JOGNN

IN REVIEW

Viewing the Fetus Following Termination of Pregnancy for Fetal Anomaly

Eileen P. Sloan, Sharon Kirsh, and Mary Mowbray

Correspondence
Eileen P. Sloan, PhD, MD, FRCP(C),
University of Toronto, Room 935, 600 University Avenue, Toronto, On, Canada M5G 1X5.
esloan@mtsinai.on.ca

Keywords
pregnancy termination
deceased fetus
parental viewing
fetal anomalies
mourning rituals

ABSTRACT

Objectives: To determine what evidence exists to support the practice of viewing the deceased fetus by women terminating pregnancy for fetal anomalies.

Data Sources: Electronic databases searched (1966-2007) were Medline, PubMed, Cumulative Index to Nursing and Allied Health Literature, and Dissertation Abstracts Index.

Study Selection: Literature was reviewed that either directly or parenthetically dealt with the emotional effects on women of viewing the fetus post termination of pregnancy for fetal anomalies.

Data Extraction: No randomized or controlled trials were found. The main conclusion of each article was noted.

Data Synthesis: Topical focus is on viewing of the fetus by women following termination of pregnancy for fetal anomalies. Thematic emphasis is on the beneficial and detrimental aspects of fetal viewing assumed by obstetric nurses and physicians and by mental health practitioners.

Conclusions: Despite an absence of empirical evidence, most articles concluded that viewing of the fetus by women post termination of pregnancy for fetal anomalies is beneficial and should be promoted. Concerns are expressed that health professionals may be inadvertently encouraging women and their partners to see the fetus because of their own or their institution's particular beliefs and practices. Health professionals must remain mindful of their underlying motives and stay open to respecting the decision of women who conclude that viewing is not appropriate for them.

JOGNN, 37, 395-404; 2008. DOI: 10.1111/j.1552-6909.2008.00260.x

Accepted May 2008

Eileen P. Sloan, PhD, MD, FRCP(C) is a staff psychiatrist, Maternal/Infant Mental Health Clinic, Department of Psychiatry, Mount Sinai Hospital, Toronto, ON, Canada, and is an assistant professor of psychiatry, University of Toronto, Toronto, ON, Canada.

Sharon Kirsh, PhD, is a research assistant, Perinatal Mental Health Unit, Department of Psychiatry, Mount Sinai Hospital, Toronto, ON, Canada.

Mary Mowbray, MN, RDMS, is a CNS/APN, Antenatal Maternal Fetal Medicine, Mount Sinai Hospital, Toronto, ON, Canada.

With advances in imaging techniques that facilitate prenatal anatomic and genetic diagnoses, pregnant women and their partners are faced with the option of terminating a pregnancy when a fetal abnormality is detected or when pregnancy outcome is likely to be poor. Often by the time testing has been completed, the pregnancy is well advanced and women are emotionally invested. Questioning of the decision by the couple and by family and friends, feelings of guilt for "choosing" to end the life of their fetus, and a shattering sense of loss can continue long after the event (Elder & Laurence, 1991; Kersting et al., 2005). Women are expected by family, friends, and even by their partners to deal with the experience quickly and then to move on. Often after only a month or so, the pressure to recover begins, despite the fact that recovery usually takes months or even years, not weeks (Geerinck-Vercammen & Kanhai, 2003; Kolker & Burke, 1993).

Termination of pregnancy for fetal anomaly (TOPFA) is an elective procedure that results from a decision made by a woman to terminate her pregnancy rather than continue the pregnancy with the knowledge that the fetus/neonate will die or will develop into a child with significant or even catastrophic disabilities. An additional decision women face when undergoing TOPFA is whether or not to view the deceased fetus. There is no doubt that for some people viewing is a healing experience. However, in the course of clinical work, the researchers have treated women and some men, for whom viewing complicated the grieving process or was itself traumatic. In the researcher's hospital setting, where women and their partners are offered the option (and are perhaps subtly encouraged) to spend time with the fetus, it is estimated that of the 150 TOPFA patients who are served annually, approximately 90% to 95% of women choose to look at their fetus. On considering the origins of this

Women who terminate pregnancy for fetal anomalies perceive themselves as having created an abnormal fetus and then as being instrumental in its death.

practice, it was clear that it was rooted in popular opinion rather than scientific principle.

