for the neonate (Pierucci *et al.*, 2001). A task for further research is to assess whether a palliative care team would be feasible in the neonatal end-of-life care.

The current survey indicates that the staff involves the parents in care and decision making. But, in the above mentioned interview study (Lundqvist *et al.*, 2002b), all the women had encountered both empowering and disempowering care. Thus, practice, as described in the survey answers, indicates a good intention by the staff, but in reality stress, overcrowded units and emotional reactions may affect their behaviour and treatment.

## CONCLUSION

The practice, as described by the registered nurses, was largely similar in all neonatal units. A respectful treatment of both the neonate and the parents during neonatal end-of-life care was indicated. Differences were found in prenatal care concerning information about the risk of pre-term birth, offering the parents the opportunity to see a preterm neonate and meet its family, as well as a social worker. Practice directly after birth was also different in a few aspects. A little less

than half of the units answered that they gave a description to the parents of the seriously ill neonate before the first visit to the ward. Practice during dying was that only a few units permitted the neonate to die at home.

We believe that the results from the current survey are the first stage in developing clinical practice in neonatal end-of-life care, and that it could be used as an educational instrument especially as neonatal death is rare. The educational instrument is suggested as an aid to establish care efforts that are meaningful, clinically and socially acceptable, but also gives a free scope for individual care.

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