FACTORS INFLUENCING AUTOPSY CONSENT FOR SOUTH AFRICAN MINERS

A research report submitted to the School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Public Health.

Johannesburg, April 2017

Declaration

I, Julian Qedizaba Mthombeni, declare that this research report is my own, unaided work. It is being submitted in partial fulfilment of the requirements for the degree of Master of Public Health, in the field of Social and Behaviour Change Communication, in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination to this or any other university.

Julian Qedizaba Mthombeni

7th April 2017 in Johannesburg

Dedication

I dedicate this work, firstly to unknown numbers of South African mineworkers who have suffered from compensable lung diseases and departed this world without their families getting a chance to claim compensation.

To my daughters, Danielle, Daniella and Thando, you have made me better and stronger by giving me your tireless support and love throughout my academic life. Luanda my son, thank you for tying up many loose ends while I concentrated on my studies, I love you my boy.

Abstract

Introduction

Men and women working in the mines are exposed to health hazards that lead to disability and even death. The Occupational Diseases in Mines and Works Act (ODMWA) provides compensation to families of deceased mineworkers with autopsy-diagnosed occupational lung disease(s). Written consent is required from the next kin before the organs are examined. In the last couple of decades, the numbers of autopsied miners has declined and this may be related to the manner in which consent is requested from families. This study described and compared consent processes autopsy uptake, processes for obtaining consent and the experiences and perceptions of personnel involved in these processes in selected South African mines.

Methods

A sequential mixed-methods study was conducted. Autopsy uptake was determined using NIOH and hospital records, followed by exploratory qualitative research investigating the processes for obtaining consent in three mining hospitals among relevant staff. Transcripts of 14 audio recorded interviews and one focus group were coded and analysed using ATLAS.ti 7. Thematic content analysis was applied using a deductive and inductive approach.

Results and discussion

There was an overall 38% decline in autopsy uptake from 183 in 2009 to 113 in 2012 among the participating hospitals. Over the five-year period, the average autopsy uptakes for two of the hospitals were low: 34% and 12%, respectively. The third hospital recorded a high autopsy uptake of 86%. Procedures for offering autopsies were similar among the three hospitals but differed in the categories of personnel performing the tasks. In one of the hospitals with poor autopsy uptake, autopsies were offered to families only if officials thought the deceased miner had a compensable disease. A receptionist who had other competing responsibilities was responsible for offering autopsies in the other hospital. In the hospital with good uptake, the offer of autopsies was done by a prosector who was also a mine union representative and therefore understood the autopsy process and was trusted by the families.

Service providers identified lack of knowledge and awareness of ODMWA autopsies as an important factor that influenced family consent amongst a basket of many other factors including language barriers; distrust in the poorly functioning compensation system; traditional, religious beliefs and practices; and the lack of access to autopsy facilities especially in rural areas of South Africa. Some participants were dissatisfied or frustrated with the legal requirements for consent as it is a time consuming task that interfered with their other duties.

Conclusion

This study has shown that obtaining consent for ODMWA autopsy is a tedious and long process and can be a barrier to autopsy uptake. The personnel involved in offering autopsy play a very important role and need to understand the benefits and processes of autopsy compensation. The major recommendation of this study is the training of personnel involved in offering autopsies to improve their communication skills and, understanding of the purpose and provisions of the ODMWA in order to promote autopsy uptake.

Acknowledgements

I express sincere appreciation to everyone who made this work achievable. Each one of the persons I met in the course of this study journey played an integral role in the completion of my research report.

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Definitions

Autopsy – a dissection and examination of a body after death to determine the cause of death or the character and extent of changes produced by disease. In this study it refers to the pathological examination of cardio-respiratory organs for compensation purposes

Autopsy uptake – the annual number of lungs submitted to the NIOH per year per number of miners who died in that same year

Cardio-respiratory organs – lungs and heart

Mineworker – A person who works or worked in a mine

Prosector - A person trained to dissect cadavers/ perform autopsies for pathological examination

Acronyms

CCOD	Compensation Commissioner of Occupational Diseases
COIDA	Compensation for Occupational Injuries and Diseases Act, 1993
COPD	Chronic Obstructive Pulmonary Disease
CWP	Coal workers pneumoconiosis
CT	Computerised Topography
DoL	Department of Labour
FGD	Focus group discussion
GP	Gauteng Province
HR	Human Resources
HRM	Human Resources manager
HRO	Human Resources Officer
H&S	Health and Safety
IDI	In-depth Interview
LP	Limpopo Province
MBOD	Medical Bureau of Occupational Diseases
MHSC	Mine Health and Safety Council
MRI	Magnetic Resonance Imaging
NC	Northern Cape Province

NDOH	National Department of Health
NIOH	National Institute for Occupational Health
NSM	Nursing Services Manager
NW	NW –North West Province
OAD	Obstructive Airway Disease
ODMWA	Occupational Diseases in Mines and Works Act 78, 1973
OHSA	Occupational Health and Safety Act 85 of 1993
OLDs	Occupational Lung Diseases
PATHAUT	Pathology Automation System
PROS	Prosector
PTB	Pulmonary Tuberculosis
RN	Research Nurse
RS	Reception Supervisor
SAIMR	South African Institute for Medical Research
SBCC	Social and Behaviour Change Communication
SOP	Standard Operating Procedure
TAT	Turnaround Time
TEBA	The Employment Bureau of Africa
TB	Tuberculosis
UK	United Kingdom
WHO	World Health Organization
WO	Welfare Officer

CHAPTER ONE - INTRODUCTION

This chapter provides a background on the Occupational Diseases in Mines and Works Act 78 of 1973 (ODMWA), autopsy consent and the burden of occupational lung diseases in South African miners. This study sought to identify factors influencing the autopsy consent process from the perspective of those offering autopsy services. These factors can be identified pre- or post-mortem. The rationale is that there might be facility-based factors responsible for the low utilization of autopsy services by relatives of deceased miners, despite the possibility of compensation pay-out as an incentive for consenting to an autopsy. This chapter reviews the general literature on autopsies to frame what is already known about factors that influence autopsy utilization, with a particular focus on those factors specific to consent.

1.1 Introduction

1.1.1 Occupational lung diseases

Occupational lung diseases (OLDs) are respiratory diseases caused by the inhalation of dusts, chemicals, or proteins. These diseases include occupational asthma, black lung disease (coal worker's pneumoconiosis), chronic obstructive pulmonary disease (COPD), mesothelioma, and silicosis, all of which affect the respiratory system (NIOSH, 2012). The severity of the disease(s) relate to the material inhaled and the intensity and duration of the exposure. The development of OLDs depends on the toxic properties of the inhaled substance, extent of the exposure and the physiologic and biologic susceptibility of the individual (Balmes et al., 2003). Occupation-related diseases do not only affect the worker and their families, but also can cause loss in productivity and increase the use of health services leading to economic loss to the government, which ultimately affects public health service delivery (Leigh et al., 1999).

In South Africa (SA), gold miners are exposed to crystalline silica dust found in quartz rock containing gold, causing numerous lung diseases and increasing mortality (Beckett et al., 1997). South Africa also has a high burden of TB which the World Health Organization (WHO) estimated as 450 000 per 100 000 persons incident cases of

active TB in 2013 giving South Africa the third highest TB incidence, after India and China, making TB one of the major causes of morbidity and mortality in South Africa (WHO, 2015).

The comorbidity of silicosis and TB, in particular, are also of public health concern as these diseases threaten the health of gold miners with consequent economic effects on families. Silicosis is a predisposing factor for TB (Hnizdo and Murray, 1998). Tuberculosis also is exacerbated by the human immunodeficiency virus (HIV) pandemic causing a triple burden of disease in the South African gold mines. This burden places miners at a disproportionate risk of morbidity and mortality, which is worsened by the hazardous working conditions and their crowded living arrangements, particularly among black miners (Srivastava, 2013).

In the platinum industry, platinum specific diseases are reportedly rare for active miners. However, platinosis which is an allergic reaction due to platinum salts has been reported (Calverley et al., 1995). This condition, according to literature, occurs among platinum refinery workers post mining of the mineral. Platinum salt induced asthma has also been reported in platinum refinery workers (Merget, 2000, Taylor, 2001).

Asbestos mining has been linked to a number of OLDs, including mesothelioma, asbestosis and pleural plaques. In the 1950s, a physician observed pleural effusions characteristic of tuberculosis which at the time was endemic in the Kimberly mine areas in the Northern Cape. Not long after, this new condition was discovered to be associated with asbestos and later confirmed to be mesothelioma upon autopsy of deceased miners (Wagner, 1991). Mesothelioma is a malignancy that is characterised by a thick, firm, white tissue that covers the lining of the lung cavity (Kumar et al., 2010). Mesothelioma, associated with work in asbestos mines, has a long latency period and people affected by it often have minimal chances of survival (Robinson, 2012). Asbestosis is an interstitial fibrosis caused by the inhalation of asbestos fibres. Similar to mesothelioma, asbestosis and pleural plaques develop due to exposure to asbestos fibres and have long latency (Wagner, 1991). Asbestos poses huge environmental risk and endangers the lives of people living around asbestos mining areas. Reviewed literature show that families living around asbestos mining areas and exposed to

sufficient asbestos fibres develop mesothelioma as a result of an environmental exposure (Abratt et al., 2004). Even though asbestos mines have all officially been closed down, there is still the risk of environmental asbestos exposure to miners in non-asbestos mines situated in the Northern Cape, which has huge deposits of asbestos (Ndlovu et al., 2013).

1.1.2 Compensation Acts for miners

South Africa has two compensation Acts for occupational diseases; these are the Compensation for Injuries and Diseases Act 130 of 1993 (COIDA) and Occupational Diseases for Mine Workers Act (ODMWA). The Compensation for Injuries and Diseases Act provides compensation for injuries, diseases and deaths sustained by all employees in the course of their employment except for OLDs in miners the and is governed by the Department of Labour (DoL) whereas ODMWA is a separate occupational health law explicitly for occupational lung diseases in mineworkers and is governed by the Department of Health (DoH). The latter is administered by the Medical Bureau for Occupational Diseases (MBOD) in Johannesburg. The compensation pay-out decision is based on certification made from autopsy findings (RSA, 1973).

Section 34 (2) of the ODMWA clearly makes it the duty of the last attending doctor or pathologist who performs a post-mortem on a deceased body to arrange for removal of cardio-respiratory organs (heart and lungs) and the delivery of those organs to the National Institute for Occupational Health (NIOH) (RSA, 1973). The Act further states that these organs can only be removed with written consent from the next of kin after death, unless the family cannot be reached for consultation:

> *Notwithstanding anything contained in subsection (1) or (2), a medical practitioner shall not perform a post-mortem examination on any deceased person or remove his cardio-respiratory organs or any other organs or parts of his body, without the consent of his widow (if any) or an adult near relative of the deceased, if the widow or such a relative can readily be consulted (RSA, 1973).*

Indeed, the Act is silent on what step(s) the person performing the autopsy should take should he or she encounter a situation where the family cannot be reached for consent. This leaves a window for the exercise of discretion by the one to perform the autopsy.

Enshrined in the Act are provisions for determining eligibility for compensation. In certain circumstances, such as where a miner has received full compensation due to a compensable disease while alive, such a miner may not be eligible for compensation after he or she has died. There are two levels of compensation based on impairment. The first degree is when there is cardiorespiratory impairment of ≥10% ≤ 40% disability and second degree is when cardiorespiratory impairment is more than 40%. People who are compensated for second degree impairment while still alive do not receive further compensation and there is no need for autopsy examination (Banyini, 2013). In Section 36, the Act stipulates that the employer (mine) is responsible for the cost of medical examination of miners who die while in employment (active miners) whereas, if the person is out of employment, the overall provision of autopsy examinations and compensation is paid for by the Director of the MBOD to aid the process of autopsy uptake (RSA, 1973).

