

ORIGINAL ARTICLE

Parental assessment of comfort in newborns affected by life-limiting conditions treated by a standardized neonatal comfort care program

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OBJECTIVE: To assess the perception of parents concerning the state of comfort maintained in their infants born with life-limiting conditions and treated by a standardized neonatal comfort care program.

STUDY DESIGN: Participants were parents ($n = 35$ families) who elected comfort care for their newborns diagnosed with life-limiting conditions. Standardized comfort measures including family/infant bonding, warmth, nutrition/hydration and pain/discomfort management were provided to all infants. Parents consented to receive a questionnaire with quantitative response options and open-ended questions.

RESULTS: Forty-two questionnaires (26 from mothers and 16 from fathers) were collected and analyzed. Most parents reported that their child was treated with respect, in a caring, peaceful and non-invasive environment. To the question 'Do you think that overall your baby received comfort' mode response was 'always'.

CONCLUSION: Parents of infants with life-limiting conditions perceive that their babies experience comfort as a result of the care provided by the standardized Neonatal Comfort Care Program.

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INTRODUCTION

Perinatal detection of life-threatening conditions, including congenital anomalies and extreme prematurity at the cusp of viability, leads to identification of infants with short life expectancy. When patient's prolongation of life is no longer the goal of care, a proper plan of care focused on the infant's comfort is essential. While there are evidence-based recommendations for pain management in this population,¹ there is no consensus about best clinical practice in promoting comfort for the neonate.

Previous studies have assessed parental perspective of end-of-life care experience for their infants by means of interviews with parents^{2,3} or data collection from internet parental support forum.⁴ However, the infants' state of comfort was either not evaluated^{3,4} or limited to pain assessment,² or estimated in a qualitative fashion only.⁵ More importantly, no study provided the experience of a standardized/multidisciplinary program in achieving infant's comfort.

The Neonatal Comfort Care Program (NCCP), a multidisciplinary team at Columbia University Medical Center, has established and implemented standardized guidelines to achieve a state of comfort in newborns with life-limiting conditions. Clinical outcomes have been reported;⁶ however, the effectiveness of this management in promoting the infants' comfort is unknown.

The aim of the present study is to assess the perception of parents concerning the state of comfort maintained in their infants affected by life-limiting conditions when treated by the NCCP standardized plan of care.

METHODS

This is a prospective mixed method self-report study of parents whose infants were diagnosed with life-limiting conditions and treated with standardized comfort measures.

Subjects

Parents of infants diagnosed with life-limiting conditions and of any gestational age and birth weight, who had been managed by the NCCP at Columbia University Medical Center between 2010 and 2015 were eligible for the study. Parents were informed about the study during their baby's admission or at follow-up encounters. Those who elected to participate received a copy of the questionnaire by mail at least 3 months after their baby's death. The study was approved by the institutional IRB and the parents who elected to participate confirmed their consent through questionnaire completion.

Questionnaire design

The questionnaire was investigator-designed and based on the aims of the program. It included a first section with demographic information. A second section contained 24 statements with quantitative Likert responses (1 = never, 2 = rarely, 3 = sometimes, 4 = often, 5 = always) exploring the influence of environmental, interpersonal and management factors on parental perception of infant comfort, adequacy of professionals' plan of care and parents' opportunity to connect with the infant and take care of the baby's basic needs. Additionally, the questionnaire included three open-ended questions. The first question asked parents to identify any missing aspect of the care to promote comfort. This question was included in an effort to improve parents' experience despite the sad nature of the situation. The second question asked parents to express their experience of comfort care using an image, a symbol or a metaphor. Research

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suggests that the use of metaphors can facilitate expression of feelings, better self-understanding and meaning making during counseling.⁷ Moreover, it is well-established that the use of metaphor and storytelling promotes resilience during bereavement.⁸ Thus, this question was included to learn about the metaphors and imagery associated with parents' experience of comfort care for their babies. Finally, a third question asked if participants wished to add anything else about their baby's comfort care experience.

As the questionnaire was designed, face validity was developed by receiving feedback from non-experts as to the understandability of the items and their match to the program. Next, two advanced practice nurses with expertise in end-of-life care reviewed all items and confirmed content validity related to comfort care. In the course of this study, construct validity began to be established as 22 of the 24 items, which were drawn from the program guidelines, and were substantiated as experienced by program participants. Following the study, Cronbach- α for internal consistency reliability was calculated at an acceptable level of 0.80.

