# Stillbirths at Khayelitsha Hospital: Issues in the provision of care

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## Declaration

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#### Abstract

This dissertation focuses on the provision of care to those who experience stillbirths at Khayelitsha Hospital in the Western Cape, South Africa. The research is based on a psychosocial paradigm and draws from a psychoanalytic understanding of healthcare organizations. I conducted a critical organizational ethnography with multiple sources of data including observations in the labour ward, interviewing labour ward staff, and the female patients who used the ward. Secondary data were sourced from hospital documents. From my observations and interviews, it is clear that no one is being overtly mistreated in Khayelitsha hospital and patients are medically well attended to. Although there was no apparent physical or emotional abuse, however, I noted a silence in the ward which I later learned was experienced as alienating by the mothers. I noted that there were limited interactions between the women and the healthcare practitioners, apart from a competent and caring focus on medical issues. I suggest that the limited engagement between patient and healthcare providers was founded partly on deep cultural and socio-economic differences between many staff and the patients, and on varying degrees of expectation of care on the part of different people in the system. In the overburdened healthcare system (where both staff and patients are often overwhelmed or traumatised), silence can be a way in which a system defends itself against what it knows it cannot provide. While the challenges in the provision of healthcare in South African state institutions are complex, this research provides a window into the opportunity for training and a new perspective on the provision of maternal mental healthcare for mothers who have stillbirths, and more broadly.

### Opsomming

Hierdie proefskrif fokus op die verskaffing van sorg aan vrouens wat 'n stilgeboorte by Khayelitsha Hospitaal in die Wes-Kaap, Suid-Afrika beleef het. Hierdie navorsing is op 'n psigososiale paradigma gebaseer en 'n psigoanalitiese verstaan van die dinamika van gesondheidsorgorganisasies is gebruik. Ek het 'n kritiese organisatoriese etnografie, bestaande uit verskeie bronne van data naamlik waarnemings in die kraamsaal, onderhoude met die kraamsaalpersoneel, sowel as die vroue-pasiënte wat die saal benut het, gedoen. Sekondêre data is verkry uit hospitaaldokumentasie. My waarnemings en onderhoude het bevestig dat die pasiënte in Khayelitsha-hospitaal vanuit 'n mediese oogpunt goed versorg word, en dat niemand openlik mishandel word nie. Alhoewel daar geen oënskynlike fisiese of emosionele mishandeling was nie, het ek wel 'n stilte in die saal beleef, wat, soos ek later uitgevind het, deur die moeders as vervreemding ervaar is. Ek het opgemerk dat daar beperkte interaksies tussen die vroue en die mediese personeel was, behalwe vir 'n bevoegde en sorgsame fokus op mediese probleme. Ek stel voor dat die beperkte interaksies tussen die pasiënte en die gesondheidsorgpersoneel deels op diep kulturele en sosio-ekonomiese verskille tussen baie van die personeel en pasiënte, asook wisselende grade van verwagting van sorg deur verskillende persone in die stelsel, gegrond is. In die oorlaaide gesondheidsorgstelsel (waar beide die personeel en pasiënte gereeld oorweldig of getraumatiseer is), kan stilte 'n manier wees waarop 'n stelsel hom verdedig teen iets wat dit weet dit nie kan bied nie. Terwyl die uitdagings in gesondheidsorgvoorsiening in Suid-Afrika se staatsinstansies kompleks is, verskaf hierdie navorsing insae rakende opleidingsgeleenthede en 'n nuwe perspektief op geestesgesondheidsorgvoorsiening vir moeders wat 'n stilgeboorte beleef het, en selfs wyer.

## Acknowledgements

Not in my wildest dreams did I ever think I would do my PhD. I do not think of myself as an academic but have learnt so much about myself in this process. James (the love of my life), thanks so much for the encouragement along the way. I would never have done this without you!!!

Thanks to Avril Cowlin who suggested I ask Leslie Swartz to supervise me. Leslie has been an incredible supervisor and I do not think this PhD would be here today without his enthusiasm and belief that I could do it.

There were many others who have assisted me along the way or just encouraged me to "just keep swimming". Thank you! A big and special thank you Mamta, Dorothea and Jane.

Thanks to the staff and patients at Khayelitsha Hospital that allowed me to interview them. I appreciate your kindness and interest in my research.

# Dedication

To the community of Khayelitsha and my colleagues at Khayelitsha Hospital.

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# List of acronyms and abbreviations

KH	Khayelitsha Hospital
FANI	Free Association Narrative Interview
HIV	Human Immunodeficiency Virus
ТВ	Tuberculosis

## **Terminological definitions**

#### **Medical officer**

A qualified medical doctor working for government

#### Stillbirth

A baby born with no signs of life at or after 28 weeks of gestation

#### Race

Throughout this dissertation, I refer to population groups as Black, White, Indian or Coloured. During the apartheid era in South Africa, the Population Registration Act (1950) classified the South African people into 'Black', 'Coloured' (mixed race), 'Indian' or 'White'. Although apartheid laws have not been applicable since 1994, these categories are embedded and still influence the socio-economic conditions, the provisions of health and the health status of the people in the various groups (Mpahlwa, 2019; Posel, 2001).

#### Low- and Middle-Income Countries (LMIC)

This term is taken from World Bank terminology and is based on the Bank's operational lending categories. LMIC economies are at times also referred to as developing economies (The World Bank, 2019). South Africa is presently classified as a developing upper-middle income country.

#### Township

This term, in South Africa, refers to low resourced and racially segregated urban areas. From the late 19th century until the end of apartheid, these areas set aside for non-Whites. Townships were constructed on the periphery of towns and cities and maintain their peripheral status today (Pettman, 1913; Seekings & Nattrass, 2008; Sills, 1968)

## PART 1: INTRODUCTION & BACKGROUND

#### Overview

In its broadest sense, this dissertation focuses on the provision of care to those who experience stillbirths at Khayelitsha Hospital in the Western Cape, South Africa. The dissertation is divided into three parts and was completed by "thesis-by-publication" format. A total of five articles and one book chapter were submitted, based on the findings of this study.

<u>Part 1</u> of the dissertation presents the introduction and background of the study. The introduction begins by describing the study setting and outlining the research aims. It provides an overview of relevant literature by discussing studies on the provision of care to mothers experiencing stillbirths and a number of affiliated subjects. The literature review includes studies conducted in both the global North and the developing world and attempts are made to draw links between them. The relevance of these studies to stillbirths is explored and various gaps in the current literature are suggested. The study design is then explained. This includes an outline of the methodology, a description of the participants, explanation of data collection and analysis, and finally, an examination of ethical issues.

<u>Part 2</u> contains four of the five journal articles submitted for publication, making up the results section of the dissertation. In this part, I focus my observations in the labour ward and what I heard from the mothers and healthcare practitioners (specifically the nurses and doctors).

<u>Part 3</u> sums up the dissertation with reflections on the PhD process (which includes a reflection piece that has been accepted as a chapter in a forthcoming book). The final chapters include an article about the word 'violence' and a summary of the main findings. The limitations and overall significance of this study are also discussed.

#### **CHAPTER ONE: INTRODUCTION**

#### 1.1 Background and rationale for this study

This study is about stillbirths, grief and the provision of state hospital care. Suffering is an existential and unavoidable reality of the human condition. Working in a district hospital, and especially one serving an impoverished community like Khayelitsha, inevitably means exposure to patient suffering and death. It is well established that in all healthcare systems, practitioners may struggle to provide adequate care for reasons that include self-protection (emotional defence) from being overwhelmed by suffering (Byrne, Morton, & Salmon, 2001; Menzies, 1960; Obholzer & Zagier Roberts, 1994). These issues may be exacerbated in healthcare systems that are overstretched and operate in violent social contexts, such as in poor areas in South Africa (Frenkel, 2002; Hasumi & Jacobsen, 2014; Kelly, Mrengqwa, & Geffen, 2019).

I work as a clinical psychologist at Khayelitsha Hospital (KH), a large district hospital (340 beds) located in an impoverished area of Cape Town with high levels of community violence (Barolsky, 2016; Jansen, 2017; Smit et al., 2016). Many of the features of overworked and stressed healthcare systems are part of this working context. I have a particular interest in maternal mental health and studied the subject as part of my master's degree dissertation in 2011. Soon after I started work at the hospital (2014), I quickly became concerned about the lack of counselling and support provided to women who had stillbirths.

While exploring the subject of care provision for grieving mothers, I asked a medical colleague who (like me, is a White South African) why he believed that adequate provision was not made. The colleague in question said that in "*this community*" a stillbirth is equivalent "*to us taking a crap*" (the doctor's own words). While I was initially shocked by the comment, the sentiment that stillbirths were not considered as a serious concern seemed to be echoed in other hospital practices. Staff seemed unsure of how to place and treat women who had experienced stillbirths. For example, women who have had stillbirths would continue to stay in the labour ward alongside mothers giving birth to healthy infants. I struggled to imagine such a practice in a private hospital. The implication was that those from outside of the Khayelitsha community (from wealthier backgrounds) had a different grieving system to the underprivileged, uneducated members of South Africa. In contrast to what may be inferred from the above comment, the doctor in question was otherwise apparently kind, ethical and a colleague whom

I had seen behaving very kindly towards patients. I had seen no hint of racism in the colleague's behaviour towards patients, for example. I was so perturbed by the doctor's response that I decided to implement a system whereby every woman who has had a stillbirth would be required to be reviewed by the psychologist, or at the very least be offered an outpatient appointment before being discharged. I also wanted to understand the context in which a comment like this could be made by an otherwise caring person.

During the last five years, KH doctors have told me that they have received no training to deal with women who have stillbirths. The lack of training is an obvious contributing factor to tenuous or non-existing engagement with the grieving mother. However, this issue is not simply a question of training. (This will be further explored in both the literature review and in the analysis of data collected for this study.) These experiences around stillbirth started my thinking about the interface between psychology and medicine. In particular, district hospitals have a high proportion of medical school graduates as general medical practitioners. A majority of these recent graduates are not parents, come from privileged backgrounds (compared to the Khayelitsha patients) and are early career doctors (Mash, Ogunbanjo, Naidoo, & Hellenberg, 2015). How are they impacted by death? How do they make sense of a mother coming to hospital, only to be told that their baby is dead? What helps them to make sense of this type of death? What defences do they employ to protect themselves? Often these potentially grieving mothers are alone in the ward and need to process this loss in isolation, as their loved ones or family members are at work and (with low day-wage jobs) do not have the privilege of taking a day off. Does this put further pressure on the clinicians to be more supportive or more avoidant of the loss?

There is an implicit expectation (one which I hold myself) that the clinicians, as part of their duty to care, will hold these grieving women in mind (Cacciatore & Flint, 2012; O'Connell, Meaney, & O'Donoghue, 2016). But does this expectation change for low-income patients in a district hospital context? In addition, who holds these clinicians in mind? Finally, what roles do the socio-economic and other gaps between the medical practitioners from outside Khayelitsha and the community play? All these questions call for a more thorough investigation of these complex issues.

#### 1.2 Healthcare practitioners & stillbirths

Death is not routinely expected in a maternity ward (Shorey, André, & Lopez, 2017). Parents place expectations on their clinicians to help the mother have a successful pregnancy and birthing process. The death of a baby at any stage can have a lifelong impact on parents (Nuzum, Meaney, & O'Donoghue, 2018). Even when there is not this tragic outcome, mothers in South Africa (as found elsewhere) commonly define the success of a birth in part by the interpersonal treatment by their healthcare practitioners (Chadwick, 2014; Nuzum et al., 2018). This medical care during such a vulnerable time can influence the parents' grief response to the stillbirth (Cacciatore, 2013; Nuzum, Meaney, & O'Donoghue, 2014). Even up to six years (and I would argue more) after the stillbirth, some parents still remember what the healthcare practitioner said and how they were treated (Wright, 2011).

Parents are known to appreciate it when clinicians acknowledge their mourning process and allow them to participate in practices such as seeing and possibly holding the deceased baby, and taking photographs to remember the baby (Cacciatore, 2013; Flenady et al., 2014; Peters, Lisy, Riitano, Jordan, & Aromataris, 2015). Lewin and Green (2009) have studied the benefit and importance of these rituals in South Africa's primary healthcare clinics. Psychosocial support by clinicians, positive interpersonal relationships and strong social support can notably ameliorate a family's grieving process (Cacciatore, 2013; Wright, 2011).

The mother needs sensitive guidance to alleviate understandable fears and normalise the grief process, and the onus of responsibility falls on the clinicians in this process (Corbet-Owen & Kruger, 2001). However, when healthcare practitioners feel powerless and guilt-ridden, and experience a sense of disappointment and shame, this can result in the healthcare practitioners being avoidant. This avoidant defence may manifest in healthcare practitioners engaging in practices such as referring to patients as diagnoses rather than as people (Byrne et al., 2001; Menzies, 1960; Schrøder, Jørgensen, Lamont, & Hvidt, 2016; Wentzel & Brysiewicz, 2014). These behaviours give the impression that they lack concern for the patients and their families (Cacciatore, 2013). Cacciatore (2013) notes that for a healthy grieving process, clinicians need to see each family as distinctive, and worthy of respect and kindness.

Clinicians have been found to address suffering in one of two ways: through detachment for the explicit purpose of remaining objective, or alternatively to suffer together with the other in order to relieve some of the emotional angst (Coulehan, 2009). The death of a patient can also

cause notable distress in the clinician and is known to occasionally lead to mental health problems in the clinician (Coulehan, 2009; Wentzel & Brysiewicz, 2014). Whilst the grieving mother is the primary patient after a stillbirth, the lost child can be seen as a dead patient for the healthcare practitioner too. These factors amongst others, make stillbirth a significant area of study. The next section explores why stillbirths are an important subject of study.

#### 1.3 Why stillbirths matter

The day of birth is the most dangerous time for the mother and the baby. In 2015, 2.6 million stillbirths were reported globally (WHO, 2017). This meant that 7178 stillbirths occurred a day (WHO, 2017). It is reported that the highest rates of stillbirths worldwide occur in Africa (Kiguli et al., 2016; Lawn et al., 2016; Meyer, Opoku, & Gold, 2018). According to the World Health Organization (WHO) (2017), the recommended definition of a stillbirth is a baby born with no signs of life at or after 28 weeks of gestation. For about nine months, a mother may fantasize (whether with positive or negative thoughts or a mixture of these) about this new life growing in her body. Her body changes and accommodates this life growing inside her. The swelling uterus tells the world that she is fertile and competent to give life to another. Others may try to touch her growing stomach or guess the gender. The mother is given privileges not given before, like being moved to the front of a queue at the district hospital. The world may seem to rejoice with her. But then her baby is dead.

Some studies have reported that a stillbirth can cause an intense grief response which at times can be greater than when a parent or spouse dies (Neria & Litz, 2010; Raphael-Leff, 2015; Wing, Clance, Burge-Gallaway, & Armistead, 2001). Most stillbirths are preventable with regular and professional healthcare during pregnancy (de Bernis et al., 2016; Frøen et al., 2011). It has been reported that virtually all stillborn babies are not recorded in a birth or death documentation (Cacciatore & Lens, 2019; Campbell-Jackson & Horsch, 2014). This non-reporting means that the dead child has never been registered by the healthcare system (Lawn et al., 2016). This results in countries often not knowing the numbers or causes of stillborn deaths. The countries are, therefore, unable to take the appropriate actions to prevent others babies dying (WHO, 2017).

A stillbirth may affect a woman emotionally, psychologically, cognitively, socially, spiritually and physiologically (Cacciatore, 2013; Sutan et al., 2010). According to post-mortem data, the aetiology in about one-half of all stillborn infants is inconclusive and may result in mothers

internalising feelings of guilt and shame (Gold, Sen, & Leon, 2018). Mothers are often left alone to grieve, as their loss in many ways was an "invisible loss"; partly because the outside world had limited interaction with the baby (Frøen et al., 2011, p. 1354). Lovell (1983) suggests that in the context of some maternity wards there may be no physical or psychological space for a maternity case that does not result in a living baby. Recognition of the baby is essential from both within the family and outside the family; because the sense that the baby's life is not of worth implies that the mothers herself lacks worth (Cacciatore, 2013).

There has been much research on stillbirths and grieving parents especially in high-income countries (Cacciatore, 2013; Neria & Litz, 2004; Nuzum et al., 2014; Raphael-Leff, 2015; Wing, Burge-Callaway, Rose-Clance, & Armistead, 2001). However research on the impact of stillbirths in South Africa (and other low-and middle-income countries) is slowly gaining traction (Chadwick, 2014; Gausia et al., 2011; Osman et al., 2017). Research on the impact of stillbirths on the healthcare practitioners and the health system, especially in low-income contexts, is scarce.

#### 1.4 Lack of research about the psychological impact of stillbirths in Africa

The WHO (2017) reported that the highest stillbirth rates worldwide in 2015 were in Sub-Sahara Africa and southern Asia. *The Lancet*<sup>1</sup> has identified the importance of stillbirths as a subject requiring further consideration and has recently published a series of articles dedicated to stillbirths, their relevance and prevention (de Bernis et al., 2016; Frøen et al., 2016; Lawn et al., 2016). Thirteen countries in Africa have estimated stillbirth rates of more than 30 per 1000 total births; however, as most research has been conducted in high-income settings, data about the psychological impact of stillbirths in developing countries are limited (Osman et al., 2017). Apart from possible psychological impacts as noted in the studies mentioned above, social factors must be taken into account. These may include poverty (Sutan et al., 2010), cultural practices and religion (Gausia et al., 2011, Lewin & Green, 2009) and overburdened healthcare systems (Bradley, McCourt, Rayment, & Parmar, 2016; Chadwick, 2014; Kruger & Schoombee, 2010). These factors may all influence the grief process (Mannava, Durrant, Fisher, Chersich, & Luchters, 2015).

<sup>&</sup>lt;sup>1</sup> An independent international general medical journal.

#### 1.5 The study setting: Khayelitsha Hospital (KH)

Khayelitsha, in the Cape Town metropole, is the second biggest Black township in South Africa after Soweto in Johannesburg (South African History Online, 2013). The township is found in the south-eastern part of the City of Cape Town municipal area (see Fig. 1-1) and has the highest rate of poverty in the city (Smit et al., 2016).

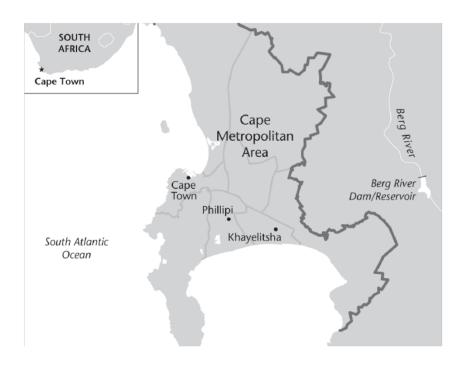


Figure 1-1 Map of Cape Metropolitan area incl. Khayelitsha (Rodina & Harris, 2016).

Under apartheid, Black South Africans were banished to the periphery of cities and forced to live in mostly temporary structures. The area was lit by large floodlights although electricity was not built into the area's infrastructure. The name Khayelitsha in Xhosa means 'new home'. Its population is estimated to be between 400,000 and 750,000 (Super, 2015). Poverty is widespread, with most of the residents sharing communal water supplies and toilets (Super, 2015). The extreme poverty, and poor community infrastructure, has led to surging crime rates, gangs, violence, drugs and other societal ills (Barolsky, 2016; Ohuabunwa, Sun, Jubanyik, & Wallis, 2016; Smit et al., 2016; Stone & Howell, 2019). Women in the Khayelitsha community are often devalued (Kaminer & Eagle, 2010; Russel, 1996) and teenage and unwanted pregnancies are common. These may lead to poor pre-natal care, often because of shame or lack of knowledge (Kruger & van der Spuy, 2007).

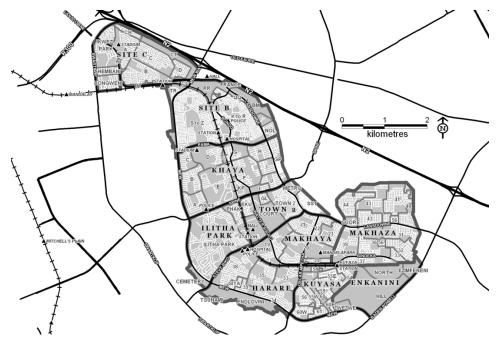


Figure 1-2 Map of Khayelitsha with multiple areas within its demarcation (http://www.mapland.co.za/khayelitsha)

KH is a large district hospital with 340 beds. In an organization like KH, the healthcare system experiences an immense patient load, the poverty of the community it serves, and the numerous traumas affecting both patients and staff. These challenges are overlaid on an apartheid history, and on-going cultural and language differences between patients and staff, and within the staff group itself. In 1994, the South African National Health System established a primary health care approach as a way of enabling disadvantaged communities to access health services (Stoops, Williamson, & Braa, 2018). As a result of this, free antenatal and intrapartum care is offered to women who cannot afford medical aid. Most births in South Africa take place in clinics or in state hospitals.



Figure 1-3 Khayelitsha Hospital in Khayelitsha (Google Maps, 2019)

The maternity healthcare system is divided into three tiers in the Western Cape. The first tier consists of community based Midwife Obstetric Units (MOUs) managed by midwives. The second tier is secondary level hospitals, such as KH, to which women are referred if there are complications in the pregnancy or delivery. Finally, the third tier is the tertiary hospitals where women with the most critical medical conditions are cared for.

Since economic disparity in the Western Cape runs largely along racial lines, the majority of women who make use of state healthcare are what in South African usage are referred to as Black and Coloured. During the apartheid era in South Africa, the Population Registration Act (1950) classified the South African people into 'African/Black', 'Coloured' (mixed race), 'Indian' or 'White'. Although apartheid laws have not been applicable since 1994, these categories are embedded and continue to influence the socio-economic conditions and consequently the provisions of health and the health status of the people in the various groups (Mpahlwa, 2019; Posel, 2001). The vast majority of people who use KH are Black and speak Xhosa as a first language, and sometimes, but not always, have limited proficiency in English and/or Afrikaans (which is the most commonly spoken language in the Western Cape Province) (Benjamin, Swartz, Hering, & Chiliza, 2016; Western Cape Language Committee, 2004).

#### **1.6 Research question**

The primary research question for this study is "What are the experiences of healthcare practitioners at KH when caring for women who have had a stillbirth, and how do the mothers themselves experience their care?"

#### 1.7 Aims of the study

I am interested in observing practices around stillbirths, the emotional experiences of healthcare practitioners in relation to stillbirths, and the defences that they use in dealing with stillbirths in a highly stressed healthcare system. With the research question in mind, the two main aims of the study are

- 1. to explore how healthcare practitioners say they feel about stillbirths.
- 2. to understand how women experience the care received at KH after a stillbirth.

#### 1.8 Theoretical points of departure

Psychosocial studies uses psychoanalytic principles and concepts, as well as insights from critical social psychology to highlight emotional issues within the social context (Clarke & Hoggett, 2018; Saville Young & Berry, 2016). This study draws on the well-established psychoanalytic approach to understanding healthcare organizations. This approach was pioneered by Isabel Menzies Lyth in her studies of nurses in the UK (Menzies, 1960). Menzies Lyth started a tradition of researching healthcare organizational dynamics which was later taken up by Hinshelwood (2000), Obholzer & Zagier Roberts (1994) and then Kruger & Schoombe (2010), amongst others. They addressed how people in organizations defend themselves from overwhelming anxiety by use of beliefs, values and attitudes that unconsciously relieve anxiety (Figlio, 2018; Gerard, 2019; Roberts & Obholzer, 1994; Skogstad, 2018; Van der Walt & Swartz, 1999). These defences have both an unconscious and conscious element to them. Both groups and organizations also deploy defences (Figlio, 2018; Lowdell & Adshead, 2008), and there is a relationship between group and individual defences (Gerard, 2019).

In KH, the health practitioners (medical doctors, nurses and allied health colleagues) deal with pain and suffering continually, which may contribute to heightened anxiety. In addition, the anxiety of a stillbirth experience in any context is traumatic for the mother and healthcare practitioners (Homer, Malata, & Ten Hoope-Bender, 2016). Some coping strategies in such overburdened service settings are conscious - for example taking deliberate breaks. Other

coping strategies may include the attempt to avoid emotional involvement with patients. Task orientation, for example, has very useful conscious practical benefits for nurses (Van der Walt and Swartz, 2002). Task orientation involves dividing up clinical work into a series of tasks. For example, in a medical ward, nurses may move from patient to patient to take their temperatures. This cycle may then be immediately repeated in the ward, this time giving medication to the patients. This form of task orientation has great advantages in that tasks are done quickly and efficiently (and nurses can also easily be trained this way, with care managed in a series of several tasks). In addition to these conscious motivations, there may be unconscious motivations as well. Menzies Lyth (1960) suggested that task orientation can also have an important unconscious defensive purpose in assisting healthcare practitioners not to engage emotionally with patients. Research approaches based on psychoanalysis attempt to understand the unconscious motivations for conscious decisions and actions. Menzies Lyth (1960) draws on the work of Melanie Klein, who has significantly influenced our understanding of the nature of anxiety and these primal defences. She found that these defences enable us to defend against anxiety that may otherwise overwhelm and destroy. Accordingly, if anxiety is a basis for how people operate in the world, then the protective defence against anxiety is an essential stabilizer that allows engagement in a threatening world. The constant threat that poverty presents in the lives of KH's patients and the staff suggests that welldeveloped defences may be expected over and above other defences which may apply to health care more generally.

Menzies Lyth and other contemporary theorists have suggested that there may be unconscious reasons in the decision to work in the helping professions (like nursing) (Obholzer & Zagier Roberts, 1994). According to Roberts (1994), some people may chose helping professions as a means for a process he terms 'reparation'. This process involves using this type of work in order to manage and resolve past anxieties and life challenges. This kind of decision is not necessarily a harmful way of dealing with anxiety. However, it may suggest that current interactions between the healthcare practitioner and patient may be influenced by the past adversities of the healthcare practitioner. An example of this from my own experience was a nurse at KH who explained that her own experience of a stillbirth contributed to her decision to become a nurse. She explained that she wanted to help other women have successful live births. In such instances, however, she may become too overwhelmed by a woman who has experienced a stillbirth and could consequently avoid contact. This connection to her own past may make this contact with the patient unbearable. This kind of situation may strengthen the

defences of depersonalisation and routinisation and thus contributing to the nurse avoiding emotional contact with the patient as a whole person.

#### 1.9 Structure and layout of thesis

This dissertation has been carried out in the dissertation-by-publication format. Article publication represents both individual and institutional competence (Horta & Santos, 2016; Sinclair, Barnacle, & Cuthbert, 2014). I was encouraged to publish early and often. The first article was submitted to a journal in November 2018.

This format also gave me a unique opportunity to focus on publishing within a supervised environment – an opportunity which may not present itself again (Horta & Santos, 2016). Furthermore, the study's data may have become dated if not disseminated in a timeous manner. Thus the "by publication" format provides an opportunity to interrogate and disseminate the data while it is fresh and while motivation is high. There has been much research on stillbirths and grieving parents, especially in high income countries (Cacciatore, 2013; Neria & Litz, 2010; Nuzum et al., 2014; Raphael-Leff, 2015; Wing et al., 2001). Considering the underrepresentation of African authors in scholarly work about Africa, the central goal of publishing as a means of disseminating new findings, which will contribute and drive innovation, can be realized through this method.

Additional advantages for this format include the opportunity for external review of the articles. Such scrutiny and in-depth critique may constitute an extension of the supervisory panel and counteracts the potential subjectivity and blinding of the authors. It also provides feedback from different cultures and contexts which serve to expand expertise, and further develops research and writing skills (Horta & Santos, 2016). This format has also given me the opportunity to share my findings with the hospital management and staff as soon as an article has been published.

This dissertation contains five articles which have been submitted for publication in international peer-reviewed journals. Each article is presented in this dissertation as a separate chapter, with a short discussion of how it is linked to the larger study presented at the beginning of the chapter. I have also included a reflective piece which has been accepted as a book chapter in a volume to be published by Routledge. The traditional Results and some of the Discussion chapters of dissertations have been omitted as each article contains these components. Even

though the goal for this dissertation is to collate the articles for the purposes of the broader study, a requirement for the publication of these articles is that each article retains structural and academic integrity independently. For this reason there is inevitable overlap and repetition, including the introductions, literature reviews and method sections within each article and chapter. There may also be some overlap in the cited references.

This dissertation is divided into three broad sections:

1. <u>Part 1</u> presents the introduction and background of the study as well as the literature review and methodology. This part is composed of Chapters one to four.

2. <u>Part 2</u> discusses the results in peer reviewed articles on what I saw in the observations and what I heard in the interviews of the healthcare practitioners and mothers. This part is composed of five to eight.

3. <u>Part 3</u> begins with my own reflections on my experiences during the research process and includes a reflective piece that is in press in a book. A conceptual, peer-reviewed discourse focused on understanding the term 'violence' in a context like Khayelitsha Hospital is included. Finally, I conclude with a summary of the findings and recommendations for future studies. This part is composed of Chapters nine to 12.

Part	Chapter	Торіс	Publication status	Publication	Article
	1	Introduction			
	2	Stillbirths, a death before life			
PART 1	3	Contextualising stillbirth services in Khayelitsha			
	4	Methodology			
PART 2	5	Observations in the labour ward	Published (2019)	BMC Int Health Hum Rights	Lappeman, M., Swartz, L. Rethinking obstetric violence and the "neglect of neglect": the silence of a labour ward milieu in a South African district hospital. BMC Int Health Hum Rights 19, 30 (2019) doi: 10.1186/s12914-019- 0218-2
	6	Interviews with the medical doctors	Published (2019)	Psychodynamic Practice	<ul> <li>Lappeman, M., &amp; Swartz, L. (2019).</li> <li>Care and the politics of shame: Medical practitioners and stillbirths in a South African district hospital.</li> <li>Psychodynamic Practice, 00(00), 1–17. doi:10.1080/14753634.2019.1670093</li> </ul>

	7	Interviews with the nurses.	Published (2020)	British Journal of Psychotherapy	Lappeman, M., & Swartz, L. (2020). "I don't want to see that the people are suffering." Nurses in an impoverished community talk about caring for women who had stillbirths. British Journal of Psychotherapy. doi: <u>10.1111/bjp.12543</u>
	8	Interviews with the mothers	Manuscript submitted (under second review)	BMC Women's Health	Lappeman, M., & Swartz, L. (2020). Stillbirth in Khayelitsha Hospital, South Africa: Women's experiences of care
	9	Research experiences reflections			
PART 3	10	Self-Reflection on own shame	Book chapter accepted (pub. 2021)	Out of Hours: Boundary Attunement with extreme trauma Ed's Sinason,V and Sachs,A (2021) Routledge, UK	Lappeman, M. (2021). I WANT TO RUN AWAY Reflections from a participant observer
	11	Understanding the word: Violence	Accepted (2020)	Women & Violence	Lappeman, M., & Swartz, L. (2020). How gentle must violence against women be in order to not be violent? Rethinking the word 'violence' in obstetric settings
	12	Concluding thoughts and directions for future research			

Table 1-1 Summary of one book chapter and five articles in this dissertation

## 1.10 Chapter summary

In this chapter, I presented the background and rationale for the research. I also discussed the research questions and objectives which guided the process. Lastly, I described the structure and layout of the thesis. In the next 2 chapters, I discuss some relevant literature on stillbirths and healthcare services in South Africa (and more specifically in Khayelitsha).

#### CHAPTER TWO: STILLBIRTHS, A DEATH BEFORE LIFE

"Death in the midst of life-making affects us deeply" Joan Raphael-Leff (2015, p. 169)

#### **2.1 Introduction**

In this chapter I explore key literature on stillbirths relevant to this study. The recognition of grief after a stillbirth was largely ignored globally before the 1970s (Meyer et al., 2018). The dead baby's body, once birthed, was removed quickly, often unseen by the mother, and parents were encouraged to have another child (Badenhorst & Hughes, 2007; Cacciatore & Lens, 2019; Crispus Jones, McKenzie-McHarg, & Horsch, 2015). Initial the research focused on symptoms of grief and mental health problems over various periods of time after the loss (Badenhorst & Hughes, 2007). This focus later expanded to investigate factors which impeded or facilitated the grief process after a stillbirth. More recently, as interest in the phenomenon of stillbirth has evolved, studies have explored women's narratives of their experience (Cacciatore & Flint, 2012; Flenady et al., 2014; Human et al., 2014). In most of these studies, concentrated in the global North, mothers who experienced stillbirths were predominately from a middle-class population. These studies emphasised focus on individuals' grief and not on social contexts. Until recently, stillbirths in low-income countries have not been seen as a priority in research. In Africa, research before the 1990s focused on overpopulation, infertility, and induced abortions (van der Sijpt, 2010; van der Sijpt & Notermans, 2010). Since then, anthropology, medical sociology and feminist studies have begun researching marginalised and vulnerable communities, focusing on the social consequences of pregnancy loss (van der Sijpt & Notermans, 2010).

In this chapter, different perspectives from research conducted in the global North and in the global South are drawn together in order to address the question of how stillbirth affects parents and healthcare practitioners. Mothers are usually affected more by the loss (Cacciatore & Lens, 2019; Wonch Hill, Cacciatore, Shreffler, & Pritchard, 2017), but there is a growing body of research that demonstrates that fathers grieve too (Cacciatore, Erlandsson, & Rådestad, 2013; Kiguli et al., 2016; Murphy, Shevlin, & Elklit, 2014). I have tried to incorporate both the mothers' and fathers' grief processes into the literature review, even though there is substantially more literature on mothers' grief processes. Researching literature solely on stillbirths was challenging as there is a lack of consensus among researchers regarding the

nomenclature used to describe the phenomenon (Murphy et al., 2014; Wright, 2011). The literature employs different terms interchangeably to describe stillbirths. This includes women who have had a loss earlier in the pregnancy (<sup>2</sup>miscarriage) while others include babies who died within a week of birth (<sup>3</sup>perinatal loss) in the research of women with stillbirths. Researchers have noted these inconsistencies of nomenclature in the literature (Cacciatore & Lens, 2019; Murphy et al., 2014; Wright, 2011).

The first section will focus on the psychological and social difficulties following the loss for parents. This will also include factors which either protect against or increase vulnerability to prolonged adjustment difficulties. Secondly, I will explore the literature on the effects of stillbirth on the healthcare practitioners.

#### 2.2 The impact of the stillbirth on the parent

In this section, I explore the impact of stillbirths on the parent. The section also includes an analysis of the grief process and the personal and social meanings ascribed to pregnancy.

#### 2.2.1 The psychological effects of a stillbirth

For decades, healthcare practitioners would separate the parents from their stillborn baby in the belief that distress could be circumvented if no attachments to the baby were formed (Koopmans, Wilson, Cacciatore, & Flenady, 2013). It was later understood that a mother already develops a relationship with the baby while the baby is still in utero. Consequently, research has focused on understanding the experience of this type of death on parents and families (Koopmans et al., 2013). An estimated 60–70% of women who have a stillbirth will experience grief-related depressive symptoms at clinically significant levels one year after their baby's death (Boyle, Horey, Middleton, & Flenady, 2019). These symptoms can last for several years in approximately half of these women. A stillbirth can affect a parent in various ways. It is a disturbing experience that can result in psychological difficulties including anxiety, depression, and suicidal ideation (Burden et al., 2016; King, Oka, & Robinson, 2019; Murphy & Cacciatore, 2017). Symptoms appear to be most pronounced in the first months, although there is evidence symptoms may continue for many years (Campbell-Jackson & Horsch, 2014).

<sup>&</sup>lt;sup>2</sup> Usually defined as loss of pregnancy before 20 weeks of gestation (Magnus, Wilcox, Morken, Weinberg, & Håberg, 2019)

<sup>&</sup>lt;sup>3</sup> Perinatal death is usually defined as the death of the infant within the first week after birth (Wright, 2011)

Grief following stillbirth may be viewed as negligible, as only parents may have experience the baby's movements or observed it by ultrasound (Cacciatore & Lens, 2019; Human et al., 2014). Grief is person-specific and not all women grieve after a stillbirth (Campbell-Jackson & Horsch, 2014). Still, common grief processes after a stillbirth have been well-documented in high-income contexts. These include a range of emotions such as denial, anger, shock, sadness, guilt, confusion and shame (Cacciatore, 2013; Frøen et al., 2011; Gausia et al., 2011; Human et al., 2014). After a stillbirth, the parent is vulnerable to developing mental health conditions such as post-traumatic stress disorder (PTSD) or complicated bereavement (Badenhorst & Hughes, 2007).

Partly because of the unknown aetiology of stillbirth in many cases (Cacciatore, 2013; Wright, 2011), mothers may blame themselves for the stillbirth (Kersting & Wagner, 2012). They may question even benign daily decisions such as eating certain foods or walking for too long. This interrogation may lead to feelings of guilt and shame being internalised (Burden et al., 2016; Cacciatore, 2013). The lack of information about the cause of the stillbirth increases self-blame and exacerbates anxiety in subsequent pregnancies (Wonch Hill et al., 2017).