The NIOH provides containers (Figure 1.1) to private doctors, undertakers, forensic mortuaries, government hospitals, for safe transportation of lungs and mine. Each container has formalin, which is used for the preservation of the lungs and a form for documenting profile information and mining service history of the deceased person for confirmation of service and exposure, and a consent form to be signed by a relative if agreeing to autopsy. Containers containing lungs are delivered or sent by courier to the NIOH.

Figure 1.1 Lung containers (lung boxes) with buckets containing formalin and autopsy documents (June 2009, used with permission)

1.2 Literature Review

1.2.1. The value of autopsies

The importance of autopsies in diagnosing diseases cannot be overemphasised. Autopsies have been central in diagnosing a number of obscure and rare conditions and have helped to further the understanding and pathogenesis of many diseases. Autopsy has been long regarded as the 'gold standard' in determining the cause of death and is used in quality assessments of clinical practice (Kuijpers et al., 2014). The process of death, gross pathology and the teaching of anatomy in medical schools also rely heavily on autopsies (Bamber et al., 2014).

Autopsies, even in this day of high technology, remain important diagnostic tools. A study done in 2012 in Berlin which analysed diagnostic discrepancy rates, comparing clinical diagnosis before death with autopsy findings in 2007 and 2012/2013, found that the frequency of minor discrepancies increased from 26.8% to 39.3% over a period of seven years (2007 to 2013) (Kuijpers et al., 2014). In another study, the quality of clinical practice by institutions was evaluated among participating institutions in a 1993 College of American Pathologists Q-Probes Quality Improvement Program. This study showed that nearly 40% of autopsies conducted revealed major unexpected findings that contributed to the death of patients (Richard J. Zarbo et al., 1999). A systematic review of autopsy-detected diagnostic errors of the 20th century in Switzerland reported about 20% major errors in clinical diagnosis (Shojania et al., 2003). In a South African study, 52% of autopsy detected TB had been missed in life and in 16% of the cases, TB was wrongly attributed as the cause of death (Field et al., 2011).

Apart from the diagnostic significance described above, autopsies can help to bring closure to both the doctor who was treating the patient and the bereaved family (Baker et al., 2013). If a patient dies unexpectedly, the treating doctor would like to understand what could have gone wrong during the treatment. Similarly, the family may also want to understand the cause of death, which may help it accept the death.

1.2.2 Trends in autopsy uptake

A global decline in autopsy utilization over the past decades has been reported (Ayoub and Chow, 2008, Oluwasola et al., 2009). In developed countries, declining autopsy rates of less than 10% were reported in the 1990s (Loughrey et al., 2000). This is in contrast to rates of 70% in the 1970s (Asnaes and Paaske, 1980). Interestingly, autopsy utilization rates are similar if not better in developing countries than in developed countries. For example, a developing country like Nigeria reported a 29% autopsy utilization rate (Diegbe et al., 1998) in the same 1990s that developed countries reported less than 10%.

1.2.3 Factors contributing to decline in autopsy utilization

Factors contributing to low autopsy uptake may be related to the providers, while others originate with the users, i.e. families of the deceased. Although the focus of this study is on the service-providers, both perspectives will be discussed in this section.

1.2.3.1 Consent

Autopsy consent is permission to perform autopsy examination on a deceased person given either by the deceased person before death (living will) or the next of kin. Generally, the surviving spouse or next of kin of the deceased can give or refuse consent for autopsy (Kligman, 2000).

Consent falls under bioethics. In the past, ethics in the medical sciences was considered less important in healthcare delivery. Issues of consent in bioethics first came to the fore following the Nuremburg trials (Glueck, 2008, Ghooi, 2011) and the Tuskegee trials (Lowenstein et al., 2009). These breaches of ethics and patients' rights culminated in the development of a ten-point document known as the Nuremburg Code. This was the first instance where the international community became incensed over bioethics and acted to require voluntary patient consent in any trial or clinical experimentation involving human subjects. Autopsy for compensation also requires the next of kin to give consent. This was done to protect individuals, families and

communities from harmful and unethical practices. The Act in Section 34 allows removal of organs without consent if the family is not readily available. The requirement for consent has been associated with the decline in autopsies (Davies et al., 2004, Banyini et al., 2013, Kligman, 2000). This has led to a heightened interest among researchers wanting to find reasons for families refusing autopsies despite the possibility of gaining monetary compensation, especially in cases of ODMWA autopsies.

1.2.3.2 Service provider factors

Healthcare workers' perceptions and attitudes towards autopsies play a significant role in determining whether families agree and give consent for autopsy or not (Burton and Underwood, 2007, Nemetz et al., 2006). Medical practitioners in general view autopsy as a valuable tool (Midelfart and Aase, 1998). However, multiple global studies have revealed a variety of challenges leading physicians not to request autopsy consent from families (Oluwasola et al., 2009, Start et al., 1994). The most common reason cited by clinicians in many studies is the burden of the convoluted process involved in obtaining consent from the family of the deceased person (Bajaj, 2006, Burton and Underwood, 2007, Oluwasola et al., 2009) A study conducted in Nigeria found excessive bureaucracy and bottlenecks involved in obtaining family consent for autopsy (Oluwasola et al., 2009).

Another documented reason for healthcare providers' reluctance to use autopsies includes advances in medical imaging technology. Several studies have found that a common reason for low utilization of traditional autopsy procedures is that medical imaging has advanced and that has reduced the value of conventional autopsy (Ayoub and Chow, 2008, Nemetz et al., 2006, Charlton, 1994). Specifically, to overcome the challenge of mutilating the body and the protracted time to obtain the results, Computed Tomography (CT) scans and Magnetic Resonance Imaging (MRI) that are quick to yield results are being used; these minimally invasive techniques to investigate the cause of death have superceded conventional methods of post-mortem diagnosis (autopsy) in some contexts (Bajaj, 2006). Although this is an option in developed countries, it has not been tried in resource scarce settings including South Africa

(Becker et al., 2014), because of the expensive nature of these imaging techniques and scarcity of experts to carry out the procedures (Roberts et al., 2012).

Fear of litigation is another barrier to autopsy in the healthcare setting as deaths may occur as a result of error or mismanagement on the part of physicians (Maharjan et al., 2015). In such instances, doctors would act to protect their careers and avoid litigation by not requesting autopsies (Anderson et al., 1990, Katz and Seidel, 1990, Oluwasola et al., 2009, Wood and Guha, 2001).

Another dynamic is a shift towards verbal autopsy (VA) in response to human resource shortages. Pathology is a scarce skill area in Africa, hence the few pathologists available are overwhelmed (Lishimpi et al., 2001). Many countries have begun to introduce verbal autopsy in order to provide a means for the collection of important information about a death from interviews with the next of kin or other caregivers (Lishimpi et al., 2001; Leitao et al., 2013). Although verbal autopsy is an epidemiological tool, it is unlikely to be used for compensation purposes as it may not be sensitive enough to identify occupational diseases and their severity.

1.2.3.3 User (community/family) factors

There is a rich global literature on factors leading families to refuse consent to conduct an autopsy, including fear of stigma if an outcome becomes known. In recent decades, many African communities have been faced with increasing and devastating deaths due to AIDS, a stigmatised syndrome, and therefore families of the deceased suffer distress when asked to give consent for autopsy (Greeff et al., 2008, Campbell et al., 2007). This distress could be contributing to the reasons for refusing autopsy.

One of the most common reasons for refusal relates to a desire to maintain the bodily integrity of the deceased and to adhere to burial requirements, or perhaps due to religious requirements or the cultural beliefs of the family. Multiple studies in Africa have identified a fear of mutilation of the deceased's body, as families would like to keep the body in the best condition possible in respect of the dead as well as a concern that autopsy could cause funeral delays (Oluwasola et al., 2009, Lishimpi et al., 2001). Part of this is linked to religion, where Muslims, for example, are required to bury the

deceased person within 24 hours after death (Birdi et al., 1996, Oluwasola et al., 2009, Start et al., 1994). A well-known quotation by the Prophet Muhammad states, "Breaking the bone of a dead person is akin to breaking the bone of a living person," which results in some Muslim communities not allowing autopsy, as they believe it is cruel to the deceased (Rispler-Chaim, 1993).

Similar dynamics are found among those who practise ancestral worship, common in South Africa, who believe that when people die, they cross over to an ancestors' land but maintain spiritual connection with the living (Lugira, 2009). Resurrection and reincarnation are two common beliefs among ancestral worshipers (Bae, 2007) and because of this belief, they hesitate to give consent for autopsy because they want the deceased person to resurrect in the afterlife with a complete body (Banyini et al., 2013). It is further believed that ancestors become devastated when their relative arrives in the ancestral world with disabilities caused by autopsy examination and may be rejected in the spiritual world. African traditional religious worshipers believe that a dead body feels pain and that opening a cadaver causes undue pain (Banyini et al., 2013).

Another factor in families' decisions to consent, which is not reflected in most legal consent processes, is the role of community. In many African societies, the sense of community and belongingness is highly valued, which means that families are also subject to social norms (Tindana et al., 2006, Masina, 2000). As such, in some African societies, consenting to autopsy or any medical procedure or research outside of community values is not acceptable. For instance, some communities in Ghana need permission to be granted by the chief (Tindana et al., 2006). A similar dynamic has been noted in some South African groups, where in an effort to live harmoniously with other members of the community and show respect to the community's values and practices, called *Ubuntu*, families refuse autopsy consent if it is not practiced or approved by the local chief (Masina, 2000).

Witchcraft (ukuloya) is practiced by many African communities and is generally accepted to be a bad cultural practice. Misfortunes such as a loss of a relative could

be blamed on witchcraft. Hence, the removal of organs for any reason is unacceptable (Ashforth, 2005). Therefore, families may decline autopsies in order to maintain the integrity of the body.

1.2.3.4 Communication

The consent process is an interaction between the autopsy service provider and the families of the deceased. The nature of the communication itself may relate to whether or not autopsy consent is given. One study found that constant communication between the attending physician and the deceased's relatives helps to build trust and establish rapport for the approval process to consent (McHaffie et al., 2001). Similarly, the credibility and familiarity of health care workers is a very important factor families consider before giving consent (Sherwood and Start, 1995, McHaffie et al., 2001).

1.2.4 Conceptual framework for autopsy consent

The importance of the consent process and specifically the interaction between families (users) and institutions (service-providers) has been highlighted in the work of Banyini and colleagues, who developed the conceptual framework presented in Figure 1.2 (Banyini *et al*., 2013). Their framework identified the enablers and barriers affecting ODMWA autopsy in South Africa. This included, but was not limited to cultural and religious beliefs and practices. They found that the autopsy decision was taken in line with the family's cultural or religious belief system. The framework highlights the fact that service providers are key players in the autopsy consent process, both in terms of the services they deliver, as well, as their attitudes. This falls under both institutional and socio-cultural perspectives. Institutionally, the provision by management of adequate resources such as human resources, autopsy equipment and finances necessary for the smooth provision of autopsy and autopsy related service. On the socio-cultural dimension, willingness and courtesy on the part of service providers to offer autopsy services were very important in the acceptance of the service by relatives of deceased miners as highlighted in the framework.

