

Developing a PERINATAL MEMORY-MAKING PROGRAM at a Children's Hospital

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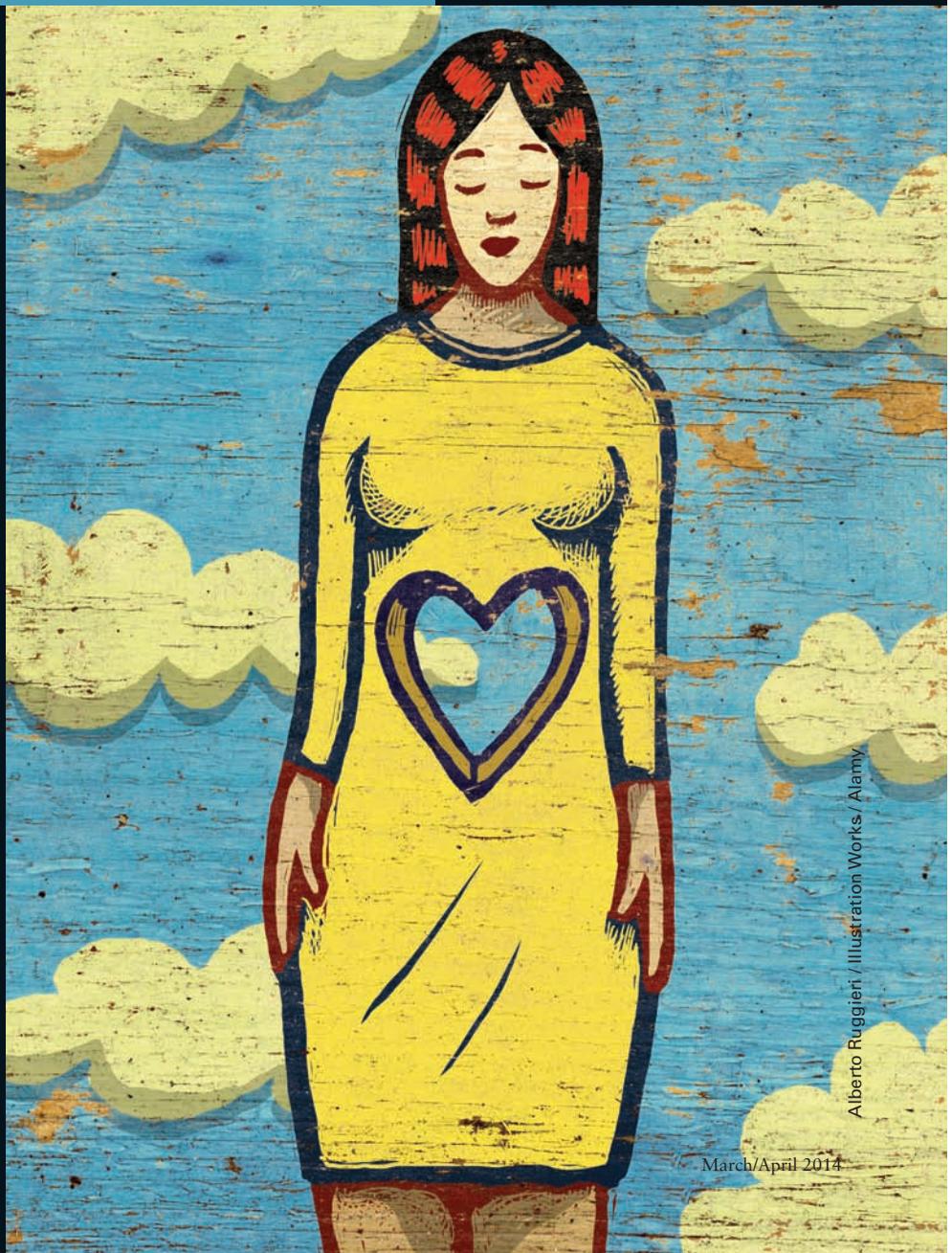
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Abstract

Most pregnancies are a time of joy and anticipation, but unfortunately there are families who instead suffer one of life's most difficult events: a perinatal loss. Although grief processes have some common aspects, grief over a child can be especially intense, and those grieving such a loss have unique needs. One of the things that nurses can do to assist families in these situations is to assist them by creating memories of their child to help ease perinatal grief. This article describes the *Precious Prints Project*, a perinatal memory-making program designed to comfort families grieving the loss of a child. We discuss the development and implementation of this project, explore the literature, and show the strategies used to address the challenges encountered.

Key words: Bereavement; End-of-life; Keepsake; Memory-making; Perinatal.