Data collection

Of 55 eligible families identified during the baby's admission, 20 were excluded at time of questionnaire distribution for the following reasons: lost contact because of wrong phone number (9); language barrier (3); no family contact with the baby after delivery (3); declined participation (5). Questionnaires for both mother and father were mailed with pre-stamped return envelopes to 35 families who elected to participate.

Infant's characteristics

The infants' prenatal diagnoses included: trisomy 18 to 13 (8), bilateral renal agenesis and/or dysplasia (4), anencephaly (3), limb-body wall syndrome (3), hypoplastic left heart syndrome (7) and complex multiple anomalies (4). Six infants were postnatally diagnosed with CHARGE syndrome (1), multiple anomalies (1), renal dysplasia (1) and extreme prematurity (3). The mode length of life was less than 1 day, with 80% of the infants dying in delivery room and only six infants surviving more than 3 days.

Data analysis

Forty-two questionnaires were collected and analyzed. Demographic and questionnaire data were entered into an SPSS version 22.0 data base. Frequency and descriptive statistics were calculated. Open-ended responses were analyzed qualitatively for emergent themes (content analysis), which were discussed to consensus by those authors (EP, MB)

who had expertise respectively in developing and implementing the comfort care guidelines and in qualitative data analysis.

Definition of life-limiting condition

Life-limiting condition in this study was defined as a condition not compatible with life beyond hours or days with or without life support (e.g. anencephaly, renal agenesis), or a condition where the burden of intensive care may exceed the benefits in terms of length of survival (e.g. trisomy 13 and 18, extreme prematurity at the cusp of viability).

Multidisciplinary NCCP team

At Columbia University Medical Center, the NCCP includes a core team (neonatologist director of the program, nurse clinical care coordinator, social worker) and other professionals available for consultation (psychologist, speech pathologist, lactation consultant, Child Life specialists and chaplain).

Perinatal counseling and birthing plan

The core team meets the family at the time of the fetal diagnosis and during the course of the pregnancy to clarify diagnosis and prognosis and to develop a tentative birthing and postnatal plan of care, contingent upon postnatal confirmation when the diagnosis is uncertain. The NCCP core team follows directly each delivery and manages the postnatal medical plan.

Postnatal care

The NCCP operates with previously reported standardized guidelines⁶ developed from evidence-based data obtained in neonatal populations^{1,9-13} and focused on promoting patient's comfort. A state of comfort is defined as a condition where specific basic needs of the neonate (bonding, maintenance of body temperature, relief of hunger/thirst and alleviation of discomfort) are satisfied (Table 1).

RESULTS

Demographics

Twenty-six mothers and 16 fathers from 35 families participated in questionnaire completion. Parents' age ranged from 19 to 43 years with mean age 31.3 years. Race was predominantly

Table 1. Guidelines to achieve a state of comfort for newborns with life-limiting conditions

Bonding

Holding, skin-to-skin care

Provide parents the opportunity to take care of their baby's needs (breast/bottle feeding, nutrition via NG/OG/G-tube, diaper change, bath, dressing, etc.)

Provide parents the opportunity to help with their baby's medical needs (taking temperature, suctioning, help with medical dressing, etc.)

Bonding is promoted in delivery room, on the postpartum floor while the baby rooms-in with the mother or in the NICU. A private space should be provided. If no family members are available, the baby is held by health care personnel or trained volunteers.

Maintenance of body temperature

Skin-to-skin care, holding

Warmer, heat lamps, isolette, swaddled in blankets in bassinet

Relief of hunger/thirst

Breast/bottle feeds (breastfeeding/lactation consultant/speech pathologist support)

Special nipples or devices (speech pathologist support)

Use of NG/OG/G-tube as appropriate

Infant NPO or end-of-life care: non-nutritive strategies (speech pathologist support)

Alleviation of discomfort/pain

Assessment of respiratory distress (air hunger, agitation, increased work of breathing, gasping) and use of non-pharmacological strategies (i.e. gentle suctioning upper airways, positioning) or pharmacological treatment (Morphine Sulfate PO/IV; Fentanyl IN)

Assessment of pain by validated clinical scores (NIPS or PIPP) and use of non-pharmacological strategies (meet the baby's basic needs as listed above) or pharmacological treatment (Acetaminophen PO/PR; Morphine Sulfate PO/IV; Fentanyl IN; Lorazepam PO/IV; Midazolam IN)

Abbreviations: G-tube, gastric tube; IN, intranasal; IV, intravenous; NG, nasogastric; NIPS, Neonatal Infant Pain Scale; NPO, nil per os; OG, orogastric; PO, per os; PIPP, premature infant pain profile. Adapted with permission from Parravicini *et al.*⁶

Table 2. Averaged Likert responses to 24 questions related to infant comfort as perceived by parents