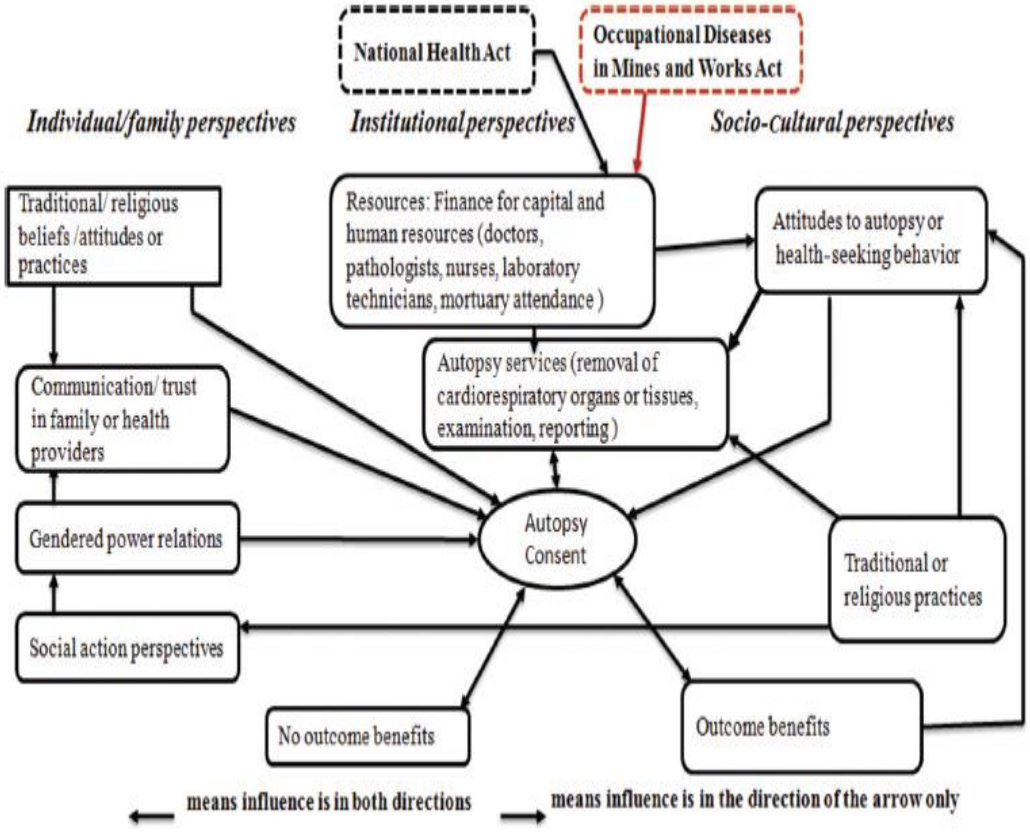

Figure 1.2 Conceptual framework of factors influencing clinical autopsy utilization (Banyini et al., 2013).

1.3 Problem Statement

There is an epidemic of occupational lung diseases facing miners in the world, with pneumoconiosis, a disease of the lungs, characterized by fibrosis and caused by the chronic inhalation of mineral dusts, responsible for 30 000 deaths annually in the world (Lehtinen and Goldstein, 2002) and South Africa reported a prevalence range of 26% to 36% among ex-miners (Girdler-Brown et al., 2008). Though deaths due to occupational diseases are high in South Africa (Nelson, 2013), the number of ODMWA autopsies is declining (see Figure 1.3 below). Several authors have noted that a barrier is the ODMWA requirement for getting family consent to perform an autopsy of the deceased miner (Banyini et al., 2013, Davies et al., 2004, Kligman, 2000). The autopsy trend observed in South Africa is similar to the global pattern. As observed in Figure 1.3, autopsy utilization as reported by the NIOH, lingered around 3000 autopsies per

year from 1975 to 1995, when it recorded its highest level. Since then, it has been dropping till date. For example, there was a decline from 344 000 in 1994 to 131 591 in 2014 representing a 61.7% decrease. However, the decline in autopsies is likely to be explained by a combination of factors, including an increase in autopsy consent refusals.

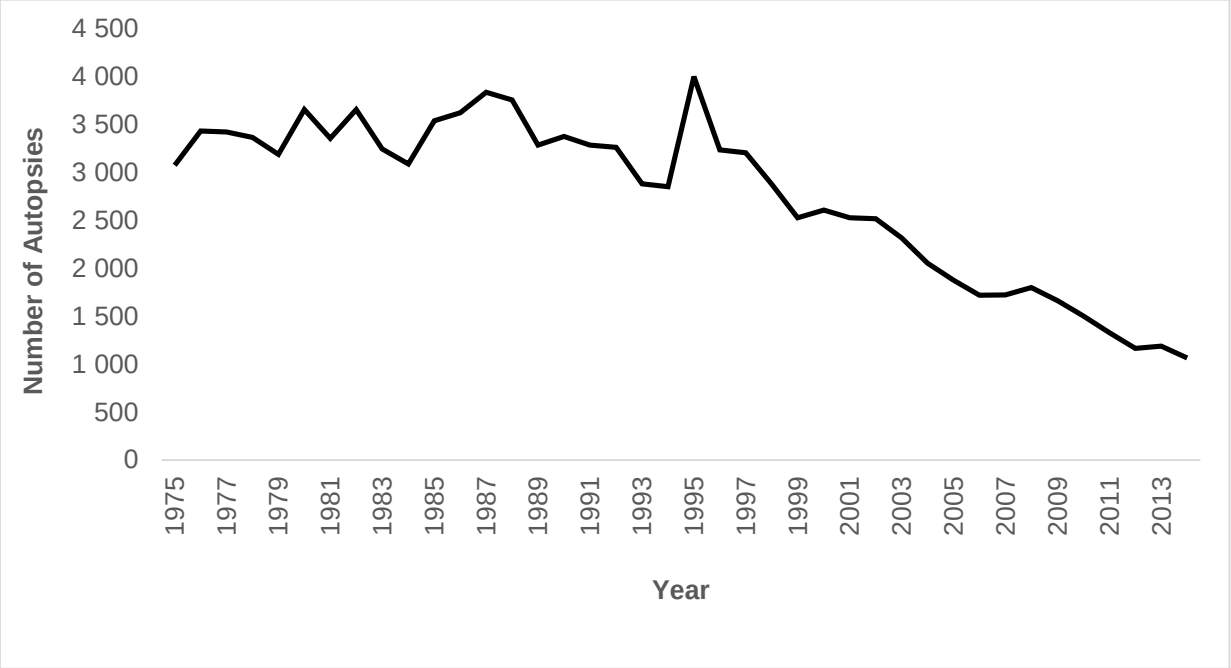

Figure 1.3 Annual numbers of total autopsy performed at the NIOH (1975 – 2014) (NIOH, 2014)

1.4 Justification

Requesting family consent to perform the ODMWA autopsy is ethically correct and in line with the Act. However, it has been reported as a barrier to autopsy examination for compensation. The rates of OLDs seen at the NIOH are high. In 2013, the overall Pulmonary Tuberculosis (PTB) rate was 192/1000, silicosis was 232/1000 and the rate was 355/1000 for emphysema, making these the three diseases with high rates in miners (NIOH, 2014). In clinical practice, misdiagnosis is very common. A 2000 study revealed that as high as 64% of clinical diagnosis was rebutted at autopsy. For

example, out of a total of 1571 patients who were clinically diagnosed without PTB, 64% of them were later found at autopsy to have PTB (Murray et al., 2000). With such high disease rates, it makes it vital that miners are autopsied after death to increase the rates of compensation claims. An increase in autopsy can only come about if families agree and give consent.

While Banyini and colleagues explored consent from the perspective of miners and their families, less is known about provider perspectives or behaviours related to consent. This study will attempt to inform interventions directed at increasing autopsies for deceased miners in South Africa by accounting for provider's experiences and perceptions regarding autopsies for deceased miners. The study focused on providers who interacted with families of active miners, that is, those who died while in employment.

1.5 Aim

The aim of this study was to describe and compare the autopsy consent processes in selected South African mines, and the experiences and perceptions of people involved in autopsy process for families of deceased miners in South Africa.

1.6 Study Objectives

The objectives of this study were:

1. To determine autopsy uptake by families of deceased active miners in selected gold and platinum mines from 2008-2012.
2. To describe the procedures for offering autopsies to the families of deceased miners in the selected mines and any significant changes in procedures in the period 2008-2012.
3. To compare procedures for offering autopsies among mines with declining autopsy uptake and those that maintained high autopsy uptake.
4. To explore the experiences and perceptions of mine officials and persons involved in offering autopsies for compensation to the families of deceased miners.

CHAPTER TWO - METHODOLOGY

2.1 Introduction

This chapter describes the methods used to determine autopsy uptake by families of deceased active miners and, to explore the experiences and perceptions of people involved in the provision of autopsy services to active South African miners. It also describes the settings and context where the study took place, the population, sampling, data collection, data analysis and ethical considerations.

2.2 Study Design

A sequential mixed methods study design was used. Study sites were purposively selected for the determination of autopsy uptake at each site. Qualitative techniques then were used to document the autopsy process and obtain information on the experiences and perceptions of autopsy service providers at each site.

2.3 Study Setting and Context

The study focused on statutory autopsies for SA miners. Mine hospitals/ mines were selected using information in the NIOH's autopsy registers and PATHAUT database for the years 2008 to 2012. PATHAUT database that has stored the pathological records of miners examined at the NIOH in Johannesburg since 1975 and contains 100,000 records (Ndlovu et al., 2016). Information on PATHAUT includes pathology findings, demographic characteristics and summaries of occupational histories.

The numbers of lungs received submitted by each mortuary or healthcare provider were retrieved from the PATHAUT database. The annual numbers of deaths in mining hospitals were obtained from the participating hospitals. Interviews were conducted with staff members at three hospitals serving the selected platinum and gold mines. The study took place at a time when there was major unrest, which began in the platinum mines and spread to the gold mines (Antin, 2013). This resulted in difficulties in obtaining permission to conduct the study in some of the mining hospitals which had been identified. Four of the selected hospitals were in the platinum belt and were

closed at the time of the study and five gold mine hospitals did not grant permission. Permission to conduct the study was obtained from three mining hospitals located in Gauteng and North West provinces, where gold and platinum mining activities are concentrated in South Africa. Each hospital belonged to a major mining company and serviced mines and shafts belonging to the relevant company. Hospital A serviced three platinum mines, whereas Hospitals B and C serviced three gold mines, respectively. These hospitals also served the communities living in the areas surrounding the mines.

A professional nurse who had been involved in offering autopsies to former asbestos miners in Kuruman (Northern Cape Province) on behalf of the Asbestos Relief Trust (ART) and Kgalagadi Relief Trust (KRT) was also recruited to participate in the study. These Trusts compensate former asbestos miners, their families and community members with asbestos-related disease related to having worked on or lived in the vicinity of the mines operated by Kumba Cape Blue Asbestos (KCBA) and/or Danielskuil Cape Blue Asbestos (DCBA) between 1952 and 1981 (ART, 2010). This respondent was included in the study because only half of the selected sites gave approval for the study and to obtain the perspective of someone who had worked for a long time with miners. Her inclusion also gave an opportunity for the study to learn best practices and draw her expertise in matters relating to autopsy consent. Due to her record in submitting a high number of lungs to the NIOH, it was assumed that certain positive attitudes of hers accounted for her ability to secure consent hence, her recruitment into the study in order to learn this positive attributes.

2.4 Study Population

For the determination of autopsy uptake, all miners who died in each of the hospitals (2008-2012) and those whose organs were submitted to the NIOH were included. Information for selection of study sites and denominators (all miners deaths recorded per hospital per year) for calculation of autopsy uptake were obtained from the hospital death registers. The numerators (all lungs sent to the NIOH per hospital per year) for

the calculations of autopsy uptake were extracted from the NIOH autopsy registers where the lungs were received.

