

Clinical Practice Guidelines

Communicating with Families of High-risk Neonates

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The contributors and editors have made effort to ensure that all information is according to currently accepted recommendations. However, given the rapidity with which new information emerges, the reader is urged to check for latest updates.

Executive summary

The neonatal intensive care unit (NICU) and the special newborn care unit (SNCU) offer unique challenges for healthcare providers in the area of counselling. The admission of a sick newborn baby to the NICU can be highly stressful for parents, who are often unprepared for the course of illness, treatment options, and short-term or long-term outcomes. Parents experience anxiety, sleep disturbance, and emotional distress. Doubts and fears regarding their parenting roles, disruptions in work and income, and feeling of helplessness add to their distress. Effective counselling is essential for the family's well-being and continued care after discharge in this scenario. However, the recommendations and guidelines for counselling of parents and families of sick, admitted neonates are still fluid. Research in this area is inclined toward qualitative studies, case studies, and anecdotes.

The Guideline Development Group short-listed 5 priority questions on communication and counselling strategies for the parents and families of hospitalized sick neonates. The Grading of Recommendations Assessment, Development, and Evaluation (GRADE) approach was used for grading the quality of evidence wherever feasible. Recommendations were formulated based on the summary and quality of evidence, the balance between benefits and harms, values and preferences of the family, feasibility, and cost-effectiveness in Indian settings.

SUMMARY OF RECOMMENDATIONS FOR COMMUNICATING WITH FAMILIES OF HIGH-RISK NEONATES

S. No.	Recommendations	Strength of Recommendations	Certainty of evidence
1.	Health care workers should be formally trained in counselling of parents and families of sick, hospitalized neonates	Strong	Not GRADED
2.	Counselling by health care providers for parents of sick neonates should be 'structured'. <i>Units can choose from many of the existing counselling frameworks and use visual aids based on the situation. The counselling should be individualized.</i>	Strong	Not GRADED
3.	One-to-one counselling should be preferred over group counselling for updating infant condition, prognosis, or decision making. <i>Individual counselling protects parents' privacy and is especially important while breaking bad news or sharing complex information.</i>	Strong	Not GRADED
4.	A designated area should be used for counselling in preference to a random location. <i>A designated room offers privacy during complex or difficult situations and allows parents to share their emotions and improves their confidence to ask questions.</i>	Strong	Not GRADED
5.	Family support groups or peer-to-peer support, in addition to counselling provided by health care providers, should be encouraged. <i>It offers unique support through experience sharing. These support groups should be considered an additional component and not a replacement for the services provided by professional NICU staff.</i>	Strong	Not GRADED

Introduction

Clear, empathetic, and regular communication or counselling alleviates stress for the families of sick neonates admitted to a neonatal unit. A recent systematic review identified parent-provider communication as a crucial determinant for parental well-being and satisfaction with care during and after hospitalization.¹ Communication interventions appeared impactful, particularly in reducing parental stress and anxiety.¹ With increasing awareness, understanding, and adoption of family-centered care in the sick neonatal care, the role of skilled communication and counselling by healthcare professionals is paramount. However, counselling in these settings may not be adequate for many reasons. Many pediatricians, neonatologists, nurses, and residents do not receive formal training in counselling. The interactions between healthcare providers and families are often unstructured, brief, irregular, and driven by hierarchies in the healthcare system. Parents are frequently counselled informally, whenever and wherever are met and many a times in a group counselling session. Often the support needed by parents and families is not provided by the health care workers due to latter's overwhelming commitments, and peer support is not available. Given the increasing medico-legal issues facing healthcare systems and the complexities and uncertainties of the neonatal care, it is imperative to improve communication by following guidelines based on best available evidence.

Scope of the guidelines

The purpose of these guidelines is to provide evidence-based recommendations regarding the communication and counselling of parents and families of sick neonates admitted to the NICU. The guidelines address the communication to help parents in shared decision-making, breaking bad news, parental support at end-of-life situations, documentation of communication, and using tools (e.g., checklists) to aid in communication

Target population

These guidelines are intended for the counselling of parents or families of sick newborns admitted to the NBSUs, SNCUs and NICUs.

Setting

Hospital settings

Target audience

The primary audiences for these guidelines are healthcare professionals involved in the care of sick neonates and the parents/families of neonates. The guidelines are expected to be used by policymakers and program managers to guide policy and programmatic action at national and sub-national levels. The Clinical Practice Guidelines (CPG) working group for Parent Family Communication initially identified nine research questions of interest related to various facets of parent and family communication and counselling. GDG group chose five high priority questions for addressing in the current version of the guidelines.

Practice Questions

1. Does formal training of healthcare providers for communicating with counselling family compared to no formal training improve the relevant outcomes for the family and health system?
2. Does a structured approach to counselling versus unstructured counselling by health care providers improve the relevant outcomes for the family and health system?
3. Does one-to-one counselling in comparison to group counselling improve the relevant outcomes for the family and health system?
4. Does using a designated room/area for counselling improve the relevant outcomes for the family and health system?
5. Does setting up formal peer-support groups for families of neonates in SNCU/NICU improve the relevant outcomes for the family and health system?

Other Questions

1. Effect of team counselling (doctor, nurse, and stakeholders) versus doctor or nurse-led counselling on outcomes and benefits for NICU/ SCNU parents
2. Effect of health care provider-driven (single) counselling versus parent-driven (multiple) counselling on outcomes and benefits for NICU/ SNCU parents.
3. Effect of AV recording of counselling/ communication versus no recording on outcomes and benefits for NICU/ SNCU parents.
4. Effect of face-to-face counselling alone versus face-to-face counselling with AV aids on outcomes and benefits for NICU/ SNCU parents.

Of the Other Questions, Q 1 and 2, which were initially judged to be important, were subject to literature searches that did not yield any specific results and were set aside. Questions 3 & 4 related to audio-visual (AV) aids were set aside to be included in a separate guideline due to the evolving impact of the digital world in health care.

Finally, the five priority practice questions listed above are addressed in this guideline.

Methods

Criteria for considering studies for this review :

Types of studies

Controlled trials, observational studies, and case series were considered for inclusion in this review if the study compared any professional support for the families of sick neonates admitted in the neonatal unit with standard care as practiced at the time of the study. Studies were excluded if they described communication addressing well new-borns, OPD follow up cases, or were published as case studies, conference abstracts, dissertation abstracts, letters, commentaries, and non-research articles or were not written in English.

Types of participants

- Parents or families of neonates admitted to neonatal units (recipients of counselling)
- Physicians, health care workers, nurses (who deliver the counselling)

Outcomes of interest

The outcomes (critical and important) considered for each priority question were validated using a questionnaire administered to paediatricians practicing in different neonatal care settings. Other outcomes were considered when information on critical or important outcomes was not available in studies.

Types of interventions

Communication or counselling was defined as any health professional consultation with parents or families during the hospital stay of the sick neonate in which parents or families were informed and updated relevant to their neonate's clinical status. This included any form of general support, parent information provision about the clinical condition and outcome, or bereavement counselling and counselling either in single or multiple sessions

Comparator

The control group ('usual care group') was a mix of interventions parents would usually receive during their infant's hospitalization. Although lack of a clear control group makes interpretation of findings complicated, the external validity of study findings is increased and such studies provide a relevant comparison group in the real-world scenario.

Outcome measures

Critical outcomes

- a) Parental stress
- b) Parental satisfaction with healthcare
- c) Parent awareness/understanding/knowledge regarding the condition of the baby

There is less consensus concerning the appropriate parent satisfaction, stress, awareness, or knowledge measures, which means that the measurement scales used in different studies may not be fully validated. Both self-reported and interviewer-rated measures were eligible for the review, and measures could use continuous scales or dichotomous categories.

Important outcomes

- a) Incidence of medico-legal cases
- b) Incidence of patient leaving or discharged against medical advice
- c) Parental empowerment (shared decision-making)
- d) Parents-healthcare worker conflict (difference of opinion with healthcare providers)
- e) Healthcare provider (HCP) satisfaction
- f) Healthcare provider burnout

Search strategy

The literature search included PubMed, Cochrane Central Trials Registry, Scopus, CINAHL, and Google Scholar using the relevant keywords (newborn, neonate, NICU, 'Neonatal Intensive Care Unit,' SNCU, Nursery, Parents, Family, Communication, Counselling, Stress, Knowledge, Satisfaction). All the relevant studies for each question were uploaded onto the Rayyan website (Ouzzani M, et al. Rayyan — a web and mobile app for systematic reviews. *Systematic Reviews* (2016) 5:210, DOI: 10.1186/s13643-016-0384-4). Two members of the group screened and selected studies for inclusion, first individually and then by mutual reconciliation for differing choices. In cases of disagreement, a third independent member was asked to finalize the study for inclusion. Details of the search of the important questions are shown in Appendix in the online version of the complete document.

Data abstraction and summary tables of individual studies

A standardized form was used to extract information from relevant studies. Systematically extracted data included: author, setting, design, participants, sample size, intervention or exposure, control or comparison group, outcome measures, and results. The quality characteristics recorded for observational studies were likelihood of reverse causality, selection and measurement bias, loss to follow-up, and analysis adjusted for confounding factors. Where possible, studies were stratified according to the type of intervention or exposure, study design, birth weight, and gestational age. Effects were expressed as relative risks (RR) or odds ratios (OR) for categorical data and as mean differences (MD) or weighted mean differences (WMD) for continuous data where possible. All studies reporting on a critical outcome were summarized in a Table of Individual Studies.

