

Review Article

Creating Memories with a Terminally-Ill Neonate

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Abstract: Dealing with a terminally-ill neonate has a significant emotional toll for both the parents and the entire family. The experience of creating memories with a terminally-ill neonate can be deeply emotional and challenging, but it can also be profoundly meaningful and comforting for both the family and the neonate. Memories may involve celebrations related to naming or milestone celebrations, parental involvement in neonatal care and spending quality time with the neonate as well as creating mementoes, capturing or videotaping moments. The creation of memories, despite the neonate's limited lifespan, acknowledges its individuality and affirms its dignity and identity as a human being, whereas it creates a sense of unity during such difficult times. Specialized multidisciplinary teams, with advanced training and professional skills, and national initiatives are critical for families' support to the grieving process and their guidance to emotional and ethical complexities associated with the caring of a terminally-ill neonate.

Keywords: Memories, memory-making, mementoes, memory box, terminally-ill, neonate, neonatal intensive care unit.

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INTRODUCTION

The neonatal period in human development is defined as the period from birth to the 28th day of life for neonates born after a full-term pregnancy (for neonates born prematurely, the period is longer) (UNICEF, 2013). This transitional period is the most critical for the adaptation to extrauterine life and child's survival as well. This fact is evidenced by the high number of neonatal deaths recorded worldwide in 2021 and these were approximately 6,400 deaths every day.

A terminally-ill neonate refers to a neonate who has a severe, life-limiting medical condition or illness, not curable, and its life expectancy is very limited. Terminally-ill neonates often require specialized medical and neonatal care, including palliative care, which focuses on relieving the neonate's pain and improving its quality of life, rather than trying to cure the underlying condition (Wool & Catlin, 2019). Palliative care involves, inter alia, provision of comfort measures, pain management, and emotional support for both the neonate and its family (Miller *et al.*, 2014; Wool & Catlin, 2019). Dealing with a terminally-ill neonate is an incredibly difficult and affecting experience for the parents and

healthcare providers involved (Camacho-Ávila *et al.*, 2019; Metallinou *et al.*, 2021). It often requires careful communication and decision-making about the neonate's care, including whether to continue with aggressive medical interventions or to prioritize comfort care and allow natural processes to take their course.

Memories are a significant aspect of human's nature. Creating memories with a terminally-ill neonate is a deeply emotional and challenging situation but it can also be a profoundly meaningful and comforting experience for both the parents and the neonate. Families dealing with tough situations in a neonatal intensive care unit (NICU) may seek counseling and support to help them navigate the emotional and ethical complexities associated with caring for a terminally-ill neonate (Clarke & Connolly, 2022). In this paper we outline some ways to create and cherish memories and outline suggestions for making the most of this precious time.

Naming

Naming a neonate near the end of life is a complex and sensitive matter that involves emotional, cultural, and ethical considerations. While there may be situations where this becomes necessary, it is crucial to

approach it with utmost care and thoughtfulness (Kilcullen & Ireland, 2017).

Parents with terminally-ill neonates frequently choose a name for their child. This may help them and their families communicate about the neonate in the future by making the neonate feel more real to them. A name may also be essential for current and future siblings, especially if one or more neonates survive a multiple gestation. Naming a child, even if it has a limited life expectancy, acknowledges its individuality and affirms its identity and dignity as a human being, regardless of its lifespan. As every person, regardless of age or health, these neonates deserve respect and recognition (Sands, 2013; Sands, 2016).

Additionally, giving a name can help establish a stronger connection between the child and its parents or caregivers. This bond can provide comfort and closure to both the child and the family while the existence of a name assists communication and interaction with healthcare professionals. When the parents have given the neonate a name, healthcare professionals should always use it to communicate more effectively about its medical care and needs (Haward *et al.*, 2020). Staff should keep in mind, however, that some parents will refuse to name their child or will choose to use a nickname that they were already using antenatally.

In many cultures and religions, naming is a significant and symbolic act. It may be tied to specific rituals, beliefs, or traditions that can provide solace and meaning during a difficult time (Kain, 2021).

Parents often choose a meaningful name for their terminally-ill neonate (Sands, 2013). For instance, they can name the neonate after a grandparent, a God or a Saint. A name can become a lasting memory and be a way for the family to remember and honor the child in the years to come (Sands, 2013). Finally, naming a neonate is essential for legal and administrative purposes, including the issuance of a birth certificate and other official documents (UNICEF, 2019). These documents can be important for the family's closure and for any potential memorialization or commemoration.

It is important to note that naming a neonate near the end of life is a highly personal decision, and there is no one-size-fits-all approach. Conversations with healthcare professionals, social workers, and ethicists may be helpful in making this decision. Parents and caregivers should be supported in making this choice based on their cultural, religious, and emotional needs. Healthcare professionals, religious leaders and support networks should be available to provide guidance and assistance during this challenging time (Caulfield *et al.*, 2019).