For the qualitative component, individuals directly and indirectly involved in the process of offering autopsies to the families of deceased active miners were included.

2.5 Sampling

In line with objective 1, the total annual numbers of organs submitted to NIOH by each mine hospital over the five year period was determined. Purposive sampling was used to select six mine hospitals which had shown a significant decline in annual numbers or had stopped submitting organs, and six which had maintained constant numbers. For reasons explained in 2.3 above, two of the three mine hospitals had maintained high autopsy uptake and the third one had low uptake. Participants were purposively recruited for interviews if they performed autopsy consent-related duties. All recruited participants from the hospital setting consented to be interviewed except for one doctor who was not available during the data collection period.

In addition, the researcher approached the National Union of Mineworkers (NUM) for permission to interview health and safety (H&S) representatives. The union preferred that the researcher took advantage of the representatives from gold and platinum mines attending a health and safety meeting in the North West Province (NW). A convenience sample of eight H&S representatives was recruited from the union representatives who attended this workshop. The eight H&S representatives who participated were from the group of mines that were served by the three hospitals that participated in the study.

Purposive sampling was also used to recruit the professional nurse who offered autopsies for compensation to the families of former asbestos miners. Although not based at a mine hospital, this nurse had worked for a private medical practitioner who oversaw the removal of organs in the Northern Cape Province (NC).

2.6 Data Collection

2.6.1 Autopsy uptake

Autopsy registers provided information on mining hospitals and were used to link each lung container (box) to a facility/person that sends lungs to NIOH (sender). Each lung box is allocated a unique number by NIOH which is linked to a specific sender. This number is captured/ recorded for each case. The researcher followed a manual process to group container numbers for each sender. This information was used to create a new variable on PATHAUT which enabled identification and counting of the numbers of organs submitted by each hospital sent per year. The numbers of deaths per hospital were taken from death registers of each mine hospital. The death registers record all deaths of miners employed by the mines serviced by the hospital and who die in the hospital or in the vicinity of the mine and brought in to the hospital mortuary.

2.6.2 Autopsy procedures

A checklist (Appendix 1) was used to obtain information on procedures for offering autopsies at each mine hospital. Copies of Standard Operating Procedures (SOPs) were collected and verbal descriptions given during the interviews were noted and recorded on the checklist.

2.6.3 Interviews

The researcher conducted 14 In-depth Interviews (IDIs) and one focus group discussion (FGD) between December 2013 and March 2014, supported by an interview guide (Appendix 2). An appointment to interview participants was arranged to ensure adequate time for the interviews. The IDIs were conducted in private, in the participant's offices in the respective hospitals. Interviews with doctors and the research nurse were conducted in English, while Zulu, Xhosa and South Sotho were used with the other participants. The interviews were audio recorded and field notes were taken. The IDIs lasted from 10 to 45 minutes and the FGD was an hour long. During the interviews, participants were allowed to talk freely beyond the scope of the initial questions.

2.7 Reflexivity: The Researcher's Role

At the beginning of each interview session, the researcher introduced herself as a Master of Public Health candidate and revealed her affiliation with the NIOH. The researcher worked for ten years in the Pathology department of the NIOH as a medical technologist until 2011 and was trained in mortuary techniques. In addition to laboratory work, the researcher's responsibilities included liaising with institutions that sent lungs for autopsy to the NIOH. The researcher was also involved in a number of outreach activities which included visits to mining hospitals, training prosectors[1] in organ removals. She also participated in various campaigns for the Northern Cape areas sponsored by the ART. The researcher also conducted workshops on compensation for union H&S representatives in partnership with mine unions and specialised small group training for health care professionals in organ removal.

During those NIOH visits, a relationship was formed with some of the people involved in autopsy offering and organ removals for autopsies. Due to the relationships that existed with a majority of the participants prior to the study, including a shared interest in autopsy compensation issues, the researcher felt that most participants felt free to speak openly about all issues related to autopsies because they were familiar with her. The researcher convinced the participants that by truthfully answering her questions, giving the required information and telling about their experiences to the researcher would in the term assist to bring positive changes in the compensation process. Participants showed confidence and trust in the researcher, evidenced in that participants talked about all their experiences and frustrations of the compensation system. Many participants identified the researcher as a peer and a comrade in the same 'struggle'. The relationship did seem to matter, where interviews were longer with those with whom the researcher had prior relationships. Doctors, who were not familiar with the researcher seemed aware of her relationship with the people involved in the day to day running of the autopsy service. During the interviews doctors often referred the researcher to the prosector and the nursing services manager. As a result, interviews with them were shorter than expected.

[1] A prosector is a person trained to dissect cadavers for pathological examination

Another factor that probably made participants freer to share their experiences was the researcher's identity as a black South African who speaks many languages, including Afrikaans, and the cultural insights she brought as a result. For instance, the researcher was able to allow participants to communicate in the language they were comfortable with. It allowed flexibility for those participants who could not freely communicate or chose not to communicate in English. The researcher also understood the cultural and work place dynamics, such as what and how to ask questions to the participants, who were all African men except for the research nurse and two doctors. African culture requires that a female should show respect when talking to adults especially men. The kind of respect that somebody of a different culture would not know, for example, you do not look directly in the eyes when talking to an adult, the kind of words you can or cannot use, some expressions that can or cannot be used and more.

However, the possibility of obtaining biased responses from the study participants cannot be entirely ignored as they might have stated what they thought the researcher wanted to hear. Even though the researcher was no longer affiliated with NIOH, participants may have believed that they could still get assistance from her. The researcher, being aware of her own biases due to having worked at the NIOH, piloted the questionnaires before the study to remove any leading questions. Her supervisors assisted with coding and analysis to minimise bias in terms of how data were interpreted.

2.8 Data Management and Analysis

The researcher calculated the proportion of cases submitted to the NIOH per sender per year to enable the determination of high or low (number of organs) senders. Autopsy uptake was determined using the formula below:

$$\text{Autopsy uptake} = \frac{\text{Number of lungs submitted per hospital per year}}{\text{Number of deaths of miners per hospital per year}} \times 100$$

Information obtained using the checklists was summarised. Audio-recordings of the IDI's and FGD were transcribed within a two week by an experienced transcriber. The verbatim transcripts were then uploaded onto ATLAS.ti 7 software for coding and analysis. The field notes taken during the interviews were consulted during data analysis to clarify areas that were unclear in the transcripts.

The researcher applied thematic content analysis, the most foundational of qualitative analytic procedures (Anderson, 2007), using a combination of deductive and inductive approaches. The deductive themes were derived from the research question and objectives, whereas inductive themes were identified from the data and emerging issues documented. For code validity, the researcher initially coded the first few transcripts and discussed the codes and themes with one of her supervisors who is experienced in qualitative research. Codes and themes that were agreed upon were consolidated and the remaining transcripts were coded using those same codes. Themes were reviewed in terms of relevance to the research question. Those themes that did not contribute to the story of the research were not used. Similar themes were combined and given an appropriate heading and written up about in relation to the study objectives and existing literature.

A visual structure linking the themes as they unfolded in the study were mapped according to the research questions of the interrelationships of the themes as they affected autopsy consent. Through coding the transcripts of study participants, a number of procedural as well as other factors emerged as influencing the autopsy consent process, which were put into a framework using a grounded approach.

2.9 Ethical Considerations

Ethical clearance for the study was obtained from the University of the Witwatersrand Human Research Ethics Committee (Medical): Clearance certificate no. M130820 (Appendix 3). Permission to conduct the study also was obtained from the NIOH, the mining hospitals and unions.

Interview and audio informed consent letters for the FGD and IDIs (Appendix 4 and 5 respectively) were obtained from each study participant prior to the interview. None of the recruited staff refused to participate. Participants of the FGD were informed that confidentiality could not be guaranteed, as information shared during the discussion could be divulged by fellow participants. The participants were requested to keep the discussion confidential. All information from IDIs and the FGD was treated confidentially by the researcher and supervisors and no names or identifying information is reported herein. In order to ensure confidentiality of study participants, codes rather than names or other identifying information were used when presenting direct quotations from participants.

Electronic materials collected were kept in a password protected file. Only the researcher and the supervisors have direct access to the files, which will be kept for two years following publication or six years after the completion of the study, if not published. After that they will be permanently deleted.

CHAPTER THREE - RESULTS

3.1 Introduction

This study sought to explore facility-based factors that influence behaviours related to offering autopsy services to the families of deceased miners. Specifically, the chapter presents findings from three gold and platinum mining hospitals in Gauteng and North West provinces, and an asbestos mining community in the Northern Cape that submitted organs to the NIOH over a five year period. The results are presented according to the study aim and objectives. Autopsy uptake patterns for the mining hospitals are presented first, as the underlying basis for qualitative exploration. Then, using a conceptual framework that emerged inductively from the data, the chapter describes the procedures and other influences linked to the autopsy consent process, comparing mines with declining autopsy utilization to those that have maintained high autopsy utilization, aligned to objectives two, three and four respectively. The proposed framework and findings draw on the experiences and perceptions of mine officials and a professional community nurse, to explain differences in autopsy procedures and autopsy uptake as well as successful strategies employed to encourage autopsy consent, which is critically important for design of appropriate social and behaviour change communication (SBCC) interventions.

3.2 Autopsy Uptake

Table 3.1 depicts annual numbers and trends of organs submitted to the NIOH by the asbestos community and the 12 mining hospitals that were selected for the study over the five year period. Data are arranged by province for each commodity and expressed as proportions of total annual autopsies submitted. The total annual number of autopsies (N) carried out at the NIOH as depicted in Table 3.1; N= 1800 in 2008, 1662 in 2009, 1502 in 2010, 1329 in 2011 and 1164 in 2012 (NIOH, 2014) are used as denominators in the calculation of proportions of organs submitted by each mining hospital (Table 3.1).

All 12 mining hospitals and the asbestos community submitted organs to the NIOH in all the years under study. The gold mine hospitals submitted the most organs (58.3%)

with the highest, 12.2% coming from the Free State province, followed by the platinum mine hospitals (28.7%) whose highest hospital contributed a proportion of 7.4%. The rest of the organs (13.0%) came from the asbestos community in the Northern Cape. The lowest contributor was a platinum mine hospital from the North West province, 0.2%.

Table 3.1 Annual numbers and proportions of organs submitted by mining hospitals to the NIOH from 2008-2012

Hospital	Commodity	Province	2008		2009		2010		2011		2012		Total	
			n	%	n	%	n	%	n	%	n	%	n	%
1*	Asbestos	NC	169	9.4	71	4.3	84	5.6	89	6.7	118	10.1	531	7.1
2	Gold	FS	179	9.9	128	7.7	63	4.2	50	3.8	46	4.0	466	6.2
3	Gold	FS	179	9.9	220	13.2	195	13	164	12.3	151	13	909	12.2
4 (B)	Gold	GP	6	0.3	8	0.5	9	0.6	4	0.3	11	0.9	38	0.5
5	Gold	GP	39	2.2	33	2.0	48	3.2	36	2.7	34	2.9	190	2.5
6	Gold	GP	47	2.6	49	2.9	64	4.3	56	4.2	46	4.0	262	3.5
7 (C)	Gold	NW	105	5.8	122	7.3	78	5.2	40	4.0	43	3.7	388	5.2
8	Gold	MP	26	1.4	53	3.2	18	1.2	17	1.3	17	1.5	131	1.8
9	Platinum	LP	16	0.9	16	1.0	13	0.9	8	0.6	4	0.3	57	0.8
10	Platinum	NW	4	0.2	2	0.1	3	0.2	1	0.1	2	0.2	12	0.2
11	Platinum	NW	71	3.9	86	5.2	32	2.1	20	1.5	23	2.0	232	3.1
12 (A)	Platinum	NW	27	1.5	53	3.2	78	5.2	103	7.8	59	5.1	320	4.3
13	Platinum	NW	124	6.9	144	8.7	128	8.5	89	6.7	66	5.7	551	7.4
Total			992		985		813		677		620		4087	

Key: NC = Northern Cape, FS = Free State, GP = Gauteng, NW= North West; MP = Mpumalanga, LP = Limpopo

* Organs submitted from an asbestos community in the Northern Cape

The three hospitals (12, 4 and 7) are referred to as A, B and C, respectively, hereafter.