Pooled effects

Pooled effects for developing recommendations were considered, wherever feasible, using RevMan 5. If the results of three or more RCTs were available for an outcome, and the overall quality of evidence using the GRADE approach was at least "low", observational studies were not considered. Pooled effects from published systematic reviews were used if the meta-analysis was appropriately done and the reviews were recent. Where pooling of results was not possible, the range of effect sizes observed in the individual studies was used to develop recommendations.

Grading the quality of evidence

Quality assessment of the body of evidence for each outcome was performed using the Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach. The GRADE approach was used for all the critical outcomes identified in the priority questions, and a GRADE profile was prepared for each quantitative outcome within each PICO question. Accordingly, the quality of evidence for each was rated as "high," "moderate," "low," or "very-low" based on a set of criteria. As a baseline, RCTs provided "high-quality" evidence, while non-randomized trials and observational studies provided "low-quality" evidence. This baseline quality rating was then downgraded based on the risk of bias, inconsistency, imprecision, indirectness, and publication bias. For observational studies, other considerations, such as the magnitude of effect, led to upgrading the rating if there were no limitations that indicated a need for downgrading. For parental counselling, we noted a paucity of randomized controlled trials. Studies varied with respect to intervention and outcomes.

In such scenarios, where outcomes could not be pooled, the recommendations were based on the WHO handbook of guideline development. The Guideline Development Group considered the following 1) confidence that the desirable consequences (benefits) of an intervention outweighed its undesirable consequences (Risks of Harm, 2) magnitude of the potential benefits and harms of alternative courses of action 3) value judgements on the trade-off between these harms and benefits 4) value judgements and preferences of the individuals affected by the recommendation and considerations about the use of resources.

Formulation of recommendations

Each recommendation was graded as strong when there was confidence that the benefits clearly outweighed the harms or weak when the benefits probably outweighed the harms with the uncertainty of the trade-offs. A strong or weak recommendation was further classified as situational or context-specific if the benefits outweighed the harms in some situations but not in others

Document review

The working group met regularly and prepared a draft of the full guideline document after extensive online meetings and deliberations with revisions to accurately reflect the decisions of the participants. The draft guideline was then shared electronically between the members for further comments. The inputs of the peer reviewers were included in the guideline document, and further revisions were made to the guideline draft as needed. After the peer review process, the revised version was prepared.

Counselling in specific circumstances

The topic being more qualitative than quantitative, it was decided to address different situations that a clinician faces when dealing with sick and chronically unwell neonates and their families. These situations have been reviewed individually and discussed under the following heads: (Appendix 1)

1. Antenatal counselling
2. Counselling at margins of viability
3. Counselling of high-risk neonates
4. End-of-life counselling

Questions, Evidence summaries, and Recommendations

Practice Question 1: Does formal training of healthcare providers for communicating with counselling family compared to no formal training improve the relevant outcomes for the family and health system?

Question in PICO format
Population: Parents of high-risk or sick neonates and healthcare professionals working in NICU or SNCU
Intervention: Training of healthcare workers in communication skills
Control: No formal training
Outcome: Parent satisfaction, parent stress, parent understanding, workplace violence Parent decision making, physician burnout, medico-legal implication

Summary of evidence

Healthcare workers (neonatologists, pediatricians, and nurses) strive to facilitate an informed, collaborative decision-making process with parents in the baby's best interest. While healthcare professionals may be trained to provide a detailed account of the morbidity and mortality data to the parents, they are not trained in communication during complex and intensely emotional scenarios. In a 2009 web-based survey² of U.S. neonatal-perinatal medicine fellows in their last month of fellowship training, 41% reported that they had never received any formal communication training, and 75% were not exposed to any type of role-play or simulated patient encounters. Insufficient training of nurses on palliative care education is recognized as a barrier in the NICU. The lack of training resulted in nurses experiencing discomfort when discussing palliative care with families³. Kyc et al. ⁴ reported that less than half of the nurses received such training in their curriculum.

Search results

Of the 2890 distinct retrieved citations, we included 15 studies that addressed health worker training in communication skills. The key outcomes are listed in Table-1, and the characteristics of included studies are provided in Supplementary Table-1 in the online version. A recent rapid review⁵ included studies testing educational interventions for palliative care to NICU nurses. Only four studies that reported education interventions lasting 6–21 h with 30–142 participants were identified. All used convenience samples and pre-posttest designs. The outcome measures included objective knowledge tests and structured clinical observations. The studies showed statistically significant improvements in at least one outcome.

Table-1 Effect of training of healthcare professionals on key outcomes

Outcome	Type and number of studies	Intervention	Effect sizes in individual studies
Parental stress assessed using scores	RCT=1 ⁶	Training HCW in Guided family-centered care	The total stress scores reported by parents (n=134) did not vary significantly between the intervention (Guided family-centered care, n=74) and standard groups (n=60), with a mean (SD) of 2.70 (0.67) versus 2.84 (0.71), respectively. Using Nurse Parent Support Tool and Parent Stressor Scale - NICU, the scores did not differ between the groups at discharge to assess parental stress.
Parental satisfaction	RCT=1 ⁷	Training of HCW in Decision Making Tool for the Neonatal Intensive Care Unit: N-DMT,	The intervention group (n=10) compared to standard of care (n=9) reported lower satisfaction with care, especially in questions regarding communication (median [range]; 26[15-28] vs 28.8 [19-32]).
	Observational study=1 ⁸	Intervention targeted to improve the quality and quantity of communication between parents and principal medical providers	Improvement in parent satisfaction score with physician communication (75% vs 95%, pre/post-intervention, n=50/33, p<0.01), The preference for more frequent communication needs was decreased (65% vs 36%, p<0.01)
	Quality improvement study =2 ^{9, 10}	Interdisciplinary family conference ⁹ Multidisciplinary family meetings ¹⁰	<ul style="list-style-type: none"> Improvement in parent satisfaction score with physician communication (76.5 vs. 78.5 % average). 9Another QI study on timely multi-disciplinary family meetings /94% of physicians reported that it improved their patient care, 81% disagreed that 'holding family meetings interfered with my other commitments' and 75% disagreed that 'holding family meetings noticeably added to my workload'. 24% returned CAT-T surveys for patient assessment of clinician communication quality. The mean score of 12.2 out of 14; 95%CI 11.2-13.1 with satisfaction and communication did not vary significantly during the study period¹⁰.
Parental understanding	Observational study=1 ⁶ (Thematic analysis)	Guided family-centered care	The intervention of guided family-centered care helped parents (n=13) cope as persons, parents, and couples viz discovering and expressing emotions, reaching a deeper level of communication,

			and obtaining a mutual understanding compared to standard group (n=9).
	Observational study=1 ¹¹ (assessed using a scale)	Care planning meetings	The study demonstrated that infant progress chart and care planning meetings led to increased scores on 6 of 9 collaboration indices. The intervention group (n= 77) had fewer realistic concerns (p=0.018), less uncertainty about infants' medical condition(p=0.003), less decision conflict (p < or = 0.01), more satisfaction with the process by which the medical decisions were made (p=0.012), the amount of decision input they had (p=0.058) and reported more shared decision making with professionals (p=0.010)
	Observational study=1 ¹² (assessed using a survey)	Empathy training	Empathy training (n= 109) enhanced NICU provider communication skills and improved emotional support and understanding. Parent survey scores significantly improved in two questions; referring to the child by first name (p=0.02) and being offered emotional support from staff (p=0.03) or information on parent support groups (p=0.03). This was sustained over 6 months of follow-up ¹² .
Health care provider communication skills	RCT=1 ¹³	Simulation based difficult conversation based Workshop training	Participation in difficult conversations workshop increased participants' empathy score (p=0.015) and the use of communication skills (p=0.013) in a simulated clinical encounter (n=7 in the intervention group, 5 in the control group). The mean number of predefined communication skill behaviors exhibited by each participant was higher than in the control group (12 skills compared to 8 skills per scenario, p =0.013). Trained participants asked more open-ended questions to parents post-intervention (p= 0.047)
	Observational studies=8 ^{2, 10, 12, 14, 15, 16, 17} Bry et al. ¹⁴	-Multiple modalities Communication skills course for nurses	Training of health care workers (n=13) led to less talking and more listening. The mean ratio between the nurse's number of words and the parent's number of words in the conversation was 3.7± 0.7 before the course and 2.0 ±0.2 after the