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The purpose of this article is to describe the *Precious Prints Project*, a perinatal memory-making program designed by nurses and nursing students to comfort families grieving the loss of a child. Perinatal losses include those that happen through stillbirths, neonatal death, and other causes. For example, each year in the United States, there are as many as 18,000 neonatal deaths (within the first 28 days of life) and 26,000 stillbirths (Kochanek, Xu, Murphy, Miniño, & Kung, 2011; MacDorman, Kirmeyer, & Wilson, 2012). Advances in medical technology now allow families to learn their baby's health status prior to birth; in-utero MRI and three-dimensional ultrasound, for instance, are used to detect birth defects with clinical precision and accuracy (Griffiths et al., 2012; Moes et al., 2011). Families who learn of a fatal diagnosis during pregnancy struggle to comprehend their baby's life-threatening diagnosis and its implications, and then start the loss and grief process.

If the child is stillborn, or lives only a short time after birth, the grief is intense. As we know, the loss of a child is considered unnatural in our society and affects families profoundly (Callister, 2006). The grief experienced by parents (Hunt & Greeff, 2011) and other family members (Fanos, Little, & Edwards, 2009; Gilrane-McGarrey & O'Grady, 2012) is often severe and prolonged. During the process of grief a family learns to live *without* the child that has died and *with* their memories. Perinatal grief is described as a mourning experience that is unique in two ways:

- A family expecting the joy of their child's birth is instead experiencing extreme grief while mourning the child's death.
- The death of the fetus or child is often invisible to society. Some parents report that they are treated as if the pregnancy and death never existed (Capitulo, 2005).

These distinctions mean that families have unique bereavement needs (Meert, Thurston, & Briller, 2011). An entire lifetime of memories must often be compressed into days, hours, or even minutes. One approach to meeting these grief needs is providing memory-making activities with transitional objects (Wender, 2012) such as tangible keepsakes that create a connection with and make meaningful memories about the deceased child (Capitulo, 2005). Transitional objects include footprints, fingerprints (either in ink or cast), locks of hair, pictures, articles of

clothing, a child's belongings, or symbolic keepsakes (Arentz & Klos, 1996; Capitulo, 2005; Doran & Downing Hansen, 2006; Gibson, 2004; Harper, O'Connor, Dickson, & O'Carroll, 2011; Perry, 2008; Whitaker, Kavanaugh, & Klima, 2010). Research has shown that transitional objects may offer comfort, create a memory when one is mourning, and assist in the grief process (Davies, 2005; Gibson, 2004).

Understanding bereavement activities such as memory making is important because the death of a child can affect parents in significant ways. In some cases, grieving family members have experienced physical illness, reduced quality of life, and even death (Davies et al., 2004; Kreicbergs, Valdimarsdóttir, Onelöv, Henter, & Steineck, 2004; Song, Floyd, Selter, Greenberg, & Hong, 2010). Additionally, the psychosocial effects can include negative consequences for the marriage, with a higher likelihood of divorce (Lehman, Wortman, & Williams., 1987; Najman et al., 1993). Thus, improving our knowledge of perinatal loss and bereavement is critical for the health and wellbeing of the affected families.

Making Meaningful Memories

Making meaningful memories is a common theme throughout the perinatal death literature. In order to develop our program, we examined a group of studies with general guidance about memory-making items that bereaved families cherished. Capitulo (2005) explored the concept of perinatal

grief and evidence-based healing interventions, and suggested a list of memory-making activities including collecting photographs, memory boxes, locks of hair, name bracelets, foot/hand prints and casts, name certificates, journals, and quilts of the baby's clothing.

Other researchers have provided a similar list of items or keepsakes that are important to families. In a study of Mexican-American families, Doran and Downing Hansen (2006) found that families cherished objects that were used by the deceased child, such as clothes, toys, and blankets. These symbolic items served as constant reminders of their children. In a qualitative study in which bereaved family members were interviewed, Gibson (2004) found that photographs and clothing were important mementos for families. She reported that families experience, process, and transition their grief with and through these objects, and demonstrated that *linking objects*, or items that help grieving individuals feel connected to their loved one, are effective in easing the mourning process.