The study was conducted in hospitals marked A, B and C. A horizontal analysis of the performance of hospitals A, B, and C reveals marked trend differences. In Hospital B, it can be observed that the number of lungs submitted to the NIOH ranged between a low of 0.3% and a high of 0.9%. Contrasting this with hospital A and C reveals the poor

performance of Hospital B. Hospital C out-performed all three hospitals with most organs submissions.

Table 3.2 Autopsy uptake in participating hospitals, 2008-2012

Year	Hospital A - Platinum			Hospital B – Gold			Hospital C - Gold		
	Autopsies (n)	Deaths (n)	(%)	Autopsies (n)	Deaths (n)	(%)	Autopsies (n)	Deaths (n)	(%)
2008	27	162	17	6	92	7	105	129	81
2009	53	127	42	8	64	13	122	137	89
2010	78	119	66	9	53	17	78	84	93
2011	103	234	44	4	43	9	40	40	100
2012	59	292	20	11	61	18	43	61	70
Total	**320**	**934**	**34**	**38**	**313**	**12**	**388**	**451**	**86**

Autopsy uptake for the three hospitals fluctuated over the study years (Table 3.2). Although most deaths were recorded in Hospital A (n=934), Hospital C had the highest overall autopsy uptake (86%). The patterns of annual autopsy uptake also varied by hospital. From 2008, autopsy uptake increased in all three hospitals up to 2010. Peak uptake was in 2010 for Hospital A, 2011 for Hospital C and 2012 for Hospital B. Uptake for the asbestos community area could not be determined because there was no denominator to use in the calculations as the annual numbers of former asbestos miners who died in the area is not known.

3.3 Institutional Structure for Provision of Autopsies

3.3.1 Standard operating procedures

All three participating mining hospitals had Standard Operating Procedures (SOPs) detailing the processes to follow from when miners died to the sending of organs to the NIOH. These SOPs were available either in the mortuary supervisors' (Hospitals B and C) or the Nursing Managers' offices (Hospital A). Hospitals reported that there had not been changes to the SOPs during the study period. Processes were similar among the

hospitals. The autopsy processes followed by each hospital are summarised in Table 3.3.

All three hospitals had a similar procedure of offering autopsies to families of deceased miners. The process following the death of a miner in a hospital starts with the doctor signing the death certificate, which is an important document for funeral claims and for burials to take place. Families are notified of a death and are asked to come to the hospital to identify the deceased. On arrival in the hospital, officers responsible for the autopsy process use the opportunity to offer autopsies and explained the procedures involved in autopsy compensation as well as the family's right to agree or disagree to autopsy. Whatever the outcome, families who were offered autopsies were asked to either sign a consent form or refusal form.

Whereas, if death takes place outside the mining hospital, a death certificate is signed either by the doctor who certified the death or the state pathologist if it is due to unnatural causes. Thereafter, processes differed per hospital.

Closely linked to the SOPs are the human resources responsible for implementing them. The SOPs were similar among the hospitals but the personnel involved in the autopsy processes were different, as shown in Table 3.3. Also noted was the category of personnel involved in the autopsy processes. There had been no changes of staff concerned with the autopsy processes in the past five years in two hospitals (A and C). However, in Hospital B the mortuary clerk who supervised autopsy services was retrenched in 2008 and his responsibilities were given to the hospital's reception supervisor. In all hospitals, the autopsy service was managed by a medical doctor, with different categories of staff overseeing the day to day running of the autopsy service. The medical doctor in-charge of mortuary services in Hospital B was not available for interview.

Table 3.3 Summary of the autopsy processes and personnel involved in autopsy service delivery in each hospital for miners who die in the hospital

Stages in process	Hospital A (34% uptake)	Hospital B (12% uptake)	Hospital C (86% uptake)
Miner dies – signing of death certificate	Doctor completes death certificate	Doctor completes death certificate	Doctor completes death certificate
Notification of family	Welfare Officer notifies, counsels the family and arranges identification of the body (WO, A)	Human Resources Manager notifies family and arranges identification of the body (HRM, B)	Human Resources Officer notifies family and arranges identification of the body (HRO, C)
Liaises with TEBA to get work history	Nursing Services Manager requests work history (NSM, A)	Reception Supervisor requests work history (RS, B)	Human Resources Officer requests work history (HRO, B)
Autopsy offering	Nursing Services Manager (NSM, A)/ Welfare Officer (WO, A) requests autopsy consent and arranges removal of organs	Prosector requests consent and removes organs (PROS, B)	Prosector requests consent and removes organs (PROS, C)
Removal of organs	Body is moved to undertaker that removes organs	Body in hospital mortuary, prosector removes organs	Body in hospital mortuary, prosector removes organs
Arranges and liaises with NIOH to collect organs	Nursing Services Manager arranges the collection of organs to NIOH (NSM, A)	Reception Supervisor arranges the collection of organs to NIOH (RS, B)	Prosector arranges the collection of organs to NIOH (PROS, C)

Outside of the mining hospital context, the research nurse offered autopsies to families in the area and communicated with the NIOH to collect organs. Union representatives only gave advice to families of deceased miners.

3.3.2 Facilities for organ removal

Hospitals B and C had mortuaries on site, whereas Hospital A only had a holding fridge and bodies were taken to a local funeral parlour for storage. This meant that Hospital A staff could only engage families in the autopsy consent process after identification of the deceased and when the family was considerably distressed. In contrast Hospitals B and C tried to engage in the autopsy consent process before the identification of the body, which was possible because the mortuaries were on site.

3.4 Autopsy Consent Conceptual Framework

Multiple factors that impact autopsy uptake emerged from initial decisions on whether or not to offer an autopsy service to a bereaved family to the final pay-out by the CCOD. This framework, depicted in Figure 3.1 was adapted from Banyini *et al*, 2013 and will be used to guide the presentation of the remaining findings. This framework highlights the complex interplay between autopsy procedures, the institutional factors and individual/family perspectives that influenced autopsy consent outcomes and ultimately, autopsy uptake.

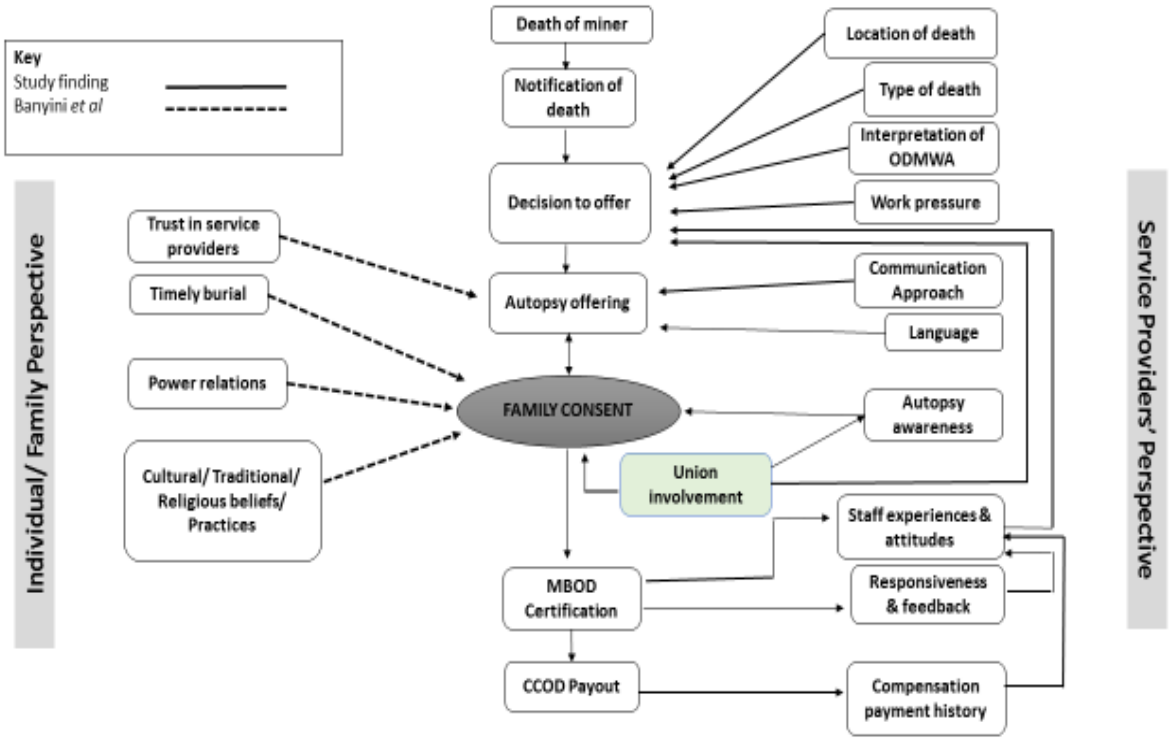

Figure 3.1 Conceptual framework of factors influencing autopsy consent

3.4.1 Decision to offer

The idea that some deceased miners were 'suitable' for autopsy, while others were not, emerged from this study. In some hospitals, this translated into some families not being approached for autopsy consent. In two hospitals, a subjective determination of suitability by staff members based on information about the deceased's work history and presumed exposure also influenced the decision on whether or not to proceed with a consent process. An IDI with an HR officer from Hospital C revealed thus:

> *Only if he falls under the risk work category, and he qualifies for his lungs to be removed for occupational deaths and injuries, then we explain the whole procedure of the removal of the lungs to the next of kin (HRO, HOSPITAL C)*

Some study participants talked about how they decided whether the family would be offered autopsy services or not. In other words, the offering of autopsy services was not automatic. For instance, when a miner died in Hospital A, the nursing services

manager decided whether to offer autopsy to the family or not based on whether he thought the family of the deceased was likely to receive compensation. The family was offered autopsy if the deceased had worked in a gold mine where he would have been exposed to silica dust or if the deceased had been diagnosed with an occupational lung disease during routine medical surveillance. Similarly, in Hospital B the reception supervisor used the deceased miner's service record to decide on the suitability. Only those who had worked underground were offered autopsy. In contrast, in Hospital C, families of all deceased miners who died of natural causes in the hospital were offered autopsies, irrespective of their exposure and medical history.

In cases where the next-of-kin was not readily contactable or available, Hospital A reported that they proceeded with organ removal if they considered that the deceased may have had a compensable disease. *"If the family is not coming forward, it is then that I would liaise with the undertaker to remove the lungs, but within the legislative parameter."(NSM A).* The other two hospitals (B and C) only removed organs after getting consent from the next-of-kin, and did not proceed with autopsy if next-of-kin were not available.

3.4.1.1 Type of death

According to participants from the mining hospitals, two critical procedural points for determining whether they offered a family autopsy services were type of death (natural or unnatural) as well as where the death itself took place. Natural deaths were when a miner died because of a presumed known disease whereas an unnatural death was when death was caused by an external source other than a disease, e.g. accident, poisoning, suicide, etc. Mining hospital staff described being responsible for seeking autopsy consent from families of deceased miners who died of natural causes within the hospital. Autopsies of such miners were either performed in the mine hospital mortuary or, if the mine hospital did not have autopsy facilities, in a local government hospital or private mortuary. Miners who died of unnatural causes, whether within or outside the mine, were taken to a forensic mortuary for a forensic post-mortem examination. Hospital B did not approach families to consent when the body was

outside the mine hospital. This was because of past experiences of not succeeding in obtaining consent from families for autopsies.