			<p>course ($p=0.003$). On average, there was increased dealing with psychological matters ($1.7 \pm 0.8\%$ before and $6.4 \pm 1.8\%$ after the course, $p= 0.00465$), more emphatic response (12.9% before and 42.9% after), and provision of an adequate response (21% decreased to 8.3%). Use of statements expressing caring, and encouragement of parents increased after the course ($p=0.0034$ and $p= 0.043$, before and after, respectively)</p>
	Kasat et al ¹²	Empathy training workshop	<p>Empathy training workshop ($n=109$) led to enhanced NICU provider communication skills. Parents' survey scores improved significantly with referring to the child by first name ($p=0.02$) and being offered emotional support by the staff ($p=0.03$) or information about the parent support group ($p=0.03$). This was sustained at 6 months follow-up.</p>
	Harris et al. ¹⁶	Structured end-of-life curriculum	<p>Structured end-of-life curriculum ($n=17$) led to increased knowledge about the patient qualification of comfort care and withdrawal of support ($p=0.03$). The training was perceived to be adequate ($p=0.02$).</p>
	Ghoneim et al. ¹⁵	A simulation-based training	<p>A simulation-based study ($n=15$) emphasizing the SPIKES protocol for delivery of bad news led to significant improvement in self-perceived effectiveness and knowledge of taught concepts, and the improvement was retained for 3-4 months.</p>
	Boss et al. ²	Training in core-curriculum	<p>Training ($n=13$) in core communication challenges led to increased self-perceived competence to talk with the families about bad news(2.6 to 4.5 after a workshop on Likert type scale ($p<0.05$), palliative care (4.3), discontinuing intensive care (4.4) and code status (4.3). A month later, participants felt much willing to engage in difficult conversations.</p>

	Weiss J et al. 17	Systematic guided family-centered care	With systematic guided family-centered care (n=45), nurses gained insight into their communication techniques. Reflection sheets were useful in nurse-parent communication. Increasing a sense of ownership promoted a positive attitude to the study and increased efforts by nurse managers to stimulate the implementation
	Sabnis et al. 10	Education and reminders to the professionals	Education and reminders to the professionals and the introduction of scheduling and documentation tools led to an increase in timely family meetings (10.5% to 31.3 % (p< 0.01) at the end of one year. 94% of physicians agreed "holding family meetings helped improve the care of my patients," 81% disagreed that "holding family meetings interfered with my other commitments," and 75% disagreed that "holding family meetings noticeably agreed to my workload." Nurses reported empowered to propose and document meetings between parents and physicians.
	Lechner et al., 2015	Difficult conversations Workshop based training	In another study, the difficult conversations curriculum workshop (n=12) led to increased respondent comfort in delivering bad news (p=0.04). The fellows reported a significant increase in the teaching of the communication skills body position (p=0.002) and pausing after bad news (p=0.05) in the simulation group (Lechner et al., 2015)

Balance of benefits and harms

Compared to no training, interventions that focused on healthcare-workers' training either using a structured methodology resulted in better parent satisfaction and lower parent stress levels. Physicians, trainees, and nurses favorably perceived the interventions. No adverse events were noted, although, in a few studies, there was no difference between control and intervention groups in some outcomes.

Values and preferences

As guideline authors, we believe that critical outcomes of this guideline, namely parent stress, parent satisfaction, parent understanding, health care provider communication skills, are valued highly by all the stakeholders, including patients, families, clinicians, and policymakers.

Cost

We did not identify cost-effectiveness studies. Looking at the potential benefits to the health professionals and parents, the intervention is feasible to implement as it can be done using the existing infrastructure and resources without extra expenses. Both public and private sector healthcare set-ups can implement the intervention.

Limitations of the review

Most of the included studies had less rigorous study designs, a small sample size, and less-objective outcome measures. While the evidence from these studies suggests positive outcomes, additional studies using more rigorous research methods are needed.

RECOMMENDATION

1. Health care workers should be formally trained in counselling of parents and families of sick, hospitalized neonates

Strong recommendation, Not graded

Additional considerations

1. Each institution should have a communication curriculum that includes common topics¹⁸. The curriculum should teach staff how to provide information about the baby's diagnoses, expected course and prognosis using local language in simple terms without jargon and presented in a warm, sympathetic manner. It should also address provision of psychosocial support to families in crisis and active listening to a family's concerns and fears. The program should also train care providers in shared decision-making.
2. Mode of training: A variety of models for communication training for physicians and nurses exists, and each NICU should tailor the program based on the needs of their staff, balanced with the resources available to the hospital. Curricula that combine practical and theoretical aspects are preferred, such as role-plays and reflective learning.^{2, 19}

Practice Question 2: Does a structured approach to counselling versus unstructured counselling by health care providers improve the relevant outcomes for the family and health system?

Question in PICO format
Population: Parents of high-risk or sick neonates and healthcare professionals working in NICU or SNCU
Intervention: Structured counselling
Control: non-structured counselling
Outcome: Parent satisfaction, parent stress, parent understanding, workplace violence Parent decision making, physician burnout, medico-legal implication

Summary of evidence

We identified 15 studies that evaluated some form of structured parental communication compared to controls. The various structured frameworks used by different studies are described in Table 2, and the study characteristics and the outcomes are provided in Supplementary Table 2.

Table 2: Framework for parental counselling used in various studies

Framework for counselling or communication	Description
Care Planning Meetings	Penticuff et al. ¹¹ Parents participated in three parent-professional care planning meetings (CPM) during the infant's NICU stay. Both parents (or the mother and her designated support person) participated in the meetings. The CPM format was intended to facilitate the development of parent-professional relationships characterized by open communication, shared decision authority, and trust, thereby enhancing collaborative treatment decision-making.
Timely multidisciplinary family meetings	Sabnis et al. ¹⁰ To make meetings more customary, authors provided education and reminders to professionals. They defined timely meetings as a documented discussion between a parent, neonatologists, and non-physician professionals, such as nurses, within 5 days of hospitalization. Trujillo et al. ⁹ the team decided that holding an interdisciplinary family conference (IFC) within the first two weeks of a baby's NICU admission is critical for parental involvement for infants born at less than 32 weeks gestation and those with congenital birth anomalies
Family communication plan	Weiss et al. ⁸ Family communication plan consisted of 1. Initial Meeting - Meet parents within a day of admission 2. Daily/Weekly Contact - Talks with parent daily while baby is acute, daily to weekly when more stable - Talk on the phone or at the bedside - At the end of each talk, schedule next talk

	<p>3. Discharge Meeting - Discusses discharge plan with the parent</p>
<p>Use of baby diaries</p>	<p>Van de Vijver et al.²⁰</p> <p>Baby communication diaries were intended to aid in improving communication with parents and complement face-to-face communication. The diary aims to achieve this by providing brief and regular bursts of information and providing a space for parental reflection and questions. It also acts as a keepsake of their baby's journey through the neonatal unit.</p>
<p>Use of decision aids</p>	<p>Decision aid for patent ductus arteriosus</p> <p>AlFaleh et al.²¹ The DA is a computer-based interactive tool. In the first part, the DA provides information about patent ductus arteriosus (PDA) as a disease, the different treatment options, and the benefits and downsides of using indomethacin therapy in preterm infants. The second part coaches the parent in the decision-making process by clarifying values and preferences.</p> <p>Decision-making tool (DMT)</p> <p>Clarke-Pounder et al.⁷ The DMT was adapted as an interview tool. Questions addressed four main areas including:</p> <ul style="list-style-type: none"> (1) medical indications for treatment ("Give a brief description of your baby's condition") (2) parent preferences ("How do you like things explained to you?") (3) quality of life ("What goals and hopes do you have for your baby's life?") (4) contextual issues ("How do your cultural or spiritual beliefs impact how you make decisions?"). The goal was to encourage parents to articulate needs and values relevant to medical decision-making.
<p>Aids for fruitful communication</p>	<p>Janvier et al.²² (Expert opinion)</p> <p>mnemonic "SOBPIE" may help providers have fruitful discussions:</p> <ul style="list-style-type: none"> 1. What is the Situation? Is the baby imminently dying? Should withholding or withdrawing life-sustaining interventions be considered? 2. Opinions and options: personal biases of healthcare professionals and alternatives for patients. 3. Basic human interactions. 4. Parents: their story, their concerns, their needs, and their goals. 5. Information: meeting parental informational needs and providing balanced information. 6. Emotions: relational aspects of decision making which include the following: emotions, social supports, coping with uncertainty, adaptation, and resilience.
<p>A common algorithm for communication</p>	<p>Coscia et al.²³ explain the project 'Not alone,' related to counseling at their NICU, which aims to let</p>

	counseling become a 'shared culture' for all the caregivers. They use an 'algorithm' that follows a pattern: (1) information always given; (2) frequent questions from parents; and (3) frequent difficulties in communication. Record important moments, for instance, the 'case history of the communication': it would be desirable to have the case history, a sheet dedicated to important communications that are absolute to be shared with other professionals.
Three talk model for shared decision making	Elwyn G et al. ²⁴ proposed a new three-talk model of shared decision making is proposed, based on "team talk," "option talk," and "decision talk" to depict a process of collaboration and deliberation. Team talk emphasizes the need to provide support to patients when they are made aware of choices and elicit their goals to guide decision-making processes. Option talk refers to comparing alternatives using risk communication principles. Decision talk refers to the task of arriving at decisions that reflect the informed preferences of patients, guided by the experience and expertise of health professionals.
SPIKES protocol for communicating bad news	Baile et al. ²⁵ proposed a protocol for communicating bad news. SPIKES stands for <ul style="list-style-type: none"> a. Setting - start properly, preparing the environment, how what, and who should be present, that is, the beginning itself, including normal cordial attitudes; b. Perception - perception of how much the patient knows about his/her illness; c. Invitation - an invitation to discover how much the patient wants to know; d. Knowledge - pass the knowledge, share the information; e. Empathy - empathy for responding to the feelings of the patient; f. Strategy and summary - strategy to combine the therapeutic planning of the patient.

