Reviewer’s report

Title: Perceptions of parents and religious leaders regarding minimal invasive tissue sampling to identify the cause of death in stillbirths and neonates: results from a qualitative study

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Reviewer: Sherri Bucher

Reviewer’s report:

Thank you for the opportunity to review this interesting and important article, "Perceptions of parents and religious leaders regarding minimal invasive tissue sampling to identify the cause of death in stillbirths and neonates: results from a qualitative study." This manuscript will be of interest to researchers, implementation scientists, program implementers, and international partners whom are concerned, in particular, with the global challenge presented by high rates of stillbirth and neonatal mortality. This article will also be of potential interest to investigators exploring both the underlying mechanistic, and contextual factors which underpin morbidity and mortality among premature infants. Results reported in this paper will also help to inform the efforts of colleagues whom are working to understand, and prevent, premature births, stillbirths, and neonatal mortality among predominately Muslim populations, particularly within Pakistan and other Southern and Southeastern Asian settings, where high rates of premature delivery, stillbirth, and newborn mortality are pernicious challenges.

Although this paper describes a small, qualitative study, in which focus group discussions and key informant interviews were conducted among a variety of stakeholders (parents, families, and religious leaders), to ascertain the feasibility and acceptability of minimal invasive tissue sampling (MITS) to identify cause of death among stillbirths and neonates, it makes an important contribution to the literature. Due to the large numbers of stillbirths and neonatal deaths which occur around the globe each year (around 5 million deaths total), most of which occur in low/middle-income countries (LMICs), neonatal mortality now comprises nearly 45% of all under-5 years child deaths each year. Complications from premature birth are a leading cause of death among live born infants from 0 - 28 days, and intrapartum asphyxia is thought to underlie many fresh stillbirths. Pakistan has one of the highest rates of stillbirth and newborn death globally. Any new knowledge or use of techniques, such as minimal invasive tissue sampling, that can be applied to address the twin challenges of stillbirths and neonatal mortality, and potentially uncover the mechanistic causes of death, are of potential benefit.

Stillbirths and neonatal deaths are often highly traumatic, and stigmatizing events for the families and communities involved. Full autopsy, the gold standard for determining certain or probable biological causes of death, is often considered to be a highly invasive and unacceptable option by grieving families. In addition, within many poorly resourced health systems, neither the skilled human resources nor infrastructure may be available to support adequate conduction of full autopsy. Finally, some stakeholders may have religious objections to autopsy, considering the procedure to be a desecration of a loved one's body. In order to address some of these challenges and barriers, researchers in the past have conducted "verbal" autopsies, or "social"
autopsies, to identify clinical surrogates which, considered as a whole, may help determine probable cause of death, based on clinical symptomology, and/or social determinants which are proximal causes of death. These methods, although they have utility and importance as part of an integrated strategy by which researchers can unravel the complexity of premature birth, stillbirth, and neonatal mortality, still do not provide actual biological samples that might help determine the underlying pathologies, or mechanistic cascades, which lead to fetal or newborn death.

The authors conclude that, among the respondents in their sample, MITS is generally feasible and acceptable. One limitation of this study is the fact that it was conducted among a small sample of parents whom were not suffering from immediate fetal or newborn loss. This somewhat limits the generalizability of the results. However, as this is a preliminary feasibility and acceptability study that is part of a larger on-going protocol, in which MITS is being offered to parents and family stakeholders as an option to determine cause of death, these additional data, regarding the potential feasibility and acceptability of MITS among mothers, fathers, and relatives experienced a fresh fetal or neonatal loss, will be collected.

The design, methods, and analysis employed for this study were appropriate. Ethical approval was obtained; the authors report that appropriate informed consenting procedures were followed. The manuscript is well-written.

It is recommended that this paper be accepted for publication.

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