3.4.1.2 Location of death

There was variation in how hospital staff understood their responsibility to the family of deceased miners if the death took place outside of the mine or hospital setting. Study participants in Hospital B, which had the lowest uptake during the study period, reported that for both natural and unnatural deaths, the mining hospital did not take responsibility for offering autopsy if the location of death was beyond a 60 km radius from the mine. In contrast, Hospitals A and C had procedures in place for miners who died outside the hospital, which were only followed if the hospital was notified of the death early enough to arrange for the removal of organs before burial. For deaths occurring outside the hospital, the next of kin or whoever was near the deceased could report the death to the mine's human resources department where the deceased worked. The organs of such deceased miners were removed in either government or private mortuaries at family request. All hospitals reported that for miners who died within 100 km around Johannesburg, bodies were sent directly to the NIOH for lung removal.

Participants noted that most miners who died at home were not autopsied because the notification was too late to arrange for the removal of organs. Another reason was the lack of autopsy facilities locally. In Hospital A, after receiving notification of a death which occurred outside the hospital, the nursing services manager, after getting a written consent, notified the NIOH, which took responsibility for the rest of the autopsy process. Hospital C's policy, which had the highest autopsy uptake during the study period, was slightly different. They offered autopsies to families of miners who died in and around the nearby town and gave advice for those who died far away, if they contacted the hospital and were willing to have organs removed. Alternatively, they could request the NIOH for assistance. The consent process for miners who died away from the mine was expected to be carried out by the NIOH rather than the hospital staff in Hospital C.

3.4.1.3 Notification of death

In cases of death within the mining hospital, the hospitals notified the next-of-kin of the death, who was asked to identify the body of the deceased person in the hospital's mortuary if death was due to natural causes. In the case of unnatural causes, families were notified, then offered autopsy before being directed to the forensic mortuary to identify the deceased.

The criteria for death notification were not the same in all three hospitals. In Hospitals B and C, deaths were immediately reported to the human resources officers who notified families of the death. In these hospitals, besides notifying families, deaths were also reported to the union to which the deceased was a member. Hospital staff then saw it as the duty of the union representative to advise the family about the compensation process. A union representative from Hospital B expressed their responsibility thus: "*We intervene and try to explain to the families what the whole procedure entails and that they have the right to agree or to decline." (UNION REP, HOSPITAL B).* In Hospital A, deaths were reported to the mine's welfare officer, who notified the families and assisted them with compensation processes.

For ex-asbestos miners in the Northern Cape area, the research nurse was notified by occupational health nurses of the hospitals where the death occurred. Deaths that occurred outside the hospitals were reported to her directly by families, because she was well known as an advocate for deceased miner's rights to compensation, and also through the private practitioner with whom she worked.

3.4.1.4 Interpretation of ODMWA

Hospitals A and C had specific criteria to determine a deceased person's suitability for autopsy, which Hospital B did not. The criterion that Hospital A used was that the miner must have worked in a gold mine or/ and having been diagnosed with an occupational health related disease. Whereas, in Hospital C, all miners who had worked underground and their families were willing to give consent for autopsy were autopsied.

3.4.1.5 Staff experiences and attitudes

Doctors generally valued autopsies but expressed frustrations that the Act requires them to request family consent, while it is so important to conduct autopsies for every deceased miner. One doctor and the welfare officer had qualms that may have emanated from their abhorrence of the law requiring consent before autopsies. Otherwise, it could be said that the overall attitude of allied health professionals concerned with autopsies was good. They also questioned the legal right given to the director of the MBOD to command the last attending doctor to perform a medical examination on the dead miner when the family's consent was still required. A doctor vented his frustration about this Act:

> *The Act can't dictate that if I need consent from the family. Otherwise then the Act should then dictate to the family "You don't have a choice" (DR 2 HOSPITAL C).*

The welfare officer at Hospital A reinforced this idea, as follows: "*It should be an automatic thing meaning that if a guy passed on, as long as the family is made aware, the service providers should be allowed to go ahead with the autopsy" (WO, HOSPITAL A).*

Support for autopsies was not universal. Another doctor from Hospital C got angry because it reminded him of the previous trauma he had with autopsies and said:

> *We are not gonna do it… I am not gonna start doing autopsies. I have done autopsies before and I am not prepared to do it again. I did it in the horrible years in Kwazulu-Natal with a lot of trauma and it was just bad and I am not gonna do it again. (DR 2, HOSPITAL C).*

This doctor further felt that it was a waste of time to concentrate on a deceased person when there were live patients who needed his attention. He felt that embarking on autopsy discussions would take time away from his busy schedule. He also felt that when a person was dead, a doctors' job was not to seek consent for autopsy but to issue a death certificate. He reported that they did not talk about death to their patients as autopsy compensation was common knowledge and the lung boxes had been

around for decades. Other than that, it was the miners' responsibility to notify their families of autopsies.

Whereas some staff portrayed a negative attitude towards autopsy offering and its services in general, most were positive. This was especially evident among prosectors and the nursing services manager in Hospital A, who were profoundly positive. The researcher observed a high level of commitment and empathy demonstrated by most of participants in their work. For example, the WO in Hospital A showed empathy in relation to families suffering and needs. Sometimes he even went out of his way and used his own resources to make sure that families had access to autopsies.

> *This widow comes all the way from Lesotho and she goes through a lot to get here… I have personally gone to an extent of fetching the widow from her house myself in order to bring her here. (WO, HOSPITAL A).*

3.4.1.6 Union involvement

Health and safety representatives in all mines were mandated by their unions to promote autopsy discussions among their peers and encourage miners to consent to the removal of organs for autopsy examination after death. However, most union representatives who participated in the study focus group discussion were not involved directly in the autopsy process. They reported that they only gave advice to those families that requested assistance. In Hospitals B and C, however, union representatives guided families through autopsy decisions. After receiving a notification of death, the union representative in Hospital B joined the prosector in discussions with families. The role of the union representative became important when families refuse to consent for autopsy. Then, union representatives, because of their close interaction with families, would intervene as a matter of last resort to explain the autopsy compensation process and to highlight the benefits of compensation and their right to agree or decline. In Hospital C, the prosector, who offered autopsies to the families also represented the union. Therefore, it was easier for him to persuade families to give consent. The prosector articulated his role thus:

> *I am part of the Health and Safety Union. I always encourage safety representatives whenever we have union meetings to explain in the mine shafts the necessity of taking out the heart and lungs… I make it a point that I paint a clear picture because we are working in risk areas. (PROS, HOSPITAL C)*

Although in some mines unions were not directly involved in offering autopsy services, union representatives are expected to educate their members about autopsies and compensation through campaigns in the mines.

3.4.2 Offering of autopsy

During the interviews, participants placed emphasis on the actual act of offering autopsies as being directly linked to consent outcomes. Two themes emerged as important in the offering of autopsies: communication approach and language.

3.4.2.1 Communication approach

The approach used by officials in offering autopsies was perceived to be an important aspect of communication, determining whether the family will consent to autopsy or not. Participants stated that autopsy is a sensitive and confidential issue that people do not talk about openly. They unanimously felt the need to professionally address families and treat them with courtesy when offering autopsies. *When talking to families, it is important to show respect, sympathy and understanding of their grief.* (PROS, HOSPITAL C).

Participants reported that they used different strategies to persuade families to give consent. A strategy used by staff in all three hospitals involved an initial persuasive conversation with the families of the deceased before the viewing of the deceased's body. The prosector from Hospital C summarised the strategy which all three hospitals used in approaching families as follows: "*We normally talk to the families before body viewing. They are at least still interested in hearing about the autopsy at that time" (PROS, HOSPITAL C).* The reason that emerged from all three hospitals for why they all employed this strategy of approaching families before viewing of the body was that

family members were often distressed after body identification and would not be receptive to the cutting of the body to remove organs. This approach did not always work well for Hospital A because they used a private mortuary which was outside the hospital and therefore families often went straight to the mortuary to identify the deceased without the hospital officials.

Participants emphasised that they had to avoid creating pay-out expectations, because families often think that consenting to autopsy confirms compensation pay out. However, some officials sometimes found it difficult to convince bereaved families to consent to autopsy without talking about the possible pay-out. They had to reinforce the use of a possible compensation pay-out to obtain consent by appealing to the bereaved families to consider the possible benefit of a pay-out to the children for education, healthcare and other expenses associated with their upbringing. This strategy was successful where children were minors.

> *The lump sum can be deposited into a trust fund and the monthly interest can be used to educate the children…If no autopsy was done then they stand to lose out because the children or the family of the deceased could have perhaps benefited financially…This really motivates them to understand and give consent especially if the deceased had small children… (WO, HOSPITAL A)*

Another communication approach was to ensure privacy. All hospitals ensured privacy when in offering autopsies to families in order to prevent any interruptions. The importance of offering autopsies in a private space was highlighted by staff at all three hospitals. This was done in the nursing services manager's office in Hospital A and in the prosectors' offices in both Hospitals B and C, with only close family members or family representatives present.

The other strategy used was that during explanation of autopsy, in some cases they would show pictures of a diseased lung showing a TB cavity and OLD to convince the family about the need for an autopsy. There was also a common understanding of the importance of building rapport, allowing the family to ask questions or to seek clarification about autopsy issues. The participants reported that families often ask about where the organs would be taken to and if organs would be returned to the body

before burial. In all three hospitals, whenever these issues were raised, officials involved were frank about how organs were handled after autopsy, explaining the process and the reasons why organs are kept even after autopsy examination and reassured families to have faith in the system.

3.4.2.2 Language

The language of communication was also deemed important by participants in the offering of autopsy services. There was general consensus that when talking to bereaved families, it was important that officials communicated in a language that families would understand. This made it difficult for person who could not speak the same language as most families in the area when offering autopsies and for the family to understand the process when explained in a different language. The research nurse described always needing somebody to translate.

3.4.3 Factors that influence family consent

All three hospitals had adapted the NIOH consent form (Appendix 6) to match their own policies. They also developed their own refusal clause for families who refused autopsies because the NIOH did not supply consent refusal forms. In all of the adapted consent forms, families were consenting or refusing to:

> *A post-mortem examination to be performed and the removal of any tissue or bodily fluid specimens and subsequent laboratory examination of such specimens that may be required by the attending doctor to assist in determining cause of death or disease or for the purpose of complying with section 34 of the ODMWA.*

After the signing of forms, these forms were filed by the nursing services manager in Hospital A, the reception supervisor in Hospital B and by the mortuary supervisor at the HR department in Hospital C. All hospitals reported that families who chose not to have organs removed were informed of the consequences of their decision, which was that they could not claim autopsy compensation without the removal of organs. A

refusal form was signed giving a reason for refusal and then filed the same way as the consent form, in the deceased's file and kept in the hospital archives.

3.4.3.1 Trust in service providers

Participants expressed the importance of trust between families and the person offering autopsies. They felt that it is easier to get consent if the family trusted that they would not lead them astray. The research nurse felt that it was easier for her to get people of Kuruman to consent for autopsy because they trusted her. She has lived and worked in the mines in Kuruman as a professional nurse her whole life. Therefore, most people in the area knew and trusted her.