	N	Minimum	Maximum	Mean	s.d.
<i>Items for which higher score means more comfort</i>					
Do you think that the environmental conditions (temperature, light, noises) during your baby's admission were adequate?	42	3	5	4.76	0.532
Do you think that health care workers involved in the care of your baby treated him/her respectfully?	42	3	5	4.86	0.417
Do you think that your baby was treated well by health care workers involved in his/her care?	42	2	5	4.76	0.617
Do you think that the noise level during your baby's admission allowed him/her to rest quietly?	42	2	5	4.88	0.504
Do you think that overall your baby was treated adequately?	42	3	5	4.86	0.417
Do you think that during your baby's admission the environment was comfortable for him/her?	42	4	5	4.88	0.328
Do you think that the level of lighting during your baby's admission allowed him/her to rest quietly?	42	3	5	4.86	0.417
Do you think that health care workers involved in the care of your baby were concerned with obtaining comfort for him/her?	42	4	5	4.88	0.328
Do you think that your baby received comfort and affection from health care workers involved in his/her care?	42	1	5	4.71	0.774
Did you have the opportunity to do Kangaroo Care?	40	1	5	2.3	1.324
Do you think that your baby received adequate treatment for pain and discomfort?	42	2	5	4.71	0.596
Did your baby have opportunity to spend time with you and your family?	42	1	5	4.36	1.358
Did you have the opportunity to show your affection to your baby?	42	1	5	4.62	0.987
Do you think that health care workers involved in the care of your baby were considerate in their interventions with him/her?	42	3	5	4.88	0.395
Do you think that your baby had the opportunity to receive comfort and love from you and from family members?	42	3	5	4.88	0.395
Did you have the opportunity to feed your baby?	42	1	5	1.83	1.102
Do you think that the primary needs of your baby were respected?	42	3	5	4.77	0.520
Do you think that overall your baby received comfort?	42	3	5	4.88	0.395
<i>Items for which lower score means more comfort</i>					
Do you think that there was a lack in health care workers's interventions?	42	1	5	1.38	1.058
Do you think that your baby received too invasive/aggressive medical interventions?	42	1	5	1.46	1.191
Do you think that your baby suffered from cold during the admission?	42	1	5	1.40	0.989
Do you think that your baby suffered from hunger during the admission?	42	1	5	1.55	1.131
Do you think that your baby suffered pain during the admission?	42	1	5	1.86	1.181
Do you think that your baby suffered from thirst during the admission?	42	1	5	1.64	1.206

Caucasian (64%) and secondarily Hispanic (24%). Religious affiliation was 48% Catholic, 29% Jewish, 19% Protestant, 2% other religion while 2% stated to be atheists. Most parents (64%) had a college or higher degree, 21% were high school graduates and 2% had only elementary school education.

Results of questions on parents' perceptions of infant comfort

Parents perceived their infants' comfort as positive in all but these areas: Kangaroo Care and feedings (Table 2). The mean score for answer to the question 'Did you have opportunity to do Kangaroo Care?' was 2.3/5, with 20/40 responders scoring between 4 and 5. Among the 20 responders scoring between 1 and 3, seven parents posted a note that Kangaroo Care was not applicable because the mother was either sick with postpartum complications or under general anesthesia or declined. The mean score for answers to the question 'Did you have the opportunity to feed your baby?' was overall on the low end (1.8/5), and eight parents who scored 1 posted a note that feeding was not applicable because the infant was in terminal condition or died.

When asked whether something had been missing in the infant's care to promote comfort, most parents answered no. About 30% of the parents stated 'not sure' but could not identify what might be missing.

Qualitative comments were offered in response to the second and third open-ended questions by almost half of the participants (43% and 38%, respectively). Qualitative content analysis of metaphors and images revealed themes of: Caring, Support, Healing and Transcendence (Table 3).

Responders to the third question provided additional information dominated by poignant expressions of gratitude and praise

for the program (e.g. 'I have so much gratitude for the attention, the love and the care that my daughter received for the short time she was with us; The care for (baby named) made a world of difference; We did not feel alone'), along with feeling of fragility in uncertain time (e.g. 'I was able to know my son for 5 h. It was hard but I know that we did everything we could. We were able to look into his eyes and he looked at us. The health care workers did the best they could for us in that very hard time') and of distress (e.g. 'I just hope they would have done something more to help the baby; I believe it is impossible to prepare for the death of your child').