Balance of benefits and harms

Compared to non-structured communication, some form of framework or a structure resulted in better parent understanding, higher satisfaction, lower parent stress level. The intervention was also perceived favorably by the physicians, trainees, or nurses. No adverse events were noted.

Values and preferences

Both parents and clinicians are likely to value the benefits of structured communication or decision aid as they reduce decisional conflict, facilitate shared decision-making, and decrease stress.

Cost

We did not identify cost-effectiveness studies. Intervention can be implemented using the current infrastructure and resources.

Limitations of the review

Most of the included studies had less rigorous study designs, small sample sizes, and less objective outcome measures. While the evidence from these studies suggests benefit, the interventions were heterogenous. One specific framework might not fit all scenarios.

RECOMMENDATION

2. Counselling by health care providers for parents of sick neonates should be 'structured'.

Units can choose from many of the existing counselling frameworks and use visual aids based on the situation. The counselling should be individualized.

Strong recommendation, Not graded

Practice Question 3 - Does one-to-one counselling in comparison to group counselling improve the relevant outcomes for the family and health system?

Question in PICO format	
Participants	Parents of high-risk or sick neonates and healthcare professionals working in NICU or SNCU
Intervention	Group Counselling/Communication
Comparison	One-to-one counselling/ Communication
Outcome	Stress, satisfaction, decision making, violence, litigation

Summary of evidence

We identified two systematic reviews and five studies on group versus individual counselling. Only two studies compared group and individualized counselling head-to-head. The characteristics and outcomes of the studies are given in the supplementary Table 3.

The systematic review by Catling CJ et al.²⁶ included trials that compared the effects of group pregnancy care versus conventional individual pregnancy care on psychosocial, physiological, labor and birth outcomes for women and their babies and care provider satisfaction. Four randomized controlled trials (involving 2350 women) were included: two were undertaken in the USA, one in Sweden, and one in Iran. The reviewers found no differences between women who received group pregnancy care and those given one-to-one care regarding important pregnancy outcomes such as preterm birth, infant birth weight, or death

of the baby. Women who attended group pregnancy care were no more likely to initiate breastfeeding than those receiving standard care. In one trial, women who attended group pregnancy care rated their satisfaction similar to those receiving individual care. This review is limited owing to the small numbers of studies, with one study contributing to 42% of the included subjects. More research is required to determine whether group pregnancy care is associated with significant benefits. This review was about pregnant women and hence there is indirectness about this evidence.

Gangnon et al. ²⁷, in their systematic review, looked at the effects of structured antenatal education programs on knowledge acquisition, anxiety, sense of control, pain, labor and birth support, breastfeeding, infant-care abilities, and psychological and social adjustment. The review found nine trials involving 2284 women. Interventions varied greatly, and no consistent outcomes were measured. The review of trials found a lack of high-quality evidence from trials, so the effects of antenatal education remain largely unknown. Further research is required to ensure that effective ways of helping health professionals support pregnant women and their partners in preparing for birth and parenting are investigated so that the resources are used to meet the needs of parents and their newborn infants.

Weiss et al. ⁶ compared guided family-centered care (GFCC) versus standard care on parental stress. The GFCC intervention included regularly scheduled dialogues between parents and their primary nurse while their infant is in the NICU, preparing parents for dialogues using semi-structured reflection sheets and person-centered communication techniques used by nurses. Standard care included unrestricted visits by parents as per unit policy. Parents were able to discuss their infant's condition during daily rounds, and physicians provided consultations as needed. There was no comparison with group counseling and the parents received one-to-one sessions of varying frequency and duration.

While evidence on group therapy compared to individual therapy is available in pediatric and adult literature, there is a paucity of evidence on group parental counselling in the NICU. Evidence is available for the following sub-groups; teen parent groups, breastfeeding support, and prenatal care. Porteus et al found in a RCT that individualized professional support commenced in the hospital and continued in the community significantly increased the incidence and duration of breastfeeding.⁵⁶

RECOMMENDATION

3. One-to-one counselling should be preferred over group counselling for updating infant condition, prognosis, or decision making.

Individual counselling protects parents' privacy and is especially important while breaking bad news or sharing complex information.

Strong recommendation, Not graded

Practice Question 4 : Does using a designated room/area for counselling improve the relevant outcomes for the family and health system?

Question in PICO format	
Participants	Parents of high-risk or sick neonates and healthcare professionals working in NICU or SNCU
Intervention	Counseling/ Communication in a designated area (counselling room)
Comparison	Counseling / Communication in any random area (including bedside)
Outcome	Stress, satisfaction, decision making, violence, litigation

Summary of evidence

No randomized studies were identified for this practice question. Focused group discussions and parental interviews provided information about parental preferences. Parents preferred having regular conversations in a secluded location such as a single room as it increased their sense of privacy, their confidence to ask questions, and the idea that providers take the time to listen. In one study²⁸ parents reported a preference for conversations in a secluded location such as a single room to maintain privacy and feel confident to ask questions. This also allows parents to show their emotions, enabling providers to support parents during difficult conversations²⁸. Parents also preferred that information such as bad news or unexpected or complex information be conveyed to them privately^{29, 30, 31, 32, 33}

RECOMMENDATION

4. A designated area should be used for counselling in preference to a random location.

A designated room offers privacy during complex or difficult situations and allows parents to share their emotions and improves their confidence to ask questions.

Strong recommendation, Not graded

Practice Question 5 :Does setting up formal peer-support groups for families of neonates in SNCU/NICU improve the relevant outcomes for the family and health system?

Parents providing peer-to-peer support are called “peer-to-peer parents,” “buddy parent/mother,” “support parent,” “parent coordinator,” “parent hosts,” or “parent spokesperson.”³⁴ Peer to peer parents offer support in one of the various ways;

Direct interaction with families

- Provide welcome visit for new parents: Information about the unit organization, people in the unit, visitation policy
- Offer support at the bedside
- Parent information sessions: discharge planning, transition from the tube feeds to the breast
- One-to-one sessions related to baby care: feeding, kangaroo care, and developmental care
- Parent navigator: navigating the hospital, finding a place to stay close to the hospital, support for living in the hospital
- Structured testimonies: sharing life stories and experiences.
- Matched buddies: One resource parent matched for a new parent or matched buddies for bereavement support
- Social and cultural activities: Groups for relaxation and group activities
- Activities for other family members: siblings, grandparents
- Culturally sensitive activities for parents of minorities: new immigrants, religious ceremonies,
- Meeting with expectant parents who wish to learn about the NICU
- Peer-to-peer support in the delivery room for parents who are delivering a baby who will go to the NICU

Support without direct interaction with families: Some parents do not feel comfortable sharing their personal stories, and some families do not want to come back to the NICU due to lack of time, issues related to distance, or lack of desire. These parents can contribute indirectly in the following ways

- Participation in meetings: providing parental perspectives related to parental concerns/needs
- Participation in clinical committees: infection control, breastfeeding committee, quality improvement committees, family friendly NICU committee
- Participation in improving the clinical environment: visits before moving to a new unit, evaluation of new equipment or procedures.
- Organization of hospital infrastructure for parent's stay in hospital
- Participating in recruitment, training, or support of “new” resource parents

Summary of evidence

We identified a review by Hall et al. ³⁵ on recommendations for peer-to-peer support for NICU parents. No randomized trials were identified. Observational studies, pre-post studies reporting on the use of peer-support are provided in Table 3. The characteristics of the studies are given in the supplementary Table 3.

Table 3 : Observational Studies on Parenteral Outcomes with Support Groups in NICU

Outcomes	Study type	Comments
Better parental confidence ³⁶	Ainbinder et al. ³⁶ performed a qualitative evaluation of parental experiences of families participating in Parent-to-Parent programs.	The study identified four qualities in the supporting parent- <ol style="list-style-type: none"> 1. supporting parent is perceived as similar to the referred parent 2. Both share a common experience that enables a full understanding of the parent's situation, acceptance of her thoughts and actions without judgment 3. supporting parent is easily accessible or available to provide support 4. The support given between the two parents is bi-directional.
	Cooper et al. ³⁷ , in a quasi-experimental study, evaluated the impact of family support services in their NICU	Surveys of NICU staff showed that NICU family support enhances the overall quality of NICU care resulting in less stressed, more informed, and confident parents. Surveys of NICU families showed that support services reduced their stress and made them feel more confident as their baby's parent.
	Singer et al. ³⁸ , in a non-randomized study, assigned parents to either a treatment group or a waiting list comparison group. The treatment group participated in Parent to Parent for 2 months. Groups were compared on coping, attitude, and progress on addressing problems.	Parents who use parent to parent support for non-emergency help benefit by (a) feeling better able to cope with their child and family situation, (b) feeling better able to view their family and personal circumstances in a more positive light, and (c) helping other parents make progress on goals that are important to them
Parental well being and Problem-solving capacity	Ainbinder ³⁶ and Singer ³⁸ et al	Noted better parental well-being and problem-solving capacity
Better coping	Ardal et al. ³⁹ reported mothers' assessment of a peer support program matching them with linguistically and culturally similar parent-buddies.	Parent-buddies helped non-English-speaking mothers mobilize their strengths. Culture and language are important determinants.
Better social support	Preyde et al. ⁴⁰ evaluated the effectiveness of parent-to-parent peer support for mothers of very preterm infants in a NICU	The peer support group reported less state anxiety, less depression, and greater perceived social support
Greater self-esteem	Roman et al. ⁴¹ reported on a nurse-managed program of parent-to-parent support program	The study noted that one-to-one veteran parent support in a nurse-managed program might influence maternal and maternal-infant interaction outcomes.