The impact of the loss on the mother's emotional well-being, in conjunction with thoughts of self-blame, may cause disruptions in social functioning (Gausia et al., 2011; Wonch Hill et al., 2017). In the parents' relationship, where the loss is often felt more by the mother than the father, the exhaustion of the emotional loss may result in the deterioration of the sexual functioning, in turn causing additional stress on the relationship (Cacciatore, 2013; Gausia et al., 2011; King et al., 2019). In a study in Somalia, pregnant mothers reported knowing that the baby had died due to no foetal movements, but decided to not tell their husbands or partners, family and community so as not to worry them (Osman et al., 2017).

#### 2.2.2 Factors affecting parental grief outcomes

Grieving is a personal experience. Grief after a stillbirth can include experiences of despondency, irritability, broken sleep and poor appetite. There may also be a sense of longing for the lost baby, and occasionally visual or auditory hallucinations of the deceased baby (Badenhorst & Hughes, 2007; Cacciatore & Lens, 2019). The initial trauma of the loss is often followed by feelings of low mood or depression. Anger after a stillbirth is usual and may be directed towards others, or towards the self, for real or imagined failure to protect the lost baby (Cacciatore, 2013). The mourning process of a stillbirth may be a pathway for the parent to

recover, with gradual lessening of distress and return to usual patterns of living. It is important that healthcare practitioners do not pathologise a usual response to a stillbirth and treat it as though it were an illness.

How parents grieve after a stillbirth can be affected by several factors. These factors include personal and social meanings ascribed to the pregnancy, pregnancy history, personality characteristics, social support and religion. Each of these factors is discussed below.

#### Personal meaning of pregnancy

There may be many reasons for wanting children, including the desire for a new identity (Robinson et al., 1999); to strengthen or secure the bond with a partner (Dyer, 2007, Robinson et al., 1999; van der Sijpt & Notermans, 2010); or for pleasure and fulfilment (Dyer, 2007). A stillbirth is often accompanied by other losses such as the loss of an anticipated future, hope, and a sense of the world as a benevolent place (Corbet-Owen & Kruger, 2001; Sturrock & Louw, 2013; Wing et al., 2001). Conversely, an unplanned pregnancy may cause anxiety, relationship discord or financial difficulties. For those parents, pregnancy loss may be an experience of relief and shame (Corbett-Owen & Kruger, 2001).

#### Social meaning of pregnancy

The expectations to have children vary across socio-economic and cultural settings. Having a child, for many women, is a role infused with meaning and expectations (Wonch Hill et al., 2017). This is particularly true in a context like Khayelitsha where motherhood is highly valued (Sturrock & Louw, 2013). With increased medical advancements in the global North, parents have come to assume that they have a level of control over reproduction. The death of a baby may not only be an unexpected trauma but may also be construed as a personal failure and affect their self-esteem (Badenhorst & Hughes, 2007; Wonch Hill et al., 2017). Many authors note that in African society, children are a symbol of prestige, status, identity and economic power (de Kok, Hussein, & Jeffery, 2010; Dyer, 2007). In poor communities, children are expected to assist their parents with work, and provide for their aging parents (Dyer, 2007). In South Africa, unemployed mothers are given child support grants for each child, which can marginally ameliorate the burden of poverty. Also there is an expectation for married couples to have children. Those who do not, whether by choice or pregnancy loss, are shamed and sometimes the women are mistreated (de Kok et al., 2010; Kiguli et al., 2016).

#### Pregnancy history

There is ongoing research into whether later gestational loss results in more intense grief. Some studies found that later gestational loss resulted in more grief symptoms (Bennett, Litz, Maguen, & Ehrenreich, 2008), while others found that gestational age had no effect on the intensity of grief (Elklit & Björk Gudmundsdottir, 2006; Hutti et al., 2016). Research has also found that a stillbirth in a woman's first pregnancy may be associated with greater distress as it disrupts the mothers new identity (Cacciatore & Lens, 2019; Shreffler, Greil, & McQuillan, 2011). This may also be true of recurrent pregnancy losses. How invested a mother is in her pregnancy may also determine how strongly she responds to a loss (Kersting & Wagner, 2012). These diverse findings suggest that pregnancy history alone cannot predict grief responses. The varying research results are likely to be specific to an individual, to the attachment to the baby, and the causal relation between this and gestational age, number of pregnancies or difficulty conceiving remains unclear.

#### Personality structure

Personality structures which predict better grief outcomes are those with ego strength, defined as the "*capacity for delayed gratification, lack of impulsivity, and emotional balance*" (Zeanah & Harmon, 1995, p. 91), and the ability to endure difficulties (Badenhorst & Hughes, 2007; Lang, Goulet, & Amsel, 2004). Those who are proned to guilt, shame and anxiety may have heightened distress after a stillbirth (Barr & Cacciatore, 2008; Cacciatore, Frøen, & Killian, 2013). All of these traits are considered to contribute to a maladaptive coping style which affects grief negatively because they hamper cognitive processing (Bennett et al., 2008; Kersting & Wagner, 2012). A review of several studies suggests that pre-existing mental illness, such as depression and anxiety render women more vulnerable to complicated grief responses or PTSD (Kersting & Wagner, 2012; Klier, Geller, & Ritsher, 2002).

#### Social support

Social support after a stillbirth is well researched. The parents' social systems are often illequipped and ambiguous regarding how to respond after of a stillbirth. This may result in the parents feeling isolated and misunderstood (Campbell-Jackson & Horsch, 2014). Poor support from others has been associated with increased anxiety and depression (Cacciatore, Schnebly, & Froen, 2009). However, strong social support from family, friends and institutions (such as a church or a community-based organization) has consistently been found to be strongly correlated with positive grief outcomes (Abboud & Liamputtong, 2005; Cacciatore & Lens, 2019; Cacciatore et al., 2009; Hutti et al., 2016; Wing et al., 2001). Talking to others about the baby may be an important source of support, especially considering the disenfranchised grief the parents may feel (Cacciatore & Lens, 2019). Opening dialogues about the baby who has died, helps the bereaved parent to find social validation for their experience (Sutan et al., 2010). Talking to others who have had similar experiences may help reduce distress and give meaning and comfort to the parent. Similarly, practical support and gestures which demonstrate care, seem to comfort the mothers and also assists in reducing distress by recognising and validating feelings of loss (Abboud & Liamputtong, 2005; King et al., 2019). Examples of practical support and caring gestures may include; financial assistance, providing meals or providing temporary child care for the mother's other children. Social rituals also (such as funerals or family gatherings) seem to facilitate healthy grieving (Sturrock & Louw, 2013). This may be because the rituals also validate the experience and normalize the grief the parent is experiencing (King et al., 2019). However, in a study conducted in Ghana, Meyer et al (2018, p. 10) reported that their findings are "consistent with the few other studies from Africa and confirm that women are often discouraged from mourning or speaking publically about neonatal loss". This further isolates grieving parents as there is no acknowledgement of their loss (Cacciatore & Lens, 2019).

The quality and nature of the relationship between parents is an important predictor of grief responses and outcomes, as often parents rely on each other for emotional and practical support after the loss (Corbet-Owen & Kruger, 2001; Hutti et al., 2016; Wing et al., 2001). When a partner is not supportive or blames the other for a stillbirth, it can exacerbate distress (Hutti et al., 2016; Kersting & Wagner, 2012). Parents who already have other children appear to less intense grief responses than those who have no children. Since these parents still have a purpose and a role to fulfil, may be protective factor against depression (Sturrock & Louw, 2013; Wonch Hill et al., 2017). Grief often decreases with the birth of a live born baby (Gravensteen et al., 2018).

#### Religion and spirituality

Religion has been found to be an important source of social support and a medium for meaningmaking following bereavement (Cowchock et al., 2011; King et al., 2019; Daniel Nuzum, Meaney, & O'Donoghue, 2017; Wright, 2017) . However, it has also been found that the spiritual reality of a stillbirth baby on bereaved parents can be tremendous. This can significantly impact the faith, spiritual practices and convictions of parents (King et al., 2019; Wright, 2017). Spiritual upheaval and distress can complicate the grief process. Parents may struggle to reconcile beliefs in a caring, compassionate God whilst contending with the reality of their baby's death (Nuzum et al., 2017; Wright, 2017). Others may perceive the stillbirth as a possible punishment for their sins (Bakker & Paris, 2013; King et al., 2019).

From the discussion above, it is evident that complex interactions between several factors may influence parental grief outcomes. This section explored research on mothers' responses to stillbirth. However, it is evident that the grief process can involve other role players in addition to the parents. The next section I will explore the impact of a stillbirth on healthcare practitioners.

#### 2.3 The impact of a stillbirth on the healthcare practitioners

How healthcare practitioners care for the family during this vulnerable time can influence the parents' grief responses (Cacciatore, 2013; Nuzum et al., 2014; Nuzum et al., 2018; O'Connell et al., 2016). Also, how healthcare practitioners experience a stillbirth and how they are impacted by this experience may conceivably affect the nature of this care. Furthermore, how the healthcare system respects and supports the family may strongly influence how the parent will recover from the loss (Homer et al., 2016). Research demonstrates that it is essential for the parent, that staff exhibit; sensitivity and empathy; validate the loss, and clearly communicate with the parent about the loss (Homer et al., 2016; Peters et al., 2015; Shakespeare et al., 2019). This will be further explored in the various articles.

In the global North, some researchers have reported that healthcare practitioners' wellbeing is associated with their capacity to provide assistance to grieving parents (Byrne et al., 2001; Gandino, Bernaudo, Di Fini, Vanni, & Veglia, 2017; Wentzel & Brysiewicz, 2014). Research has found that healthcare practitioners may enhance their well-being and self-efficacy with appropriate support and structure (Gandino, Di Fini, et al., 2017). This would include increasing their knowledge and skills of how to care, purposeful reflection on their current practices and providing a space where they are able to voice their experiences through training and supervision. In a district hospital, often healthcare practitioners do not have the time, internal tools or desire to process loss since resources are limited. Consequently, a head-in-the sand approach is often employed to cope with pain.

#### 2.3.1 Defending against a mother's pain after a stillbirth

It is well established that a patient's pain can cause distress to clinicians (Byrne et al., 2001; Wentzel & Brysiewicz, 2014). Research has predominantly concentrated on maternal or parental experiences of a stillbirth and the quality of care that is afforded to bereaving families. Fewer research studies focus on how healthcare professionals are affected, even though a stillbirth represents a stressful and emotionally demanding event for healthcare practitioners. Practitioners have to manage caring for their patients, whilst simultaneously coping with the additional burden of managing their own emotions (Gandino, Bernaudo, et al., 2017; Ravaldi et al., 2018). This is particularly relevant in a context like KH where many of the doctors are community service doctors<sup>4</sup> or recently qualified and are still contending with issues around their own competency (Zaidi et al., 2019). Many theorists have suggested that prolonged exposure to constant pain and trauma causes healthcare practitioners to think and behave in ways to protect themselves from overwhelming feeling of helplessness. This helplessness emerges from a perceived inability to ease their patients' emotional pain (Balme, Gerada, & Page, 2015; Gerada, Chatfield, Rimmer, & Godlee, 2018; Wentzel & Brysiewicz, 2014). They may even begin to question their own competence to help others (Farrow, Goldenberg, Fretts, & Schulkin, 2013; Gandino, Bernaudo, et al., 2017; Gerada et al., 2018). This may lead healthcare practitioners to employ defences such as minimizing their awareness of the mother's distress, depersonalizing and distancing themselves from the mothers and ritualizing how care is offered (Lewin & Green, 2009).

Healthcare practitioners are continuously exposed to suffering, pain and death whilst caring for traumatized patients (Gandino, Bernaudo, et al., 2017). This can result in secondary traumatic stress or vicarious trauma. Both forms of trauma closely resemble symptoms associated with PTSD. These symptoms include: intrusive thoughts, nightmares involving the patients' trauma, fatigue, irritability, and anger (Newell and MacNeil, 2010). Recognising and acknowledging these symptoms is essential to identifying risk factors and for creating effective prevention programmes to assist healthcare practitioners. A greater understanding of how healthcare practitioners' sense of agency. This may encourage investment in additional resources to

<sup>&</sup>lt;sup>4</sup> After their medical training, a doctor is required to work for one year in a public health facility while receiving supervision (Hatcher, Onah, Kornik, Peacocke, & Reid, 2014). This applies to most medically trained personnel (including nurses and allied health professionals).

increase professional efficacy and wellbeing for healthcare practitioners (Gandino, Bernaudo, et al., 2017). Limited research has focused on professional exposure to trauma in healthcare practitioners and most are confined to wealthier countries, limiting their generalizability (Nuzum et al., 2014).

My study examines several pertinent points relevant to the research topic, including practices around stillbirths, the emotional experiences of healthcare practitioners in relation to stillbirths, and the defences that they use dealing with stillbirths in a highly stressed healthcare system. To my knowledge, this is a significant gap in research and no other study of this nature has been conducted in South Africa.

#### 2.3.2 Healthcare practitioners' responses and how it shapes care

Research in the global North has concluded that the responses of a health system, to the care of women who experience stillbirth, is an indicator of a health system's overall performance (Homer et al., 2016). All healthcare practitioners require access to training and support. Training and support could ensure that they are equipped to provide appropriate care after a stillbirth, as well as, access support for themselves (Homer et al., 2016).

It can be emotionally challenging for healthcare practitioners to be with a woman who experienced a stillbirth (Cacciatore & Lens, 2019; Farrow et al., 2013; Homer et al., 2016). Additionally, different cultural beliefs about stillbirths can make it difficult for parents and families to accept and manage the loss. Some of these beliefs include not naming the baby, not having a burial, and having no public mourning for the lost child (Homer et al., 2016; Meyer et al., 2018). These practices need to be understood and respected by healthcare practitioners, in order to provide effective and appropriate emotional support. This leads to additional questions regarding specifically the kind of supplementary bereavement related training that is required in cross-cultural environments.

Bereavement care and support for healthcare practitioners is essential in all contexts and countries. When such support is absent due to scarce resources, the burden of loss is even greater for all role players. This includes the women and their families, as well as for midwives, doctors, and nurses who attend to them. Consideration must be given to the care of both families and the healthcare practitioners who attend to them. This is necessary to ensure that the burden

of grief, after a stillbirth, does not affect the capacity of healthcare practitioners to provide quality care to women and new-born babies (Homer et al., 2016).

From the discussion above, the significant impact of stillbirths on healthcare practitioners is evident. Healthcare practitioners require support from the systems in which they function in order to be more aware and better equipped to care for mothers, parents and families coping with a stillbirth. The ensuing section examines institutional care and how organizational structures contribute, condone and precipitate certain practices in that organization.

#### 2.4 Understanding institutional care

The final section of this chapter explores the role of institutional care in the issues related to the provision of care for parents experiencing stillbirth. Since this section focuses on a macrocosm rather than individual experiences, it is a less personally identifiable phenomenon in the study of stillbirths. Whilst the patient and medical practitioner's role in stillbirth theory is apparent, the impact that institutions have may be unobtrusive, yet no less significant. Consequently, the role of institutions has become a growing theme in healthcare research. This section explores concepts born from social environments and organizations such as institutions and their defences. These concepts include structural violence and obstetric violence, and how they relate to my study.

#### 2.4.1 Defences in healthcare systems

Isabel Menzies Lyth (1960) was instrumental to foundational theory on creating better hospital environments. Whilst not specifically focused on the labour ward, Menzies Lyth researched nursing services in a general hospital in Britain in the 1950s. Her research is considered invaluable for the understanding the dynamics of relationships in hospitals. She noted that healthcare practitioners developed practical strategies for mediating their inherently stressful contact with patients (Van Der Walt & Swartz, 1999).

#### 2.4.2 Obstetric violence

Structural violence is the invisible manifestation of violence built into the fabric of society. Structural violence produces and reproduces social inequalities across groups (Montesanti & Thurston, 2015). Obstetric violence is a form of structural violence, and the subject has developed out of the growing interest in mistreatment of women in childbirth (Bradley et al., 2016; Briceño Morales, Enciso Chaves, & Yepes Delgado, 2018; Chadwick, 2014, 2016, 2018; Chattopadhyay, Mishra, & Jacob, 2017; Lambert, Etsane, Bergh, Pattinson, & van den Broek, 2018; Sadler et al., 2016). The term 'obstetric violence' originated in South America in 2007 (Briceño Morales et al., 2018; Williams et al., 2018). Chadwick (2016) defined obstetric violence as the disrespectful, aggressive and humiliating treatment of women and girls during labour and birth. Morales, Chaves, & Delgado (2018) suggest that obstetric violence is a manifestation of violence during the provision of healthcare, and that it occurs in a social environment favouring the development of power relationships between patients and healthcare practitioners. It may originate in a healthcare system in which political and economic foundations foster inequality based on the patients' buying power (Briceño Morales et al., 2018). In its entirety, the term encompasses problematic practices such as neglect, verbal and emotional abuse, physical abuse, and sexual abuse. More subtle expressions of obstetric violence may include lack of confidentiality and consensual care, and inappropriate use of medical intervention such as episiotomies, inductions and unnecessary caesarean sections.

The milieu, may form an important component of structural violence in medical contexts. It has been primarily studied in the context of inpatient psychiatric holding environments (Papoulias, Csipke, Rose, McKellar, & Wykes, 2014). Milieu is defined as the physical or social setting in which something occurs or develops (Merriam Webster, 2018). Milieu may also include the feelings or moods associated with a particular place, person, or thing (Merriam Webster, 2018). Furthermore, the milieu may influence clinical outcomes (Johansson & Eklund, 2004; Papoulias et al., 2014). In a hospital context, patient-practitioner interactions are crucial for creating ward milieu. These hospital ward interactions act as a "social defence system [which] develops over time as the result of collusive interaction and agreement, often unconscious, between members of the organization as to what form it will take" (Menzies, 1960, p. 11). Since obstetric violence is a manifestation of structural violence, the two phenomena share many of the same features.

An examination of the literature on childbirth in South Africa amongst other countries, reveals a trend of overt aggression, lack of support, lack of privacy and gender inequality. Indeed, even in South Africa, a large divide exists between those who able to access private health care and those forced by poverty, to rely solely on the services offered by the government. This context undoubtedly, lends itself to the creation of power relations. Lambert et al. (2018, p. 256) contextualised some of these challenges with simplistic approaches to childbirth by expressing that, "an approach that ignores the relationships and culture central to care provision is

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fundamentally flawed." A growing body of contemporary literature, is highly critical of medicalised and overtly violent obstetric environments. When specifically researching obstetric violence in South Africa, Chadwick (2016, p. 423) reported that:

"Violence in obstetric contexts in SA is multi-layered and complicated by the fact that it includes both individual acts of abuse and structural components such as degrading spatial configurations that lead to lack of privacy and impede the use of labour companions."

## 2.5 Chapter summary

This chapter served to explore and examine the relevant literature related to stillbirths. According to the literature, stillbirths negatively affect not only parents, but also the healthcare practitioners that attend to them. The articles in Chapter 6 and 7 comprehensively address these issues. Contextual specific issues persist when considering under-resourced environments such as Khayelitsha. In this context; tight budgets, understaffing and high patient loads leave little space or time for debriefing. Healthcare services in South Africa, specifically focusing on the Western Cape Province healthcare system where KH is located will be addressed in the next chapter.

# CHAPTER THREE: CONTEXTUALISING STILLBIRTH SERVICES IN KHAYELITSHA

#### **3.1 Introduction**

In the previous chapter, I explored literature on stillbirths, and evidenced why it is an important field of research. In this chapter, I explore context specific literature pertinent to stillbirth services in Khayelitsha. My research study focusses on healthcare practitioners' responses to stillbirths in the Western Cape healthcare system. First, I am going to explore the South African healthcare system in order to contextualise what a woman experiencing a stillbirth encounters. The South African healthcare system exists within a broader socio-economic context. Similar to all societies, it has systems to care for those with health concerns (Amzat & Razum, 2014). However, South Africa is a unique context comprised of diverse peoples and cultures. Consequently, culture should be carefully considered, as it plays an important role in the way people conceptualize health and healing (Vaughn, 2019).

#### 3.2 Healthcare system in South Africa: contextual factors

In this section I briefly explore the healthcare system in South Africa and the contextual factors that help us understand why the system functions as it does. This section begins with the influence of Apartheid and then examines the system currently.

#### **3.2.1 Historical contributions**

Apartheid was a system which further entrenched and deepened the inequities of a colonial past. The White minority disproportionately received the majority of public expenditure for healthcare, amounting to four times more per capita than Black people (Brauns & Stanton, 2016). Universities were largely demarcated to educate the White population, and few Black people were allowed into the medical field (Brauns & Stanton, 2016). Only one medical school (University of Natal Medical School) in the country admitted Black medical students (Coovadia, Jewkes, Barron, Sanders, & McIntyre, 2009). In 1972 only 15 Africans qualified as doctors against 440 Whites (Brauns & Stanton, 2016), despite Africans comprising approximately 80% of the population. Those who were permitted admission, were exposed to limited resources and discriminatory practices in White institutions. For example, Black medical students were not permitted to wear white medical coats and stethoscopes in White hospitals. Also, Black nurses poorly trained and denied the opportunity to use their skills in appropriate settings (Brauns & Stanton, 2016; Shabalala, 2019).

A shortage of medical professionals in clinics and hospitals that delivered services to the Black population epitomized the health system under the Apartheid regime. Furthermore, services for the Black population were extremely under-funded, and health workers struggled to manage the tremendous need for health care (Coovadia et al., 2009). Routinely, patients queued for hours to receive care. Hospitals serving the Black population were overcrowded, with patients often sleeping on the floor. Private medical care was available to those who could afford it. Most private medical doctors practiced in White areas. During the apartheid era, there was one doctor for every 308 White patients in Cape Town as compared to one doctor for every 22 000 people in KwaZulu Natal and one doctor for every 30 000 people in Limpopo (Brauns & Stanton, 2016).

Although apartheid ended over 20 years ago, South Africa still has health inequalities and the consequences of apartheid are still felt today. There are many more White health professionals (including psychologists) than Black health professionals, although programmes have been put in place to encourage and support Black medical students (Mayosi & Benatar, 2014). It is still common for patients in Khayelitsha to sit for the whole day in community clinics and district hospitals waiting to be attended to. Some clinics do not always have medical doctors to assist patients and the nurses are required to take responsibility for running the clinics. Even today, in a relatively well-resourced hospital like KH, many patients sleep on the floor in the emergency centre and in the psychiatry wards.

#### **3.2.2 Healthcare today**

South Africa is a middle income country with approximately 58,75 million people as of mid-2019 (StatsSA, 2019). South Africa has made political strides since 1994, but is still struggling to overcome the legacy of apartheid and the challenge of transforming institutions and promoting equity in development (Harris et al., 2011; Mayosi & Benatar, 2014; Rispel, Blaauw, Ditlopo, & White, 2018). South Africa has large socio- economic gaps when compared globally. The World Bank reported that South Africa's richest households are almost 10 times wealthier than poor households (Scott, 2019). This results in wealthy communities coexisting alongside some of the poorest communities. Poverty levels are the highest in Black populations such as in the community that KH provides treatment and services for (Mayosi & Benatar, 2014; McKendrick & Dudas, 2016). The health system which was in place in 1994 during the transition to democracy was structurally fragmented, centralised, biased toward curative services and unevenly distributed (Brauns & Stanton, 2016; Mcintyre & Klugman, 2003). Since then substantial changes in policy, structure and service provision have been implemented (National Department of Health, 1997). Still, there remains significant health challenges for the country and its health services, whose goal is to ensure a long and healthy life for all South Africans (Department of Government Communication and Information System, 2018). Currently, South Africa has four health/disease epidemics, this includes poverty related diseases and an increasing burden of chronic and non-communicable diseases. The HIV/AIDS epidemic, accounts for 31% of the total disability-adjusted life years of the population. Lastly, violence and injuries further contribute to death and disability (Chopra, et al., 2009; Coovadia, et al., 2009).

The Department of Health (DoH), of which I am an employee, is required to provide a healthcare system that is structured and nationally provides a uniform standard of care for all South Africans (Department of Government Communication and Information System, 2018). This mandate comes from the National Health Care act of 2003 and is in line with The Bill of Rights (Section 27) which states that access to health care is a basic human right. A survey done in 2017 reported that 7 out of 10 households in South Africa used public health, facilities (Department of Government Communication and Information System, 2018). As of December 2019, South Africa is nationally on the brink of implementing a National Health Insurance (NHI) scheme. A central goal of the NHI is that all South Africans have access to quality health services on an equitable basis (Department of Government Communication and Information System, 2018). At the time of writing, there has been much controversy and debate about the funding of the NHI, with some authors questioning whether the scheme is financially viable (Gilson, 2019). Health services in South Africa are in a period of transformation, which is causing much uncertainty and may be exacerbating existing anxieties in the system.

Providing the best level of health care for all is an insurmountable goal for a socioeconomically disparate country. Nevertheless, the Department of Health is continually implementing new initiatives at a primary health care level to meet that vision.

Some of these initiatives include:

1. The utilization of Community Health Workers (CHW) who work in the community at a grass-roots level by going into people's homes. They play a crucial role where they

provide care associated with the treatment and counselling support services for HIV and TB (Swartz & Colvin, 2015).

- 2. The national Policy for Nursing Education and Training which aims to ensure uniformity and standardization in nursing education so ultimately a generalist nurse will be able to manage low-risk health problem. The plan to implement this in January 2020, will also incorporate a one-year advance diploma programme in midwifery to up skill nurses in maternal and neonatal care. This falls within the purview of this study specifically when considering these potential midwives training in patient care.
- 3. The Integrated School Health Programme (ISHP) which medically screens learners in schools and refers them for treatment. This is a proactive initiative which assists learners to access interventions earlier in the health system.
- 4. The Central Chronic Medicines Dispensing and Distribution (CCMDD) which dispenses chronic medication for patients at 855 accessible pickup points. This helps with the elimination of long queues at the day clinics.
- 5. The Mom Connect programme "aims to improve access to early antenatal services and to empower pregnant women with relevant health knowledge" (Department of Government Communication and Information System, 2018). This is done through mothers receiving health promotion messages through cellphone based technologies. It is a voluntary service and mothers can opt out at any point.
- 6. The Health Patient Registration System (HPRS) is a computer system where patients are registered using their identification document or passport. This helps with tracking patient's medical histories.

Even though all these initiatives are national programmes, each province is responsible for implementing and funding them. KH falls under the purview of the Department of Health in the Western Cape.

#### 3.2.3 Influence of language in South African healthcare

South Africa has 11 official languages with an additional 33 living languages, not including the languages of numerous foreign nationals living here (Benjamin et al., 2016). South African sign language, though not an official language, is also recognized. Each language may be associated with distinctive cultures, religions and meaning making of illness (or stillbirths) (Matthews & Van Wyk, 2018; Pascoe, Mahura, & Rossouw, 2019). Incidentally, English is only the fourth most spoken language in South Africa. Despite this, English is spoken in most

South African hospitals (Benjamin et al., 2016). South African studies have reported that language is a major barrier to effective healthcare delivery (Benjamin et al., 2016; Matthews & Van Wyk, 2018; Mol, Argent, & Morrow, 2018). Clinical notes in most hospitals like KH are always written in black pen and in English. The South African constitution stipulates that a patient can request an interpreter, so that information can be communicated in their native language, even if they understand English. Yet, many patients do not, as they are unaware of this right (Benjamin et al., 2016). Consequently, misunderstandings and confusion about diagnoses, treatments, and prognoses endure. This can have serious, and, at times, life-threatening, consequences (Deumert, 2010; Haricharan, Heap, Coomans, & London, 2013; Levin, 2007; Penn, Watermeyer, & Evans, 2011; Watermeyer, Penn, Scott, & Seabi, 2019).

## 3.3 The Western Cape Health Department and Khayelitsha Hospital

"The core function and responsibility of the Western Cape Department of Health is to deliver a comprehensive package of health services to the people of the province" (https://www.westerncape.gov.za/dept/health.).

In the previous section I looked at the broader health system in South Africa. In this section, I look more specifically at the health system in the Western Cape where KH is located.

In comparison with other South African provinces, the Western Cape Health Department entered the post-apartheid period with a relatively intact, functioning bureaucracy and a legacy of socioeconomic advantage (Gilson et al., 2017). For instance, the infant mortality rate for the Western Cape province was more than 1.5 times lower than the national average in 1994 (27 per 1 000 live births versus 48 per1 000 live births)(Gilson et al., 2017).

As noted previously, the health sector has been divided into health districts to ensure that citizens, in every part of the country, have access to a primary health care and district hospital services (Hunter, Lahri, & van Hoving, 2017). Primary or community level health services are provided through local community clinics (often by nursing staff) and 24-hour community health centres. More advanced level services are generally provided at hospitals categorised as district (level 1), regional, (level 2), or tertiary/central (level 3) hospitals (Cullinan, 2006; Zaidi et al., 2019).

The characteristics of services offered at a district hospital (such as KH) can be dependent on the community it serves. Generally, services essentially consist of outpatient and inpatient services, a 24-hour emergency service and an operating theatre (Cullinan, 2006). District hospitals commonly have fewer than 200 beds (although KH has 340 beds) and provide basic diagnostic and therapeutic services (Cullinan, 2006). Specialist services are not always available in district hospitals, although more specialist posts are becoming available in KH. From working in the health system, I have heard continually that the Western Cape Health Department is one of the more functional health departments in the country, although I have not found any studies to collaborate this claim.

It is important to understand the healthcare system in which KH falls and how patients access the services. As mentioned previously, KH is a large district hospital in the Western Cape. KH has an emergency centre that services approximately 30000 patients a year (Hunter et al., 2017). No potential patient may access the hospital services directly unless they require services from the emergency centre, due to life-threatening medical trauma or illness (Hunter et al., 2017). Patients are triaged by nursing staff and subsequently assessed, stabilized and treated by a medical officer and then discharged. When necessary, patients are admitted to one of the hospital wards, or referred to a tertiary institution. Alternatively, they are referred to outpatient clinics. KH emergency centre has a 30% admission rate (Hunter et al., 2017).

Patients require a referral, in order to access other hospital services such as the maternity unit or allied health services like occupational therapy or psychotherapy. Patients are referred to KH by local clinics, day hospitals and occasionally private general practitioners. Typically patients are referred to the outpatient department of the KH. Patients are required to join long queues at admissions for an outpatient folder before proceeding to the outpatient clinic of the specialised service required. Patients then queue once more, to consult a healthcare practitioner or allied health professional who will assess them. The healthcare practitioner then determines a diagnosis, if necessary order additional diagnostic tests and subsequently, whether further diagnostic initiates a treatment plan. If the necessary resources for specific treatments are unavailable the patient is referred to a specialist clinic. These additional clinics may include paediatrics, orthopaedics, gynaecology, internal medicine, surgery and psychology

Given the socio-economic constraints of the majority of this population, frequently, the alternative option of private medical facilities is unfeasible. Private medical practitioners in the

Khayelitsha township usually require cash payments on consultation. Furthermore, not all private practitioners offer a sliding scale of fees. These private fees are impractical for most.

The majority of patients utilising the government healthcare system, do not have access to medical aids. Consequently, in order to recuperate some costs, government implements a healthcare fee structure. This provides a sliding scale payment structure to accommodate all patients. This includes patients who are employed and have access to medical aids, as well as those patients with little or no income. Theoretically this ensures that every South African has the right of access to appropriate healthcare (Kleinert & Horton, 2009). However, as previously discussed, due to the history of racialized care and current status of economic disparity, the burden on State hospitals to provide subsidized healthcare is enormous. Consequently facilities are generally over-burdened and understaffed and equipped (Coovadia et al., 2009; Gilson, 2005).

### 3.3.1 Obstetric care at KH

KH is well-resourced with medical doctors and equipped with some of the latest medical treatment facilities in the Western Cape (Rossouw, 2012). There is a 24-hour theatre facility available, as well as a CT scan and ultrasound department. There is also a women's health unit. In the obstetric team, there are two full time qualified obstetricians with many years of experience. Additionally, since KH is associated to a tertiary education centre, there are four obstetric registrars rotating through the hospital. Obstetrically, only women with high risk pregnancies are brought to KH to deliver. All other patients receive obstetric care and deliver at the community health clinic's maternity units. In the context of high-risk patients, higher anxiety levels would be expected amongst the staff and patients of KH, than might be expected in the community clinics. Furthermore, the caesarean rates and mortality rates are similar when compared to other hospitals in the province. This is noteworthy since the area that the hospital serves is in a poorer community.

#### 3.4 Stillbirths in Khayelitsha: an under-researched population

On review of the literature on stillbirths, to date I have found only one study related to adverse pregnancy outcomes in Khayelitsha (Davies et al., 2013, p. 116). The aim of the aforementioned study was "to investigate the utility of the gestational body mass index method to screen for adverse birth outcomes and maternal morbidities". There were several studies that researched maternal depression and pregnancy (Cragg, 2015; Lund et al., 2019; Munodawafa,

2018; Schneider, Baron, Davies, Bass, & Lund, 2015; Schneider, Bolton, & Myer, 2019), but no studies specifically on stillbirths. This highlights the need for this research specifically focused on stillbirths in Khayelitsha. Therefore, my study aspired to begin to address this substantial gap in research

## 3.5 Chapter summary

In this chapter, my focus was on the existing South African healthcare system and how it has been influenced by the past and more specifically the aforementioned apartheid regime. Although there has been transformation in the healthcare system since 1994, South Africa still has significant health service challenges that need to be addressed. This chapter also described the contextual milieu experienced by pregnant mothers, from low socio-economic means.

In the next chapter, I will discuss the methodology of the study.

#### **CHAPTER FOUR: METHODOLOGY**

#### 4.1 Introduction

In Chapters Two and Three, I reviewed relevant literature related to stillbirths and the provision of care. The primary research questions for this study focused on the experiences of healthcare practitioners at KH when caring for women who have had a stillbirth. Additionally, how the mothers themselves experience the care was explored. My main focus in this study was on care and how it is experienced – rather than the experience of stillbirth itself. In order to construct a sound theoretical framework, I reviewed literature on stillbirths and explored existing theoretical and explanatory models. In particular, I focused on aspects of South Africa's overextended healthcare systems, as it pertains to the participants in this study. Moreover, I highlighted the relevance and importance of research in this subject. In order to pursue the research objectives, a methodology that allowed for observations of practices, emotional experiences and defences of practices around stillbirths, was required. Specifically, insight into the emotional experiences of healthcare practitioners in relation to stillbirths, and the defences that they use in coping with stillbirths in this healthcare system was required. In order to conduct research that provides a contribution to existing literature, researchers must have a clear understanding of the theoretical and methodological assumptions that underpin the field of the research (Silverman, 2013). In the current chapter, I describe and defend the research paradigm and methodology used to formulate, initiate and conduct my research project.

#### 4.2 Research within a psychosocial framework

This study makes use of a psychosocial paradigm. A major construct of this paradigm is that it assumes that thoughts, feelings, and behaviours co-exist in the individual's unconscious and conscious minds. Psychosocial research draws on psychoanalytic theories of the mind and strives to understand social, cultural, political, and other influences that affect individuals' thoughts, feelings, and behaviours (Clarke & Hoggett, 2018; Frosh & Baraitser, 2008; Saville Young & Berry, 2016; Stamenova & Hinshelwood, 2018). It is important to note that in the broader psychosocial research paradigm, there are those who do not adopt a psychoanalysis approach (Frosh, 2014; Redman, 2016; Taylor & McAvoy, 2015), however my research approach does.

I wanted to understand the parallel dynamics of the internal mind interacting with the external social world of individuals and groups. The concept of the associative unconscious asserts that

we exist in a matrix of relationships and cannot be understood in isolation (Stamenova & Hinshelwood, 2018).

"The most fundamental concept in psychoanalysis is, of course, the notion of the unconscious which assumes that much of human behaviour is determined not by conscious thoughts but by unconscious phantasies, motives, and anxieties, and that all human activities are imbued with unconscious meanings" (Skogstad, 2018, p. 108).

According to this paradigm, the unconscious influence of an individual's past is critical in determining personality and behaviour (as well as conscious motives)(Clarke & Hoggett, 2018). Psychoanalytic theory postulates that anxiety is inherent in the human condition. Anxiety is an inherent element of all health care, but may be especially pronounced in settings where danger, deprivation and social division are prevalent, as is the case where KH is situated (Barolsky, 2016; Smit et al., 2016). The psychosocial paradigm has been applied in a range of healthcare contexts (Hinshelwood & Skogstad, 2000; Ramvi, 2015; Roberts & Obholzer, 1994), and may be especially relevant in the KH context (Van Der Walt & Swartz, 1999) where health care is delivered under exceptionally demanding circumstances.

As a clinical psychologist in the hospital I am experienced in working clinically from a psychoanalytic framework. A part of this clinically work is with mothers in the community through the maternity ward service. There is a good fit between my clinical work and my research paradigm. Furthermore it is a paradigm which others have found useful in exploring situations of high anxiety (Hollway, Frosh, Palacios, & Hook, 2015; Saville Young & Berry, 2016). I wanted to have access to a paradigm which would allow me to explore the contradictions that very difficult clinical work may engender. I could not find a paradigm which was not psychoanalytically based which allowed me as a researcher both to be shocked and disapproving of stillbirths being likened to "taking a crap", and to be curious to understand as empathically as possible where views like this might originate.

