Shari Munch and Judy Levick

"I'm Special, Too": Promoting Sibling Adjustment in the Neonatal Intensive Care Unit

> Zachary [born at 24 weeks gestation] was 13 inches long, and my parents often compared him to the size of my Barbie doll. He weighed one pound 12 ounces and was just skin, bones, and machine.
>
> *Nicole, age 13, reflecting back on her experience as a six-year-old neonatal sibling* (Parent-to-Parent Program, 1999)

Sisters and brothers of newborns hospitalized in neonatal intensive care units (NICU) are faced with powerful and frightening images as they are unexpectedly hurled into this unfamiliar world. Siblings often experience strong emotions and reactions in response to this situational crisis, requiring support in the adjustment to the associated changes. The birth of a premature or critically ill newborn creates a crisis for the family (Bachman & Lind, 1997), as most of the family's energy is focused on the well-being of the infant. Similarly, the NICU staff engages in the minute-to-minute challenge of life-threatening events faced by the neonate. Thus, both parent and staff efforts are primarily aimed at the NICU baby who needs their attention and care. This is as it should be. There are, however, other members of the family—the siblings— who desperately need attention and care, but who may be overlooked—not intentionally, but because of the very nature of the crisis. In the midst of the chaos, commotion, and disorganization, there is often little time or energy for parents and caregivers to focus on what is happening in the daily lives of siblings.

NICUs across the United States promote a family-centered care approach (Johnson, 1995) by offering programs and interventions designed to meet the unique needs faced by siblings. The literature describes the positive effects of sibling visitation programs in the neonatal ICUs on siblings (Oehler & Veleisis, 1990), their parents and family (Montgomery, Kleiber, Nicholson, & Craft-Rosenberg, 1997), and the bonding process with the hospitalized neonate (Burke, 1991). Psychoeducational interventions through hospital brochures and newsletters (Neo-Fight, Inc., 1994) and popular magazines (Jabs, 1992) inform parents about the unique needs of siblings, often offering a forum for parents (Pankow, 1997) and siblings (Monique, 1993) to share their stories. Books, written for children (Hawkins-Walsh, 1985), and coloring books (Gibson, 1997) explain the NICU environment and technology and help siblings identify and express their thoughts and feelings about the birth and hospitalization. There is no documentation to date regarding the use of parent or sibling groups as forums for specifically addressing the psychosocial needs of siblings.

This article describes the "Sibling Night" program at DeVos Children's Hospital Neonatal Services at Spectrum Health that uses both parent and sibling groups to address the needs of siblings. In the context of sibling awareness of the "specialness" of the new baby because of the attention given to the neonate by hospital staff and parents, the sibling group is designed to help the siblings also feel special. It does so through parent education about the needs of siblings and by focusing on siblings in relationship to **their** world. Katie, age 6, echoes this need of siblings, "I liked Matthew's nurse! She asked me lots of questions about myself. She wanted to know all about **me.** I liked that!" (Peters, 2000).

"Sibling Night"

The NICU "Sibling Night" takes place every six to eight weeks and comprises a parent group and

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sibling group. Social workers serve as group facilitators and co-facilitate with nursing, social work interns, and trained parent volunteers. Parents, other adult caregivers and children (ages 3 to 16) are invited to attend. The meeting begins by inviting parents and their children to sit together in a circle on the floor. Sitting together in this manner creates a sense of informality and safety for the children. Because many of the children have never met the group facilitators, it is important that this introduction time be spent together. The social worker addresses the siblings with an introduction about the plan for the evening, focusing on the special role of brothers and sisters, and emphasizing that this particular night is a time created just for them. After this introduction the parents are taken across the room, and the two groups meet concurrently, separated by a flexible wall divider. Meeting in the same, yet divided, room works nicely to further enhance the sense of security and familiarity. It is not unusual to see younger children walk over to the divider, peek through to confirm that their parents are there, and then return to the sibling group without saying a word. This close proximity tends to decrease anxiety and enables the children to comfortably participate in the sibling group.

Sibling Night: The Parent Group

Use of the parent group is essential because in the midst of this birth crisis, parents are left with the extremely difficult task of finding internal strength and external resources for both themselves and their children. Parents may become so encumbered by their own experience that it is difficult for them to notice the effect on their other children. The parent group follows a format common to NICU support groups (Macnab, Sheckter, Hendry, Pendray, & Macnab, 1985) by addressing psychosocial issues related to the neonatal experience (Doering, Dracup, & Moser, 1999; Zaichkin, 1996). Also discussed are stages of child development and strategies to enhance parents' effectiveness and confidence in addressing their children's needs.