<p>Participation in baby care</p>	<p>Minde et al. ⁴² reported on 28 families who met for seven to ten weeks with a nurse coordinator and a "veteran mother" who had given birth to a premature infant within the past year compared with 29 control families.</p>	<p>Parents who participated in the groups visited their infants significantly more often in hospital than the control parents. They also touched, talked, and looked at their infants in the en face position more during their visits and rated themselves more competent on several infant care measures. The benefits were sustained at 3 months of discharge.</p>
<p>Shorter hospital stay</p>	<p>Nearing et al. ⁴³, in a retrospective study, reported the association between an individualized psychosocial parental support (PPS) program on short-term clinical outcomes of extremely low-birth-weight infants admitted to the NICU</p>	<p>The study noted that the addition of individualized psychosocial parent support programs to standard care in the NICU might reduce the length of stay in surviving infants discharged home.</p>

RECOMMENDATION

5. Family support groups or peer-to-peer support, in addition to counselling provided by health care providers, should be encouraged.

It offers unique support through experience sharing. These support groups should be considered an additional component and not a replacement for the services provided by professional NICU staff.

Strong recommendation, Not graded

Additional considerations when utilizing peer support programs in hospitals

1. Majority of the evidence is from well-resourced settings. Research is required to know the impact in low-resource settings.
2. Group support programs, one-to-one support programs, telephonic support are types of peer support. One study noted that parents preferred group support as it offered more opportunities for families to solve communication issues with nursery personnel. A range of parent support programs may be needed for providing the range of support needed by many NICU families.⁴⁴ However, the size of the NICU and its ability to support a peer resources program determines the variety of the program offered to the parents.

3. Peer-support programs do not replace the need for counselling services provided by professional NICU staff. They only complement or support existing services³⁵
4. Resource parents need to be trained to provide support to new parents and operate within the unit's rules. Support programs are not risk-free; confidentiality and ethical issues need to be considered. This is especially so in bereavement situations and complex scenarios. In these cases, detailed guidelines are required to delineate the responsibility of support parents and those of healthcare providers.
5. Volunteer and resource parents need to be identified by the health professionals of the NICU, who should also train them to support families
6. Hospital administration should collaborate and offer a commitment for such programs.
7. There are resources for hospitals to find more information on starting a peer support program and training them^{34, 35} (www.support4nicuparents.org).

References

1. Labrie NHM, van Veenendaal NR, Ludolph RA, Ket JCF, van der Schoor SRD, van Kempen A. Effects of parent-provider communication during infant hospitalization in the NICU on parents: A systematic review with meta-synthesis and narrative synthesis. *Patient Educ Couns* 2021, 104(7): 1526-1552.
2. Boss RD, Urban A, Barnett MD, Arnold RM. Neonatal Critical Care Communication (NC3): training NICU physicians and nurse practitioners. *J Perinatol* 2013, 33(8): 642-646.
3. Ferrell B, Thaxton CA, Murphy H. Preparing Nurses for Palliative Care in the NICU. *Advances in neonatal care : official journal of the National Association of Neonatal Nurses* 2020, 20(2): 142-150.
4. Kyc SJ, Bruno CJ, Shabanova V, Montgomery AM. Perceptions of Neonatal Palliative Care: Similarities and Differences between Medical and Nursing Staff in a Level IV Neonatal Intensive Care Unit. *J Palliat Med* 2020, 23(5): 662-669.
5. St Louis JR, Pesut B, Zhao R. Best practices for educating NICU nurses about palliative care: A rapid review. *Journal of Neonatal Nursing* 2021.
6. Weis J, Zoffmann V, Greisen G, Egerod I. The effect of person-centred communication on parental stress in a NICU: a randomized clinical trial. *Acta Paediatr* 2013, 102(12): 1130-1136.
7. Clarke-Pounder JP, Boss RD, Roter DL, Hutton N, Larson S, Donohue PK. Communication intervention in the neonatal intensive care unit: can it backfire? *J Palliat Med* 2015, 18(2): 157-161.
8. Weiss S, Goldlust E, Vaucher YE. Improving parent satisfaction: an intervention to increase neonatal parent-provider communication. *J Perinatol* 2010, 30(6): 425-430.
9. Trujillo JA, Fernandez Y, Ghafoori L, Lok K, Valencia A. Interdisciplinary Family Conferences to Improve Patient Experience in the Neonatal Intensive Care Unit. *Health Soc Work* 2017, 42(4): 241-246.
10. Sabnis A, Hagen E, Tarn DM, Zeltzer L. Increasing Timely Family Meetings in Neonatal Intensive Care: A Quality Improvement Project. *Hospital pediatrics* 2018, 8(11): 679-685.
11. Penticuff JH, Arheart KL. Effectiveness of an intervention to improve parent-professional collaboration in neonatal intensive care. *The Journal of perinatal & neonatal nursing* 2005, 19(2): 187-202.
12. Kasat K, Stoffels G, Ellington M. Improving communication with parents: the Neonatal Intensive Care Unit Empathy Workshop. *J Perinatol* 2020, 40(9): 1423-1432.
13. Bowen R, Lally KM, Pingitore FR, Tucker R, McGowan EC, Lechner BE. A simulation based difficult conversations intervention for neonatal intensive care unit nurse practitioners: A randomized controlled trial. *PLoS One* 2020, 15(3): e0229895.
14. Bry K, Bry M, Hentz E, Karlsson HL, Kyllonen H, Lundkvist M, et al. Communication skills training enhances nurses' ability to respond with empathy to parents' emotions in a neonatal intensive care unit. *Acta Paediatr* 2016, 105(4): 397-406.
15. Ghoneim N, Dariya V, Guffey D, Minard CG, Fruge E, Harris LL, et al. Teaching NICU Fellows How to Relay Difficult News Using a Simulation-Based Curriculum: Does Comfort Lead to Competence? *Teach Learn Med* 2019, 31(2): 207-221.
16. Harris LL, Placencia FX, Arnold JL, Minard CG, Harris TB, Haidet PM. A Structured End-of-Life Curriculum for Neonatal-Perinatal Postdoctoral Fellows. *Am J Hosp Palliat Care* 2015, 32(3): 253-261.
17. Weis J, Zoffmann V, Egerod I. Improved nurse-parent communication in neonatal intensive care unit: evaluation and adjustment of an implementation strategy. *J Clin Nurs* 2014, 23(23-24): 3478-3489.
18. Hall SL, Cross J, Selix NW, Patterson C, Segre L, Chuffo-Siewert R, et al. Recommendations for enhancing psychosocial support of NICU parents through staff education and support. *J Perinatol* 2015, 35 Suppl 1: S29-36.
19. Meyer EC, Brodsky D, Hansen AR, Lamiani G, Sellers DE, Browning DM. An interdisciplinary, family-focused approach to relational learning in neonatal intensive care. *J Perinatol* 2011, 31(3): 212-219.
20. van de Vijver M, Evans M. A tool to improve communication in the neonatal unit. *BMJ Quality Improvement Reports* 2015, 4(1): u203180.w203084.
21. Alfaleh KM, Al Luwaimi E, Alkharfi TM, Al-Alaiyan SA. A decision aid for considering indomethacin prophylaxis vs. symptomatic treatment of PDA for extreme low birth weight infants. *BMC Pediatr* 2011, 11: 78.
22. Janvier A, Barrington K, Farlow B. Communication with parents concerning withholding or withdrawing of life-sustaining interventions in neonatology. *Semin Perinatol* 2014, 38(1): 38-46.
23. Coscia A, Bertino E, Tonetto P, Giuliani F, Varalda A, Di Nicola P, et al. Communicative strategies in a neonatal intensive care unit. *J Matern Fetal Neonatal Med* 2010, 23 Suppl 3: 11-13.