> *I feel that it is easier for me to get families to agree to autopsies because they know and trust me either because I have worked with them in the mines or because I have lived in Kuruman for many years. (RN)*

Some union health and safety representatives reported that they are not involved in the offering of autopsies, because of issues of distrust due to perceptions of the system being corrupt. There seemed to be a belief among these participants that there was a gang of people who took compensation money due to bereaved families for their own gain. They unanimously expressed this perception as follows:

> *Gauteng is a place of "Tsotsis" (criminals)… I do not want to be associated with those criminals that take peoples' compensation money … Ha! When they do not get paid compensation they will think that I sold their relatives' lungs for my personal gain. (UNION REPS, FGD)*

Other FGD participants truly believed that healthcare workers were gaining something from the compensation system by requesting autopsies.

The H&S representatives took it as common knowledge that miners considered their respective union representatives as the safest and most trustworthy people to listen to when it came to all issues of health in the mines. Most of the union representatives in the FGD reported to have withdrawn from advising families about autopsies because they did not want to be blamed for compensation not paid out. Participants were also

concerned that there seemed to be a common belief among miners and their families that organs were taken out to make traditional medicine, for example. However, they reported that they always clarified that such beliefs are just myth. This further confirms that questions of this kind were easier when handled by a person who understood their culture because other people would not understand an origin of a myth, lest explaining to families.

3.4.3.2 Autopsy awareness

Lack of awareness among family members was noted as an important area that may be hindering them from accepting autopsy. Participants reported that it was easier to communicate removal of organs to people who were aware of the service. They were of the opinion that families would accept and give consent for removal of organs if they were aware of the removal and examination of organs while the miner was still alive.

There was concern among the union representatives that information on removal and examination of organs does not reach the elders who take decisions when there is a death in the family. A union representative raised a concern that families are not educated about autopsies, therefore, they may decide against autopsies. "*There are awareness campaigns in the mines but when you are dead, uncles take decisions about autopsy." (UNION REPS, FGD)* This was linked to an idea that miners in general do not discuss issues of after death and compensation with their wives because they fear that their wives might kill them to gain compensation.

A union representative suggested that communities needed to be educated about autopsies the same way as they were educated about HIV/AIDS:

> *Through education, people can be empowered. For example, the government has invested a lot giving information on HIV/ AIDS. If the autopsies can also be given the same attention, we can win the battle. (H&S REP)*

Though some families arrived knowing and willing to give consent for autopsy, the most common scenario described by participants was that people needed to be convinced by the officials of the value of autopsy. Hence, the importance of explaining the autopsy

claim process and that compensation was only paid out if a compensable disease was diagnosed.

In contrast, the research nurse reported that in general, there was high autopsy awareness among miners and communities in the Northern Cape. She further stated that it was a norm in the area that when a person died, autopsy followed. The reasons given for the high autopsy awareness levels were due to asbestos exposure in the area and the role played by the ART in compensating deceased asbestos exposed people.

3.4.3.3 Cultural and religious beliefs, and practices

One element of building trust was in finding common ground. Study participants described how they would make families feel comfortable by demonstrating that they understand their culture and respect their beliefs. They understood that some cultures are against removal of organs based on the belief that it disturbs a resting soul. A welfare officer noted:

> *You also need to be very tactical and make them understand that it might not be cultural and also against our beliefs to conduct an autopsy. (WO HOSPITAL A)*

Participants who were not of African descent, with little understanding of African languages, cultures and traditions found it more difficult to persuade bereaved families to accept autopsies. The participant described finding it extremely difficult to contextualise the offering of an autopsy to a bereaved family in sync with traditional values.

> *You need to understand their culture, once always adjust to each and every family's culture, it's a difficult thing if you don't speak their language… I wish I could at least learn their language (RN)*

However, the H&S representatives, when asked about the different cultures contributing to the low autopsy uptake, responded that culture was not a problem. In their discussion, they felt such barriers could be overcome if people were informed of their rights and processes were thoroughly explained. One union representative

insisted that *"… the problem is lack of awareness and communication." (UNION REP FGD)*

This perspective was not universally held. Another union representative reported that often people from Mozambique are unlikely to give consent for no obvious reasons, stating that "*…Mozambicans are very staunch followers of their culture…" (UNION REP HOSPITAL C)*

The research nurse showed a high level of cultural sensitivity in dealing with families on consent issues. She described her success strategy as follows:

> *I always tried to involve somebody with the same culture and language or at least one of the family members that could understand me well to sort of translate or to interpret what I was saying to the family members. (RN)*

One of the weaknesses identified in the process of autopsy compensation practice is that families living far from the mines often send a friend or neighbour unrelated to the deceased to represent the family. These individuals are therefore unable to make decisions about autopsies as they fear of being accused of having enriched him/herself with the deceased benefits should there be no compensation pay out.

Two peripheral factors that came up but were not very conspicuous were timely burial and power relations. These two have been highlighted in previous discussions above under autopsy awareness.

3.4.4 Administrative issues

Hospital-based study participants highlighted the inefficiency in dealing with compensation issues at the MBOD. When they called to make enquiries at the MBOD, the phones were either not answered or, if answered, they were sent from one person to another which adversely affected their morale towards the decision to offer autopsy. Of concern is that even when they had raised the issue with the MBOD management, nothing seemed to have been done. Union representatives in a FGD raised the same complaint as above but identified it in relation to two categories of access: *there is no*

direct line for inquiries ...Compensation offices are only based in Johannesburg which makes it difficult to follow up cases. (UNION REP FGD)

Another issue that was raised by union representatives was the high staff turnover at the MBOD.

> *Every time you phone in to inquire about a claim, you find different people. It is never the same person who checks your claim and every time you get a different story after reiterating your query to a new person. (UNION REP FGD)*

Hospital staff also reported frustrations they go through when following up on cases at the MBOD and CCOD. This discouraged them from continuing to offer autopsies to families of deceased miners because they did not see the outcome of their effort.

During the interviews, many participants expressed their dissatisfaction in that they do not receive all feedback of the compensation outcome from either the MBOD or CCOD. Service providers reported that they only received notice of compensation outcomes for a few cases and even for those that had a positive outcome, they had not been paid. The welfare officer reported that claims documents sometimes went missing at the MBOD and participants were asked to resubmit their documents which further delayed the process. The welfare officer in Hospital A told the story of his frustration as follows:

> *There was one case that disappointed me the most, the one where we took all the required documents to your MBOD offices in Johannesburg and we have since been instructed to resubmit upon enquiry because apparently the documents went missing… (WO HOSPITAL A).*

Compensation outcome is important for people who offer autopsies because they talk about it when convincing families of the possible positive outcome that could lead to a compensation pay-out.

In summary, factors affecting ODMWA autopsy consent are multifaceted. All participants involved in autopsy compensation were either dissatisfied with the legal requirements for consent or frustrated. This was because of not getting feedback on the autopsy compensation outcomes. In turn, this impacted on their offering of

autopsies, which had a knock-on effect on getting positive family consent. The frustration was expressed most strongly by the doctors, whose attitude was that if the government cannot make the removal of organs of deceased miners compulsory then they are not going to be involved in autopsy talks, offerings and consent requesting. In conclusion, beyond family factors that emerged in this study as a key hindrance to obtaining consent, structural factors such as the absence of mortuaries owned by mine hospitals and policies related to the Act were found to impact the consent process.

CHAPTER FOUR – DISCUSSION

4.1 Introduction

The number of autopsies conducted for compensation purposes is declining in South Africa, despite the continuous value of awarding compensation. This chapter discusses the study findings, in relation to the broader literature on the factors affecting consent for autopsy services. Furthermore, this chapter discusses the differences in the way families of deceased miners are offered autopsies from a communication perspective. This study did not look at the future sustainability of autopsy compensation, given the declining numbers of autopsies and the many barriers. The intention is to explore interventions that could be employed to arrest the shortfalls in autopsy uptake patterns and its negative consequences on compensation for families of the deceased. The chapter concludes with study limitations, which were beyond the researcher's control.

4.2 Autopsy Uptake

Autopsy for compensation is unique to South Africa, so there is no available similar autopsy data from other countries with which a comparison can be made. Therefore, autopsy utilization is compared to that in general hospital settings. While the overall autopsy uptake over the five-year period for each mining hospital varied, it was high from a regional perspective. The average autopsy utilization for all three hospitals was 44%. Even though this level of less than 50% could be regarded as low, it is higher than that observed in other hospital settings around the African continent (Lishimpi et al., 2001, Oluwasola et al., 2007, Tette et al., 2014). The hospital uptake of 44%, was, however, similar to data from TEBA which showed the autopsy utilization declining from 71% in 2001 to 46.7% in 2010, among mineworkers who were eligible for autopsies (Banyini et al., 2013).

There has been no change in the legislation with regards to obtaining consent for autopsies. A possible contributor to the declining number of autopsies could be the reduction in employment rates especially in gold mines. Data from the Department of Mineral Resources (DMR), 2007, spanning the period 2008 to 2010 show a decline in

employment statistics from a 146 487 in 2008, 143 268 in 2009 to 133 898 in 2010. A year on year analysis of this data show a corresponding decline in autopsies from 1800 in 2008, 1662 in 2009 and 1502 in 2010 respectively. Interestingly, employment in the gold mines sector rose to approximately 145 000 in 2011 and declined again in 2012 to 142 201 but the number of autopsies performed continued to decline from 1329 to 1164 in 2012. This data does not include miners who were already unemployed before the study period.

The fact that the type of commodity mined may be a factor in autopsy uptake was not strongly supported. High autopsy utilization is expected from gold mines because of recognition of OLDs for over a century, silicosis and more widespread knowledge of compensation (Hessel et al., 1987). Indeed, the highest autopsy utilization was seen in one gold mining hospital, with an annual average of 86%. However, this was not sufficient to guarantee a high autopsy uptake, as seen in the other gold mining hospital. This gold mine showed the lowest uptake of autopsies. Therefore, the type of commodity did not seem to matter in this study.

Declining autopsy utilization, as seen in the platinum mine hospital, may have been a reflection of the dynamic socio-political contexts in which mines operate in South Africa. The high utilization (66%) seen in 2010 in the platinum mine hospital, was probably due to the NIOH staff visit and presentation to staff of this hospital (NIOH, 2009). It has been demonstrated that intense autopsy training of medical staff increases autopsy rates (Souza and Rosner, 1997). An increase in autopsy uptake was observed by the increase following the NIOH visit, from 42% in 2009 to 66% in 2010. The downward trend seen in 2011 and 2012 could be due to the unrest that disrupted mining activities in the platinum belt and compromised the autopsy service as employees were sent home.

It was observed that all hospitals had similar SOPs but with slight differences in the category of personnel who implemented these SOPs. This did not show any effect in the autopsy uptake. For example, autopsies were offered by a prosector in both gold mining hospitals which recorded the highest and the lowest autopsy uptake.

4.3 Frameworks for Consent

The framework established by Banyini et al. (2013), gave insight into consent from the perspective of service providers and families. Both frameworks show that autopsy consent is clearly influenced by individual, institutional and sociocultural-level factors. The individual/family factors reported in this study were the perceptions of mine officials. However, they mirrored direct observations of individuals and families recorded by other researchers (Lishimpi et al., 2001, Oluwasola et al., 2009, Start et al., 1994). This study, as opposed to the previous study by Banyini et al. (2013), focused primarily on institutional enablers and barriers to ODMWA autopsy consent, which allowed new themes to emerge.