DISCUSSION

To our knowledge, this is the first peer-reviewed prospective study to evaluate parental perception concerning the state of comfort maintained in their newborns affected by life-limiting conditions and treated by a multidisciplinary team implementing standardized guidelines.⁶ The study's main findings show that parents perceived the achievement of a 'state of comfort' for their babies with short life expectancy as a result of the care provided by the NCCP.

The questionnaire was designed to capture parental perception of their baby's end-of-life experience. The questions assessed the satisfaction of the baby's basic needs as they were addressed by concrete interventions (Table 1). As detailed in Table 2, the study results showed that, overall, both mothers and fathers felt that their baby was comfortable and treated with respect, care and compassion by professionals. They felt that the environment was mostly peaceful, private and non-invasive. Nearly all parents stated that their baby had the opportunity to receive comfort and

Table 3. Themes derived from parents' answer to the question: Could you describe comfort care (CC) offered to your baby with an image, a metaphor or another similar situation? *n* = 18 (43%)

<i>Mothers</i>	<i>Fathers</i>
<p><i>Caring</i> My baby was treated like family. The medical team was so respectful and loving to my baby and my family. We are just so grateful for the care he received.</p> <p>A place where people are compassionate and caring</p> <p>The health care workers did a very good job making sure (baby's name) was comfortable.</p> <p>As I watched the doctors and nurses care for my daughter I saw so much love in their words, actions and demeanors. It was if they were caring for their own daughter, niece or granddaughter. That was such a gift to me.</p>	<p>The name [CC] describes the care perfectly and the help received was just what was needed.</p> <p>The staff was compassionate and caring.</p> <p>After we got into the delivery room, our comfort care experience would be compared to a situation in which everyone involved was equally interested in the well-being of one person. We felt like everyone involved loved our daughter like she was his or her own.</p>
<p><i>Support</i> I would describe CC as an umbrella that tries to protect babies.</p> <p>CC was a place where everyone involved in my son's care continued to treat him as if he might survive until the moment he did not. Then they treated all of us with respect and dignity in front of our fragility. We felt like we might fall apart, but everyone was gentle and kind towards us and kept us together.</p>	<p>The care provided wrapped us and our baby in a blanket of love and support through a difficult time.</p>
<p><i>Healing</i> [CC is a place] full of love and peace.</p> <p>I think that comfort care is like a hug.</p>	<p>CC is like a band that helps healing.</p>
<p><i>Transcendence</i> [CC team] was better than family, they are angels, a miracle, a blessing.</p> <p>I got to meet my precious angel.</p> <p>I think of Comfort Care as a beautiful and calming corridor between this world and the 'next world'.</p>	<p>Little angel settled in locked body serving some high-concealed purpose, [we felt] radiant sensation of purification, submission and modesty.</p> <p>I imagine comfort care as love, pure unadulterated longing for goodness.</p>

love from the family. Moreover, they felt that their baby was not hungry, thirsty, cold or in pain. Certainly the striking positive answers by the parents indicate that the standardized comfort measures were administered properly and successfully.

The impact of neonatal palliative care programs on the state of comfort of terminally ill infants has been measured mainly through pain assessment and management.^{14,15} However, data of parents' perception as reported by this study suggest that families envision the state of comfort for their baby well beyond the pure absence of pain. The vast majority of responders felt that comfort for their infant entailed bonding (opportunity to spend time with their baby and to show their love), and relief of primary needs (baby was not cold, thirsty, hungry or in pain). A policy statement by the American Academy of Pediatrics¹⁶ offers scientific evidence of the effectiveness of several strategies (e.g. holding, skin-to-skin, breastfeeding) in reducing stress and discomfort in healthy newborns undergoing painful procedures. The results of the current study suggest that these same strategies can promote a state of comfort, even in the absence of pain, by addressing the baby's basic needs in end-of-life care settings.

It was surprising to find that the mean score for answers to the questions 'Did you have the opportunity to do Kangaroo care?' and 'Did you have the opportunity to feed your baby?' was on the low end. Unfortunately, the questionnaire does not ask why there were 'missed' opportunities with Kangaroo Care and feedings. Some parents who reported fewer opportunities included an explanation why the intervention was not possible. In most cases, however, it is unclear if these interventions were not offered at all, parents declined, one parent had the opportunity while the other

did not, or these comforting measures were missed because of maternal or infant medical complications. Different religious practices regarding holding babies as they die may explain some of the low reports of Kangaroo Care.¹⁷ Regarding feeding, most parents reported that their baby did not look hungry or thirsty, and that most babies of the study cohort died in the delivery room. As a result, we propose that the babies' terminal conditions, rather than lack of professional support, explain the low rate of feeding experiences by parents.