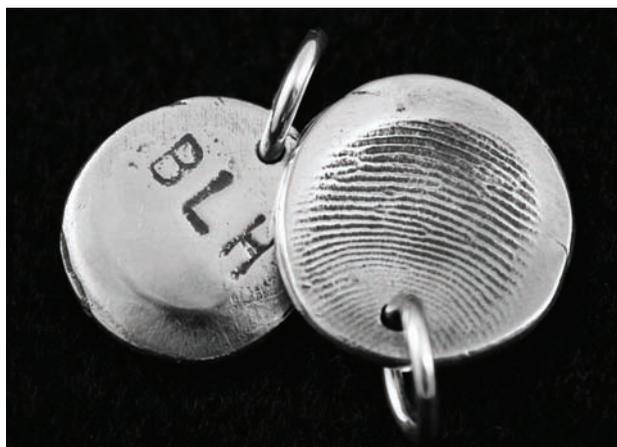


FIGURE 1. Pendant of an Infant's Fingerprint.

Used with permission of Precious Metal Prints.

Few studies were identified that examined specific programs of creating memories. In an early study that focused on the intensive care unit, Arentz and Klos (1996) described the process of making a handprint of a deceased child and presenting it to the families. Schwarz, Fatzinger, and Meier (2004) explained a program that was developed for parents of infants admitted to an NICU at Rush University Medical Center. The *Rush SpecialKare Keepsakes* program combined therapeutic photography, journaling, and memento preservation with the goal of documenting the infant's birth and place within the family. The program included weekly scrapbooking sessions and Holiday Family Photo Shoots in which infants were photographed with their family members to celebrate traditional holidays throughout the year. Data from the first 6 months of the program indicated that all 173 parent participants overwhelmingly appreciated the opportunity to attend these sessions, which they perceived as a brief respite from the NICU, an opportunity to interact with other families, and to share the unique challenges of babies and families in the NICU.

Although these studies contribute to our understanding of perinatal bereavement and memory making, a gap in the literature remains. Most of the work in this area was published over a decade ago and therefore may not be as relevant to the needs of families today. Information on the specifics of a current perinatal memory-making program is needed to provide examples and guidance for clinicians who wish to develop or expand their own programs.

Program Development

The idea for the Precious Prints Project first originated when a nurse observed a young mother leaving the hospital without her infant. The mother had nothing tangible to validate her experience of giving birth. At the same time, one of the authors met the owner of a company that created silver pendants of fingerprint impressions (Figure 1). An idea was conceived to form a partnership between a regional children's hospital, College of Nursing, Student Nurses Association (SNA), and a local business (Precious Metal Prints(tm)) to initiate a perinatal bereavement program. Since its implementation in March 2012, more than 50 pendants have been distributed.

The details of the Precious Prints Project were developed based on dialog between students, faculty, NICU

nurses, and the hospital chaplain. Although the children's hospital offered families a variety of memory-making options including a mold of the hand or foot, lock of hair, professional photo, and foot print, there were no tangible objects of the child that a parent could personally carry with them as a perpetual reminder of their infant. After team discussions about alternative memory-making approaches, it was decided to initiate a program with a silver pendant finger print and then evaluate integrating other approaches after implementation. The program starts with Nurses in the NICU identify families who have experienced a loss. The next steps are:

- Although nurses deliver care to infants and families in the NICU, the focus of the nursing care transitions to the family after the death of the baby. As part of the bereavement process, NICU nurses provide counseling and resources for the family, along with the social worker and hospital chaplain, when appropriate. The nurse also engages the family in a discussion about their psychosocial needs. It is during these conversations that the topic of memory making is broached with the family, and the option to create a silver pendant of the infant's finger impression presented. Nurses and other members of the healthcare team provide support for the family while they say goodbye to the child after holding, rocking, and/or bathing the infant. Nurses also connect families with support services to assist in making funeral arrangements and further bereavement counseling.
- The creation of the silver pendant. Nurses retrieve the bereavement materials from the unit's storage area. The kit includes silver molding material and instructions. The infant's finger impression is made in the mold, which is later forged into the actual pendant. To see a YouTube Video of the process, go to www.youtube.com/watch?v=s7jX2rftEsU&feature=plcp (Barton, 2012). Nurses at the hospital received in-service training from the SNA on how to make a quality impression, especially in the case of extreme prematurity or deformity. For example, nurses learned to press the infant's finger down, not sideways, on the mold to create an indentation. This process allows the object the child touches to become a living memory of that child.
- The family completes a customized informational sheet requesting the child's initials, which will be engraved on the back of the pendant, and a postal address for the completed pendant. The mold and sheet are returned to the box and stored in the chaplains' office for 24 hours to harden and then sent via mail to the vendor. Precious Metal Prints(tm) creates the pendant and ships it directly to the family in approximately 2 weeks. The family receives the sterling silver pendant of their infant's fingerprint along with a card stating that the gift is from the SNA, College of Nursing, children's hospital, and the vendor.

