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Vigilance in Parents' Experiences of Fetal and Infant Loss

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ABSTRACT

Objective: To develop an in-depth understanding of the experiences and contexts of fetal and infant mortality from the perspective of women and men who experienced a fetal or infant loss.

Design: Qualitative, descriptive.

Setting: Small urban community of 100,000.

Participants: Eleven women and four men who experienced a fetal (>14 weeks) or infant loss between 2006 and 2008.

Methods: Naturalistic inquiry.

Results: Vigilance was described as a part of the experience of fetal and infant mortality for study participants. *Vigilance* was defined as "doing everything possible to help this baby make it" despite poverty, health care inequity, and stress. Stories demonstrated vigilance amidst neighborhood violence, poverty, and stress; during early pregnancy; during changes occurring in the participants or with their babies; and when explanations of cause of death(s) were not clear. The participants desired healthy pregnancies and healthy infants; however, vigilance may have contributed to the risk for fetal and infant loss with these families.

Conclusions: Further study about vigilance has the potential to help health care providers understand the dynamics and consequences of fetal and infant mortality.

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Fetal and infant mortality rates are key indicators of the health and wellness of communities and nations and represent the value placed on population health and health care accessibility and quality (MacDorman & Mathews, 2007; Singh & Yu, 1995; World Health Organization [WHO], 2007a). Each year 28,000 infants die in the United States as a result of maternal and infant complications (MacDorman & Mathews, 2008). In a study by Traynor (2006), the United States ranked 24th in infant mortality compared to 23 other developed countries in the world, including Iceland, Japan, and Finland. Fetal and infant mortality, defined as the number of fetal deaths (greater than 20 weeks gestation) and infant deaths (birth to 364 days of life) that occur per 1,000 live births, is a known, widespread, past and present, global problem. Maintaining low rates of fetal and infant mortality is thought to demonstrate social, economic, civic, and environmental well-being, and basic human equality (WHO, 2007b). Factors associated with high fetal and infant mortality include poverty; lack of access to health care; minority race; various maternal morbidities such as diabetes, high blood pressure, and obesity; infant morbidities such as congenital defects and complications associated with premature delivery; and sudden infant death syndrome (SIDS) (Collins, David, Handler, Wall, & Andes, 2004; D'Angelo et al., 2007; David, 2007).

In the United States, African Americans are disproportionately affected and routinely experience 3 to 4 times more fetal and infant deaths than Whites (Byrd, Katcher, Peppard, Maureen, & Remington, 2007; David & Collins, 2007). Wisconsin, the location of the current study, has the highest African American infant mortality rate of all states in the United States (Centers for Disease Control and Prevention [CDC], 2009). Fiscella (2004) reported that exposure to risk factors such as lifelong stress, high rates of poverty, discrimination, unstable partnerships, whether the pregnancy is wanted, urogenital tract infections, lack of prenatal care, and genetic factors may contribute to these disparate findings. However, even when controlling for these factors, Byrd et al. found that African Americans in Wisconsin were still twice as likely to experience fetal or infant mortality as compared to Whites.

Positive pregnancy and infant outcomes have been linked to the social and physical well-being of mothers, fathers, and the communities in which they live, before, during, and between pregnancies (Thompson, 2007). Although official statistics and quantitative studies provide some answers, they are insufficient in representing the personal experience of fetal and infant mortality. Thus, a better understanding of the circumstances and contexts in which individuals experience loss is needed.

The fetal infant mortality review process (FIMR) is a powerful method to identify factors associated with mortality (Baltay, McCormick, & Wise, 1999; Minkler, Thompson, Bell, Rose, & Redman, 2002; Misra et al., 2004; Strobino, Misra, & Grason, 2004). During 2006 to 2008 a FIMR process was conducted due to high rates of fetal and infant mortality in one small urban community located in southeast Wisconsin. This community reached a statewide high fetal and infant mortality rate of 23.47/1,000 (Wisconsin Interactive Statistics on Health [WISH], 2008). As part of that FIMR process, a qualitative study was conducted to identify and describe factors associated with this high risk population.

Methods

Design

In 2006 to 2008, we conducted a qualitative descriptive study in a small urban Wisconsin community with reported high rates of fetal and infant mortality. Women who had experienced a fetal or infant death were recruited using a purposive sampling technique. For the initial investigation of this community, data from fetal losses as early as 14 weeks were also collected due to the disproportionate number of losses that occurred between 14 and 19 weeks gestation as compared to reported nationwide statistics (Michels & Tiu, 2007). Data from these losses could provide meaningful information on fetal and infant mortality in this community.

Sample

A total of 11 women and 4 men were recruited from the FIMR project. Recruitment was done in conjunction with the larger FIMR project and is described in Johnson, Malnory, Nowak, and Kelber (2010). Enrollment criteria for the current study included fetal ($\geq$ 14 weeks gestation) or infant (birth to 364 days of life) death during 2006 to 2008, English or Spanish speaking, age 18 years at time of consent, and resident of the studied urban community. Families were excluded only if the woman, man, or other household member was knowingly being investigated by the legal system related to the fetal or infant death. Institutional Review Board approval was obtained.

The purpose of the study was to develop an in-depth understanding of the experiences and contexts of fetal and infant mortality in this community.

The sample consisted of four African American, four White, and three Hispanic women. Of the men that participated, one was African American, two were White, and one was Hispanic. The mean age for women and men was 27 years. Regarding educational attainment, two women did not complete high school, four women had a high school diploma or had passed the General Equivalency Diploma test, and four women completed education beyond high school. One participant did not share. Nine women were single, and two were married. The incomes of participants ($n = 7$) varied from \$8,000 to \$50,000, with most participants ($n = 4$) reporting incomes $<$ \$24,999.

Fetal deaths occurred from 14 to 37 weeks gestation, whereas infant deaths occurred from 4 to 120 days of age. Average time from death to interview was 3 months for fetal deaths and 6 months for infant deaths. After infant deaths, the average time until the interview was 4 months with one outlier interview occurring 1 year later.

Data Collection Procedure

After obtaining informed consent, the researcher conducted a tape-recorded interview of 1 to 3 hours duration with each woman and her partner when available in a private setting of her choice. One interview with a woman and man was conducted in Spanish with the assistance of an interpreter employed by the health care institution involved in the current study. Translation occurred consecutively. The other interviews were completed in English. A structured interview guide was used to begin the interview and to gather contextual information (Table 1). Open-ended questions were interspersed throughout the interview that pertained to the loss of the baby and the context in which that loss had occurred, such as,Can you tell me about the loss of your baby? What happened after your baby died? How would you describe the health care you received? Questions varied by interview and were dependent on the content shared by the woman (and man).