Qualitative data obtained by the question 'Could you describe comfort care offered to your baby with an image, a metaphor or another similar situation?' reinforce and amplify the positive results expressed by the quantitative data (Table 3). Themes of 'Caring', 'Support', 'Healing', and 'Transcendence' were identified.

'Caring' is the most common theme provided. This suggests that parents' experiences of their babies' comfort is impacted by their perception of the team's care of their newborn (e.g. 'As I watched the doctors and nurses care for my daughter I saw much love').

The second and third themes embodied parents' descriptions of being embraced and held along with their baby, and 'provided support through a difficult time'. Responders expressed an experience of being supported and 'kept together' within the uncomfortable atmosphere of uncertainty as a result of feeling 'wrapped up' by the team's care. The physical and emotional holding of the baby and family by the multidisciplinary program leads to an experience of 'healing' (e.g. 'Comfort Care is like a band that helps healing').

The fourth theme of 'Transcendence' highlighted parents' experiences of meeting 'my precious angel' with the help of the team described as 'a beautiful and calming corridor between this world and the 'next world''. These descriptions create a sense of meaning making through imagery that is within the liminal space between the physical and spiritual realms. Parents' perceptions underline the important role of spirituality in the understanding of a painful experience.

One of the main findings is that the parents' mode response to the question 'Do you think that overall your baby received comfort' was 'always' selected by 38/42 responders (mean score 4.9/5). Yet, when asked if anything was missing from comfort care, almost 30% of the parents were 'not sure' and could not identify what might be missing. Since all responders stated that this was the first time they faced a child with a life-limiting condition, their uncertainty regarding 'something missing' might reflect their lack of awareness of what else could have been offered by the medical team. However, this uncertainty is more likely related to the experience of the 'loss of a healthy baby', which started when they learned of the baby's life-limiting diagnosis.

While parents expressed gratitude and praise for the program, they also shared their feelings of fragility and distress in uncertain times. A comment by one mother exemplifies the complexity of families' experiences: 'You feel everything all at once: angry, upset, but even joy ... People at the hospital helped celebrated the 15 days that my son and I had together ... My husband and I made the decision to be joyful'. This mother's description speaks to the liminality experienced by families living at the threshold of uncertainty, in the 'betwixt and between' space between life and death that exists for expectant parents who are uncertain about how much time they will have to be with their babies.^{18,19} The findings of this study, quantitatively and qualitatively, highlight the complexity of medical and non-medical needs of these families and their babies as recognized by previous studies.^{3,5,20,21}

There are some limitations to this study. First, the questionnaire was given at different time intervals after death. The questionnaire was mailed to the family at least 3 months after the event; however, the range of time between death and mailing was 3 months to 3 years. Moreover, the time-gap between mailing and parents completing the questionnaire is unknown. Although the ideal time to collect data regarding parental perception of their infant's comfort is unknown, studies collecting data on parental grieving show that time is a key factor in the grieving process and thus it is possible that time lapsed may have influenced some answers.^{22,23}

Preliminary data of a later self-report study of 25 parents of 18 infants treated by the NCCP showed that the parental grief process for their deceased baby can persist or intensify over the course of the first year (Byrne MW *et al.* unpublished data). A grief trajectory of this length is consistent with findings of other studies of infant loss.^{24,25} Future research should assess if there is an association between perception of comfort and length/quality of the grieving process in this population.

Some might consider a limitation that the quantitative analysis was done using the conventional (but still debated) treatment of ordinal data as if it were interval level data.²⁶ However, when means were compared with medians and modes for each item, similar patterns were shown.

One potential limitation could be the non-reproducibility of this study given that the NCCP guidelines were developed in a single institution. However, these guidelines have been published and described in detail⁶ and can be implemented by other institutions.

Lastly, the investigator-developed questionnaire used in this study has had limited opportunity for validity and reliability testing yet results were promising. There are no similar assessment tools for comfort care. Assessing a state of comfort for a baby with a life-limiting or terminal condition is paramount.²⁷

Thus, we will continue psychometric testing of this measure with the goal of providing a gold-standard to assess parents' perceptions of comfort measures for babies with life-limiting or terminal conditions.

CONCLUSION

This innovative study shows that parents of infants with life-limiting conditions and short life expectancy strongly perceive that their babies experience an overall state of comfort as a result of standardized comfort measures provided by the multidisciplinary NCCP. Further studies are warranted to optimize the questionnaire, and to verify whether standardized guidelines, as proposed by the NCCP at Columbia University Medical Center, can achieve a state of comfort for newborns with life-limiting conditions in other institutions. Lastly, short- and long-term parental grieving experience and its association with perception of infant's comfort need to be studied.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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