Celebrating milestones

Celebrating milestones with a terminally-ill neonate, including things like reaching a certain weight or successfully completing a medical procedure, can be an emotionally challenging and delicate situation (Children's Hospital Colorado, 2023). Neonates with terminal illnesses require a great deal of care, support, and compassion from their families and healthcare providers (Together for Short Lives, 2018). Thus, parents should always consult with the neonate's healthcare team to understand its specific condition, prognosis, and any limitations or precautions that need to be taken (Kilcullen & Ireland, 2017). Healthcare providers can provide guidance on what activities or celebrations are appropriate and safe for the neonate and the NICU environment and be involved also in the organization to minimize parents' stress caused by relevant arrangements (Falck *et al.*, 2020). Moreover, incorporating family members, siblings and loved ones in these celebrations is crucial as they may provide significant emotional support and create a sense of unity during this difficult time (Collaborative for Children, 2023).

Balloons or candles might be used to decorate the place (Wool & Catlin, 2019). Participants can offer the neonate personalized gifts, write down wishes, or/and create an album with snapshots from the celebration (Sands 2013; SiMBA Charity, 2023). However, realistic expectations must be set, given the neonate's fragile condition. Celebrations may need to be adapted to the neonate's abilities and comfort level to ensure that the neonate's well-being is the top priority. It is understandable that they should not cause distress or discomfort to the neonate. This may involve adjusting lighting, noise levels, and temperature.

Celebrating milestones with a neonate may provide an opportunity to build precious memories (Clarke & Connolly, 2022). It should be considered that every situation is unique, and what is appropriate for one neonate may not be for another (Children's Hospital Colorado, 2023). Open communication between caregivers and the healthcare team, and support from specialized palliative care teams can be beneficial for families facing these difficult circumstances (Ministry of Health, 2019).

Spend quality time

Spending quality time with a terminally-ill neonate requires a great deal of sensitivity, care, and understanding, as well as a willingness to provide comfort and support (Wool & Catlin, 2019). First and foremost, it is essential that parents and caregivers consult with the neonate's care team to understand specific care requirements and receive guidance on how to interact with the neonate (Sands, 2013; Sands, 2016; Wool & Catlin, 2019). Then a calm environment and a soothing atmosphere must be ensured before any physical contact is attempted. This might include holding

the neonate, cuddling, or providing skin-to-skin contact (kangaroo care) (UNICEF UK, 2023). Skin-to-skin contact, specifically, helps the neonate to regulate body temperature, stimulates digestion and interest in feeding, and stabilizes the heart rate and breathing. In neonatal units, kangaroo care has been found to reduce cortisol levels (stress), especially after painful procedures, and improve oxygen saturation (UNICEF UK, 2023). Professionals' advice on handling the neonate however, should be always followed. Parents and caregivers often need private moments with their neonate and professionals must be understanding and give them the space they require to spend some quality time together as a family (Sands, 2016; Wool & Catlin, 2019).

Other activities that parents, siblings and caregivers can be engaged with are talking, singing and reading books (Raising Children Network, 2022). Talking to a terminally-ill neonate in soft tones, singing lullabies or simply speaking reassuringly and rhythmically, can be a source of comfort. Furthermore, comfort items such as a pacifier, a soft blanket, or a crochet octopus, can be offered (Çövener *et al.*, 2022). Such interactions promote family bonding, create feelings of love and safety, and sensory engagement (Raising Children Network, 2022).

For many parents/caregivers and family members, spending quality time with the terminally-ill neonate becomes the most precious memory (Sands, 2013). It should not be neglected though that a neonate has limits. They should be attuned to the neonate's responses. Some neonates may be more alert and responsive at certain times, while others may need more rest. The neonate's needs must be always respected.

In conclusion, the specific needs and preferences of a terminally-ill neonate and its family will vary greatly. The well-being and comfort of the neonate must be prioritized while professionals must appear supportive and understanding of the family's emotions and decisions during this tough period (Kilcullen & Ireland, 2017; Wool & Catlin, 2019).

Parents' involvement in neonatal care

Parental involvement in the care of a terminally neonate is crucial for both the well-being of the neonate and the early parental bond (Akyempon & Aladangady, 2021). NICU staff often encourages and facilitates parent participation in various ways by giving them the opportunity to actually take care of their own child (Akyempon & Aladangady, 2021; Ravaldi *et al.*, 2022). Parents are urged on feeding their neonate through breastfeeding, bottle feeding or even nasogastric tube after relevant training and under the supervision of the NICU staff. Parents can receive additional education regarding medical procedures, equipment and monitoring devices (Davidson *et al.*, 2017).

Some NICUs invite parents to take part in medical rounds where the healthcare team discusses the neonate's condition, treatment plan, and progress. This helps parents feel involved in their child's care and decision-making process, allows them to ask questions, understand options, voice concerns and express their preferences, being in this way, the best advocates for their neonates (Davidson *et al.*, 2017).

