Women’s Experience of Perinatal Loss: A Collaboration to Develop a Learning Resource for Nurses

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PURPOSE
The death of an infant is a profound and devastating experience for women and families. Nurses who work in emergency departments; obstetric, neonatal, and pediatric units; and in public health settings are likely to encounter women who experience a miscarriage, stillbirth, or infant death. These nurses are responsible to address women’s physical, psychosocial, and instrumental needs, however the existing research suggests that many feel ill prepared to do so and there is limited research evidence to guide nurses on how to best do this.

Our purpose is to collaborate with women to describe their experience of perinatal infant loss and develop a learning resource to help nurses effectively support bereavement.

METHOD
We are using purposive sampling will be to recruit 10 – 12 English speaking women who have experienced perinatal infant death, in hospital, during the previous eighteen months and provide informed consent. In phase I of the study, women will be interviewed about their experience of perinatal infant death. The interviews are being recorded, transcribed verbatim, and analyzed for themes using Interpretive Description. Phase 2 of the study will employ photovoice, a participatory action method, which invites participants to collaborate with researchers to document significant aspects of their everyday lives in photographs and descriptive texts. Participants and researchers will meet five times as a group to discuss and refine the themes identified in the interviews; take photographs that reflect the themes; and write about the meaning of the photographs. Through consensus, the group will then select photographs and textual descriptions to develop a learning resource for nurses.

PRELIMINARY RESULTS
In keeping with Interpretive Description (Thorne et al., 1997; Thorne & Sandelowski, 2009), data collection and analysis are proceeding concurrently and inform each other. We have completed seven (n=7) interviews to date.

Preliminary themes:

It seemed like something was wrong…
“So, he probably stopped kicking the day before …I said, ‘Oh, I’ll just go to the hospital because I hadn’t felt anything’. Usually by that time of the morning [I would get] a ‘good morning’ push on my belly and a kick.” (Olivia)

“So she was 33 weeks and 3 days when I felt her die and I knew she died. It happened at about 3 a.m. and I woke up with this crazy abnormal movement and then complete silence and of course, I knew in my heart that she was dead. But I still laid there and sort of thought, “Don’t be neurotic, just go back to sleep.” (Jennifer)

Nothing in the world that can prepare you for that
“It was so surreal, so surreal. There is nothing in the world that can prepare you for that. Even though I’m a doctor and I’ve been involved in the care of families who have had this happen, it’s a loss like no other. The only place this person ever existed was inside your body and nobody really understands that”. (Jennifer)

“Death in children is a taboo and I feel like nurses are very prepared in every other sectors of healthcare but not where it hurts the most” (Olivia)

Little things matter
“I did have a nurse come in and say that these will be your options for like a burial, cremation, and stuff like that. We will give you time to think about it, but we want you to know right away, so you can decide. I thought that was really really helpful, that I got that almost immediately after we got there because that is something you don’t ever expect to plan for…” (Angela)

“Just being there and be a listening ear in the midst of all the crazy things that they have to get done every day… I know that they are extremely busy but knowing that they took that special time to give me that attention/care and to listen was exactly what I needed.” (Andrea)

NEXT STEPS
In Phase 2 of the study, researchers and participants will work as collaborators to refine the themes identified in the interviews and take photographs that reflect these themes. Through consensus the group will select photographs and accompanying textual descriptions to be included in a learning resource to help nurses understand the experience of perinatal loss and about how to support women’s bereavement.