

The Deliverance of Miscarriage Information and Fetal Loss in Multiple Pregnancies and Vanishing Twin Syndrome (VTS): Enhancing Patient-Provider Relationships by Improving the Patient Experience

Nichole McTurk Cabbage, MS

Enhancing patient-provider trust and relationships is more important than ever. One way to achieve this is with improved quality (e.g., informative) delivery of miscarriage information when Vanishing Twin Syndrome (VTS) occurs. Although all types of pregnancies deserve attention regarding this matter, individuals with multiple pregnancies appear to have a high propensity for not only being ill-informed of their miscarriage(s) but more likely not to be informed that fetal loss has occurred. Research illustrates there is a long-standing misconception that informing a patient who is pregnant with multiples of fetal loss (especially early in the pregnancy) may cause increased stress and anxiety when, in fact, the opposite is true. By identifying information that ought to be conveyed or could be conveyed more effectively, patients and survivors may be better equipped with information that can benefit them medically, socially, legally, and more. Moreover, by adequately informing patients of fetal loss, patients may have more trust and confidence in care providers.

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Vanishing Twin Syndrome (VTS), first identified in 1945, occurs when one or more fetuses vanish during pregnancy with multiples (Zamani & Parekh, 2021). The term *vanishing* can be misleading because there are three possible outcomes for VTS patients, none of which guarantee that the deceased fetus(es) will vanish. Depending on several factors, the deceased fetus(es) may calcify and become compressed against the growing surviving multiple(s). In other cases, the deceased fetus may be completely or partially resorbed by the surviving multiple(s).

Reabsorption presents developmental and health risks for the survivor(s) and mother, even when the loss(es) occurs as early as six weeks gestation (Davies et al., 2016; Li et al., 2022; Shinnick et al., 2017; Song et al., 2020). In many cases, women with VTS develop a blighted ovum, a sac that does not contain a living embryo (Zamani & Parekh, 2021). VTS can occur during any trimester but is most common in the first trimester (Evron et al., 2017; Sun et al., 2017). When VTS occurs later in gestation, the potential risks for harm to the surviving multiple(s) and mother are even greater compared to the first trimester (Sun et al., 2017).

Current standards of care surrounding VTS warrant a need for protocol regarding patient information, specifically mandating the conveyance that a woman may be experiencing a miscarriage in a multiple pregnancy. Hayton (2010) demonstrates the need for a policy(-ies) outlining patient miscarriage information protocol for VTS patients. According to Hayton (2010), many providers actively choose not to inform their patients with VTS that they are experiencing a miscarriage. Swanson et al. (2002) and Hayton (2010) argued that if patients are not informed of the loss that is taking place within their bodies, they may not be able to make informed decisions with medical guidance.

Depending on the time of loss in gestation, cause of death, and multiple chronicity, the mother and surviving fetus(es) may be at increased risk for developmental impacts regardless of whether the loss(es) occur during pregnancy (Davies et al., 2016; Li et al., 2022; Zamani & Parekh, 2021). Thus, it is vital that patients receive all information that could potentially impact

them, their fetus(es), and any subsequent generations (Császár & Bókkon, 2019; Fjeldstad et al., 2020; Segal, 2017; Seong et al., 2020; Magnus et al., 2017; Yu et al., 2002). Moreover, with the increased use of assisted reproductive technologies and their association with increased VTS rates, the need for more policies surrounding VTS patient care will likely increase (Zamani & Parekh, 2021).

Unlike many patients with singleton pregnancies, patients with VTS may not be informed of their fetal demise, depending on whether the provider believes it will do more harm than good to inform the patient (Hayton, 2010; Swanson et al., 2002). Murray (2012) states that doctors are “required to disclose information if it is reasonable to do so. Essentially, [...] a physician is now required to disclose all risks that might affect a patient’s treatment decisions” (para. 7). Despite disclosure of information being required for informed consent, providers are not explicitly required to inform their patients that a miscarriage is taking place or has taken place. Most miscarriages during singleton pregnancies are obvious to the patient, but this is not always the case in multiple pregnancies, depending on when cessation of viability occurred in gestation. While pregnancies with multiples (and therefore miscarriage during multiple pregnancies) have naturally occurred throughout history, the increased use of reproductive assistance has begun to highlight this issue.

According to Zamani and Parekh (2021), “[the VTS] phenomenon occurs in about half of pregnancies with three or more gestational sacs, 36% twin pregnancies, and 20 to 30% of pregnancies achieved with assisted reproductive techniques” (para. 1). In the past 20 years, there has been a rise in the use of assisted reproductive techniques as many women are opting to have children later in life (Zamani & Parekh, 2021). If this trend continues, the rates of VTS will also continue to rise as the rate of twinning, in general, has also increased across the globe (Monden et al., 2021). Nonetheless, the numbers for this medical phenomenon’s prevalence warrant attention to health policy surrounding its treatments to provide quality care. Lack of protocols for providing VTS patients with information, resources, and assistance is imperative as the negative consequences of improperly handling VTS patients can have multigenerational effects on the unborn surviving multiple(s), mothers, and possibly others (Császár & Bókkon, 2019; Fjeldstad et al., 2020; Seong et al., 2020; Swanson et al., 2002). Thus, care policies and standards surrounding VTS are related to the population’s health, as these

effects (e.g., psychiatric disorders) could potentially proliferate within the communities and larger populations (Song et al., 2020).