24. Elwyn G, Durand MA, Song J, Aarts J, Barr PJ, Berger Z, *et al.* A three-talk model for shared decision making: multistage consultation process. *BMJ* 2017, 359: j4891.
25. Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer. *Oncologist* 2000, 5(4): 302-311.
26. Catling CJ, Medley N, Foureur M, Ryan C, Leap N, Teate A, *et al.* Group versus conventional antenatal care for women. *Cochrane Database Syst Rev* 2015(2): CD007622.
27. Gagnon AJ, Sandall J. Individual or group antenatal education for childbirth or parenthood, or both. *Cochrane Database Syst Rev* 2007(3): CD002869.
28. Gergana Damianova K, Constance C, Loretta W, Mary L, Susumu I, Joseph A, *et al.* Health Communication in Neonatal Intensive Care: Results of Focus Groups or Interviews with Parents, Nurses and Physicians. *Californian Journal of Health Promotion* 2017, 15(3).
29. Phuma-Ngaiyaye E, Welcome Kalembo F. Supporting mothers to bond with their newborn babies: Strategies used in a neonatal intensive care unit at a tertiary hospital in Malawi. *International Journal of Nursing Sciences* 2016, 3(4): 362-366.
30. Guillaume S, Michelin N, Amrani E, Benier B, Durrmeyer X, Lescure S, *et al.* Parents' expectations of staff in the early bonding process with their premature babies in the intensive care setting: a qualitative multicenter study with 60 parents. *BMC Pediatr* 2013, 13: 18.
31. Harvey ME, Nongena P, Gonzalez-Cinca N, Edwards AD, Redshaw ME, e PRT. Parents' experiences of information and communication in the neonatal unit about brain imaging and neurological prognosis: a qualitative study. *Acta Paediatr* 2013, 102(4): 360-365.
32. Russell G, Sawyer A, Rabe H, Abbott J, Gyte G, Duley L, *et al.* Parents' views on care of their very premature babies in neonatal intensive care units: a qualitative study. *BMC Pediatr* 2014, 14: 230.
33. Lemmon ME, Donohue PK, Parkinson C, Northington FJ, Boss RD. Communication Challenges in Neonatal Encephalopathy. *Pediatrics* 2016, 138(3).
34. Bourque CJ, Dahan S, Mantha G, Robson K, Reichherzer M, Janvier A. Improving neonatal care with the help of veteran resource parents: An overview of current practices. *Semin Fetal Neonatal Med* 2018, 23(1): 44-51.
35. Hall SL, Ryan DJ, Beatty J, Grubbs L. Recommendations for peer-to-peer support for NICU parents. *J Perinatol* 2015, 35 Suppl 1: S9-13.
36. Ainbinder JG, Blanchard LW, Singer GH, Sullivan ME, Powers LK, Marquis JG, *et al.* A qualitative study of Parent to Parent support for parents of children with special needs. Consortium to evaluate Parent to Parent. *Journal of pediatric psychology* 1998, 23(2): 99-109.
37. Cooper LG, Gooding JS, Gallagher J, Sternesky L, Ledsky R, Berns SD. Impact of a family-centered care initiative on NICU care, staff and families. *J Perinatol* 2007, 27 Suppl 2: S32-37.
38. S. Singer GH, Marquis J, Powers LK, Blanchard L, Divenere N, Santelli B, *et al.* A Multi-site Evaluation of Parent to Parent Programs for Parents of Children With Disabilities. *Journal of Early Intervention* 1999, 22(3): 217-229.
39. Ardal F, Sulman J, Fuller-Thomson E. Support like a walking stick: parent-buddy matching for language and culture in the NICU. *Neonatal network : NN* 2011, 30(2): 89-98.
40. Preyde M, Ardal F. Effectiveness of a parent "buddy" program for mothers of very preterm infants in a neonatal intensive care unit. *CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne* 2003, 168(8): 969-973.
41. Roman LA, Lindsay JK, Boger RP, DeWys M, Beaumont EJ, Jones AS, *et al.* Parent-to-parent support initiated in the neonatal intensive care unit. *Res Nurs Health* 1995, 18(5): 385-394.
42. Minde K, Shosenberg N, Marton P, Thompson J, Ripley J, Burns S. Self-help groups in a premature nursery-a controlled evaluation. *J Pediatr* 1980, 96(5): 933-940.
43. Nearing GB, Salas AA, Granado-Villar D, Chandler BD, Soliz A. Psychosocial parental support programs and short-term clinical outcomes in extremely low-birth-weight infants. *J Matern Fetal Neonatal Med* 2012, 25(1): 89-93.
44. Hurst I. One size does not fit all: parents' evaluations of a support program in a newborn intensive care nursery. *The Journal of perinatal & neonatal nursing* 2006, 20(3): 252-261.
45. Weis J, Zoffmann V, Egerod I. Enhancing person-centred communication in NICU: a comparative thematic analysis. *Nurs Crit Care* 2015, 20(6): 287-298.
46. Weyand SA, Frize M, Bariciak E, Dunn S. Development and usability testing of a parent decision support tool for the neonatal intensive care unit. *Annu Int Conf IEEE Eng Med Biol Soc* 2011, 2011: 6430-6433.
47. Guillen U, Mackley A, Laventhal N, Kukora S, Christ L, Derrick M, *et al.* Evaluating the Use of a Decision Aid for Parents Facing Extremely Premature Delivery: A Randomized Trial. *J Pediatr* 2019, 209: 52-60 e51.
48. Haward MF, John LK, Lorenz JM, Fischhoff B. Effects of description of options on parental perinatal decision-making. *Pediatrics* 2012, 129(5): 891-902.
49. LeGrow K, Hodnett E, Stremler R, Cohen E. Evaluating the feasibility of a parent-briefing intervention in a pediatric acute care setting. *Journal for specialists in pediatric nursing : JSPN* 2014, 19(3): 219-228.

50. Pontoppidan M, Klest SK, Sandoy TM. The Incredible Years Parents and Babies Program: A Pilot Randomized Controlled Trial. *PLoS One* 2016, 11(12): e0167592.
51. Moore GP, Lemyre B, Daboval T, Ding S, Dunn S, Akiki S, et al. Field testing of decision coaching with a decision aid for parents facing extreme prematurity. *J Perinatol* 2017, 37(6): 728-734.
52. O'Brien K, Robson K, Bracht M, Cruz M, Lui K, Alvaro R, et al. Effectiveness of Family Integrated Care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial. *Lancet Child Adolesc Health* 2018, 2(4): 245-254.
53. Walsh J, Goser L. Development of an innovative NICU teen parent support program: one unit's experience. *The Journal of perinatal & neonatal nursing* 2013, 27(2): 176-183.
54. Pearson J, Andersen K. Evaluation of a program to promote positive parenting in the neonatal intensive care unit. *Neonatal network : NN* 2001, 20(4): 43-48.
55. Barnes J, Stuart J, Allen E, Petrou S, Sturgess J, Barlow J, et al. Randomized controlled trial and economic evaluation of nurse-led group support for young mothers during pregnancy and the first year postpartum versus usual care. *Trials* 2017, 18(1): 508.
56. Porteous R, Kaufman K, Rush J. The effect of individualized professional support on duration of breastfeeding: a randomized controlled trial. *J Hum Lact* 2000, 16(4): 303-308.
57. Chourasia N, Surianarayanan P, Bethou A, Bhat V. Stressors of NICU mothers and the effect of counseling-experience from a tertiary care teaching hospital, India. *J Matern Fetal Neonatal Med* 2013, 26(6): 616-618.
58. Mansson C, Sivberg B, Selander B, Lundqvist P. The impact of an individualised neonatal parent support programme on parental stress: a quasi-experimental study. *Scand J Caring Sci* 2019, 33(3): 677-687.
59. Maryam T, Lida N, Azam Shirinabadi F, Nezhat S. The Effect of a Peer-Group Support Intervention Program on the Tensions of Mothers with Premature Neonates Admitted to the Intensive Care Units in Babol, Iran. 19-15: *رسال بیست و هشتم*: □□□□□□ □ □□□□□□□.
60. Turner M, Winefield H, Chur-Hansen A. The emotional experiences and supports for parents with babies in a neonatal nursery. *Advances in neonatal care : official journal of the National Association of Neonatal Nurses* 2013, 13(6): 438-446.
61. Buarque V, Lima Mde C, Scott RP, Vasconcelos MG. The influence of support groups on the family of risk newborns and on neonatal unit workers. *Jornal de pediatria* 2006, 82(4): 295-301.
62. Brett J, Staniszewska S, Newburn M, Jones N, Taylor L. A systematic mapping review of effective interventions for communicating with, supporting and providing information to parents of preterm infants. *BMJ open* 2011, 1(1): e000023.

Appendix 1 : Counselling in specific circumstances

1. Antenatal Counselling

Parents facing the delivery of a preterm neonate or the birth of a baby with a problem should be provided with information in a transparent and individualized manner. Antenatal counseling is the process of helping parents to understand the postnatal care of an "at-risk" fetus and arrive at their own decision by providing appropriate, accurate, and unbiased information and emotional support.

Indications for antenatal counseling

- Preterm or very low birth weight infant
- Peri-viable births
- Previous infant deaths
- Family history of genetic diseases
- Surgical conditions detected antenatally
- Other conditions including antenatally detected anomalies, maternal infections like HIV or TORCH, medications in the mother that affects the newborn etc.

General content of counselling

- Resuscitation plan – This is particularly important in the periviable gestation.
- Breastfeeding: All families whose baby is likely to come into the NICU should be counseled regarding the importance of
 - Early breastfeeding and milk expression by within 1 hour
 - Frequent milk expression even if the baby is not being fed orally
 - Night expression
 - Steps to ensure mother's lactation is well established
- Possible need for a NICU stay- a brief tour of the NICU for parents whose babies are likely to need NICU care helps build confidence in parents and families
- Possible need for respiratory support and surfactant
- Survival and long-term outcomes: the unit survival rates can be discussed with the family in a way that the family can understand
- Kangaroo mother care: when preterm or low birth weight delivery is predicted, counselling regarding KMC should be provided in detail, and a chance to interact with KMC mothers given
- NICU visitation policy and role of mother in NICU
 - The visitation policy of the NICU should be informed to the family. Mothers should be encouraged to come into the NICU as soon as they can
- Duration of hospital stay and cost of care- a realistic estimate of the cost should be provided to aid the family to prepare for hospitalization

Benefits of antenatal counseling

- Shared decision making
- Improves the trust of families in health care providers
- Permits both the NICU staff and the family in birth preparedness

2. Counselling at margins of viability

Perinatal management of extremely preterm birth is a medical and ethical challenge for frontline providers in the delivery room. The acceptance as the exact gestational age of viability varies the world over. Generally, a fetus who has completed 24 weeks of gestation and is at least 500 gm, and shows signs of life at birth has a reasonable chance of survival. We aim to provide a framework to assist clinicians in better decision-making and support parents when faced with the birth of an extremely preterm infant.