The following seven suggestions for supporting siblings of hospitalized neonates are shared with parents during the parent group (Levick, 1993).

1. Model and encourage open expression of feelings. Children observe the coping skills of their caregivers, learning positive and negative behavioral responses to crisis. Individual personalities and developmental stages of children need special consideration. Seek support from trusted adults during times of intense grief.
2. Reassure siblings that their baby's illness is not their fault. Children have a tendency to display magical thinking by believing that their negative and secret thoughts (for example, not wanting a brother or sister) may have caused their baby's illness and hospitalization.
3. Be alert to the possibility of behavioral changes as siblings attempt to cope with the crisis. It is not unusual for children to regress in toileting skills, and experience mood swings, excessive fears, sleeping and eating disturbances, and difficulty concentrating in school.
4. Maintain the household routine as much as possible. Children feel more secure when their daily schedules are not significantly altered. Select caregivers with whom the children feel most comfortable.
5. Visit the NICU with siblings. This reinforces the importance of the family unit and enhances the bond between siblings and neonate. When visitation is not possible, the following suggestions are recommended:
   - ❒ Take pictures or videotape the neonate. When videotaping, talk to the neonate about their siblings. Relate baby's sounds or movements to the siblings to enhance the connection.
   - ❒ Give siblings an idea of baby's size by comparing the baby to a doll or stuffed animal or by placing an adult hand next to the neonate in a photograph. Trace the neonate's footprint and handprint for the siblings to keep. Leave space to trace the siblings' prints for comparison.
   - ❒ Make an audiotape of the sibling talking, singing, and reading to the neonate, and ask the nurse to play the tape for the baby.
6. Elicit questions and seek opportunities to share honest, brief, and simple explanations about the baby's medical status. Children may hesitate to ask questions because they feel protective of their

parents and fear causing them further sadness.

7. Arrange "special time" with undivided attention for each sibling. Share activities that were enjoyed together prior to the neonate's birth.

Sibling Night: The Sibling Group

The second component of Sibling Night is the sibling group. The use of art, in the form of drawing and coloring in a non–NICU-specific coloring book is the treatment modality used. To facilitate the primary goal of providing an atmosphere that acknowledges daily events of importance to siblings, a workbook entitled *My Me Book!* (Munch, 1991) is used.

Additional goals of the sibling group are to laugh and have fun, encourage expression of feelings, enhance self-esteem, and identify individual needs to be addressed by parents at a later time.

My Me Book!

My Me Book! (Figure 1) is a 15-page black and white workbook used in the sibling group. The *My Me Book!* was developed specifically to support the primary purpose of the group: to focus on siblings in relation to their world rather than solely in relation to the NICU. Although numerous issues can and do arise when children participate in the sibling group, the book primarily facilitates discussion about concepts such as social support, feeling states, hopes and dreams, current life events, and self-confidence. Additional goals for the workbook are to assess overall coping abilities, identify any problem areas, help parents understand the child's emotional responses, and explore intervention strategies as needed.

Keeping with the philosophy that NICU siblings need and deserve special attention, the wookbook intentionally contains no pages specifically eliciting information about the NICU or the baby. However, many pages contain open-ended statements that afford the opportunity to address reactions to the NICU (for example, "Something new in my life is _____," "My new _____ makes me feel," "I worry a lot about _____," "I wish _____"). The opportunity for siblings to discuss their reactions to the NICU and the baby is certainly present and elicited as appropriate, yet it is neither an expectation nor the primary goal of the sibling group intervention. Completing the workbook in a structured, therapeutic atmosphere enhances siblings' feelings of being special in their own right—independent from the neonate.

The informal nature of the sibling group allows the flexibility for children to sit at tables, stretch out on the floor, work alone, or interact

Figure 1. My Me Book!

— **My ME Book** _____ (name)
— _____ (date)
— People I live with:
— Best friends . . . Other people I like . . .
— Something new in my life is . . .
— My new _____ makes me feel . . .
— Everybody has feelings. There are lots of kinds. All feelings are o.k.!
— Draw some feeling faces.
— It feels good to tell someone my feelings. I can tell my feelings to….
— I feel good when…
— I feel sad when…
— Something happy!
— I worry a lot about…*
— Me…doing something I am good at!*
— I wish…

THE END

*Reprinted from *When Someone Special Dies: Children Can Learn to Cope with Grief* (1988) with permission from the author, Marge Heegaard and publisher, Woodland Press, Minneapolis, MN.

with others. A one-to-one staff–child ratio is required with very young siblings who are unable to read or write. Depending on the number of children attending, additional staff (for example, nurse or social work intern) may be needed to facilitate an interactional, verbal process with each child. Siblings are allowed to work at their own pace, skipping pages if desired. They are told that they can do whatever they want to do with the workbook—during and after completion. Most are quite proud of their artistic creation and desire to show the members of the group, as well as their parents, immediately after the group ends. Additional issues to be considered when using *My Me Book!* are

- It is important to redirect siblings to talk with their parents, relatives, clergy, friends, teachers, and others about their feelings. The group ends, but the feelings will continue. Children need to be reminded of all the support resources available to them.
- Although the book is geared for ages 10 and younger, older siblings actively participate and complete the book in creative ways.
- Confidentiality is addressed as appropriate. An adolescent who shares issues that are of concern to the social worker can be approached privately: "I think that what you've shared with us today is important for your parents to hear. They need to understand how you are feeling. I'd like to talk with your mom and dad about this so that they can support you during this time. Would it be all right with you if I talk with them?" It is important to be clear about the plan, when the parents will be contacted, what will be said, and how the issue will be handled. Dealing directly in a one-on-one situation with adolescent siblings imparts a sense of caring that the feelings expressed in the group did not go unrecognized. Moreover, a respect for siblings' feelings and privacy is demonstrated, and a plan for action to address issues that they may be reluctant or embarrassed to discuss with their parents is established.
- *My Me Book!* can serve as an invaluable assessment tool. Group facilitators from both parent and sibling groups meet briefly after Sibling Night to discuss any concerns they may need to address with the family and their primary social worker or nurse. It is imperative that the social worker, as group facilitator, follow-up with the parents of each sibling to provide an assessment of the sibling's coping. Because contact with the child is brief, emphasis is given to the fact that this is a general assessment and in no way an all-inclusive evaluation. Follow-up is especially important because children frequently offer verbal comments that they do not write in their workbook. Moreover, young children often write or draw incomplete or seemingly irrelevant items that require interpretation. The social worker can explain the context in which the communication occurred. Parents can be needlessly hurt or confused by their children's artistic expressions when the proper perspective is not provided. Therefore, the follow-up contact ensures an opportunity to reframe, clarify, and alleviate any misconceptions that might arise.

Case Vignettes: Siblings' Stories

When considering the psychosocial aspects of sibling adjustment in the NICU, no great mysteries require uncovering. Children have the same feelings as adults. They may experience emotional responses such as sadness, anger, guilt, jealousy, excitement, fear, impatience, confusion, worry, and abandonment. Siblings will teach us what we need to know about their thoughts and feelings. It is the responsibility of adults to find creative ways to elicit and identify children's unexpressed feelings. When siblings' feelings are expressed, parents and caregivers must know how to be responsive and supportive—thereby enhancing children's coping skills. The following case examples are siblings' stories that illustrate the range of emotional responses and experiences elicited by the use of *My Me Book!* in Sibling Group:

Case 1. Susan, age 5, is the sibling of a term neonate who suffered severe meconium aspiration. When attempting to respond to the page, "Something new in my life is . . .," she initially couldn't think of anything to write. After much thought, her eyes lit up, and pointing to her missing tooth, she exclaimed,

S: "I know. My tooth fell out!"
MSW: "It did! That's really neat!"
S: Sounding disappointed, "Uh huh, but the tooth fairy didn't come."

MSW: "She didn't? I'm sorry. Maybe if you put it under your pillow again, she will come."

S: Responding with confidence and satisfaction, "That's what I did."

The relevance of this scenario is that in the midst of an emergency cesarean section and the birth of a critically ill newborn whose death seemed imminent, the "tooth fairy" forgot to visit. Susan's mother expressed much guilt about this situation. The social worker was able to provide the mother with the needed reassurance that Susan was quite satisfied with their decision to put the tooth under the pillow a second time. The group setting provided an opportunity to acknowledge an event that was lost in the chaos of the NICU experience but that was most important in Susan's life—the loss of her tooth, not the birth of her new baby.

Case 2. Julie, age 8, is the sister of a 27-week neonate who was, at the time of Sibling Group, only four days from discharge. Julie meticulously colored every page in her workbook with one exception—"I worry about . . ." In reviewing the completed book, and based on previous comments by Julie, the social worker attempted to explore this further.

MSW: "What do you worry about?"

J: "I don't know. I don't worry."

MSW: "Did you ever worry anytime since Jon's been in the hospital?"

J: Nodding, "Yes."

MSW: "What did you worry about?"

J: Looking down, she let the words rapidly roll off her tongue and immediately placed a cup of popcorn to her mouth: "That Jon might die."

MSW: "A lot of brothers and sisters worry that their baby might die."