As previously denoted, protocols are needed because many providers are still becoming familiar with VTS due to its limited research. In addition, there is a need to improve general provider communication skills regarding delivering miscarriage information and infant/fetal loss (Brann et al., 2020). Because of the relative novelty of VTS, some provider providers may have misconceptions about the level of perinatal effects caused by the death of one or more multiples in the womb. Thus, in addition to potentially lacking the skills to effectively communicate the difficult topic of fetal loss in a compassionate and informative manner, providers may not see the need to inform their patients that a loss has occurred in the case of VTS.

Numerous studies have shown that more informed patients experience less stress and anxiety (Bolejko & Hagell, 2021; Fischbeck et al., 2021; Legg et al., 2015). Legg et al. (2015) also illustrated that patients who feel informed have more hope. Moreover, informed consent is exercised patients are entitled to choose what treatments may be used on their bodies (Hall et al., 2012). If patients are never adequately informed of what has occurred or is occurring within their bodies, how can they adequately know what treatments they wish or do not wish to undergo?

One example of why patients need to be fully aware and informed of the fetal loss of multiples can be seen with a mother whose twin's DNA was found to be in four locations across her body due to resorption (Yu et al., 2002). Confusion ensued when it was discovered that this mother, who had not been previously informed, could be harboring a twin's DNA, as the DNA of the children she birthed did not match hers. Harvard and the Red Cross launched a joint study where they discerned that her deceased twin was, in fact, genetically the mother of her children- making the woman what is known as a *chimeric* (Yu et al., 2002). Although chimerism occurred long before the advent of advanced reproductive technologies, the rise in the use of such technologies only increases the rates of twinning and, as a result, the rates of chimerism as well (Monden et al., 2021).

A Proposed Model for Enhanced Information Delivery Regarding Fetal Loss

Providing patients with information regarding when, how, and why a fetal loss occurred and the anticipated health impacts for both the patient and fetus(es) and offering additional resources when needed can contribute to better preparedness for health outcomes, strengthen patient-provider relationships, and enhance the overall well-being of the survivor(s).

Thus, the following is a proposed model for enhancing the deliverance of miscarriage information:

1. Inform all patients (whether pregnant with singletons or multiples) that conceptus has formed or been lost within their bodies no matter what stage conceptus may be discovered or loss occurs.
2. Provide information and resources regarding the loss. Such information could include, but not be limited to, information on the loss itself, grief resources, or resources for preserving remains (e.g., funeral homes).

If the loss is of multiples, the following detailed information ought to be conveyed in order to help providers and patients understand chances for specific risks and equip the patient/survivor(s) with future information they may need for medical, social, legal, or other reasons, and allow patients to exercise fully informed consent:

- a. Chorionicity (i.e., type of placentation) of multiples;
- b. Cause of death in gestation if able to be identified (typically not discernable but most often believed to occur due to genetic abnormalities (Zamani & Parekh, 2021));
- c. Known or estimated timing of cessation of viability.

Limitations

Despite existing and surrounding evidence, more research is needed on the experiences of patients who experience miscarriage and fetal loss, especially those of pregnant patients with loss of multiples. The author of this text is currently undergoing review by an institutional review board for a study that analyzes the experiences of patients with Vanishing Twin Syndrome during their initial diagnosis and subsequent prognosis. However,

it should be noted that research in this area can be complex. Ultrasonography, the primary means of identifying VTS, was not of mainstream use in maternal medicine in the United States until the mid-90s.

Therefore, numerous patients were born between the initial VTS discovery in 1945 and the mid-90s. As a result, many patients have been the product of a VTS pregnancy who may not be aware of their VTS status or, if they are somehow aware, they may or may not have ever received a formal medical diagnosis simply due to an absence in technology. In some cases, these VTS patients may have received a diagnosis at birth where, at times, there can be evidence of a deceased fetus or blighted ovum to indicate fetal formation/cessation of viability. Individuals falling into the older population must not be excluded simply due to this inconvenient age-related technological disparity. Good science accounts for all the data, and good clinical protocols are established by accounting for the views of all stakeholders and constituents. Accurate conclusions and inclusive policies cannot be curated when pieces of data or important points of view are missing.

To make matters slightly more complex, protocols for miscarriage information and disposal of fetal remains can vary between hospitals, states, and nations (Forster, 2003). For example, a Catholic hospital may have different protocols for what they define as *life* or *resembling life*, which may determine what type of fetal remain disposal options are presented/available to patients. A brief search on this topic will reveal a global, rather hostile landscape containing legal feuds of patients wanting to memorialize remains but legally being unable to and patients who want little or nothing to do with deceased fetal remains that are legally forced to make arrangements (Nahidi et al., 2021; Middlemiss, 2021; Morgan, 2002; Sheriar, 2020). The landscape becomes crowded with views asserting various defining points for the beginning of life. However, some may argue this is a red herring and what constitutes the definition of *life* or the *beginning point of life* on behalf of the medical system and provider is distinct from what the patient may or may not believe. Nonetheless, the *life* views of providers and the overall medical system in which the patient participates should be considered when analyzing the patient experience during the diagnosis and prognosis of fetal loss, especially in the case of multiples, as these views can have both direct and indirect ramifications that may have varying effects.

Conclusion

Such protocols and policies, as proposed above, can affect patient experiences during pregnancy, at birth, and post-partum as well as the lives and well-being of any surviving child(ren). Thus, any model for enhancing miscarriage information delivery must consider these variances and the extent of their potential impacts. Quality care must be provided for all patients who experience fetal loss, including those who experience loss of multiples, as with VTS patients. Standards of care, policies, and protocols must be established and continuously evaluated to enhance treatment.

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