Objectives of peri-viable counseling

- To assist in informed decision-making and care options
- To provide individualized and family-centered care respecting their needs and resources

Decision-making: This is based on several factors that directly or indirectly affect clinical outcomes

- **Gestational age:** Estimation of gestational age with the first-trimester crown-rump length measurement carries a margin for error of 5–7 days. By 24 weeks, ultrasound dating may carry an error of up to 2 weeks. For uniformity, gestational age should be summarized in weeks of gestation and refers to the completed week of gestation and the next 6 days; for example, "24 weeks of gestation" refers to 24 0/7 weeks through 24 6/7 weeks of gestation. At these levels of gestation, every day counts. A preterm born at a gestation of 24 + 0 days has a different outcome than 24 + 6 days. Pregnancy dating according to the last menstrual period is often unreliable and inaccurate. A treatment approach based solely on the gestational age misses other important factors like gender, antenatal steroids, fetal distress, chorioamnionitis, malformations, single or multiple pregnancy, and inborn or outborn delivery.
- **Clinical assessment:** Based on the clinical condition at birth, gestational age assessment and response to resuscitation is error-prone in predicting outcomes.
- **Parental wishes:** Decision-making is influenced by social, cultural, religious factors as well as parental wishes
- **Facility:** The care offered also depends on the availability of skilled personnel, infrastructure, and resources.

Important considerations for peri-viable counselling

- Each neonate and family is unique. Therefore a personalized approach is needed.
- Each family has different expectations, values, and beliefs. Patient listening and empathy is needed
- Provide information according to parental preferences; in the amount and type of information desired and the preferred processes for deliberation.
- Words are important. Pre-birth avoid using 'everything' or 'nothing' care.
- Address parental concerns. Support them in shared decision making

3. Counselling for high-risk neonates

A high-risk neonate has a higher-than-normal risk for morbidity, mortality, and long-term disability. They include ELBWs, asphyxiated term neonates, and infants with significant diseases or congenital anomalies requiring complex therapeutic interventions. The NICU is a frightening setting for parents of such babies, and they depend heavily on NICU staff for information and support. There is a learning and acclimatization process during the duration of stay in the NICU. Apart from daily updates and information in times of crisis, parents need to have a sense of involvement with the management of their infants. They also require a quiet, supportive environment to discuss 'bad news' involving complicated diagnoses and poor prognosis and support in processing and coming to terms with the same. Most times, good communication makes the difference between whether or not the parents choose to litigate.

Common conditions which are high risk that needs to be stressed upon regarding management include

- i. Complications of prematurity and ELBW babies in particular
 - ii. Growth restricted babies -immediate problems and long-term implications
 - iii. Dangers of high levels of jaundice
 - iv. Long term issues in congenital infections and congenital anomalies
 - v. Issues related to genetic disorders
 - vi. Effects of specific conditions/ interventions like prolonged ventilation, high oxygen requirement, resuscitation, IVH, hypoglycemia, encephalopathy, etc.
- a. **Communication regarding the NICU environment-** Prolonged hospital stay in the NICU requires parents to get familiar with the terms and machines used. A simple picture chart that shows the commonly used equipment labelled in layperson language is helpful. Do's and Don'ts are also important to maintain safety and asepsis.
 - b. **Communication regarding diagnosis and treatment-** Simple language diagrammatic description of the basic medical or surgical conditions affecting the neonate should be available to help in explaining to the parents or family what is happening to the baby and what best is being done. Since most conditions are fluid in the first few days of the illness, this may have to be done more frequently, sometimes even twice a day. Parents should be involved in difficult decision-making, especially regarding realistic goals of care, keeping the infant's best interest in mind.
 - c. **Communication regarding prognosis-** For critically ill neonates, uncertainty in their prognosis encompasses both short-term survival and long-term developmental outcomes. Explaining the risk for disability or death quoting local, national, and international statistics is helpful to reassure that the best is being done. Many parents have reported that discussions regarding treatment recommendations appear slanted toward aggressive intervention with little information regarding outcomes.
 - d. **Counselling on follow-up of high-risk neonates.**
Follow-up frequency, hearing assessment, ROP screening, neuroimaging, biochemical screening etc. will need to be explained.
 - e. **Helping parents in informed decision-making and end of life care**
Studies have found that when confronted with overwhelming uncertainty, parents identify both the cognitive and affective aspects of communication as crucial. Cognitive aspects of communication engage the brain and relate to the content of information and the context in which it is delivered. The affective aspect of communication engages the heart, which can make a significant difference in perception of the problem in many cases. Addressing emotional distress with legitimation, validation, empathy, and support is important.

4. End of Life Care and Counselling

The decision to terminate the care of a critically ill neonate who is not responding to the medical and surgical treatment is extremely challenging and distressing. The parents and health care providers deal with ethical dilemmas and moral distress. The family is important as it is the integral component of patient care and the ultimate care provider. The impending or actual death of neonates results in a profound and unexpected feeling of loss and is associated with complex suffering. It affects the parental hopes, dreams, and future purpose in life. Parents have reported that the pain of loss never went away, but they become more tolerable over time. The parents need to stay mentally and physically healthy to make a rational decision in the best interest of their baby and participate in care. It is vital to take care of the family's mental health, and health care providers can help parents in this process of loss and grief by utilizing the palliative and bereavement care recommendations in the unit.

Parental support during end-of-life care for their neonates

1. Establish a palliative care team for your NICU/neonatal unit. The team members may vary in structure, number, and nature from institution to institution. It has been recommended to have mental health professionals in the team like full-time social workers, part-time doctoral-level psychologists, nurses trained in psychiatry/psychology, and treating doctors and nurses for a 20 bedded NICU. The team is required to perform screening, counselling, and education of parents. The mental health professional should also educate staff about interacting and communicating with the families and their mental health in such critical situations.
2. Two designated comfortable areas are preferable - one for families to have their discussions and the other for confidential discussions between families, mental health professionals, and the treating team.
3. Assessing and screening the parents for physical problems, complicated grief, depression, posttraumatic stress disorder using a valid and reliable questionnaire and refer for detailed assessment. Help them seek expert advice if needed.
4. It is essential to ensure a psychosocial support program in NICU to ensure optimism and hope. This includes family integration, peer to peer/parent to parent support program, and support provided by the mental health professional/physician or nurses trained to deliver such support to the parents. The four principles of a psychosocial support program include a) interdisciplinary collaboration, b) continuity of care c) note the emotional recovery trajectories like resilient, chronic, recovered, and delayed. Whenever possible, psychosocial support d) layered level of care. The counseling and support should begin from the antepartum period, continue in NICU, and post NICU stay.
5. It is recommended that the principles of communication include acknowledging (making other person as being heard), clarifying or reinterpreting parents' concerns, providing information about the treatment and tests regularly, and delivering 'bad news' empathetically are helpful. The communication should be continuous and clear to empower them. Allow parents to clarify their doubts. This will help parents take even difficult decisions in the best interest of neonates. Remember to include parents in the decision-making process whether the loss is anticipated or unanticipated.
6. Prepare a structured bereavement program and share it with the staff. The written policies and standards should be available. Help parents to accept what happened and to accept painful feelings. The level of understanding of parents varies depending upon their state of mind, education level, the extent to which the information is provided, anxiety and prior experience.
7. Some families may wish to take memories by taking a photograph, footprint or handprint or offer prayers near baby's bed, lock of hair, take some of the baby belongings home.
8. Be sensitive to the parents who are experiencing the loss. Although it is important to be culture-sensitive, do not assume the reactions to be culture-specific, and hence it is advisable to ask the parental preferences.

9. Help parents to identify their strengths, coping strategies, support system. Identify the best coping strategy that has been useful in the past and help them accept and find out the support of relatives and family members. Give support by communicating politely and giving assurance.
10. Extremely complex volatile state is when one of the multiple (twin/triplets) is dying. This is the stage when parents may become lost and unable to focus on the care of the other. Provide bereavement support, be sensitive to their situation.
11. Acknowledge that fathers also grieve, and the reactions of both parents may be different. In some cultures, fathers are expected to be strong and not to express their feelings. On the other hand, mothers may blame themselves for not giving birth to a normal-term baby. Encourage parents to talk and express their feelings during counselling.
12. Facilitate family coping and help the family prepare a schedule of their duty at the hospital to have adequate rest and sleep.
13. Develop and provide a guide on coping strategies and how to adapt to the loss to the parents.
14. Provide a follow-up call and offer support based on their need.