In the following section, I will explain the study design in more detail. This design includes the various methods used to explore the environment of KH and the study participants as each of these relates to the research questions.

#### 4.3 Study design

In the previous section I began with a description of the psychosocial research framework, drawing on psychoanalysis as the backdrop to this project. In this section I will discuss the research design I utilised to answer my research question.

#### 4.3.1 Qualitative methodology

This study utilised a qualitative design, located within a broader framework of an overarching psychosocial studies paradigm. Qualitative studies are recognised as a valuable tool for obtaining rich exploratory data. Hence, a qualitative design is ideal for a study of this nature (Liong, 2015; Silverman, 2013).

#### 4.3.2 Critical organizational ethnography

Dorothy Smith (2005) was instrumental in developing organizational ethnography. Ethnography is a method of research that explores individual's common daily experiences, including social interactions within the context of organizations. This method incorporates more than just what participants say. Rather "the emphasis is on what people do—their work broadly conceived—and what individuals say and know about their work as expert knowers and doers" (Kearney, Corman, Hart, Johnston, & Gormley, 2019, p. 18). In selecting this method, I was able to examine how healthcare practitioners' work processes are influenced the institutional relations at KH (DeVault & McCoy, 2004). As an employee of KH since 2014, I was a participant observer and was able to hold a dual role (with all the complexities of each role, which will be discussed in later chapters). Thus, I was able to develop an understanding of how healthcare practitioners feel and manage their experiences of stillbirths at KH, whilst maintaining the stance of an observer. My role was not only to observe the other, but to observe myself as well, insofar as that is possible (Skogstad, 2018).

Ethnographic studies have proved useful in researching health systems since it permits the simultaneous exploration of multifaceted social identities, in complex environments that influence an individual's behaviour. Thus, this research method permitted an in-depth exploration of how healthcare practitioners are influenced by psychological, historic contexts, social, economic and political factors and how they act as agents in complex environments (Bantjes & Swartz, 2017; Long, 2018; Morse, 2016). This is valuable in exploring how the cultural context shapes doctors' and nurses' behaviours. I selected a critical ethnography because the research goal was to understand the organizational dynamics of the hospital and

ultimately, use this study's findings to inform the development of future interventions to improve care for the mothers who have stillbirths.

In planning this critical ethnographic methodology approach, I located my study within constructionism. I selected this epistemology since it, "*rejects the idea that there is some ultimate objective reality that can be known or discovered through research*" (Bantjes & Swartz, 2017, p. 5). This selection was further motivated because of the intersubjectivity, inherent in the nature of this study. Specifically that in the research process, as a researcher I influence the research process and am influenced by the research (Bantjes & Swartz, 2019; Clarke & Hoggett, 2018; Madill, Jordan, & Shirley, 2000; Saville Young & Berry, 2016). This approach acknowledges that the researcher is limited by their perspective, therefore interpretations and findings are tentative (Madill et al., 2000; Saville Young & Berry, 2016).

#### 4.3.3 Data collection methods

The basis of the study design was an ethnographic research model with multiple sources of data. This included observations in the labour ward, hospital documents, interviewing mothers who experienced stillbirth and interviewing healthcare practitioners (doctors, nurses and any other employees who are involved with the care of mothers who experience stillbirths). Interviews focused on exploring their practices with women who had stillbirths.

#### 4.3.3.1 Observations in the labour ward

As is common in ethnographic research, the main source of data came from my six week period of observations of the labour ward. I attended ward rounds, observed day-to-day practices in the ward, and maintained a register of all mothers who had a stillbirth in the hospital during that time period. These observation sessions lasted for several hours per day (at different times) from Monday to Friday over the six week period. I recorded these observations in my research journal. Since ethnographic research entails attempting to understand practices in a particular setting, such as KH, the use of journals is common in recording observations and interactions (Bantjes & Swartz, 2017; Gobo, 2008; Smith, 2005).

#### 4.3.3.2 Free association narrative interviews with healthcare practitioners and mothers

A significant feature of this ethnographic approach was the use of Free Association Narrative Interviews (FANI) to interview both healthcare practitioners and mothers (Hollway & Jefferson, 2013). In research using FANI, the interviewee is viewed within the surrounding social discourses and is seen to be motivated by unconscious investments and defences against anxiety (Clarke & Hoggett, 2018; Hollway & Jefferson, 2013; Long, 2018; Saville Young & Berry, 2016). This method is powerful since "*unconscious dynamics are crucial in determining a person's relation to external reality*" (Hollway & Jefferson, 2013, p. 98). In the journal articles that focused on interviews (see chapters 6, 7 and 8), this method is explored in depth. This method also adopts Bion's notion of containment (Bion, 1962). Thus the interviewer is required to be that container that is able to hold difficult emotions expressed by the interviewee. This allows for the development of rapport between the pair. This also allows enables interviewee to manage more painful emotions since the pain is now shared. This sharing also occurs through the processes of transference and countertransference, and these processes affect the research relationship. Transference can be defined as, a process in which aspects of the interviewe's internal object relationships are projected into another person or group and experienced in them. Countertransference is the interviewer's emotional response to the interviewee (Clarke & Hoggett, 2018; Hollway & Jefferson, 2013; Skogstad, 2018).

With the FANI method, recording the feelings and emotions of the researcher is crucial, as data is co-constructed with both the interviewer and interviewee. Every researcher enters a field with past experience and some pre-existing ideas which must be acknowledged (Silverman, 2013). This type of research does not strive for objectivity, but rather aims to acknowledge the emotions and feelings that arise. Hence subjectivity is acknowledged as a potential source of data (Clarke & Hoggett, 2018; Green & Thorogood, 2018).

Most qualitative studies utilise individual interview methods to explore individual's lived experiences (Silverman, 2013). First-person narrative interviews usually make the assumption that the questions have a shared meaning (the question asked will be the one understood). In the context of Khayelitsha, patients are often second language English speakers whose lives are vastly different from my own as a professional and a researcher. In all interviews, but perhaps especially in the KH context, there can be no certainty that different people will share the same meanings when it comes to making sense of a question. The FANI method addresses the issue of multiple and contested understandings. The role of the interviewer is paramount in the mediation of meaning making, further justifying an approach beyond pure interviews alone (Clarke & Hoggett, 2018; Hollway et al., 2015).

In the application of FANI in interviews, the questioning style is kept as open as possible. This allows for the interviewee's ideas, views and narratives to emerge wherever possible in their own words (Long, 2018). This enables the interviewer to identify any inconsistencies and contradictions. By asking the interviewee to say whatever comes to mind, the interviewer is eliciting a narrative and allowing unconscious logics to have greater potential to be observed. This results in a narrative that is not as structured or tightly organized according to conscious logic (Hollway & Jefferson, 2013; Stamenova & Hinshelwood, 2018). Hollway and Jefferson (2013) postulated that most people like telling their story (even the difficult stories) in a setting that feels safe and when trust is established with the interviewer. I recognise this too, in my clinical work. Initially patients are reluctant to speak, as they may not understand what a psychologist is. However, if given a space where they feel heard, they will disclose the unspeakable narratives of their lives.

### 4.3.3.3 Hospital documents

Data were also collected from several types of hospital documents. I examined hospital reports of deliveries and of stillbirths. The monthly maternity report from January to May 2018 was also analysed. Also doctors' and nurses' clinical notes, as well as my past notes on mothers who had stillbirths were reviewed.

Figure 4-1 provides a schematic overview of the project as a whole.

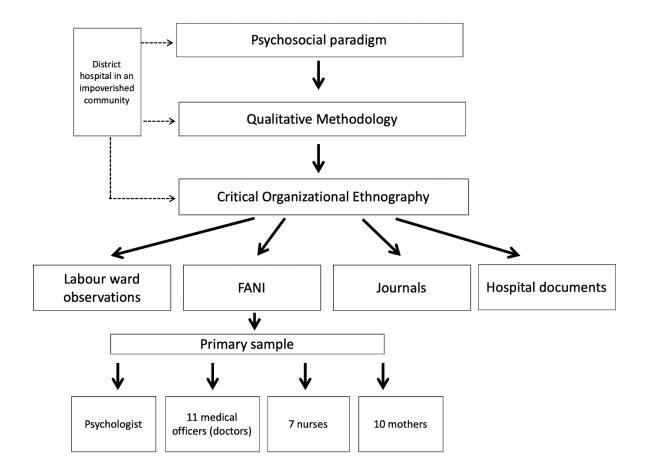


Figure 4-1 Summary of research methodology

The following section will describe the sampling method utilized, to choose participants for the interview (FANI) data collection.

#### 4.4 Sampling

I included two groups of participants from KH in this study. The first group consisted of professional health practitioners at KH. This included, medical officers (doctors), nurses and a community service psychologist. Each of these staff members had been involved in the care of mothers who experience stillbirths at KH. The second group of participants consisted of mothers who received care for their stillbirths at the hospital. The sample design was divided into two parts to represent each of the two participant groups. Each of these samples is explored in this section.

## 4.4.1 The sample of healthcare practitioners

First, the participants used for the elements of the research focusing on KH's provision of care were chosen according to a purposive sampling approach. Purposive sampling (also known as judgmental sampling) is a non-probability sampling method. In purposive sampling, a sample is selected based on characteristics of a population and the objective of the study. A clear set of criteria were applied in identifying participants for this study. In devising these criteria for inclusion of healthcare practitioners, the following was considered:

- Medical officers and nurses who have worked in the labour ward for at least four months and have cared for at least one mother who had experienced a stillborn.
- The community service psychologist at the hospital must have counselled at least one grieving mother.

At the time of data collection, there were 24 healthcare practitioners who met the criteria for selection for the sample because of their direct participation in labour ward care at KH. Of the sample, a total of 11 were medical officers (doctors), 12 were nurses and one was a community service psychologist. Due to the manageable size of the sample, all health professionals working at the labour ward were approached to be interviewed.

As I am an employee of hospital, most of the staff knew who I was and they were familiar with my role as the hospital psychologist. I had discussed my research intention with the obstetrician consultants many months before I considered making a formal proposal to conduct the research. I also talked to the nurses and other doctors. When my proposal was accepted and I had ethical approval (see Addendum A and B), I formally invited the staff to participate during their ward round meeting. I also gave them a brochure explaining the research. I also placed brochures around the labour ward in the event a staff member misplaced theirs. Eighteen labour ward staff were willing to be interviewed, which included obstetric consultants, an obstetric registrar, medical officers, nurses and a clinical psychologist.

Name	Age	Sex	Rank	Marital status	Children	Race	Language
Dr T	26	Female	Community service	Married	0	Coloured	English
Dr P	38	Male	Consultant	Married	1	Coloured	English
Dr M	28	Female	Medical officer	Married	1	Coloured	English
Dr Mb	25	Female	Intern	Single	0	Black	Zulu/English
Dr K	31	Female	Medical officer	Single	0	Coloured	English
Dr E	35	Female	Consultant	Married	2	White	Afrikaans
Dr DJ	27	Female	Medical officer	Single	0	White	Afrikaans
Dr G	27	Female	Intern	Single	0	White	English
Dr J	29	Male	Registrar	Single	0	White	Afrikaans
Dr B	28	Female	Community service	Engaged	0	White	Afrikaans
Clinical Psychologist	33	Female	Community service	Married	2	Black	Xhosa/English

The final sample for both medical officers and clinical psychologist (table 4.2) and nurses (table 4.3) can be seen below.

Table 4-2 Medical officers and clinical psychologist sample

Name	Sex	Age	Marital status	Children	Years as Professional Nurse
Sister A	Female	53	Married	3	6
Sister B	Female	33	Married	2	1
Sister C	Female	32	Single	2	3
Sister D	Female	29	Single	1	5
Sister E	Female	35	Single	1	10
Sister F	Female	47	Married	1	5
Sister G	Female	37	Married	3	7

#### Table 4-3 Nurses sample

Biographical information such as marital status and children were included, to show the diversity of the sample.

## 4.4.2 The sample of mothers who had given stillbirths at KH

The patient participants were also selected using purposive sampling. The selection criteria for mothers in the sample were:

• Women who had experienced stillbirths at Khayelitsha District Hospital within six months of the interview.

A number of exclusion criteria were applied to the sample of patients. The exclusion criteria included:

- Women younger than 18 years old. They were excluded on ethical grounds because this study was not focused on youth or teenage mothers.
- Women who deliberately drank medication or self-harmed to terminate the foetus. This form of behaviour has been reported and seen at KH<sup>5</sup>.
- Women who abused substances during their pregnancies which might alter their emotional response to the stillbirth.
- Women who have family members working in the labour ward of KH.

According to hospital documents, KH experienced 72 stillbirths during the year of the study. A total of, 58 patients had experienced the stillbirth within six months of the data collection period. These patients were considered to be appropriate to include to the potential sample. The contact details for these mothers were downloaded from the hospital database. These patients were contacted and their participation in the study was requested. From the potential sample, a total of between ten and twenty mothers was considered an appropriately sized sample.

A total of 58 women were contacted. Eighteen women agreed to participate in the study, but only ten women arrived for the interviews. The other eight were followed up with, but reported that they were no longer able to come in to be interviewed. Some of the reasons patients provided, were work or family commitments. One woman rescheduled with me three times but

<sup>&</sup>lt;sup>5</sup> It is of course difficult to be fully confident about this exclusion criterion, because of stigma surrounding substance abuse. I asked both ward staff and the women themselves about substance abuse, and if either said there was abuse, I excluded them from the study.

failed to attend. These ten mothers who had experienced stillbirths at the hospital between January and August 2018 were subsequently interviewed. The study was explained briefly to the women. Also participants were informed that transport costs or any additional costs such as babysitting would be reimbursed.

Name	Age	Race	Language	Marital Status	Living Children	Occupation	Planned or unplanned pregnancy
Pt A	25	African	Xhosa	Single	0	Unemployed	Planned
Pt B	23	African	Xhosa	Single	0	Retailer	Unplanned
Pt C	18	African	Xhosa	Single	0	Unemployed	Unplanned
Pt D	21	African	Xhosa	Single	0	Student	Unplanned
Pt E	27	African	Xhosa	Single	1	Call centre agent/student	Unplanned
Pt F	20	African	Xhosa	Single	0	Unemployed	Unplanned
Pt G	29	African	Xhosa	Single	1	Unemployed	Planned
Pt H	23	African	Xhosa	Single	0	Unemployed	Unplanned
Pt I	23	African	Xhosa	Single	0	Unemployed	Unplanned
Pt J	26	African	Xhosa	Single	1	Security Officer	Planned

 Table 4-2 The final sample of mothers for the study.

As in the other sample, biographical information such as marital status, children, occupation and whether the pregnancy was planned were included, to show the diversity of the sample.

## 4.4.3 General inclusion criteria and sample limitations

No specific racial inclusion or exclusion criterion was applied, since as a reflection of the demographics of Khayelitsha, all patients were Black, Xhosa-speaking women. The KH nurses are predominantly Black (from various ethnic groups, but mainly Xhosa-speaking) and Coloured (from Cape Town). The medical staff is predominantly White. All participants from both samples were required to speak English. In the years since joining the hospital in 2014, I have realised that the intimacy and connection in a session with a patient is far greater without an interpreter (Benjamin et al., 2016). From experience, the majority of my patients at KH are reasonably fluent in English (albeit as a second or third language).

This is a limitation to my research as this method tends to favour urban-born mothers who have had exposure to English.

As part of my observations, I noted that groups such as clerks, cleaners, social workers and security guards had interactions with the women who have had stillbirths. I decided not to include them as they had limited patient contact as per the ethnographic observations.

### 4.5 Data collection

Data were collected from the 12 March to 13 July 2018. The process of gathering data according to the research design was as follows:

- I conducted six weeks of observation sessions in the labour ward before engaging in any interviews. In these six weeks; I attended ward rounds, observed day-to-day practices in the ward, and maintained a register of all mothers who had a stillbirth in the hospital. I spent several hours per day (at different times), from Monday through Friday. In the six week observation period, I also reviewed my clinical notes on previous patients who experienced stillbirths.
- 2. I analysed, the monthly maternity report from January to May 2018, as well as doctors' and nurses' clinical notes.
- 3. I conducted interviews with the staff in the labour ward at KH. I also conducted individual informal briefing sessions a week prior to the formal interviews, so that staff had an opportunity to ask questions and decide whether or not to participate.
- 4. I interviewed ten mothers about their experiences in the hospital and the impact of the clinicians' interactions with them.
- 5. Throughout the research process, I wrote in my research journal beginning on the 12 March 2018. This journal included descriptions of my conscious internal dialogue (my thoughts, ruminations, anxieties, and emotions) through the research process. This included conversations and interactions with the healthcare practitioners and patients. The journal described my subjective and internal ruminations regarding individual participants from both samples, as well as considerations of my own engagement with the data and procedures. The journal provided me with valuable supplementary data

through insights into my own processes. This facilitated my writing two reflection pieces (see Chapters Nine and Ten). The journal informed and promoted reflexivity, which is recognised as an important component of responsible qualitative research (Clarke & Hoggett, 2018; Fitzpatrick & Olson, 2015; Green & Thorogood, 2018; Greene, Caracelli, & Graham, 2011; Vicary, Young, & Hicks, 2017). Reflexivity has been increasingly highlighted as a valuable adjunct to the qualitative process. Previously held suggestions of "subjectivity with bias" are being challenged (Frosh & Baraitser, 2008; Roulston & Shelton, 2015).

Written consent to conduct research was obtained from Stellenbosch University, the Western Cape Department of Health and KH. I then commenced with observation sessions in the labour ward. A document explaining the research, was displayed prominently in the ward (see Addendum C).

Ethnographies originate from the anthropology discipline, and are based on observational work in distinct social settings Anthropologists argue that, if one is to truly understand a group of people, one must engage in an extended period of observation of that group. Anthropological fieldwork routinely involves immersion in a culture over a period of years, during which the fieldworker will learn the language and participate in social events with the people (Silverman, 2013). I thought this appropriate for my research as I have been based in the hospital for almost 6 years and have become accustomed to the hospital culture.

The consent form (see Addendum D and Addendum E) was provided to all willing participants, and a clear explanation was provided regarding the research. Interviews were scheduled, once consent was obtained. Interviews were audio recorded and transcribed. Interviews with participants from both samples were conducted in the available consultation rooms in the hospital to ensure privacy and were approximately an hour long.

#### 4.6 Data Analysis

I considered several methodologies for data analysis, including the use of grounded theory and interpretative phenomenological analysis. Ultimately, I selected thematic analysis so as to keep most closely connected to the data which evolved from my observations and interviews. I looked to Braun and Clarke (2006, 2019)'s work to guide me in the analysis process. "Themes are creative and interpretive stories about the data, produced at the intersection of the

researcher's theoretical assumptions, their analytic resources and skill, and the data themselves" (Braun & Clarke, 2019, p. 7). I needed to engage in the data and immerse myself in the stories to ensure that I understood what I was being told and not just what I think I heard. The daily thirty minute drive to and from work for over a year gave me additional opportunity to reflect thoughtfully on what I was seeing and hearing from the stories.

In qualitative research, the researcher is the primary tool for analysis across all phases of the research project and the subjectivity of the researcher needs to be accounted for. The researcher inevitably has their own preconceptions, including assumptions, defences, values, interests, emotions, biases and theories (Tufford & Newman, 2012). These preconceptions influence how data are gathered, interpreted, analysed, and reported (Tufford & Newman, 2012). The ability to reflect on one's preconceptions and biases (known as bracketing) is therefore crucial for the researchers. Bracketing ensures that researchers do not act out and assume more about the data than is there. Bracketing helps to mitigate the potential damaging effects of unacknowledged preconceptions related to the research, thereby to increasing the rigor of the project (Tufford & Newman, 2012). Self-reflection is an ongoing process and I realized I required ongoing supervision and individual therapy to assist me with managing some difficult topics that arose in the research.

#### 4.6.1 Analysing ethnographic and documentary data

Ethnographic data were recorded in detail in research journals which contained my notes of observations of the daily practices in the labour and antenatal wards. I read through hospital documents, official policies and any protocols relating to the care of mothers with stillbirths. I initially browsed through the documents and then took time reading and underlining any important sections (Bowen, 2009). I then noted any interesting data, such as the amount of live births versus stillbirths in 2018. In the six week observation period, I also reviewed my clinical notes on patients who experienced stillbirths that I had previously seen. Throughout the observation period, I reviewed my notes by identifying developing themes.

### 4.6.2 Analysing the interviews

Creswell's (2009) steps to analysing data provided a structure which I could systematically follow. I read each transcript, in conjunction with my reflective notes, in order to obtain a holistic perspective. I then reviewed each transcript more thoroughly by highlighting and noting the sections relevant to the research questions. During this process I recorded notes in

the allocated margins on both sides of the transcribed documents. As I executed this process both themes and subthemes were identified, listed and grouped. I then examined the data once again within the parameters of these groupings. Themes were then abbreviated into codes. I used key words to categorize the themes which were then grouped together to reduce the number of categories in order to ensure efficient data management. After I had created abbreviations for the categories, I used a colour coding system to identify the specific codes. I then organised the information under each category followed by an initial analysis. I subsequently, perused the documentation and recoded.

For the analysis of the data from the interviews, guidelines from the principles of the FANI method were applied (Hollway & Jefferson, 2013). This method focuses closely on the emotions, thoughts and motivations of the interviewee. This method also takes into account unconscious dynamics and processes. In this method, the relationship between the interviewer and interviewee is explored and analysed as both parties enter the interview situation with our own anxieties, defences, political and social positioning and histories which can affect the data that are created. This is imperative to note in a country like South Africa, where the history still prominently influences the individual. An important question which my study cannot adequately answer is, how the socio-political context of the study itself may have influenced the data. I am a White South African psychologist interviewing mostly non-white participants. I do not know how the interviewees may have spoken with a non-white researcher. It is also difficult to determine to what extent, the racial, professional and privilege disparities between the researcher and researched may have affected the data.

Hollway and Jefferson stated that in their research utilising this method they:

"...intend to construe both the researcher and researched as anxious defended subjects, whose mental boundaries are porous where unconscious material is concerned. This means that both will be subject to the projections and introjections of ideas and feelings coming from the other person. It also means that the impressions that we have about each other are not derived simply from the 'real' relationship, but that what we say and do in the interaction will be mediated by internal fantasies which derive from our histories of significant relationships" (2013, p. 42). Hollway and Jefferson (2013) postulate that interviewees are psychically defended which suggests that everyone has an unconscious which contains motivations, instincts and impulses which are constrained by the social and political world in which they live. A defended subject may not tell a complete and transparent story, whether that is a conscious or unconscious act. Some topics or memories are too difficult to talk about because they threaten to break down emotional defences. This may be particularly applicable in KH where there is considerable trauma. Both the patients and the health practitioners are defended subjects in order to survive in such a precarious and threatening environment like Khayelitsha. An awareness of these defences and their underlying causes helped me to gain a deeper, richer understanding of why healthcare practitioners respond the way they do to these mothers after a stillbirth.

In this psychoanalytic approach, I was careful not to interpret during the interview. This is unlike therapy where interpretations are made in the session. Interpretive work comes later when data is analysed. I endeavoured to be respectful, sympathetic and honest about my research throughout the research process. The interviewing process is followed by a detailed analysis of the full experience, including the relationship between the interviewer and participant. This includes; the emotions involved, examining the words in the transcript, and a careful consideration of the narrative construction. "Our method aimed to access latent meaning through eliciting and focusing on the associations between ideas, as opposed to exclusively on words and word clusters" (Hollway, 2009, p. 3). Data analyses thus depends on psychoanalytic interpretation. Themes were identified by thoroughly revisiting interview transcripts, listening to the recordings, and contemplating journal entries. After the interviews, notes made during and after, and these were triangulated with audio-recordings and transcripts (Mello 2002, Terre Blanche et al. 2006). The participants' narratives served as the primary units of investigation, and narrative data were examined and interpreted for common themes (Babbie & Mouton, 2007).

## 4.7 Triangulation of the results

In order to produce a trustworthy and descriptive qualitative description of the institutional culture and the organization of care for mothers with stillbirths, multiple sources of data were obtained which could be used to triangulate my findings. Triangulation, in this context, is when the researcher uses more than one method to collect data (Lune & Berg, 2016). This is a way of addressing the question of the validity of research.

The analysis of the observations, the hospital documents, the interviews and the research journal allowed me to both see and hear from the participants about their experiences. This allowed me to reach "beyond and below the text" (Hollway, 2009, p. 2). I gained a deeper, richer understanding of the emotional experiences of healthcare practitioners in relation to stillbirths, and the defences that they used dealing with stillbirths in a highly stressed healthcare system.

As I work at the hospital full time, the medical officers and nurses who participated in the study asked me about themes that were emerging from the data. They gave me feedback which helped in verifying the interpretations of themes as they emerged from the data, as well as the validity of subsequent results. The participants were able to add information to confirm aspects of data, or ask that inaccurate interpretations be removed. Participants were interested for results to be disseminated in peer reviewed publication format, and eager to read the journal articles created from the data.

#### 4.8 Ethical Considerations

#### 4.8.1 The Labour Ward: Ethnographic observations

After approval of my research from the Stellenbosch University Committee and Stellenbosch Ethics committee (REC-2018-1844) (see Addendum A), I then submitted the proposal to the Western Cape Department of Health as well as the Khayelitsha District Hospital ethical committee for ethical clearance (WC 201801 033) before proceeding with my research and data collection (see Addendum B). I firstly recognized that I was privy to insider knowledge of the workings of the labour ward which I believed add to the depth and understanding of data (M. Greene, 2014). However, I needed to continually evaluate issues of confidentiality and possible conflicts of interest. Researchers with an insider's perspective are required to engage even more rigorously with self-reflection and openness about choices made throughout the research process (M. Greene, 2014). As previously mentioned, I informed all the labour ward staff about my research and provided them information about my observations in the labour ward (see Addendum C). I attempted to remain unobtrusive and did not initiate direct interaction with ward staff or patients during observational sessions. I was however aware that my presence may have had an effect of the staff's behaviour (Skogstad, 2018). I endeavoured to remain respectful of relationships between staff and patients, did not impinge on the ward environment, and tried not cause any upset to any person during the observations. At times the staff came to ask me about my research or came to speak to me about a patient they were

worried about psychologically. I also told the staff they would not be identifiable in my research results (Spradley, 2016). Another ethical consideration that I held in mind during my research was that being a member of KH. I needed to account for my biases and how they might have affected my observations (Greene, 2014; Takyi, 2015). This is where I used my journal to note all my emotions and counter transferences. As mentioned previously, bracketing was used. The supervision space was incredibly important to decipher my biases.

#### 4.8.2 The Staff and mothers: Free association narrative interviews

Participation in the study was voluntary for both KH staff and mothers who delivered stillbirths at the hospital. An information leaflet was included with the informed consent form (see Addendum C). The information leaflet explained the purpose and objectives of the study, what participation entailed, the possibility of harm or risk, as well as the potential benefits of the study. The leaflet also outlined how confidentiality and anonymity would be maintained, and the participants' right to withdraw from the study at any time with no penalties. Contact information for all those involved in the study were also provided, including my supervisor and the details of the contact person at the Division for Research Development of Stellenbosch University (see Addendum C, Addendum D and Addendum E for information sheet and consent form). No payment was offered for participation. I did however provide refreshments at my own cost and if a mother had already been discharged from the hospital, I paid for her transport costs. All participants were required to sign an informed consent form which clearly outlined the risks and benefits of participation. Confidentiality was assured by the use of pseudonyms. I explained to each participant that they were able to leave the study at any point. Furthermore, I assured them that their narratives would not be included in the research if they chose to withdraw from the study. I reiterated that their withdrawal from this study would not affect a mother's care in the hospital in any way. No participant withdrew from the study.

Doing qualitative research required that I needed to immerse myself in the research as the primary data collector (Padgett, 2016). In the interviews with my colleagues, I was mindful of our how our relationship might result in my colleagues sharing more than they may have wanted to (Takyi, 2015). Alternatively, they could be more guarded than with an outsider. After each interview I did ask each person where I could incorporate what they disclosed into my research. Two colleagues did ask that the recorder be switched off at certain points when they discussed personal information. I also had informal interviews prior to the main interview where I explained the research and that they were under no obligation to participate.

A concern did exist about traumatizing mothers by exploring their loss. To address this, participants were offered the option of counselling. This counselling would be provided by one of the two community clinical psychologists based at the hospital. None of the mothers required follow up counselling sessions. None of the staff requested further counselling either. However if they had requested counselling, they would have been referred to ICAS, which is a governmental health and wellness programme which offers employees counselling.

The data obtained from the transcripts were stored electronically on a laptop computer that is password protected. The hard-copy interview transcripts were kept in my locked office and were only read by my supervisor and myself.

#### 4.9 Chapter Summary

This chapter has provided an overview of the rationale for the methodologies utilised, research designs and ethical considerations used in order to collect, analyse and present the resultant data.

Research Method	Subject	Data Collection	Data Capturing	Data Management	Data Analysis
Critical Organizational Ethnography	Labour ward at KDH Staff in labour ward: Doctors, nurses & psychologist	Own process notes Observation Hospital documents Free Association narrative Interviews	Field journal Digital voice recorder Research Journal	Interpretation of field notes Triangulate with data from B and C Transcription Triangulate with data from A and C	Observational data examined and interpreted for common themes Analysis of content further using FANI methods and thematic analysis.
	10 consecutive mothers who delivered stillbirths at the hospital.	Free Association narrative Interviews	Digital voice recorder Research Journal	Transcription Triangulate with data from A and B	Analysis of content further using FANI methods and thematic analysis.

Table 4-3 Summary of the research methods used in this study

The next part of this thesis is the results chapter of this thesis and is comprised of four peerreviewed, published, journal articles. In this part I focus on what I saw from observations in the labour ward and what I heard from the mothers and healthcare practitioners (specifically the nurses and doctors).

# **PART 2: FINDINGS**

In Part 1, the background, rationale literature and methodology for this study was presented. Part 2 is the results section of this dissertation. In this part, I discuss what I saw in the observations and what I heard in the interviews with the healthcare practitioners and patients.

Part 2 is made up of the following chapters:

- a. Chapter Five (Article 1): Observations in the labour ward
- b. Chapter Six (Article 2): Interviews with the medical officers
- c. Chapter Seven (Article 3): Interviews with the nurses
- d. Chapter Eight (Article 4): Interviews with the mothers who had stillbirths

## **CHAPTER FIVE: ARTICLE 1**

# Rethinking obstetric violence and the "neglect of neglect": the silence of a labour ward milieu in a South African district hospital

## **Introducing Article 1**

This chapter contains the first of the four articles which form part of the results section of this dissertation. In this paper, I wanted to gain contextual information on how high-risk pregnancies are handled in general in Khayelitsha Hospital. The primary data source was observations in the labour ward, interviewing labour ward staff (doctors, nurses, a clinical psychologist and cleaners) and the patients who used the ward. The secondary data source was the analysis of hospital documents, specifically those related to labour ward policy. From my observations and discussions, it is clear that no one is being overtly mistreated in this hospital and patients are medically well attended to. In summary, although I saw no physical abuse, I noted the silence in the ward. Beside medically related interactions, I also noted that there were limited interactions between the women and the healthcare practitioners. In this article I tried to explore what this silence could mean. In an overburdened healthcare system where both staff and patients are often overwhelmed or traumatised, silence can be a way in which a system defends itself against what it knows it cannot provide.

## Article 1 has been published at the following reference:

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## **RESEARCH ARTICLE**

BMC International Health and Human Rights

Open Access

Rethinking obstetric violence and the "neglect of neglect": the silence of a labour ward milieu in a South African district hospital

Maura Lappeman 0 and Leslie Swartz

#### Abstract

Background: Research into the mistreatment of women during childbirth has increased over recent years. Overt violence is an important focus of research, but recently there has been increasing recognition that there are other ways in which women in labour may be uncared for or even hurt. As part of a larger study focussing on staff responses to stillbirths, we wanted to gain contextual information on how high risk pregnances are handled in general in Khayelitsha Hospital, a district hospital in an impoverished urban setting in the Western Cape Province of South Africa. This health care system experiences an immense patient load, the poverty of the community it serves, and the numerous traumas affecting both patients and staff.

**Methods:** In order to obtain rich exploratory data, a qualitative research methodology was used. The primary data source was observations in the labour ward, interviewing labour ward staff (doctors, nurse, and cleaners). The secondary data source was the analysis of hospital documents, specifically those related to labour ward policy.

**Results:** From our numerous observations and discussions, it is clear that no one is being overtly mistreated in this hospital and patients are medically well attended to. Although we saw no physical abuse, we noted the silence in the ward. Beside medical related interactions, we also noted that there were limited interactions between the women and the health care providers.

**Conclusions:** Silence can be a form of neglect as it leaves the women feeling uncared for and not seen. In an overburdened health care system where both staff and patients are often overwhelmed or traumatised, silence can be a way in which a system defends itself against what it knows it cannot provide.

Keywords: South Africa, Obstetric violence, Milieu, Neglect, Qualitative

#### Background

In recent years there has been growing interest in the mistreatment of women in childbirth [1–11]. The term "obstetric violence" originated in South America in 2007, and is often used for this particular kind of maltreatment [2, 9]. Chadwick [5] specifically defined the concept of obstetric violence as the disrespectful, aggressive and humiliating treatment of women and girls during labour and birth. Morales et al. [2] further argue that obstetric violence is an expression of violence during the

\* Correspondence: MauraLappernan@westemcapegov.za Department of Psychology, Stellenbosch University, Private Bag X1, Matieland 7602. South Africa provision of health care, which occurs in a social environment favouring the development of power relationships between patients and health care practitioners. Its origin may lie in a health care system where political and economic foundations encourage inequality based on the patients' buying power [2]. In its entirety, the term encompasses problematic practices such as neglect, verbal and emotional abuse, physical abuse, and sexual abuse, lack of confidentiality and consensual care, and inappropriate use of medical intervention, such as episiotomies, inductions and unnecessary caesarean sections.

When reviewing the literature on childbirth in South Africa and a number of other countries, themes that



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emerge are overt aggression, lack of support, lack of privacy and gender inequality. Indeed, even in South Africa, a large divide exists between those able to access private healthcare and those forced by poverty to rely solely on the services offered by the government. Lambert et al. [7], however, contextualised some of the challenges with simplistic approaches to childbirth by expressing that "an approach that ignores the relationships and culture central to care provision is fundamentally flawed" (p. 256). A growing body of current literature is highly critical of medicalised and overtly violent obstetric environments. When specifically researching obstetric violence in South Africa, Chadwick (p. 423) [5] reported that:

"Violence in obstetric contexts in SA is multi-layered and complicated by the fact that it includes both individual acts of abuse and structural components such as degrading spatial configurations that lead to lack of privacy and impede the use of labour companions."

Within the boundaries of Chadwick's [5] conclusion is the notion that abusive structural contexts may even include good medical care. The concept of obstetric violence is helpful and provocative, as it focusses attention on the nature of abuse of women during labour - a very important public health problem. But although overt violence is an important focus of research, recently there has been increasing recognition that there are other ways in which people may be uncared for, or even hurt. Nixon [12], for example, speaks of what he terms "slow violence", which he defines as "a violence that occurs gradually and out of sight; a delayed destruction often dispersed across time and space" (p. 2) [12]. Chadwick [4] also wrote on a similar violence which she named 'gentle violence" where women become submissive, compliant body subjects who willingly accept their role as patient. In the context of health care (including obstetric care), even where there is no overt violence or ill-will toward women giving birth, there are ways in which care practices, however well-meant, may not be best for these women and may even have deleterious consequences. This brings to light the idea that obstetric violence can be the result of structural design and well-intentioned care.

In this study we specifically look at a labour ward milieu in a government hospital in South Africa. This study was part of a larger study focussing on staff responses to stillbirths, and resulted from our need to gain contextual information on how high risk pregnancies are managed in general in the hospital.

#### Understanding institutional care

Isabel Menzies Lyth [13] was instrumental in foundational theory on creating better hospital environments. While not specifically focused on the labour ward, Lyth researched nursing services in a general hospital in Britain in the 1950s. Her research is considered a valuable tool for understanding the dynamics of relationships in hospitals. She noted that health care providers developed practical strategies for mediating their inherently stressful contact with patients [14]. Lyth addressed what today is termed "structural violence", which is the unseen expression of violence weaved into the fabric of society, perpetuating social inequalities [15–18].

Milieu may form a component of structural violence in medical contexts, and has primarily been studied in the context of inpatient psychiatric holding environments [19]. Milieu [20] is defined as the physical or social setting in which something occurs or develops. Milieu also includes the feeling or mood associated with a particular place, person, or thing [20], and may affect clinical outcomes [19, 21]. In a hospital context, patientpractitioner interactions are crucial for creating the ward milieu. These hospital ward interactions act as a "social defence system (which) develops over time as the result of collusive interaction and agreement, often unconscious, between members of the organisation as to what form it will take" (p. 11) [13]. Since obstetric violence is a manifestation of structural violence, the two phenomena share many of the same features. Chadwick [5] does not specifically look at milieu, but the results of Lyth's [13] research strongly suggest that the milieu of a labour ward may increase or decrease the potential for obstetric violence.