In some cases, when a neonate's condition stabilizes, parents may be allowed to stay overnight or longer periods in the NICU or be involved in the daily care. For example they can weigh, bathe or massage their neonate with products of their preference (Sands, 2013). Such procedures can enhance parent-neonate bonding and facilitate care continuity.

Overall, involving parents in the care of a terminally neonate not only benefits the neonate's physical and emotional well-being but also supports the parents during a challenging and stressful time in their lives (Sands, 2013; Sands, 2016; Wool & Catlin, 2019). Collaboration between healthcare providers and parents is essential for achieving the best outcomes and quality of life for the neonate (Ministry of Health, 2019).

Create a memory box

Creating a memory box is a unique way to preserve and cherish special moments and keepsakes from the neonate's life (Marc-Aurele & English, 2017). It is usually offered by NICU staff who took care of the neonate in critical conditions or at the end of life, to families who were unable to return home with a neonate alive (Scapin *et al.*, 2015). Healthcare professionals use memory boxes as a fundamental tool to provide quality care to families during times of mourning because they help them develop a positive relationship with their neonate, remember details and moments, create a lasting bond and provide material evidence of the neonate's short life (Clarke & Connolly, 2022; Noizet-Yverneau *et al.*, 2013).

More specifically, memory boxes can be made from any material, but most commonly wood or cardboard is used. Its coloring may match the gender of the newborn, with classic colors like pink for females and blue for males or present with a neutral one, such as beige, gray or light green. The exterior of the box can be covered with decorative paper or be decorated with other crafting techniques to make it visually appealing. The box may also have an inscription with the neonate's name or even words from a poem or a song that the parents find heartwarming. Sometimes it can be just labeled with a title or a date. Its content can be: the birth/death certificate, clay or ink footprints/handprints keepsakes, stuffed animals, lock of hair, personal blanket or clothing that the neonate used during hospitalization in the NICU (e.g. cotton cap, gloves, socks), charms, identification bracelet, identification tag that was attached to the incubator or the crib, the navel clip, daily newborn care

products (e.g. shampoo, shower gel or moisturizer to stimulate odor-linked memories), drawings from siblings, notebook with thoughts and photos (Centre of Clinical Excellence, 2014; Falck *et al.*, 2020; Sands, 2013; SiMBA Charity, 2023). Finally, books for parents or family members regarding neonatal loss or perinatal bereavement, as well as information about self-help programs and organizations may also be included (Sands, 2013).

It is important to remember that the death of a neonate has an impact on every family member, not just the parents (Ravaldi *et al.*, 2022). Having a box of memories can help fulfill the needs of other family members who may not be able to visit the hospitalized neonate in the NICU and bond with it (Noizet-Yverneau *et al.*, 2013). It is also essential to have a designated place to store the boxes that parents/caregivers intend to keep, as it is likely that they may return alone or with their family in the future weeks or months to retrieve them.

Generally speaking, creating a memory box is a sensitive process that allows families to preserve moments that have been shared with the bereaved neonate. The items collected can provide context to revisit memories over time or make the memories more meaningful to future viewers. Undoubtedly, memory boxes are a source of solace and help families cope with the loss of the neonate.

Capture moments

Capturing moments with a terminally-ill neonate is a delicate and important endeavor. The comfort of the neonate should always be prioritized and privacy and dignity should be respected. Parents may consider hiring a professional photographer or videographer who specializes in end-of-life photography. These professionals are trained to handle the sensitive nature of these moments; moments including interactions with the family, moments of reflection or special milestones. Alternatively, parents can record with their own smartphones as many moments as possible with their neonate (UNICEF UK, 2023). If siblings exist, parents may choose to take photos of the siblings together so as to remember the neonate's existence as they grow up (Sands, 2013). Videos and photos can assist parents to remember the last moments with their neonate and for the extended family to get to know the neonate (Kilcullen & Ireland, 2017; Wool & Catlin, 2019). Recording and videotaping the neonate also helps parents remember the neonate's unique sounds or cry. It may also be very meaningful for parents to be able to obtain a recording of their child's heartbeat. With the help of a handheld Doppler, the heartbeat can be recorded on a USB flash drive and given to the parents, adding in this way depth to the memories (Falck *et al.*, 2020).

CONCLUSIONS

Creating memories with a terminally-ill neonate facilitates the mourning process, helps family members to cope with the emotional toll of the situation and utilizes the quality of the family's limited time with the neonate. It is important for healthcare professionals to handle situations sensitively, ask parents for specific wishes and respect spiritual and cultural values, attitudes and practices, even if distance is preferred.

In order to strengthen families' bereavement support in cases of neonatal loss, it is necessary for each country to take national initiatives to develop continuing training programs for healthcare care professionals working especially in NICUs. Despite the fact that palliative and end-of-life care have a long history, still some economically strong countries lack facilities and advanced multidisciplinary teams. Perinatal and other healthcare professionals should receive specialized education and training to be qualified to support the terminally-ill neonate in its unique journey to life and provide sufficient guidance to bereaved families.

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