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Signature:

Ashley Meehan

Date

“It is the Will of God:”
Religion’s Influence on Minimally Invasive Tissue Sampling (MITS) through the CHAMPS
Network in Bangladesh and Sierra Leone

By

Ashley Meehan
Master of Public Health

Hubert Department of Global Health

John Blevins, ThD
Committee Chair

Ahoua Kone, MPH
Committee Member

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By

Ashley Meehan

Bachelor of Applied Health Science
Bowling Green State University
2017

Committee Chair: John Blevins, ThD
Committee Member: Ahoua Kone, MPH

An abstract of
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Abstract

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Eighty-five percent of under-five deaths occur in African and South Asian countries and causes of these deaths are often misreported. Minimally Invasive Tissue Sampling (MITS) procedures were developed to collect body fluid and tissue with minimal damage to the body. The Child Health and Mortality Prevention Surveillance (CHAMPS) Network seeks to improve cause of death determination and reporting through the use of MITS. CHAMPS conducted formative research to understand community beliefs and practices surrounding death and burial in the sites where they planned to implement MITS. Secondary qualitative data analysis was conducted on interview and focus group data from Bangladesh and Sierra Leone to understand the influence of religion on the acceptability, practicality, and implementation of MITS. Religion was found to influence beliefs about causes of death, practices related to burial preparation, and desires to learn the cause of death, all of which had implications for the feasibility framework developed by CHAMPS, which assessed feasibility according to three factors: acceptability, practicality, and implementation. Participants in both countries hold spiritual and non-spiritual beliefs about causes of death, with the most prominent belief that death is “the will of God.” In Bangladesh, Shariah justified burial preparation and funeral rituals, but was not referenced by participants in Sierra Leone. Participants desired to learn the cause of death if it meant future death could be prevented in Bangladesh, but they did not find the MITS procedure to be acceptable due to Islamic doctrine related to harming or causing pain to the body. In Sierra Leone, there was less desire to learn causes of death because of the belief that death was God’s will, but more acceptance towards the MITS procedure. Timing of the MITS procedure and tissue extraction was the most notable consideration for practicality in both countries, and the use of community leaders is essential for the implementation of MITS in Sierra Leone.

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Acronym List

- **CDA:** Complete Diagnostic Autopsies
- **CHAMPS:** Child Health and Mortality Prevention Surveillance Network
- **CoD:** Cause of Death
- **MITS:** Minimally Invasive Tissue Sampling
- **VA:** Verbal Autopsy
- **FoD:** Father of Deceased
- **MoD:** Mother of Deceased
- **ReL:** Religious Leader
- **TDH:** Traditional Healer
- **TBA:** Traditional Birth Attendant

Definition of Key Terms

- **Akromon:** “genie attack”
- **Allah:** Arabic term for God
- **Alem:** Learned men, the guardians of the legal and religious traditions of Islam.
- **Amulet:** An ornament of small piece of jewelry thought to give protection against evil, danger, or disease. In Islam, amulets are generally lockets containing verses from the Quran or other Islamic prayers and symbols.
- **Atman:** In Hinduism, “the soul”
- **Batash laga:** “supernatural force”
- **Bhagavad Gita:** A sacred Hindu text
- **Bhagavān:** Deity or God in the Hindu tradition
- **Brahmin:** A class in Hinduism specializing as priests, teachers, and protectors of sacred learning across generations.
- **Dai:** A traditional birth attendant in Bangladesh
- **Dosh:** “faultiness”
- **Dushon Batash:** “bad air”
- **Fatwa (Fatawa pl.):** A formal legal opinion or decision of a religious scholar on a matter of Islamic law.

- **Genie:** In Arabian and Muslim mythology, an intelligent spirit of lower rank than the angels.
- **Hadith** (Ahadith pl.): Documented traditions of the teachings and actions of the Prophet Muhammed, which were not in the Quran, but which were recorded for posterity by his close companions and the members of his family.
- **Haram:** Something that is forbidden in Islam.
- **Hujur, Huzur, Huzoor:** Muslim religious leader.
- **Imam:** The leader of the Muslim community.
- **Janaja Prayer:** A ritual Muslim death prayer that releases the soul from the body.
- **Jin, Jheen, Jin Ashra:** Genies
- **Kabiraj, Kaviraj:** Traditional healer
- **Karma:** A doctrinal belief across Hinduism that all actions, good or bad, will produce appropriate moral consequences, either in this life or a next life
- **Kasankay:** “to wrap in a shroud”
- **Mal:** Property, often referred to in Islam as Allah’s property.
- **Maslaha:** Islamic principle that when the benefits outweigh the damages, the beneficial action should be taken.
- **Milad:** A religious ritual performed after the death of a person.
- **Muru:** “dustbin”
- **Pa kuru konon:** “it is the work of God”
- **Pishach:** Ghost, spiritual body, or other evil spirit
- **Purohit:** A Hindu priest.
- **Shariah:** The body of Islamic sacred laws derived from the Quran, the sunnah and the Ahadith.
- **Takbir:** Literally translated “God is greatest,” phrases used in prayer, in times of distress or joy, or to express resolute determination or defiance.

CHAPTER 1: INTRODUCTION

GLOBAL CHILD MORTALITY

In 2017, 5.4 million children died before the age of five, 4.1 million (75%) of those dying before completing their first year of life (World Health Organization (WHO), 2017). Eighty percent of under-five deaths in 2017 occurred in sub-Saharan Africa and south Asia. Countries in sub-Saharan Africa have the highest under-five mortality rate in the world, followed by south Asia; about 1 in 13 children in sub-Saharan Africa and 1 in 22 in south Asia die before their fifth birthday. Most of these deaths are from preventable causes and treatable diseases. In contrast, rates of under-five mortality are lowest in Australia and New Zealand, where only 1 in 263 children die before their fifth birthday (UNICEF, WHO, World Bank, & UN-DESA Population Division, 2018).

ESTIMATIONS OF AND ERRORS IN REPORTING CHILD MORTALITY

While rates of under-five mortality have improved globally in recent years, there are many shortcomings in child mortality reporting which hinder efforts of mortality prevention. Countries with high rates of premature mortality often have poor-performing vital registration systems and incomplete and inaccurate data about causes of death (Bassat et al., 2017; Jha, 2014; Mathers, Fat, Inoue, Rao, & Lopez, 2005; Soleman, Chandramohan, & Shibuya, 2006; You et al., 2015). For reference, only eight of the 54 countries on the African continent and two of the eight countries in south Asia have medically-certified deaths reported in civil registry systems; countries like Bangladesh and Sierra Leone are not included in the World Health Organization's Mortality Database (World Health Organization (WHO), 2018b). The absence of these countries in this database can be due to lack of or poor-functioning mortality reporting systems, failure to report deaths according to the international coding standard (ICD codes), or lack of medical

certifiers to complete death certificates (Mathers et al., 2005; World Health Organization (WHO), 2018a).

The Gold Standard: Complete Diagnostic Autopsy

Acquiring detailed information about specific causes of under-five deaths requires timely and accurate measurements of mortality (Mathers et al., 2005; UNICEF et al., 2018). Globally, the complete diagnostic autopsy (CDA) is the gold standard for determining a cause of death (Bassat et al., 2017, 2013; Byass, 2016; Garenne, 2014). In many cases, deaths that do not occur in health facilities do not get reported in a timely manner, if at all; many societies and cultures around the world bury bodies of deceased individuals as quickly as possible in home villages (Bassat et al., 2013; Cox et al., 2011; Garenne, 2014). For deaths that do occur in health facilities, infrastructure and resource constraints inhibit performance of autopsies and histopathological testing to determine cause of death (Bassat et al., 2017, 2013; Gupta, Bharti, Singhi, Kumar, & Thakur, 2014). Even if health facilities had the capacity to perform autopsies, social and cultural influences may lead to low consent rates. In both high- and low-income settings, the most common reasons for denying an autopsy of a relative include fear of mutilation of the body, not wanting to delay the funeral/burial, and cultural and religious objections (Bierig, 2001; Cox et al., 2011; Fan et al., 2010; Lewis et al., 2018; Lishimpi et al., 2001; Oluwasola et al., 2009; Sanner, 1994).

VERBAL AUTOPSIES

In low- and middle-income countries, complete diagnostic autopsies are often not performed due to the level of expertise and demand on infrastructure required to perform them in addition to the cultural factors listed above. In lieu of CDAs, a verbal autopsy (VA) is a tool often used to determine the cause of death. Verbal autopsies involve interviewing relatives about

behaviors and potential signs and symptoms the deceased may have exhibited in the time leading up to their death, and includes utilizing physician review or algorithms to determine a cause of death (Butler, 2010; Garenne, 2014). In places where clinical autopsies and other diagnostic tools are unavailable, VA is a more feasible option for making a cause of death determination (Byass, 2016; Garenne, 2014; Soleman et al., 2006).

In addition to being the most feasible alternative to clinical autopsies in limited-resource settings, VAs are able to provide individual patient context that clinical autopsies may fail to recognize. Consideration for an individual's lived experience is an important necessity in medicine. While disease, illness, and death are often reduced to the cellular level in biomedical science, knowing the patient's specific physical and social condition provides critical information to complete the larger picture of illness and death (Bassat et al., 2017).

Limitations of Verbal Autopsies

Despite the benefits of VAs, they have many limitations. Often criticized for poor reliability and validity, VA questionnaires and disease classification algorithms may differ by community, country, and region, making cause of death determination and comparative analyses over time difficult (Fligner, Murray, & Roberts, 2011; Garenne, 2014; Soleman et al., 2006). Aside from VA questionnaires and algorithms, interviewers and respondents are also sources of bias and error; relying on others to recall observations of another individual and communicate illness accurately can lead to misclassifications and discrepancies in determining cause of death (Bassat et al., 2017; Fligner et al., 2011; Garenne, 2014; Snow & Marsh, 1992; Soleman et al., 2006). In areas where communicable diseases are common causes of death, distinguishing among potential infectious agents to identify specific infections can be difficult because most virologic illnesses present similar, non-specific symptoms. This is further complicated if

individuals did not exhibit any signs or symptoms or illness before death, or if there were multiple underlying causes of death (Fligner et al., 2011; Jha et al., 2005; Quigley, Armstrong Schellenberg, & Snow, 1996; Snow & Marsh, 1992; Snow et al., 1992).

Additionally, social and cultural norms regarding family and household power dynamics and appropriate mourning time complicate the accuracy and utility of VA. If norms expect that only the male leader of the household is to be consulted for VA permission and patient information and they were not the caregiver or in closest contact with the patient, the VA will not yield the most detailed and precise information. If families are contacted for VA too soon after death, they may still be mourning and unlikely to consent to VA (Amuyunzu, 1998; Soleman et al., 2006). On the contrary, if families are sought out for VA too long after death, there may be a more recall error (Snow & Marsh, 1992; Snow et al., 1992; Soleman et al., 2006). In situations where death was sudden or unexpected, especially among child deaths, mourning may go on longer and influence willingness to consent to VA (Soleman et al., 2006).

Public and global health efforts to improve child survival and prevent under-five mortality rely on information about causes of death to inform policy and community interventions. Inaccurate estimations and information about cause of death ultimately generate unsuccessful prevention efforts and inefficient use of limited funds (Bassat et al., 2017; Garenne, 2014). Thus, in regions where under-five mortality is high, verbal autopsy must be supplemented by improved tools and methods for determining cause of death.

IMPROVING CAUSE OF DEATH DETERMINATION AND REPORTING

Minimally Invasive Autopsies (MIAs)

Recognizing the limitations of verbal autopsies and barriers to complete diagnostic autopsies, minimally invasive autopsies (MIAs) were developed to collect samples from a body

quickly and with little alteration of the body (Bassat et al., 2017; Ben-Sasi et al., 2013; CHAMPS, 2017a; Fan et al., 2010). These minimally invasive autopsies involve a procedure known as minimally invasive tissue sampling, or MITS. MITS involves taking small samples of tissue and fluid from key organs in the body by needle puncture. Samples may be taken from key organs such as: lung, liver, spleen, brain, bone marrow, skin, cerebrospinal fluid, blood, stool, and urine. These samples then undergo laboratory testing to determine a more specific cause of death. MITS procedures have demonstrated high sensitivity and specificity in cause of death determination, showing promise for more accurate and reliable mortality data (Bassat et al., 2017; CHAMPS, 2017a; Fan et al., 2010).

The CHAMPS Network

In 2015, the Bill & Melinda Gates Foundation announced a partnership with the Emory Global Health Institute (EGHI) and launched the Child Health and Mortality Prevention Surveillance (CHAMPS) Network in seven countries across sub-Saharan Africa and south Asia (CHAMPS, 2017b; Korschun, 2015). Over the duration of the 20-year program, CHAMPS “seeks to identify definitive causes of death, and prevent child deaths through community engagement, diagnostic and laboratory innovations, surveillance network advances, policy-to-action activities and rapid, open access to data” (CHAMPS, 2017c). Through the implementation of MITS in these countries, CHAMPS is attempting to improve child mortality data collection and reporting (CHAMPS, 2017b).

In many of the countries where CHAMPS is working, complete diagnostic autopsies (CDAs) are uncommon because of poor infrastructure and low consent rates; thus, there is incomplete and inaccurate information about causes of child death (CHAMPS, 2017a).

Considering that MITS is significantly less invasive than CDAs and can be performed quickly,

there is reason to believe that individuals and families may be more likely to consent to a MIA because the main fears of body mutilation and delaying of burial are mitigated (Ben-Sasi et al., 2013; CHAMPS, 2017a; Lewis et al., 2018). However, MITS procedures have been carried out and studied primarily in high-income settings, due to high financial cost and technical resources necessary for the procedures (Bassat et al., 2017, 2013; Byass, 2016; Lewis et al., 2018). In low- and middle-income settings, some research has been conducted regarding the hypothetical acceptability of the procedure, but there is still missing information about actual acceptability and feasibility of implementing MITS (Bassat et al., 2013; Byass, 2016; Maixenchs et al., 2018, 2016).

Given that each country and community being explored by CHAMPS has their own unique and specific cultural, social, and religious dynamics, the potential influence of these dynamics on the acceptability and feasibility of implementing MITS must continually be assessed (Ben-Sasi et al., 2013; Byass, 2016). To evaluate the acceptability and feasibility of implementing MITS at the CHAMPS study sites, formative research was conducted to understand the different cultural, social, religious, and geographical factors that might influence acceptability and feasibility of implementing MITS (CHAMPS, 2016). Because religious and cultural objections are often reasons for denying a complete diagnostic autopsy, the potential influence of religion on MITS specifically must be explored in the CHAMPS country contexts (Oluwasola et al., 2009).

THE IMPORTANCE OF AND NEED FOR COMPARING CULTURAL AND RELIGIOUS CONTEXTS IN BANGLADESH AND SIERRA LEONE

Bangladesh and Sierra Leone exist in the two regions where under-five mortality rates are highest: Bangladesh in south Asia and Sierra Leone in sub-Saharan Africa (UNICEF, 2017b;

UNICEF et al., 2018). Under-five mortality rates in Bangladesh and Sierra Leone are 32.4 and 110.49 deaths per 1,000 live births, respectively (UNICEF, 2017a, 2017c). For reference, the United States has an under-five mortality rate of 6.6 deaths per 1,000 live births, demonstrating the stark contrast between childhood death in these different regions of the world (UNICEF, 2017d).

To improve knowledge about causes of childhood death in these two countries, acceptability and implementation of autopsy tools must be explored with consideration to the cultural and religious contexts. Bangladesh and Sierra Leone both have largely Muslim populations, but interfaith harmony and cultural norms differ between these two countries and may provide different interpretations of how religious and spiritual beliefs shape faithful responses after death (Harding, 2011; Uddin, 2006a).

Doctrines in Islam are generally more prohibitive than doctrines in Christianity or Hinduism in regard to the acceptability of autopsy; primary teachings in tension with autopsies include the dictum that bodies of deceased individuals should be washed, wrapped in a shroud, and buried within 24 hours and within 1-2 miles of the site of death; the belief that the deceased individual can still feel pain after death; and the belief that the body of an individual belongs to God and should be returned to God (Gatrad, 1994; Hedayat, 2006; Lewis et al., 2018; Sajid, 2016; Sarhill, LeGrand, Islambouli, Davis, & Walsh, 2001; A Sheikh, 1998). Exploring perspectives of individuals within two communities with different religious and cultural landscapes can inform how CHAMPS should address specific community needs and concerns, improve child mortality surveillance in each context, focus global health funding, and tailor health promotion and mortality prevention initiatives to the specific causes of child mortality (Gatrad, 1994; Hedayat, 2006).

CONCEPTUALIZING RELIGION

While it may be difficult to identify a singular, comprehensive definition of religion, Émile Durkheim's suggested definition from 1912 can be used as a starting point to conceptualizing what religion is: "A religion is a unified system of beliefs and practices relative to sacred things, that is to say, things set apart and forbidden – beliefs and practices which unite into one single moral community called a Church, all those who adhere to them" (Durkheim, Cosman, Cladis, & Cladis, 2001; Jones, 1986; Platvoet & Molendijk, 1999). For the purposes of this thesis, I am accepting Durkheim's definition of religion as a system of beliefs and practices but will depart from his description about the uniting of beliefs and practices into "one single moral community called a Church." Specifically, I will emphasize the importance of beliefs (i.e. doctrine) and how the influence of religious belief in people's lives often manifests in practices – not only limited to a church or other place of worship, but also in daily life. In contemporary religious life, people's moral frameworks are often a blend of many influences, not a single moral view as described by Durkheim (Graham, Walton, & Ward, 2005).

PROBLEM STATEMENT

Recognizing that religious beliefs and practices are lived out in the context of daily life that is shaped by local community and culture means that there are complex nuances that must be explored to fully understand the influence of religion on people's lives. During experiences of death and burial, religious doctrine provides normative claims about what is right thought and right action. At times, individuals may choose to act in ways that align with or are in tension with religious doctrine. As a result, it is unclear how these potential alignments and tensions at the time of death will influence beliefs about death, practices surrounding burial, and acceptability towards CHAMPS and MITS in Bangladesh and Sierra Leone.

PURPOSE STATEMENT

Exploring religious and spiritual influences on beliefs, practices, and rituals surrounding death and burial using qualitative methods is critical to inform the implementation of MITS in CHAMPS country sites. Information about the religious and spiritual underpinnings of individual and communal beliefs and practices regarding death and burial can be used to maximize the utility of future CHAMPS efforts while maintaining respect and dignity for host communities.

RESEARCH OBJECTIVE AND AIMS

In order to adequately describe acceptability and practicality of implementing CHAMPS child mortality surveillance in Bangladesh and Sierra Leone, it is important to understand the religious beliefs about death and practices surrounding burial in each country context.

The aims of this study are as follows:

Aim 1: Identify beliefs about causes of child death in Bangladesh and Sierra Leone.

Aim 2: Document the enactment of religious beliefs surrounding death and burial in Bangladesh and Sierra Leone.

Aim 3: Determine how religious beliefs and practices influence acceptability and feasibility of MITS implementation by CHAMPS.

SIGNIFICANCE STATEMENT

The findings of this study could be utilized to guide future community engagement activities within the CHAMPS Network and to contribute to the existing body of knowledge about the dynamic nature of religion as a social phenomenon that influences health behavior and decision making, specifically in regard to autopsies and child mortality surveillance.

CHAPTER 2: LITERATURE REVIEW

INTRODUCTION

In order to understand the influence of religion on MITS in Bangladesh and Sierra Leone, a more detailed conceptualization of religion must first be presented. Then, religion will be explored as a social determinant of health and in the contexts of Bangladesh and Sierra Leone, followed by discussion of religion's influence on burial customs and objections to autopsies.

EXPANDING OUR UNDERSTANDING OF RELIGION

To expand Émile Durkheim's description of religion as a set of beliefs and practices, we can refer to Mary Pat Fisher's introduction from her 2011 work, "Living Religions":

"The word [religion] is probably derived from the Latin, meaning 'to tie back,' 'to tie again.' All of religion shares the goal of tying people back to something behind the surface of life – a greater reality, which lies beyond, or invisibly infuses, the world that we can perceive with our five senses. Attempts to connect with this greater reality take many forms. Many of them are organized institutions, such as Buddhism or Christianity. These institutions are complexes of such elements as leaders, beliefs, rituals, symbols, myths, scriptures, ethics, spiritual practices, cultural components, historical traditions, and management structures. Moreover, they are not fixed and distinct categories, as simple labels such as "Buddhism" and "Christianity" suggest. Each of these labels is an abstraction that is used in the attempt to bring some kind of order to the study of religious patterns that are in fact complex, diverse, ever-changing, and overlapping. In addition, not all religious behavior occurs within institutional confines. The inner dimensions of religion – such as experiences, beliefs, and values – can be referred to as spirituality. This is part of what is called religion, but it

may occur in personal, non-institutional ways, without the ritual and social dimensions of organized religions” (Fisher, 2011, p.1)

In this description, Fisher outlines a number of key components that are helpful for conceptualizing religion and understanding its impact on human belief and behavior. First is the notion that religion connects humans to something beyond the five senses. This may include connection to spirits, deities or a God, or other sacred things and beings. This does not limit our understanding of religion to monotheist or well-known theologies like Christianity and Hinduism, but can include belief systems that see the spiritual capacity of the natural world, such as traditional religions and animism. In his book, *Religions in Practice*, John Bowen defines religion similar to how Durkheim and Fisher define it, as a set of “ideas and practices that postulate reality beyond that which is immediately available to the senses” (Bowen, 1998).

Second, it is important to note that belief in and connection and interaction with the world and things beyond our physical senses “takes many forms” and is often practiced in, but not limited to, formal institutions. The doctrine of these institutions often informs how believers are to connect and interact with the spiritual, supernatural, and sacred realms, but not all religious belief and practice is rooted in a formal institution or written doctrine. When thinking about this relationship between belief and practice or action, we can think about *orthodoxy* (right belief) and *orthopraxis* (right action). Elaine Graham points out that right belief cannot exist without right action, that “a way of knowing is inseparable from doing” (2005, p. 162). The precedence of *orthopraxis* leads us to believe that humans will act in whatever way they feel constitutes a faithful response to what they believe to be right or true. At times, people take these actions even if they challenge or violate religious teachings.

Lastly, Fisher notes that institutions that make up religion “are not fixed and distinct categories, as simple labels ... suggest” (p.1). The complex elements that compose religious institutions are fluid, influenced by their specific contexts and the individual believers that make up the institution (Platvoet & Molendijk, 1999). This also implies that while institutional doctrine is common among a large group of people, there are bound to be regional, communal, and individual differences in the way religion is interpreted and beliefs are lived out. Different explanations of what it means to exist as a human that help orient a person’s understanding of the world are reliant on the cultural, temporal, and spatial lenses with which people see the world (Bowen, 1998; Eliade, 1959; Graham et al., 2005). Rather than thinking about religion as categories such as “Christianity,” “Hinduism,” or “Islam,” it can be understood as a function of daily life that includes beliefs and practices that may or may not be aligned with larger common beliefs and practices of a world religion. Thus, the influence of social and cultural influences on religious beliefs and practices must be taken into consideration when understanding religious influence on health behavior and decision making.

RELIGION AS A SOCIAL DETERMINANT OF HEALTH

Because religion is rooted in local contexts and influenced by the groups of people that share common beliefs and practices of faith, it can also be analyzed in relation to the social structures it helps create (Idler, 2014). Shared belief and practice create communities that can provide social support to its members, having positive mental and social health outcomes. *Orthopraxis* and *orthodoxy* also help regulate behavior by outlining what is right and what is wrong. These moral rules can have positive impacts on health (i.e. prohibition of binge drinking), but can also have negative impacts on health (i.e. anti-LGBTQ doctrine can lead to poor mental health outcomes) (Idler, 2014, p.5-6). Marshall & Smith expressed a similar understanding that

religious beliefs and practices can positively and negatively inform what is considered “right behavior” in their exploration of religion’s impact on the Ebola outbreak and response (Marshall & Smith, 2015). Religious institutions have also been instrumental in caring for their communities as well; relief teams are sent from religious groups to help after natural disasters, schools and hospitals have been established, and religious institutions often serve as a point of contact for a wide range of its community members, ranging from a meeting space for alcoholics’ anonymous groups to the Boy Scouts of America.

Around the world, religious clergy, faith communities, or individual people of faith have realized that ‘right action’ is to serve and care for others. This has led to the formation of small and large-scale faith-based and faith-informed health service organizations. Faith-based organizations (FBOs) have unique ties to their communities that situate them to establish care networks unlike other organizations (Brown, 2014). In Kenya, for example, faith-based health providers provide the most care to people living with HIV of all non-governmental organizations, and were shown to be the most trusted organizations among adolescents in Nairobi (Blevins, 2016; Blevins, Kiser, Lemon, & Kone, 2017).

It is important to note that while faith communities and faith-based organizations have done a tremendous amount of good, it would be unwise to assume that these communities and organizations have done no harm. Religious motivations for abstinence-only-until-marriage education in schools has shown to be ineffective at preventing teenage pregnancy and sexually transmitted infections and religiously-motivated stigma against people living with HIV and AIDS has negatively impacted global HIV and AIDS efforts, to name a few (Blevins, 2016; Santelli et al., 2017). Even though this thesis is not focused on the efforts or outcomes of faith-based organizations or health providers, it has been important to provide some context about the

social power faith communities and religious institutions can have on a community and how they have appeared on the global health landscape.

RELIGION IN CONTEXT

In Christian traditions, there is generally a hierarchy of religious leadership, with clergy going through processes of ordination. In Islam, however, this is not the case. Instead, there are scholars and community leaders who are sought out during times of contention or uncertainty for opinions on how to best proceed faithfully (Kaltner, 2016). Because of this, the idea that interpretation of religious doctrine and practice is dependent on the individual and their cultural context is further emphasized (Hedayat, 2006). Before outlining the different cultural and religious contexts of Bangladesh and Sierra Leone, it is worth mentioning some of the themes and beliefs about parenting, illness, and death that are present among the two major denominations of Islam.

In Islam, parents are thought of with high regard and are understood as more than just legal guardians; parents are supposed to protect their children and raise them well. When children get sick or die, parents often feel responsible for the outcome (Hedayat, 2006). When children do die, it is believed they automatically go to heaven because of their innocence and can then plead with God (intercede) to let their parents in with them (Hedayat, 2006). This belief is often used when comforting parents who have lost a child, as well as the Quranic scripture that says, “Surely we are from God and to Him we are returning (2:156)” (Hedayat, 2006). This sense of belonging to and returning to God has appeared in research surrounding death and autopsy, which will be explored later.

Religion in Bangladesh

Prior to the emergence of Islam in Bangladesh, it is believed that people residing in the region of Bengal belonged to a number of faith traditions, including local traditional religions, Hinduism, and Buddhism. As people began to explain Islam in the Bengali language, many of the words they used had already been ascribed and associated with Hinduism (Uddin, 2006a). Over time, Islam has blended with these pre-existing religions to exert its own political, social, and cultural influence (Eaton, 1993; Hossain, 2012). While the overlap of Hindu and Muslim celebrations is less common now than it was before, the influences of Hinduism on Islam in Bangladesh, in addition to cultural influences of India and Pakistan, make religious and cultural life in Bangladesh unique (White, 2012).

In the Hindu tradition, there is no single authoritative individual or institution, but belief in the authority of the four Vedas and of the Bhagavad Gita (a sacred text) are pervasive across Hindus (Rambachan, 2012). Hindus generally believe in one God with many different forms and names, which are often recited as a mantra prayer during times of mourning or lament (Bhuvaneshwar & Stern, 2013; Gruessner & Benedetti, 2008; Gupta, 2011; Mysorekar, 2006; Rambachan, 2012; Ziffren, 1995). A pervasive doctrinal belief across Hindus is karma, or the belief that all actions, good or bad, will produce appropriate moral consequences, either in this life or a next life (Rambachan, 2012). In focus group discussions with Hindu immigrants in the United States, the death of a child is seen as both bad karma for the parents and for the deceased child (Gupta, 2011). Once all karmic debts and credits have been resolved, the soul, or Atman, is truly liberated and can live with God eternally. This understanding of karma and results of our actions in this life or the next strongly influence beliefs and practices surrounding death and

burial, because failing to aid the soul of a deceased relative may produce bad karma for the living relative (Gupta, 2011; Rambachan, 2012).

While not much research has been done to understand traditional religions in Bangladesh – those that originated in this specific geographic location and have been passed orally from one generation to the next – their presence in daily life, especially among rural Bangladeshis, makes them important for consideration (Awolalu, 1976; Haque, Chowdhury, Shahjahan, & Harun, 2018). Considering our conceptualization of religion as a system of beliefs and practices, the influences of traditional religions on burial and autopsies are just as important to explore as religions such as Islam and Christianity. Traditional religions can include magic/sorcery, sacrifices, spiritual chants and intonations, and amulets for protection against evil spirits (Haque et al., 2018). Traditional religions may also involve the use of herbs and local plants as medicines for physical and spiritual healing, which influences health seeking behavior and relationships with biomedical care providers (Awolalu, 1976; Bakshi et al., 2013; Haque et al., 2018).

Across the Indian subcontinent, it is estimated that around eighty percent of people utilize traditional and herbal medicines as a part of their regular health care. A common traditional form of healing in Bangladesh includes Ayurveda, a healing system that originated in India around 5000 BCE (Krupa, Sureshkumar, Silambarasan, Priyadarshini, & Ayyanar, 2019; Shankar, 2018). Now practiced widely in Bangladesh, Ayurvedic medicine utilizes a systems approach to understand well-being as a component of the biological and social systems that exist – a connected relationship between human beings, the communities and societies they create, and the natural world (Payyappalli, 2018; Ramaswamy, 2018; Shankar, 2018). Ayurveda focuses on the use of herbal remedies to achieve harmony among the biological, ecological, and social worlds

an individual exists within; when harmony among these worlds is attained, individuals will experience true well-being (Ramaswamy, 2018). The pervasiveness of a worldview that conceptualizes human identity as a producer and as a product of the natural world will strongly influence individuals' conceptualization of other world religions, death, and the afterlife.

Additionally, Islam is more strongly tied to political history and contemporary political life in Bangladesh than in other countries. In 1971, Bangladesh declared independence from Pakistan and professed a commitment to secularism in their constitution (Uddin, 2006a). By the mid-1970s, however, a number of changes in government softened the proclamations of secularism and opened Bangladesh to the influence of Islam in state and public affairs (Devine & White, 2013). Even though Bangladesh is not an official Islamic state and citizens have religious freedom, Islamic principles and teaching are prominent throughout the country and in government parties (Ahamed, 1990).

In Islam, Shariah, or Islamic law, provides guidance on the ways Muslims are to relate to Allah and to one another, both in rituals of worship as well as in informal customs and formal laws (Britannica Concise Encyclopedia, 2017). Slightly different variations of Shariah exist in different Islamic schools of law, which have developed and adapted over time (Esposito, 2003; Vikør, 2014). Because variations in Shariah exist and guidance on modern-day issues may not be represented in Shariah, people may turn to scholars of Islam to issue a fatwa – “a legal-theological opinion based on Shariah, the religious law” (Berger, 2014; Vikør, 2014). When a fatwa is issued, there are no legal obligations to comply because they are determinations based on religious law about what a Muslim *should think*, not what Muslims *must* do or think (Berger, 2014). The absence of a central governing leader in Islam who has religious authority over the faithful leads followers to trust and value determinations made by scholars of Islam, providing

more power and weight to fatawa (Hedayat, 2006). In 2001, the Bangladesh High Court ruled that issuing a fatwa was illegal after a number of fatawa led to the violation of human rights against women (Reproductive Health Matters, 2001). However, in 2011, the ruling was overturned allowing those fatawa to stand, indicating that they “[are] an integral part of Islamic religious practice” (BBC News, 2011). Islam in Bangladesh has clearly played an influential role in political and civilian life, and understanding where Islam can overlap and diverge from governmental rule is important for determining the most appropriate action for CHAMPS to take to ensure that communities are respected in Bangladesh.

Religion in Sierra Leone

In Sierra Leone, the influence of religion in political life and national development differs from that in Bangladesh. In Bangladesh, some national parties have been developed on the basis of religious identity, but in Sierra Leone, the civil war during the 1990s led religious groups to develop interfaith coalitions to restore peace on all sides of the turmoil in the government. Interfaith harmony in Sierra Leone among members of African Traditional Religions, Christianity, and Islam has been highlighted as an example for countries and communities across the world (Graybill, 2017; Penfold, 2005).

Similar to Bangladesh, traditional religions in Sierra Leone existed long before colonialism and the introduction of Christianity and Islam (Awolalu, 1976; Brown, 2014). Today, most people across the continent of Africa identify as Christian or Muslim, but neither of these identities are completely independent from the influence of traditional religions; a synthesis of Christian and Islamic belief with traditional belief in things like witchcraft and natural spiritual entities persists and was actually re-invigorated during the height of the HIV and AIDS epidemic (Ashforth, 2002; Brown, 2014; Lindland, 2005). In 1976, Dr. Joseph Awolalu from

Nigeria pointed out that traditional African religions have often been reduced to animism—the attribution of a soul to plants, inanimate objects, and natural phenomena. While there are many traditional religions that involve belief in supernatural powers of the material world, to simplify traditional religions in this way is to misrepresent the complexity and misunderstand the powerful influence these beliefs and practices have on the everyday lives of people across the continent (Awolalu, 1976).

Considering the historical presence of traditional religions and traditional healing therapies across Africa and in Sierra Leone, traditional leaders and healers have significant clout in their communities (Bakshi et al., 2013). People of both Temne and Mende ethnic groups, two of the largest in Sierra Leone, expressed their reliance on traditional healers; in many places around the country, biomedical care is often unavailable, too expensive with inflexible payment systems, and too impersonal, which often leads people to seek care from traditional healers that have established relationships in the community (Bakshi et al., 2013).

When Islam arrived in Sierra Leone during the 13th through 19th centuries, indigenous people groups were already practicing traditional religions. As Islam began to take root, new believers often blended traditional beliefs and practices with Islamic beliefs and practices. As European colonists began to arrive with Christianity, European culture and Christian beliefs and practices further convoluted what it meant to follow traditional religions, Islam, and Christianity as a Sierra Leonean (O'Brien & Rashid, 2013).

Interfaith harmony between Muslims and Christians in Sierra Leone has been an example for countries and communities everywhere. Interfaith marriages are not uncommon, and leadership from both faith groups have been active in politics, economics, and social life. The degree of interfaith harmony has contributed to a religious landscape where conversions and

overlapping of religious affiliation is common – it is not unusual to be both Christian and Muslim (African Press Organization, 2013; Marshall & Smith, 2015; The Economist, 2014). The mutual appreciation of different faith groups was strengthened during the civil war in the 1990s, as both groups strongly advocated for peace. During this time, Muslim and Christian religious leaders formed the Inter-Religious Council of Sierra Leone (IRCSSL). With the support of other national and international organizations, the IRCSSL was able to help negotiate peace agreements at the end of the war and was tasked to lead reconciliation activities across the country (Graybill, 2017; Penfold, 2005).

Less than fifteen years after the civil war ended in 2014, Sierra Leone was one of three West African countries to experience a massive outbreak of the highly-infectious and highly-fatal Ebola virus (World Health Organization (WHO), 2016b). International actors worked to create guidelines on safe handling of deceased individuals, build partnerships with local community leaders to track and contain cases, and establish stronger infrastructure for future outbreaks (World Health Organization (WHO), 2016a). This outbreak was a catalyst in the global conversation about the role of religion and burial practices in global health. One of the key lessons learned in Sierra Leone was that “religious dimensions of behavior change, for example on burials, highlight the value of community expertise and the need to draw on it more purposefully and systematically” (Marshall & Smith, 2015). CHAMPS has taken this recommendation seriously by conducting formative research with community leaders and members in an attempt to understand religious influences on death and burial and how that might impact the acceptability and implementation of MITS.

BURIAL, AUTOPSIES, AND RELIGION

Burial Customs in Islam

Burial practices “endorse and duplicate the natural feelings of survivors: they create a social event out of a natural fact” (Innes, 1999, p. 59). Often rooted in religious or traditional belief about death and the afterlife, these practices can also be understood as a way to “speed the deceased on the way to their final destination” (Innes, 1999, p. 60). When an individual in the Muslim community dies, their body is to be washed, wrapped in a shroud, and buried as soon and as close to the site of death as possible, preferably within 24 hours and within 1-2 miles (Cox et al., 2011; Gatrad, 1994; Hedayat, 2006; Lewis et al., 2018; Sajid, 2016; Sheikh, 1998). Islamic doctrine states that the body of a deceased individual should never be cremated or embalmed because they will be returning to Allah (God) in the afterlife, leading many relatives to bury as quickly as possible in hot climates (Gatrad, 1994; McDermott & Ahsan, 1980; Sajid, 2016). In some Muslim communities, relatives do not eat until after the funeral as a sign of respect to the deceased individual, further emphasizing the need to bury quickly (Gatrad, 1994).

Burial Customs in Hinduism

In the Hindu tradition, the belief that we are from dust and will return to dust is common. When a body is inhabited by an Atman, or soul, it is seen as a temple of God. However, after death, the body serves no purpose, which makes autopsies and organ donation more acceptable (Gupta, 2011). While no doctrinal objections to autopsies or organ donation exist in the Hindu tradition, they may be thought to interfere with the transition of the soul to the next life (Gruessner & Benedetti, 2008). When a follower of the Hindu tradition dies, relatives of the deceased wash the body (preferably with holy water from the Ganges river) (Bhuvanewar & Stern, 2013; Gupta, 2011; Mysorekar, 2006). After the body is washed, it is placed in an open

casket or similar structure to be transported for cremation. Dressed in white, the color of death, relatives transport the body chanting the mantra prayer of the names of God, which is believed to help the soul transition to its next stage, either towards liberation and eternity with God or towards its next life (Bhuvaneshwar & Stern, 2013; Gupta, 2011; Michaels, 2004; Rambachan, 2012).

After a Purohit (Hindu priest) prays over the body, it is cremated, and the ashes are spread in the holy Ganges river or in a river or pond (Bendann, 2007; Bhuvaneshwar & Stern, 2013; Gupta, 2011; Laungani, 1996, 1997; Mysorekar, 2006). In the focus groups conducted by Gupta (2011), participants noted that babies and young children are not cremated; participants in one focus group mentioned that any child over the age of two was cremated, but this age was not confirmed in other focus groups.

Objections to Autopsies

In Nigeria, researchers found that fear of mutilation of the body was the most salient reason to deny an autopsy (Oluwasola et al., 2009). This fear is not just held by individuals in Nigeria, however. Studies from Zambia, China, and Sweden showed similar results: relatives rejected autopsies because they feared mutilation of the body (Bierig, 2001; Lishimpi et al., 2001; Sanner, 1994).

Regardless of faith tradition, relatives of deceased in Uganda declined autopsies of their family members because they did not wish to delay burial. If a death occurred in a health facility and an autopsy was offered to be completed that same day, families were more likely to consent. However, in settings where resources are limited, completing an autopsy quickly is unlikely (Cox et al., 2011). In this specific study, “religion” was the reason for declining an autopsy in only 1% of cases, which was not explored further. It is possible that the reason for declining an

autopsy of “not wanting to delay burial” is rooted in a religious belief about the timing of burial, but this was not explored and it is unclear how differences in faith tradition did or would have impacted these results.

The third most-commonly identified reason for declining an autopsy in both the Nigerian study and the Ugandan study related to cultural and religious reasons (Cox et al., 2011; Oluwasola et al., 2009). The study in Nigeria found that 40% of relatives who had once previously denied consent to an autopsy stated that religious objection was their primary motivator to *not* consent, and 82% of all participants who would not consent to an autopsy on themselves identified as Muslim; overall, Christian counterparts were six times more likely to consent to an autopsy on themselves than their Muslim counterparts (Oluwasola et al., 2009). In the United Kingdom, researchers found that Christians and individuals with no religious belief were more accepting of autopsy than their Muslim, Hindu, and Sikh counterparts. When asked about acceptability of a minimally invasive autopsy, there was no significant difference in acceptability between faith groups (Ben-Sasi et al., 2013).

Many Islamic scholars call on the words of the Prophet Muhammed “to break the bone of a dead person is like breaking the bone of a living person,” which has been understood to mean that the body of a deceased individual can still feel pain (Sajid, 2016; Sheikh, 1998). To prevent pain of the body is to respect the body, which is what Muslims are called to do (Sajid, 2016). Performing a CDA or MIA would cause pain, thus disrespecting the body and going against the teachings of Muhammed. Additionally, belief that the body is sacred and belongs to and will return to Allah often motivates people to deny autopsies (Sarhill et al., 2001).

Celine Lewis and others conducted interviews and focus groups with Jewish and Muslim clergy and lay people in the United Kingdom, which revealed that non-invasive autopsies were

most acceptable because they did not cause any harm or alteration to the body. Non-invasive autopsies (NIAs) uses imaging such as computed tomography (CT) or magnetic resonance imaging (MRI) instead of making incisions to the body (Lewis et al., 2018). MIAs were less acceptable than NIAs, but more acceptable than a CDA. Some of the key findings included that both Jewish and Muslim communities are supposed to bury the body as quickly as possible, that Muslims are supposed to leave the body intact, so the body can “be returned in the manner in which it arrived,” and that the deceased individual can still feel pain. Participants noted that inflicting pain needlessly is a sin, thus, steps should be taken to prevent causing pain to the body. Since MIAs make small incisions to the body, they were seen to be “more acceptable” than a CDA because there is less disfigurement and are likely to be less painful. Even though non-invasive autopsies would be religiously permissible, Muslim participants talked about why they might still object, including a desire to bury the body quickly, and because if it was God’s will for their child to die, any autopsy would be unnecessary – emphasizing the “cognitive mechanisms religion provides for explaining [causes of disease and death]” that Peter Brown pointed out in 2014. When talking with leaders from Christian and Hindu traditions, Lewis and her colleagues found a different sentiment: because the soul, not the body, is what matters, there were no obvious religious objections to autopsies (Lewis et al., 2018).

There are, however, circumstances where autopsies may be permissible in Islam. In countries like the United States, autopsies may be legally required in incidences of suspected homicide to determine the cause of death and protect the public’s health (Centers for Disease Control and Prevention (CDC), 2015). Because Muslims are called to follow the law, they have “no choice but to comply” in situations where an autopsy is legally required (Gatrad, 1994; Sheikh, 1998). In some instances, Muslims may decide that something which is haram

(forbidden) may be permissible if it contributes to the greater good of the community or society (Atighetchi, 2007; Beal, 2019; Davis & Peterson, 1996; El-Reshaid, El-Reshaid, & Mada, 2005; Gurley et al., 2011; Rispler-Chaim, 1993). This belief is rooted in the Islamic principle of *maslaha* – when the benefits outweigh the damages, the beneficial action should be taken (Al-Adnani & Scheimberg, 2006; Bamousa et al., 2016; Opwis, 2005; Rispler-Chaim, 1993). In 2011, Emily Gurley and others conducted interviews and focus group discussions in Bangladesh to explore perceptions and potential consent to MITS procedures. They found that participants would agree to MITS in some situations if the results benefitted society, thus reinforcing the principle of *maslaha* and affirming the need to explore MITS in context (Gurley et al., 2011).

In conclusion, it is important to remember that religion is a system of beliefs and practices, understood and enacted differently around the world. Complex local historical, political, and cultural contexts strongly influence religious life, as seen in Bangladesh and in Sierra Leone. Religious *orthopraxis* guides an individual's or community's actions and has been shown to both positively and negatively impact health outcomes. Faithful responses to death and burial in Islam are often at odds with autopsies, making cause of death determinations difficult. Therefore, understanding local religious contexts in Bangladesh and Sierra Leone is critical for the CHAMPS project as they evaluate the acceptability and feasibility of implementing MITS.

CHAPTER 3: MATERIALS AND METHODS

INTRODUCTION

The purpose of this secondary qualitative analysis was to understand the influence of religion on the acceptability, practicality, and implementation (these terms are defined in a subsequent section) of minimally invasive tissue sampling through the CHAMPS program. Formative research was conducted at CHAMPS country sites to capture beliefs, practices, and attitudes towards under-five mortality reporting and potential of implementing MITS. This formative research included interviews, focus groups, and observations (e.g. of burial rituals such as funerals or of the processes by which CHAMPS staff approached families about participating in CHAMPS). Each country site was responsible for recruiting participants and modifying interview and focus group discussion guides for their local contexts in light of their own site-specific research protocols for assessing acceptability, practicality, and implementation. The CHAMPS program office developed a standardized protocol for all social behavioral science research activities, which included interview guides for key informant interviews and semi-structured interviews and a focus group discussion guide. Each country site adapted the guides to their specific contexts by adding in their own questions and topic areas as needed.

Interviews and focus groups were audio recorded, transcribed verbatim, and translated to English at each CHAMPS country site before being sent to the CHAMPS program office in Atlanta, GA. In coordination between the sites and the Program Office, a number of analyses of these narrative data had already been completed by the CHAMPS network to identify challenges and inform the specific ways that surveillance activities are carried within individual sites and across the network. This thesis represents a secondary analysis of these transcripts to understand beliefs about causes of death, document practices surrounding death and burial, and understand

religion's influences on these beliefs and practices in the context of the CHAMPS conceptual framework that examines acceptability, practicality, and implementation. This analysis is original and carried out by the author of this thesis, even though the transcripts were generated through CHAMPS activities independent of this thesis.

DATA

Formative research took place at the CHAMPS country sites, using nomination and snowball sampling techniques to identify potential participants. In consultation with the Program Office, each country site was responsible for identifying participant inclusion and exclusion criteria to ensure that local social, cultural, economic, political, and/or environmental circumstances were considered and appropriately addressed. Recruitment began at centralized institutions in the community and then at local level and more informal institutions and organizations. Initial meetings were conducted with Community Advisory Boards (CABs), local Health Committees, and other community representatives to identify different interest groups and generate lists of initial contacts for participation. The key sampling frame included members of the community who were knowledgeable leaders (elders or matrons), healthcare workers, professionals involved in proceedings related to death (body preparers or mortuary attendants), religious leaders (including representatives of global religious traditions such as Christianity or Islam and representatives of indigenous religious traditions), and other village or traditional authorities.

Interviews were classified as key informant interviews (KIIs) and semi-structured interviews (SSIs). While KIIs are semi-structured in format, they were understood for CHAMPS research to elicit input from key stakeholders; people who have social capital; those who could inform the topic such as religious leaders, elders and matrons, parents of deceased children; and

those who have firsthand knowledge about disease notification and practices surrounding death. KIIs were given more weight in the formative research process, and lasted around an hour in length, with one KII in Bangladesh lasting two hours.

Semi-structured interviews (SSIs) were designed to elicit general perceptions and opinions from representatives such as community health workers and traditional authorities. SSIs were generally shorter than KIIs, lasting around 45 minutes. Focus groups lasted around an hour and a half in length and allowed for semi-structured discussion between interviewer and participants. In each of the focus groups, a note taker was also present to help facilitate conversation and understanding between interviewer and participants, as well as take additional notes that the interviewer may have missed.

The sample of transcripts analyzed in this thesis included 8 KIIs from Bangladesh and 7 KIIS, 3 SSIs, and 4 focus groups from Sierra Leone. The breakdown of participants in each country can be seen below:

	Healthcare Worker		Religious Leader		Traditional Healer or Birth Attendant		Mother of Deceased		Father of Deceased		Total	
	BD	SL	BD	SL	BD	SL	BD	SL	BD	SL	BD	SL
Key Informant Interviews	0	2	3	3	2	2	1	0	2	0	8	7
Semi-Structured Interviews	0	2	0	0	0	1	0	0	0	0	0	3
Focus Groups	0	0	0	0	0	0	0	17 (2 groups)	0	14 (2 groups)	0	4
Total	0	4	3	3	2	3	1	17	2	14	8	14

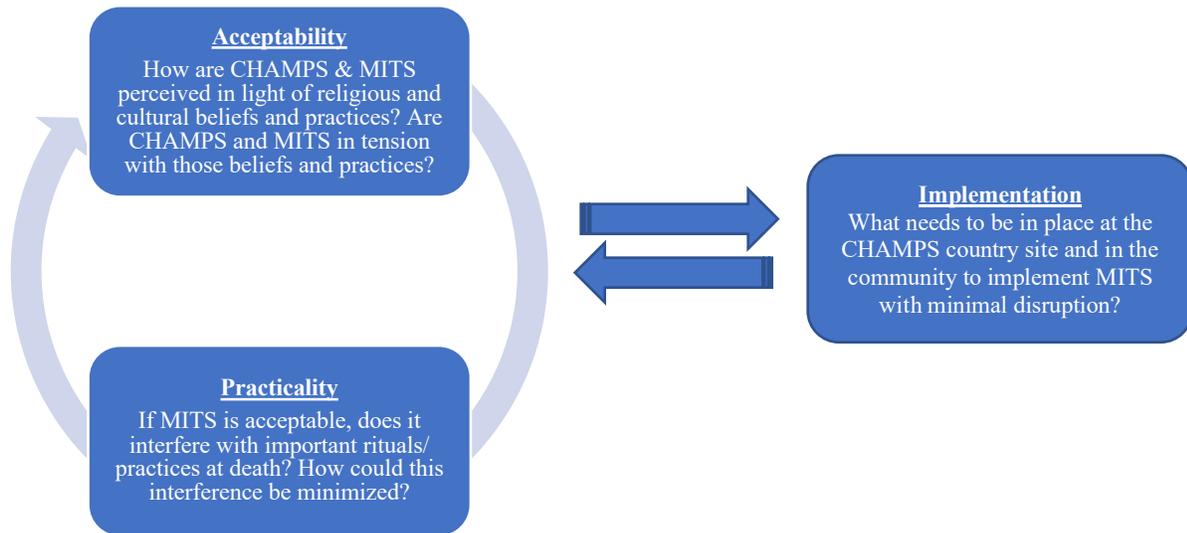
All interviews and focus groups were audio-recorded with permission, transcribed verbatim, and translated to English. The CHAMPS staff in Bangladesh and Sierra Leone

translated the participants' responses from local languages into English on a word-by-word basis rather than by phrases so as to minimize the possibility of interpreter bias during translation. As a result, the transcriptions may not follow standard rules of English grammar. Site supervisors in Bangladesh and Sierra Leone performed quality checks to ensure quality transcription of audio recordings. Bangladesh and Sierra Leone country offices provided the transcripts to the CHAMPS program office in Atlanta, GA. After receiving transcripts that were transcribed verbatim and translated to English, the author entered them into NVivo version 12, a qualitative text-organizing software.

DATA ANALYSIS

Thematic analysis was used to identify patterns or themes relating to the central research question in the data. Braun and Clarke's six phase framework for thematic analysis was used and included: 1) become familiar with the data; 2) generate initial codes; 3) search for themes; 4) review themes; 5) define themes; 6) write-up themes (Braun & Clarke, 2006). During the review of the literature, a short list of codes was developed (*a priori*). As the author became more familiar with the data, *a priori* codes were modified and updated, and emergent codes were created. This process was iterative: as more interviews were read and nuances became more apparent, codes were modified, and segments were re-coded. Once coding was complete, broader themes were identified and described.

Conceptual Framework



The themes identified in the data were explored in the context of CHAMPS' conceptual framework of: acceptability, practicality, and implementation. In this framework, acceptability is understood as the perceptions of surveillance, especially minimally invasive tissue sampling. At this level of the framework, the main question explored is, "How are CHAMPS and the MITS procedure perceived in light of religious and cultural beliefs and practices?" If CHAMPS and MITS are hypothetically acceptable, the next question of feasibility can be addressed: "Is it practical?" Given that people perceive CHAMPS and MITS to be acceptable in theory, CHAMPS and the MITS procedure must also not interfere with the things seen as important at the time of death. In the event that CHAMPS and MITS do interfere with important rituals and practices at the time of death, potential participants may re-assess whether they find it to be acceptable.

If CHAMPS and MITS are acceptable in light of cultural and religious beliefs and practices, practical in that they do not interfere with important proceedings at the time of death, then implementation of MITS by CHAMPS must be considered: "What capacities need to be in place at the CHAMPS country site and in the community to implement MITS?" This component

of the framework explores necessary resources to carry out these activities (specifically MITS) in ways that cause minimal disruption to peoples' daily lives, burial preparation, and funeral ceremonies. If some of the resources needed for implementation with minimal disruption are not in place, then CHAMPS and MITS may cause significant interference at the time of death, which could cause potential participants and community members to re-assess whether or not they find CHAMPS and MITS acceptable.

INSTITUTIONAL REVIEW BOARD (IRB) AND ETHICAL CONSIDERATIONS

Institutional review board (IRB) approval was received from Emory University, the Centers for Disease Control and Prevention, and the local ethical review committees at each country site before beginning formative research. Before beginning secondary analysis for this these, a determination was made by the Emory University Institutional Review Board (IRB) that the secondary qualitative data analysis did not require a review because it was not considered human subjects research. The transcripts were de-identified and participant records were owned by each individual country site staff, to which neither the student researcher nor thesis chair member had access to.

When participants arrived for an interview or focus group, the interviewer read a verbal consent script. The script outlined the purpose of the formative research and the procedures to be followed; described anticipated risks and benefits and participant rights, informed participants that their participation was voluntary and they could refuse to answer any question; and indicated that the interview or focus group would be audio-recorded and transcribed, that it could be erased if the participant requested, and that participation or lack of participation would in no way influence ability to receive health services in the future. Verbal consent for participation was considered sufficient for these interviews and focus groups; signature documentation was not

requested on the basis that consent forms would be the only record linking subjects to participation, that such a record with signed consent could risk confidentiality; and that the research presented no more than minimal risk of harm to subjects. During translation and transcription, all names were removed from transcripts, and participant names were replaced with unique codes to protect confidentiality while still allowing narrative data to be linked to demographic characteristics of the participant.

LIMITATIONS AND DELIMITATIONS

One limitation identified was the inability to make determinations about saturation. Saturation is reached when no new information is found in the data and is often used to inform sample size (Glaser & Strauss, 1967). During the formative research process, CHAMPS was assessing for saturation around their central questions related to the project. Considering that this research is a secondary qualitative data analysis, saturation is out of our control. There are limits on the extent to which religious beliefs and practices are described and explained because religion was not the sole focus of the interviews or focus groups when they were conducted.

CHAPTER 4: FINDINGS

INTRODUCTION

Secondary analysis of eighteen interviews and four focus groups across Bangladesh and Sierra Leone presented three main themes for understanding the influence of religion on the acceptability and implementation of MITS by the CHAMPS program: 1) beliefs about causes of life and death; 2) practices surrounding death and burial; and 3) learning the causes of death and attitudes towards MITS.

Participants in both countries demonstrated that understanding causes of death was not limited to either the biomedical or the religious paradigm but was often a mix of both; most participants that identified God as the cause of death also identified demons, curses, congenital heart defects, and malaria as causes of death. Participants in Bangladesh provided more detail than participants in Sierra Leone about practices surrounding death and burial, but participants in both countries of all faith traditions shared similar desires for the body to be buried as quickly as possible. In both countries, religious structures and authorities serve as a way for community members to report deaths and gather the community for the funeral. Burial prayers for Muslims in Bangladesh are important for releasing the soul from the physical world, and participants discussed the importance of following Shariah law and teachings from the Hadith. In Sierra Leone, social sequelae on the reporting and burial processes from the Ebola outbreak in 2014-2015 were identified. Participants in Bangladesh expressed unanimous desire to learn the cause of death if it meant that that future death and suffering could be avoided but had strong objections to the MITS procedure. Participants in Sierra Leone were less likely to want to learn the cause of death because they believed death was an act of God, but were much quicker to express their acceptance of MITS than participants in Bangladesh.

FINDINGS

Aim 1: Identify beliefs about causes of child death in Bangladesh and Sierra Leone.

Theme 1. Beliefs about Causes of Life and Death

In each of the interviews and focus groups, participants were asked about what caused deaths in cases of miscarriage, stillbirth, and for other children under age 5. Responses about causes of death were categorized into sub-codes of biological (i.e. disease-related), God (i.e. the will of God), and other spiritual causes (i.e. bad air, demons, curses, hexes, witchcraft).

Participants demonstrated that understanding the cause of death is not limited to either the biomedical paradigm or the supernatural/religious paradigm, but is often a mix of both. While the most common response to cause of death was related to God's will, other spiritual causes like "bad air," demons, ghosts, witchcraft, and curses and biological causes such as malaria, congenital heart defects, and germs and sickness were also discussed as legitimate causes of death. In many cases across both countries and all religious identities, participants would identify causes of death from all of these three categories as legitimate causes of death in their communities.

There were a few exceptions to believing in all three categories as legitimate causes of death. In Bangladesh, one traditional healer did not recognize God as a legitimate cause of death, but instead focused on biological and other spiritual explanations. In Sierra Leone, three healthcare workers only explained biological causes as legitimate causes of childhood death. They referenced how other community members believe that God and other spiritual forces are the causes of childhood death, but that they do not recognize these as legitimate. One Christian pastor in Sierra Leone distinctly separated God as a legitimate cause of death from other spiritual forces as illegitimate causes of death.

1a. God

The most prominent response across participants was that the death was part of God's will, in God's timing, or for a reason nobody other than God could know. This was consistent across the majority of participants in Bangladesh and in Sierra Leone, and across faith traditions in both countries; 6 out of 8 participants in Bangladesh and 7 out of 10 interview participants in Sierra Leone talked about child death as a part of the will of God. Of the 31 focus group participants in Sierra Leone, 10 brought up death as the will of God, and all 10 participants of one focus group agreed when asked if death was "in the hands of God."

Of the two participants in Bangladesh who did not talk about death being part of the will of God, one was a traditional healer and the other was a father of a deceased child (FoD). When asked if religion provided any explanation of death, the FoD said he did not know. Of the 3 participants in Sierra Leone who did not talk about death being part of the will of God, all of them were health workers in a biomedical setting.

For 5 of the 6 participants in Bangladesh (83%) and 9 of the 17 participants in Sierra Leone (53%) that brought up death as the will of God, this understanding of God as the one who "takes life away" is predicated on the understanding of God as the one who also gives life and to whom our lives belong. When participants believed that God was the one in charge of creating life, then God has divine power to take back "what was His," or, "His property":

¹"Firstly, birth, death ... everything depends on Allah ... The question that you are actually asking is; first of all, Allah Almighty, the owner of all birth and

¹ Transcriptions of interviews and focus groups are quoted verbatim in this thesis. The CHAMPS staff in Bangladesh and Sierra Leone translated the participants' responses from local languages into English on a word-by-word basis rather than by phrases so as to minimize the possibility of interpreter bias during translation. As a result, the transcriptions may not follow standard rules of English grammar.

death; he does everything, he does everything.” (Bangladesh, Religious Leader, Muslim)

“Hmm, as for me, when I believe in God, if I have a child and he died, I will just say it’s God that took him or her, because he is the one that gave me the child, if he takes the child away again, then it’s all up to him.” (Sierra Leone, Traditional Birth Attendant (TBA), Muslim)

The one participant in Bangladesh that did not describe God as the source of life in their understanding of God’s role in death instead described how the “keys of life” are in God’s hands, and how nobody can know or understand God’s “wish”:

“No, such type of death, how many days is its hayat? The keys of life are in Allah's hands, some baby may die five days later, someone twenty days later, someone one month later, someone five years later and someone ten years later after born. Is there any fixed plan for it? It depends on Allah’s wish, no one have ability [sic] that this is the cause of his/her death.” (Bangladesh, Religious Leader, Muslim)

The remaining 8 participants in Sierra Leone that did not describe God as the source of life in their understanding of God role in death focused on death being in “God’s time” and generally as “God’s will.”

“Interviewer (I): Ok pastor; you as pastor do you play any role in finding out what makes the....to help the family to find out what makes the child dies [sic]?”

Participant (P): My own role I play is when we are in the church and also when they call upon me to offer prayers for dead body the role I do play, I always tell

people that death either a child dies or elderly person dies is the will of God. Death is not in the hands of any other person but it is God that kills and I also preach to them that we should believe that it is God that kills.” (Sierra Leone, Religious Leader, Christian)

1b. Other Spiritual Causes

The influence of traditional religious belief systems on one’s understanding about causes of death was apparent in both Bangladesh and Sierra Leone. These beliefs were classified as beliefs about “other spiritual causes,” i.e. not related to God, and included comments about the devil, ghosts, other spirits, “bad air,” curses, hexes, witchcraft, or spiritual “faults” of the mother or father as the cause of a child’s death.

In Bangladesh, participants described how death was often due to Batash laga (“supernatural forces”) against the pregnant women. This included: Dushon Batash (“bad air”), dosh (“faultiness”), Jin (“genies”), or akromon (“genie attack”). If a pregnant woman was outside at “inappropriate” times of day (typically dawn, dusk, and during the nighttime) or failed to follow orders from community elders and in-laws regarding when to work and when to rest, then she would be susceptible to these Batash laga, most commonly Dushon Batash, dosh, and possession by demons, which could “gobble the fetus”:

“P: Sometimes a demon (Jin) possessed on a pregnant women then it destroy its fetus or gobble the fetus. Like the way the fetus becomes mess up or loss [sic].

I: Suppose, as you have told us about the bad air (Dushon Batash) or possessed a demon (Jin) ...do you have any perception like these?

P: Such kind of perception...if she move by her own judgement that if I go there then this problem may happen. If she doesn’t move in a particular time then the

bad air can't attack her. Therefore the child may survive if she takes steps safely.” (Bangladesh, Father of Deceased, Muslim)

In cases of miscarriage or stillbirth, the pregnant woman is often blamed for moving in a way and at times that caused harm to the fetus. All participants in Bangladesh shared that blame on the pregnant woman for causing death was often decided and communicated by the elders in the community.

“I: What for fault?

P: Physical problem, you move around in bad ways, move around in bad places, people believe in ghosts. The elders. Most of them believe in ghosts, some people say that ghosts were caught by them. they give many excuses

I: Ok apa, the worst thing to say is to walk, what they mean to behave badly?

P: Now this is evening, but look at the pregnant lady, roaming. She is roaming near Shaincha, elders take it badly, it is bad, see, she is standing picking up her legs, this is bad. Around evening will not do badly, but elders say that a lot of things are going on in the evening of Azan. The elders maintain this.”

(Bangladesh, Mother of Deceased, Muslim)

One participant, a FoD, clarified that supernatural forces can only cause death while still in the womb or under 1 month old. Once the child is older than a month, they are grown enough to not be affected by these supernatural forces. Other participants from Bangladesh did not specify that supernatural forces can only cause death while in utero or less than one month of age; they did, however, identify the cause of death of children as the will of God once asked about causes of death among children older than a month.

“I: Such as, does any child die from the influence of ghost or pishach?

P: No. None dies due to that reason after growing enough.

I: Does it attack one month child too?

P: It may attack one month baby, as well” (Bangladesh, Father of Deceased, Hindu)

In Sierra Leone, participants did not speak about other spiritual causes of death with as much detail as participants in Bangladesh did. They spoke generally about witchcraft and curses from others as causes of death but did not specify the ways in which witchcraft is done or curses are delivered. One traditional healer described how relational disequilibrium can lead to miscarriage or stillbirth. If a dispute between two people has led one person to “threaten,” or curse, the other, then she will have a stillbirth. This participant also talked about how a pregnant woman can unknowingly be the target of witchcraft, which can cause either miscarriage or stillbirth:

“I have seen it with my own eyes when someone has threatened another person but the person did not say it in front of that person then you go and “GBagba” that woman who born the child death. Sometimes they will facing witch craft the baby will be in the worm [sic] of the pregnant woman they will tie that pregnancy in the witch craft ways which the pregnant woman will not know but when it time to deliver, the pregnant woman will be able to deliver that child or sometimes they will born the child dead and also I have seen one pregnant woman who deliver a child already rotten I have seen that one here but that person was affected by evils and it was an evil cause.” (Sierra Leone, Traditional Healer, Christian)

Later in the interview, this traditional healer discussed how they comfort parents who experience miscarriage, stillbirth, or child death, by re-affirming that God is the one who gives life and God

is the one who takes life away, and that the child's death is not the parents' fault. The relationship between these seemingly contradictory explanations of death is not clarified, which further emphasizes the negotiations that Sierra Leoneans make when navigating life and death.

“God is the one who gives and God is the one again who takes so let them take courage but when you look into those issues, God is the one who bring deaths to man.” (Sierra Leone, Traditional Healer, Christian)

1c. Biological

The third and final category used to describe beliefs about causes of death is biological; death is caused by disease, sickness, or other pathophysiological explanation. In Bangladesh, 7 of 8 participants discussed biological causes of child death including: congenital heart defects, taking harmful medications during pregnancy, cancer, having sex during pregnancy, malnutrition and lack of breastfeeding, drowning, road accidents, pneumonia, eating certain foods during pregnancy, cholera, chicken pox, and asthma. The one participant in Bangladesh that did not identify biological causes was a traditional healer, who instead talked about Kaviraji principles (traditional healing principles, classified as “other spiritual causes”). Biological explanations for death came from many of the same participants that also described death being the will of God, or God taking back what was His.

“Among this child, some are suffering from heart disorder like congenital heart disease. Some suffers from liver diseases like liver abscess. Different problems occur, suppose jaundice but little children.” (Bangladesh, Mother of Deceased, Muslim)

In Bangladesh, but not in Sierra Leone, two religious leaders and one traditional healer discussed how having sex during pregnancy can lead to miscarriage or stillbirth. One Imam described how

Shariah law specifically forbids sex during pregnancy and giving into temptations and earthly pleasures causes the fetus to die. This same religious leader also talked about how the Quran mandates at least 30 months after the birth of a child to have another child. Failure to wait long enough could lead to miscarriage of the fetus:

“I. Yes. According to Sariah [sic] law what are the reasons; why the children is dead?”

P. According Sariah law there is a rule of sexual intercourse between the spouses.

I. Another one I was saying that baby die in the womb of the mother... are there any reasons? According to your opinion how do they die?

P. The reasons of baby dying in mother’s womb are...it may be happened due to the excessive sexual intercourse during pregnancy time. Secondly, because of having consecutive children, it is found that a year old child is being lactated, and the first year has not been passed through. In the Holy Quran, it is mentioned that at least a gap of thirty months that means two and half years should be taken between having two children.

I. Two and a half years...

P. Two and a half years means from the pregnancy to the time of leaving breastfeeding.... Total two and half years, it is the right of the infant to have breastfeeding. It was seen that they are taking children before completing of the required time.” (Bangladesh, Religious Leader, Muslim)

Similar to Bangladesh, participants in Sierra Leone often described spiritual (God and other spiritual) and biological causes of death as both legitimate causes of death. Biological causes of death identified from 8 of 10 interview participants in Sierra Leone included: Ebola, malaria,

diarrhea from bad water, poor hygiene (not washing hands after defecation and then eating), sexually transmitted infections, and coming into contact with “germs.”

“More especially this sickness call malaria, swollen stomach, and when a child start feeling sick, they will say that child has got malaria and you will treat that child for a very long time but still that child will not survive and those are the sicknesses that are danger for children and even the elders, that is malaria.”

(Sierra Leone, TBA, Muslim)

Two participants from the same focus group shared narratives about how they knew some children died, but spoke of the causes of death vaguely. These narratives included a child becoming “short of blood,” a child being born feet first (breech), and more simply, from “illness.” While they did not specify that they believed an etiologic agent was at play, they also did not specify that these complications were caused by God or another spiritual force. One participant, a religious leader in Sierra Leone, described biological “sickness” as the mechanism by which God causes death for an individual:

“Are well we don’t understand. If an individual sick it is the almighty God who gave him or her that sickness, if God have given him or her the sick no matter how hurry [sic] you are, you just need to leave it to the almighty God do you understand me.” (Sierra Leone, Religious Leader, Muslim)

While many participants in Sierra Leone talked about God and biological disease as causes of death, no other participants explicitly said that God actively causes death by means of biological disease. Some participants expressed that if it was in God’s will for someone to live, then He would cure them – both through direct divine intervention and through the provision of

biomedical treatments and cures – but did not explicitly state that God killed anyone through a disease.

Aim 2: Document the enactment of religious beliefs surrounding death and burial in Bangladesh and Sierra Leone.

Theme 2. Practices Surrounding Death and Burial

Participants were also asked to describe what happens after a child dies in a community. Post-death actions were separated into three categories: preparation of the body, preparation for the burial, and funeral rites. While a similar pattern for preparing the body, preparing for burial, and funeral rites appeared in both Bangladesh and Sierra Leone, some participants were probed further for details and justification of why certain actions were taken.

Although the results are presented here in three separate segments, preparing the body, preparing the grave, and performing the funeral ceremony are usually not isolated segments in real life. This categorization is used for organizing the presentation of findings. For many participants, prayers begin immediately after death, and are continued throughout the funeral ceremony. Washing and wrapping the body, for example, often occur at the same time relatives and neighbors are preparing the grave and coffin. In some participant experiences, the funeral ceremony is held at the grave site, and once the prayers are over, then the grave will be dug, and the body will be buried.

2a. Preparation of the Body

All participants, regardless of country or religious identity, described a general ritual for preparing the body: wash the body and wrap it in a shroud (usually a new, clean, white cloth).

2ai. Miscarriages and Stillbirths

Participants in Bangladesh specified differences in preparing the body between miscarriages (“jotted blood”), stillbirths, and children. In cases of miscarriage and stillbirth, a Hujur (Islamic leader) told one father that the remains can just be “earthened,” or placed under the soil near the parents’ home, without needing to be washed and wrapped. A Purohit (Hindu priest) also stated that for miscarriages and stillbirths, there is no need to wash or wrap the remains, they can just be placed under the soil close to the parents’ home.

I: The fetus who dies before delivery, that fetus, do we say it fetus or anything...

P: We do not call it fetus but we termed it as jotted blood.

I: What do you do with it then?

P: This was thrown away or buried under land.

I: How do you do this, could you tell me?

P: Huge bleeding occurs when jotted blood come out, we dig a hole and buried it in the hole.

I: By throwing...?

P: It was been covered or covered by the soil.” (Bangladesh, Father of Deceased, Muslim)

I: I am trying to say that how you do you do the funeral of dead baby/fetus?

P: According to our thoughts, dead baby/fetus is not incinerated for the funeral.

Then it is inhumed normally in the ground.” (Bangladesh, Religious Leader, Hindu)

In cases of miscarriage or stillbirth, participants in Sierra Leone described how the mother and other women present for the birth will take the body and bury it on their own, without washing or wrapping the body.

“Well if a child dies before been [sic] born, nothing is done about that hence the mother is advice. The mother is treated at the hospital because if a child die inside the womb [sic], it will take time before the mother delivers the child. Some even take one or two months. So if such a child is delivered, it does not have any process they will just say that the child has left the Buma (Leaves/Herbs), and the same thing happens to the child that dies immediately after delivery. Such children are buried secretly and the men do not witness such burial but this is normally done by the elderly women.” (Sierra Leone, Mother of Deceased, Muslim)

“For stillbirth men do not have to see the dead, only the old women who were in the room where the woman give birth will do the process of burial.” (Sierra Leone, Father of Deceased, Muslim)

2a.iii. Children Born Alive but Die Shortly After

If a child is born alive but dies days or weeks later, then Muslim participants in Bangladesh and Muslim and Christian participants in Sierra Leone said they would prepare the child’s body just like they would an adult’s body: wash, wrap, and pray over it. A mother of a deceased child and a dai (traditional birth attendant) in Bangladesh describe the “Muslim” way to prepare a body:

“Being Muslims, we heat up the water. After that, soup, white clothes, perfume, rosewater, etc. are bought from the marketplace and set in place. Then, an elderly will bathe the body, with that warm water. Then, it’s wrapped in the shroud after the bath.” (Bangladesh, Mother of Deceased, Muslim)

“Baby is washed; baby is washed with warm water including jujube leaf (boroi pata). It is needed to do “oju”, deceased is dressed with burial cloth after washing, attar-rose and kohl (surma) is used.” (Bangladesh, TBA, Muslim)

A religious leader outlined the purpose of using jujube leaves according to the Hadith and justifies why washing the body is necessary:

“P: We usually use hot water, mild hot water, baby cannot be tolerate [sic] if the water is not mild. Sometimes, jujube leaf (boroi pata) is mixed with water. According to Hadith, water becomes beautiful if jujube leaf is used. It lessens iron if the water contains iron. It is like medicine. People use different soap. We use mild hot water to wash (the deceased). We have Imam saheb or there are religious minded people who pray namaj and kalam, they give wash and clean it (the deceased) before making deceased wear burial cloth.”

I: Then, hujur you have told that hujur, you use jujube leaf after washing, sometimes soap is also used, anything else?

P: Jujube (boroi) leaf is given, it is told in hadith about the leaf of boroi. Both jujube leaf and soap are given, four to five jujube leaves are mixed during boiling water, soap is used on towel by hand during washing it (the deceased).

I: Is soap used before using jujube leaf or soap is not used if jujube leaf is given, what is done with the soap hujur?

P: That is, after death man becomes profane (napak). However, man was sacred before. After death man lost its sacredness. Then, a towel is spiral over hand and the baby is washed beautifully.

I: Would you mind explaining a bit hujur what do you mean by “profane after death”?

P: After death a man become profane, that means after death there is no sacredness exist rather man become profane, according to sharia [sic] after washing it (deceased) become pure again.” (Bangladesh, Religious Leader, Muslim)

In this exchange, it is clear that while not all participants discussed the specifics of why these actions are taken, they are rooted in Islamic scripture and teaching (the Hadith). This religious leader was the only participant in either country to explain why washing the body is done, and that too, is rooted in Islamic law (Shariah). This same Islamic religious leader also discussed that after washing, they usually use camphor to avoid decomposition and protect the body. No other participant in either country spoke about the use or permissibility of camphor or other embalming substance. This comment was surprising, considering that existing literature consistently showed that embalming was not permissible in Islam.

“I: Suppose, hujur, to avoid decomposed or to protect damage of deceased ...

P: We usually use camphor.

I: Hujur, when camphor is given, when it is given?

P: It is usually given after washing.” (Bangladesh, Religious Leader, Muslim)

While Hindus in Bangladesh also wash and wrap the body in white cloth, a father of a deceased child and a Purohit identified a few differences from the practices Muslims described. While Muslim participants from Bangladesh described that washing and wrapping the body is typically done by people of the same gender, the father of the deceased shared that the father will bathe the body of the deceased child, even if it is a girl. Instead of using jujube leaves, Hindus smear the body with ghee or oil. The participant does not offer justification for why ghee and oil are rubbed on the body other than that it is the rule of the religion. The Purohit adds that after ghee or oil are rubbed on the body, it is bathed in water with basil leaves:

I: Who does give it bath?

P: Its father will give it bath.

I: Does a father give bath to either a boy or a girl?

P: Mother will not give the child bath.

I: Okay.

P: After the bath, we smear the body with ghee. It can be ghee or oil as well.

Using these.

I: It's okay that they smear with oil. But why do they give ghee?

P: It's according to our rules (religious) that oil or ghee is to be used here. We usually smear the whole body with it." (Bangladesh, Father of Deceased, Hindu)

I: Okay, now can you please tell that how the dead baby is given bath.

P: There are some rules for giving bath to a child, like before giving bath water is mixed up with basil leaves." (Bangladesh, Religious Leader, Hindu)

Even though none of the Hindi participants described the purpose of washing the body in terms of what it means for the soul of the deceased, washing the body is still an important part of preparing the body for burial and cremation. They still wrap the body in white cloth similar to their Muslim counterparts, and then infants are buried, while adults are cremated.

None of the participants in Sierra Leone discussed how practices or decisions related to preparation of the body were specifically informed by their faith tradition; they simply shared about the actions that are taken to prepare a body. All participants described washing the body and kasankay (wrapping in a shroud), and most added that depending on if the family of the deceased was Christian or Muslim, then they would pray in the “Christian or Muslim way.”

Participants in Sierra Leone did not discuss details of washing the body to the extent that participants in Bangladesh did; only one religious leader identified who typically performs the washing of the body:

I: Who are the people responsible for the washing of this child?

P: Well if there are elder people, these are the people who are going to wash him or her. Just like when this man was lying (referring to the deceased man) I and my colleagues were responsible for washing him and after that we dress him neatly waiting after two o'clock before they bury him. In fact that is what we are waiting and so if that is so you have nothing to do only the almighty God; but if you have plenty things to think about, then that means you don't have faith in God; but if you have believing in God you have no one to blame is just to bury him or her.

I: Are the people washing the dead body also responsible for the dressing of that child?

P: Well if they understand it.

I: Who are the people in this community responsible for dressing this corpse?

P: The elderly people

I: Who are these people are they males or females?

P: If it is a woman who die then women are responsible for that and also for the man is the same thing they do. Do you understand me there is no difference; if it is a woman who die, women are going to dress her likewise for man is the same thing. I only know about males.” (Sierra Leone, Religious Leader, Muslim)

The best example of the brevity with which participants in Sierra Leone discussed preparing the body is seen through this focus group interaction:

“Now when the child dies we will wash the body and “Kasankay” (wrap in a shroud) and bury. Nothing is done after that.” (Sierra Leone, Father of Deceased, Christian)

“What I know from what my elders have said, when the child dies, they wash and “Kasankay” and bury.” (Sierra Leone, Father of Deceased, Muslim)

In Sierra Leone, participants also described the ways in which Ebola has changed the way they prepare a body for burial. During the Ebola outbreak in 2014-2015, participants contacted local authorities whenever a person died. Most described how they were not allowed to wash and bury their own dead, but health authorities usually did that. They shared that now, they are back to their usual body preparation of washing and wrapping, but discussion of Ebola was pervasive among Sierra Leoneans when asked what they do after a child dies.

“Whenever a child dies, they go and meet the brigade commander and the commander give them a paper to go ahead but the last time when Ebola was here, they use to come and collect the swab from the dead so that they will know what kills that person but now they are not doing it again as soon as they come they will just wrap the person with the white clothing (Kansakay) and spray the body and after that they will go with that corpse.” (Sierra Leone, Traditional Healer, Christian)

2b. Preparation for Burial

In addition to preparing the body for burial, participants from both countries and all faith traditions discussed social and logistical preparations for burial. Actions taken to prepare for burial included alerting community and religious leaders, digging the grave, and building or retrieving a coffin.

2bi. Alerting Community and Religious Leaders

In Bangladesh, participants shared that they report to the religious leaders after a child has died. Not only are religious leaders contacted to pray over the body and assist in burial activities, but their social capital is also used to mobilize the community for funeral preparation and social support for the bereaved family. In many cases, the Imam will be notified and visit the household to offer prayers and assist in washing and wrapping of the body. Then, the Imams announce the death over the microphone at the mosque so that the community is informed and can attend the burial.

“If a child die at the age of 2, 3, or 4 years, it is seen that death news is announced by village mosque’s microphone that the child of this parents has died... It is seen that when mosque authority are requested to announce it they

will do it. Announce occurs like the way that son or daughter of this person has died and the janaja prayer will be held on that time. This is the way.”

(Bangladesh, Father of Deceased, Muslim)

A dai in Bangladesh added that while religious leaders in the community are often present for the burial-shroud (washing and wrapping of the body), there are other local community leaders that are also present.

“I: So, when you perform burial-shroud, who present [sic] there as a religious person?

P: Religious person present there, as well as neighbors who live beside our house present there.

I: And who present there as a religious person?

P: Religious person, suppose, there is a Madrasha. So, hujur, mollah, mawlana all are usually present there.

I: And what about other important person in the society?

P: Other important person means, mokkel-matobbor (local leader) and intelligent people would present there also.” (Bangladesh, TBA, Muslim)

A Hindu father of deceased described that local leaders are not needed during decision-making for burial preparation. Instead, only the guardian of the family (typically a grandfather or elderly uncle) and a Gurudev (Hindu religious leader) or Gosai (devoted followers of Hinduism on a path to become a sadhu (saint)).

“I: In that case, as you do or follow some religious activities, who does give the decision about doing these religious activities?

P: He, who is the guardian of the family, gives the decision. We don't need any matobor for these.

I: Isn't there any Gurudev (religious master or leader) here?

P: Yes. Obviously, there is Gurudev. There is Gosai. We do according to whatever Gosai says. For say, a child has died. Then, Gosai suggests what to do." (Bangladesh, Father of Deceased, Hindu)

This participant also noted that while the Gurudev may be informed immediately after death, they have no role in preparing the body for the funeral and typically do not come until later, when the funeral will take place.

When participants in Sierra Leone were asked "Who do you tell when a child dies?" some participants mentioned that they inform the religious leader. However, participants first identified that they inform the chief of the community. Once the chief was notified, religious authorities and other members in the community were notified:

"I: Who do you tell when a child dies?

P: The chief is informed and also those that are responsible to dig the grave, and they also wash the child. If you are going to church (Christian) the pastor will go and pray for the child and the pastor and the others burry [sic] the child." (Sierra Leone, Mother of Deceased, Muslim)

"Well just as they said when your child dies you will not bury the child without telling the chief it is not easy the chief will pass on the message to those next to him, he will show the place to bury the child." (Sierra Leone, Father of Deceased, Muslim)

“I: So is there no other things that happens when a child dies in this community, is just that burial?”

P: They will go and report to the chief and said so and so child has died. The chief will allow the people for burial; and before burial the deceased child will even stop the activities of the community for that particular day.” (Sierra Leone, Religious Leader, Christian)

“I: what happens in your community when a child dies, what you do until you bury the child. That’s what we want to know okay?”

P: We will wash the child, after washing the child, you dress the child after that they will dig grave to bury the dead child.

I: Is that all? Are there any other things that you do?

P: We tell the chief, they tell the chief that we have a dead body in the community, but before we bury the child, we should first call 117, and before we take water to wash the child, we first tell the chief to know about that.” (Sierra Leone, TBA, Muslim)

One religious leader in Sierra Leone shared that they were the “owner of the funeral” and an “advisor to the community,” so they are often one of the first people notified when a death occurs. This religious leader described their role as being the one to inform the community about death and mobilize social support for the grieving family.

“P: They will inform me that someone has died and after that we put modalities in place to inform other people in the community.

I: After they have informed you that this child is died, what help do you do in this situation?

P: I have told you what I do. I will talk to the entire community for us to sympathize with the bereaved family.” (Sierra Leone, Religious Leader, Muslim)

While it is possible that the community chiefs in Sierra Leone are also religious leaders, it appears that for most communities, chiefs and religious leaders are separate and that chiefs are the leaders who are told about a death first.

The Ebola outbreak in Sierra Leone also impacted reporting of death; participants described how when there was a death in the community, they also had to call “117,” the hotline for Ebola. In some instances, the chief of the community was also used as the 117 contact. In communities where this was not the case, participants contacted the chief first, and then called the 117 hotline.

“We tell the chief, they tell the chief that we have a dead body in the community, but before we bury the child, we should first call 117, and before we take water to wash the child, we first tell the chief to know about that.” (Sierra Leone, TBA, Muslim)

2bii. Preparing the Grave and the Coffin

While not discussed as thoroughly as other aspects of burial preparation, participants in both countries described the process for preparing the grave and securing a coffin for the deceased. In both Bangladesh and Sierra Leone, participants described how family members and neighbors usually assist in digging the grave while the parents prepare the body and mourn. The people responsible for preparing the grave are usually men, such as a brother-in-law or uncle of

the family. In some cases, an in-law or uncle may be responsible for telling someone else to go dig the grave.

“I: Who are these 2-3 people?”

P: These are men needed to dig out the graves. As adults need to be dug graves for, kids need to be dug graves for too.” (Bangladesh, Mother of Deceased, Muslim)

“Then my brother in law took me that place and showed me the grave.”

(Bangladesh, Religious Leader, Hindu)

“I: Ok now you as a TBA in this community what role(s) do you play or do when a child dies in this community?”

R: when a child dies they will inform me and I will go there to wash and dress the dead, the men will dig the grave and after that I will take the dead to the bed of God.” (Sierra Leone, TBA, Muslim)

Women were described as being too distraught to coordinate or prepare burial sites, busy preparing the body, busy preparing a meal, or simply just “unable” to dig the graves:

“Yeah, the youths also will be alert for the digging of the grave; wherein the older ones and the young ladies will also be around to make flour.” (Sierra Leone, Healthcare Worker, Muslim)

“I: Who does the digging?”

P: Males are responsible for the digging of the grave. Females are unable to dig unless otherwise in some situation males are not available.” (Sierra Leone, Religious Leader, Muslim)

In Bangladesh, bamboo is cut and used for a coffin, while in Sierra Leone, building or securing a coffin was not discussed when talking about preparing for burial. For Muslims in Bangladesh, the coffin was identified as extremely important to keep soil off the body of the deceased; once the bodies have been washed and wrapped, they are considered “pure” and “clean” and should not come in contact with soil. During the washing and wrapping of the body, relatives and neighbors go cut fresh bamboo to fit the size of the body.

“I: Then?

P: Then, we keep in that way, bamboo is given in upper portion, it covered with soil so that baby cannot be touched of soil, face is not touched with soil, then we plain the soil beautifully and return home.” (Bangladesh, Religious Leader, Muslim)

“I: Can you please explain in details the process of burying?

P: A child deadbody’s [sic] measurement is taken to burry [sic] when it dies, 2 to 4 fingers or 1 hand sized grave is dug after taking the measurement, all the materials are taken ready according to the child’s size e.g bamboo [sic], after taking the measurement, the child is buried in the grave placing mat (shitalpati) on bamboo. So that soil does not fall down on its body. Punishment may be increased if the soil falls down on its body. Soil is placed nicely on Mat (shitalpati) upon the bamboo.” (Bangladesh, Father of Deceased, Muslim)

For Hindus in Bangladesh, the coffin is primarily used to transport the body to the crematorium, where the body will be cremated in the coffin. A FoD identified, however, that bodies of children are not cremated; a body will only be cremated if they are above the age of 14 or 15. Thus, children are buried underground in their coffin, but no spiritual or religious significance of keeping soil off the body was identified.

I: What ages of babies do you burn?

P: It's at least 14 to 15 years old child that we burn." (Bangladesh, Father of Deceased, Hindu)

In Sierra Leone, both Christians and Muslims spoke about burying the body without specifying if a coffin is used. Two participants spoke about how women will sometimes bury the bodies of under-five deaths in “muru” (a dustbin) instead of burying at the general burial site, but did not explain if general burial includes the use of a coffin.

“For us when a child dies that is under- five some people will say let us not take the child to the general burial site to burry [sic] in “Muru” (dustbin) so that the parents will not loss another child. People do not have the understanding to find out what killed the child and they will just wash the body and bury in “muru.”
(Sierra Leone, Father of Deceased, Muslim)

Muslims in Sierra Leone also wrap the body in a shroud before burial, but did not discuss the use of a coffin or importance of keeping soil from touching the body, as Muslims in Bangladesh described. The only discussion of an item to hold the corpse was when one participant in a focus group described the disruption Ebola caused; when Ebola was present in the community, they could not prepare the body as usual (wash and wrap), and bodies were placed in bags:

“During the Ebola If a person dies, we will call them to know what led to the death, we don’t wash the dead body, and the Ebola people will check and put the body in the bag for burial.” (Sierra Leone, Father of Deceased, Muslim)

2c. Funeral Rites

After the body is washed and wrapped in a shroud, religious and community leaders have been notified of the death, and the burial site and coffin (in the case of Bangladesh) is prepared, a funeral ceremony is performed to honor the body of the deceased through the burial process. The results are presented in three different categories to help understand funeral proceedings: praying over the body, burial and cremation, and timing of funeral ceremonies.

2ci. Praying Over the Body

Praying over the body of the deceased child may begin or occur when the body is being prepared for burial – washed and wrapped. In Sierra Leone, participants spoke about praying over the body after death, but did not specify the timing of the prayers or their purpose. One healthcare worker in Sierra Leone talked about how parents will go to the local religious leaders and ask them to pray over their deceased child that will be buried:

“Any child that dies if the father is a Muslim, they must tell the Imam, My child is dead go and pray for him. If he is a Christian, you must tell the Pastor go and pray for my child, my child is dead ... Okay if is a under-five child, if you are a Christian they will pray for him in the Christian way they go and buried. If you are a Muslim, you that give birth to the child they will pray for the child in the Muslim way they go and buried.” (Sierra Leone, Healthcare Worker, Muslim)

Four participants in one focus group in Sierra Leone shared similar stories about seeking prayer from religious leaders before burial. One participant explicitly said they *have* to pray before the body is buried:

“P4: If someone dies they will always know. A child will not die and just be buried like that without the knowledge of the headman, the imam or the pastor.

I: How do you see that?

P1: That exactly it. Because as soon as you hear a child dies and the child have not started praying like me am a Muslim but the child has not started praying, hence the mother is praying they will to pray for the child because the mother is praying. So the imam will be able to do that, because as soon as it happens they will call him.

P2: Even the pastor if it's a Christian that die they have to pray before ever they bury.

P3: Because when a child dies they will tell the pastor, and when they do that the pastor will pray, and if it's a Muslim they will also pray and console you.

P4: When your child dies if you are used to going to the church unless you tell the pastor that pastor this child is dead and we don't want to bury like that: to pray for him. They will pray and Kasankay (wrap the body with white cloth), and the pastor and other people go to bury the child. And before putting the child in the grave, they pray first.” (Sierra Leone, Fathers of Deceased, Muslims)

Despite the lack of detail provided by participants in Sierra Leone, participants in Bangladesh offered much more detail about what prayers are said, by whom, and what they mean for the soul of the deceased.

All of the Muslim participants in Bangladesh talked about the janajah prayer, the burial prayer. Janajah prayer typically includes the recitation of four takbirs, as demonstrated by the Prophet Muhammed. At the end of the fourth takbir, the sins of the deceased are cleaned, and the soul is released from the physical world. One religious leader in Bangladesh clarified that according to Shariah, the janajah prayer for a child must be said by the father or another close relative. In cases of child death, the parents and relatives are typically too distraught in mourning and the Imam says the janajah prayer:

I: Who says Janaza (burial prayer)?

P: There is a rule according to the Shariah; Son will say the prayer of father or father will say the prayer of son; or the person who is the close relative to the deceased, Otherwise the Imam has the main right.

I: Imam, okay. in this area, does the Imam says more or father says more for the son?

P: The imam says more.

I: Well, Imam; does the Imam of the mosque say more?

P: Yes, They say prayer; because in general, when the child die in a family, then the whole family gets mourn, [sic] therefore they provide the responsibility to the Imam.

I: Sir, you have told that Imam said the prayer; at what time do they say the burial prayer?

P: Generally burial prayer is said after the death.” (Bangladesh, Religious Leader, Muslim)

While all of the Muslim participants in Bangladesh spoke about the janajah prayer, another religious leader clarified that the burial prayer is not necessary for children under the age of four or five:

I: Ok, hujur, what is the age to announce it?

P: It is normal that janajah is not performed less than four or five year age.

Because little babies are sinless, they have no sins. And people make sin when they grow up. Soap would be increased as many as participate in janajah. For this reason, little babies are sinless, they have no sin. There is no janajah for them, so too many people are not called for them.” (Bangladesh, Religious Leader, Muslim)

For Hindu participants, Purohits will read the names of gods into the ear of the deceased as they sing praises and transport the body for burial or cremation. There are many funeral rituals that are performed before a body is cremated, but because children’s bodies are not cremated, the rituals will not be discussed.

I: During funeral do priests or religious person observe any responsibilities?

P: They read the god’s (Baghavan) in the ear

I: In whom ear it is read?

P: This is rule for over five years children and often also applied for under five years old children.

I: What actually they say?

P: They say a tone “Horre Khishno, Horre Ram”, and carry the dead body singing.” (Bangladesh, Religious Leader, Hindu)

2cii. Burial

Similar to praying over the body, participants in Sierra Leone did not identify consistent traditions or rituals followed during burial, just that the body is buried. One focus group participant shared that there's no tradition to bury:

“As my brother have said we do not have any tradition to bury: when a child dies we will wash and “Kasankay” and bury for any child that is not yet five years old.” (Sierra Leone, Father of Deceased, Muslim)

Participants in a different focus group shared a similar sentiment, that there is not much to be done but just bury the child and leave everything to God:

“I: So what happened when a child died?”

P1: Nothing much is been done they just buried the child.

I: what happens when a child dies in your community?

P3: Well, unless they wash the child and bury because they cannot keep the dead child because the child already dead.

I: Yes mummy [sic] do you want to add (to P4)?

P4: well when a child dies, we just leave everything to God. We do not have anything else to do about that. Just few days back, my brother's child died at the hospital. We just leave everything to God because God is the one that gave us.

P2: We cry and cry and cry.

P4: When my child died, they washed the child and bury the death and we seat to mourn the child. We went to the market to buy goods to prepare food for the sympathizers because there is nothing else we can do because the child is already dead.” (Sierra Leone, Mothers of Deceased, Muslims)

In contrast, participants in Bangladesh described the burial process in detail. After the body is washed and wrapped, a father of a deceased child described how Muslims place the head facing north and the legs facing south as it is carried to the grave. A religious leader also described why the body is placed facing a certain direction, saying that the chest should be directed in *Qibla*.

“I: What are other rituals are performed from Islamic aspect what we usually do after a child death?”

P: After bath and covering up the body people bury it by placing its head at the north side and leg on the south side.” (Bangladesh, Father of Deceased, Muslim)

“I: Then hujur, what do you do after digging?”

P: Deceased’s head is lain down in north side because the chest should be towards in Qibla.

I: That means... land is slanted up by digging, is it?

P: Yes...it is slanted up a little bit so that after lain down, deceased face should be totally towards in Qibla.” (Bangladesh, Religious Leader, Muslim)

After the janajah prayers have been said and the soul is released from the physical world, the body is laid in the grave in bamboo. After the deceased is laid in the grave, more bamboo is cut to make a scaffold that sits a few inches away from the body. Similar to a roof or lid on a box, this bamboo helps protect the body from the soil. Then, soil is added on top to complete the burial.

2ciii. Timing of Funeral Ceremonies

The process of washing and wrapping the body, cutting bamboo and digging the grave, saying the burial prayer, and burying the body can be completed in two to three hours. For Muslims in both Bangladesh and Sierra Leone, there is no waiting to proceed with burial preparation and funeral; Muslim participants in Bangladesh stated that according to Shariah, children are innocent and when they die, they remain closer in proximity to Allah than adults do, and thus need to be buried faster than adults are buried. Another participant shared that waiting to bury the body is punishment:

“The dead body will be punished as long as it will not be buried. The dead body is buried cautiously as soon as possible to avoid the rotten of the dead body.”

(Bangladesh, Father of Deceased, Muslim)

The underlying belief that the body will be punished is consistent with the purpose of the janajah prayer: if the soul is not released from the body until the end of janajah, and janajah is delayed, then the soul is suffering in the rotting body.

Hindu participants in Bangladesh did not specify the timing of funeral ceremonies or cremation, but the timing of post-cremation fasting and feasts indicate that they likely perform funerals quickly after the time of death as well.

In one focus group in Sierra Leone, a participant shared that parents do not waste time to bury a child; if a child dies in a hospital, the time from bringing the child home to the time the burial is complete will be about two hours, whereas a child that dies at home will be buried in an hour and a half.

“The child is taken directly to the father at home and without wasting much time they just bury the child at the back of the house and such process will take place

for about two hours from the hospital unto burial that's all. If they are at home, they will take about one hour thirty minutes.” (Sierra Leone, Mother of Deceased, Muslim)

Later in the same focus group, three participants shared that the burial of their children was delayed. In two instances, the child died in the middle of the night or early morning, so they waited until later in the morning when others could join them to do the burial. One participant shared that her husband was away when her child died early in the morning. She waited over seven hours for the father to return and give permission to bury the child, which then only took about an hour and a half.

Aim 3: Determine how religious beliefs and practices influence acceptability, practicality, and implementation of MITS by CHAMPS in Bangladesh and Sierra Leone.

Theme 3. Learning the causes of death and attitudes towards MITS

The final theme to understand the influence of religion on the acceptability and implementation of MITS captures participants' desire and lack of desire to learn the cause of death, and attitudes towards MITS.

Participants across both countries and all religions had differing levels of desire to learn the cause of death. In Bangladesh, all 8 participants said that finding out the cause of death would be beneficial for a number of reasons: to prevent suffering among women who feel like they are at fault, to find treatments so that others do not die from the same cause, and so that others are aware and can take actions to prevent it in other children. Ultimately, all participants shared an altruistic desire to prevent death in other children.

“I: After knowing the reason of the death of child, how could they be aware of the second child? I said, sir? How could they take advantage by knowing the cause of death?”

P: The parents will be aware of the reason for which the last child died so that they can pay more attention for the upcoming child. He will be pay visit to the doctor, traditional healer, will seek suggestion from the religious scholar (Alem). They will move to them to prevent that incident or reason so this situation might not emerge further. He himself will be aware of and provide advice to others on this regard.” (Bangladesh, Religious Leader, Muslim)

One FoD in Bangladesh talked about how in Bangladesh, mothers are often blamed by the mother-in-law for the death of their child. He felt this blame on the mother was causing family problems, because he felt no mother would carry a child to term only to wish for them to be born dead. As a husband, he felt it was difficult to navigate between his wife and his mother, and that everyone should try to understand why miscarriages occur.

“Some people used to blame their son’s wife, why the child died, for this she was beaten by her mother in law or husband. People should realize it; nobody wants to kill her child. Every mother tries to deliver a healthy baby after growing it in her fetus. But some mother in law and husband don’t want to understand it and started to beat and scold her when miscarriage happens and dead child born. They start to say that why have you done this with the child? They don’t try to understand that why a miscarriage has happened? Wife (the mother) does not have knowledge about this miscarriage, they don’t know anything. That is why they (mother) are beaten and scolded by the mother in law. Again there are many

families whose mother in law and husband used to support by saying no worry to the mother after miscarriages and delivering dead child. They use to say “Allah has taken his creature, if you survive then you can give birth again another child.” If you die, then nobody will born. So many family supports by giving such kind of hope.” (Bangladesh, Father of Deceased, Muslim)

One Hindu religious leader in Bangladesh emphasized the importance of determining the cause of death—to identify causes of death would allow future deaths to be prevented, and benefitting others is an act of religion.

“P: They will think of it as hurting the dead, because of the act of the needle making a wound into the body. Like, I pinched the dead body, which means I hurt it. The guardian might not allow that hurt to be done. It’s solely based upon the guardian. “Alright, whatever could have happened to me, happened anyway; if this can help 5 other people, then why not?”

I: Are there any steps taken religiously?

P: Religiously taken steps don’t come to my mind. What are the problems that can be caused religiously and such; I’m not an expert in all of this. Maybe they took something from this point to that points of the body, and that benefitted them. Why will there be a religious problem for this? I don’t understand any sort of religious problems like these. If doing something like that helps 5 more people, then I think...

I: What do you think?

P: If this helps 5 more people around me, then I think that’s what religion actually is.” (Bangladesh, Religious Leader, Hindu)

In Sierra Leone, one's belief about the cause of death was more strongly tied to one's level of desire to learn the cause of death. If a participant believed that death was the will of God and that there was nothing else that could have been done, then they would be less likely to see the benefit in learning the cause of death. In their mind, the cause of death was God, so there's nothing else to be done. To seek biomedical or traditional or other spiritual methods to determine a cause of death would be a mistrust of God's will:

"I: May God forbid, if someone lost a child here now will you be willing to find out the cause of death?"

P2: For me I will not find out because I am a Christian I believe in God. I know it is God that gave me the child and if God takes him back I will not want to question that.

P1: I am a Muslim its God that gave me the child and he dies I know its God.

I: Why not finding out?"

P1: I will not find out because I believe in God and I know God killed the child."

(Sierra Leone, Fathers of Deceased, Muslims)

If an individual or family in Sierra Leone felt that death was caused by some other spiritual cause, such as a curse or witchcraft, then they would go see a traditional healer to determine the cause. Three participants mentioned that in addition to visiting a traditional healer, women will go down to the water to perform a ritual ceremony to determine the cause of death. In one focus group, three participants felt that using traditional and other spiritual methods to determine cause of death could actually cause more problems than it would solve. If you go to a witch doctor and it is revealed that the child died because the father of the child or the father's extended family put a curse on the child, then family strife will ensue. As a way to avoid this blame and family

problems, parents may decide to simply trust that it is the will of God, lessening their interest in learning about a cause of death.

I: Do they really find out? Are they willing to find out?

P: Hmm some are willing to find out what is killing their children. Some if I advise them they will take to the advice but others will say “Pa kuru konon” (it is the work of God) and they will just avoid doing anything that will be against their believes [sic].

I: So some will not find out?

P: No some will say they will visit the “so sorer” (traditional doctor) to find out what killed their child. Others will ask me to treat them so that it will not happen to them again. Some will still say it is the work of God.” (Sierra Leone, Healthcare Worker, Christian)

I: All these explanation you have made about the dead child what the family does?

P: Nothing to do they will just leave it to God do you hear me; nothing to do they will leave it to God; only the Almighty God we are going leave the case with. No one to blame about that we will just say it is God, so that is all.” (Sierra Leone, Religious Leader, Muslim)

In Sierra Leone, a desire to learn the cause of death reflected one’s acceptance of MITS. This was not the case in Bangladesh. When the process of MITS was described to participants in Bangladesh, five participants quickly objected, even though all eight participants said knowing the cause of death would be beneficial. Two of the participants who did not object were Muslim,

and one was Hindu. Reasons for objection included: the procedure would cause harm and pain to the child's body, which is against Shariah; the procedure would not be possible because the blood is "dried up" after a child dies; questions about how the samples would lead to knowledge about the cause of death, tissue donation or disfigurement of the body after death is forbidden in Islam; the procedure will not be able to bring the child back to life; burial would be delayed; and the failure of CHAMPS to establish relationships, communicate intentions, and build trust in the community.

"I: Suppose, sometimes an alive person die due to any reason, to know the cause, sometimes to know the reason of illness blood or sample is collected with syringe, in the same way, if a baby die, after death, to know what is the reason of death, suppose, blood or sample is collected with syringe to detect the reason, or if we take permission from him, what do you think hujur, in that case, if such type of think can be done, how is that?"

P: No, according to rule of Sharia, after death there is no permission of hurt a deceased body

I: Ok

P: There is rule, according to sharia [sic], it is totally forbidden to cut organs after death." (Bangladesh, Religious Leader, Muslim)

"I: Ok, we want your advice that how can we make parents agree?"

P: You cannot make parents agree mother, they would never be agreed any time.

I: No, for this reason I am seeking your advice.

P: That's all; parents will never be agreed to give sample.

I: Why won't they give it?

P: They won't give it because parents will say that my child has already died, there is no necessity of giving sample. We can give it, if you wish to take before death.

I: Ok

P: It has already passed away; it has only one sample which is burial-shroud.”

(Bangladesh, Traditional Birth Attendant, Muslim)

In Bangladesh, participants shared that certain steps could overcome some of these objections: Islamic religious leaders could review the procedure and declare that it was acceptable and beneficial for the community; CHAMPS could hold community meetings the procedure was explained to everyone; CHAMPS would need to ensure that the procedure could happen quickly (within an hour of death); and community leaders (Bacchu members) could bring CHAMPS staff to households. Through these activities, more people would be willing to accept and consent to MITS.

“I. Can you please make me understand about the religious and knowledgeable doctor; what does this mean?

P. It is in the hadith that in the month of fasting, if person suffer from health related problem, now a doctors says he has to take food and medicine immediately unless he will face health hazard. Then in consent from a pious doctor this person can be able to withdraw his fasting. Here is a little thing to be considered. This case solely depends on the treatment. Now what would be the utility of taking sample from a deceased child? If the doctor says the for the better of mankind the sample to be collected for future benefits and to find out the cause

of child death, and it will be helpful for diagnosis, then it can be done; it is permissible.” (Bangladesh, Religious Leader, Muslim)

“P: Member of an area, like Bacchu Member of our area. If you tell the Bacchu member that we are doing this your locality, if you can take us in his house? Before that you’ll find out in which house this incidents [sic] happened, then take permission from member, we want go his house with you.

I: Won’t we take permission from him?

P: He’ll go with you, no question will arise after reaching that house.”

(Bangladesh, Mother of Deceased, Muslim)

Participants in Sierra Leone were much quicker to show acceptance towards MITS, even though they had less desire to determine the cause of death. None of the participants in Sierra Leone identified that performing any procedure on the body would cause pain or be forbidden according to Shariah or Islamic law. The only objection identified was that it would delay burial, which was also mentioned by participants in Bangladesh. In Bangladesh, the desire to bury quickly was tied to the role of the janajah prayer in releasing the spirit from the physical world. In Sierra Leone, the desire to bury quickly was motivated by the feeling that there was nothing else to be done and no point in waiting to bury the body.

“The problem I will encounter only is..... [Thinking] the grumble of the community people, the family that last the child, they will grumble saying....Aaaaaa I want my child to be buried quick. The time wasting will be the only difficulties, time wasting.” (Sierra Leone, Healthcare Worker, Muslim)

Participants all identified ways to improve acceptance of MITS, and each participant noted two key actions that would lead to community acceptance. First, if CHAMPS went to the community chief/chairman and had them call the community together to announce this would be taking place, then everyone in the community would be willing to listen to the work being proposed. Second, if CHAMPS took initiative to hold community sensitization and education sessions, then people would be willing to delay burial shortly to participate.

“I: Do you think people in this communities will be willing to do MITS to find out the cause of death of their children?”

P: Yes provided CHAMPS engages the people and sensitize them well on the need to use MITS to establish the cause of death of their children. You should tell the people the need to do MITS to find out the cause of death and if they understand this before you implement it they will be ready to do it.” (Sierra Leone, Healthcare Worker, Christian)

“I: Ok now, when we come to this community what advice will you give us on what we should do to get you and other elderly people involve and work together to carry out this process successful?”

P: First of all, you will have to meet the head of the community and explain the purpose of your work in the community about the sicknesses that causes the children to die. So after you have summon yourself to the head of the community, then the head of the community will call his people and explain to them about the purpose of coming to their community. So after they heard of that, then it just left

with you if what you are finding out is true.” (Sierra Leone, Religious Leader, Muslim)

OTHER FINDINGS

While not directly related to religion, there were two additional findings related to social support and community structure and authority that are worth noting. First, participants in both countries talked about social support from other relatives, religious leaders, and community members, but the involvement of neighbors and non-relatives was more pervasive in transcripts from Bangladesh. When a child in Bangladesh dies, the parents are often too busy mourning the loss of their child. As a result, relatives and neighbors are most often the people who go and inform the religious leaders, cut bamboo for burial, dig the grave, and cook food for the family and guests at the funeral.

“After a child’s death if someone asked their neighbor to do a work, then she/he will help them (that family). Whatever it is, may be they (that family) will ask for cutting bamboo, washing dead body, carrying the dead body’s cot or anything. If my child would die then it will not be possible for me to cut bamboo, so people will come and do these.” (Bangladesh, Father of Deceased, Muslim).

Religious congregations are often known for the community of social support that they create. While sharing the burden of death in this situation is not explicitly linked to a religious congregation, it is reflective of a religious community.

Second, participants in both countries also discussed the importance of community leaders, but the role of a community chief or chairman was pervasive in the transcripts from Sierra Leone. It became clear that in order to establish a relationship with the community and ensure success of MITS implementation, the hierarchy of power within these communities must

be respected and CHAMPS must go to the community leader first. Similar to the first additional finding, systems of power and authority in these Sierra Leonean communities are not necessarily tied to religion, but reflect the structure of authority in many religious denominations.

SUMMARY

Religion influences beliefs about causes of death, burial practices, and desire to learn about the cause of death and acceptance towards MITS in complex ways that sometimes aligned and sometimes differed between Bangladesh and Sierra Leone. Participants in both countries hold God, other spiritual causes, and biological causes all as legitimate causes of death, and these different causes are often believed to be true simultaneously. Preparing the body, preparing for burial and the funeral, and the funeral proceedings were all influenced by religious beliefs and practices, with participants in Bangladesh referencing Islamic doctrine and Shariah more often than participants in Sierra Leone. Desires to learn the cause of death was strongly influenced by participants' beliefs about the causes of death and the potential benefit of learning the cause of death. Participants in Bangladesh showed more desire to learn the cause of death because they believed it would prevent future deaths of other children in the community, whereas participants in Sierra Leone expressed less desire to learn the cause of death because they believed death was an act of God and that there was nothing to learn. On the contrary, Bangladeshi participants were less accepting of MITS because they believed it to be in tension with Islamic teaching that the body still feels pain after death, and it is wrong to cause harm, while Sierra Leonean participants were accepting of MITS as long as it did not delay burial.

CHAPTER 5: CONCLUSION AND DISCUSSION

INTRODUCTION

The analysis presented explored the influence of religion on participants' beliefs about causes of life and death, practices surrounding death and burial, and desire to learn cause of death and acceptance towards MITS in Bangladesh and Sierra Leone. In Bangladesh, the world religions of Islam and Hinduism and local spiritual beliefs regarding bad air, demons, and genies all had strong influences on individuals' understandings of life, death, and what constitutes a faithful response after death. Islamic teaching and Shariah law were most commonly used as rationale and justification for participants' beliefs and practices. While all participants from Bangladesh acknowledged that knowing cause of child death would be beneficial to prevent future death, most felt that determining cause of death through the MITS procedure was unacceptable due to the Islamic belief that the body can feel pain after death.

In Sierra Leone, Islamic and Christian doctrine were not overtly stated as the source of participants' beliefs and practices as they were in Bangladesh. Instead, these participants discussed how their identities as a Muslim or Christian meant they believed in God's divine authority as ruler over life and death. Local spiritual beliefs in witchcraft, curses, and hexes influenced participants' desire and method for determining the cause of death. In contrast to Bangladesh, not all participants in Sierra Leone were interested in learning the cause of death, but more participants found the MITS procedure to be acceptable and not in tension with religious beliefs.

DISCUSSION OF THEMES

Beliefs about causes of life and death

In these transcripts, it was clear that religion strongly influenced participants' beliefs about causes of life and death. For participants, attempts to understand the cause of death are generally not limited to either the biomedical paradigm or the supernatural/religious paradigm, but are often a mix of both. While 3 of the 18 total interview participants – all healthcare workers from Sierra Leone – did not describe God or other spiritual forces as legitimate causes of death, the remaining 15 interview participants and 31 participants from the four focus groups all described these causes as legitimate. These participants often described both God *and* other spiritual forces as causes of child death, and most also described biological causes of death. While one participant explicitly described “sickness” as the mechanism for God to “take back what was His,” it is not clear how the remaining participants make sense of seemingly contradictory causes of death or conceptualize the relationship between the material and non-material worlds.

In a biomedical paradigm, where disease and death can often be reduced to objective pathophysiology, there is no opportunity for causes of death that are subjective, abstract, or beyond the material world to be legitimate (Cabrera, 2015). Participants from both countries demonstrated that they may hold a certain cosmology that is distinct from biomedicine: death can be a result of both biological and spiritual causes. It is possible that in the participants' cosmology, biological causes such as germs or disease may be understood as the means by which God or another spiritual force reclaims its property. It is also possible that this other cosmology simply holds biological and spiritual causes of death as equally legitimate, possible, and normal

in their co-existence, where one person may die from the parasite that causes malaria while their neighbor dies from a curse and the next because it was the will of God.

While a paradigm may hold spiritual forces as valid causes of death, not all spiritual forces are seen as equally legitimate. Some individuals and communities may hold clear distinctions between God and other spiritual forces like magic or witchcraft, while others may consider all spiritual forces to be related. For example, in Sierra Leone, spiritual forces are spiritual forces; a participant that claimed God as the cause of death also described visiting the traditional healer to confirm that it was God and not due to witchcraft. Only one participant in Sierra Leone, a Christian Pastor, clearly distinguished Christianity and God as “religion,” while other spiritual forces such as witchcraft were seen as traditional beliefs. In his eyes, if you believed in God, there was no believing in witchcraft or curses. This separation of God versus other spiritual forces could be due to any number of factors, including the ways that world religions historically were integrated and continue to integrate into local traditional beliefs or the ways in which missionaries of those religions often denigrated traditional beliefs in introducing these religions to people in places such as Sierra Leone and Bangladesh (Blevins, 2018; Graham et al., 2005; Prince, 2007).

In Bangladesh, there was a clearer distinction of what was related to Allah and Islam and what was related to other spiritual forces because of the pervasive reference to the Quran, Hadith, and Shariah law among participants there. While spiritual forces were often discussed in reference to causes of miscarriage and stillbirth and as something perpetuated by elders in the community, the majority of Muslim participants referenced Islamic teaching and law. These differences reflect the varying religious landscapes in Bangladesh and Sierra Leone, even when the same religious traditions are at work. In Bangladesh, where a higher proportion of the

population are Muslim and there are historic ties between Islam and government proceedings, reference to Islamic doctrine and sacred texts may be more commonplace. On the contrary, the history of interfaith harmony and dual-identification between Christians and Muslims in Sierra Leone has created an environment where neither Christian nor Islamic sacred texts are referenced as the ultimate guide, reflecting the varying landscapes between these countries and even within these traditions (African Press Organization, 2013; Ashforth, 2002; Blevins, Jalloh, & Robinson, 2019; Graybill, 2017; Lindland, 2005; Marshall & Smith, 2015; O'Brien & Rashid, 2013; Penfold, 2005; The Economist, 2014).

Practices surrounding death and burial

Preparation of the body

In both Bangladesh and Sierra Leone, Muslim participants described how cases of miscarriage and stillbirth did not require the same preparation for burial as other children and adults. Instead of washing and wrapping the body or remains, they were buried under the soil. In Islamic teaching, fetal development occurs in stages with an identified period of time where the fetus receives a soul. The time that the fetus receives a soul depends on the school of Islamic thought and can be anywhere from 40, 90 or 120 days after conception (al-Hibri, 1993; Hessini, 2007).

According to Quranic verses, the stages of development include semen, blood clot, bones, and flesh. It is believed that ensoulment occurs during this last stage (al-Hibri, 1993; Hessini, 2007). In the interviews and focus groups from both countries, participants referred to miscarriages, and sometimes stillbirths, as “clotted blood.” For these participants because the fetus was not at the stage at which received a soul, the full washing, wrapping, and janajah prayer were not required to release the soul back to God. Thus, miscarriages and some cases of

stillbirth can be buried underground without the requisite preparation of the remains or funeral activities carried out for all adults or children who had been born.

One Muslim religious leader in Bangladesh described the use of camphor after washing the body:

I: Suppose, hujur, to avoid decomposed or to protect damage of deceased ...

P: We usually use camphor.

I: Hujur, when camphor is given, when it is given?

P: It is usually given after washing.” (Bangladesh, Religious Leader, Muslim)

This comment was surprising, considering that the literature review revealed that embalming was considered forbidden, or haram, in Islam. Further exploration on the use of camphor reaffirmed that embalming is not permissible in Islam, and instead of using camphor to preserve the body or prevent decay, camphor is often used in the final stage of washing the body as a perfume to cover odors (Al-Haddad, 2012; Biswadeep & Patowary, 2015; Ekpo & Is’haq, 2016; Gardner, 1998; Razavimaleki & Martinez, 2014; Tritton, 1938). Camphor is often mixed with water during the final wash of the body, and then typically applied to the areas of the body that touch the ground during prayers: the forehead, nose, hands, and feet (Ekpo & Is’haq, 2016; Shamma, 2013). Camphor is also known to be popular in Hindu religious rituals in India, so it is possible that the use of camphor as more than just perfume in Bangladesh, but a substance that holds religious significance because of the cultural, historical and geographic connections to Hinduism (Fuller, 1992).

Burial

In Bangladesh, there were very clear patterns of ritual when it came to the burial process, such as which direction the body should face when being buried. Mothers of deceased children in

Sierra Leone who participated in focus groups described that there is “nothing else to do” after a child dies except bury the child and leave everything to God. While these participants did not discuss formalized rituals like those in Bangladesh did, community practices have become ritualized in informal ways. In everyday life, rituals provide meaning and order for people around the world (van Gennep, 1960). For example, after a child dies in Sierra Leone, participants described reporting the death to the village chairman and preparing food after the burial. While these practices may not be articulated as formalized rituals, there is no doubt that they will occur. These informal rituals create a common shared experience of death and burial for members of the community.

It is possible that while these unarticulated rituals provide structure and order to experiences of death and burial, the women in the focus group prefer to understand death as an act of God’s sovereignty and divine will. There is an underlying spiritual belief that actively choosing to rely on God at the time of death rather than trying to make amends for the deceased through certain burial or funeral ritual is an act of faith, rather than hopelessness or helplessness. In this community, the reinforced belief that there is nothing else to do but leave things to God after death has the ability to also act as a ritual in its own way, providing comfort, order, and meaning to the mystery of death (Irion, 1991; O’Gorman, 1998).

At least one participant in Bangladesh also described how the bodies of the deceased need to be protected from the soil during burial, but the concept of protection from the soil was not reinforced by existing literature. On the contrary, one source described how bodies of Muslims are buried without coffins to speed up decomposition and returning of the body to the earth (Morgan, 2002). Participants specifically described protecting the body from the soil using bamboo. The bamboo creates a vault-like structure in the ground for the body to be buried. While

coffins may be used to transport the bodies of deceased Muslims, burial in coffins is discouraged; fiqh (Islamic jurisprudence) prescribes that the body should be buried in shrouds because it is believed the physical body belongs to the earth and should return to the earth (Aggoun, 2006; Ahaddour, Van den Branden, & Broeckaert, 2019; al-Jaziri, 2009; Baddarni, 2010; Campo, 2014; Kadrouch Outmany, 2016; Morgan, 2002; Sabiq, 1991; Sheikh & Gatrad, 2008). In Germany, the United Kingdom, and in the United States – all Western cultures – Muslims have been known to bury their dead in simple wooden coffins. This is likely because of cultural norms and cemetery regulations in these countries (Colman, 1997; Gatrad, 1994; Jonker, 1996).

In South Asia, bamboo is readily available and a large part of daily life in countries such as India, Bangladesh, and Nepal. It is used in the construction of homes, furniture, crafts, and tools for farming and fishing, and most notably, used by Hindus to carry the bodies of deceased individuals to their funeral or cremation site (Gubhaju & Bhattarai, 2018; Nirala, Ambasta, & Kumari, 2017; Pande, Kumar, & Singh, 2012; Vijendra Rao, Gairola, Shashikala, & Sethy, 2008). Considering the “religious sanctity” of bamboo for Hindus, some researchers have found that the use of bamboo in death and burial by Muslims was influenced by Hinduism and cultural appropriateness of the region (Vijendra Rao et al., 2008).

Timing of Burial

Participants in both countries and of all faith groups discussed the desire to bury the body quickly. For Muslim participants, this desire was rooted in Islamic doctrine and teaching to return the body and soul back to God (Cox et al., 2011; Gatrad, 1994; Hedayat, 2006; Lewis et al., 2018; Sajid, 2016; Sheikh, 1998). Christian doctrine, on the other hand, does not prescribe a quick burial. This further highlights the extent to which Christians and Muslims in Sierra Leone

live in harmony with one another, which would not be the case in communities or countries with interfaith tension.

In one focus group in Sierra Leone, three participants shared that the burial of their children was delayed. In two instances, the child died in the middle of the night or early morning, so they waited until later in the morning when others could join them to do the burial. One participant shared that her husband was away when her child died early in the morning. She waited over seven hours for the father to return and give permission to bury the child, which then only took about an hour and a half.

For Muslims, the decision to wait until morning for burial may correlate to the timing of prayers. Because there are no prayers during the middle of the night, they may wish to wait until the morning prayers to pray for the deceased and then bury the body. In Bangladesh, participants discussed how being outside at night makes pregnant women susceptible to genies and evil spirits. In other West African contexts, specifically Cameroon and Mali, (CHAMPS Program Office staff noted that participants in formative research activities conducted by staff in the CHAMPS country site in Mali spoke of this danger), spirits are known to be out and strongly active at night, similar to Bangladesh (Jindra & Noret, 2011). While none of the participants in Sierra Leone mentioned these as a reason to avoid night time burial, it may also be unspoken but at play in parents' decisions related to burial timing. Regardless, participants in Sierra Leone noted that burials were not conducted at night.

Desire to Learn Cause of Death and Acceptance Towards MITS

Desire to learn the cause of death in cases of under-five death was strongest in Bangladesh; all eight of the participants expressed a desire to learn cause of death to prevent future child deaths. Only one of these eight participants, a Hindu priest, described the influence

of religion on their desire to learn the cause of death. For this priest, participating in CHAMPS would contribute to knowledge of this causes of death and this benefit others; because of that beneficence, participating in CHAMPS would be a religious act. For participants in Bangladesh – even among those that claim the cause of death was God taking back what was His – there was still a desire to know the cause of death. This desire could be reflective of a worldview where humans have agency to shape their fate and should take action to prevent harm and death, and once all human efforts have failed, God has the final say. It could also be reflective of a worldview where God “takes what is His” by means of biological diseases.

This desire in Bangladesh was not as pervasive among Sierra Leonean participants. In Sierra Leone, participants’ desire to learn cause of death was strongly influenced by their belief about the causes of death. For participants that claimed God as the cause of death, there were no other determinations to be made; it was known and understood that God was the cause of death. However, there were some participants who described God as the cause of death, but who also desired to learn the cause of death so that future death could be prevented. Similar to Bangladesh, this may be indicative of a worldview where both biological and spiritual causes of death are equally possible and valid. In both contexts, individuals are grappling with negotiations about the nature of their existence when faced with child death.

When the MITS procedure was described and participants were asked if it was acceptable in their community, responses of acceptability were reversed between the two countries. Bangladesh had much more explicit objections to the procedure, which were rooted in Islamic teaching and law. In Sierra Leone, they were more likely to express permissibility of the MITS procedure, given that community leaders were aware and involved in community sensitization. The objections towards MITS on religious grounds in Bangladesh could be influenced by the

politicization and pervasive use of Islamic law in the region, while the acceptance towards MITS in Sierra Leone is indicative of their flexibility of using religious texts as justification.

Other Findings

In Sierra Leone, participants discussed how village chiefs and chairmen were the authorities of communities rather than religious leaders. While it is possible that village chiefs and chairmen are consulted as authorities on religious or spiritual issues, participants discussed religious leaders like imams and pastors as separate entities that were not as important for ensuring acceptability or the implementation of MITS. This is in contrast with previous documentation from Sierra Leone about hierarchies of authority within communities during the 2014-2015 Ebola outbreak. During the outbreak, religious leaders were trained on Ebola prevention and reporting messaging, and served as critical points of contact in communities when people died (America: The Jesuit Review, 2014; Bah & Aljoudi, 2014; Blevins et al., 2019; Marshall & Smith, 2015). CHAMPS interviews and focus groups revealed that while religious leaders were essential for addressing Ebola, they would not be the most appropriate authority for establishing a child mortality reporting system for MITS.

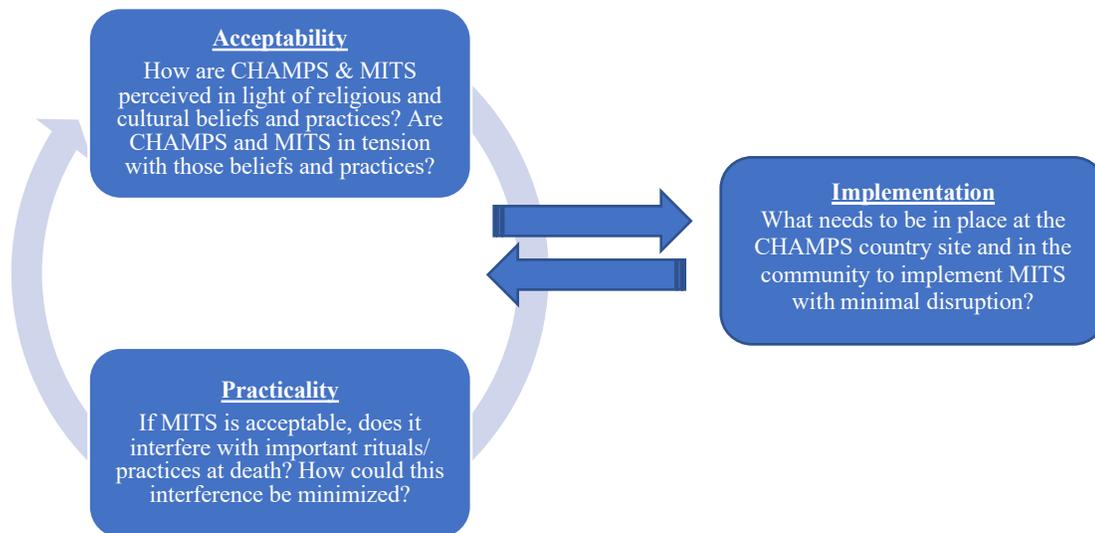
Additionally, FOCUS 1000, an international non-profit that was involved in community mobilization activities during the Ebola outbreak, was working to engage religious leaders and traditional leaders for a unified response to Ebola. Through the Christian Action Group (CHRISTAG), Islamic Action Group (ISLAG), and the Sierra Leone Indigenous Traditional Healers Union (SLITHU), the promotion of tribal leaders as authorities for community initiatives may also influence participants' responses about who holds authority in their communities (FOCUS 1000, 2015; The Freetown Society, 2015).

Participants also described that religious leaders would not be important in the establishment of MITS and mortality surveillance because they would be too busy in prayer or preaching to tend to child death. Seeing religious leaders as inaccessible during a time of need is also likely to impact who community members contact or visit when problems arise. If village chiefs and chairmen are the ones that respond when it matters, then their authority will be reinforced.

IMPORTANCE AND IMPLICATIONS

The influence of religion on the three themes – beliefs about causes of life and death, practices surrounding death and burial, and desire to learn cause of death and acceptance towards MITS – are important and have considerable implications for understanding CHAMPS contextual framework of acceptability, practicality, and implementation.

Conceptual Framework



In this framework, acceptability is assessed in light of perceptions of surveillance, especially minimally invasive tissue sampling. At this level of the framework, the main question explored is, “How are CHAMPS and the MITS procedure perceived in light of religious and cultural beliefs and practices?” If CHAMPS and MITS are hypothetically acceptable, the next

question of feasibility can be addressed: “Is it practical?” Given that people perceive CHAMPS and MITS to be acceptable in concept, CHAMPS and the MITS procedure must also not interfere with the things seen as important at the time of death. If CHAMPS and MITS are practical in that they do not interfere with important proceedings at the time of death, the final question is about implementation: “What capacities need to be in place at the CHAMPS country site and in the community to implement MITS?” This component of the framework explores necessary resources to carry out these activities (specifically MITS) in ways that cause minimal disruption to peoples’ daily lives, burial preparation, and funeral ceremonies.

Acceptability

When exploring perceptions related to acceptability of CHAMPS and MITS in light of religious and cultural beliefs and practices, acceptability among participants in Bangladesh was strongly influenced by religious beliefs, specifically rooted in Islamic doctrine. In Islam, it is believed that the body continues to feel pain from the time of death to the time of burial and that it is wrong to cause harm. For this reason, complete diagnostic autopsies are considered impermissible (Gatrad, 1994; Sajid, 2016; Sarhill et al., 2001; Sheikh, 1998; Sheikh & Gatrad, 2008). Participants in Bangladesh referenced the same teachings when describing their objections to the MITS procedure; they did not want to cause more harm to the body of the deceased child. It is clear that religious beliefs about the spirit and the body after death influence participants in Bangladesh to perceive the MITS procedure unfavorably. However, the Islamic principle of maslaha that outlines when the benefits outweigh the damages, the beneficial action should be taken creates the possibility for Islamic scholars and leaders to determine MITS to be acceptable through the issuing of a fatwa. Considering that all participants in Bangladesh desired to know the cause of death because it would be beneficial for the rest of society to prevent

further death, engaging religious leaders in Bangladesh could be one way to begin shaping attitudes and perceptions in favor of MITS.

It should be noted that while the issuing of a fatwa may help improve individual and community understandings about the acceptability of MITS, they may not be effective at changing beliefs or perceptions. During the CHAMPS formative research data collection, two fatawa were issued in Bangladesh in support of MITS, but showed little success at changing perceptions towards the procedure. No fatawa about MITS have been issued in Sierra Leone. While there is potential for Imams and other Muslim religious scholars and leaders to advocate for the acceptability of MITS through the issuing of fatawa, there is no guarantee they will be effective at changing or shaping beliefs and perceptions.

Among participants in Sierra Leone, acceptability of CHAMPS and MITS was strongly influenced by cultural norms, specifically related to who was involved in the introduction of MITS into the community. Participants in Sierra Leone were quick to express approval towards MITS and shared that engaging with village chiefs and chairmen would ensure others in the community found it acceptable too. As long as these community leaders accompanied CHAMPS staff to households, sponsored community sensitization events, and were general voices of encouragement for participation in the project, then acceptability of MITS in the community would be achieved. This response highlights the importance of cultural authority structures and respect for hierarchies of power.

Some participants in both countries also shared that determining the cause of death and the MITS procedure would be unnecessary, because God is the cause of death. Because God is the cause of death, then there would be nothing new to learn and the procedure would not be useful or important. Achieving acceptability among these participants would require significant

motivation and justification from religious leaders. Participants in both countries also shared that religious leaders could be useful in spreading the word and promoting CHAMPS activities through sermons or prayer times. So, while religious doctrine was a source of objection to MITS in Bangladesh and religious leaders were considered unimportant for ensuring community acceptability in Sierra Leone, the principle of *maslaha* in Bangladesh could be important and foundational for issuing *fatawa* to overcome current objections.

Practicality

If CHAMPS and MITS are seen as acceptable in light of religious and cultural beliefs and practices, then the practicality can be considered. The most notable consideration for CHAMPS at the time of death is the timing of the MITS procedure in relation to the timing of burial preparation and funeral ceremonies. At the time of death, participants in both countries described the desire to bury quickly, both in observance of religious teaching in Islam and the desire to ease suffering of relatives of the deceased. While previous research identified that Islamic doctrine called for the body of a deceased individual to remain close to the home, having to transport the body for the MITS procedure was not discussed.

Participants shared that the time from the death of a child to the end of the funeral ceremony is around two hours. If CHAMPS could arrive as soon as they were called, preferably within thirty minutes to an hour, and perform the procedure quickly before the body was washed and wrapped, then MITS would be possible. This would also require all decision makers and key players during burial preparation and funerals to be present and in agreement on timing of activities. If the mother of the deceased child must wait for her husband to return home and provide consent for MITS, then the timing of MITS and burial preparation activities may be in jeopardy. Similarly, if a religious leader is present to pray over the body and release the soul

back to Allah and then must go back to the Mosque to lead prayers, MITS may not be practical during that time. Thus, if CHAMPS was unable to arrive quick enough and collect the sample within a short time frame, then it would interfere too much with preparation of the body and the funeral ceremony.

Now that CHAMPS has begun implementing mortality surveillance and reporting with the use of MITS, the practicality of the timing of the procedure has been called into question for reassessment. In Bangladesh, it is now known the ideal two-hour window reported by participants in interviews is not feasible. The Bangladesh country site is now meeting with local Imams and other community leaders to determine if MITS would still be considered acceptable if the process delayed burial. Because the timing of burial is important to Muslims to ensure the body and soul are returned to God, to minimize potential harm to the body, and to align with times of prayer, having religious and community leaders advocate for the acceptability of a delayed burial will be critical for ensuring that conducting MITS is still possible in Bangladesh.

Implementation

If CHAMPS and MITS are seen as acceptable and do not interfere with important proceedings at the time of death, then implementation can explore what needs to be in place within the community and the CHAMPS country site to cause minimal disruption to daily activities. In terms of successful implementation of MITS, religious and cultural considerations were most important and pervasive around acceptability and practicality. For the implementation of MITS in Sierra Leone, the history of Ebola reporting and response to death influenced how they would advise CHAMPS to proceed with implementing MITS.

During the Ebola outbreak, an Ebola hotline, “117” was established across Sierra Leone. For the implementation of CHAMPS, a similar hotline may be needed to report deaths to local

leaders and then to CHAMPS. Participants identified that 117 should not be used, because it has a negative connotation from the Ebola outbreak. If CHAMPS decided to use the 117 hotline, community members may get the impression that Ebola is back, or that this outside organization is bringing Ebola back. While the trauma of the Ebola outbreak is present in Sierra Leone, they were open to the idea of “English” medicine and outside interventions. During the Ebola outbreak, sick family members were transported far away to receive laboratory confirmation of Ebola. In many cases, family members did not receive the body back for proper burial. During the early community meetings held by CHAMPS in Sierra Leone, there was significant support for a local laboratory to be built by CHAMPS. This could lead to positive community partnerships, more opportunities to build capacity for mortality surveillance, and successful implementation of MITS by CHAMPS.

RELATION TO PREVIOUS RESEARCH

With consideration to previous research, a number of findings reinforced previous conclusions. First, Islamic teaching about the body being able to feel pain after death was reinforced by participants in Bangladesh. Participants referenced the same scriptures referenced in previous research when describing their objections to MITS. Participants in both countries also discussed the desire to bury quickly, which was described as a characteristic for Muslims after death (Sajid, 2016; Sarhill et al., 2001; Sheikh, 1998). In Bangladesh, participants described their desire to bury quickly in relation to Islamic teaching, but participants in Sierra Leone just discussed the desire to bury quickly without reference to specific Islamic teaching. In Sierra Leone, both Christians and Muslims expressed a desire to bury quickly, despite the lack of Christian doctrine that prescribes quick burial. This is a reflection of the harmonious integration of Christian and Muslim beliefs and practices during times of death and burial. Similarly,

participants in Bangladesh described that if religious leaders determined MITS to be acceptable, then there would be a higher possibility of acceptance. This reinforces previous research related to seeking of fatawa and about circumstantial permissibility of autopsies (Berger, 2014; Hedayat, 2006).

Second, the presence of Hinduism, Christianity, and local traditional belief systems influenced interpretations of Islam. The crossover of bamboo use from Hindu rituals to Muslim burial in Bangladesh and the exemplification of the historical relationship between Islam and politics through participants' frequent references to Shariah law reinforce notions that religion is shaped by daily practices in an individual's immediate environment (Ahamed, 1990; Devine & White, 2013; Fisher, 2011; Graham et al., 2005; Platvoet & Molendijk, 1999; Uddin, 2006b). The level of interfaith harmony in Sierra Leone was demonstrated by the way that participants never referenced one specific religious text, which reinforces previous knowledge that there is significant intermingling of religions and religious identities (African Press Organization, 2013; Ashforth, 2002; Brown, 2014; Graybill, 2017; Lindland, 2005; Marshall & Smith, 2015; Penfold, 2005; The Economist, 2014).

Lastly, the lingering effects of the Ebola outbreak in Sierra Leone are still felt. Participants echoed previous research about how burial rituals and practices were disrupted during the outbreak (Marshall & Smith, 2015; World Health Organization (WHO), 2016a).

LIMITATIONS

This research is not without limitations. First, the main research questions during the formative research process were not solely focused on religion. For this reason, not all participants were probed in significant depth about religious motivations or claims, and underlying belief was not always clear or obvious. In Bangladesh, participants describe the

source of their beliefs as Islamic texts and teachings such as the Quran, Hadith, and Shariah law. In Sierra Leone, participants did not reference these texts or Christian texts, so the relationship between their beliefs and a specific religious tradition is not as clear. Because religion was not the main focus of the formative research process, saturation of information related to the influence of religious beliefs and practices on the acceptability, practicality, and implementation of MITS cannot be determined.

Last, there may be limitations in the analysis because of translation of transcripts from local languages to English. When translating between languages, there are words in one language that are not fully captured in the other. Thus, it is likely that the true meaning or salience of issues was not conveyed in English as they would have been in the local language and context.

SUGGESTIONS FOR FUTURE RESEARCH

Future research could focus on a number of aspects related to the influence of religion on acceptability, practicality, and implementation of MITS by CHAMPS. First, conducting interviews with a central research question related to religion would allow for determination of saturation and a more comprehensive analysis of religious beliefs and practices in each community.

Second, this formative research was all conducted prior to the launch of mortality surveillance activities including MITS. As CHAMPS develops country sites and begins to implement MITS in communities, future research could continue to explore how MITS is actually perceived during its implementation. For participants in Sierra Leone who expressed acceptance towards MITS, it would be important to know if that acceptance is maintained as MITS is rolled out. A participant could find MITS acceptable in theory, but when their child is the one that passes away, will they still find it acceptable and be willing to consent to MITS?

Similarly, as community and religious engagement and sensitization occurs in Bangladesh, how do perceptions towards MITS change, if at all? What role do fatawa play in shaping the acceptability of MITS? Considering that only two Hindi participants were interviewed in Bangladesh, future research exploring broader Hindu perspectives on MITS in Bangladesh would be beneficial for further understanding the potential for widespread implementation of MITS.

Lastly, future research could focus on ways to engage community and religious leaders to use results from MITS procedures to develop disease prevention and health promotion programs in each country context. If communities are not receiving the data and information about causes of death collected through the MITS procedure, then preventing future death would not be possible.

CONCLUSION

Holding seemingly contradictory paradigms that explain causes of death as legitimate is common among participants in Bangladesh and Sierra Leone. Worldviews that incorporate different cosmologies influence the beliefs about causes of death, practices related to preparation of the body for burial, funeral rituals and timing, desires to learn cause of death, and perceptions of MITS. Acceptability of MITS is strongly influenced by religious doctrine in Bangladesh, but not as strongly influenced by religion in Sierra Leone. The most notable consideration for practicality of implementing MITS relates to timing of the procedure and how that may impact the timing of the burial. The most important mechanism necessary for implementing MITS is a structure of community leaders in Sierra Leone that can be utilized to report deaths in a way that eliminates possibility of being misperceived as related to Ebola.

The findings from this secondary analysis are mostly consistent with previous literature. Use of camphor for embalming the body and the notion that soil cannot touch the corpse when it is buried were departures from existing literature, but it was able to be clarified that camphor is often used as a perfume rather than for body preservation. A main limitation of this research is that it is a secondary analysis of qualitative data, so the main questions and areas of interest of the interviews and focus groups were not specifically focused on religion. This limits possibilities for saturation, but identifies possible areas for future research specifically related to how attitudes towards MITS change as it is implemented, further exploration of Hindu perspectives, and how this data will be most effective for both global health actors and local community members.

REFERENCES

- African Press Organization. (2013, July 5). Sierra Leone: “Interreligious cooperation, an asset for rebuilding the nation” - UN expert. *African Press Organisation. Database of Press Releases Related to Africa; Lausanne*. Retrieved from <http://search.proquest.com/docview/1504545664/abstract/A7C1EB5A7A3A4C29PQ/1>
- Aggoun, A. (2006). *Les musulmans face à la mort en France*. Espace éthique.
- Ahaddour, C., Van den Branden, S., & Broeckaert, B. (2019). “God’s land is vast”. Attitudes and practices of Moroccan Muslims regarding burial and repatriation of the deceased. *Mortality*, 24(1), 32–60. <https://doi.org/10.1080/13576275.2017.1413543>
- Ahamed, E. (1990). Islam in Bangladesh. *Asian Survey*, 30(8), 795.
- al-Hibri, A. Y. (1993). Family Planning and Islamic Jurisprudence.
- al-Jaziri, A. al-Rahman. (2009). Islamic jurisprudence according to the four Sunni schools. *Fons Vitae*.
- Al-Adnani, M., & Scheimberg, I. (2006). How can we improve the rate of autopsies among Muslims? *BMJ: British Medical Journal*, 332(7536), 310–310. Retrieved from PMC. (PMC1360419)
- America: The Jesuit Review. (2014, August 18). C.R.S. Fights Fear and Ebola As Crisis Worsens in Sierra Leone. *America; New York*, 211(4), 8–9.
- Amuyunzu, M. (1998). Willing the Spirits to Reveal Themselves: Rural Kenyan Mothers’ Responsibility to Restore Their Children’s Health. *Medical Anthropology Quarterly*, 12(4), 490–502.

- Ashforth, A. (2002). An Epidemic of Witchcraft? The Implications of AIDS for the Post-Apartheid State. *African Studies*, 61(1), 121–143.
<https://doi.org/10.1080/00020180220140109>
- Atighetchi, D. (2007). *Islamic bioethics : problems and perspectives*. New York?]: New York? : Springer.
- Awolalu, J. O. (1976). What is African Traditional Religion? *Studies in Comparative Religion*, 10(2), 10.
- Baddarni, K. (2010). Ethical Dilemmas and the Dying Muslim Patient. *Asian Pacific Journal of Cancer Prevention*, 11, 107–112.
- Bah, S. M., & Aljoudi, A. S. (2014). Taking a religious perspective to contain Ebola. *The Lancet*, 384(9947), 951. [https://doi.org/10.1016/S0140-6736\(14\)61344-1](https://doi.org/10.1016/S0140-6736(14)61344-1)
- Bakshi, S. S., McMahon, S., George, A., Yumkella, F., Bangura, P., Kabano, A., & Diaz, T. (2013). The role of traditional treatment on health care seeking by caregivers for sick children in Sierra Leone: Results of a baseline survey. *Acta Tropica*, 127(1), 46–52.
<https://doi.org/10.1016/j.actatropica.2013.03.010>
- Bamoussa, S., Manal, Al-Fehaid, A. A., Suha, Al-Madani, A. A., Osama, Al Moghannam, A. A., Salah, Galeb, A. A., Sherien, Youssef, A. A., Mohammed, & Kharoshah, A. A., Magdy. (2016). The Islamic Approach to Modern Forensic and Legal Medicine Issues. *The American Journal of Forensic Medicine and Pathology*, 37(2), 127–131.
<https://doi.org/10.1097/PAF.0000000000000234>
- Bassat, Q., Castillo, P., Martínez, M. J., Jordao, D., Lovane, L., Hurtado, J. C., ... Ordi, J. (2017). Validity of a minimally invasive autopsy tool for cause of death determination in

- pediatric deaths in Mozambique: An observational study. *PLOS Medicine*, 14(6), e1002317. <https://doi.org/10.1371/journal.pmed.1002317>
- Bassat, Q., Ordi, J., Vila, J., Ismail, M. R., Carrilho, C., Lacerda, M., ... Menéndez, C. (2013). Development of a post-mortem procedure to reduce the uncertainty regarding causes of death in developing countries. *The Lancet Global Health*, 1(3), e125–e126. [https://doi.org/10.1016/S2214-109X\(13\)70037-8](https://doi.org/10.1016/S2214-109X(13)70037-8)
- BBC News. (2011, May 12). Bangladesh court lifts fatwa ban. *BBC News*. Retrieved from <https://www.bbc.com/news/world-south-asia-13379016>
- Beal, S. (2019). Religions and the Autopsy: Overview, Islam, Judaism. Retrieved March 25, 2019, from MedScape website: <https://emedicine.medscape.com/article/1705993-overview#showall>
- Bendann, E. (2007). *Death Customs: An Analytical Study of Burial Rites*. London, UK: Kessinger Publishing, LLC.
- Ben-Sasi, K., Chitty, L. S., Franck, L. S., Thayyil, S., Judge-Kronis, L., Taylor, A. M., & Sebire, N. J. (2013). Acceptability of a minimally invasive perinatal/paediatric autopsy: healthcare professionals' views and implications for practice. *Prenatal Diagnosis*, 33(4), 5. <https://doi.org/10.1002/pd.4077>
- Berger, M. S. (2014). Fatwa. In *The Oxford Encyclopedia of Islam and Politics*. Retrieved from <http://www.oxfordreference.com/view/10.1093/acref:oso/9780199739356.001.0001/acref-9780199739356-e-0003>
- Bhuvanewar, C. G., & Stern, T. A. (2013). Teaching cross-cultural aspects of mourning: A Hindu perspective on death and dying. *Palliative & Supportive Care*, 11(1), 79–84. <https://doi.org/10.1017/S1478951512000946>

- Bierig, J. R. (2001). Informed Consent in the Practice of Pathology. *Archives of Pathology & Laboratory Medicine*, 125(11), 1425–1429. [https://doi.org/10.1043/0003-9985\(2001\)125<1425:ICITPO>2.0.CO;2](https://doi.org/10.1043/0003-9985(2001)125<1425:ICITPO>2.0.CO;2)
- Blevins, J. (2016). Are Faith-Based Organizations Assets or Hindrances for Adolescents Living with HIV? They Are Both. *The Brown Journal of World Affairs*, 22(2). Retrieved from <https://www.questia.com/magazine/1P3-4202982431/are-faith-based-organizations-assets-or-hindrances>
- Blevins, J. (2018). *Christianity's Role in United States Global Health and Development Policy: To Transfer the Empire of the World*. In *Routledge Research in Religion and Development*. Retrieved from <https://books.google.com/books?id=3DhjDwAAQBAJ>
- Blevins, J., Jalloh, M. F., & Robinson, D. A. (2019). Faith and Global Health Practice in Ebola and HIV Emergencies. *American Journal of Public Health*, 109(3), 379–384. <https://doi.org/10.2105/AJPH.2018.304870>
- Blevins, J., Kiser, M., Lemon, E., & Kone, A. (2017). The percentage of HIV treatment and prevention services in Kenya provided by faith-based health providers. *Development in Practice*, 27(5), 646–657. <https://doi.org/10.1080/09614524.2017.1327027>
- Bowen, J. R. (1998). *Religions in practice : an approach to the anthropology of religion*. Boston: Allyn and Bacon.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Britannica Concise Encyclopedia. (2017). Shaṛī‘ ah. In *Encyclopaedia Britannica*. Retrieved from

<https://proxy.library.emory.edu/login?url=https://search.credoreference.com/content/entry/ebconcourse/shari%CA%BFah/0?institutionId=716>

Brown, P. (2014). *Religion as a Social Determinant of Public Health* (E. L. Idler, Ed.).

<https://doi.org/10.1093/acprof:oso/9780199362202.001.0001>

Butler, D. (2010). Verbal autopsy methods questioned. *Nature*, 467, 1015.

Byass, P. (2016). Minimally Invasive Autopsy: A New Paradigm for Understanding Global Health? *PLOS Medicine*, 13(11), e1002173.

<https://doi.org/10.1371/journal.pmed.1002173>

Cabrera, L. Y. (2015). The Biomedical Paradigm. In L. Y. Cabrera (Ed.), *Rethinking Human Enhancement: Social Enhancement and Emergent Technologies* (pp. 31–54).

https://doi.org/10.1057/9781137402240_2

Campo, J. E. (2014). Muslim ways of death: Between the prescribed and the performed. In *Death and religion in a changing world* (pp. 161–191). Routledge.

Centers for Disease Control and Prevention (CDC). (2015). Investigations and Autopsies - Coroner/Medical Examiner Laws. Retrieved December 21, 2018, from Public Health law website: <https://www.cdc.gov/phlp/publications/coroner/investigations.html>

CHAMPS. (2016). Plans and Protocols. Retrieved November 18, 2018, from CHAMPS

Resources website: <https://champshealth.org/protocols/>

CHAMPS. (2017a). CHAMPS FAQs. Retrieved November 21, 2018, from

<https://champshealth.org/faqs/>

CHAMPS. (2017b). CHAMPS Sites. Retrieved from Where We Work website:

<https://champshealth.org/where-we-work/>

- CHAMPS. (2017c). Who We Are. Retrieved November 25, 2018, from Vision & Mission website: <https://champshealth.org/1857-2/>
- Colman, P. (1997). *Corpses, coffins, and crypts : a history of burial* (1st edition). New York: New York : Henry Holt.
- Cox, J. A., Lukande, R. L., Kateregga, A., Mayanja-Kizza, H., Manabe, Y. C., & Colebunders, R. (2011). Autopsy acceptance rate and reasons for decline in Mulago Hospital, Kampala, Uganda. *Tropical Medicine & International Health*, 16(8), 1015–1018. <https://doi.org/10.1111/j.1365-3156.2011.02798.x>
- Davis, J., Gregory, & Peterson, R., Bradley. (1996). Dilemmas and Solutions for the Pathologist and Clinician Encountering Religious Views of the Autopsy. *Southern Medical Journal*, 89(11), 1041–1044. <https://doi.org/10.1097/00007611-199611000-00003>
- Devine, J., & White, S. (2013). Religion, Politics and the Everyday Moral Order in Bangladesh. *Journal of Contemporary Asia*, 43(1), 127–147. <https://doi.org/10.1080/00472336.2012.735544>
- Durkheim, É., Cosman, C., Cladis, M. S., & Cladis, A. P. C. D. R. M. S. (2001). *The Elementary Forms of Religious Life*. In *Oxford World's Classics*. Retrieved from <https://books.google.com/books?id=3j5tyWkEZSYC>
- Eaton, R. M. (1993). *The rise of Islam and the Bengal frontier, 1204-1760*. Berkeley: Berkeley : University of California Press.
- Ekpo, C. G., & Is'haq, A. B. (2016). Islam and the Environment: Implications of Islamic Funeral Practice on Environmental Sustainability. *ISOR Journal of Research & Method in Education*, 6(1), 58–63.

- Eliade, M., 1907-1986. (1959). *The sacred and the profane : the nature of religion / by Mircea Eliade ; translated from the French by Willard R. Trask*. In *Dr John Cooper Theosophy Collection: Vol.* Accessed from <https://nla.gov.au/nla.cat-vn3114878>. New York: Harcourt Brace Jovanovich.
- El-Reshaid, W., El-Reshaid, K., & Madda, J. (2005). Postmortem Biopsies: The Experience in Kuwait. *Medical Principles and Practice, 14*(3), 173–176.
<https://doi.org/10.1159/000084635>
- Esposito, J. L. (Ed.). (2003). Shariah. In *The Oxford Dictionary of Islam*. Retrieved from <http://www.oxfordreference.com/view/10.1093/acref/9780195125580.001.0001/acref-9780195125580-e-2168>
- Fan, J. K. M., Tong, D. K. H., Poon, J. T. C., Lo, O. S. H., Beh, P. S. L., Patil, N. G., & Law, W. L. (2010). Multimodality minimally invasive autopsy—A feasible and accurate approach to post-mortem examination. *Forensic Science International, 195*(1), 93–98.
<https://doi.org/10.1016/j.forsciint.2009.11.019>
- Fisher, M. P. (2011). *Living Religions* (2011 Custom Edition). Boston, MA: Pearson Learning Solutions.
- Fligner, C. L., Murray, J., & Roberts, D. J. (2011). Synergism of verbal autopsy and diagnostic pathology autopsy for improved accuracy of mortality data. *Population Health Metrics, 9*, 25–25. <https://doi.org/10.1186/1478-7954-9-25>
- FOCUS 1000. (2015). Getting and Maintaining Zero Ebola Cases - SLITHU. Retrieved March 18, 2019, from Focus 1000 News website: <http://www.focus1000.org/index.php/nw/109-getting-and-maintaining-zero-ebola-cases-slithu>

- Fuller, C. J. (1992). *The Camphor Flame: Popular Hinduism and Society in India*. Retrieved from <https://books.google.com/books?id=To6XSeBUW3oC>
- Garenne, M. (2014). Prospects for automated diagnosis of verbal autopsies. *BMC Medicine*, *12*, 18–18. <https://doi.org/10.1186/1741-7015-12-18>
- Gatrad, A. R. (1994). Muslim customs surrounding death, bereavement, postmortem examinations, and organ transplants. *BMJ: British Medical Journal*, *309*(6953), 521. <https://doi.org/10.1136/bmj.309.6953.521>
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: strategies for qualitative research* (4. paperback printing). New Brunswick: Aldine.
- Graham, E. L., Walton, H., & Ward, F. (2005). *Theological Reflection: Methods*. In *Theological Reflections*. Retrieved from <https://books.google.com/books?id=65pIPwAACAAJ>
- Graybill, L. S. (2017). *Religion, tradition, and restorative justice in Sierra Leone*. Notre Dame, Indiana: Notre Dame, Indiana : University of Notre Dame Press.
- Gruessner, R. W. G., & Benedetti, E. (2008). *Living Donor Organ Transplantation*. Retrieved from <https://books.google.com/books?id=9d6hwYiCfV4C>
- Gubhaju, M. R., & Bhattarai, A. (2018). Utilization Pattern of Bamboo in Madanpokhara, Tansen-8, Palpa. *Journal of Plant Resources*, *16*(1), 141–149.
- Gupta, N., Bharti, B., Singhi, S., Kumar, P., & Thakur, J. S. (2014). Errors in Filling WHO Death Certificate in Children: Lessons from 1251 Death Certificates. *Journal of Tropical Pediatrics*, *60*(1), 74–78. <https://doi.org/10.1093/tropej/fmt059>
- Gupta, R. (2011). Death Beliefs and Practices from an Asian Indian American Hindu Perspective. *Death Studies*, *35*(3), 244–266. <https://doi.org/10.1080/07481187.2010.518420>

- Gurley, E. S., Parveen, S., Islam, M. S., Hossain, M. J., Nahar, N., Homaira, N., ... Luby, S. P. (2011). Family and community concerns about post-mortem needle biopsies in a Muslim society. *BMC Medical Ethics, 12*(1), 10. <https://doi.org/10.1186/1472-6939-12-10>
- Haque, M. I., Chowdhury, A. B. M. A., Shahjahan, M., & Harun, M. G. D. (2018). Traditional healing practices in rural Bangladesh: a qualitative investigation. *BMC Complementary and Alternative Medicine, 18*(1), 62–62. <https://doi.org/10.1186/s12906-018-2129-5>
- Harding, S. (2011). Sierra Leone: A Model of Religious Tolerance? In P. Denton (Ed.), *Believers in the Battlespace: Religion, Ideology, and War*. Canadian Defence Academy Press.
- Hedayat, K. (2006). When the Spirit Leaves: Childhood Death, Grieving, and Bereavement in Islam. *Journal of Palliative Medicine, 9*(6), 1282–1291.
- Hessini, L. (2007). Abortion and Islam: Policies and Practice in the Middle East and North Africa. *Reproductive Health Matters, 15*(29), 75–84. [https://doi.org/10.1016/S0968-8080\(06\)29279-6](https://doi.org/10.1016/S0968-8080(06)29279-6)
- Hossain, A. A. (2012). Islamic Resurgence in Bangladesh's Culture and Politics: Origins, Dynamics and Implications¹. *Journal of Islamic Studies, 23*(2), 165–198. <https://doi.org/10.1093/jis/ets042>
- Idler, E. L. (Ed.). (2014). *Religion as a Social Determinant of Public Health*. <https://doi.org/10.1093/acprof:oso/9780199362202.001.0001>
- Innes, B. (1999). *Death and the Afterlife*. Retrieved from <https://books.google.com/books?id=GbmRNQAACAAJ>
- Irion, P. E. (1991). Changing Patterns of Ritual Response to Death. *OMEGA - Journal of Death and Dying, 22*(3), 159–172. <https://doi.org/10.2190/1MY9-7P2B-GWF2-A53X>

- Jha, P. (2014). Reliable direct measurement of causes of death in low- and middle-income countries. *BMC Medicine*, *12*(1), 19. <https://doi.org/10.1186/1741-7015-12-19>
- Jha, P., Gajalakshmi, V., Gupta, P. C., Kumar, R., Mony, P., Dhingra, N., ... RGI-CGHR Prospective Study Collaborators. (2005). Prospective Study of One Million Deaths in India: Rationale, Design, and Validation Results. *PLOS Medicine*, *3*(2), e18. <https://doi.org/10.1371/journal.pmed.0030018>
- Jindra, M., & Noret, J. (2011). *Funerals in Africa: Explorations of a Social Phenomenon*. Retrieved from <https://books.google.com/books?id=ShGkIMp5EnAC>
- Jones, R. A. (1986). *Emile Durkheim: an introduction to four major works*. In *Masters of Social Theory*. Retrieved from <https://books.google.com/books?id=r5MpAQAAAJ>
- Jonker, G. (1996). The knife's edge: Muslim burial in the diaspora. *Mortality*, *1*(1), 27–43. <https://doi.org/10.1080/713685827>
- Kadrouch Outmany, K. (2016). Religion at the cemetery Islamic Burials in the Netherlands and Belgium. *Contemporary Islam*, *10*(1), 87–105. <https://doi.org/10.1007/s11562-015-0341-3>
- Kaltner, J. (2016). *ISLAM: What Non-Muslims Should Know* (Revised & Expanded). Minneapolis, MN: Fortress Press.
- Korschun, H. (2015, May 6). Gates Foundation names Emory Global Health Institute lead partner in child health network. *Emory News Center*. Retrieved from http://news.emory.edu/stories/2015/05/gates_foundation_emory_ghi_ianphi_champs_partner/campus.html
- Krupa, J., Sureshkumar, J., Silambarasan, R., Priyadarshini, K., & Ayyanar, M. (2019). Integration of traditional herbal medicines among the indigenous communities in

- Thiruvarur District of Tamil Nadu, India. *Journal of Ayurveda and Integrative Medicine*, 10(1), 32–37. <https://doi.org/10.1016/j.jaim.2017.07.013>
- Laungani, P. (1996). Death and bereavement in India and England: A comparative analysis. *Mortality*, 1(2), 191–212. <https://doi.org/10.1080/713685836>
- Laungani, P. (1997). Patterns of bereavement in Indian and English society. In J. D. Morgan (Ed.), *Readings in Thanatology* (pp. 67–76). Amityville, NY: Baywood Publishing Co.
- Lewis, C., Latif, Z., Hill, M., Riddington, M., Lakhanpaul, M., Arthurs, O. J., ... Sebire, N. J. (2018). “We might get a lot more families who will agree”: Muslim and Jewish perspectives on less invasive perinatal and paediatric autopsy. *PLoS ONE*, 13(8), e0202023. <https://doi.org/10.1371/journal.pone.0202023>
- Lindland, E. H. (2005). *Crossroads of culture : religion, therapy, and personhood in Northern Malawi*. 2005: 2005 : publisher not identified.
- Lishimpi, K., Chintu, C., Lucas, S., Mudenda, V., Kaluwaji, J., Story, A., ... Zumla, A. (2001). Necropsies in African children: consent dilemmas for parents and guardians. *Archives of Disease in Childhood*, 84(6), 463–467. <https://doi.org/10.1136/adc.84.6.463>
- Maixenchs, M., Anselmo, R., Sanz, A., Castillo, P., Macete, E., Carrilho, C., ... Munguambe, K. (2018). Healthcare providers’ views and perceptions on post-mortem procedures for cause of death determination in Southern Mozambique. *PLOS ONE*, 13(7), e0200058. <https://doi.org/10.1371/journal.pone.0200058>
- Maixenchs, M., Anselmo, R., Zielinski-Gutiérrez, E., Odhiambo, F. O., Akello, C., Ondire, M., ... Munguambe, K. (2016). Willingness to Know the Cause of Death and Hypothetical Acceptability of the Minimally Invasive Autopsy in Six Diverse African and Asian

- Settings: A Mixed Methods Socio-Behavioural Study. *PLOS Medicine*, 13(11), e1002172. <https://doi.org/10.1371/journal.pmed.1002172>
- Marshall, K., & Smith, S. (2015). Religion and Ebola: learning from experience. *The Lancet; London*, 386(10005), e24–e25. [http://dx.doi.org.proxy.library.emory.edu/10.1016/S0140-6736\(15\)61082-0](http://dx.doi.org.proxy.library.emory.edu/10.1016/S0140-6736(15)61082-0)
- Mathers, C. D., Fat, D. M., Inoue, M., Rao, C., & Lopez, A. D. (2005). Counting the dead and what they died from: an assessment of the global status of cause of death data. *Bulletin of the World Health Organization*, 83(3), 171–177. Retrieved from PMC. (PMC2624200)
- McDermott, M. Y., & Ahsan, M. M. (1980). *The Muslim guide: for teachers, employers, community and social administrators in Britain*. Retrieved from <https://books.google.com/books?id=UU8wAAAAYAAJ>
- Michaels, A. (2004). *Hinduism: Past and Present*. Princeton, N.J.: Princeton University Press.
- Morgan, J. D. (2002). Islam, the Straight Path: Islam Interpreted by Muslims. In P Laungani (Ed.), *Death and bereavement around the world* (1st ed., pp. 153–157). Amityville, NY: Baywood Publishing.
- Mysorekar, U. (2006). Spirituality in palliative care: A Hindu perspective. In C. M. Puchalski, *A time for listening and caring : spirituality and the care of the chronically ill and dying*. Oxford; New York: Oxford University Press. /z-wcorg/.
- Nirala, D. P., Ambasta, N., & Kumari, P. (2017). A Review on uses of Bamboo Including Ethno-Botanical Importance. *International Journal of Pure & Applied Bioscience*, 5(5), 515–523.
- O'Brien, K. A., & Rashid, I. (2013). Islamist militancy in Sierra Leone. *Conflict, Security & Development*, 13(2), 169–190. <https://doi.org/10.1080/14678802.2013.796207>

- O’Gorman, S. M. (1998). Death and dying in contemporary society: an evaluation of current attitudes and the rituals associated with death and dying and their relevance to recent understandings of health and healing. *Journal of Advanced Nursing*, 27(6), 1127–1135. <https://doi.org/10.1046/j.1365-2648.1998.00659.x>
- Oluwasola, O. A., Fawole, O. I., Otegbayo, A. J., Ogun, G. O., Adebamowo, C. A., & Bamigboye, A. E. (2009). The Autopsy. *Archives of Pathology & Laboratory Medicine*, 133(1), 78. Retrieved from aqh.
- Opwis, F. (2005). Maṣlaḥa in Contemporary Islamic Legal Theory. *Islamic Law and Society*, 12(2), 182–223. Retrieved from JSTOR.
- Pande, V. C., Kumar, A., & Singh, A. K. (2012). Uses of bamboo and its marketing in ravines. In *Bamboo Plantation Based Technological Interventions for Reclamation and Productive Utilization of Ravine Lands* (Vol. 4, p. 13). Uttarakhand, India: Indian Council of Agricultural Research.
- Payyappalli, U. (2018). Broadening perspectives of global health – Prospects for AYUSH and integrative medicine. *Journal of Ayurveda and Integrative Medicine*, 9(2), 87–89. <https://doi.org/10.1016/j.jaim.2018.05.003>
- Penfold, P. (2005). Faith in resolving Sierra Leone’s bloody conflict. *The Round Table*, 94(382), 549–557. <https://doi.org/10.1080/00358530500303601>
- Platvoet, J. G., & Molendijk, A. L. (1999). *The Pragmatics of Defining Religion: Contexts, Concepts, and Contests*. BRILL.
- Prince, R. (2007). Salvation and Tradition: Configurations of Faith in a Time of Death. *Journal of Religion in Africa*, 37(1), 84–115. Retrieved from JSTOR.

- Quigley, M. A., Armstrong Schellenberg, J. R., & Snow, R. W. (1996). Algorithms for verbal autopsies: a validation study in Kenyan children. *Bulletin of the World Health Organization*, 74(2), 147–154. Retrieved from PubMed. (8706229)
- Ramaswamy, S. (2018). Reflections on current Ayurveda research. *Journal of Ayurveda and Integrative Medicine*, 9(4), 250–251. <https://doi.org/10.1016/j.jaim.2018.11.001>
- Rambachan, A. (2012). “Like a ripe fruit separating effortlessly from its vine” Religious understandings of a good death: Hinduism. In *Religious Understandings of a Good Death in Hospice Palliative Care* (pp. 29–50). Albany, NY: State University of New York Press.
- Reproductive Health Matters. (2001). Court Rules against Fatwas, Bangladesh. *Reproductive Health Matters*, 9(17), 223–223. Retrieved from JSTOR.
- Rispler-Chaim, V. (1993). The Ethics of Postmortem Examinations in Contemporary Islam. *Journal of Medical Ethics*, 19(3), 164–168. Retrieved from JSTOR.
- Sabiq, A.-S. (1991). *Fiqh us-sunnah: Hajj and Umrah* (Vol. 5). Amer Trust Pubns.
- Sajid, I., Mohammed. (2016). Autopsy in Islam: Considerations for Deceased Muslims and Their Families Currently and in the Future. *The American Journal of Forensic Medicine and Pathology*, 37(1), 29–31. <https://doi.org/10.1097/PAF.0000000000000207>
- Sanner, M. (1994). In perspective of the declining autopsy rate. Attitudes of the public. *Archives of Pathology & Laboratory Medicine*, 118(9), 878–883. Retrieved from PubMed. (8080356)
- Santelli, J. S., Kantor, L., Grilo, S., Speizer, I. S., Lindberg, L. D., Heitel, J., ... Ott, M. A. (2017). *Abstinence-only-until-marriage : An Updated review of U.S. policies and programs and their impact*. 273-280. ISSN 1054-139X.

- Sarhill, N., LeGrand, S., Islambouli, R., Davis, M. P., & Walsh, D. (2001). The terminally ill Muslim: Death and dying from the Muslim perspective. *American Journal of Hospice and Palliative Medicine*®, 18(4), 251–255. <https://doi.org/10.1177/104990910101800409>
- Shamma, T. (2013). How Muslims Wash, Bury Their Dead. *WFAE* 90.7. Retrieved from <https://www.wfae.org/post/how-muslims-wash-bury-their-dead>
- Shankar, D. (2018). Directions for revitalization of Ayurveda in the 21st century. *Journal of Ayurveda and Integrative Medicine*, 9(4), 245–247. <https://doi.org/10.1016/j.jaim.2018.12.002>
- Sheikh, A. (1998). Death and dying--a Muslim perspective. *Journal of the Royal Society of Medicine*, 91(3), 138–140. Retrieved from PubMed. (9659326)
- Sheikh, Aziz, & Gatrads, A. R. (2008). *Caring for Muslim patients*. Radcliffe Publishing.
- Snow, R., & Marsh, K. (1992). How useful are verbal autopsies to estimate childhood causes of death? *Health Policy and Planning*, 7(1), 22–29. <https://doi.org/10.1093/heapol/7.1.22>
- Snow, R., Winstanley, M. T., Marsh, V. M., Newton, C., Waruiru, C., Mwangi, I., ... Armstrong, J. R. M. (1992). Childhood deaths in Africa: uses and limitations of verbal autopsies. *Originally Published as Volume 2, Issue 8815, 340(8815), 351–355.* [https://doi.org/10.1016/0140-6736\(92\)91414-4](https://doi.org/10.1016/0140-6736(92)91414-4)
- Soleman, N., Chandramohan, D., & Shibuya, K. (2006). Verbal autopsy: Current practices and challenges. Soleman, N., Chandramohan, D., & Shibuya, K. *Bulletin of the World Health Organization*, 84(3), 239–245.
- The Economist. (2014, May 31). All things happily to all men; Religion in Sierra Leone. *The Economist; London*, 411(8889), 41.

- The Freetown Society. (2015). *Faith on the Frontline*. Retrieved March 18, 2019, from Freetown Society website: <http://freetownsociety.org/faith-on-the-frontline/>
- Uddin, S. (2006a). *Constructing Bangladesh: Religion, Ethnicity, and Language in an Islamic Nation*. University of North Carolina Press.
- Uddin, S. (2006b). *Constructing Bangladesh: Religion, Ethnicity, and Language in an Islamic Nation*. In *Islamic Civilization & Muslim Networks*. Retrieved from <https://books.google.com/books?id=stw9siqzHVYC>
- UNICEF. (2017a). Bangladesh (BGD) - Health Data & Infant Mortality Rates. Retrieved November 25, 2018, from UNICEF DATA website: <https://data.unicef.org/country/bgd/>
- UNICEF. (2017b). Levels and Trends in Child Mortality. Retrieved November 25, 2018, from UNICEF DATA website: <https://data.unicef.org/resources/levels-and-trends-in-child-mortality/>
- UNICEF. (2017c). Sierra Leone (SL) - Health Data & Infant Mortality Rates. Retrieved December 19, 2018, from UNICEF DATA website: <https://data.unicef.org/country/sle/>
- UNICEF. (2017d). United States (USA) - Health Data & Infant Mortality Rates. Retrieved December 19, 2018, from UNICEF DATA website: <https://data.unicef.org/country/usa/>
- UNICEF, WHO, World Bank, & UN-DESA Population Division. (2018). *Levels and trends in child mortality report 2018* (p. 48). Retrieved from http://childmortality.org/files_v22/download/UN%20IGME%20Child%20Mortality%20Report%202018.pdf
- van Gennep, A. (1960). *The rites of passage*. Chicago: Chicago : University of Chicago Press.
- Vijendra Rao, R., Gairola, S. C., Shashikala, S., & Sethy, A. K. (2008). Bamboo Utilization in Southern India. *Indian Forester*, 134(3), 379–386.

- Vikør, K. S. (2014). Sharī‘ah. In *The Oxford Encyclopedia of Islam and Politics*. Retrieved from <http://www.oxfordreference.com/view/10.1093/acref:oso/9780199739356.001.0001/acref-9780199739356-e-0026>
- White, S. (2012). Beyond the Paradox: Religion, Family and Modernity in Contemporary Bangladesh. *Modern Asian Studies*, 46(5), 1429–1458.
<https://doi.org/10.1017/S0026749X12000133>
- World Health Organization (WHO). (2016a). Ebola outbreak 2014 - present: How the outbreak and WHO’s response unfolded. Retrieved December 21, 2018, from Emergency preparedness, response website:
<http://www.who.int/csr/disease/ebola/response/phases/en/>
- World Health Organization (WHO). (2016b). WHO | Ebola situation reports: archive. Retrieved December 21, 2018, from WHO website: <http://www.who.int/csr/disease/ebola/situation-reports/archive/en/>
- World Health Organization (WHO). (2017). *Global Health Observatory Data: Under-five Mortality*. Retrieved from http://www.who.int/gho/child_health/mortality/mortality_under_five/en/
- World Health Organization (WHO). (2018a). Mortality Database Frequently Asked Questions. Retrieved November 23, 2018, from WHO Mortality Database website:
<http://apps.who.int/healthinfo/statistics/mortality/whodpms/help/faq.htm>
- World Health Organization (WHO). (2018b). WHO Mortality Database. Retrieved November 23, 2018, from Health Statistics and Information Systems website:
http://www.who.int/healthinfo/mortality_data/en/

You, D., Hug, L., Ejdemyr, S., Idele, P., Hogan, D., Mathers, C., ... Alkema, L. (2015). Global, regional, and national levels and trends in under-5 mortality between 1990 and 2015, with scenario-based projections to 2030: a systematic analysis by the UN Inter-agency Group for Child Mortality Estimation. *The Lancet*, 386(10010), 2275–2286.
[https://doi.org/10.1016/S0140-6736\(15\)00120-8](https://doi.org/10.1016/S0140-6736(15)00120-8)

Ziffren, A. (1995). Religious rituals surrounding illness and death: Hinduism. *Journal of Pediatric Oncology Nursing*, 12(3), 156–157. [https://doi.org/10.1016/1043-4542\(95\)90124-8](https://doi.org/10.1016/1043-4542(95)90124-8)

APPENDICES

APPENDIX A: IRB DETERMINATION



EMORY
UNIVERSITY

Institutional Review Board

October 11, 2018

Ashley Meehan
Rollins School of Public Health
Hubert Department of Global Health

RE: Determination: No IRB Review Required
Title: *Secondary data analysis of CHAMPS SBS data*
Responsible Investigator: Ashley Meehan

Dear Ms. Meehan:

Thank you for requesting a determination from our office about the above-referenced project. Based on our review of the materials you provided, we have determined that it does not require IRB review because it does not meet the definition of “research” with human subjects or “clinical investigation” as set forth in Emory policies and procedures and federal rules, if applicable. Specifically, in this project, you will have access to CHAMPS Network data “from: community elders and matrons, community level health care providers, professionals involved in proceedings related to death and dying, religious leaders, and local community members representing the potential participants. Only the country sites’ collection teams have access to participant identifiers.” All analysis will be done with de-identified data.

Please note that this determination does not mean that you cannot publish the results. This determination could be affected by substantive changes in the study design, subject populations, or identifiability of data. If the project changes in any substantive way, please contact our office for clarification.

Thank you for consulting the IRB.

Sincerely,

Ashton Hughes
Research Protocol Analyst
Emory IRB

Emory University
1599 Clifton Road, 5th Floor - Atlanta, Georgia 30322
Tel: 404.712.0720 - Fax: 404.727.1358 - Email: irb@emory.edu - Web: <http://www.irb.emory.edu>
An equal opportunity, affirmative action university

Ver. 1/17/2014

APPENDIX B: VERBAL CONSENT SCRIPT

Date (dd/mm/yyyy): ____ / ____ / ____

Introduction

Thank you for participating in this interview. I am _____ from _____.

What is this interview?

This is an interview we are asking members of your community to participate in. This is part of a bigger effort to better understand what members of your community do when: 1) a woman becomes pregnant, 2) she experiences problems during her pregnancy, or 3) when a child dies. The results of the interview will help us better understand the causes of child deaths so that we can help to reduce preventable deaths in the future. Your participation is voluntary (your choice). If you do not want to participate in the interview, it will not affect your job, your ability to access health care, or your participation in CHAMPS activities, now or in the future.

What are the possible risks and benefits?

You will be asked to give at most 1.5 hours of your time and you can choose to stop at any time even if the interview is not complete. We will also give you a form you can send in later if you change your mind and want us to remove your information from our records. We will not record your name, but we will record some simple information about you such as your gender, age, and the country you live in. The only foreseeable risk to you is a potential loss of privacy. However your privacy is very important to us and we will be very careful with your information. The only people who will have access to the information shared in the interview will be the members of the CHAMPS socio-behavioral science team and they will not share individual results with anyone else for any reason. When the CHAMPS social-behavioral science team shares findings from these interviews, all information that could identify any individual who was interviewed will be removed before the findings are shared.

There will be no direct benefit to you or your family members from participating in this interview. However, the information that you provide may ultimately help us to improve the health of babies and children in your country in the future.

If you have any further questions about this interview or your participation in this study, please ask now or contact the following individual: [Name of site lead Socio-Behavioral Scientist]. We can send you a copy of this information, if you would like.

Contact Information

If, at any time, you have questions about this screening process, your rights as a research participant, or if you have questions, you may contact the Emory University Institutional Review Board at +01 404-712-0720 or toll-free at +01 877-503-9797 or by email at irb@emory.edu

Consent

Do you have any questions about anything I just said? Were there any parts that seemed unclear?

Do you agree to take part in the study?

Participant agrees to participate: Yes No

If Yes:

Name of Participant

Name of Legally-Authorized Representative (if non-treatment study, must be parent/legal guardian of minor, or have Power of Attorney for Research)

Relationship of Legally-Authorized Representative to Participant

Signature of Person Conducting Informed Consent Discussion Date Time

Name of Person Conducting Informed Consent Discussion

APPENDIX C: KEY INFORMANT INTERVIEW GUIDE

Please note that the purpose of this guide is to provide examples for key informant in-depth interview consent and questions reflective of the specific aims listed in the protocol. These should be modified to satisfy the cultural norms, timing and sensitivities in each site accordingly. Interviewing strategies involving question sequencing, probing structure, timing and transition should also be designed based on each site's current methodologies.

Example Types of Interview Questions

Topic 1: Death and related practices (feasibility)

Example questions for the general sample population:

1. Please describe what happens when a child dies in [name of community].
Probes:
 - Ask about cultural practices and rituals
 - What happens to the corpse?
2. When a child dies, what happens to the child's spirit and what does the family or the community do to help this happen?
Probes:
 - Why are those things done? What happens if they're not done?
 - Are there specific things done in the family? Are they done in private? How does the family tell the community that the child has died? When do they tell?
3. Who are the people who take the lead in doing these things in your community
Probes:
 - What do religious or spiritual leaders do? Is there more than one type of religious leader in your community?
 - What do healthcare workers do?
 - What do women do? What do men do? What do children do?
4. Can you tell me what happens to the body of a child who dies?
Probes:
 - How is the body cared for after death?
 - How is the body buried?
 - Who prepares the body?
 - Is there a religious service or some activity the community does together when the child's body is buried? If so, who leads it?
5. Are these things always done for everybody or do people decide that some things don't have to be done?
Probes:
 - How important is it to carry out these activities?
 - Imagine that these activities weren't carried out. What would happen?
6. What helps a woman to be healthy during her pregnancy? What causes her to lose her child during pregnancy?
Probes:

- If she loses her child, what does she do?
 - What does the community do?
 - Are there specific things done in the family? Are they done in private?
How does the family tell the community that the child has died? When do they tell?
7. Is someone or something to blame for the death of a child or the loss of a child during pregnancy?
Probes:
- If so, who is it? What is it?
 - What does the community do in response?
8. People are often sad when a child dies. How do people in your community show their sadness?
Probes:
- Does a family member do anything specifically? Does the mother?
 - How does the community support the family?
 - Is anything done long after the child has died (e.g., at the anniversary of the child's death)?
 - What things are done to show sadness when a mother loses her child during pregnancy?
9. Do you feel there is value in knowing what caused a child to die?
Probes:
- Why would this be valuable?
 - Explore the desire/willingness to consent.
 - How much or what information would be valued?
10. Our project wants to work collaboratively and respectfully with your community? Do you have any suggestions for helping us to do that?
Probes:
- How can we be mindful and respectful of mothers' and families' needs after the death of a child?
 - How can we be mindful and respectful of the community's needs after the death of a child?

Example questions for community health care providers, public health practitioners, clinicians, policy and political representatives, researchers, etc. (can be used with conjunction with general questions):

1. What are some of the requirements for the health system (i.e. medical facilities) to conduct MITS procedures?
Probes:
 - What might be the level of current knowledge (about MITS and/or other CHAMPS activities)?
 - Explore the acceptability of MITS among health care workers.
2. Having named those requirements, which of them are in place in your health system?
Probes:
 - What would need to be put in place in regard to facilities? Equipment? Personnel?

3. What role could your health system play in carrying out MITS?
Probes:
 - Could MITS be carried out in your health facilities?
 - Could your healthcare workers go out into the community to carry out MITS?
4. What role could your health system play in carrying out pregnancy surveillance?
Probes:
 - Could pregnancy surveillance be carried out in your health facilities?
 - Could your healthcare workers go out into the community to carry out pregnancy surveillance?
 - Do you have access to an existing disease surveillance database that could provide data for pregnancy surveillance?
5. How can CHAMPS activities work with the existing health priorities and activities in the community?
Probes:
 - How can CHAMPS activities integrate with and/or support the activities of your health system?
 - How can CHAMPS contribute to the public health infrastructure of your community?

Example questions for next of kin and/or parents (can be used with conjunction with general questions):

1. Do you feel there is value in knowing the cause of death of your [child, niece, nephew, grandchild, etc.]?
Probes:
 - Explore the desire/willingness to consent.
 - How much information would be valued?
2. What is most important for us to do in showing our respect to your family during this difficult time?

Topic 2: Ethical Considerations

Example questions for the general sample population:

1. Do you think people should be offered something for taking part in a health-related activity?
Probes:
 - Have you had any past experiences with receiving food or money by participating in [example health activity] (receiving incentives)?
 - If something were offered to members of your community when they take part in this activity, how would people respond?
2. We want to find out what causes children to die so that we can do something about those things and have fewer deaths of children. Do you think finding out this information would be valuable?
Probes:
 - If it's valuable, why? If not, why not?
3. [Follow-on to question #2] To find out this information, we have to gather some tissue and fluids from the body of the child after they die so they we can know what caused the child to die. We need to do that within 24 hours after a child dies. We

would only do it if the child's parents agreed. How would your community feel about this being done?

Probes:

- Explore any concerns from the perspective of the community.
 - Explore any concerns from the perspective of the family.
 - Is there anyone in your community who would need to give their approval to allow community members to take part in CHAMPS?
4. Should women in the community talk with our project staff so that the staff can find out about the things that women face when they're pregnant and learn about the things that can make pregnancy difficult? Doing this would only involve us talking with women and we would only talk with them with their permission.

Probes:

- If yes, why? If no, why not?
 - Do you think that families in your community would be willing for the wife/mother to do this?
5. You described for us things that are important in the community to do when a child dies. We've described for you the importance for CHAMPS of identifying the things that cause children to die so that we can do something about those things. How important are each of these things to your community?

Probes:

- If community activities are more important, why?
 - If CHAMPS objective is more important, why?
6. Do you think that it's possible to do the things that are important in the community when a child dies **AND** to gather the tissue and fluid samples from the child's body?

Probes:

- If no, please describe the reasons why both aren't possible in your opinion
 - If yes, please describe the ways that both can be done
7. How can CHAMPS be respectful of and build the trust of community members?

Probes:

- Can you think of anything we might do accidentally that would be offensive to the community?
- What are the best ways for us to work with the community? What are the best ways to share what we find?

Example questions for community health care providers, public health practitioners, clinicians, policy and political representatives, researchers, etc. (can be used with conjunction with general questions):

1. What is the role of the government, if any, when a child dies?

Probes:

- What are the reporting requirements?
- Are there any investigations conducted (i.e. if there is suspicion of intentional injury causing the death)?

2. What is the process for reporting deaths in [facility name or community]?

Probes:

- Do clinicians feel threatened by results of MITS if different from their diagnosis?

- Would others (i.e. clinical personnel) see MITS as helpful?

Topic 3: Community Entry and Engagement

Example questions for the general sample population:

1. What places do people go to most often for healthcare?

Probes:

- Which facilities in your community are most often used?
- Which facilities or health providers are most trusted?
- Outside of health facilities, who do people see for their health (e.g., a faith healer, a traditional healer)?

2. We want to find out what causes children to die so that we can do something about those things and have fewer deaths of children. Do you think finding out this information would be valuable?

Probes:

- If it's valuable, why? If not, why not?

3. [Follow-on to question #2] To find out this information, we have to gather some tissue and fluids from the body of the child after they die so they we can know what caused the child to die. We need to do that within 24 hours after a child dies. We would only do it if the child's parents agreed. How would your community feel about this being done?

Probes:

- Explore any concerns from the perspective of the community.
- Explore any concerns from the perspective of the family.
- Is there anyone in your community

4. If tissue and fluids from the body of a child who dies were to be collected with the parents' permission, what kinds of rumors might start in the community?

Probes:

- Do you have any suggestions about ways we could work in your community to address those rumors if they started?

5. People are often sad when a child dies. How do people in your community show their sadness?

Probes:

- Does a family member do anything specifically? Does the mother?
- How does the community support the family?
- Is anything done long after the child has died (e.g., at the anniversary of the child's death)?
- What things are done to show sadness when a mother loses her child during pregnancy?

6. How can CHAMPS be respectful of and build the trust of community members?

Probes:

- Can you think of anything we might do accidentally that would be offensive to the community?
- What are the best ways for us to work with the community? What are the best ways to share what we find?

Example questions for community health care providers, public health practitioners, clinicians, policy and political representatives, researchers, etc. (can be used with conjunction with general questions)

1. Who are the most important people that need to be involved in activities related to community entry [describe community entry]?

Probes:

- Religious leader?
- Village chiefs?
- Others?

2. What do you think would be the best method of educating the community about MITS?

Probes:

- Explore facility and community discussions

3. What are some of the best ways to speak with and involve community leaders in CHAMPS activities [describe CHAMPS activities]?

Probes:

- Explore rituals and traditional practices.

Topic 4: Pregnancy and Birth (perceptions)

Example questions for the general sample population:

1. Please describe how pregnant women receive care during their pregnancy.

Probes:

- How do women share the news of their pregnancy? When does this usually occur?
- Do women typically go to an antenatal care facility or receive care at home?
- Who provides the care for pregnant women (at home and/or in a facility)?
- Where do women go to deliver? Who provides the care during delivery?

1. What are some barriers to seeking care?

2. What are some barriers to care for women who are pregnant?

3. What do people in the community do when they find out a woman is pregnant?

Probes:

- What happens among women when they find out another woman is pregnant?
- What happens among men when they find out a man's wife is pregnant?
- What happens in the family when the mother finds out she's pregnant?
- What happens in your faith communities when the members find out that a woman in the community is pregnant?

Example questions for community health care providers, public health practitioners, clinicians, policy and political representatives, researchers, etc. (can be used with conjunction with general questions)

1. What are the current capacities in this [facility or community] to date pregnancies and postpartum and newborn exams?

Probes:

- Explore types of care and quality of care.
2. Can you describe any policies related to antenatal care?

Probes:

- Explore strengths and weaknesses of antenatal care.
3. How could CHAMPS activities be aligned with and complement your current antenatal and postpartum services?

APPENDIX D: SEMI-STRUCTURED INTERVIEW GUIDE

Please note that the purpose of this guide is to provide examples for semi-structured interview consent and questions reflective of the specific aims listed in the protocol. These should be modified to satisfy the cultural norms, timing and sensitivities in each site accordingly. Interviewing strategies involving question sequencing, probing structure, timing and transition should also be designed based on each site's current methodologies. It is anticipated that 8 to 10 questions will take approximately 1 hour using a semi-structured method.

Example Types of Interview Questions

Demographic information

Topic 1: Death and related practices (feasibility)

Example questions for the general sample population:

1. Please describe what happens when a child dies in [name of community].
Probes:
 - Ask about cultural practices and rituals
 - What happens to the corpse?
2. When a child dies, what happens to the child's spirit and what does the family or the community do to help this happen?
Probes:
 - Why are those things done? What happens if they're not done?
 - Are there specific things done in the family? Are they done in private? How does the family tell the community that the child has died? When do they tell?
3. What helps a woman to be healthy during her pregnancy? What causes her to lose her child during pregnancy? Are the common beliefs and practices around early pregnancy loss, stillbirth, or neonatal death?
Probes:
 - If she loses her child, what does she do?
 - What does the community do?
 - Are there specific things done in the family? Are they done in private? How does the family tell the community that the child has died? When do they tell?
4. People are often sad when a child dies. How do people in your community show their sadness?
Probes:
 - Does a family member do anything specifically? Does the mother?
 - How does the community support the family?
 - Is anything done long after the child has died (e.g., at the anniversary of the child's death)?
 - What things are done to show sadness when a mother loses her child during pregnancy?

5. Do you feel there is value in knowing the cause of death?

Probes:

- Explore the desire/willingness to consent.
- How much or what information would be valued?

Example questions for community health care providers, public health practitioners, clinicians, policy and political representatives, researchers, etc. (can be used with conjunction with general questions):

1. What are some of the requirements for the health system (i.e. medical facilities) to conduct MITS procedures?

Probes:

- What might be the level of current knowledge (about MITS and/or other CHAMPS activities)?
- Explore the acceptability of MITS among health care workers.

Example questions for next of kin and/or parents (can be used with conjunction with general questions):

1. Do you feel there is value in knowing the cause of death of your [child, niece, nephew, grandchild, etc.]?

Probes:

- Explore the desire/willingness to consent.
- How much information would be valued?

Topic 2: Ethical Considerations

Example questions for the general sample population:

1. Do you think people should be offered something for taking part in a health-related activity?

Probes:

- Have you had any past experiences with receiving food or money by participating in [example health activity] (receiving incentives)?
- If something were offered to members of your community when they take part in this activity, how would people respond?

2. We want to find out what causes children to die so that we can do something about those things and have fewer deaths of children. Do you think finding out this information would be valuable?

Probes:

- If it's valuable, why? If not, why not?

3. [Follow-on to question #2] To find out this information, we have to gather some tissue and fluids from the body of the child after they die so they we can know what caused the child to die. We need to do that within 24 hours after a child dies. We would only do it if the child's parents agreed. How would your community feel about this being done?

Probes:

- Explore any concerns from the perspective of the community.
- Explore any concerns from the perspective of the family.
- Is there anyone in your community

4. Should women in the community talk with our project staff so that the staff can find out about the things that women face when they're pregnant and learn about the things that can make pregnancy difficult? Doing this would only involve us talking with women and we would only talk with them with their permission.

Probes:

- If yes, why? If no, why not?
- Do you think that families in your community would be willing for the wife/mother to do this?

Example questions for community health care providers, public health practitioners, clinicians, policy and political representatives, researchers, etc. (can be used with conjunction with general questions):

1. What is the role of the government, if any, when a child dies?

Probes:

- What are the reporting requirements?
- Are there any investigations conducted (i.e. if there is suspicion of intentional injury causing the death)?

2. What is the process for reporting deaths in [facility name or community]?

Probes:

- Do clinicians feel threatened by results of MITS if different from their diagnosis?
- Would others (i.e. clinical personnel) see MITS as helpful?

Topic 3: Community Entry and Engagement

Example questions for the general sample population:

1. What places do people go to most often for healthcare?

Probes:

- Which facilities in your community are most often used?
- Which facilities or health providers are most trusted?
- Outside of health facilities, who do people see for their health (e.g., a faith healer, a traditional healer)?

2. We want to find out what causes children to die so that we can do something about those things and have fewer deaths of children. Do you think finding out this information would be valuable?

Probes:

- If it's valuable, why? If not, why not?

3. [Follow-on to question #2] To find out this information, we have to gather some tissue and fluids from the body of the child after they die so they we can know what caused the child to die. We need to do that within 24 hours after a child dies. We would only do it if the child's parents agreed. How would your community feel about this being done?

Probes:

- Explore any concerns from the perspective of the community.
- Explore any concerns from the perspective of the family.
- Is there anyone in your community

4. If tissue and fluids from the body of a child who dies were to be collected with the parents' permission, what kinds of rumors might start in the community?

Probes:

- Do you have any suggestions about ways we could work in your community to address those rumors if they started?

5. People are often sad when a child dies. How do people in your community show their sadness?

Probes:

- Does a family member do anything specifically? Does the mother?
- How does the community support the family?
- Is anything done long after the child has died (e.g., at the anniversary of the child's death)?
- What things are done to show sadness when a mother loses her child during pregnancy?

Example questions for community health care providers, public health practitioners, clinicians, policy and political representatives, researchers, etc. (can be used with conjunction with general questions)

1. Who are the most important people that need to be involved in activities related to community entry [describe community entry]?

Probes:

- Religious leader?
- Village chiefs?

2. What do you think would be the best method of educating the community about MITS?

Probes:

- Explore facility and community discussions.

3. What are some of the best ways to speak with and involve community leaders in CHAMPS activities [describe CHAMPS activities]?

Probes:

- Explore rituals and traditional practices.

Topic 4: Pregnancy and Birth (perceptions)

Example questions for the general sample population:

2. Please describe how pregnant women receive care during their pregnancy.

Probes:

- How do women share the news of their pregnancy? When does this usually occur?
- Do women typically go to an antenatal care facility or receive care at home?
- Who provides the care for pregnant women (at home and/or in a facility)?
- Where do women go to deliver? Who provides the care during delivery?

3. What are some barriers to seeking care?

Example questions for community health care providers, public health practitioners, clinicians, policy and political representatives, researchers, etc. (can be used with conjunction with general questions)

1. What are the current capacities in this [facility or community] to date pregnancies and postpartum and newborn exams?

Probes:

- Explore types of care and quality of care.

2. Can you describe any policies related to antenatal care?

Probes:

- Explore strengths and weaknesses of antenatal care.

APPENDIX E: FOCUS GROUP DISCUSSION GUIDE

Please note that the purpose of this guide is to provide examples for focus group consent and questions reflective of the specific aims listed in the protocol. These should be modified to satisfy the cultural norms, timing and sensitivities in each site accordingly. Interviewing strategies involving question sequencing, probing structure, timing and transition should also be designed based on each site's current methodologies.

Example Types of Focus Group Discussion Questions

Topic 1: Death and related practices (feasibility)

Example questions for the general sample population (i.e. community health care leaders and providers, public health practitioners, clinicians, etc.)

1. Please describe what happens when a child dies in [name of community].
Probes:
 - Ask about cultural practices and rituals
 - What happens to the corpse?
2. Can you tell me what happens to the body of a child who dies?
Probes:
 - How is the body cared for after death?
 - How is the body buried?
 - Who prepares the body?
 - Is there a religious service or some activity the community does together when the child's body is buried? If so, who leads it?
3. Are these things always done for everybody or do people decide that some things don't have to be done?
Probes:
 - How important is it to carry out these activities?
 - Imagine that these activities weren't carried out. What would happen?
4. What helps a woman to be healthy during her pregnancy? What causes her to lose her child during pregnancy?
Probes:
 - If she loses her child, what does she do?
 - What does the community do?
 - Are there specific things done in the family? Are they done in private? How does the family tell the community that the child has died? When do they tell?
5. Our project wants to work collaboratively and respectfully with your community? Do you have any suggestions for helping us to do that?
Probes:
 - How can we be mindful and respectful of mothers' and families' needs after the death of a child?
 - How can we be mindful and respectful of the community's needs after the death of a child?

6. What are some of the requirements for the health system (i.e. medical facilities) to conduct MITS procedures?
 - Probes:
 - What might be the level of current knowledge (about MITS and/or other CHAMPS activities)?
 - Explore the acceptability of MITS among health care workers.
7. Having named those requirements, which of them are in place in your health system?
 - Probes:
 - What would need to be put in place in regard to facilities? Equipment? Personnel?
8. What role could your health system play in carrying out MITS?
 - Probes:
 - Could MITS be carried out in your health facilities?
 - Could your healthcare workers go out into the community to carry out MITS?
9. What role could your health system play in carrying out pregnancy surveillance?
 - Probes:
 - Could pregnancy surveillance be carried out in your health facilities?
 - Could your healthcare workers go out into the community to carry out pregnancy surveillance?
 - Do you have access to an existing disease surveillance database that could provide data for pregnancy surveillance
10. How can CHAMPS activities work with the existing health priorities and activities in the community?
 - Probes:
 - How can CHAMPS activities integrate with and/or support the activities of your health system?
 - How can CHAMPS contribute to the public health infrastructure of your community?

Topic 2: Ethical Considerations

Example questions for the general sample population (i.e. community health care leaders and providers, public health practitioners, clinicians, etc.):

1. Do you think people should be offered something for taking part in a health-related activity?
 - Probes:
 - Have you had any past experiences with receiving food or money by participating in [example health activity] (receiving incentives)?
 - If something were offered to members of your community when they take part in this activity, how would people respond?
2. Should women in the community talk with our project staff so that the staff can find out about the things that women face when they're pregnant and learn about the things that can make pregnancy difficult? Doing this would only involve us talking with women and we would only talk with them with their permission.
 - Probes:
 - If yes, why? If no, why not?

- Do you think that families in your community would be willing for the wife/mother to do this?
3. Do you think that it's possible to do the things that are important in the community when a child dies **AND** to gather the tissue and fluid samples from the child's body?
Probes:
 - If no, please describe the reasons why both aren't possible in your opinion
 - If yes, please describe the ways that both can be done
 4. How can CHAMPS be respectful of and build the trust of community members?
Probes:
 - Can you think of anything we might do accidentally that would be offensive to the community?
 - What are the best ways for us to work with the community? What are the best ways to share what we find?
 3. What is the role of the government, if any, when a child dies?
Probes:
 - What are the reporting requirements?
 - Are there any investigations conducted (i.e. if there is suspicion of intentional injury causing the death)?
 4. What is the process for reporting deaths in [facility name or community]?
Probes:
 - Do clinicians feel threatened by results of MITS if different from their diagnosis?
 - Would others (i.e. clinical personnel) see MITS as helpful?

Topic 3: Community Entry and Engagement

Example questions for the general sample population (i.e. community health care leaders and providers, public health practitioners, clinicians, etc.):

1. What places do people go to most often for healthcare?
Probes:
 - Which facilities in your community are most often used?
 - Which facilities or health providers are most trusted?
 - Outside of health facilities, who do people see for their health (e.g., a faith healer, a traditional healer)?
2. If tissue and fluids from the body of a child who dies were to be collected with the parents' permission, what kinds of rumors might start in the community?
Probes:
 - Do you have any suggestions about ways we could work in your community to address those rumors if they started?
3. People are often sad when a child dies. How do people in your community show their sadness?
Probes:
 - Does a family member do anything specifically? Does the mother?
 - How does the community support the family?
 - Is anything done long after the child has died (e.g., at the anniversary of the child's death)?

- What things are done to show sadness when a mother loses her child during pregnancy?
4. How can CHAMPS be respectful of and build the trust of community members?
Probes:
 - Can you think of anything we might do accidentally that would be offensive to the community?
 - What are the best ways for us to work with the community? What are the best ways to share what we find?
 5. Who are the most important people that need to be involved in activities related to community entry [describe community entry]?
Probes:
 - Religious leader?
 - Village chiefs?
 - Others?
 6. What do you think would be the best method of educating the community about MITS?
Probes:
 - Explore facility and community discussions
 7. What are some of the best ways to speak with and involve community leaders in CHAMPS activities [describe CHAMPS activities]?
Probes:
 - Explore rituals and traditional practices.

Topic 4: Pregnancy and Birth (perceptions)

Example questions for the general sample population (i.e. community health care leaders and providers, public health practitioners, clinicians, etc.):

1. Please describe how pregnant women receive care during their pregnancy.
Probes:
 - How do women share the news of their pregnancy? When does this usually occur?
 - Do women typically go to an antenatal care facility or receive care at home?
 - Who provides the care for pregnant women (at home and/or in a facility)?
 - Where do women go to deliver? Who provides the care during delivery?
2. What are some barriers to care for women who are pregnant?
3. What do people in the community do when they find out a woman is pregnant?
Probes:
 - What happens among women when they find out another woman is pregnant?
 - What happens among men when they find out a man's wife is pregnant?
 - What happens in the family when the mother finds out she's pregnant?
 - What happens in your faith communities when the members find out that a woman in the community is pregnant?
4. What are the current capacities in this [facility or community] to date pregnancies and postpartum and newborn exams?
Probes:

- Explore types of care and quality of care.
5. Can you describe any policies related to antenatal care?

Probes:

- Explore strengths and weaknesses of antenatal care.

How could CHAMPS activities be aligned with and complement your current antenatal and postpartum services?

APPENDIX F: CODEBOOK

Name	Description	Files	References
Anticipated acceptance of MITS	includes comments about who might accept, why the might accept, and proactive actions that can be done to ensure acceptance	21	104
Beliefs about causes of death	Includes any comments about why an individual has died that is not related to biological causes (disease, hygiene), Ebola, or spiritual explanations such as witchcraft or curses	22	263
Beliefs about causes of illness	includes mentions about causes of illnesses or sickness, which may be interpreted as biological or spiritual in nature	11	22
Biological - Disease	includes biological and pathophysiological explanations about cause of death such as not taking the child or mother to the clinic early enough or on time, disease, malaria, poor hygiene of the mother and/or child	16	47
Spiritual - God, Witchcraft, Curses, Hexes	includes supernatural explanations about cause of death such as curses or hexes from community or family members and the belief that it was the will of God to take what was His. This includes comments about believing what a traditional healer says is the cause of death (for example)	17	85
Burial preparation, rites, and rituals	includes reference to washing the body, wrapping the body in a shroud or other garment, praying over the body for the soul to pass on, comments about funeral proceedings such as if a religious leader needs to lead ceremony, prayers that are said during the ceremony/burial, location of ceremony/burial, and timing of ceremony/burial	22	202
Current methods of determining cause of death	includes visiting a witch doctor, sorcerer, or other traditional healer, use of herbs, spells, or witchcraft, finding out from a local clinic or a nurse. Does not include comments about outcomes of visiting traditional healers or clinics or what the causes of death were concluded to be (see beliefs about causes of death). This includes comments by community	16	51

Name	Description	Files	References
	members about where they go and how they determine a cause of death, as well as methods used by healthcare workers and religious leaders to determine CoD		
Desire to gain knowledge about cause of death	includes comments about someone's desire or lack of desire to know what the cause of death was (i.e. it is important to know to prevent deaths of others, it is not important to know because it won't bring back the deceased, etc.)	22	109
Ebola	includes any reference to the Ebola virus, Ebola as an illness or sickness, and information about the Ebola response from local and international partners. Also includes changes to burial practices that were caused by previous health events such as Ebola. The main purpose of this code is to help identify co-occurrence and how Ebola changes the context for which health interventions and MITS are understood, accepted/not accepted, and implemented	9	35
Hinduism	Any mention of Hindu, Hinduism, Hindu people, or Karma	6	27
Location of MITS	Includes any reference or discussion about where MITS procedure or tissue extraction should be done, such as in the home or a specific room in the home, at a health facility, etc.	4	5
Perceived objections to MITS	includes comments about who might object, why they might object, and what can be done to ensure acceptance with specific consideration to those objections. This is different from anticipated acceptance because anticipated acceptance includes comments about what can be done beforehand to ensure acceptability without direct reference to objections. This code includes comments about acceptance as it pertains to objections.	20	134
Religion	Includes any reference to religion, religious systems, religious beliefs, and religious practices that do not explicitly use the terms in the God, Allah, Christian/Christianity, Muslim/Islam, and traditional religion codes	17	69

Name	Description	Files	References
Christianity	includes any mention of the word church, pastor or priest, the Bible, Jesus, identifying oneself as a Christian, or referencing beliefs and practices specifically as “Christian”	11	19
God, Allah	includes use of the word “God,” or “Allah”. This code was developed to identify overlap between mention of “God” or “Allah” with other codes to ascertain where in the process of death, burial, and determining cause of death the participants include or place “God” or “Allah.” This is not limited to just the Muslim God or just the Christian God, but any use of the word “God” “Allah.”	19	125
Islam	includes any mention of the word mosque, imam or mufti, the Quran, the Hadith, or fatawa, the prophet Muhammed, identifying oneself as a Muslim, or referencing beliefs and practices as specifically belonging to or rooted in “Islam”	14	118
Traditional religion and healing	includes any mention of visiting a traditional or native leader, healer, or doctor, sorcerer, or witch doctor, use of herbs, hexes, or spells,	19	61
Social support	includes reference to providing or receiving social support during or after death and burial such as giving/receiving money, visiting/being visited by relatives and community, and other social support provided during bereavement and mourning. also includes references to lack of social support or being left alone purposefully	17	98
Timing of MITS	includes how quickly CHAMPS should come to see the family and collect the sample	15	57
Verbal autopsy	includes any mention of or reference to verbal autopsies as they pertain to MITS	7	7