Informed by the work of Menzies Lyth, and as part of a larger study on obstetric care practices, we report here on a context in which it would be incorrect to speak about obstetric violence. However, we believe it is important to think about structural arrangements which are not optimal for women. We are interested in what occurs where no one is being mistreated and birthing mothers are medically well attended to. We show in this article how in a hospital in a stressed public health system, we found disengagement, alienation and depersonalisation of both the birthing mother and the health care practitioners. As we shall show in the results section, the trauma was found not in overt violence or acts of perpetration, but in the silence of a ward where no one was talking to anyone and all were left unseen. How do we understand this form of invalidation? In raising this question, not about abuse but about more subtle (and possibly more pervasive) forms of invalidation, we are reminded of the concept introduced by Music [22], in a very different context, of "neglecting neglect". Music [22] notes that in studies of childcare practices, though it is essential, for good reasons, to focus on abusive practices, what is often less considered is the ways in which neglectful practices (not always overtly ill intentioned) (2019) 19:30

may have deleterious effects. We shall show in this paper how good quality care from a technical point of view may be compromised by silence and invalidation – by what may be termed a form of defensive neglect.

#### Location of the study: Khayelitsha hospital, Cape Town, South Africa

The research took place in Khayelitsha Hospital (KH). KH is a large district hospital with 340 beds situated in Khayelitsha, the second biggest Black township in South Africa after Soweto in Johannesburg [23]. South African townships developed as a result of the Apartheid regime's attempt to enforce the Group Areas Act of 1950. This act, which designated separate residential areas along racial lines, forcing people of colour to live in areas further away from the city centre, often in dire living standards [24]. South Africa has a growing population. Midyear of 2018 the population of South Africa was 57, 73 million people [25]. The Recorded live births, 2017 report released by Statistics South Africa today shows that a total of 989,318 births were registered in South Africa in 2017. In the last 10 years the population of Khayelitsha has risen from 400,000 to 2.4 million, 50% of whom are under 19 years of age [26]. The area's unemployment rate is 73%, with 70% living in temporary structures called shacks [26]. Eighty-nine percent of homes are considered moderately to severely food insecure. The extreme poverty, and poor community infrastructure, has led to surging crime rates, gangs, violence, drugs, as well as other societal ills [27]. Khayelitsha is currently known as the murder capital of South Africa, with attempted murder increasing by close to 30% in 2012/13 [26].

KH opened in 2012 and is the only district hospital serving the Khayelitsha area. The hospital is well resourced with medical doctors and some of the latest medical treatment facilities in the Western Cape [28]. There is a 24-h theatre facility availability, and a CT scan and ultrasound department. There is also a women's health unit. In the obstetric team, there are two full time qualified obstetricians with many years of experience. There are also four obstetric registrars rotating through the hospital as the hospital is linked to a tertiary education centre. With regards to obstetrics, only women with high risk pregnancies are brought to the hospital to deliver, otherwise they would deliver at the community health clinic's maternity units. With this in mind, higher anxiety would be expected amongst the staff and patients than might be expected in a community dinic.

In an organisation like KH, the health care system experiences an immense patient load, the poverty of the community it serves, and the numerous traumas affecting both patients and staff. During staff interviews, the hospital healthcare workers from the Khayelitsha community expressed exposure to rape, neglect, financial struggles, domestic violence, murder of loved ones and their own obstetric trauma. These challenges are overlaid on an apartheid history, and on-going cultural and language differences between patients and staff, and within the staff group itself. Specifically, women in the Khayelitsha community are often devalued [29, 30], and teenage and unwanted pregnancies are common, which lead to poor pre-natal care, often because of shame or lack of knowledge [31].

#### Methods

In order to obtain rich exploratory data, a qualitative research methodology is regularly used. Ethnographic research is known to produce a trustworthy and descriptive qualitative accounts of complex phenomena [32]. In addition, using multiple sources of data helped us to triangulate the findings.

#### Ethnographic sampling and data collection

This study employed an ethnographic research model, which entails trying to understand practices in a particular setting [32–34]. The data comprised three sources of primary data and one source of secondary data. The primary data source was observations in the labour ward, interviewing labour ward staff (doctors, nurse, and cleaners) and patients who used the ward. The secondary data source was the analysis of hospital documents, specifically those related to labour ward policy.

#### Participant observation

Employed as a Clinical Psychologist at KH since 2014, the first author (we use the pronoun "I" for the first author as data collector throughout) was a participant observer, and this was the primary source of ethnographic data. I had the dual role of maintaining the stance of an observer while developing an understanding of how health care practitioners and patients experience the labour ward at KH. As suggested by Hollway et al. [35], I relied heavily on supervision in this complex task. Psychoanalytically informed research relies on our minds to aid reflection on the data. A research journal was used to record observations of the day-to-day practices in the labour and antenatal wards. This journal included descriptions of the difficulties - both practical and ethical - which I encountered during the process. It described my subjective and internal ruminations regarding the ward and individual participants - both patients and health care practitioners - as well as considerations of my own engagement with the data and procedures. The journal provided me with important supplementary data in terms of insights into my own processes which may have been lost without a written record. The journal informed and promoted the reflexivity which is acknowledged to be an important component of responsible qualitative research [35, 36]. In the 6 week observation

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period, I also reviewed my clinical notes on previous patients that I had consulted in the labour ward. Throughout the observation period, I reviewed my notes by identifying and developing themes.

Every day I would spend at least an hour just observing the daily rituals in the ward over a period of 6 weeks, although I am familiar with the ward, having been working at the hospital for 5 years. My presence was duly noted and at times caused anxiety. A cleaning staff member thought I was from Cutting Edge (an investigative television show exposing shameful practices), whereas others thought I was monitoring their behaviours to criticize them at their next performance review. In this study we have chosen a psychoanalytic paradigm which assumes that anxiety is inherent in the human condition.

Psychoanalysis, particularly the work of Melanie Klein, has contributed significantly to our understanding of the nature of anxiety and the primitive defences. These defences enable us as individuals to defend against the anxiety, which otherwise may overwhelm and destroy. If anxiety is the basis of the way in which the individual operates, then the protective defence of anxiety is essential for the stability of the individual and the individual's ability to engage in a threatening world.

#### In-depth staff interviews

Sixteen labour ward staff interviews were conducted at KH, which included obstetric consultants, medical doctors, nurses and a clinical psychologist. Purposive sampling was used. Each interview was about an hour. Hollway and Jefferson [37] postulate that interviewees are psychically defended, which implies that everyone has an unconscious which contains motivations, instincts and impulses which are constrained by the social and political world in which they live. A defended subject may not tell a complete and transparent story, this being either a conscious or unconscious act. Some topics or memories are too difficult to talk about because they threaten to break down emotional defences. This may be seen to be true in KH where there is much trauma.

To ensure practicality, the interviewing process begins with a free association narrative interview technique (FANI) in which the questioning style is kept as open as possible, letting the interviewee's ideas, views and story emerge as much as possible in their own words. This allows the interviewer to look critically at any inconsistencies and contradictions. The interviewing process is then followed by a detailed analysis of the experience as a whole, including the relationship between the interviewer and interviewee, the emotions involved, examining the words in the transcript, and a careful consideration of the narrative construction. We did also interview patients, but this article focusses on staff experiences and understandings, so these data will be reported elsewhere.

#### Document and policy analysis

Hospital documents, official policies and any protocols relating to the labour ward and care of mothers were also collected for analysis. In particular, the monthly maternity report from January to May 2018 was analysed, as well as doctors' and nurses' clinical notes Table 1.

The data collection took a total of 21 weeks. The first 6 weeks were purely observational, and the interviews were conducted in the remaining weeks. Informal briefing sessions were conducted a week prior to the formal interviews so that interviewees could ask questions and decide whether or not to participate. As I work at the hospital full time, the medical doctors and nurses who participated in the study asked me about themes that were emerging from the data. They gave me feedback which helped in verifying the interpretations of themes as they emerged from the data, as well as the validity of subsequent results. The participants were able to add information to confirm aspects of data, or ask that inaccurate interpretations be removed. The audio recordings, transcripts and notes from the observations and interviews were kept in my office at work under password protection, and were only read by my academic supervisor and myself.

#### Ethical considerations

Ethical clearance was obtained from the Humanities Research Ethics Committee at Stellenbosch University (REC-2018-1844) and the Western Cape Department of

Table 1 Summary of the research methods used in this study

Research Participation	Research Method	Data Collection	Data Capturing	Data Management	Data Analysis
Labour ward observation at KDH	Ethnography	Own process notes Observation Hospital documents	Field journal	Interpretation of field notes Triangulate with data from B and C	Observational data examined and interpreted for common themes
Staff in labour ward: • Doctors • Nurses • Community service Psychologist	Free Association narrative Interviews	Free Association narrative Interviews	Digital voice recorder Research Journal	Transcription Triangulate with data from A and C	Analysis of content further using FANI methods.

Health (WC 201801 033) before proceeding with my research and data collection.

Participation in the study was voluntary. An information leaflet was included in the informed consent form, and written consent was given by all participants. The information leaflet explained the purpose and objectives of the study, what participation entailed, the possibility of harm or risk, as well as the potential benefits of the study. The leaflet also outlined how confidentiality and anonymity would be maintained, and the participants' right to withdraw from the study. Contact information for all those involved in the study were also provided, including my supervisor and the details of the contact person at the Division for Research Development of Stellenbosch University, should they have any further questions. No payment was offered for participation. I did, however, provide refreshments at my own cost. Confidentiality was assured by the use of pseudonyms. I explained to each participant that they were able to leave the study at any point and their story would not be included in the research. No participant withdrew from the study.

An option of counselling was offered to the participants. None of the staff requested further counselling, however if they had, they would have been referred to ICAS which is a governmental health and wellness programme which offers employees counselling.

For ethnographic observation in the labour ward, an explanation sheet of the research was put up in the ward before I started with observations. I spoke regularly to the staff about my research at the ward round and gave a space for staff to ask any questions or make any objections. I attempted to remain unobtrusive and did not initiate direct interaction with ward staff or patients during data collection. I remained respectful of relationships between staff and patients, did not impinge on the ward environment, and tried not to cause any upset to any person during the observations.

#### Data analysis

The analysis of the data utilised the guidelines provided by the principles of FANI by Wendy Hollway and Tony Jefferson [32]. The FANI method pays close attention to the emotions, thoughts, and motivations of the interviewee, as well as taking into account unconscious dynamics and processes. The relationship between the interviewer and interviewee is seen as crucial as both come to the interview situation with their own anxieties, defences, political and social positioning and histories, which can affect the data that are created.

The combination of ethnographic data, the hospital documents and the interviews provided a deep, rich understanding of the emotional experiences of staff and patients in a highly stressed health care system. The analysis focussed on the most relevant emerging themes as well as on a deepening understanding of what was happening around me consciously and unconsciously, as far as possible. Scripts and the journal were read and reread and reflected upon.

#### Findings

During the research, a set of themes emerged that directly contributed to the labour ward milieu. We discuss themes under two main headings: The world of the hospital and the world the mother brings. Contributions came from the hospital structure and polity itself as well as staff and patients. We discuss the details of these findings below and the significance of the findings are further discussed thereafter.

#### The world of the hospital

Walking into the ward, the first encounter is with the security guard who asks any visitor what their purpose is and writes down the particulars of the person. Then one would walk down the passage, passing the doctors' office and the nurses' tea room. The doctors' office has computers, a coffee machine and fridge. It is often filled with various foods such as fruit and muffins. The nurses' tea room is equipped with a fridge, lockers and a large table where the nurses/deaners can bring their own lunch. I thought about the separate tea rooms as indicative of a social environment favouring the development of power relationships between the medical doctors and nurses; and wondered how this plays out with the staff and the patients. Evidence for this reality came from one of the interview participants who stated,

"Because sometimes there might be a misunderstanding between the nurse and the doctor. Because sometimes you figure out there is a problem, but the problem now, you will tell the doctor, and then the doctor doesn't act the way that they're supposed to act. And you feel like if you were in that authority you are going to do something for this patient, but at the same time you are not the one who is doing the decision because at the end it's going to depend on the doctor for that decision. So when things go wrong you will blame yourself." (Professional Nurse & Midwife M, 35 years old)

"If the doctor is not doing anything, you cannot just decide to take the patient to theatre yourself. So that's another thing. Otherwise, with the other things, there are some doctors who will understand, especially the permanent ones, we understand each other. But the problem is the locum one, the ones who are working in some places, you are just a nurse and you cannot tell me what to do." (Professional Nurse & Midwife M, 35 years old) There is a nursing station in the middle of the ward. It is mainly functional. No staff greets incoming patients or other staff. The staff will engage in conversation if individually addressed. No hostility is noted in their tone.

The ward has an admission room, an induction room, a postnatal room, five delivery rooms with sliding doors and a quiet room allocated for women who have had an IUD or miscarriage. The ward is well maintained and clean. The admission room, induction room and postnatal room are able to accommodate four women each. Curtains are closed around a mother when the staff is assessing or examining her. For this reason, women in these rooms are not allowed to have visitors because of the privacy of the other patients. During active labour, women are brought to the delivery room and the door is shut for privacy. The women generally deliver on the bed although there are large birthing balls. Since the women are alone in the delivery room, visitors are allowed, although few come, as discussed below. Occasionally there are brief grunts and muffled screams with the surges of labour pains, but then the ward returns to a silent milieu.

The consultant asked me to make special mention about the windows of the delivery rooms that look onto the gardens. Reportedly, workers in the gardens often look through the windows whilst a woman is in labour until they are shooed away by the doctors or the nurses. He laughed telling me, but again I thought about the physical design and why no one thought about putting in one way glass so the mothers can look outside but no one can look in.

#### Long periods of silence

During my daily observations, I would sit quietly and wait. The ward was quiet around me (even the new-born babies barely cry). Only the occasional nurses speak to each other in Xhosa at the nursing station. A dinical psychologist noted,

"It's quiet. Because the noisier one is the postnatal. But I mean, even when you walk into the labour ward, it's warm, temperature-wise, it's very warm. I remember, last week it was cold in the passage, but as soon as I walked in there, nice and warm. But it's so quiet. Because now I'm thinking this quiet is almost like a ... it's almost weird and cold." (Community Service Clinical Psychologist, 33 years old)

The contrast of a typical bustling labour ward stereotype and this reality was significant.

#### Few sounds of staff-patient engagement

While silence was descriptive of this environment, there was some engagement. Occasionally, a nurse would go to the mother to ask a question or fill in a note in the folder, but otherwise very little human contact was displayed between people.

"I haven't spent much time with the patients to really find out honestly how they are doing, how they have coped." (Obstetric Registrar, Dr J, 29 years old)

"I think that from a psychosocial point of view we are failing our patients because we come and write their needs, are you okay muonmy? Do you need to speak to anyone? Okay, bye. And that's about the extent of our interaction with the mums. If they are very distressed and the nurses are like, oh, doctor, the patient is very upset, then we'll sit with them a little bit longer. But it's like minutes, maybe five or ten minutes." (Medical doctor, Dr M, 28 years old)

Only one doctor monitored the ward per day and was called when needed. The doctor was alone as she walked from room to room and asked the occasional question – only medically related questions. My observation led me to feel pervasively lonely and I imagined that this is what the mothers and the staff were feeling. No life. No vibrancy for a ward that is synonymous with life and new beginnings. Another medical doctor commented,

"So usually it is quite stressful because 99 percent of the time we're the only doctor, say, in the ward at the time. So it does take quite a bit of concentration and effort because you need to focus and kind of know which patients require reviews, how often they need to be reviewed if there are certain things you're more worried about. So there's a lot of multi-tasking, if I can say it like that." (Obstetric Registrar, Dr J, 29 years old)

"I'm not a huge fan of talking about personal things, so I tend to not check in with the patients on an emotional level. I'm kind of like, I have questions that I want to ask, answer them, and then I'm walking away kind of thing." (Intern Medical doctor, Dr G, 27 years old)

When there is talk, it is often impersonal and lacking in empathy.

I attended ward rounds with the doctors on occasion. The rounds were conducted in English with a predominantly White staff. I noted it was "typical doctor interaction" where there was some engagement with the patient but the doctors often used medical terms that even I, as an English speaker, had to ask for darification on. Patients were not addressed by their names but were often spoken about using their diagnosis.

"I think I do do that, I do see them as a diagnosis. I mean, you've joined our ward rounds and we would be like, oh, this is a 35, para 3, and I'm like, no, it's a person. With adults I find it easier to kind of create that barrier. But ja, I do tend to see patients as a diagnosis. I'm not good with names so I tend to not make the effort." (Intern Medical doctor, Dr G, 27 years old)

Some unintentional micro-aggressions were noted, such as when a young White intern doctor called an older mother "sweetheart" and then used a condescending tone to explain why she was still in the ward. The demographics of almost all the mothers are Xhosa speaking Black females. I noticed there was an awkwardness between the non-Xhosa staff and the patients.

"I must be honest, here I'm more careful about what I say. Not that I have said anything there, but I'm more careful with regard to offending someone because I'm hyper-aware of the fact that I'm not from their community. So you tippy-toe around the fact that you are not from their community and you don't want to say something that's going to perhaps make it worse where they see you as this outsider." (Community Service Medical doctor, Dr T, 26 years old)

I wondered how the mothers felt being in their own community but not able to speak their home language to the doctors. Is the language further isolating, as when language is spoken to the mothers it is very medicalised and not in Xhosa? One morning, I entered the labour ward and the doctors were listening to a case presentation in very medicalised language that I could not understand. I felt very awkward. Many thoughts of "I don't belong here", "I don't want to be here", "I am not sure where to sit" lead me to think about these mothers entering this well designed and well-resourced hospital but feeling they had entered a foreign land and feeling alienated. The experience of one English speaking medical doctor articulated relief at not being able to engage more with patients,

"I think the language barrier does actually benefit me in that sense, whereas I think my colleagues who can speak Xhosa and Zulu probably get a lot more of the emotional side of things because they can communicate better with the patients." (Intern Medical doctor, Dr G, 27 years old)

Policy and practice inclined away from positive milieu. The hospital's labour ward policy also had an impact on the ward milieu. For example, I attended a Morbidity and Mortality meeting regarding the labour ward. This was a dedicated hour to discuss with the obstetric team, and anyone else who is interested, what went wrong in the ward and how the staff could learn from the experience. The discussion was medical (almost like discussing a mathematical equation). Emotion or feelings were not discussed. I wonder if there is space to discuss emotions in a meeting like this. The staff were not engaged, as noted by how many played on their phones, and a doctor even fell asleep. It felt like women are not seen as more than their medical condition. They are not acknowledged as more than their symptoms. The women did not appear to be seen as mothers, aunts, friends, lovers, daughters. Is this a departmental defence to keep the staff removed from the pain of engagement? Some of the staff, however, seemed aware of the apparent issue,

"People forget that its people and they become wrapped up in treating the disease and they are not treating the person." (Obstetrician E, 36 years old)

Both doctors and nurses also spoke to apparent gaps in training, specifically crossing cultural divides. While there was no actual mention of divides, the use of phrases like 'those patients' and 'these patients' in the quotes below speak to an us-and-them perspective,

"But when we started nursing no, there's no training. It's only about the policies that tell you which documents to complete. It's not specifically related to the personal stuff and how to care for those patients or counselling." (Professional Nurse & Midwife M, 35 years old)

"My feeling is that all staff should be trained on how to manage these patients emotionally and not just medically." (Obstetrician P, 38 years old)

"When you study to become a doctor you get taught how to be a doctor, but unfortunately you don't get taught how to be a human being." (Obstetrician P, 38 years old)

"But when we started nursing, no, there's no training. It's only about the policies that tell you which documents to complete. It's not specifically related to the personal stuff and how to care for those patients or counselling." (Professional Nurse & Midwife M, 35 years old)

When asking the staff about debriefing, all the staff said none was offered and that they often leave work with unprocessed feelings.

"Maybe they don't think it's necessary. I guess maybe if I felt like I needed to speak to them (referring to the

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consultants), I could, I just never thought about it." (Intern Medical doctor, Dr B, 25 years old)

"And after that I felt actually traumatised and I sort of avoided going to the labour ward for a while. But you have to get back into it because there's no other option." (Medical doctor, Dr M, 28 years old)

"They don't care much about the counselling of the staff." (Professional Nurse & Midwife, Q, 35 years old)

"So generally if you were to bring that up in the meeting in the mornings, but there's no specific debriefing session." (Community Service Medical doctor, Dr T, 26 years old)

"When you are here, you are too busy. So we don't have time for those counsellings. I think it's a lack of time. I think so." (Professional Nurse G, 29 years old).

In a stressed environment where emotions are not allowed to be spoken about, sometimes the emotions are acted out. This is what I thought about when one of the professional nurses said to me:

"Sometimes the doctors are hard with us. But not all the doctors, just some of the doctors. And also some of my colleagues, those who are experienced in labour ward. Like I'm not that experienced in labour ward. I never worked in labour ward before I came here to this labour ward." (Professional Nurse & Midwife F, 47 years old)

#### High turnover of staff and patients

KH is a district training hospital which means that there are numerous interns and community service health practitioners rotating through the hospital. Every quarter the hospital receives an influx of new faces. Many health practitioners have expressed that the hospital is but a stepping stone to further specialising or gaining more experience before moving to a private facility. This results in people leaving and posts not being filled for many months. Locum staff are heavily depended upon.

"The doctors ... it's also sometimes a challenge because there are new doctors maybe every second or third month, so there is that change. When we get used to these doctors, then we need to teach the other doctors who are new from the school to fit them in." (Professional Nurse & Midwife B, 37 years old) "Working in Khayelitsha, it's beautiful, but there are a lot of challenges and workload than in other areas that I was exposed to. The first challenge that we have here, it's short staffed." (Professional Nurse & Midwife A, 32 years old) The labour ward has not only a high turnover of staff but also a high patient load.

"Working in the labour ward is nice, but it is also challenging with the shortage of staff and being busy with ... like Khayelitsha has a lot of patients and this hospital sometimes is not enough to cater for everyone. So that's the challenge we have. Because sometimes we'll be full and the patients ... there won't be beds ... so we have to struggle and we have to keep some of the patients in chairs. That's another challenge that we're experiencing. And when you ask the patient to sit in the chair, it's not nice, and they don't take it very nice. And sometimes now you feel guilty because they just gave birth and they have to sit on a chair, which is not nice if you take it to yourself." (Professional Nurse & Midwife, Q, 35 years old)

#### The world the mother brings with her

The impoverished setting of KH, and the predominantly Xhosa patient profile brings with it a stark contrast to labour wards in more privileged settings. No visitors sat with the expectant mothers as they waited for the new life. This added further silence to the deathly quiet ward. Was this not supposed to be a life changing, wonderful experience for these expectant mothers, but instead they lay quietly in their beds alone. Phones seemed to be the only other connection to the outside world for the mothers which they were told to put on silent.

When I interviewed a senior professional nurse about the visitors, she told me:

"Visiting times are 3pm to 4pm after the woman has delivered but no visitors before unless the woman is in active labour (4cms or more dilated), then we call someone in her family. The women usually do not want someone to come because they do not want people looking down there (she motioned towards her vagina). We love someone supporting them." (Professional Nurse G, 29 years old)

Birthing companions were rarely seen despite the literature claiming that a birthing companion reduces the need for medical interventions, including medicated births, and improves both matemal and neonatal outcomes [38].

"You know, some of them, culturally, we as Black people, it's few of them that would want someone to be with them when they are in labour. And even when they go to the clinics they are being told that when you are in labour someone can come, and they can sign that companion form. There's a form that most of the clinics give them. They can come, they know that, but we as

Black people, like the boyfriends, they don't want to see someone who is giving birth. Because even when they come to drop the stuff for them, if you ask them, boetie, can you stay? They say, no, no, no, I don't want to be in, I don't want to. So sometimes some of them chase their partners away and they'll say, oh, go, you are the one who is giving me pain, I don't want to see you." (Professional Nurse & Midwife M, 35 years old)

While no single cause would explain the silent milieu in the ward, the combination of these themes compounded into a significant distortion of an ideal labour ward as discussed below.

#### Discussion

A silent milieu characterises the KH labour ward. In contrast to the wards 'new life' symbolic nature, this silence was unsettling as a participant observer. From our numerous observations and discussions with staff and patients, it is dear that no one is being overtly mistreated and all are medically well attended to. Could we categorise this silence as obstetric or gentle violence according to Chadwick's [4, 5] definitions? While the definition of gentle violence is fairly new and inclusive [4], we believe that a silent labour ward milieu as experienced in KH should be included in the definition for a number of reasons.

First, the hospital itself has some systemic orientations that lead to silence. Meetings are strictly medical and the patients' feelings are not factored into overall patient care. The result of this is a systemic neglect of emotional pain and a minimisation of visits and discussion with patients. The multiple patients in the labour ward also mean that visitors are not allowed into the space for privacy related reasons. The lack of visitors adds to the silence. General visiting hours (15 h00-16 h00) are also narrow and inconvenient for anyone who works a full day.

Second, the hospital staff structure and the staff themselves contribute to the silent milieu. Understaffing means that the staff on duty have little time to stop and connect with patients. They move quickly between beds just checking on them medically before moving on. Lack of training amplifies this as the doctors feel helpless to cross the cultural and socio-economic divide. While acknowledging these problems, there seems little incentive to actually change as most medical doctors are on short rotations and will move on from the labour ward within weeks. Silence can, therefore, be seen as a defence as the less you talk to someone, the less you build a relationship and you are thus able to depersonalise the individual. Menzies Lyth [13] addressed how staff defended against anxiety with the employment of defences such as splitting. She stated that splitting is employed as a defence by breaking up the work in a way that limits contact with patients. The same applies to referring to patients as diagnoses. Their personhood is stripped away. No debriefing for the staff again reinforces the denial of feelings and inevitably trains the health care providers not to become involved in patients' emotional affairs. The staff's feeling too are not acknowledge and they are left unseen and silenced.

Finally, the patients themselves passively contribute to the silence in a number of ways. The patients bring with them a world very unfamiliar to many of the staff as most speak Xhosa as a first language. Some of the mainly English and Afrikaans speaking doctors admitted that this language barrier was a relief as they did not know how to engage emotionally. T Although we saw no physical abuse, silence (actual and symbolic) in such a place may be interpreted as evidence of neglect, aloneness and a submissive compliance from patients. Silence can be a form of neglect as it leaves the women not cared for and not seen. Chadwick [4] specifically addresses this form of gentle violence where women accept that they are patients and comply with what they think is expected of them. Only women who have had a complication in a previous pregnancy or in this pregnancy are brought to the hospital to deliver, otherwise they deliver in the community health clinic. Are these mothers more susceptible to defensive neglect because they fear the pending outcome of the delivery which could result in trauma to themselves or the new life inside of them? Maybe it is easier to be alone and quietly deal with the prognosis like one in a medical ward trying to deal with a physical ailment that takes time, medication and rest. Maybe the women and the staff do not feel that this time is a rejoicing time as the outcome is uncertain.

Does the fact that they are in a hospital lead to furthering the silence - as a sign of powerlessness - as they have accepted their role as a patient? The women are made to enter a hospital setting, get into a hospital gown and get into a bed and assume the sick role which is normalised and accepted. With the sick role assumed, the health care practitioners do become the experts, resulting in the women feeling inferior. The medical language is communicated in a language that is not the mothers' mother tongue, further establishing unequal power dynamics. This is congruent with Morales et al.'s [2] findings that obstetric violence occurs in a social environment favouring the development of power relationships between patients and health care practitioners. Morales et al. [2] stated that violence can be expressed through equitable access to health care and that in a poorer community they must invariably accept what they are given.

#### Conclusion

We agree with Morales et al. [2] who stated, "neither medicine nor health care staff are violent by nature" (p.

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7). Most enter the health world wanting to help. In Khayelitsha we saw this to be true. Staff provide excellent medical care and will engage when they need to. Patients' basic needs such us food, blankets and pillows are attended to. The staff will answer all questions in a nonhostile manner and even assist the patients to the bathrooms or help with making phone calls to family members. However, in a stressed environment where most of the birthing mothers are traumatised, both staff and birthing women appear to keep quiet to defend against the anxiety that is aroused in them. The women willingly submit themselves to the supposed experts and the supposed experts quietly perform their tasks. Silence is protective for both the staff and the mothers. No one gets emotionally involved and therefore no one hurts. There are no clear perpetrators as the organisational system is built on a community that is powerless and lacks agency. Both staff and patients are victims and both collude with the defensive neglect of silence.

We do think staff need to be held accountable for their actions, as addressed by Chadwick [5], but we think they need to be supported as much as their patients need to be. In order to create a favourable milieu in the ward, all parties need to be thought about and held in mind.

Silence is always difficult to interpret because it is silence. Through this paper we have suggested various interpretations of why there is silence. One of the doctors said the following:

"I think the nurses and the doctors here are really doing the best that they can. I think our patients are getting excellent care from a medical point of view. But our population needs so much attention, and they don't need attention from the doctor on call for one day. This population needs attention." (Medical doctor, Dr M, 28 years old)

In this the participant describes not a lack of care, but an appreciation of the extent of the need and the deprivation of this community. Silence can therefore been seen as possibly an act of gentle violence, but we see it more as a way a system defends against what it knows it cannot provide.

#### Abbreviations

FANI: Free Association Narrative Interview; KH: Khayelitsha Hospital

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#### Authors' contributions

ML is the primary researcher responsible for literature review, data collection, data analysis and writing of the first draft of manuscript. IS is responsible for academic supervision and substantial help with positioning the paper. LS contributed substantially to conceptualizing the paper, to its final writing up, and to the design of the study. Both authors accept responsibility for the article in its current (final) form. Both authors read and approved the final manuscript.

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#### Ethics approval and consent to participate

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#### Consent for publication

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#### Competing interests

The authors declare that they have no competing interests.

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# **CHAPTER SIX: ARTICLE 2**

# Care and the politics of shame: Medical practitioners and stillbirths in a South African district hospital

#### **Introducing Article 2**

Article 1 looked broadly at the labour ward milieu and the healthcare practitioners who work with the patients. In this second article, I focused in on the medical officers. The primary data source was interviews with medical officers regarding their practices with women who have stillbirths. From the interviews, previous findings about this topic are corroborated by our work within the hospital. Additionally, we include and discuss new findings that we discovered in our research, such as frustrations in communication, feeling culturally different, feeling overwhelmed and shame. This was a difficult article for me to write as I identified strongly with the medical officers. I shall discuss this more in depth in my reflection piece.

From my findings I can conclude that dealing with stillbirth is emotionally challenging anywhere in the world. However, in a context like South Africa, there is the added burden of trying to right the wrongs of a brutal and divided society. These medical officers are dealing not only with stillbirths but also, to a degree, with the stillbirth of the hope that, twenty-five years after becoming a democracy, South Africa is far from becoming a unified and caring society. There is a great irony, of course, in the fact that we see in the data here the re-enactment of dehumanising discourses by the very people who are working very hard to restore humanity in a fractured society. It would be easy simply to condemn these dehumanising, detaching and discriminatory statements and practices. To do so, we believe, would be defensive in itself – for change to occur, we need to understand the complex personal and political roots of what health practitioners do to survive under very difficult circumstances.

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# Care and the politics of shame: Medical practitioners and stillbirths in a South African district hospital

#### Maura Lappeman & Leslie Swartz

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# Care and the politics of shame: Medical practitioners and stillbirths in a South African district hospital

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Research into the abuse of women during childbirth has increased over recent years. Many studies have focussed on labouring women, how they may be physically maltreated, neglected, or shouted at, and on how their needs are unmet by healthcare practitioners. As part of a larger study focussing on staff responses to stillbirths, we wanted to focus our attention on how medical doctors, working in a district hospital in an impoverished urban setting in the Western Cape Province of South Africa, manage, and feel regarding, stillbirths. This healthcare system experiences an immense patient load, with the poverty of the community it serves, and the numerous traumas, affecting both patients and staff. In order to obtain rich exploratory data, a qualitative research methodology was used. The primary data source was interviews with medical doctors regarding their practices with women who have stillbirths. From the interviews, previous findings about this topic are corroborated by our work within the hospital. Additionally, we include and discuss new findings that we discovered in our research, such as frustrations in communication, feeling culturally different, feeling overwhelmed and shame. From our findings we can conclude that dealing with stillbirth is emotionally challenging anywhere in the world, however, in a context like South Africa, there is the added burden of trying to right the wrongs of a brutal and divided society. These medical doctors are dealing not only with stillbirths but also, to a degree, with the stillbirth of the hope that, twenty-five years after becoming a democracy, South Africa is far from becoming a unified and caring society. There is a great irony, of course, in the fact that we see in the data here the re-enactment of dehumanising discourses by the very people who are working very hard to restore humanity in a fractured society. It would be easy simply to condemn these dehumanising, detaching and discriminatory statements and practices. To do so, we believe, would be defensive in itself - for change to occur, we need to understand the complex personal and political roots of what health practitioners do to survive under very difficult circumstances.

Keywords: South Africa; medical doctors; stillbirths; trauma; qualitative

#### Introduction

It is well established that, in all healthcare systems, practitioners may struggle to provide adequate care for a range of reasons, including the need for healthcare

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practitioners to protect themselves emotionally from being overwhelmed by suffering (Byrne, Morton, & Salmon, 2001; Menzies, 1960; Obholzer & Zagier Roberts, 1994). These issues may be exacerbated in healthcare systems which are very over-stretched and operate in violent social contexts, such as South Africa (Frenkel, 2002; Van Der Walt & Swartz, 1999). It is also well established that certain kinds of contexts may be particularly evocative, such as obstetric care (Stotland & Stewart, 2008). Within obstetric care, stillbirths may be the most difficult for healthcare workers to deal with.

#### Healthcare providers and stillbirths

Parents place expectations on their clinicians to assist the mother through a successful pregnancy. Chadwick (2014) found that mothers may define the success of a birth by how they were treated interpersonally by their healthcare providers. These issues may be brought into even sharper focus in the case of stillbirths. Death is not routinely expected in a maternity ward (Shorey, André, & Lopez, 2017). The death of a baby at any stage can have lifelong impacts on parents. How clinicians care for the family during this vulnerable time can influence the parents' responses (Cacciatore, 2013; Nuzum, Meaney, & O'Donoghue, 2014). As long as six years after the stillbirth, some parents still remember what the healthcare provider said and how they were treated (Wright, 2011). Parents appreciate when clinicians acknowledge their mourning process and allow them to participate in rituals such as holding the baby, taking photographs and collecting mementos (Cacciatore, 2013). Lewin and Green (2009) have studied the benefit of these rituals in healthcare and their importance in South Africa's primary healthcare clinics. Psychosocial support by clinicians, positive interpersonal relationships and strong social support can significantly improve a family's grieving process (Cacciatore, 2013; Wright, 2011). The mother needs sensitive guidance to alleviate natural fears and normalise the grief process, and the onus of responsibility falls on the clinicians. However, when healthcare providers feel helpless and guilty, experiencing a sense of failure and shame, this can result in the healthcare provider being avoidant, thus engaging in practices such as referring to patients as diagnoses (Menzies, 1960; Schrøder, Jørgensen, Lamont, & Hvidt, 2016), and giving the impression that they lack concern for the family (Cacciatore, 2013). Cacciatore (2013) noted that for a healthy grieving process to unfold it is necessary for the clinicians to see each family as unique, worthy of openness, curiosity and compassion.

Given the emotional impact of suffering, clinicians have been commonly found to address suffering in one of two ways. Either, they may become emotionally detached, for the explicit purpose of remaining objective (Frenkel, 2002). Alternatively, they may suffer together with the bereaved family in order to relieve some of their own emotional angst (Coulehan, 2009). Death of a patient can also cause notable distress in the clinician, leading to mental health problems (Coulehan, 2009). Psychodynamic Practice

In the medical profession, the expression of emotions in distressing situations is often perceived as unprofessional, which results in many medical doctors learning to suppress and ignore their feelings (Kerasidou & Horn, 2016). The acknowl-edgement of the emotional burden of stillbirths is an important step towards creating a more supportive environment for all healthcare providers, reducing burnout, stress and compassion fatigue, and increasing professional engagement and satisfaction (Nuzum et al., 2014). There have been an increasing number of publications, especially in the Global North, regarding this topic, primarily investigating the psychological impact of perinatal loss on healthcare professionals and their emotional response, as well as discussing how to implement supportive interventions for healthcare providers (Gandino et al., 2017; Shorey et al., 2017).

Implications emerging from two recent literature reviews regarding the needs of healthcare providers, in order to help them deal with their anxiety over the emotional burden after a perinatal loss, have been the need of support from colleagues (especially senior colleagues' support of junior colleagues), support from family and friends, and formal training, the latter being highlighted by numerous studies (Gandino, Bernaudo, Di Fini, Vanni, & Veglia, 2017; Shorey et al., 2017).