Thirty years ago, women who suffered any sort of perinatal loss (spontaneous or elective) were prevented from viewing or holding their dead fetus. Not until the 1970s, when the concerns of Kennell, Slyter, and Klaus (1970) and Lewis (1979) were expressed, did an appreciation grow for the psychological severity of perinatal loss and for the consequent need of a sensitive approach to patients following the loss. Lewis (1979) argued that women's lack of exposure to the deceased body inhibits the mourning process, with possible adverse effects such as bonding difficulties in next-born infants. Soon hospital policies began to undergo re-evaluation with regard to stillbirths and selective terminations. Practice evolved from not viewing to the current clinical practice in North America that encourages women to see and hold the fetus's body. Embedded in the belief that viewing is the healthier option are the assumptions that memories are key to healing (Capitulo, 2005), and its corollary that nurses are duty-bound to promote and support the creation of memories among patients who suffer fetal loss.

A historic perspective (Burgoine et al., 2005) for the contemporary model of care indicates that while viewing, holding, dressing the fetus, keeping mementos, and holding a funeral were initially applied to term stillbirths, they were later extrapolated to include early third-trimester stillbirths and eventually even earlier gestations, as age of fetal viability shifted to second trimester. Whether extrapolation needs to occur again to TOPFA women in mid-trimester remains unknown. There are a number of reasons why such extrapolation may not be appropriate. Women who undergo TOPFA can find themselves grappling with overwhelming feelings of guilt and shame (McKinney & Leary, 1999). In their minds, they have not only produced a "defective fetus," they have also pronounced "a death sentence" upon it (Kersting et al., 2004). Characteristically what emerges is a series of paradoxes unique to this type of perinatal loss. As Vantine (2000) pointed out, women are caught between the following: seeing the termination as an act of love versus an act of killing; feeling the loss of being a parent to the child, but/and also feeling incapable of parenting the child; wanting to be absolved by others for their decision, but/and feeling that no degree of human absolution would ever be enough; feeling grateful for the technology that allows them this choice, but/and resenting the technology that puts them in this position.

Social isolation is often worsened by others (family, friends, coworkers) who feel awkward in the face of this strange misery, or by TOPFA patients themselves who hide behind their "terrible shame" (Britt, Risinger, Mans, & Evans, 2002; Rillstone & Hutchinson, 2001). As a response to the shame, it is not an uncommon strategy for TOPFA women to fabricate a spontaneous loss, rather than to reveal the decision-making that led to an abortion or induction of labor. The volitional component of the loss remains secret (e.g., Bryar, 1997; Furlong & Black, 1984; Vantine, 2000). Regardless of how firmly women believe their decision was right, they worry about social opprobrium for "killing" their baby, and the statistical rarity of TOPFA results in minimal understanding and support from family, friends, and even health care workers (Kolker & Burke, 1993).

The volitional component of termination must not be underestimated because it is believed to actually complicate and prolong the tasks of mourning (Dallaire, Lortie, Des Rochers, Clermont, & Vachon, 1995; Elder & Laurence, 1991; Lloyd & Laurence, 1985). In certain ways, the grief reaction following TOPFA is indistinguishable from that suffered as a consequence of spontaneous loss or neonatal death (Zeanah, Dailey, Rosenblatt, & Saller, 1993) or that provoked by the death of a partner or child (Seller, Barnes, Ross, Barby, & Cowmeadow, 1993). In other ways, the reaction is distinct. Kersting et al. (2005) compared the post-traumatic stress responses and grief responses of three groups: 83 TOPFA women 2 to 7 years after termination, 60 TOPFA women 14 days following termination, and 65 women after the spontaneous delivery of a full-term healthy baby. The results indicated no significant differences between the two TOPFA groups (days-vs.-years post-termination), suggesting that TOPFA can be seen as "an emotionally traumatic major life event, which leads to severe post-traumatic stress response and intense grief reactions that are still detectable some years later" (p. 9).

TOPFA women may be considered lucky in that they have had the good fortune to learn of the fetal anomalies in time to take action to prevent the birth. The expectation is that they ought to feel relieved. On the contrary, they and their partners tend to consider themselves cursed and doubly unlucky: