

Donating milk as a way of making meaning from the loss of a child

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In the second trimester of pregnancy, the breasts begin secreting milk. Even if a baby dies at birth or is stillborn, milk production will still automatically ramp up following delivery.

In cases such as this, many parents are advised to suppress milk production. However, in a new study conducted through the Human Milk Banking Association of North America, or HMBANA, researchers found that some parents who experienced a loss wanted to pump and store their milk explicitly to donate it. These parents reported that milk donation was an important and meaningful component of their grieving.

"For some families, expressing milk is a huge part of the grieving process, a huge part of giving meaning to their child's life," says the study's senior author, Diane Spatz of Penn's School of Nursing and the Children's Hospital of Philadelphia (CHOP). "It's such a neglected topic but such an important one."

Spatz says the study's findings, published in the journal *Breastfeeding Medicine*, underscore the importance of investing in services that support families in making and carrying out decisions related to childbearing and breastfeeding.

"Given the concerning situation that's playing out with the formula shortage, this space and time seems like an important one to really think about the ways that we as a society and as health care experts can really improve the care of childbearing families," Spatz says.

Spatz was instrumental in establishing CHOP's Mother's Milk Bank, which opened in 2015 and screens and regulates the process of donating human milk and using it for critically ill infants whose parents can't produce enough milk. CHOP's milk bank is part of HMBANA, which oversees all nonprofit milk banks in the United States and Canada.

In the study, Spatz—together with Molloy College's Ann Marie Paraszczuk and Laura M. Candelaria and New York University Langone Health's Karen Hylton-McGuire—interviewed parents who had opted to donate milk following the loss of a baby.

"A lot of people don't think of that as an option," Spatz says. "But, if your baby dies, you still make milk, so what do you do with it? Most people would say, suppress it. But that's not the preferred option for every family."

At CHOP, Spatz says, some expectant parents arrive knowing that their baby will not survive long past birth. As part of the palliative-care and bereavement-planning processes, families are given a variety of options for what they would like to do. One of those options is to pump and register to donate milk to the milk bank.

The study included 21 parents in 11 states who donated to seven HMBANA milk banks. Among the themes that emerged from interviews, bereaved parents shared that donating milk helped them form a connection with their child, reduced grieving, and created a positive outcome—supporting another family—from a negative one.

Spatz recalls one mother whose baby died and who continued to pump and donate milk for three months following the loss, hand-delivering her milk to CHOP.

"She said it gave her such comfort that part of her child's life was still being sustained through the fact that she could give this tangible gift to help other people's children," Spatz says. "That's so powerful."

While HMBANA nonprofit milk banks offer assistance to parents who wish to donate milk, some people interviewed in the study reported difficulty in navigating the donation process, including challenges in accessing a breast pump. While not all parents will choose to donate, Spatz



says, removing obstacles could make it a more positive experience for those who do.

And more milk in milk banks is a positive thing for the families of critically ill babies who depend on the donations, Spatz says. The current formula shortage is putting additional stress on milk banks because there is an increased demand for donated milk. The crisis is also revealing racial, ethnic, and socioeconomic disparities in breastfeeding and formula use.

"The families who are being disproportionately affected by this formula crisis are low-resource families in the Women, Infants, and Children Program," Spatz says. "WIC doesn't give you 100% of the formula you need, and we know that WIC spends 25 times as much on formula as they do on breastfeeding support."

Spatz, a nurse scientist, clinician, and educator, has long advocated for <u>health care providers</u> and members of society to understand the critical role of human <u>milk</u> in both short- and long-term health outcomes.

"For me," she says, "the takeaway message is that all of us should be invested and committed to helping families make informed feeding choices, to supporting people on their lactation journeys, and to making care better for families, whether they have a healthy child or they are a bereaved family."

More information: Ann Marie Paraszczuk et al, The Voice of Mothers Who Continue to Express Milk for Donation After Infant Death, *Breastfeeding Medicine* (2022). DOI: 10.1089/bfm.2021.0326

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