There has also been a call for more research into this topic, and there is very little research exploring the issues in low-income contexts in the Global South. The current study contributes to the published literature by highlighting the emotional experiences of medical practitioners dealing with stillbirth in an impoverished community context.

#### The context of this research

The hospital where this study was conducted is a large metropolitan hospital located in an impoverished area of the Western Cape in South Africa, where high levels of community violence are prevalent (Barolsky, 2016). Many of the features of overworked and stressed health systems are part of this working context. Working in a hospital in this context inevitably means the exposure of healthcare workers to significant levels of patient suffering, including the culmination in the death of patients.

The first author (for whom we will use the pronoun 'I' for the remainder of this article, as she conducted the fieldwork and works as a clinical psychologist at this hospital) became concerned at the lack of counselling or support provided to women who had stillbirths. When I asked a medical colleague why this provision was not made, I was told that in 'this community' a stillbirth is equivalent 'to us taking a crap' (the medical doctor's own words). The implication was that those from outside of the community (from wealthier backgrounds) had a different grieving system to the underprivileged, uneducated majority of South Africans. In contrast to what may be inferred by many from the above comment, the medical doctor in question was otherwise apparently kind and ethical. I was so perturbed by the medical doctor's response that I decided to implement a system whereby no woman who had a stillbirth was permitted to be

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discharged without a review by the psychologist or, at minimum, being given an appointment as an outpatient. I also wanted to understand the context within which a comment like this could be made by an otherwise caring person.

While I was initially shocked by the comment, the sentiment contained therein seemed to be echoed in other hospital practices. Staff seemed unsure of how to place and treat women who had experienced stillbirths. For example, women who have had stillbirths continue to stay in the labour ward alongside mothers giving birth to healthy infants. During the last five years, medical doctors employed at the hospital have told me that they have received no training to deal with women who have stillbirths. The lack of training may be one of the contributing factors to ineffectual or non-existing engagement with the grieving mother, but as a review of the literature will demonstrate below, the issue at hand may not be simply a question of training.

These experiences regarding stillbirth prompted my thinking about the interface between psychology and medicine in a district hospital with the medical doctors being recent medical school graduates. How are they impacted by death? How do they make sense of a mother coming to hospital only to be told that the baby is dead? What helps them to make sense of this death? What defences do they employ to protect themselves? Often these potentially grieving mothers are alone in the ward and need to process this loss in isolation, as their loved ones or family members are at work and do not have the luxury of compassionate leave to sit beside and support the mother in her grief. Does this put further pressure on the clinicians to be more supportive or more avoidant of the loss? There is an implicit expectation (one which I hold myself) that the clinicians, as part of their duty to care, will hold these grieving women in mind. But who holds these clinicians in mind? Finally, what role does the socio-economic gap between the medical practitioners and the community play? This includes the observation that most all the medical doctors are not from the community and do not speak isiXhosa, the primary language of many of the mothers. It has been found that African languages are usually excluded from the hospital setting (Deumert, 2010). Informal interpreting is only used in desperate cases, and is understandably fraught by problems of accuracy and confidentiality. Language, communication and cultural understanding are needed for effective health delivery in multilingual and multicultural societies such as South Africa (Deumert, 2010). How do language and cultural context effect the medical doctors in the delivery of their service? These questions call, in the first instance, for a more thorough investigation of the complex issues at stake.

As part of a larger study focusing on staff responses to stillbirths, the objective of this study was to observe practices pertaining to stillbirths, the emotional experiences of medical practitioners in the hospital in relation to stillbirths, and the defences they employ in dealing with stillbirths in a highly stressed healthcare system. We will firstly show that previous findings regarding this topic are corroborated by our work within the hospital. Secondly, we include and discuss new findings revealed in our research.

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### Methodology

This study draws on the well-established psychoanalytic approach to understanding healthcare organisations. This approach was pioneered by Isabel Menzies Lyth in her studies of nurses in the UK (Menzies, 1960). Menzies Lyth started a tradition of researching healthcare organisational dynamics which was taken up by Obholzer and Zagier Roberts (1994), Hinshelwood and Skogstad (2000), and later Kruger and Schoombee (2010), amongst others. This approach addresses how people in organisations defend themselves in the face of overwhelming anxiety by utilising beliefs, values and attitudes that unconsciously relieve anxiety (Van Der Walt & Swartz, 1999; Obholzer & Zagier Roberts, 1994). These defences have both an unconscious and conscious element to them. Both groups and organisations deploy defences (Lowdell & Adshead, 2008), and there is a relationship between group and individual defences. Writing about healthcare in Cape Town, Frenkel (2002) found that, in extremely traumatic work, healthcare practitioners inevitably use defences to protect themselves from pain, anxiety and the impact of the workload. Some strategies which people who work in overburdened service settings use are of course conscious - people may for example make deliberate choices to take breaks, to try not to become too emotionally involved with clients or patients, for example. But there may be unconscious motivations as well. For example, as Van der Walt and Swartz (2002) note, the practice of what is called task orientation in nursing has very useful conscious practical benefits. For example, moving from patient to patient and taking their temperatures, and then starting again to move around the ward giving medication to all the patients has great advantages: tasks are done quickly and efficiently, and there is good opportunity for nurses in training to learn defined skill sets. But at the same time, task orientation may well fulfil, as Menzies (1960) suggested, an important unconscious defensive purpose in assisting health care practitioners not to engage emotionally with patients.

Taking this research tradition into account, the analysis of the data in this study utilised the guidelines provided by the principles of the Free Association Narrative Interview Method (FANI) developed by Hollway and Jefferson (2013). The FANI method is guided by the psychoanalytic method of free association to elicit accounts of specific memories which are filled with emotional content (Hollway & Jefferson, 2013). Hollway and Jefferson (2013) locate their method within the psychosocial studies tradition, an approach to research and data analysis which links broader socio-political and organisational issues to personal experience. Within the FANI approach, emotion is viewed as constructed both politically and personally.

This method is especially appropriate for a topic as emotionally charged and anxiety-provoking as stillbirths. The FANI method addresses unconscious defences and keeps in mind the whole data set for a given individual when interpreting part of it. In particular, the associations that led up to any part of the data are accounted for (Hollway & Jefferson, 2013). Analysis of data within the

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FANI approach requires that the researcher has an understanding of, and experience in, psychoanalytic methods; I have such training and experience by virtue of my training as a clinical psychologist. It is important to note, though, that the FANI method does not regard the collection of research data as equivalent to psychotherapy, and psychotherapeutic techniques, beyond generic interviewing skills, are not used in data collection. The FANI method relies on facilitation of open-ended discussion and the interpretation of data is conceptually separate from data collection.

#### Study design

A qualitative research methodology was employed to capture the complex social processes of the relationships and dynamics occurring in the hospital labour ward and understand practices in this particular hospital setting, and why they are performed in such a way (Bantjes & Swartz, 2017; Gobo, 2008; Smith, 2005). I (first author), as an employee of the hospital since 2014, conducted interviews with medical doctors regarding their practices with women who have stillbirths.

#### **Participants**

Following ethical clearance from the Research Ethics Committee at StellenboschUniversity (REC-2018-1844) and the Western Cape Department of Health (WC 201801 033), a purposive sample of eight medical doctors (including two consultants) were invited to participate in the study. Participation in the study was voluntary. Inclusion criteria required that medical doctors had worked in the labour ward for at least four months and cared for at least one stillborn birth. An explanation sheet regarding the research was posted in the ward. None of the medical doctors were members of the community where the hospital was situated. The community served by the hospital is primarily African; as Table 1 shows, all but one of the medical practitioners was not classified African.

#### Data collection, management and analysis

FANI interviews were conducted with the medical doctors in the labour ward (Hollway & Jefferson, 2013). The FANI method pays close attention to the emotions, thoughts, and motivations of the interviewee, as well as taking into account unconscious dynamics and processes. The data obtained from the transcripts were stored electronically on a password protected computer and the actual interview transcripts were kept in my office and were read exclusively by my supervisor and myself.

According to the FANI method, the relationship between the interviewer and interviewee is seen as crucial as both come to the interview situation with their own anxieties, defences, political and social positioning and histories, all of

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Name	Age	*Self Identified Race	Language
Dr T	26	Coloured	English/Afrikaans
Dr P	38	Coloured	English/Afrikaans
Dr M	28	Coloured	English/Afrikaans
Dr K	31	Coloured	English/Afrikaans
Dr A	25	African	Zulu/English
Dr E	35	White	Afrikaans/English
Dr D	27	White	Afrikaans/English
Dr G	27	White	English
Dr J	29	White	Afrikaans/English
Dr B	28	White	Afrikaans/English

Table 1. Participant characteristics.

\*During the Apartheid era in South Africa, the Population Registration Act classified the South African people into 'African', 'Coloured' (mixed race), 'Indian' or 'White'. In contemporary South Africa the mentioned labels continue to be used to monitor employment equity, among other indicators. The term 'Coloured' is used for a diverse formally disenfranchised group of people who generally speak Afrikaans/English as a home language. The racial labels used in South Africa, as elsewhere, have no objective biological basis but the categories still continue to carry social meaning in what remains a divided society (Posel, 2001).

which can affect the data that are created. Hollway and Jefferson state that, in their research using this method, they:

... intend to construe both the researcher and researched as anxious defended subjects, whose mental boundaries are porous where unconscious material is concerned. This means that both will be subject to the projections and introjections of ideas and feelings coming from the other person. It also means that the impressions that we have about each other are not derived simply from the 'real' relationship, but that what we say and do in the interaction will be mediated by internal fantasies which derive from our histories of significant relationships (2013, p. 42).

Hollway and Jefferson (2013) postulate that interviewees are psychically defended, which implies that everyone has an unconscious which contains motivations, instincts and impulses which are constrained by the social and political world in which they live. A defended subject may not tell a complete and transparent story, whether that is a conscious or unconscious act. Some topics or memories are too difficult to talk about because they threaten to break down emotional defences. This may be seen as true in a hospital, where there is much trauma. We use the word 'trauma' in two senses in this article. First, hospitals treat patients who have experienced medical traumas such as motor vehicle accidents, burns and gunshot wounds, all of which are more common on low-income contexts than in high-income ones (Diamond et al., 2018). Second, we use the word 'trauma' to refer to psychological reactions, conscious or unconscious, to being exposed to acute or onoing traumatic events or processes (Frenkel, Swartz, & Bantjes, 2018; Kaminer & Eagle, 2010). An awareness of these defences and their underlying causes assists in facilitating a deeper

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understanding of why the healthcare practitioners respond towards these mothers in the way they do after a stillbirth.

In practicality, the FANI technique, in which the questioning style is kept as open as possible, allows the interviewee's ideas, views and story to emerge as much as possible in their own words. This in turn allows the interviewer to look critically at any inconsistencies and contradictions. All the medical doctors are colleagues of, and so are known to, the first author. Informal individual interviews were conducted a week prior to the formal interview, allowing the medical doctors to ask questions and decide whether or not to participate. This facilitated building further rapport. After each formal interview, I allowed each medical officer to debrief, as suggested by Harvey (Harvey, 2017). This debriefing allowed the medical doctors the opportunity to speak about any unprocessed emotions that were aroused. Several medical doctors cried during the interviews but none were distressed or uncontained by the end of the debriefing. The interviewing process was then followed by a detailed analysis of the experience as a whole, including the relationship between the interviewer and interviewee, the emotions involved, journal notes of reflections about each interview, examining the words in the transcript, and a careful consideration of the narrative construction.

#### Bracketing in this study

In qualitative research, the researcher is the tool for analysis across all phases of the research project. The researcher inevitably comes with their own preconceptions (assumptions, defences, values, interests, emotions, biases and theories) (Tufford & Newman, 2012). These preconceptions influence how data are gathered, interpreted/analysed, and reported on (Tufford & Newman, 2012). The ability to reflect on one's preconceptions and biases (known as bracketing) is therefore crucial for the researchers to not act out and assume more about the data than is there. Bracketing helps to mitigate the potential damaging effects of unacknowledged preconceptions related to the research and thereby to increase the rigour of the project (Tufford & Newman, 2012). Self-reflection is an ongoing process. I came face to face with my own shame through the research process in identifying strongly with the medical doctors and though it was not pleasant, it helped me with understanding of the medical doctors' shame deeper. After some self-reflection through journaling(Vicary, Young, & Hicks, 2017), supervision and own personal therapy, I was able to regain a some perspective and return to the task ahead of me which was not only holding myself in mind but also those who work alongside me day by day. As I saw in her process, I needed regular supervision, reading of theoretical articles and writing of reflections to understand my own internal battle with the overwhelming anxiety of working in such a context.

Findings

Some of the findings were similar to those of studies elsewhere in the world, and some were more particular to the context. For convenience of presentation, we have divided the findings into these two broad sections.

# Findings similar to those in studies in high-income countries

The ongoing need for support from the hospital, colleagues, family and friends

All the medical doctors interviewed expressed a need for support, whether it be from colleagues or family. They felt the overwhelming burden of carrying the heavy emotional load of their work and needed to share it with others. The younger medical doctors believed they needed to toughen up or find a way of dealing with their anxiety outside the hospital context. I wondered about their expectations of themselves as being healers and not necessarily needing healing. Their feelings seemed to be suppressed or ignored. The rawness of the trauma in their work permeated through the interviews, with several crying when given a space to reflect. They apologised for their tears and tried to suppress their sobs. I assured them that I was not afraid of their tears, but it was evident that they were afraid of their tears and the risk of seeming unprofessional.

There's no formal debriefing for anywhere in this hospital, for any speciality, and it is something that we have raised before, saying that there should be ... a lot of health practitioners are suffering from mental health because of it. (Dr G)

*I think at most I'll go home and speak to my husband about it. That's about it.* (Dr T)

After (an infant death) I felt actually traumatised and I sort of avoided going to the labour ward for a while. But you have to get back into it because there's no other option. (Dr M)

Maybe they (referring to senior colleagues) don't think it's necessary. I guess maybe if I felt like I needed to speak to them, I could, I just never thought about it. (Dr A)

Let's say there is a bad outcome, then I try and see what I could have done differently, so I try and critique myself a little bit and then I will try and focus on all the other good things that happened in the last call that I did or whatever. And then I exercise a lot. I think that's my distress. (Dr J)

#### The need for formal training in bereavement care

This topic made me wonder why universities do not equip their medical students with this soft skill. Do they believe that it is not necessary, or maybe the lecturers themselves do not know how to impart this skill?

So it does become a bit tough and you kind of don't know how to ... so it's difficult to broach the subject with them because you don't know how to. You don't know

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whether you're now being insensitive. You want to make them feel better, but like what can really make them feel better? So it's difficult and you can't just go through that tick-box sheet. I even feel uncomfortable talking to them about it, then I don't ... I just kind of have to say that I'm sorry for the loss, and then that's as far as I will go, because distancing myself from the problem is better than overstepping something and causing worse emotions. Like I'm causing more emotional trauma. (Dr T)

Well, I don't know if I'm doing it right, but I think it's just one of those skills that you're going to develop as you grow, like how to empathise with someone. But ja, I don't know actually, am I doing it right? (Dr J)

I had a very nice consultant who always taught us about life stuff, proper management of patients emotionally and physically and so on. So that's where I got my, if you want to call it informal training from, but no formal training. (Dr P)

So at first, I don't know exactly what I'm supposed to tell the person. So when I ask if the pregnancy was planned, I feel like I'm diminishing the emotions for her. Just because it wasn't planned, it doesn't mean that it should be okay. (Dr A)

You can't even look at the mummy because you can't imagine what she must be going through. She's in pain. She's uncomfortable. She's exposed, and now she's got this thing coming out of her that's not even alive anymore and she's carried it for nine months. (Dr M)

#### Seeing patients as a diagnosis to defend against the pain

The less that is known about a patient, the less likely their pain will cause the practitioner distress and anxiety. Labelling patients in the literature is well reported on because it is the easiest way a healthcare practitioner can defend against the overwhelming anxiety of not feeling good enough (Van Der Walt & Swartz, 1999).

I do see them as a diagnosis ... I'm not a huge fan of talking about personal things, so I tend to not check in with the patients on an emotional level. I'm kind of like, I have questions that I want to ask, answer them, and then I'm walking away kind of thing. (Dr G)

#### Findings particular to the local context

#### Frustration at barriers of communication

Effective communication has long been considered an essential component for enhancing rapport between patients and healthcare providers (Jolly, Aminu, Mgawadere, & van Den Broek, 2019). But what happens when the medical officer cannot understand the patient, nor the patient the medical doctor?

*Communication difficulties between patients and healthcare practitioners.* We wondered about language being another form of splitting from the pain. It is

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convenient not to speak to the patients. It makes the medical doctor the 'other' and distances them from the responsibility of the patient as you cannot treat what you do not know about.

And then it's also challenging sometimes to work past the language and the cultural barriers here, whereas there (different hospital) it's much easier to communicate things. I think sometimes that can frustrate you or sometimes that can make you not give the same service that you would ... not intentionally ... but just because you really can't communicate the same way. (Dr J)

I'm hyper-aware of the fact that I'm not from their community. So you tippy-toe around the fact that you are not from their community and you don't want to say something that's going to perhaps make it worse where they see you as this outsider. (Dr T)

If I'm translating, if it's something sensitive, then I would try and get a nurse or another medical officer that could, but if it's just something general I'll sometimes ask a patient that's there, which is probably not the best thing, but I mean, you just need to get going. (Dr J)

*Communication difficulties amongst healthcare practitioner's colleagues.* 

It was a bit difficult at first because they (referring to other medical doctors) tend to speak Afrikaans a lot and so it was very difficult for me in the first couple of months, having constantly to remind them to speak English. (Dr A)

One would expect colleagues to create a group identity. However, from the only African medical doctor, and the only one able to communicate directly with the patients, there is a sense of feeling alienated and alone. I also wonder why the other medical doctors could not maintain English as the professional language as all clinical notes need to be in English. Was speaking in Afrikaans another way of separating them further from the patients? The patients in the ward have very little understanding of Afrikaans so they cannot question the decisions of the medical doctors.

But I was told that in obstetrics there were Black medical doctors before, but they didn't stay. Because when people speak a different language and you have to constantly remind them, it feels almost as if they don't want you to be involved ... I even told that maybe it's better to just change and go to another hospital ... Because you know, you miss some part of the management, because when someone retranslates they're not going to say everything exactly as it was. (Dr A)

In the quote below, a White medical doctor acknowledges that it may protect her emotionally by not speaking the language as this enables her to separate herself from the patients' pain. On the other hand, there appears to be no reflection that the language barrier may also result in a separation from her colleagues as her Xhosa speaking colleagues are left with *'the emotional side of things'*. And further isolation from the colleagues.

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I think the language barrier does actually benefit me in that sense, whereas I think my colleagues who can speak Xhosa and Zulu probably get a lot more of the emotional side of things because they can communicate better with the patients. (Dr G)

# Feeling culturally different

I think with the legacy of our country, this population in general is used to having the short end of the stick. And I think in general, with bad news and bad diagnosis like cancer and IUDs, they handle it very well because they are used to having difficulties. Because they are so used to having difficulties around them, when you hand them another one, it's just like, oh, this is just another thing. And I think that's just got to do with their day-to-day, everything for them is not easy. So that is why they handle things so well. (Dr M)

Coming to work in this community has been difficult for all those clinicians interviewed because they are culturally different and have not taken time investing in getting to know the culture. Assumptions and fantasies are made about the community.

It's much easier to relate if you are working with your community. But I do think that a big part of it is like an unconscious coping, like try and separate yourself or remove yourself from the community so that you are less affected about what happens to people. (Dr J)

*It's* (names the area of the hospital), *maybe it's dangerous, it's working so far from home.* (Dr K)

The people are different. It's a different culture and it's a different community, if I can say it that way ... I might be a bit more tired and frustrated sometimes. (Dr D)

People on the labour ward will tell you, 'I can't go home now doctor. Can I rather sleep over until tomorrow because it's not safe?' (Dr C)

Medical doctors reported having fantasies about what the patients want but do not ask the patients. They appear to operate from a sense of what they think the patient wants, not from an attitude of seeking to understand her needs. This may be in part a product of the busyness of the hospital, which every one of the respondents commented on. It may also develop out of an anxiety which rather avoids really trying to understand the patient's needs, culture or desires – a further avoidance of feeling the pain of the grieving mother.

I think from our side we try and get them out of hospital as soon as possible because we feel that lying here ... or the babies ... but in the same way, maybe they feel like we're rushing and we don't care about them in the way we care about the mummies who are having live babies. I've never actually asked. I don't know how they feel. (Dr G)

I actually haven't given the mum a chance to ... ja, I haven't heard her views. (Dr K)

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# Feeling overwhelmed

At the end of two interviews, the medical doctors responded with: 'I don't have answers' and 'I didn't know a lot'. It was also not uncommon that, as a result of the interviews, the medical doctors routinely said: 'I can't answer that question' or 'Sorry, I have no idea' or 'I don't know. I actually don't know'.

I wondered whether these comments represent an unconscious desire to be free from responsibility; to return to an unknowing, ignorant state before they were expected to know. Feeling overwhelmed. Feeling out of their depths.

# Shame

Shame is difficult to describe. It is what we feel when we do not get affirmation for trying to help or when we fail to achieve what we hope to achieve (L.-M. Kruger, 2012). All the medical doctors interviewed stated that they studied medicine because they wanted to help people. Some reported experiencing losses in the earlier years which drove them to study medicine so they could '*fix*' people. All their intentions to study medicine appeared to resonate out of a desire to interact with others and make a difference. They studied hard and for many years. Several of the medical doctors cried in the interviews as they spoke about how this work was not what they had expected.

Am I making a difference? (Dr A)

I've never cried with a patient, but you know, I couldn't. (Dr J)

Because I'm always scared of missing something. (Dr K)

You can't even look at the mummy because you can't imagine what she must be going through. She's in pain. She's uncomfortable. She's exposed, and now she's got this thing coming out of her that's not even alive anymore and she's carried it for nine months. (Dr M)

I'm always scared that I'm doing something wrong or maybe I'm not noticing what I need to in time and it might lead to complications with their pregnancies. (Dr A)

#### Discussion

Certainly it is clear that to do this work there needs to be a strong support and supervision structure in place. (Frenkel, 2002, p. 499)

The world of healthcare is fraught with challenges in South Africa (Deumert, 2010). In a community with so much deprivation, medical doctors may be idealised, and they may also be called upon, whether explicitly or not, to heal all the ills of both individuals and society. Projections from patients and others can be a heavy burden to carry, especially for a newly qualified medical officer who needs to adopt defences to defend against the pain and anxiety of working in a context of so much anxiety and

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loss. The shame these medical doctors seem to carry feels tangible at times. They know they cannot fix the problems, but they are sensitive to the expectation to do so, some of which comes from themselves. Their defences may be protective of their own wellbeing, but unfortunately the defences can be counterproductive and can hurt others and themselves from receiving the healing that they need.

Donald Kalsched (Sieff, 2008) suggested that the psyche's internal response to trauma is to set up a 'self-care system' designed to ensure survival. In the context of the work of the medical doctors in our study, paradoxically, this defensive system ultimately retraumatises the medical officer from within. Defences prevent the capacity for empathy which is crucial to the forming of attachments (Kerasidou & Horn, 2016). The defences may work in the short term, but may interfere in the longer term with the process of healing from the trauma of the work, and learning in the context of meaningful relationships (Kahn, 2005).

Splitting, detachment, depersonalisation, blaming and denial of feeling/guilt are all defences employed by these medical doctors in dealing with the work. Menzies (1960) addressed the ongoing conflict of healthcare staff regarding accepting responsibility for caring for patients. These medical doctors face the same burdens as others in helping professions but have the added burden of the explicit and implicit demands of the context within which they do their work.

#### Conclusion

The pain of a stillbirth is multifaceted and needs to be considered carefully. Not only does the parent's pain need be acknowledged, but also the medical doctors' pain, with unprocessed loss, working with these mothers. In order for these medical doctors to engage with their patients' feelings, they need to be aware of their own feelings (Kerasidou & Horn, 2016). This study highlights common themes of needing support and additional training, but also further highlights the unacknowledged difficult nature of the work these medical doctors do, and often the shame they feel for not being good enough and thus unable to do more.

So to return to the quote from the medical doctorwho told me that in 'this community' a stillbirth is equivalent 'to us taking a crap'. Why would a nice person say that? Because the work is unbearable for him so he dehumanised the foetus and turned it into 'crap'.

For healthcare professionals to deal with stillbirth is emotionally challenging anywhere in the world. In the South African context, there is the added burden of trying to right the wrongs of a brutal and divided society. Metaphorically, perhaps, these medical personnel are dealing not only with the literal stillbirths they see, but also, to a degree, with the stillbirth of the hope that, twenty- five years after becoming a democracy, South Africa would be significantly progressed in terms of becoming a unified and caring society. This is of course our own interpretation of what we have observed. Nevertheless, there is a great irony, of course, in the fact that we see in the data here the re-enactment of

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dehumanising discourses by the very people who are working very hard to restore humanity in a fractured society. It would be easy simply to condemn these dehumanising, detaching and discriminatory statements and practices. To do so, we believe, would be defensive in itself – for change to occur, we need to understand the complex personal and political roots of what health practitioners do to survive under very difficult circumstances.

#### **Disclosure statement**

No potential conflict of interest was reported by the authors.

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# **CHAPTER SEVEN: ARTICLE 3**

"I don't want to see that the people are suffering." Nurses in an impoverished community talk about caring for women who had stillbirths.

# **Introducing Article 3**

Article 2 listened to the voices of the medical doctors, whereas this article explores the way that nurses working in an environment full of trauma understand and speak about their work caring for mothers who have stillbirths. The primary data source was interviews with nurses regarding their practices with women who have stillbirths.

Reflecting on the findings from these interviews, I believe that the nurses' talk followed an overarching narrative that connected their cultural identity and personal suffering to the care that they administer. These connections between identity and job perpetuate a broken healthcare system where the nurse often gives not only out of duty and selflessness, but also out of brokenness. While the nurses' role is seen as a support to the doctors, in the case of stillbirths, they are far more central and often underequipped for the role as grieving partner. They need to be seen and adequately supported.

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# 'I DON'T WANT TO SEE THAT THE PEOPLE ARE SUFFERING': NURSES IN AN IMPOVERISHED COMMUNITY TALK ABOUT CARING FOR WOMEN FOLLOWING STILLBIRTHS

MAURA LAPPEMAN <sup>D</sup> and LESLIE SWARTZ

This article explores the way in which nurses working in a high-risk and dangerous environment understand and speak about their work caring for mothers following stillbirths. As far as we are aware, it is the first study of its kind from a low- or middle-income country, and the first on this topic to apply the theoretical insights of Menzies Lyth in such contexts. In order to obtain rich exploratory data, a qualitative research methodology was used. The primary data source was interviews with nurses about their practices with women who have stillbirths. Reflecting on the findings from these interviews, we believe that the nurses' disclosures followed an overarching narrative that connected their cultural identity and personal suffering to the care that they administer. These connections between identity and profession perpetuate a healthcare system where the nurse often gives, not only out of duty and selflessness, but also out of her own sense of vulnerability. As hospitals in low-income countries seek to improve their capacity to heal and support those in need of medical attention, nurses should be a focus of research. While their role is generally seen as a support to the doctors, in the case of stillbirths, they are far more central and often ill-equipped for their role as grieving partner. Nurses need to be acknowledged and adequately supported.

# *KEYWORDS:* NURSES, UNCONSCIOUS DYNAMICS, PSYCHO-SOCIAL RESEARCH, SOUTH AFRICA, TRAUMA, STILLBIRTHS

#### INTRODUCTION

Nurses are crucial in a hospital. It may even be argued that a hospital would cease to exist without the nurses who look after the patients continually throughout the day and night. The need for another, as is the case with early attachment with the caregiver, is essential for health. Nurses have been at the forefront of health research for many decades, partly because they are the healthcare profession with the most contact with patients (Aiyegbusi & Kelly, 2015; Byrne, Morton & Salmon,

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2001; Lopes & Cutcliffe, 2018; Menzies, 1960; Van der Walt & Swartz, 1999; Winship, 1995). In addition, nurses, like other healthcare practitioners, reflect and reinforce social, cultural, and ethnic divisions in society as a whole (Kruger & Schoombee, 2010; Steege *et al.*, 2018; Walker & Gilson, 2004).

Isabel Menzies Lyth (1960) is known for initiating the tradition of researching modern healthcare organizational dynamics (focusing particularly on nurses) from a psychodynamic perspective, establishing a strong tradition in research, which continues in the work of Hinshelwood and Skogstad (2000), Obholzer and Zagier Roberts (1994), and Kruger and Schoombe (2010). Menzies Lyth (1960) was interested in how nurses coped with a working life that was often repetitive, distasteful, and at times frightening. She addressed how nurses in the United Kingdom defended themselves in overwhelming situations by employing beliefs, values, attitudes and practices that unconsciously relieve anxiety (Hinshelwood & Skogstad, 2000; Menzies, 1960; Van der Walt & Swartz, 1999). Sources of distress for nurses have been acknowledged to include the witnessing of patients' pain and the nurses' own inability to stop the pain and distress (Byrne, Morton & Salmon, 2001; Wentzel & Brysiewicz, 2014). Emotional challenges have been seen to increase when the nurse identifies strongly with the patient or when nurses fear their own mortality or vulnerability (Byrne, Morton & Salmon, 2001). Nurses working in high risk and dangerous environments have been observed to think and behave defensively. Specifically, nurses have been observed to minimize their contact with patients' pain, resulting in them distancing themselves from their patients, and in the ritualizing of patient care (Frenkel, 2002; Winship, 1995). In addition, there is often little personal appreciation (contrary to that often received by doctors) or reciprocity, and although rewarding at times, there is a cost to caring for the nurses (Hutti et al., 2016).

This study forms part of a larger qualitative research project that explores the complex social processes and dynamics in a South African hospital labour ward. The study is aimed at developing a psychological understanding of the social forces that underpin practices in such a hospital setting (Bantjes & Swartz, 2017; Gobo, 2008; Smith, 2005). Other parts of the study which will be reported on elsewhere include observations of the milieu of the labour ward, interactions with the medical doctors and the patients, and understanding obstetric violence in the current context. The objective of this paper is to explore how the nurses feel and talk about their work in the labour ward, specifically as it relates to stillbirths. We are interested in 'the social and personal realities that are constructed through talk and how these constructions shift and change temporally and contextually' (Saville Young & Frosh, 2018, p. 200).

# STILLBIRTHS AND NURSES: A SITUATION OF HEIGHTENED ANXIETY

The day of birth is the most dangerous time for the mother and baby. In 2015 there were 2.6 million stillbirths globally, with more than 7178 deaths a day (World Health Organization, 2017). According to the World Health Organization (2017),

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the recommended definition of a stillbirth is a baby born with no signs of life at or after 28 weeks of gestation. A stillbirth can cause an intense grief response which at times can be greater than when a parent or spouse dies (Neria & Litz, 2004; Raphael-Leff, 2015; Wing *et al.*, 2001). A stillbirth may affect a woman emotionally, psychologically, cognitively, socially, spiritually and physiologically (Cacciatore, 2013; Sutan *et al.*, 2010). Importantly, research shows that how a parent responds to such a death can be influenced by how the healthcare providers treat them (Cacciatore, 2013; Kahn, 2004; Nuzum, Meaney & O'Donoghue, 2014). Some parents reported remembering how they were treated and what was said to them during their hospital stay at the time of the stillbirth six years later (Wright, 2011). Meaningful relationships with the hospital staff, therefore, can help facilitate healing for the patients (Kahn, 2005; Lambert *et al.*, 2018).

There has been much research on stillbirths and grieving parents in countries in the global North (Cacciatore, 2013; Neria & Litz, 2004; Nuzum, Meaney & O'Donoghue, 2014; Raphael-Leff, 2015; Wing et al., 2001). These studies indicate that stillbirth is commonly a hidden loss which is therefore difficult to process, and that this may pose difficulties for both parents and staff. Research of this kind in South Africa, and other low- and middle-income countries, is only slowly gaining traction (Chadwick, Cooper & Harries, 2014; Gausia et al., 2011; Osman et al., 2017). In particular, research on nurses (and the surrounding systems) who look after grieving mothers in low-income contexts is scarce. One recent South African study found that nurses working with perinatal loss in a rural community coped with the stress by accepting the loss as unalterable, binge *eating* and substance use and then by using a 'spiritual coping strategy' (Ntuli et al., 2018, p. 5). Besides this study, there was limited research on this topic. It may be hypothesized that in this context both nurses and patients may be traumatized by the stillbirth; in our context, whatever emotions are experienced are also layered on to a very difficult social context of deprivation and violence (Frenkel, Swartz & Bantjes, 2018; Van der Walt & Swartz, 1999).

Our study was conducted in a hospital located in an impoverished and violent area of the Western Cape Province in South Africa (Barolsky, 2016; Lappeman et al., 2017; Swartz & Colvin, 2015). Low-income communities in countries like South Africa are often affected by high rates of violence, trauma and criminal activities (Swartz & Colvin, 2015). These communities are often marginalized, particularly in terms of accessing resources (Bellas et al., 2019; Swartz & Colvin, 2015). The first author (for whom we will use the pronoun 'I' in the rest of this article, as she conducted the fieldwork) works as a clinical psychologist at this hospital and became concerned at the lack of counselling or support provided to women who had stillbirths. I also noted that the women with stillbirths were often left to deliver the baby with a nurse and then left exclusively in the management of the nurses. This phenomenon would not happen in private hospitals which cater for wealthier families, and I started to question how nurses working in the labour ward feel about the experiences of women who have stillbirths. The issue of my own positioning in relation to this research is discussed in detail in a forthcoming chapter (Lappeman, in press); part of the impetus for this research, however, is my own emotional

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struggle to provide what I believe to be appropriate care in a context of great need and deprivation. Indeed, the research itself formed part of my attempt to create some distance from my work in order to think about it and to sustain my involvement under difficult circumstances.

#### METHODOLOGY

To gain a deeper and richer understanding of individual and group dynamics in the hospital, the Free Association Narrative Interview Method (FANI), developed by Hollway and Jefferson (2013), was used. This psychosocial method is an approach to qualitative research and data analysis which takes into account the broader socio-political and organizational issues, as well as personal experience, which are intrinsically linked. In this interconnected group, the perception of reality is impressed by one on another without conscious awareness (Stamenova & Hinshelwood, 2018). The FANI method focuses on defences that the defended subject is not consciously aware of and keeps in mind the whole dataset for a specific interviewee when interpreting part of it (Hollway & Jefferson, 2013).

Studying the unconscious is difficult as, implicit in its definition, the unconscious is unknown. As a clinical psychologist I have been trained in psychodynamic methods,<sup>1</sup> and I have also received research training which takes account of psychoanalytic-based research approaches. I have brought these trainings to bear in the analysis of data in the FANI approach (Harvey, 2017). The FANI method does not regard the collection of research data as equivalent to psychotherapy, and a psychotherapeutic technique beyond generic interviewing skills for data collection. The FANI method relies on facilitation of a safe space where the interviewee can tell their narrative freely and the interpretation of data is psychoanalytically informed and conceptually separate from data collection.

By asking the nurse to say whatever comes to mind, the interviewer is eliciting a narrative that is not structured according to conscious logic, but according to unconscious logic (Hollway & Jefferson, 2013). Hollway and Jefferson (2013) postulated that most people like telling their story (even the difficult stories) in a setting that feels safe and within which a trust has been built with the interviewer. I have seen this too in my clinical work where patients are reluctant to speak, as they may not understand what a psychologist is, but if given space where they feel heard, they will disclose horrific narratives of their lives.

With the FANI method, recording feelings, emotions, transference and countertransference of the researcher is crucial as data are co-constructed with both the interviewer and interviewee. Every researcher enters a field with past experience and/or some pre-existing ideas which must be noted (Silverman, 2013). Having worked in this community for almost six years, it was crucial to have ongoing supervision to reflect on my biases and prejudices. I needed to have the ability of being a container (from Bion's notion of containment) for difficult emotions to be expressed by the nurses as this allowed for rapport to be built so the nurses felt free to express as the pain was shared. Transference and countertransference did affect

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the research relationship and was reported on in my supervision and journals (Hollway & Jefferson, 2013).

Qualitative research in general has commonly been criticized regarding questions of validity, and there have been a range of methods used to address these questions (see, for example, Creswell & Miller, 2000). In this study, we were strongly influenced by Hollway *et al.*'s (2015) approach to this issue; we used supervision and insights from the first author's own personal psychotherapy to interrogate the claims we made. It is central to the method we used that we do not claim neutrality in the data: the data were produced in the context of an attentive research relationship and further interpreted through the lens of supervision.

The nurse was seen within the surrounding social discourses as well as motivated by unconscious investments and defences against anxiety (Hollway & Jefferson, 2013; Saville Young & Berry, 2016). 'Unconscious dynamics are crucial in determining a person's relation to external reality' (Hollway & Jefferson, 2013, p. 98). Data are obtained by free association interviews and data analysis depends on psychoanalytic interpretation. Interpretations were not made during the interviews. This is unlike therapy where interpretations are made in the session. Interpretive work comes later.

#### **Participants**

Once ethical clearance from the Research Ethics Committee at Stellenbosch University (REC-2018-1844) and the Western Cape Department of Health (WC 201801 033) was received, a purposive sample of seven professional nurses (PNs) was invited to participate in the study. Participation in the study was voluntary. Inclusion criteria were that nurses needed to have worked in the labour ward for at least four months and have cared for at least one stillborn birth. An explanation sheet of the research was put up in the ward. All the nurses were Black female members of the community where the hospital was situated. Please see Table 1 for participant details.

#### Data Collection, Management and Analysis

The FANI technique of interviewing is an open-ended questioning style which allows for the interviewee's ideas, views and story to emerge as much as possible in their own words. The interviewer, when analysing the data, can then look for any inconsistencies and contradictions, as well as paying close attention to the emotions, thoughts and motivations of the interviewee, and also taking into account unconscious dynamics and processes. The interviews were recorded with permission and transcribed verbatim. All the nurses are known to the first author as they are colleagues in the hospital. Informal individual interviews were conducted a week prior to the formal interviews when the nurses could ask questions and decide whether or not to participate. After each interview, I did allow for each nurse to debrief, as suggested by others (Harvey, 2017). This debriefing allowed the nurses the opportunity to speak about any unprocessed emotions that were aroused.

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Name	Age	Marital status	Children	Years as PN
Sister A	53	Married	3	6
Sister B	33	Married	2	1
Sister C	32	Single	2	3
Sister D	29	Single	1	5
Sister E	35	Single	1	10
Sister F	47	Married	1	5
Sister G	37	Married	3	7

Table 1: Participant details

PN: professional nurse.

The interview process was then followed by a detailed analysis of the experience as a whole, including the relationship between the interviewer and interviewee, the emotions involved, journal notes of reflections about each interview, examining the words in the transcript, and a careful consideration of the narrative construction. The analysis followed a thematic approach, which is known to be an effective way to analyse data collected through the FANI method (Capri & Buckle, 2015). Themes were coded and are presented next. Within the FANI method, overarching themes are sought, and we took care to make sure that all talk from the nurses was covered by the themes. For reasons of space, only selected results are presented.

#### FINDINGS

From the analysis, three core themes emerged that spoke directly to the objective of the study. Specifically, the exploration of how the nurses feel and talk about stillbirths in the labour ward centred on cultural identification, overcoming their own trauma and removing pain and suffering. Each of these themes is described below.

#### Culture as Central to the Nurses' Experience of Their Work

The nurses identified strongly with the patients. Unlike many of the doctors in the labour ward, who come from outside this impoverished community, the nurses had a stronger cultural identification with the grieving mothers, as heard in their explanations. It became apparent that in this particular community cultural, spousal and family support during labour was not seen as appropriate:

According to our culture the people don't like to be here when a woman is giving birth (Sr B).

You know, some of them, culturally, we as Black people, it's few of them that would want someone to be with them when they are in labour (Sr E).

The theme was supported by the observation that the hospital labour ward was often quiet and devoid of the bustle of family visits and supporting spouses. In describing

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the apparent lack of partner support, the nurses appeared to understand that they would mostly be alone to support the grieving women. Their accounts also made it clear that their work is influenced by their role as a member of the community. There were multiple times when the nurses referred to themselves and the community as a collective:

In our culture we are not used to these things of having a man next to you when you are giving birth (Sr A).

We as Black people are not used to that. We don't feel comfortable when your boyfriend is here or your husband is here (Sr F).

In the Xhosa society in which the labour ward is situated, tasks that involve caring tend to be seen very much as related to female gender (Swartz & Colvin, 2015), and the women are often left to raise children alone and to look after the elderly and sick. Looking after their patients appears to speak more to their femininity as Xhosa women than to their role as a nurse. The nurses are well aware that, culturally, they are left alone to care for these women:

I just go as a person and see what you need and try to help you as a person (Sr D).

None of the nurses questioned their central, and gendered, role in relation to caring for their patients – they seemed to view the cultural prescriptions as a given and unproblematic. As something of an outsider, I did question whether this apparent acceptance of a culturally prescribed and highly gendered role brought with it an emotional toll and even, possibly, an unconscious resentment at what felt to me like a considerable emotional burden to care not only for the women themselves but also for the maintenance of a social order under threat. In keeping with my chosen methods, though, I am not able to vouch for the veracity of this interpretation as it may represent my own reactions rather than those of the participants. While the nurses' cultural embeddedness and collectivistic outlook is clear, however, they also shared their personal struggles through the interviews.

#### Overcoming Their Own Trauma

The seven nurses appeared to present an accurate reflection of their own traumatized community as each one's story was full of suffering, distress and overcoming adversity. None of the nurses went straight from high school to study nursing. Six out of the seven nurses actually had to wait several years (and for some, decades) to get financial assistance before they could study. One nurse spoke about how she never wanted to be a nurse, but it was the only course to give her a bursary to study. They did other jobs whilst they saved to study, such as being a security guard, a domestic worker and a factory worker. The nurses spoke openly of their trauma. One, for example, shared her own experience of being raped:

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...on the way to church that boyfriend grabbed me on the way and then went to sleep with me (anonymized).

Others spoke of their own stillbirths, miscarriages, death of a child at five months, infertility, domestic violence, poor attachment history and failures. They are all familiar with suffering and this pain was interwoven with their stories of the pain of the grieving mothers in the ward. Interestingly enough, none of the nurses spoke of stillbirth as separate from or qualitatively different from other difficulties and struggles – they mentioned stillbirth along with a host of other contextual challenges. There was no question in my mind that by any standards these were women subjected to considerable emotional and physical trauma, and I wondered whether the ubiquity of the trauma, though in some ways possibly making the pain easier to bear because it was shared, also disallowed a conscious recognition of what this might mean personally for the nurses.

# The Nurses See Care as Removing Pain or Suffering

During the research, the interviewed nurses appeared to operate out of a deep sense of care for the patients who had lost their babies. Their own pain and difficulties seem to have guided the way they see others in pain. The results showed a sense of desire to remove suffering, as expressed in the following quotes:

I love caring for other people. I love people also. So I don't want to see someone sick, crying with pain, I don't like that (Sr F).

I don't want to see that the people are suffering (Sr B).

She cried. I cried that morning. We don't cry normally, but we cried. But we talked to her. We spoke to her, like we made her to know that it was not her fault (Sr C).

There are times when patients may be so emotional ... I mean, you support them and eventually they become okay and they smile. So for me specifically, it's wonderful. If they can smile, then it's wonderful (Sr D).

Some of the nurses also showed empathy as they internalized the pain of the grieving mothers:

You know, and you really put yourself in the patient's shoes, like if this could happen to me (Sr C).

When it comes to stillborns, even if you are not friendly, you will feel that as a parent and you will feel the need. And if you never went through what they are going through that time, you have to feel that emotion (Sr E).

Other nurses showed a care rooted in the fact that available support may sometimes be missing from other sources (like doctors and family):

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I don't have a problem to care for them, honestly, because someone needs to care for them. They must be cared for and they need all the support (Sr G).

Here again we see the burden of care, but also possibly the unbearability of the extent of vulnerability and pain this community, the community which is not only that of their patients, but that of the nurses themselves.

#### DISCUSSION

Listening and digesting the narratives of the nurses, our thoughts were that the nurses' narratives connected their cultural identity and personal suffering to the care that they administer. The nurses with whom we spoke did not seem to be cut off from patients in the way described by Menzies Lyth and others, but their contact with patients was nevertheless defensive to a degree in the sense that they did not wish to acknowledge pain. This may relate to issues of culture.

Being embedded in the same culture as the mourning mothers was seen by the nurses as an advantage and a reality. In particular, the nurses all showed a belief in the call to care as a woman as part of a very collectivist Xhosa worldview in which they are rooted (Venter, 2012). African culture is often constructed as placing a great emphasis on caring for others as opposed to pursuing purely individualistic motives (Masina, 2000). The word 'Ubuntu' is derived from Nguni languages (isiZulu and isiXhosa, the home language of the nurses and patients) that translates to mean 'a person is a person because of or through others' (Tutu, 2004, pp. 25–6, cited in Nurse Hero, 2019). Ubuntu has been described as the capacity in an African culture to express compassion, reciprocity, dignity, humanity and mutuality in the interests of building and maintaining communities with justice and mutual caring (Swartz & Colvin, 2015). While the positives of collectivist cultures are clear, the challenge for these nurses is that they take on an additional burden from the absence of partners during the trauma. Instead of blaming the men for not being supportive, they chose to internalize the role of carer.

This additional burden on the nurses is not shared by other health professionals in the hospital. All the higher paid healthcare professionals, such as doctors, psychologists, and physiotherapists, live outside of the community in which the patients live (as observed in the larger study). They may experience the respite of having more distance from the patients and their traumatic experiences than do the nurses. Unlike the nurses, they are not, as Van der Walt (2002) put it, 'too close for comfort'. The challenges the nurses face mirror and are intertwined with those of the patients, as discussed by Van der Walt and Swartz (1999) in relation to nursing in the public health system more generally in South Africa.

Issues of identification with patients and lack of distance from them related not only to cultural identity issues, as we have discussed, but also to the nurses' own histories and ongoing exposure to trauma and violence outside the hospital. While every healthcare practitioner has their own life hardships (Tillett, 2003), these nurses live and work in the context of ubiquitous trauma. The nurse who was raped had to deal with being pregnant without counselling or the support of someone thinking

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about what she was going through. She reported that her boyfriend had raped her so it was not seen as rape within the local community. She received no apparent support from family, nor counselling, but had a growing child in her womb as evidence of what her boyfriend had done. Her social system served only to prevent the idea of her rape from surfacing into social consciousness to avoid repercussions (Long, 2018). We wondered if caring for these hurting mothers would conjure up their own primitive fears of death combined with unconscious hostility and unconscious envy for not being cared for in their own trauma (Gerard, 2019). At a conscious level, the nurses believe in their ability to continue to help and give in an empathetic way. The nurses do not appear cut off or burnt out, but they do express a feeling that they want to avoid pain.

The connection between the nurses' cultural duty and their personal pain expressed itself in their approach to helping the grieving mothers. While grief therapy acknowledges the need for pain to run its unique course (Worden, 2018), these nurses appeared to be ill-equipped and arguably unable to provide such an environment. As they recounted their own stories and described their approach to care, it seemed that they might be approaching their patients in the same manner as they had been treated. The nurse who had a stillbirth of her own told me that immediately after she delivered, the attending nurses took the baby away and she packed her bags and left the hospital. No thoughtful interactions, no being asked if she wanted to see her baby or being asked how she felt. When asked in the interview if she required counselling now, she responded, 'Will it really help?' Her unprocessed hurts were tangible in the room during the interview. Both she and the nurse who had been raped did not appear saddened by telling their stories, but a deep sadness still filled the interview room. Thinking through each nurse's narrative, it is difficult to expect them to have the capacity to give more to the patients than they are doing now. No one helped these nurses to process their losses, so how can we expect them to help process loss with another? They have not experienced the transformative power of having an other see their suffering.

The question of the nurses' closeness to their patients, both in terms of coming from the same community and in terms of how they described their relationship with their patients, is interesting to consider in terms of the history of nursing both in South Africa and further afield. In her classic study of the history of nursing in South Africa, Marks (1994) notes that in the context of a highly racialized society, African nurses (as opposed to White nurses) were seen as close to patients, and bridging the (politically constructed) gulf between the world of 'White' biomedicine and that of Black patients. The global process of the professionalization of nursing (Yam, 2004), some have argued, has been accompanied by an increase in the sense of distance between nurses and patients, something which Menzies Lyth discusses. For our nurses, the power of a local trope of identification with patients, both through the discourse of Ubuntu and through their constructed sameness with their patients as Black women in a society which remains deeply racist in many respects (Erasmus, 2017), may have placed burdens on them to care which nurses in other contexts may not face to the same degree.

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All the nurses said that they did not like to see people sick or in pain. While one might expect that these nurses had become less affected by pain and suffering after long exposure to living and working in a trauma ridden community, they were not. It was clear that the nurses had the best of intentions, but in their talk was a repetitive story line of: 'I do not want to see pain and I do not want to see suffering'. At an unconscious level, we wonder if the nurses may be split off from their own personal trauma and therefore want to avoid the patients' trauma, as connecting with patients' trauma could possibly trigger their own pain. While this issue may have been partly an issue related to personal trauma, there may also be a more conscious reason for this stance. It appears to us that the nurses understand their work partly as cheering people up – helping people, in this view, amounts to helping people avoid rather than confront their pain. It is well established in psychoanalytic theory that humour (or cheerfulness) may be used defensively, for example, as a substitute for rage or helplessness (Baker, 1993). We believe these nurses truly care for the patients but we were left wondering whether, with the best intentions, they were able to hold patients and their pain in mind and to give the mothers a safe space to explore the loss. Culturally they identify strongly with the patients, and may feel obligated to help them get back to their premorbid functioning by making them feel better in the short term. This approach may further perpetuate the challenges embedded in the facilitation of healthy grieving from mothers of stillborn babies.

An important question which our study cannot adequately answer is that of how the socio-political context of the study itself may have influenced the data. The first author is a White South African professional working with these Black South African nurses. We do not know how the nurses may have spoken with a Black researcher, and whether, or to what extent, the fact of the racial, professional, and privilege differences between researcher and researched may have affected the data in some way. Because the first author worked in the same setting as the nurses she was not a complete outsider, but this insider status may also have influenced the findings in some ways. It would be interesting to see research like this conducted in the future by researchers who are differently positioned.

## CONCLUSION

The narrative that underpinned the interviews followed a pattern that requires further exploration. This pattern started with the assertion that, according to the nurses' culture, labour ward patients do not have or want support from their families, so this function falls on them. These nurses, however, are from the community themselves. While they feel that it is their identity and desire to care, they are affected by the same violent and unsafe community faced by the women for whom they care. This may make them empathetic in some ways, but it equally may disable them from meeting the needs of the grieving mothers. To some degree, it may be that the nurses' desire not to see suffering, in their attempt to cheer patients up, may relate to an anxiety on the part of the nurses that they may not be able to hold or bear the women's pain. Despite the inherent difficulties, these nurses have deep concern for

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the patients and try to provide excellent medical care to the mothers who have stillbirths.

When we examine this pattern in relation to the contribution of Menzies Lyth, we see many similarities in that it is clear that the nurses are finding ways to manage the overwhelming anxiety of their work. This is consistent with other studies we have done on anxiety in work spaces in South Africa (see, for example, Van der Walt & Swartz, 1999; Evans & Swartz, 2000; Gibson & Swartz, 2000). But what seems distinctive about our findings in comparison to both those of Menzies Lyth and our own earlier work is the prominence of cheerfulness and cheering up as a key feature of how nurses talk about their work. This may be partly artefactual, as the issue of nurses cheering patients up and being jolly is of course well established, and goes back at least as far as Nightingale's prescriptions for appropriate nurse behaviour (Helmstader, 2019). For this reason, cheerfulness may not be remarked on or noticed in some contexts. But it may also be the case that the degree of unbearability of their patients' lives (and not just of the experience of stillbirth), and the degree of their identification with these lives, may lead to cheering up as a means not only of soothing the other, but also of the self.

It is interesting to note that the nurses did not discuss stillbirth separately from the many other challenges that they and their patients face. In this respect, our study differs from studies conducted in the global North which commonly see stillbirth as qualitatively different from other experiences surrounding obstetric care. In our study, stillbirth formed part of a pattern of ongoing loss and bereavement in a society in which such issues are all too common. In this respect, our findings can be related to the findings of Scheper-Hughes (1993) in Brazil. Scheper-Hughes (1993) notes that in a context within which there is very high infant mortality, the experience of infant death is not marked in the same way as it is in contexts of lower infant mortality rates. Scheper-Hughes aptly entitles her book Death Without Weeping and the subtitle of her book refers to 'the violence of everyday life' - something which the nurses we spoke with experience as well. Building to some extent on the work of Scheper-Hughes, the South African anthropologist Ross (2010) refers to what she terms 'raw life' in a South African community not dissimilar to the one in which we conducted this study. Here, Ross (2010) is clearly drawing on Agamben's (1998) concept of 'bare life'. What is remarkable in our study may not be the extent to which the nurses themselves seemed unable to fully take on the pain of their patients (this is to be expected), but the degree to which they showed their willingness under extremely difficult circumstance to continue to do their best for their patients. None of the nurses interviewed had their own therapy or counselling for their own difficulties, but none seemed to be able not to think about the patients and their welfare.

Looking ahead, a number of interventions could bring much help to the grieving mothers through the care they receive from nurses. First, helping the nurses to understand that helping people is more than cheering them up. While the discomfort regarding pain is evident, helping the nurses to sometimes stay with the difficulties of the patients will have long-term benefits to the holistic grieving process. Second,

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and more fundamentally, perhaps, in order to help facilitate a better grieving environment (especially in the absence of family and partners), we think that the nurses themselves may need someone to sit with them in their own trauma and help them to process it. Third, the fact that both cultural and trauma identification is so strong with the nurses (in comparison to the doctors who often come from outside of the community), they would be well served to be better acknowledged for their role as caregiver in the hospital setting. The role of a hurting member of a traumatized community who surrogates for absent family members and also overworked doctors is unenviable. Simple acknowledgement can go a long way to promoting strength in adversity among the members of the nursing team. Finally, in the absence of sufficient resources, elementary training in grief counselling would also allow the nurses to help each other through some of the feelings associated with their role during stillbirths in the ward.

As hospitals in low-income contexts seek to improve their capacity to heal and support those in need of medical attention, nurses should be central. While their role is seen as a support to the doctors, in the case of stillbirths, but in other roles as well, they are far more central and often underequipped for the role as grieving partner. Proper care for patients may be contingent on proper care for nurses.

#### NOTE

1. The first author was trained as a clinical psychologist at the University of Cape Town, which has a long tradition of psychoanalytically informed practice and research; see, for example, Swartz, Gibson and Gelman (2002); Watermeyer (2012); Swartz (2018).

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# CHAPTER EIGHT: ARTICLE 4 Stillbirth in Khayelitsha Hospital, South Africa: Women's experiences of care

# **Introducing Article 4**

The two previous articles listened to the voices of the healthcare practitioners. This study focusses primarily on the practitioners, but in order to address this issue fully, I believed that we also needed to hear the voice of the grieving mothers and how they experienced care at the hospital. The primary data source was interviews with the mothers. In summary, none of the mothers I interviewed viewed the medical staff as negligent or uncaring, and this correlated with the findings from the larger study. However, the mothers wanted more emotional engagement from the staff.

Without due attention to the emotional needs of the staff, who seem to be trying their best, it is unlikely that the staff will be able to provide fully accessible emotional care for patients. The stories told to me by the mothers may suggest that more expenditure on the emotional needs of caregivers in the health system, may contribute to a more emotionally accessible, sustainable workforce. This is something which needs to be researched and evaluated in our context, and other poorly resourced health care contexts.

Article 4 has been submitted to the BMC Women's Health.Submitted:7 November 2019Resubmitted with corrections:15 April 2020

# Stillbirth in Khayelitsha Hospital, South Africa: Women's experiences of care

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## Stillbirth in Khayelitsha Hospital, South Africa: Women's experiences of care

#### Abstract

#### Background

In this study we explore the hospital care experience of women who experience stillborn babies in an impoverished urban setting in the Western Cape Province of South Africa. This research was part of a larger study exploring how healthcare providers at Khayelitsha Hospital (KH) feel about and manage stillbirths. In order to get a holistic picture, we felt the need to hear the voice of the grieving woman and to hear her experience of care at the hospital.

#### Methods

In order to obtain rich exploratory data, a qualitative research methodology was used by collecting primary data using the Free Association Narrative Interview Method with 10 women who experienced stillbirths at Khayelitsha Hospital.

#### Results

The study found that the women were well looked after from a medical point of view but they wanted more emotional engagement by the staff.

## Conclusions

This study explored the experiences of women whose pregnancies had resulted in stillbirth. We explored their experiences as consumers of the healthcare system in relation to the care that they received in hospital. The findings indicated that the women did not express a need for more medical interventions, but a need to be seen by the medical staff. Without due attention to the emotional needs of the staff, who seem to be trying their best, it is unlikely that the staff

will be able to provide fully accessible emotional care for the women. The stories told to us by our participants may suggest that more expenditure on the emotional needs of caregivers in the health system may contribute to a more emotionally accessible, sustainable workforce. This is something which requires further research and evaluation in our context, and in other poorly resourced healthcare contexts.

# Keywords

Stillbirths, South Africa, Hospital Care,

#### Background

Stillbirth is a difficult and usually traumatic pregnancy outcome (1). Nearly three million stillbirths occur worldwide each year, with 98% occurring in low-income and middle-income countries (2). While South Africa boasts a very sophisticated private healthcare system (3), most infant mortalities happen in government institutions that cater for the mass population that cannot afford private healthcare. South Africa is a middle-income country with approximately 58, 75 million people (4). Most of the country falls close to or below global poverty lines with millions of people living in poor urban communities where hospitals like Khayelitsha Hospital (KH) provide treatment and services (5–7). Not only does this healthcare system have to deal with poverty, but also with an extremely high incidence of violence, as the community is one of the most violent in the world (8).

Since 1994, South Africa has struggled to overcome the legacy of apartheid and the challenge of transforming institutions and promoting equity in development (6,9,10). South Africa is one of the most unequal countries in the world (11) and the inequality is particularly evident in the national healthcare system. The health system inherited by the post-apartheid government was

structurally fragmented, centralized, biased toward curative services and inequitably distributed (12,13). Despite significant changes in policy, structure and service provision, there remain significant health challenges for the country and its health services whose goal is to ensure a long and healthy life for all South Africans (14).

The Department of Health (DoH) is required to provide a healthcare system that is structured and uniform for all South Africans (14). This mandate comes from the National Health Care Act of 2003 and is in line with The Bill of Rights (Section 27) which states that access to healthcare is a basic human right. A survey done in 2017 reported that 70% of households in South Africa used public health facilities (14).

## Holding the healthcare system accountable

Healthcare providers in poorly resourced and socially excluded communities (or previously poorly resourced and socially excluded communities) have been found to treat consumers of the healthcare system poorly (15–18). In some cases, healthcare providers do not consider it their responsibility to listen carefully to consumer preferences, to facilitate access to care, to offer detailed information, or to treat patients with respect (15). This lack of provider accountability may have adverse effects on the quality of healthcare, and ultimately on health outcomes (15). Evidence shows that to enhance accountability, two factors are important. The first factor is offering consumers more information about what they should expect from the healthcare system, and the second is establishing community groups that empower consumers to take action and include non-governmental organizations in efforts to expand access to care (15). However, despite these factors increasing accountability, paradoxically, increased accountability may lead healthcare providers to be less emotionally available to those they serve.

Gilson (19) suggests that "Health systems are inherently relational and so many of the most critical challenges for health systems are relationship and behaviour problems". Healthcare systems can implement all the systems or procedures required but the relational dynamics within the system must be explored in order for systems to provide the best possible care. Healthcare systems need to take into account local, cultural and economic factors (20). Specifying a checklist of procedures which the healthcare provider must carry out medically does not necessarily equate to good healthcare. Healthcare consumers require respectful treatment and to be seen as individuals by their treating healthcare providers (21).

Healthcare providers may struggle to provide adequate care when they are emotionally overwhelmed by secondary traumatization (22–24). This need to protect the self may be exacerbated in healthcare systems which are very over-stretched and operate in violent social contexts, such as South Africa. It has also been established that certain kinds of contexts may be particularly anxiety provoking, such as obstetric care (25). In a labor ward, the death of a baby, instead of life, may be the most difficult outcome for healthcare providers to deal with. In addition to these issues, women whose pregnancies result in stillbirth may be stigmatized by healthcare workers and others, and this may have an impact on the experience of care received (26–28).

Shakespeare et al. (29) documented a qualitative meta-summary of parents' and healthcare professionals' experiences of care after stillbirth in low-middle-income countries. They found that there is a need for adequately equipped and developed health systems to provide care. They also found that women reported unfavorable experiences related to poor attitudes and communication from healthcare providers. The healthcare providers reported difficulties in

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providing care due to staff shortages, lack of training, and facilities without adequate equipment. To resolve these difficulties would require financial investment (29).

Other changes, such as use of any available analgesia and provision of respectful maternity care, require less material investment but could significantly change experience. (29)

These interventions need further exploration and must be understood in relation to the emotional consequences to the healthcare providers. Additional expectations could burden them and result in burn out, thus ultimately not improving care.

In South Africa, there has been increasing concern about the quality of care women are receiving in public maternal health facilities (30). A South African study (30) reported that relational aspects between the healthcare providers and patients are crucial to women's narratives of births – whether negative or positive. The importance of good engagement with the women after a stillbirth by healthcare providers has been confirmed by other studies elsewhere in the world (31–35).

In this study, we tried to understand the experiences of women whose pregnancies had resulted in stillbirth, as consumers of the healthcare system, in relation to the care that they received in hospital. This research was part of a larger study exploring how healthcare providers at KH feel about and manage stillbirths. This larger study also looked at the milieu of the labor ward and how each person in the ward – whether doctor, nurse, or woman added to the dynamic of the ward (36). While many studies have reported on the narratives of mothers who deliver stillbirths (31,37–42), this study addresses a gap in the literature by exploring the woman's voice after invisible loss (stillbirth) in relation to the healthcare system in an impoverished African context.

#### Khayelitsha Hospital

Khayelitsha Hospital (KH) is situated in Khayelitsha, the second biggest Black township in South Africa (43). This township was created in the 1980s as a racially segregated residential area in the south-eastern part of the City of Cape Town municipal area and has the highest incidence of poverty (44). Under Apartheid, Black South Africans were banished to the periphery of cities and forced to live in mostly temporary structures. The area was lit by large floodlights because electricity was not built into the area's infrastructure. The name in Xhosa, the local language spoken by 8,2 million people in South Africa, means 'new home'. Its population is estimated to be between 400,000 and 750,000 (45). Poverty is widespread, with most of the residents sharing communal water supplies and toilets (45). The extreme poverty, and poor community infrastructure, has led to surging crime rates, gangs, violence, drugs as well as other societal ills (8,44,46,47).

Primary level health services in South Africa are provided through local clinics and 24-hour community health centers. Hospitals provide higher-level services and are divided into district, regional, or tertiary/central hospitals (48). KH opened in 2012 in order to provide higher level healthcare services, as the Khayelitsha community had previously only had access to clinics. KH is a district hospital with 320 beds and facilities that include an emergency center, operating theatres, a <u>radiology</u> department and a laboratory. The hospital provides inpatient and outpatient services for surgical, medical, psychiatric, pediatric and obstetric patients (49). There is also a women's health unit which offers a variety of services, including termination of pregnancies. In the obstetric team, there are two full-time qualified obstetricians with many

years of experience. There are also four obstetric registrars rotating through the hospital as the hospital is linked to a tertiary education center. With regards to obstetrics, only women with high risk pregnancies are brought to the hospital to deliver, otherwise they would deliver at the community health clinic's maternity units. With this in mind, higher anxiety would be expected amongst the staff and the women than might be expected in a community clinic. In KH in 2018, approximately 72 women experienced stillbirths as recorded in hospital documents (of a total 4054 births).

## Methods

This study reports on the narrative of a sample of low-income African women living in Khayelitsha. Specifically, we explored their experiences of treatment at KH during and after experiencing a stillbirth at the hospital. The first author conducted interviews with the 10 women regarding how they felt about their treatment by the hospital staff after delivering a stillbirth. As the first author collected the data, we use the pronoun "I" to refer to her in the rest of this article.

We wanted to "go beyond more superficial descriptive accounts" (50) and access unconscious material present in the experiences related by the participants. Psychosocial studies draw on both sociology and psychoanalysis to understand the relationship between the individual's internal world and the social world. Hollway and Jefferson (51) proposed that interviewees are unconsciously defended, implying that the external world in which people live constrains the individual's unconscious motivations, instincts and impulses. The implication of this is that a defended subject, whether consciously or unconsciously, may not tell a complete and transparent story. An emotionally charged memory like a stillbirth may be too difficult to talk about because it produces anxiety thus threatening to break down emotional defenses. Keeping

this in mind, an awareness of these defenses and their underlying causes assists in facilitating a deeper understanding of how these women respond after a stillbirth.

The Free Association Narrative Interview Method (FANI) guidelines developed by Hollway and Jefferson (51) were utilized for the interviews and the analysis of the data in this study. We found this method especially appropriate for a topic as emotionally charged and anxietyprovoking as stillbirths. The FANI method addresses unconscious defenses and keeps in mind the whole data set for a given individual when interpreting part of it. In particular, the associations that led up to any part of the data are accounted for (51). Analysis of data within the FANI approach requires that the researcher has an understanding of, and experience in, psychoanalytic methods; I have such training and experience by virtue of my training as a clinical psychologist. It is important to note, though, that the FANI method does not regard the collection of research data as equivalent to psychotherapy, and psychotherapeutic techniques, beyond generic interviewing skills, are not used in data collection. The FANI method relies on facilitation of open-ended discussion and the interpretation of data is conceptually separate from data collection.

The interviews were conducted in the privacy of my office in the hospital and did not exceed an hour in duration. All the interviews were audio recorded with consent of the women. The interview questions were as open as possible which allowed for the mother's thoughts, feelings and story to emerge as much as possible in her own words. This in turn allowed me to look critically at any inconsistencies and contradictions. After each interview, I gave the women an opportunity to debrief, as suggested by Harvey (50). This debriefing allowed for the processing of any emotions that were aroused from the interview. After each interview with a mother, I wrote in my research journal. This journal included descriptions of my conscious internal dialogue (my thoughts, ruminations, anxieties, and emotions). It described my subjective and internal ruminations regarding the mother – as well as considerations of my own engagement with the data and procedures. It provided me with important supplementary data in terms of insights into my own processes. The journal informed and promoted the reflexivity which is acknowledged to be an important component of responsible qualitative research (52–54). I considered doing a second interview with the women as recommended by Hollway and Jefferson (51), but as the main focus of the larger study is on healthcare providers, I decided to keep to a limit of one interview as there was a remarkable consistency in responses from the women (55). The interviewing process was then followed by a detailed analysis of the experience as a whole, including the relationship between myself and the women, the emotions involved, journal notes of reflections about each interview, examining the words in the transcript, and a careful consideration of the narrative construction.

The analysis focused on the most relevant emerging themes as well as on a deepening understanding of what was happening around me consciously and unconsciously, as far as possible. Scripts and the journal were read and re-read and reflected upon.

#### The women who participated

Ten women who delivered a stillbirth at the hospital between January and August 2018 were interviewed about their experiences of care at the hospital. Convenience sampling was used and women were contacted telephonically. The exclusion criteria that we applied were as follows:

- Women younger than 18 years old.
- Women who purposefully drank medication or self-harmed to terminate the fetus.

- Women who abused substances during their pregnancies which might alter their emotional response to the stillbirth.
- Women who have family members working in the labor ward of KH.

A total of 58 women were contacted, of whom 18 women agreed to participate in the study, but only 10 women were ultimately interviewed. The other eight were followed up but said that they were no longer able to participate in the study. Some reasons given were work or family commitments. One woman rescheduled with me three times but failed to attend.

The community served by the hospital comprises primarily indigenous African, first language isiXhosa-speakers. All ten women interviewed were African women and their ages were between 18–29 years old. Only three were employed, one was a student and six were unemployed. Three of the women had an older child. Only three of the pregnancies were planned.

## **Ethical considerations**

Ethical clearance was obtained from the Research Ethics Committee at Stellenbosch University (REC-2018-1844) and the Western Cape Department of Health (WC 201801 033) before proceeding with the research and data collection.

Participation in the study was voluntary for the women who delivered stillbirths at the hospital. No payment was offered for participation. I did, however, provide refreshments and transportation costs, at my own cost. All participants needed to sign an informed consent form which clearly outlined the risks and benefits of participation. Confidentiality was assured by the use of pseudonyms. I explained to each participant that they were able to leave the study at any point and their story would not be included in the research. I reiterated that their withdrawal from this study would not affect the mother's care in the hospital in any way. No participant withdrew from the study. Contact information for all those involved in the study was also provided, including that of my supervisor and the details of the contact person at the Division for Research Development of Stellenbosch University, should they have any further questions.

A concern did exist about traumatizing women by evoking loss. An option of counselling from one of the two community clinical psychologists based at the hospital as a follow-up intervention was offered to the participants. Three of the women required follow-up sessions, not due to distress, but because they appeared to benefit from the one-on-one attention and being listened to as they explained their loss.

The data obtained from the transcripts were stored electronically on a password protected computer and the actual interview transcripts were kept in my office and were read exclusively by my supervisor and myself.

#### Results

#### The good and bad of the hospital experience

After speaking to the women, there was a clear divide between positive and negative sentiments related to their hospital experience. Each of these sentiments is discussed below.

#### Positive sentiments

Most of the women's narratives were ones of sadness, which would be expected by the death of a baby. The theme that dominated their narratives was that the women were all relatively positive about the medical care and service that they received in the hospital. Of the ten women, eight women said they would come back to the hospital for their next pregnancy. One of the women wanted to go to a specialist hospital (as she had a history of two previous miscarriages) and the other did not want any more children:

They are working just fine. I didn't have any complaints here. They treated me very well. (Pt H)

Everyone was very nice. (Pt I)

Only one mother reported that she was not called to receive the results from the investigations. The other women said the staff were forthcoming with the results and scheduled a six week follow- up appointment:

*They said they were going to call me to tell me what was wrong, but then they never did.* (Pt E)

All the women were allowed to have a birthing companion stay with them for the entire hospital stay. Throughout the narratives each woman expressed how their mother, sister, boyfriend or relative stayed with them the whole time. All were offered an appointment with a psychologist after the delivery. All had a visit from the psychologist but most declined a follow-up because they were no longer feeling distressed:

The psychologist I met, it was really good talking to her because when I left here I felt much better. (Pt A)

The women and birthing companions were given the option to see the baby and hold it if they wanted too. There was a feeling in the interviews that the staff had seen the baby as a person

and respected the women's wishes whether they wanted contact with the baby or not. The staff also took photographs for the women:

*The baby's father held the baby, but I was not ready at that time to hold the baby. I just saw it. (Pt B)* 

They took the baby and they wrapped it around and then they put it on the other bed, and then my boyfriend came and he saw the baby. (Pt A)

Another woman acknowledged that the staff were trying their best with the resources they had. She knew that it is emotionally difficult for any woman after a stillbirth to stay in a ward with other women who had delivered live births. It was difficult for everyone, including the staff:

I think they did the best they could do. But the fact that people who have lost children stay in the same ward as people who are giving birth, I mean, that's like torture on its own. I don't think that's fair on anyone. (Pt E)

However, despite having reported numerous positive experiences there was still the sense that these women felt unseen by the healthcare providers.

#### Negative sentiments

While none of the healthcare practitioners was experienced as being rude or aggressive, the women did experience a lack of engagement from medical staff, as referred to in these statements:

The nurses not giving me attention when I needed it the most. Because at that time I was in pain. I needed them to give me the needle so that I couldn't feel the pain and help me get through this. So they had that kind of attitude towards me. (Pt A)

The only nurse who came was the one who checked my blood pressure that was it. And then there was one doctor who came and he asked whether I wanted to have a loop (form of contraception) inserted. That was the only time someone came, and after that no one came. (Pt E)

The women also expressed that their emotional needs were not of high importance to the hospital staff:

You see, so with me, they didn't give me much attention because they knew that the baby was still small and they can't do anything to it, so let her just deliver by herself. So I thought that was the attitude they had against me...towards me. (Pt A)

The nurses just came in and went out. So it was just me and my mum when the baby came out. And then my mum just went outside to call their attention and they said, we're coming, it's fine. And then they came after the baby was already out, so they didn't even see...you know, when the baby is out you check the time, what time did the baby come out...they didn't even like do such things. (Pt A)

*I said that I wanted to see the baby. Yes, and I saw the baby and then they took it away. And then the other thing is, they didn't even like help me to get out the placenta.* (Pt A)

Sometimes you don't see the doctor or the nurse. You only see them when they come to take blood. They don't always visit. (Pt B)

The lack of noise in the ward (36) was also experienced by the women as seen in these statements:

That quiet room is not nice. It doesn't help because you sit there all day. Like there's no one. There's no noise. I like noise when I'm sick. (Pt D)

While there was a general sense that the staff were competent and were performing their duties adequately, some felt a difference in treatment between that given to them and to those delivering live births:

But maybe if I give birth to a normal baby, a live baby, then would have given me more attention. Because I've seen...I've heard from most of my friends who gave birth here, they didn't have a problem because they were helping out a baby that's alive. (Pt A)

Another woman (Pt J) told me she heard a nurse shout at a mother in labor. She said she heard the nurse saying that the patient knew how to fall pregnant so she must know how to give birth. None of the women who delivered stillbirths reported any similarly unkind words addressed to them.

Another observation was the sense that the women did not feel held in the healthcare practitioners' minds. One of the participants spoke of an openly humiliating experience where the staff were not shaming to her but shamed her in the corridors:

There were some nurses and I would hear them, not everyone, but maybe when they're walking past then they will talk about me loudly. One of them would ask what was wrong with me and the other one would tell her, no, she has lost her baby. And then the other one would ask, but why is she still here? No, because she had blood problems. She knew she had blood problems, but then she didn't come to the hospital earlier on.

Like how could I know that my blood problem was going to affect my baby? I'm not a doctor and I'm not a nurse, how would I know? So that did hurt me. I try not to think about it. (Pt E)

Both the positive and negative sentiments expressed by the participants eventually created a picture of their experience as both grieving women and as patients in an overburdened healthcare system.

## Discussion

This article explored the birth narratives of women who gave birth to stillborn babies in KH. For the study, the women were required to speak English. This is a limitation to my research as this method tends to favor urban born mothers who have had exposure to English, but in my six years at the hospital, I have realized that the intimacy and connection in a session with a patient is far greater without an interpreter (56). From my experience, I know that the majority of my patients at KH are reasonably fluent in English (albeit as a second or third language). Most of the women told narratives which aroused sadness in both the women and interviewer, which was expected as they spoke about an unexpected death. Many of the internationally recommended systems of procedures for respectful maternity care (such as letting the woman have a birth companion, letting her have contact with the baby, offering counselling, privacy, well maintained physical environment and resources) (57) were in place, and the women were able to acknowledge that the medical service was professional. However, the women also experienced a lack of staff engagement with them to the extent that they wanted or possibly needed. The women felt dismissed and left alone, even when they had a relative or friend with them. Research has shown that women need healthcare providers' engagement (31,58) so it is not surprising that the women at KH have similar needs.

While the paradoxical accounts of both positive and negative experiences were sewn into the interview narratives, there was a unified underlying theme that the woman's loss was not the center of concern from the hospital perspective in spite of its personal importance to the mother. The hospital staff's focus seemed to be on providing good medical care and even referred all the women to a psychologist unless the women declined the referral. It appeared that the staff seemed to defend themselves against the women's pain by splitting up the tasks and doing what was required of them. There is a possibility that these accounts speak to how healthcare practitioners engage less when there is loss, in order to defend themselves against overwhelming anxiety, and is evident in the findings of other studies (23,59,60). In the data we did not find any evidence that these women felt that they were treated any differently from other patients in the ward, and hence we did not find evidence for stigmatizing attitudes towards stillbirth, but, as always, the fact that something was not mentioned does not necessarily mean that it was not there, and it is also possible that had we asked more direct questions about stigma we would have had different responses. Overall, though, it does appear that the care provided for the women was affected by the overall burden of care in the hospital.

A hospital can be considered a holding environment for those in distress or in a vulnerable state. It is a place where all the necessary personnel, experience, technology and resources come together in one place so that a patient can access them and receive the necessary care. Menzies (23) states that the primary task of a hospital is to care for ill people who cannot look after themselves. Medical staff are trained to respond to patients who need them to diagnose and treat them so as to restore them to health.

From our previous observations in the labor ward in this hospital (36), we were witness to this silence between the staff and the women. We saw neglect, not in overt violence or acts of perpetration, but in the silence of a ward where no one was talking to anyone and there was a sense of distress left unseen. Our findings provide an interesting confirmation of previous studies on the importance of staff engagement. None of these women were alone as there were birth companions by their side throughout the whole process, yet they longed to be seen by those who were meant to be ensuring that they recover: the medical health practitioners.

The healthcare practitioners, by implementing the recommended best practices, were well aware of what was required but might not have had the emotional resources to actually engage with the women. As South Africa attempts to offer good quality medical care to all, should there be the expectation that care should also include thoughtful engagement by the healthcare staff with the patients? As our work with practitioners in the hospital suggests (36), there is no lack of will on the part of practitioners to do the best by their patients, but the practitioners themselves seem to be under immense emotional pressure and struggling to care for both themselves and their patients. It is important that they follow accepted international protocols on care of women who have delivered stillbirths, but if the practitioners themselves are not emotionally supported, they may not have the resources to provide emotional care to those in their care. Menzies (23) has suggested that healthcare workers use defenses to protect themselves from the emotional load of their patients, and that key to these defenses is a lack of engagement with patients as a whole, with a focus more on tasks. In earlier work, we (59) have suggested that the emotional demands on care workers may be greater in poorly-resourced contexts than in the context in which Menzies (23) was working, and this appears to be the case in the context we are researching here. A key finding emerging from this study is that of procedurally good care but care which is experienced by the women as emotionally lacking. It may be that in a very stressed healthcare system, going through the procedures of international best practice for the care of women who have experienced stillbirths, the procedures themselves may become a set of tasks of the kind Menzies (23) refers to. Instead of the tasks enabling the practitioners to be more open to relating to the women in an holistic emotional manner, the tasks may serve as a set of procedures which, when gone through, may be ticked off as if on a list, with the successful completion of the tasks being viewed (incorrectly, and defensively) as the same as providing adequate emotional care for patients.

## Conclusions

None of the women we interviewed viewed the medical staff as negligent or uncaring, and in our larger study we saw no evidence of this either. It seems to us that something more subtle and difficult to change may be evidenced here – the emotional depletion of the medical staff. Without due attention to the emotional needs of the staff, who seem to be trying their best, it is unlikely that the staff will be able to provide fully accessible emotional care for patients. If we are correct in this view, which is consistent with that of other authors (61–64), this has complex implications for healthcare provisioning in a low-resource context. In terms of the logics of a large burden of disease and the reality of many patients needing care, it may at first blush seem wasteful not to spread care resources as widely (and therefore as thinly) as possible. The stories told to us by our participants may suggest, to the contrary, that more expenditure on the emotional needs of caregivers in the health system may contribute to a more emotionally accessible, sustainable workforce. This is something which needs to be researched and evaluated in our context, and other poorly resourced healthcare contexts.

#### Abbreviations

FANI: Free Association Narrative Interview

# KH: Khayelitsha Hospital

# Declarations

# Ethics approval and consent to participate

Ethical clearance was obtained from the Research Ethics Committee at University A (REC-2018-1844) and the Western Cape Department of Health (WC 201801 033). All participants needed to sign an informed consent form which clearly outlined the risks and benefits of participation.

# **Consent to publish**

Not applicable.

# Availability of data and materials

Not applicable.

# **Competing interests**

The authors declare that they have no competing interests.

# Funding

Not applicable.

# Authors' contributions

ML is the primary researcher responsible for literature review, data collection, data analysis and writing of the first draft of manuscript. LS is responsible for academic supervision and substantial help with positioning the paper. LS contributed substantially to conceptualizing the paper, to its final writing up, and to the design of the study. Both authors accept responsibility for the article in its current (final) form. Both authors read and approved the final manuscript.

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## **PART 3: CONCLUSIONS**

In Part 3, I conclude this dissertation by reflecting on my research experiences. I also draw together the various findings and discuss potential next steps for taking my research findings beyond this dissertation.

Part 3 thus comprises the following chapters:

- Chapter Nine: Reflexivity
- Chapter Ten: Self-reflection article
- Chapter Eleven: Article reflecting on the use of the concept of "violence" to describe less than optimal care.
- Chapter Twelve: Concluding thoughts

### **CHAPTER NINE: RESEARCH EXPERIENCES & SELF REFLECTION**

"Human suffering, particularly when it includes traumatic bereavement, ignites an existential crisis from which a wellspring of concerns emerges." (Cacciatore & Flint, 2012, p. 76)

### 9.1 Introduction

Being a member of an overburdened and traumatized healthcare system has proven difficult. Especially a healthcare system that is a reminder of our country's horrific past and how the consequences of apartheid are still far-reaching even 25 years on. On top of that, I decided to become a participant observer and research this healthcare community that I am a part of. In Menzies Lyth's research on nurses, she observed that there was an increased aspiration for the nurses to study further at a postgraduate level. She suggested that this was due to the high levels of anxiety (Lyth, 1988). I am sure that my desire to do a PhD was in part to avoid what feels like the insurmountable anxiety I experience every day at work. I knew it would be a daunting task, but I did not know the extent of how daunting it was until I had my own "existential crisis" and I started wondering why I was doing what I was doing, whether my life had any meaning and whether my profession could be of any value to such a broken community. I came face to face with my inadequacy and it was not pleasant. After some reflection, supervision and personal therapy, I was able to regain a little perspective and return to the task ahead of me, which was not only holding myself in mind, but also those who work alongside me day by day. I started my research by reading "doing qualitative research differently" (Hollway & Jefferson, 2013) and looking at how one could research the unconscious. Being psychodynamically trained, I understand that what someone consciously says is guarded by many defences in order to protect the ego (Freudian terminology) or the self (Jungian terminology). I wanted to explore more than the conscious words and beliefs of my colleagues.

In this study, I chose a psychosocial paradigm informed by psychoanalysis, which assumes that anxiety is inherent in the human condition. Hollway and Jefferson (2013, p.17) describe it as "the idea of a dynamic unconscious which defends against anxiety and significantly influences people's actions, lives and relations". Psychoanalysis, particularly the work of Melanie Klein, as I have noted early in this dissertation, has contributed to our understanding of the nature of anxiety and the defences that prevent us from being overwhelmed and destroyed. If anxiety is the basis of the way in which a person functions, then the protective defences are needed to survive in a threatening world.

I wanted to go beyond those defences. Hollway and Jefferson (2013) wrote that in an interview, the interviewee and the interviewer are psychically defended, which implies that everyone has an unconscious which contains motivations, instincts and impulses which are restrained by the social and political world in which they live. A defended subject may not tell a complete and transparent story, this being either a conscious or unconscious act. Some topics or memories are too difficult to talk about because they threaten to break down emotional defences. This phenomenon is true in KH where there is much trauma.

This study primarily employed an ethnographic research model, which entails trying to understand practices in a labour ward of Khayelitsha Hospital. The data comprised three sources of primary data and one source of secondary data. The primary data source was observations in the labour ward, interviewing labour ward staff (doctors, nurses, and a clinical psychologist) and patients who used the ward. The secondary data source was hospital documents where I looked at the hospital reports of deliveries and of stillbirths. I also looked at my own clinical notes on grieving mothers whom I had previously seen.

Since my first day employed at Khayelitsha Hospital I watched others – whether patients, visitors, management or staff. I was trained psychoanalytically and I was trained to watch people. So I did as I was trained to do and watched. (The PhD only came into mind four years later). I saw many contradictions in my time at the hospital. I saw a doctor pinch a patient for not listening to her instructions and I saw an angry nurse speak kindly to a young mother with a crying baby. I saw seemingly kind patients swear at nurses and I saw quiet staff members yell at patients. This all set the scene to my thoughts about researching the organization I am a part of and thinking through how I can assist in facilitating change. In the next paragraph, I reflect on the PhD process.

## 9.2 Starting my PhD

Then I formally decided to watch the staff and patients in the labour ward for my research. No one (including staff members and patients) was being overtly mistreated and all the patients were medically well attended to. Although I saw no abuse, I experienced an uncanny silence in the ward. In looking back at my journal, some of my journal entries were: "*The women are all alone in the ward. No partners/husbands/sisters/friends around to support them. Where is their support? Feels so lonely and isolated. Quiet in the ward. People don't speak to each other*" (journal entry, 23 July 2017).

I tried to make sense of this silence. Thus I wrote my first article: *Rethinking obstetric violence* and the "neglect of neglect": the silence of a labour ward milieu in a South African district hospital (2019- see Chapter 5) and then subsequently the second article: How gentle must violence be to not be violent? Rethinking the word 'violence' in obstetric settings (under review- see Chapter 11).

It was not always completely quiet, as at times the nurses would speak loudly to each other as they went from room to room, doing their tasks. The staff (especially the medical officers) noticed my presence. I noted in my journal that the medical officers seemed anxious. A medical officer even apologized in advance to me, telling me that she hoped I would forgive her if she occasionally screams at the patients. She then laughed. Another medical officer told me that she felt like she was going to do everything wrong. The nurses did not have the same response to me. They did not seem to be anxious when I was around. There were no apologies or awkward laughs. Why such a difference between the medical officers and the nurses? My thoughts wandered to shame. It seemed like the medical officers felt like I was comparing them to some standard, whereas the nurses just accepted that I was just watching. Surprisingly, the cleaners were also anxious and one even thought I was from the media, coming to expose unethical practices.

### 9.3 Holding the contradiction between what I saw and what I was told

On interviewing the medical officers, their shame (and mine) became more tangible. I attempted writing the third article: *Care and the politics of shame: medical practitioners and stillbirths in a South African district hospital* (2019- see Chapter 6) and struggled. It felt like an impossible task. I needed to reflect on my own shame as I identified strongly with the medical officers, so I reflected on my own process in the piece I wrote entitled: *I WANT TO RUN AWAY! Reflections from a participant observer* (to be published in 2021- see Chapter 10). This helped me to consolidate my thoughts and realize I was having an existential crisis about my life, role and career. I needed to process my own countertransference, which is essential in psychodynamic research. This helped me move from my own judgment and distancing to a more empathic position. After this paper, I was able to complete the third article. I realized that the medical officers lived in a high anxiety state with no reprieve, as they had little support in the work environment. They were also different from the community they served which added a different burden to them: a burden of trying to right the wrongs of a brutal and divided society. There was a deep sense of guilt and a need to repair (Gerard, 2019).

The fifth article, *I don't want to see the people in pain: Exploring the nurses' responses to stillbirths* (under review- see Chapter 7) was fascinating to me, as the shame I felt to be so prominent in the medical officers was not there. The nurses were not as anxious in their interviews and spoke compassionately about the patients. They were not apologetic about how they worked or how they treated their patients. Even though I noted how silent the ward was and how little interaction there was between patients and staff, their interviews did not elicit that they felt they were quiet or avoiding the patients. During observations, I saw the nurses distance themselves from the patients. I reflected on how in my own parallel process, I too distanced myself from my colleagues. The nurses reported that they truly cared for their patients and were very supportive despite what I saw. I too felt like I was concerned for my colleagues, but my own anxiety resulted in distance.

Doing this research was tiring and the voice of each participant lay heavy on my heart. I was wanting it to end but then my supervisor reminded me about the grieving mothers and giving them a voice too. So I wrote one final article: *Stillbirth in Khayelitsha Hospital, South Africa: Women's experiences of care* (under review- see Chapter 8). Even re-reading it is difficult for me.

### 9.4 Conclusion

I witnessed all the staff providing excellent medical care and I saw them engage when they needed to. Patients' basic needs such us food, blankets and pillows are attended to. The staff answer all questions in a non-hostile manner and even assist the patients to the bathrooms or help with making phone calls to family members. The staff are cordial to one another. However, in a stressed environment where most of the birthing mothers are traumatized, as well as the staff, both staff and birthing women appear to keep quiet to defend against the anxiety that is aroused in them. The women willingly submit themselves to the supposed experts and the supposed experts quietly perform their tasks as their anxiety, it seems to me, stops the reflective process. Silence is protective for both the staff and the mothers. No one gets emotionally involved and therefore no one hurts. The staff believe they are engaging appropriately which they are in the capacity that they can. There are no clear perpetrators, as the organizational system is built on a community that is powerless and lacks agency. Both staff and patients are victims and both collude with the defensive neglect of silence.

As I saw in my process, I needed regular supervision, reading of theoretical articles and writing my reflections to understand my own internal battle with the overwhelming anxiety. Through this process I felt I had more capacity to connect to others in a way that I was unable to before. I believe there needs to be space for staff members to process and reflect their internal conflicts, so that they too may move from a distanced position to one of more empathy with themselves and others. The irony is that although consciously the staff (especially the medical officers) requested support and debriefing, I wonder if they would be able to commit to the intensity of such a space and truly engage in the process, as it is may be a long (and never-ending) journey to understand the internal workings of the unconscious.

In this chapter, I reflected on my process and the importance of self-reflection. In the next two chapters, I develop these themes through a book chapter and the final article submitted for publication in this dissertation. Finally, I present the concluding chapter.

## **CHAPTER TEN: BOOK CHAPTER**

## I WANT TO RUN AWAY: Reflections from a participant observer

## Introducing the book chapter

As I mentioned in the previous chapter, I wrote this piece when I was in a dark space in my PhD process, where I strongly identified with the medical doctors I interviewed and started to feel hopeless about working in Khayelitsha. This piece helped me to break away from the PhD and take a moment to reflect on what I was going through. I actually never intended for it to be a part of my PhD, but my supervisor was very encouraging about the piece and sent it to an author and international expert on trauma (Valerie Sinason) who asked to include it in her book. Behar (2014)'s work on what she terms 'the vulnerable observer' encouraged me to write with vulnerability. I hope the chapter gives the reader some sense of what I deal with on a daily basis. My aim in including the chapter, however, is not just to reflect on myself, but also to use my own experience to help communicate the issues of trauma in the context in which I conducted my study.

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### I WANT TO RUN AWAY! Reflections from a participant observer

### Maura Lappeman

Most of my community is often shocked when I tell them where I work. My family doctor often wants to book me off for longer than required when I go for a checkup. Often questions are thrown at me: "Why?", "How long do you need to be there for?" and "Do you like it there?" A psychiatrist from a hospital in my area even asked me: "Are your parents missionaries that you feel obliged to be there? Why not move back to civilization?" With these types of questions, you would not be blamed for thinking that I work in some remote part of Africa with little access to the outside world. But in fact, I work just 25 minutes away from the leafy suburbs of Cape Town in a township called Khayelitsha. Most of my commute is with the thousands of commuters racing to their corporate jobs in the CBD, but then I turn off onto Spine Road and enter into a "new body", a foreign world so to speak. It is a world I have grown familiar to over the last six years, but it is still so foreign to me. There is a sense that I am too close yet too far away from this community. The streets are lined with tin shacks that take about an hour to assemble. Each shack is the size of a small store room and is filled with a family trying to survive. There is no running water, toilets, electricity, fridges, floor boards, separate rooms, mattresses- many items most of us take for granted. Even writing this down, I can barely understand how people survive these living conditions so I know that it might sound so farfetched to those living in the global North. I cannot even begin to describe the conditions because to do true justice to the inhumane, disgusting conditions would be to traumatize the reader and that is not my intent or desire.

<u>So why do I work here?</u> I am not sure anymore. I first came to work here as assigned by the South African government to complete my clinical psychology training by doing a community service. I was the only government psychologist for an impoverished community and oversaw therapeutic services at the hospital and 3 community clinics. I was asked to stay on after the year so here I sit, 6 years later, and I am now reflecting on why I stay when all I want to do is run away. I do feel guilt at knowing that I can walk away yet most of this community cannot.

<u>Why do my PhD?</u> From the beginning of my time as a community service psychologist, the CEO of the hospital asked me to do research as it is a relatively new hospital (opened in 2012). I see myself as a clinician and did not think of myself as a researcher so I was reluctant at first.

However, my clinical work became insurmountable and I saw traumatized patient after traumatized patient. I felt like in order to stay in this work environment, I needed a distraction so my PHD was born not out of desire but out of necessity to distract me from the terror of my work. I understand that as a psychoanalytical-researcher, it is important that I understand my personal motivations for doing the research (Harvey, 2017). My own self-awareness is vital to understand my countertransference and the engagement with the other in the room.

Why stillbirths when there are so many other traumas I could focus on? This community is rife with violence, poverty, substance abuse, sexual trauma, murder...which all are respectable topics to research as most people in this community have experienced not one but many traumas repeatedly (Kaminer & Eagle, 2010). There is no clear start to their traumas and no clear end. I felt like I wanted to focus on the people (the healthcare practitioners) who were trying to help and focus on their stories in the face of all this trauma, so I looked at a topic where it is a moment of time where you can pinpoint a specific trauma: a stillbirth. It's looking at a death when people are hoping for life. This intrigued me in this context because there is very little hope from my perspective in the community, but a birth could be seen as symbolism of new hope. Yet just before the hope is realized, it is snatched away brutally leaving the mother reeling at her reality. It's often a loss that is unpreventable and unexplainable. Even with all our medical advancements, it is an uncontrollable event. It is a tragedy that confronts the grieving mother with her helplessness and often results in an irrational sense of guilt (Raphael-Leff, 2015). In this community where there is so much deprivation, a stillbirth is yet another symbol of how little grows here. The grieving mother then needs to leave the hospital and return (without hope) to her stark reality of danger, violence and poverty.

<u>Reflections on being a participant observer:</u> I decided to complete my PHD by publication to share my learnings with the broader community. My initial articles on obstetric violence were manageable and conscientiously completed and then I tried completing the 3<sup>rd</sup> article on how medical officers working in the labour ward manage and feel about stillbirths at a district hospital. On reflection, writing this article has been an incredibly hard task for me. I struggled to put to paper the thoughts and feelings of these medical officers and I had to take time to reflect on why. The clinical manager of the hospital often stops me in the hallway and tells me how the medical officers are not coping, and he is not sure why. Most of the medical officers are not from this community which results in a high turnover of medical officers, so that those of us who have been here for a longer time cannot keep track of who is who. While writing the

article, I wondered about projective identification, the unconscious communication, and whether I experienced a state of mind similar to these medical officers where it was too difficult for many of them to reflect about their experiences in the labour ward. It is very difficult to work in an environment so foreign to the environment that you go home to. The task seems impossible. The loss and poverty are out in the open which you experience as you drive into this community. The stench, the litter, the raw sewerage and the look of desperation on the faces of most residents. How does one even consider that most of this community lives in tin shacks with no electricity or running water in 2019? Just surviving is the daily goal of most. Numerous patients tell me how they wonder where they will get food from or money to take transportation to the hospital. How does one process the economic inequalities and not be changed or feel some "privileged guilt"? I detach often from the reality of my work. I feel relieved when going home and easily forget about the traumas of the day. I want to banish the atrocities to the unconscious (Herman, 2015). I want to blame colleagues (which gives me some relief) for not doing more when I see the enormity of the trauma of the work (Orange, 2008). I feel protective over the medical officers because I can identify with them. They are people like me describing experiences like mine. I understand when they do not want connection with the patients because truly caring means allowing yourself to feel your patients' desperation. It means making space for empathy. Being task-orientated at times seems more bearable where I can just check off my list what I have done instead of listening to another patient's pain. The sheer mechanics of my patients' lives (like how they access water or go to the toilet in the middle of the night) are as unimaginable to me as my life is to theirs. It was difficult to write my reflections as I could not distinguish between my feelings and the feelings of the doctors. I could no longer be objective as I could not think of their pain without my pain emerging to the surface. Judging their actions harshly would be judging myself.

I could not write a reflection paper and not reflect on my shame. I am ashamed that I was born to privilege because of my white skin. I am ashamed that I have never had to go a day wondering where I will get food from or transport money but that the majority of my patients struggle with food shortage every day. I am ashamed that I complain when the electricity goes out because it means I cannot heat up water for tea or watch a movie. I look forward to leaving Khayelitsha every day and block out what my patients need to go home to. Cold, empty shacks. No matter how hard they work, they will never obtain the material possessions I have (unless by miracle or dubious means). I sit with shame because I am helpless. There is nothing I can do for the majority of my patients. They need jobs, food, and a place to live...the basic necessities of human life. I can only offer a space to talk... Is that enough? Orange (2008, p. 87) describes my shame perfectly: 'We feel we are deficient by comparison with others, we feel we are failures in our own and others' eyes, we feel so held up to critical scrutiny in our desperate misery that we want to sink into the ground and become invisible'. As a privileged and often white South African, your skin and material possessions, immediately divide you from those in Khayelitsha. The doctors (and I) have had access to a first-class education, to a safe substantial home, to travel, to food and yet we are limited in our capacity to help. Jesus says in Luke 12:48 (New International Version): "To those who have been given much, much will be expected". The shame that that we cannot do more is suffocating.

<u>Am I traumatized working in this environment?</u> I think I am traumatized even though I have had my own psychotherapy and regular supervision for my clinical work as well as for my PHD. I practice self-care and I am involved in a spiritual community. I have tried by all means to look after myself, but I still feel my anger surface at patients and colleagues. I feel hopeless and disillusioned. Most of the patients that get referred to me are the ones no one else can bear. I wish I could be more resilient and like a superhero, supersede the trauma I experience through the voices of my patients. I strive to remember that my task is not to save South Africa but to listen to one person at a time. Psychoanalysts would argue that until I have found meaning in my trauma, I will continue to feel distressed and have unconscious reenactments of the traumatic experience of my work (Kaminer, D., & Eagle, 2010). Even as I write, I wonder if I am exaggerating my story and whether my story would be different after a long holiday. However this is my truth now and when acknowledged and brought to the conscious, healing can begin (Herman, 2015).

<u>Returning to my research</u>: Behar (2014, p. 5) noted that "Nothing is stranger than this business of humans observing other humans in order to write about them". I have found, as a participant observer, it is not only other people I have been watching but also myself. The reflections of my work have been difficult to digest thus making this "new body" I enter everyday almost nauseating. I do not know how long I can tolerate sitting with the pain that I do every day and it seems easy enough for me to pack my few belongings here and escape to my world of plenty but I feel the weight of knowing about the need of this community. I wish I could just take a tablet to forget like in the movie The Matrix. So, I hold on to the hope that if I can give one person the experience of being heard and seen, I have made a difference.

Although I identify with the medical officers strongly, it is different for me as I have a wealth of supportive others who listen and may mitigate the impact of the work (Herman, 2015). My job is one where I help others be mindful and present in the moment. I help people to mentalize and reflect on their hardships. Through teaching, I have learnt to train myself to be more reflective and grounded. Those around me encourage these practices. The medical officers are not as fortunate. Their shame is now more visible to me. I can see how they just keep trying harder, hoping for a different outcome.

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## **CHAPTER ELEVEN: ARTICLE 5**

How gentle must violence against women be in order to not be violent? Rethinking the word 'violence' in obstetric settings

## **Introducing Article 5**

In writing a PhD about stillbirths, I was confronted with many articles on obstetric violence. There is a growing concern about human rights in health. In Article 5 I reflect on the implications of the use of the word 'violence' in research on care of new mothers and infants. The word 'violence' is being used by some authors to describe apparent disrespectful treatment received by women by either healthcare practitioners or healthcare systems. As the definition of violence in health care settings broadens, questions arise over the impact of the term in describing objective reality. Specifically, does the use of the term 'violence' inadvertently disempower the women that it is meant to empower? This paper explores the changing use of the term 'violence' and specifically draws on evidence in a South African labour ward, where phenomena such as silence and limited social support have cultural underpinnings that contradict call into question the broad use of labels such as structural or obstetric violence. As global research on obstetric violence in disadvantaged communities grows, choice of terminology will become more important in filtering results into medical policy and practice.

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# How Gentle must Violence Against Women be in Order to not be Violent? Rethinking the Word "Violence" in Obstetric Settings

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## How Gentle must Violence Against Women be in Order to not be Violent? Rethinking the Word "Violence" in Obstetric Settings

### ABSTRACT

With the growing concern of human rights in health, the word "violence" is being used to describe apparent disrespectful treatment received by women by either health care practitioners or health care systems. As the definition of violence in health care settings broadens, questions arise over the impact of the term in describing objective reality. Specifically, does use of the term "violence" inadvertently disempower the women that it is meant to empower? This paper explores the changing use of the term "violence" and specifically draws on evidence in a South African labor ward, where phenomena such as silence and limited social support have cultural underpinnings that contradict labels of structural or obstetric violence. As global research on obstetric violence in disadvantaged communities grows, choice of terminology will become more important in filtering results into medical policy and practice.

Keywords: violence, health, South Africa, obstetric violence, qualitative

Violence against women during childbirth is a significant health issue (D'Oliveira et al., 2002; Silal et al., 2012; Small et al., 2002). In 2015, the World Health Organization (2014) responded to the concern about violence in obstetrics by releasing a statement accentuating the right of every woman to respectful care during childbirth, including the need for greater research and advocacy by all health stakeholders on this issue (World Health Organization [WHO], 2014). Since then, a growing body of literature continues to define what a healthy and respectful birthing experience should be.

A major barrier to addressing how women are treated during childbirth is the lack of globally accepted definitions of what constitutes respectful maternity care and mistreatment during childbirth (Vogel et al., 2016). In pursuit of better defining good maternal care, the term "obstetric violence" has gained traction as a description for mistreatment of women during childbirth (Chadwick, 2016; Chattopadhyay et al., 2017; Kukura, 2018). This term has been used to describe cases of forced surgeries, unconsented medical procedures, and other physical, sexual, and verbal abuses (Chadwick, 2018; Chattopadhyay et al., 2017; Kukura, 2018; Williams et al., 2018). Chadwick (2018) has noted that this term positions birthing women as victims to clear acts of abuse, dehumanization and appropriation by identifiable perpetrators. She has also suggested that obstetric violence should be understood not simply individually in terms of cases of abuse, but rather as the result of layered social norms and power relations, which result in subtle and often unacknowledged forms of violence that she terms "gentle violence" (Chadwick, 2018).

It is clear that those concerned with what is termed "obstetric violence" are interested not only in violence as narrowly understood, but also in an array of issues regarding the disempowerment of women during childbirth, and at other times. In this article, we draw on data from our study of obstetric practices in a hospital in Cape Town, South Africa, to explore questions concerning the utility of broadening the word "violence" beyond its foundational definition. By way of introduction, we consider an accepted standard definition of violence and some more recent developments in conceptualizing violence.

### **Violence Defined**

The World Health Organization defines violence as:

... the intentional use of physical force or power, threatened or actual, against oneself, another person, or against a group or community, that either results in or has a high

likelihood of resulting in injury, death, psychological harm, maldevelopment, or deprivation. (WHO, 2019, para. 2)

This definition, coming as it does from the global body focused on health issues, is crucial as a frame for how health care institutions may understand and decide to act to reduce or eliminate acts of violence against women during childbirth. Importantly for this discussion, the above definition suggests the intention to do harm to another as a core feature of violence.

The term "violence" has, however, been extended from earlier definitions to reach beyond the intentional harm perpetrated against people by including the potential harm committed by an organization, harm which may detrimentally affect a person or people. This harm, known as structural violence, is the "invisible manifestation of violence built into the fabric of society, producing and reproducing social inequalities across groups" (Sadler et al., 2016, p. 50). The concept of structural violence, which was originally proposed by Galtung (1969), considers violence to be a phenomenon that does not necessarily occur between individuals, but that exists at the collective or the organizational level. Galtung (1969) postulated that structural violence occurs when a social institution (such as a hospital) may cause violence to people by preventing their basic needs being met, or the achievement of their potential. In this model, the effects of violence may be (and are) experienced profoundly at the individual level, but it becomes difficult to delineate exactly who is and who is not a perpetrator of this violence. The concept of structural violence has been exceptionally useful and productive in thinking about health in the context of oppression and social inequality (Farmer, 2013). For the purpose of the current discussion, however, it is important to note that, in the case of structural violence, the "perpetrator" may be viewed as a class of people or a set of social forces. Structural violence may be reproduced by people with privilege who do not necessarily see themselves as perpetrators and who do not, consciously at least, intend to

cause violence. In this formulation, the notion of individual or group intentionality, so central to the WHO (2019) definition, is eroded.

Using the concept of structural violence as a base, Nixon (2011, p. 2) defines what he terms "slow violence" as,

... a violence that occurs gradually and out of sight; a delayed destruction often dispersed across time and space.

Nixon notes that in common discourse, violence is often associated with an event or action that is noteworthy and identifiable. He argues, however, that not all violence is out in the open, obvious, and attached to a discrete episode. In Nixon's view, violence can also be quiet, and pervasive, slowly destroying and degrading those in its path (Nixon, 2011). In this formulation, Nixon still underpins the term "violence" as an intentional human on human act, but its description appears to personify the term "violence" itself as the actor and downplays the intentional individual human component. Although Nixon did not directly address health systems, he addressed the slow violence inflicted on people living in poverty that would naturally include the degradation of health. Emblematic to his argument is the destruction of the environment, which is often slow and imperceptible at any given moment, but which may have profound health consequences. Both the concept of "structural violence" and that of "slow violence" broaden the concern with violence from a focus on individual intentional acts to considerations of how power inequities may have profound and even devastating consequences for the health and development of many people.

Within the field of obstetrics, Chadwick (2018) expands on Nixon's (2011) thinking, coining the term "gentle violence". In Chadwick's definition, gentle violence occurs in care environments where women become submissive, compliant body subjects who willingly accept their role as patient (specifically in obstetric practices). This "gentle violence" may be

making reference to Bourdieu's "symbolic violence" which is a subtle (non-physical) violence that is exerted over the oppressed, often with their collaboration and acquiescence (Bourdieu, 2003). While there may be some malicious clinicians, arguably clinicians who could be accused of gentle violence, according to Chadwick's (2018) definition, do not necessarily have the desire to maintain a harmful power dynamic. Unlike those who theorize about structural violence and slow violence, and who are interested in broad social and environmental issues, Chadwick (2018) is concerned with a very particular, and intimate, context - that of care, or lack of care, during childbirth. Clearly, broad issues of power (including gender power) must be of profound relevance to how obstetric care is organized and delivered. But, given the bodily intimacy of obstetric care, why and how, if at all, should issues of maltreatment or less than optimal treatment be understood? It is incontrovertible that there are many examples of overt violence towards women in childbirth, including direct physical violence in the form of blows to the body and interventions delivered in ways which are unnecessarily physically painful and destructive (Bradley et al., 2016; Chattopadhyay et al., 2017). But Chadwick (2018) is interested not only in this overt intentional violence and abuse, but in broader sociopolitical issues and how they may be substantiated in particular childbirth experiences. Though there is clearly something exceptionally productive in considering what happens to women in childbirth as profoundly shaped by broader sociopolitical oppressive and structurally violent contexts, might there also be unintended, unhelpful consequences to characterizing less than adequate obstetric care as a form of violence? To address this question, we consider data from our larger study of obstetric care in South Africa.

Before we explore the question of obstetric "gentle violence" in the context of our work, it is important to consider an approach to this issue which does not use the word "violence" explicitly.

Freedman et al. (2014, p. 917), writing in the *Bulletin of the World Health Organization*, define "disrespect and abuse in childbirth as interactions or facility conditions that local consensus deems to be humiliating or undignified, and those interactions or conditions that are experienced as or intended to be humiliating or undignified". These authors (Freedman et al., 2014, p. 916) provide a typology which distinguishes between different levels of what they term the disrespect and abuse of women during childbirth, considering these issues at the individual level (which includes behavior on the part of a health care provider that, as they put it, "all agree constitutes disrespect and abuse"), the structural level (which includes "poor treatment or conditions caused by system deficiencies and considered disrespect and abuse by women and providers"), and the policy level (which includes "deviations from human rights standards (available, accessible, acceptable, quality)". This typology, as we shall show, is helpful to the analysis which follows, even though these authors do not use the term "violence" as such.

## A Feminist Ethics of Care Paradigm

Many of the more useful theories of different forms of violence which we have discussed above depend fundamentally on normative ideas about justice, inequality, and how the world, ideally, should be organized. This is an excellent approach to thinking about what is and what is not violent. A feminist ethics of care paradigm, however, approaches ethical questions not in an abstract way, but within a relational paradigm which explores ethical issues in a situated, contextual way (Tronto, 2010). A key question for care ethicists is not "What is right?" in abstract, absolute terms, but, "How can care best be delivered within this particular context and set of relationships?" (Tronto & Fisher, 1990). A key challenge an ethics of care approach poses for more dominant ethical approaches is that of disallowing the kinds of binaries which may be instantiated by the imposition of a normative paradigm, where people with power are seen effectively as autonomous agents who act in a way that is either good or bad. Care ethicists are more interested in networks of relationships, including networks of care and violence (Held, 2010). A care ethics approach requires of theorists not to label individual actors as good or bad, but rather to interrogate networks of power in which relationships are embedded. It also requires feminist theorists to extend an ethic of care to all those they study. Comfortable though it may be to contrast in a dualistic way vulnerable patients with health care workers as perpetrators, a care ethics approach requires a closer attention to context, and even to the extent to which care workers are themselves subject to violence of various kinds (Kruger, 2020; Newnham & Kirkham, 2019; Perera et al., 2018). The question in this paradigm is not that of who is good and who is bad, but of how different kinds of relational engagements and interventions may lead to different outcomes in terms of the welfare, in this case, of mothers and infants.

## Relooking at Phenomena that have been Labelled "Violence": Khayelitsha Hospital Labor Ward

South Africa is a country in which violence is a daily reality for many, if not most inhabitants (Jansen, 2017). Symbols of South Africa's violent reality for the rich and those living in poverty are everywhere. Poor neighborhoods are marked by overcrowded high density dwellings, gang violence and low per capita police presence (Lilenstein et al., 2017). Wealthy areas are marked by high walls, burglar bars, barking dogs and neighborhood watches. The 2018 Global Peace Index shows that the state of safety is deteriorating rapidly in South Africa (Institute for Economics and Peace, 2018). The report also reflects that the country's murder rate is recorded at 33 people per 100 000 of the population (57 murders per day), placing South Africa firmly in the top ten of the world's most violent places (Institute for Economics and Peace, 2018). The country also has a history of racial and internecine violence that still perpetuates the reading of history and the social narrative

across all demographics. This background makes South Africa an obvious country in which to explore any form of violence, including violence within the health care system.