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One approach to meeting grief needs is providing transitional objects such as tangible keepsakes that create a connection with the lost child.

- All programs that wish to help grieving parents should be evaluated. Program evaluation for our program has just been initiated. In this phase, families will be mailed a survey and asked about their experience with receiving the pendant. Families chosen at random will be contacted to see if they are willing to participate in an interview. The on-going evaluation of the data will be conducted by students in the College of Nursing with faculty mentors. We are currently seeking external funding to conduct the evaluation research.

Implementation Challenges

We encountered several challenges in the implementation of this program. Early in the program's development, the vendor identified an issue with the fingerprint capture and quality, particularly with very low birthweight infants or extreme prematurity. The decision was made to create sample pendants using the fingerprints of two healthy premature children, one at 24 weeks gestation, and one at 32 weeks gestation. The staff now uses these sample pendants to show families an example of final fingerprint quality.

There were also challenges to staff buy-in of the program that required additional informational sharing. To accomplish this, the SNA collaborated with the NICU Staff Educator. Together, they presented information about the Precious Prints Project at the Palliative Care booth at the NICU Skills Day event. During this time of staff education, the SNA students presented the project's genesis and implementation, the availability and location of project materials, suggestions for producing a quality print, and correct disposition of completed kits. The student booth contained a poster depicting the project and its participants as well as a tablecloth bearing multicolored fingerprints of the SNA members. Sample pendant kits with sample putty were available for applied practice to help staff to synthesize the information through psychomotor involvement. Finally, examples of completed pendants were provided, one from a good-quality print and one from a poor-quality print. These examples helped emphasize the importance of the one-time opportunity to make a good print and the need to insure success. More than 180 nurses were educated about the program during the Skills Day. Many participants indicated on their evaluation forms that the Precious Prints Project booth provided the most beneficial information they gained during the event. This collaboration between

the SNA and the Nursing Education department proved to be an effective method of dealing with the staff buy-in challenge.

Strategies for Sustainability and Growth

Sustaining the program requires an on-going funding model. Through the patronage of the vendor, kits are supplied at a reduced rate. The SNA has helped fund this project by adopting it into their fundraising activities and conducting campus-wide fundraising efforts with proceeds directly benefiting the project (www.wbir.com/story/news/local/five-at-four/2013/09/13/sprint-for-the-prints-supports-grief-keepsake-project-precious-prints/2809517/). To date, the SNA has raised over \$1,000 to support this project. The Precious Prints Project was also identified as the *Fund a Cause* project for the annual College of Nursing fundraising celebration event. Community grant funding also is being explored. Sustainability requires continual support from all the partners. One key to the project's success has been the solid commitment of the Dean of the College of Nursing, the Chief Nursing Officer of the hospital, the vendor, and the SNA leadership team.

The Precious Prints Project continues to grow. The emergency room and pediatric intensive care units have already started storing the program materials, although other units—such as medical-surgical units—have been identified as areas that may benefit from the program. In addition, the hospital is in the process of identifying nursing “champions,” who will be available to discuss and demonstrate the program to other hospital units. Thus, through financial support and planning, the Precious Prints Project will continue to grow and assist families.

Clinical Implications

We learned a great deal during the development and implementation of the Precious Prints Project. The background information we uncovered highlighted the distinctive aspects and challenges of perinatal bereavement. The literature review confirmed that the information we gleaned from the program is on track to help fill the gap about designing and implementing a perinatal memory-making program to ease parental grief during their time of loss. We hope the description of the program's development will spark ideas for other organizations in need of such a program. Creative collaboration

Suggested Clinical Implications

Nurses who work with bereaved parents should know that:

- There are distinctive aspects and challenges of perinatal bereavement.
- Based on the nursing literature, a perinatal memory-making program to ease parental grief during their time of loss can be helpful to parents.
- Creative collaboration between multiple disciplines is needed to deal with the program's implementation challenges.
- Continual fundraising activities are required for such a program's sustainability and growth, along with the commitment and creativity of program stakeholders.

is needed to deal with the program's implementation challenges. The report on fundraising activities showed that the program's sustainability and growth are likely to rely heavily on the commitment and creativity of program stakeholders.

We hope to learn even more from the program going forward. We are examining mechanisms to monitor the program's impact in an effort to gauge and improve its delivery and success. In addition, we are developing a research study to assess parents' feedback and perspectives on the program. In summary, through creative collaboration among nurses, hospital administrators, and community vendors, we as nurses can assist families with the intense grief that accompanies the death of their baby. ❖

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