Further reading

1. Haward MF, Gaucher N, Payot A, Robson K, Janvier A. Personalized Decision Making: Practical Recommendations for Antenatal Counseling for Fragile Neonates. *Clin Perinatol*. 2017 Jun;44(2):429-445.
2. Kukora SK, Boss RD. Values-based shared decision-making in the antenatal period. *Semin Fetal Neonatal Med*. 2018 Feb;23(1):17-24.
3. Cummings J; Committee on Fetus and Newborn. Antenatal Counseling Regarding Resuscitation and Intensive Care Before 25 Weeks of Gestation. *Pediatrics*. 2015 Sep;136(3):588-95.
4. Myers P, Andrews B, Meadow W. Opportunities and difficulties for counseling at the margins of viability. *Semin Fetal Neonatal Med*. 2018 Feb;23(1):30-34
5. Staub K, Baardsnes J, Hébert N, Hébert M, Newell S, Pearce R. Our child is not just a gestational age. Before premature birth, a first-hand account of what parents want and need to know. *Acta Paediatr*. 2014 Oct;103(10):1035-8.
6. Drach LL, Hansen DA, King TM, Sibinga EMS. Communication between neonatologists and parents when prognosis is uncertain. *J Perinatol* 40, 1412–1422 (2020).
7. Bell EF. American academy of pediatrics committee on fetus and newborn: noninitiation or withdrawal of intensive care for highrisk newborns. *Pediatrics*. 2007;119:401–3.
8. W Yee, S Ross. Communicating with parents of high-risk infants in neonatal intensive care. *Paediatr Child Health* 2006;11(5):291-294
9. Racine E, Bell E, Farlow B, Miller S, Payot A, Rasmussen LA, et al. The 'ouR-HOPE' approach for ethics and communication about neonatal neurological injury. *Developmental Med Child Neurol*. 2016;59:125–35.
10. Sabnis A, Fojo S, Nayak SS, Lopez E, Tarn DM, Zeltzer L. Reducing parental trauma and stress in neonatal intensive care: systematic review and meta-analysis of hospital interventions. *J Perinatol*. 2019 Mar;39(3):375–86.
11. Geetanjali, Manju V, Paul VK, Manju M, Srinivas M. Loss and Grief Response and Perceived Needs of Parents with the Experience of Having their Newborn at Neonatal Care Units. *International Journal of Nursing Education*. 2012 Jul;4(2):111–6.
12. Kenner C, Press J, Ryan D. Recommendations for palliative and bereavement care in the NICU: a family-centered integrative approach. *J Perinatol*. 2015 Dec;35 Suppl 1:S19-23.
13. Carter B. S. (2018). Pediatric Palliative Care in Infants and Neonates. *Children (Basel, Switzerland)*, 5(2), 21.
14. Hynan MT, Steinberg Z, Baker L, Cicco R, Geller PA, Lassen S, et al. Recommendations for mental health professionals in the NICU. *J Perinatol*. 2015 Dec;35(Suppl 1):S14–8.
15. Hynan MT, Hall SL. Psychosocial program standards for NICU parents. *J Perinatol*. 2015 Dec;35 Suppl 1:S1-4.

Appendix 2: JOB AID FOR COUNSELLING OF FAMILIES OF SICK NEONATES

Basic Counseling Steps

By Whom

- By the pediatrician/neonatologist
- Preferred that the antenatal counselling is by both obstetrician and neonatologist in unison

To Whom

- Ideally, both parents should participate in antenatal counselling. The main decision-maker for the family should be involved. Other close family members should also be involved from the beginning.

Where

- A quiet designated area in the NICU is preferred. The family should also see the NICU where their baby is /likely to be after birth
- If the mother cannot come to NICU, bedside counselling to involve both parents is preferred.

Pre-requisites

- The counselling team should review the history and current status of the pregnant woman before counselling.
- If combined counselling is not possible, a prior discussion between the obstetrician and neonatologist is recommended.

How

- Use a checklist/ template for antenatal counselling
- Establish the best gestational age.
- The goal is not just to share information in a standardized manner but also to adapt parental needs and empower them to personalized decision-making.
- Avoid medical jargon Use lay terms like a small baby (half of normal) immature organs and its problems.
- Establish if the family would like to hear all details or the broad outlines at the onset. Excessive information in one sitting may not be comprehended well.
- Ensure the family understands the concept of percentages

Documentation

- Document the counseling and the major decisions taken in the mother's case file
- Some centers video record all counselling sessions

Decision aids: Counselling can be supported by decision aids such as pamphlets, cards, videos

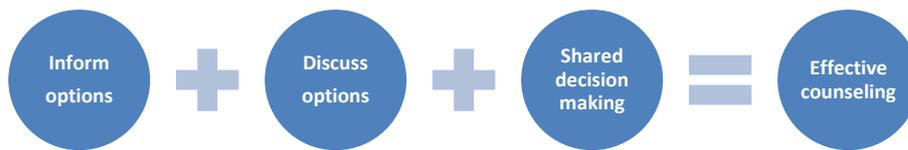
Approaches to counselling

The “GATHER” and “LISTEN” approaches are a framework for providing competent and caring counselling.

Basic Counseling Steps

G	Greet
A	Ask
T	Tell
H	Help
E	Explain
R	Return

L	Look-get interested
I	Involve by responding
S	Stay on target
T	Tell your understanding
E	Evaluate the message
N	Neutralize your feeling



Principles of Counselling		
ISSUE	ACTION	COMMENT
When?	As early as feasible when faced with threatened preterm delivery/peri viable birth or complication	Time matters as it helps provide clarity in decision making
Who?	The most experienced person skilled in counselling. A joint obstetric and neonatal consult is desirable.	Multi-disciplinary counselling may be required for complex scenarios (e.g. neural tube defect, complex heart disease)
Where?	A quiet, comfortable, and private place	Minimize distractions.
Details?	The details and extent of counselling are left to the clinician's discretion.	Focus on individual infant factors and perceived needs and wishes of the parents.
How?	Tailored and family centric counselling. Parents should be assisted in shared decision-making	The information offered to parents should be tailored to their needs, situation and in a language, they can understand
Resuscitation?	If the clinician believes there is no chance of survival, resuscitation is not indicated. When a good outcome is unlikely, parents should be given a choice, and their preferences should be respected.	When in doubt, resuscitation is indicated, and care goals are re-directed based on response.
Options of care?	Based on individual circumstances, options of care include intensive care, a trial of care, or palliative care	Care is flexible and needs to be re-directed based on clinical response.

Outcome?	Local and national statistics be shared for survival and disability separately.	It should be stated clearly that the outcome is an estimate for a population and not a prediction of a certain outcome for a particular patient in a given institution
Certainty?	Making recommendations in this area is exceptionally difficult and evidence base for clinical practice and outcome is weak.	'Grey areas' need to be navigated by shared decision making
Prognosis?	Prognosis depends on the risk factors and varies.	Effective counselling includes periodic assessment of risks, communication of those risks, and ongoing support.
Information on costs of care?	In case the family is expected to bear partial or full costs of care, information should be provided transparently. Information about funding from possible government or insurance schemes or other sources should also be provided.	Endpoints of type of care should be explained and re-emphasized periodically

Requirements for Good Communication Between Staff and Parents

1. Parents need to be shown around the NICU and familiarized with issues related to the care of their baby
2. They should be made to feel part of their baby's care
3. They should be allowed to ask questions and clarify doubts
4. There should be a quiet, private, soothing, dedicated area for breaking bad news
5. Nurses and doctors should discuss among themselves before talking to parents so that each person is clear about what to say
6. Information given to parents should be relevant to the case concerned
7. Information to parents should be provided in simple language
8. Information should be repeated as many times as necessary for understanding
9. Undue show of emotion should be avoided, but every care should be taken to show empathy while communicating
10. Staff should have some formal training in communication and counselling

Key Messages

1. Use general principles of counselling. Ensure privacy with adequate seating arrangement and eye contact. Ensure parents are comfortable. Use GALPAC.
2. Ensure that all available information on the disorder is sought prior to the counselling. Ask parents about queries regarding the baby with the disorder and elaborate on the same. Address all queries related to the baby.
3. It is imperative to avoid insensitive communication about the present when talking about recurrence. Statements like *"there is nothing more we can do, let's take about next pregnancy"* need to be avoided. Instead use statements like, *"We are doing our best to help your baby. However, it is also important to talk about the chance of this problem recurring in the next pregnancy and what needs to be done"*.
4. If the neonate has multiple problems (like cardiovascular, GI surgical etc), team counselling is preferred (neonatologist, pediatric surgeon, CTVS surgeon, social worker, genetics etc.). If this is not feasible, it is important to foster appropriate communication between the teams to provide the same content of information to parents.

5. Team counselling with obstetricians and geneticist may be required for scenarios where there is a possibility of recurrence in subsequent pregnancies. If there are options to prevent a recurrence (folic acid to prevent neural tube defects), these need to be mentioned. Provide information regarding the possibility of recurrence in the next pregnancy with the percentage risk of recurrence and the need for genetic testing in the parent if needed. (*“Caution needs to be exercised during counselling as to avoid guilt- feeling/ blame-game over baby”*). Counsel on the importance of prenatal diagnosis options and facilities where it may be available. The parents must know to seek this consult in the early part of 1st of trimester or pre-conception.

Appendix 3 : Search strategy, PRISMA flow diagram and supplementary tables for all five questions (**Please see the online version at www.nfi.org/cpg**)