South Africa has a number of government funded district hospitals to cater for the needs of its majority population who live in poverty. Our larger study focuses on staff responses to births and stillbirths at a district hospital in Khayelitsha, South Africa. Khayelitsha community, in the vicinity of Cape Town, is largely impoverished and is a context of very high rates of violence (Jansen, 2017; J. Lappeman et al., 2017).

## Methodology

For our study, we conducted observations of the labor ward of Khayelitsha District Hospital, the state-funded hospital serving the community. We also interviewed staff and patients (for details on methods please see Lappeman & Swartz, 2019).

Our study used an ethnographic approach with multiple sources of data: observations in the labor ward, hospital documents, interviewing health care practitioners (doctors, nurses, social workers and any other employees who are involved with the care of mothers who experience stillbirths) about their practices with women who have stillbirths and interviewing women who have had stillbirths about their experiences of care at Khayelitsha Hospital (KH). Ethnographic research entails trying to understand practices in a particular setting, such as KH, and why they are performed in such a way (Bantjes & Swartz, 2017; Gobo, 2008; Smith, 2005). The work of Smith (2005) was instrumental in developing institutional ethnography, which is a method of research that explores people's every day experiences, including social interactions, within the context of organizations. "The emphasis is on what people do—their work broadly conceived—and what individuals say and know about their work as expert knowers and doers" (Kearney et al., 2019, p. 18). We chose this method because institutional ethnography is helpful in looking at how health care practitioners' work processes are shaped

by and are a constituent of the institutional relations at the hospital (DeVault & McCoy, 2002).

After approval of our research from the Stellenbosch University Committee and Stellenbosch Ethics committee (REC-2018-1844), we then submitted the proposal to the Western Cape Department of Health as well as the Khayelitsha District Hospital ethical committee for ethical clearance (WC 201801 033) before proceeding with any research and data collection. Participation in the study was voluntary for both staff and mothers who delivered stillbirths at the hospital. An information leaflet was included in the informed consent form. The information leaflet explained the purpose and objectives of the study, what participation entailed, the possibility of harm or risk, as well as the potential benefits of the study. The leaflet also outlined how confidentiality and anonymity would be maintained, and the participants' right to withdraw from the study. No payment was offered for participation. We did, however, provide refreshments at our own cost and if the mother had already been discharged from the hospital, her transport costs were paid. All participants were required to sign an informed consent form which clearly outlined the risks and benefits of participation.

### The Issue of Silence in the Ward

During the first author's daily observations of the ward over a six week period, she noted that none of the birthing mothers were being overtly mistreated. In general the women were medically well attended to. In addition, while there was overcrowding in other wards, the labor ward was comparatively well-staffed to meet the patient load. Although no physical abuse was observed, the silence that permeated the ward was noteworthy. The ward was quiet (even the new-born babies barely cried). Only the nurses would occasionally speak to each other in isiXhosa (the locally used indigenous language) at the nursing station. Occasionally, a nurse would go to a mother to ask a question or fill in a note in the folder, but otherwise very little human contact was displayed between people. One doctor monitored the ward during the day and was called when needed. The doctor seemed very alone as she walked from room to room and asked the occasional, only medically related, question:

I haven't spent much time with the patients to really find out honestly how they are doing, how they have coped. (Dr J)

A hospital psychologist confirmed this:

It's quiet. Because the noisier one is the postnatal. But I mean, even when you walk into the labor ward, it's warm, temperature-wise, it's very warm. I remember, last week it was cold in the passage, but as soon as I walked in there, nice and warm. But it's so quiet. Because now I'm thinking this quiet is almost like a ... it's almost weird and cold. (Psychologist)

The silence that characterized the ward milieu was very different to what one might expect to find in a labor ward: sounds of mothers bonding to their new infants and health care professionals rallying around. Although this silence may have caused some distress, can we label this silence a form of violence?

### Women's Isolation and Lack of Support

Another observation in the same study was that participating women did not have birthing partners present. Birthing companions were rarely seen despite extensive literature stating that a birthing companion reduces the need for medical interventions, including medicalized births, and improves both maternal and neonatal outcomes (Lunda et al., 2018; Vogel et al., 2016). We asked the mothers about this, and they said that they did not want a birthing companion, whether or not this was recommended by the health care practitioners. We found that women say, "No!" to having birthing partners present even when it was encouraged by staff:

According to our culture the people don't like to be here when a woman is giving birth. They have that knowledge that the men are not supposed to go, which is not specifically about the men because you can ask someone else to be a companion. But the people don't like someone next to them while they're having the pains. They want to be alone by then. (Sister S)

We really recommend it. We do encourage it. We don't actively follow up on it, but we don't find a lot of them having companions, which is sad. (Dr G)

So sometimes some of them chase their partners away and they'll say, "Oh, go, you are the one who is giving me pain, I don't want to see you." (Sister M)

We as Black people are not used to that... Like me, when I was giving birth to my little one, my husband wanted to come into the room that I was in. I had some pains, then this husband of mine wanted to come in. Then I just said to him, "No, no, no, go, go, go, go!" I didn't want him to come in. (Sister F)

In each of the above statements, the patients demonstrate the ability and authority to make a choice to go against professional advice. While some birthing companions do join their partners, this particular context shows evidence of a sense of agency to make a choice against the better judgement of the hospital staff.

#### Violence and Agency

A sense of agency refers to one's feeling of control over actions and their consequences (Moore, 2016). In Chadwick's (2018) formulation, hospitals may be designed subtly to discourage birthing partners – an example of "gentle violence". In our study, for example, we could find no evidence that mothers were discouraged from having birthing partners present – quite the contrary. But they refused. In Freedman et al.'s (2014) typology, examples of disrespect at the structural and policy levels were clearly evident, but not at the individual level. In this specific case (which may well differ from others), the use of the word "violence" to describe the lack of birthing partners may have unintended consequence for instituting changes in how health care is delivered. We know from other data collected (Lappeman & Swartz, 2019) that the health care personnel were acutely aware of issues of poverty, exclusion and injustice as they affected their patients, and were committed to trying to ameliorate these issues to the best of their ability. They worried about the care they delivered and whether it was good enough. They were deeply affected by the intimacy of their work – their closeness to the women's bodies at a time of great vulnerability.

In this context, what are the implications of using the term "gentle violence" to describe what we observed? It is important to note that neither the health care practitioners nor the mothers themselves were educated in the different uses of the term "violence", and that the word "violence" as commonly understood in South Africa relates to overt intentional acts of harm (and is therefore close to the WHO definition). Use of the term "violence" in this context, though sociologically defensible in terms of the definitions of violence we have outlined earlier, may have implications for how both practitioners and patients position themselves. Key to this is the question of the sense of agency of patients, health care practitioners and organizations. First, positioning women in labor in this context as victims of violence when they may not consciously experience what has happened to them as violent

may deny them their sense of agency. It may position women in labor as unable to speak for themselves because of their fear of consequences manifesting from the perceived power dynamics. The victim may feel helpless, may be seen as needing to be rescued. They may be viewed as lacking personal power which perpetuates the belief that the health care professional is the expert and knows best, leaving the patient at their mercy. These perceptions, if communicated to patients, may be internalized, with patients themselves feeling that they do not have agency.

Second, labelling health care systems and practitioners as violent (as opposed to untrained, insensitive or incompetent, or even structurally positioned as having power they themselves may be unaware of or may not want, for example), has far-reaching consequences for their emotional health and the system of people required to maintain health care professions and services. Health care professionals are often expected to put the patients' needs above their own, without their own needs being considered (Kerasidou & Horn, 2016). This may result in the image of emotionally detached health care professionals who may be labelled as perpetrators of violence, instead of being seen as individuals who entered into the profession to help (Briceño Morales et al., 2018). Perpetrators, as we have seen in the WHO definition, are also seen as intentionally wanting to cause harm, whereas most health care practitioners may cause harm unintentionally through lack of knowledge and experience, or for a range of other emotional reasons (van der Walt & Swartz, 1999). Most choose health care as a career because of their desire to undo harm (Briceño Morales et al., 2018). This noble motive may co-exist with other lesser motives, such as a wish for power or wealth, but most health professions have doing good and undoing harm as an aspect of their core identities. Health care workers may resist interventions to help them change their behavior if they feel personally under attack for being violent.

Third, health care organizations need to be established in order to provide health care. There may be unintended consequences to asserting that structures such as hospitals are places of violence, unless humans are intentionally harming humans within their walls. If anything, these structures need to be designed in order to provide better care and more considered approaches to patient care without the threat of being labelled as objects of violence. Asserting that health care organizations are inherently violent, though potentially theoretically productive, may inhibit or deny opportunities to improve care.

What we are suggesting here is that if we use the word "violence" appropriately in terms of many useful, sociological understandings of the term, but in a way which may be experienced personally by people not familiar with these understandings, we may inadvertently disempower both patients and practitioners and may inadvertently deny opportunities for change. Discursively, bad people or forces cause violence, but this characterization may limit opportunities for practices to change. It should also be noted here that the word "gentle" as commonly understood potentially would be seen as referring to the ways in which individuals treat one another, and not as referring to broader issues of social power. When we speak of slow violence, symbolic violence, or structural violence, we may be cued into thinking about broad power relations; the term "gentle violence" may be more easily misunderstood as referring to individual level interactions, as discussed by Freedman et al. (2014).

### Discussion

Violence is a very serious matter. It is important that people who are serious about health consider violence to be a health issue. However, if researchers and theorists broaden the term "violence", as we see in obstetric literature, this may have paradoxical consequences which need careful interrogation.

We believe, furthermore, that there is something significant and qualitatively different between hitting a patient and not talking to a patient. Satisfying a patient's need for acknowledgement cannot be equated with providing adequate care (Tronto, 2010). From our own work, our concern is that the concept of violence, as broadly used, may substantiate the view, justified or not, that patients are on the receiving end of intentional harm and are victims. The silence we observed in the ward could be construed as a form of neglect, as the women may not be receiving appropriate emotional care. In this instance, one may argue that the silence would indicate a lack of recognition of the women's personhood; their needs and feelings. Upon careful reflection, this silence was noted as not being an intentionally violent act, but more a way in which an overstretched system defends psychologically against what it knows it cannot provide (Lappeman & Swartz, 2019). There was no overt interpersonal violence noted in any of the field notes or interview transcripts. In such a case, should we call a quiet ward, and with no birthing companions, violent? Is this assumption not a narrow, exclusive and potentially culturally encapsulated Western view of obstetric care? In this instance, the prevailing feeling of patients (and respectful acceptance by practitioners) does not fit the dominant view of obstetric care and hence could be labelled as violent.

To say that something is not good for people or to say that something is not helpful according to research is important for changes in health care. But to broaden the definition of violence to argue that this is a form of violence, though trivially true, dependent on one's definition of violence, may not assist health care institutions to bring change even if it makes those using the term "violence" appear concerned about an important issue.

#### Conclusion

In conclusion, we offer three suggestions to researchers who attribute the word "violence" to describe apparent neglect, abuse or other harmful practices. First, before labelling a medical practice as potentially violent, researchers must consider the specific voice of the patient in their specific context. To label a practice as "gentle violence" may be appropriate in one setting, but inappropriate in another. Context must inform language use. Second, when defining a new phenomenon as violent, the agency of each stakeholder must be considered. If the term negatively impacts the agency of the apparent victim in particular, then another term should be considered (e.g., neglect, misunderstanding, and cultural misalignment). Third, health care practitioners working in culturally and socially unfamiliar settings must rely on patient enquiry, local advice, observation and in-setting training in order to be better equipped for patient care without the threat of judgment from standardized norms that do not sufficiently consider context.

We understand and support the research that uses terms such as "obstetric violence", but if we want to change broken systems, we may need to entertain the possibility of using a different kind of vocabulary to engage with structures and people in direct caregiving professions. We have discussed the use of the word "violence" in a context of obstetric care, using a South African setting as an example, but it may be helpful to think about this issue in health care in general. As researchers, we need to be as focused on finding better ways to approach complex problems as we are on creating new ways to define problems. Using terms may be experienced as inherently pejorative and moralistic and may, paradoxically, stand in the way of change.

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#### **CHAPTER TWELVE: CONCLUSION**

#### **12.1 Introduction**

In this dissertation, I have documented my investigations into the experiences of stillbirths at KH. The study was based on the primary research question namely,

What are the experiences of healthcare practitioners at KH when caring for women who have had a stillbirth, and how do the mothers themselves experience their care?

Throughout this dissertation, this question was explored from not only healthcare practitioners' perspectives, but also, those of the mothers who had delivered stillbirths. My primary focus was not on the experience of stillbirth itself but on the provision and experience of care, and its strengths and challenges. In Part 1 of this dissertation, I first introduced the study and the background by exploring the need for inquiry on this phenomenon. Specifically, gaps in the research literature were explored. Thereafter the outline of the research was presented. After the introduction, two literature reviews followed. The first of these reviews focused on stillbirths themselves. This chapter reviewed current relevant theory around the impact of stillbirths on families (particularly mothers) and the attending healthcare practitioners. This chapter concluded with an exposition of institutional care and the concept of structural violence. The second review (chapter 3) focused on institutional care during the stillbirth experience in a South African government hospital in Khayelitsha. This chapter started with an overview of the healthcare system in South Africa, and explored why a hospital like KH is under significant pressure. Furthermore, this chapter explored the inequality in South Africa's healthcare system as a product of the country's colonial past. Other factors that contribute to this inequality in the health system were also explored. This chapter then focused the Western Cape Health Department, and specifically obstetric care in KH. Part 1 of the dissertation ended with the methodology chapter. In this chapter each component of the research design, sampling design and data collection was described in detail.

Part 2 of this dissertation contained four journal articles (chapter five to eight) and consisted of the core findings of the study. At the time of submission, the articles were at different phases of the review process. Two articles were already published. Each of the articles explored aspects of the research questions. The first article explored the general milieu of the labour ward. This article examined the environment that mothers enter into and the healthcare

practitioners work in. The second article specially addressed the doctor's thoughts and feelings around women with stillbirths. The third article explored the nurses' feelings and thoughts about the women under their care. Finally, the fourth article focused on the voices of the mothers who were the recipients of the care from the doctors and nurses.

Part 3 of this dissertation began with my self-reflections on the research experience. A product of this self-reflective process was a chapter I wrote for a book called '*Out of Hours: Boundary Attunement with extreme trauma*' edited by Sinason and Sachs to be published by Routledge in 2021. The chapter is called '*I WANT TO RUN AWAY! Reflections from a participant observer*'. This was a very personal reflection on some feelings of hopelessness elicited at times when working in Khayelitsha. A fifth article titled '*How gentle must violence be to not be violent? Rethinking the word 'violence' in obstetric settings'* has been submitted to *Violence against Women*. This article challenges the overuse of the word 'violence' when describing certain situations as it may become counterproductive by unintentionally disempowering the women it describes.

Thus far, a broad overview of this dissertation has been presented. In this concluding chapter, I want to examine the importance of research in this field as well as the value of this study. I will also discuss the potential implications of my findings and what it suggests for the potential improvement of care, for mothers who experience stillbirths in settings like KH. I will conclude this chapter and this dissertation with some recommendations for future research on this topic.

#### 12.2 What are the implications of this study?

"Until you make the unconscious conscious, it will direct your life and you will call it fate." Carl Jung

I began this study with no pragmatic outcome in mind. Rather, I was interested in discovering why healthcare practitioners at KH behaved the way they did towards low-resourced mothers who had stillbirths. I have been a part of the KH system for a considerable period, and I recognised that we all colluded with the dynamics of the organization. Over the years, impression is that there has been little change in the organization of care. Instead, it seemed to me, systems of procedures have become more entrenched and rigid. Obholzer (1994, p. 206) wrote about how "institutional defences within helping organizations often exacerbate rather

than reduce the stress of working with people in distress". In this section, I will first examine how this research has impacted me and then how it has impacted KH healthcare practitioners.

#### 12.2.1 What I have observed in myself since completing my research

This research made me stop and ask myself the question: Why do I do what I do? Since concluding this research, I have noted that I have become more mindful in my interactions with those around me at KH. This observation is especially true with women who had stillbirths in the hospital. Although I have never had a checklist of questions to ask grieving mothers, I think that I now engage in a more present manner as I sit with them and talk. I ask them about all aspects of their lives, including their perceptions of the care they received in the hospital. I am not so rushed to get to my next patient or appointment. I am also more acutely aware of my "whiteness" and the potential unequal power dynamics that may exist between a mother and me in this context. I may be perceived by the mothers, as being more powerful than them, culturally, given my varied identities; as clinician, and as a middle-class White woman.

I am different because I belong to a more economically and socially privileged group in South Africa. This position denotes an unequal power dynamic that may hinder the therapeutic process. The difference I feel, resulted in a collaborative effort with other authors to document my experiences of being a White South African working in a traditionally Black area. Although this article is not included in this dissertation, it is relevant to my thinking processes and experiences that inspired my research in this field. In the above-mentioned article I contrast my experience with that of a Black clinical psychologist in the setting of KH.

# 12.2.2 What I have noticed in the healthcare practitioners in KH since completion of my research

As mentioned, immediately after the first two journal articles from my research were published, I shared them with KH's management team. This stimulated discussions in the hospital. This also led to the creation of a platform, where one of the obstetricians spoke at a meeting about care of women who have had stillbirths in the hospital. This kind of engagement did not occur previously during my tenure. I have also observed more visitors in the ward rooms with grieving mothers. When asked about this change, one of the nurses reported that, they now strongly encourage the mothers to invite anyone to come be with them. Although observing elements of conscientiousness and change was encouraging to see, there has also been some negative feedback from my distribution of the article. Soon after circulating the articles, I noticed one of the doctors avoiding me. When I raised this with her, she explained that my articles made her feel hopeless and despondent. The clinical manager then called a meeting about general research done in the hospital. He addressed how some of the staff were feeling threatened by the results of recently published articles (including mine). No feedback has been provided to me since that meeting, except the request for me to keep submitting any articles to them once they are published. To manage my own fear of further rejection that this research may elicit in my colleagues, I had to go back to Roberts and Obholzer's (1994) work. The authors' work reminded me that people can be resistant to change, no matter how small the change may be and even if they agree with the necessity for the change. The authors stated that:

"Managing change inevitably requires managing the anxieties and resistance arising from the change process. It is therefore important to understand the nature of the anxieties that are stirred up, as well as those inherent in the regular work of the organization" (Roberts & Obholzer, 1994, p. 206).

I needed to re-read the very articles I had written, to be reminded of the doctors' possible anxiety about working in such a context. This reminder helped me to contain my own anxiety.

### 12.3 Study limitations and directions for further research

This study utilised multiple sources to gather data in order to answer the research questions. Despite the use of multiple measures to maximise the value of this research, inevitably there were limitations.

This study was conducted in KH in the Western Cape. The Western Cape is one of the nine provinces in South Africa. The Western Cape health care services are unique in comparison to health care services in the other eight provinces. Consequently, the findings cannot be generalized to health care services in other provinces. Findings in qualitative studies, however, do have the potential for transferability (Green & Thorogood, 2018; Silverman, 2013). I do believe that given the pervasive nature of poverty in South Africa (Chapter 1) and the nature of the country's healthcare system (Chapter 3), that many of the findings from this study will

be applicable in other provincial hospitals. However, similar studies could be conducted in other provinces, and other tiers of the health care system to make comparisons.

Additionally, further research should consider other African hospitals (outside of South Africa), which may be even more stressed and under-resourced (Osman et al., 2017). The health care needs of the poor around the world are a focus for many streams of research. The care of mothers in obstetrics, and specifically their care during and after a stillbirth, has not received enough attention. This may be fathomable given that even the most basic of health care is not always available in the poorest of communities. Nonetheless, the discipline of health care (both physical and mental) must continue to develop a stronger foundation to meet the needs of global populations in every socio-economic group. Similarly, findings from similar research in hospitals' in other (non-African) lower income countries will assist in broadening and advancing this body of knowledge.

There are a number of methodological limitations to the findings presented in this dissertation. By using an ethnographic approach, the research findings are more likely to be subjective as they are filtered through the researcher's own values, beliefs and theoretical assumptions (Bantjes & Swartz, 2017). While this is usual (and even an advantage) of ethnographic research, I was acutely aware of my own biases. Consequently, I tried to minimize these biases by using bracketing. In addition, I monitored this subjectivity and potential biases in several ways. First, I consistently recorded self-reflections in my journal as a reference point as a means to increase reflexivity. I also regularly discussed my research during academic and professional supervision. This accountability (personal and supervisory) was crucial since I work in the hospital alongside the staff that I interviewed. Thus my objectivity could be challenged. Throughout the study, my reflexive process of writing and discussion with my supervisor and trusted colleagues, tested my own assumptions. As a result I gained greater insight into my own worldviews. I also shared the articles with some of my colleagues and asked for feedback before seeking publication.

A notable limitation to this study was the disparity between me and the patients and their context. While this disparity was core to the genesis of this research, my position was, as an outsider to the socio-political context of the KH patient community. Thus my immersion as a participant observer with patients may have been limited. Conversely, as a healthcare practitioner in KH myself, I was able to easily relate too much of what was expressed by the healthcare participants. Future research from healthcare practitioners from the KH community

or similar communities that have escaped poverty through education and training, may offer very different perspectives and ethnographic skill sets to a study like this. In addition, certain language and cultural barriers could be traversed, resulting in richer insights. Future researchers should consider these researcher orientated limitations. As South Africa's research pool expands to include more diversity, richer insights may be added to those from this study.

There are a number of other subject-specific avenues for potential future research based on this study. The following discussion of these avenues of research, focus on future research on mothers of stillbirths, healthcare practitioners and institutions.

First, research on mothers who have had stillbirths in other low- and middle-income countries is still necessary as research is limited. Tronto, (2010, p. 13) reported that "the best forms of institutional care will be those which are highly deliberate and explicit about how to best meet the needs of the people who they serve". This deliberateness cannot happen without additional subject specific research on grieving mothers. Future research may include; a longer term study of the impact of stillbirth on the grieving process for mothers in contexts like KH. Also, a more detailed quantification of phenomena identified in this study may be of value. These phenomena include quantifying numbers of visitors and duration spent in the labour ward before being transferred or discharged. Looking across the data set, contradictions (for example whether or not there were birthing partners with the mothers) were noted. Further research could explore these contradictions. In addition, interviewing other grieving family members may provide a more holistic view of the grief and the emotional milieu that the mothers return to after the trauma. A longitudinal study may also allow for longer term effects to be researched.

Second, future research could focus exclusively on South African healthcare practitioners working in environments with high levels of trauma. The disparity in socio-economic status and education levels often suggests that most doctors come from some form of privilege. Even in cases where doctors grew up in disadvantaged communities, by the time they qualify they are usually able to reside outside of areas like Khayelitsha. This patient-doctor disparity in South Africa requires additional research, as the country continues to emphasise the need for a better post-colonial perspective on many elements of research and service delivery. Moreover, there needs to be better understanding on the complex personal and socio-political roots of how South African healthcare practitioners cope under very difficult circumstances. Further

psychosocial research will help to clarify how to support these healthcare practitioners and help optimise and sustain their services.

Third, more research on obstetric violence in low and middle-income countries is still needed. As presented in this dissertation (specifically article 5), the nature of structural violence is still open to interrogation. Also, the agency of pregnant and birthing women in hospital settings like KH requires further research. The power dynamics and cultural disparity cannot in itself be singularly equated to obstetric violence. However the influences of such disparity cannot be accepted without further analysis either (as discussed in article 4). Other structural and organizational elements of the South African government obstetric healthcare system that require additional psychosocial inquiry include; patient on-boarding and discharge procedures, patient feedback mechanisms and general labour ward environments (article 1). Finally, there is scope to research government hospital management and their perspectives on labour wards in district and rural hospitals. While this research focused on practitioners and patients, there are other stakeholders that have influence over budgets, staff hiring and training and management. A more holistic stakeholder perspective may yield other avenues of research and opportunities to implement change.

I have learned a great deal from doing this research, not least about myself. I am mindful of the fact that to a great degree the insights I have gained come from my own privilege but also, crucially, from the suffering of others. In conclusion I am reminded of the following unattributed quotation:

"Each new life...No matter how fragile or brief...Forever changes the world."

Author Unknown

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# ADDENDA

# Addendum A: Permission letter from Stellenbosch University Ethics Committee



### NOTICE OF APPROVAL

REC Humanities New Application Form

31 January 2018

Project number: 1844

Project Title: Stillbirths at a district hospital in the Western Cape.

Dear Mrs Maura Lappeman

Your REC Humanities New Application Form submitted on 25 January 2018 was reviewed and approved by the REC: Humanities.

Please note the following for your approved submission:

### Ethics approval period:

Protocol approval date (Humanities)	Protocol expiration date (Humanities)	
30 January 2018	29 January 2019	

### GENERAL COMMENTS:

Please take note of the General Investigator Responsibilities attached to this letter. You may commence with your research after complying fully with these guidelines.

# If the researcher deviates in any way from the proposal approved by the REC: Humanities, the researcher must notify the REC of these changes.

Please use your SU project number (1844) on any documents or correspondence with the REC concerning your project.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

#### FOR CONTINUATION OF PROJECTS AFTER REC APPROVAL PERIOD

Please note that a progress report should be submitted to the Research Ethics Committee: Humanities before the approval period has expired if a continuation of ethics approval is required. The Committee will then consider the continuation of the project for a further year (if necessary)

### **Included Documents:**

Document Type	File Name	Date	Version
Recruitment material	Stillbirths at Khayelitsha Hospital (Appendix A)	26/10/2017	1
Data collection tool	Interview Guidelines for Healthcare Practitioners	30/10/2017	1
Data collection tool	Interview Guidelines for the Mothers	30/10/2017	1
Data collection tool	Ethnographic Research Framework	30/10/2017	1
Research Protocol/Proposal	Lappeman PHD Proposal 22.01.2018	22/01/2018	2
Informed Consent Form	SU HUMANITIES Consent form healthcare practitioners	22/01/2018	2
Informed Consent Form	SU HUMANITIES Consent form mothers	22/01/2018	2
Proof of permission	Dr Kharwa's support of proposal	22/01/2018	1
Proof of permission	Dr Verster's letter	22/01/2018	2
Default	Letter to REC Humanities	22/01/2018	1

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If you have any questions or need further help, please contact the REC office at cgraham@sun.ac.za.

Sincerely,

Clarissa Graham

REC Coordinator: Research Ethics Committee: Human Research (Humanities)

National Health Research Ethics Committee (NHREC) registration number: REC-050411-032. The Research Ethics Committee: Humanities complies with the SA National Health Act No.61 2003 as it pertains to health research. In addition, this committee abides by the ethical norms and principles for research established by the Declaration of Helsinki (2013) and the Department of Health Guidelines for Ethical Research: Principles Structures and Processes (2<sup>nd</sup> Ed.) 2015. Annually a number of projects may be selected randomly for an external audit.

# Addendum B: Permission letter from the Western Cape Department of Health



Health impact Assessment Health Research Sub- Directorate Health.Research@westerncape.gov.za Tet: +27 21 483 0866; fax: +27 21 483 9895 5th Floor, Norton Rose House, 8 Riebeek Street, Cape Tawn, 8001 www.capeaateway.gov.zay

REFERENCE: WC\_201801\_033 ENQUIRIES: Dr Sabela Petros

Stellenbosch University Francie Van Zijl Drive Tygerberg Hospital Cape Town 7505 For attention: Mrs Maura Lappeman

Re: Stillbirths at a district hospital in the Western Cape

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research. Please contact following people to assist you with any further enquiries in accessing the following sites:

### Khayelitsha District Hospital

### Dr Moses Witbooi

021 360 4386

Kindly ensure that the following are adhered to:

- Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
- Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (annexure 9) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
- In the event where the research project goes beyond the estimated completion date which was submitted, researchers are expected to complete and submit a progress report

(Annexure 8) to the provincial Research Co-ordinator

(Health.Research@westerncape.gov.za).

4. The reference number above should be quoted in all future correspondence.

Yours sincerely

AT HAWKRIDGE.

DR A HAWKRINGE

DIRECTOR: HEALTH IMPACT ASSESSMENT 28/2/2018.

DATE:

# Addendum C: Labour Ward Observations Explanation Sheet

Good day Colleague,

As you know, my name is Maura Lappeman and I am the Clinical Psychologist at Khayelitsha Hospital. I am doing research on how healthcare practitioners at Khayelitsha Hospital manage and feel about stillbirths. I will be spending some hours each day for the next six weeks in the Labour ward observing different people including staff members and mothers whose babies died before or just after birth. My hope through this study is that what I find out will help other women who experience this kind of loss and improve the quality of care they receive from the healthcare practitioners who work with them (such as doctors, nurses, social workers and cleaners).

I have obtained permission from the hospital as well as from Dr Els &Dr Parker to conduct these observations. I will keep your identity confidential, and will use a different name (pseudonym) when writing up my findings. The audio recording and notes from the observations will be kept in my office at home and will only be read by my supervisor and myself.

If you have any further questions or concerns, please contact me (Maura Lappeman) at 021-360-4288 or <u>mauralappeman@gmail.com</u>. Alternatively, you may contact my supervisor (Professor Leslie Swartz) at <u>lswartz@sun.ac.za</u> or 021-808-3450.

# Addendum D: Consent Form for the Healthcare Practitioners



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# STELLENBOSCH UNIVERSITY CONSENT TO PARTICIPATE IN RESEARCH

You are invited to take part in a study conducted by Maura Lappeman, from the Psychology Department at Stellenbosch University. You were approached as a possible participant because you are a healthcare practitioner who works with mothers who had a stillbirth in 2018.

# **1. PURPOSE OF THE STUDY**

I am doing research on how healthcare practitioners at Khayelitsha District Hospital manage and feel about stillbirths. I will be interviewing many different people including staff members but also mothers whose babies died before or just after birth in 2018. My hope through this study is that what I find out will help other women who experience this kind of loss and improve the quality of care they receive from the healthcare practitioners who work with them (such as doctors, nurses, social workers and cleaners).

# 2. WHAT WILL BE ASKED OF ME?

If you agree to take part in this study, you will be asked to I will ask you questions about yourself, your training and experience of stillbirths. The interview will be conducted in my private office at the hospital. The interview that will last for about an hour, although it may take longer. The interview will be recorded and then transcribed.

# 3. POSSIBLE RISKS AND DISCOMFORTS

You may find it upsetting to talk about your experiences working with mothers who had stillbirths in which case you will be referred to another psychologist for further counselling.

# 4. POSSIBLE BENEFITS TO PARTICIPANTS AND/OR TO THE SOCIETY

Although there are no direct benefits to you from this study, the knowledge gained may help other healthcare practitioners who work with mothers who had stillbirths.

## 5. PAYMENT FOR PARTICIPATION

Interviews will be done at the hospital during working hours. Refreshments will be provided.

## 6. PROTECTION OF YOUR INFORMATION, CONFIDENTIALITY AND IDENTITY

Any information you share with me during this study and that could possibly identify you as a participant will be protected. This will be done by using a different name (pseudonym) when writing up my findings. The recording and notes from the interview will be kept in a locked cabinet in my office at home and will only be read by my supervisor and myself. All recorded information; hard copies of transcripts and data collection instruments will be destroyed and deleted from my personal computer after the study has ended.

## 7. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you agree to take part in this study, you may withdraw at any time without any consequence. You may also refuse to answer any questions you don't want to answer and still remain in the study.

# 8. RESEARCHERS' CONTACT INFORMATION

If you have any questions or concerns about this study, please feel free to contact Maura Lappeman at 021-360-2488, and/or the supervisor Professor Leslie Swartz at <u>lswartz@sun.ac.za</u> or 021-808-3450.

# 9. RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research participant, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

# DECLARATION OF CONSENT BY THE PARTICIPANT

As the participant I confirm that:

- I have read the above information and it is written in a language that I am comfortable with.
- I have had a chance to ask questions and all my questions have been answered.
- All issues related to privacy, and the confidentiality and use of the information I provide, have been explained.

By signing below, I \_\_\_\_\_\_ *(name of participant)* agree to take part in this research study, as conducted by Maura Lappeman

Signature of Participant

Date

# DECLARATION BY THE PRINCIPAL INVESTIGATOR

As the **principal investigator,** I hereby declare that the information contained in this document has been thoroughly explained to the participant. I also declare that the participant has been encouraged (and has been given ample time) to ask any questions. In addition I would like to select the following option:

The conversation with the participant was conducted in a language in which the participant is fluent.

The conversation with the participant was conducted with the assistance of a translator (who has signed a non-disclosure agreement), and this "Consent Form" is available to the participant in a language in which the participant is fluent.

Signature of Principal Investigator

Date

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# Addendum E: Consent Form for the Mothers



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# STELLENBOSCH UNIVERSITY CONSENT TO PARTICIPATE IN RESEARCH

You are invited to take part in a study conducted by Maura Lappeman, from the Psychology Department at Stellenbosch University. You were approached as a possible participant because you experienced the loss of a baby before or just after birth in 2018.

# **10. PURPOSE OF THE STUDY**

I am doing research on how healthcare practitioners at Khayelitsha Hospital manage and feel about stillbirths. I will be interviewing many different people including staff members but also mothers (who are at least 18 years old) whose babies died before or just after birth. My hope through this study is that what I find out will help other women who experience this kind of loss and improve the quality of care they receive from the healthcare practitioners who work with them (such as doctors, nurses, social workers and cleaners).

## **11. WHAT WILL BE ASKED OF ME?**

If you agree to take part in this study, you will be asked questions about yourself and your loss. I would like to hear about your experience of your pregnancy, hearing the news of the death of your baby and the delivery and then how you coped. The interview will be conducted in my private office at the hospital. The interview will last for about an hour, although it may take longer and will be conducted in English. The interview will be recorded on a digital voice recorder and then transcribed.

# **12. POSSIBLE RISKS AND DISCOMFORTS**

Talking about your loss may be distressing, in which case you will be referred to a psychologist, other than myself, at the hospital or local clinic for further counselling.

# **13. POSSIBLE BENEFITS TO PARTICIPANTS AND/OR TO THE SOCIETY**

There will be no financial benefits to taking part in this research. Many women feel better once they have spoken about their loss and what it has meant for them. By allowing me to publish the information from our interviews about your loss, health practitioners may gain a better understanding of what it is like for other mothers who experience the loss of a baby. This may lead to better care of these mothers.

### **14. PAYMENT FOR PARTICIPATION**

You will be compensated for transport cost to and from Khayelitsha Hospital for the interview. Refreshments will be provided. Please let me know of any additional financial constraints to you being involved in the study such as childcare cost which I will reimburse you for.

### **15. PROTECTION OF YOUR INFORMATION, CONFIDENTIALITY AND IDENTITY**

Any information you share with me during this study and that could possibly identify you as a participant will be protected. This will be done by using a different name (pseudonym) when writing up my findings. The recording and notes from the interview will be kept in a locked cabinet in my office at home and will only be read by my supervisor and myself. All recorded information; hard copies of transcripts and data collection instruments will be destroyed and deleted from my personal computer after the study has ended.

## **16. PARTICIPATION AND WITHDRAWAL**

You can choose whether to be in this study or not. If you agree to take part in this study, you may withdraw at any time and your story will not be included in the research. This will not affect your care in the hospital in any way. You may also refuse to answer any questions you don't want to answer and still remain in the study.

## **17. RESEARCHERS' CONTACT INFORMATION**

If you have any questions or concerns about this study, please feel free to contact Maura Lappeman at 021-360-2488, and/or the supervisor Professor Leslie Swartz at <u>lswartz@sun.ac.za</u> or 021-808-3450.

## **18. RIGHTS OF RESEARCH PARTICIPANTS**

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If

you have questions regarding your rights as a research participant, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

## DECLARATION OF CONSENT BY THE PARTICIPANT

### As the participant I confirm that:

- I have read the above information and it is written in a language that I am comfortable with.
- I have had a chance to ask questions and all my questions have been answered.
- All issues related to privacy, and the confidentiality and use of the information I provide, have been explained.

By signing below, I \_\_\_\_\_\_ *(name of participant)* agree to take part in this research study, as conducted by Maura Lappeman

Signature of Participant

Date

# DECLARATION BY THE PRINCIPAL INVESTIGATOR

As the **principal investigator**, I hereby declare that the information contained in this document has been thoroughly explained to the participant. I also declare that the participant has been encouraged (and has been given ample time) to ask any questions. In addition I would like to select the following option:

 The conversation with the participant was conducted in a language in which the participant is fluent.

 The conversation with the participant was conducted with the assistance of a translator (who has signed a non-disclosure agreement), and this "Consent Form" is available to the participant in a language in which the participant is fluent.

Signature of Principal Investigator

Date

# Addendum F: Consent

RE: rpco20: Care and the politics of shame: Medical practitioners and stillbirths in a South African district hospital

Academic UK Non Rightslink <permissionrequest@tandf.co.uk>

14 November 2019

Dear Maura Lappeman,

**Material Requested:** Maura Lappeman & Leslie Swartz (2019): Care and the politics of shame: Medical practitioners and stillbirths in a South African district hospital, Psychodynamic Practice, DOI: 10.1080/14753634.2019.1670093

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