J: Julie waited briefly for another boy in the group who explained what he worries about. With an animated expression, Julie exclaimed, "I also worried when my dad told me my mom had to stay in the hospital. I cried enough tears to fill two cups!"

Although Julie's brother was ready for discharge and doing well, it was important to provide an opportunity to speak about the unspeakable—death. Julie did not elaborate on her earlier fears that her brother might die, and perhaps did not need to. Yet, she expressed a terrifying fear out loud, possibly for the first time; and her feeling was validated as common and normal. She was then able to elaborate on additional worries regarding separation from her mother.

Case 3. Bobby, age 5 (brother of a 32-week neonate) was typically outspoken. However, he became timid during the "I worry about . . ." discussion. After listening to Julie, Bobby spoke up:

B: "I worry when my mom says she'll be gone a minute and it's longer than a minute."

MSW: "What is it you worry about when your mom is gone longer than a minute?"

B: "That Jessica will get sick."

MSW: "What else do you worry about?"

B: "That my mom won't come home until 12:30 midnight."

Bobby was worried about his baby sister. She recently overcame an infection, and he feared another. However, his primary concern was that of being separated from his mother. As Bobby listened to Julie express her worries, he felt more comfortable in discussing his fears.

Case 4. Sometimes adolescents are overburdened with child care responsibilities of the younger siblings as parents attempt to maintain consistent involvement with the neonate. Cindy, age 14 (sibling of a 25-week neonate), could think of only one response to the page, "Me, doing something I'm good at." She wrote "babysitting." For weeks Cindy provided child care for her two younger sisters while her parents visited the NICU. She had few friends and limited social activities. She presented with low self-esteem and expressed concern about her school grades. She responded to the, "I wish . . ." page by writing: "I wish I was a senior, that I had an older brother or sister, that I had a Corvette." It was evident that Cindy's life was dramatically affected by the birth of a premature baby; and that she was overwhelmed with added responsibilities because she was the eldest. She longed to have an older sibling to take care of her or take on her responsibilities of child care, while fantasizing of fleeing her stressful life in the dreamed-of sports car. Intervention with Cindy was focused on validating her feelings and exploring other interests. Generating a sense of excitement and praise for her strengths as a "babysitter" and her other endeavors was essential. With Cindy's permission the social worker summarized for her parents the key issues, assisted them in

understanding the perspective and needs of adolescents, and explored problem-solving options. The parents eventually altered their visitation schedule so that one parent was home at all times.

Case 5. Peter, age 13, is the sibling of twins born at 30 weeks gestation. Peter wrote about what angers him: "When people call and stop by to see videos about the babies." Peter described that he would go up to his room when visitors came because he was "sick of hearing about the babies." On the "I worry a lot about . . ." page, he explained that he worried that he "will have to help out more at home" and "that the babies will get special attention." Although Peter expressed much concern for the babies' health and safety and was a very proud "big brother," he struggled with feelings of jealousy. It was important to validate these seemingly contradictory emotions and work with Peter's parents, developing a constructive plan for addressing his anger.

Conclusion

Programs designed to focus on siblings' daily lives, rather than solely on their adjustment to the NICU experience, offer a creative and fresh approach. The Sibling Night model provides social workers the opportunity to collaborate with interdisciplinary team members to address the complex needs of siblings and their families. First, because the design of the group is time limited such that most siblings attend only one group, the social worker–group facilitator serves the team not only by educating parents and primary caregivers but also by identifying parent and sibling issues that require further exploration and intervention by the family's primary social worker or nurse. Second, despite anecdotal evidence expressed by parents and siblings regarding the benefits of Sibling Night, there has been no systematic program evaluation. Collaborative team research efforts that investigate the efficacy of this program, and NICU support groups in general, are needed. Third, the health care team can advocate for the development and implementation of creative programming strategies that move beyond established sibling visitation/participation policies. For example, expanding existing Parent-to-Parent programs (Roman et al., 1995) to include sib-to-sib support could be explored. Addressing the unique needs faced by NICU siblings is an essential component in striving for excellence in family-centered care. HSW

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About the Authors

Shari L. Munch, MSW, PhD, *is assistant professor, School of Social Work, Rutgers, The State University of New Jersey, 536 George Street, New Brunswick, NJ 08901; e-mail: smunch@rci.rutgers.edu.* **Judy Levick, MSW, ACSW,** *is Parent-to-Parent program coordinator, Neonatal Services, Devos Children's Hospital, Spectrum Health, Downtown Campus, Grand Rapids, MI; e-mail: judy.levick@spectrum-health.org.* *An earlier version of this article was presented at the Seventh National Conference on Perinatal Social Work, May 1993, Cincinnati.*

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