4.3.1 Discretionary determination of suitability

Section 36 of the ODMWA allows every deceased miner a right to an autopsy irrespective of clinical cause of death. This study showed that a barrier to consent is the discretionary determination of suitability by some staff, offering an autopsy. The ability for individuals to determine *a priori* who is likely to be awarded compensation is supported by ODMWA. However, the interpretation of the Act which violates ODMWA is where the medical history of the deceased miner is reviewed for purposes of determining whether or not the eligible deceased should be autopsied, rather than for compensation purposes. The distinction between determining eligibility, as allowed by the law, and the determination of suitability, by some mine hospitals, which is against the Act, is very thin. The difference lies in the purpose of the determination of eligibility. According to this Act, every miner who has done risk work is entitled to an autopsy and the decision to offer an autopsy should not be at the discretion of the person offering the autopsy. This discretionary determination of whether to offer of an autopsy or not should be discouraged because the requirement for consent has always been there and a refusal to perform an autopsy with a prior assumption that consent would not be given is unacceptable. This study gathered that some officials used institutionally established criteria to assess eligibility. These criteria involved the review of the medical and work history of the deceased in order to determine whether the person could have been exposed enough to cause a compensable disease in order to inform

the decision to perform or not to perform an autopsy. The risk here is that if the practice of determining suitability based on certain institutionally laid criteria, or upon the whims of the autopsy personnel, is allowed to continue, there remains the possibility that miners with an acute compensable disease could be ruled out from an autopsy, and, therefore, be deprived of compensation, which might have been awarded, had they been autopsied.

This study would expect to see high rates of silicosis in the cases autopsied in those institutions that relied on the exposure to silica dust as baseline for inclusion into an autopsy offering service. However, this may have played a role in the year on year rising trend in the proportion of autopsies found to have silicosis (Nelson, 2013), but that dimension was not explored in this study.

Criteria for determining suitability of a deceased for autopsy were not uniform despite the provisions of the ODMWA. Where there was good uptake, the provision of the law was followed, that is, autopsies were offered to all families of deceased miners. Whereas, hospitals with low uptake did not observe the law and as such yielded the poor results as observed by the study.

4.3.2 Trust in service providers

Study participants reported that some bereaved families believe that the organs are either offered for sale or are used in the manufacture of potions, a view which has been reported elsewhere (Cox et al., 2011, Banyini et al., 2013). This perception created deep mistrust between the officials rendering autopsy services, union representatives and those who represent families. As a consequence of the deep mistrust by miners and their families for those persons actively encouraging autopsy services, some union representatives had stopped advising families to accept autopsy for purposes of compensation.

Mistrust can lead to detrimental outcomes. This has been demonstrated by the Marikana unrest which was caused by mistrust between miners the National Union of Mineworkers (NUM) and mine management (Antin, 2013) and therefore, the autopsy

offering service was disrupted. If union representatives, who are supposed to be advisers and sources of influence on autopsy and compensation issues, find faults with and do not trust the system, it makes it difficult for people offering autopsies to act as effective links between the system and families of deceased miners. The dual role played by the prosector in the high performing hospital as a prosector and a mine union representative and, his positive attitude enabled him to assure his colleague miners and educate them about misconceptions that exists about the whole autopsy procedure.

4.3.3 Cultural and religious beliefs, and practices

Religious and or cultural beliefs and practices were mentioned as one of the clusters of factors for families refusing consent in this study. Even though religious and cultural beliefs of people offering autopsies were not explored, their experiences and perceptions when offering autopsies to bereaved families were explored. Clearly, based on their experiences and perceptions, autopsy offerors reported that cultural beliefs of the families of deceased miners negatively impacted on the autopsy utilization levels of these institutions that were mandated to perform mine related autopsies. For example, one participant noted that Mozambicans strongly believed in burying their relatives complete, without removing any organs. Service providers were reluctant in pursuing consent from families who came from ethnic groups with strong taboos against mutilating the bodies of the deceased. This concurred with the findings of Banyini et al. (2013) that some families believed that the deceased needs the heart and lungs for existence in the afterlife and they fear ancestral anger and rejection if the deceased arrives incomplete in the ancestral land (Banyini et al., 2013). The findings of this study also are consistent with the findings of a previous study conducted in Ghana and Uganda where barriers to autopsies were largely influenced by the cultural and religious reasons (Cox et al., 2011, Tette et al., 2014).

Timely burial is important in South African communities (Khabazela funerals, personal communication, July 1st, 2016). Most families do not welcome any change in dates once they have decided on a date for burial. When a person has died, the body has to be prepared for the funeral. It should be ready for collection in time for burial. Religious

considerations may influence a bereaved family to object to an autopsy because of delays caused by removing organs especially if the deceased person died outside the mining hospital where there may not be a nearby prosector, doctor nor autopsy facilities to remove organs in time.

4.3.4 Institutional barriers

In this study, institutional barriers were an important parameter contributing to the decline of autopsy uptake. Mine officials who offered autopsies to bereaved families felt discouraged to request consent for autopsies when they did not get feedback from the MBOD and CCOD. This caused stress. Feedback indicating a positive outcome of previous claims would help them to convince bereaved families to give permission for the removal of organs. This finding is consistent with the findings of Oluwasola et al. (2009) who is of the opinion that autopsy services should be devoid of bureaucracy and organized appropriately so as to remove administrative bottlenecks in order to ensure that bereaved families are exposed to minimal stress. This study extends this observation to the service providers as well. Tette et al. (2014) recommend that hospital management should implement internal and external quality control mechanisms to regulate autopsy services. Lack of response to inquiries and the delays in certification and payments of compensation at MBOD and CCOD puts pressure on mine officials who then become reluctant to ask other families for autopsy permissions.

The low performing hospital did not have any arrangements for the removals of organs for miners who did not die in the vicinity of the mine. In addition, the perception of the prosector was that people did not want autopsies and therefore there was no need to offer autopsies to people who died away from the mine However, in such cases, the best performing hospital had arrangements with a private undertaker with nationwide service outlets who either delivered the body to the hospital for the removal of organs or removed the organs and sent them to the mine hospital. This practice contributed to high uptake.

4.3.5 Offering of autopsies

Talking about death and autopsies to families is a sensitive issue. This was confirmed by De Villiers and Ruhaya (2005), who highlighted how the topic can stimulate feelings of anxiety and that most people do not like to talk about it. Acceptance of autopsies is facilitated by appropriate communication and the show of empathy, as demonstrated in this study. Although residency training of pathologists includes communication skills, in most cases autopsy services are rendered by other health professionals who may not have had the requisite training in communicating appropriately with bereaved families. Communication with patients and their families is a known challenge for healthcare professionals for a variety of reasons, including overload of work and inadequate skills in professional communication (De Villiers and Ruhaya, 2005, Thompson and Sunol, 1995). A previous study recommended that all personnel involved with autopsy services be given refresher courses supporting the fact that effective communication with bereaved families enhances autopsy uptake (Tette et al., 2014, Thompson and Sunol, 1995).

To overcome the daunting task of convincing already distressed family members to accept autopsy, a persuasion strategy involving the discussion of the possibility of a compensation pay-out was often used to encourage families of the deceased to accept the offer for autopsy to be performed. Though the monetary value of compensation has declined (Ehrlich, 2012), it is not an ideal strategy. This is because when compensation pay-outs are discussed, hopes and expectations of families of the deceased often get high and in the event that the deceased was not eligible for compensation, it could become a challenge to convince families to accept the outcome. Even with this strategy, families continued not to accept autopsies. The expectation would be that families would welcome the possibility of gaining compensation money as this award has been shown to give a short term financial relief to relatives of the deceased miners (Stewart and Jennings, 2007). This is in agreement with Ehrlich, 2012 hypothesis that the decline in autopsies may be because the compensation is not high enough to attract families to accept autopsies.

The procedure of offering autopsy in all three hospitals was similar. The only exception was the person rendering the offering. In both gold mining hospitals, a prosector was involved whereas a professional nurse was involved in the platinum hospital. On the bases of offering autopsy, no specific reason can be attributed to the differences in the performances of all hospitals.

4.3.6 Act awareness, interpretation and union involvement

According to the Occupational Health and Safety Act (OHSA, 1993), mines, unions, mine hospitals and occupational health units have a responsibility to raise awareness for both their staff and miners. Though, Roberts (2009), revealed that medical staff are not aware of their obligation to autopsies and the processes involved in getting consent from families of deceased miners - arranging removal of lungs and submitting the organs to the NIOH, this study found high general awareness among the people interviewed. This could be because of the training and workshops for healthcare providers and union representatives provided to mine officials by the NIOH to mines officials. Despite the high general awareness among service providers, their awareness and interpretation on specific provisions of the Act was not as good as was expected by the researcher. An example is that the provision in the Act that requires every miner, irrespective of the cause of death, be autopsied, was not well understood and applied. Some service providers introduced suitability clauses inconsistent with the provisions of the Act to determine eligibility of a miner for an autopsy.

Awareness of the Act is not limited to service providers, but is also important among those accessing the services. Awareness of compensation processes can aid families to make informed decisions when faced with a consent request for their deceased relatives (Maiese, 2003). It is critically important that miners and their communities are made aware of the relevance of an autopsy (Banyini et al., 2013). This idea was also expressed by the participants in this study.

4.3.7 Ethical issues

Engaging the family in the autopsy process is a crucial step, because of the need for consent, without which there would be no autopsy done. Without consent, the family may lose the last chance of claiming compensation. Appropriate processes should be adhered to if there is a need to retain any human tissues or organs from the deceased for research purposes, in order to avert scandals such as those which occurred at the Alder Hey Children's Hospital and the Bristol Royal Infirmary in England in 1999, where organs were collected without consent (Bryant et al., 2008). This scandal led to the decline of autopsies in the UK (Burton and Underwood, 2007). Koo (2010) in his award winning essay indicated that the public's appreciation of the essence of post-mortems plays a very important role in determining whether or not consent will be given by bereaved family members.

According to the NIOH consent form (Appendix 6), when the family signs the consent form they are not only consenting to removal of lungs for ODMWA purposes, but they are consenting to four things;

1. Post-mortem examination and the removal of tissues considered necessary for ODMWA, for
2. Diagnostic,
3. Medical education and research, and
4. Scientific purposes.

In this study it emerged that mining hospitals developed their own consent and refusal forms using the NIOH consent form as a template. It is important though to note that mining hospitals keep all the relevant information, the use of organs or any part thereof for diagnostic, research and scientific purposes besides ODMWA, in their modified consent and refusal forms. All the mines had refusal forms.

4.4 Experiences and Perceptions

Differences in the personnel involved in notifying families of death were important. Obtaining consent afterwards depended on how the person communicated the bad news to families of deceased miners. The method and style of communication of the death of a miner determined whether the family would want to listen to the autopsy consent request or not. The refusal form is a very useful tool that can be used as evidence that families are offered autopsies and should be encouraged.

Experiences and perceptions of healthcare workers may cause them to be reluctant to request an autopsy consent. For instance, a healthcare worker may assume that all Mozambicans would not give consent to an autopsy based on a previous experience of refusal to give consent. As a result, the healthcare workers do not offer autopsies and would not even offer in the future to the families of deceased Mozambican miners. However, Tsitsikas et al. (2011) in his study showed that the overall attitude in the general public is actually positive if the value of autopsy is honestly presented and procedural details adequately explained.

In Hospital A, it was noted that the staff generally considered exposure to silica dust as the only predisposing factor to acquiring a compensable occupational disease. Because of this, they did not consider miners from other commodities apart from gold mining for autopsy. This study assumes that had this qualifying bias not been in place, this hospital would probably have had a higher autopsy uptake than it recorded.

The low performing hospital staff's attitudes heavily influenced their decision to include people who died beyond a certain radius and those who died unnaturally. The general attitude was that people who died beyond a 60 km radius did not fall within their jurisdiction and so would not pursue the death of a miner beyond such a radius. This hospital failed to perform autopsies on miners who died unnaturally for example, road traffic accident. This meant that if a miner had a compensable disease and was involved in a car accident, he or she lost eligibility to be autopsied for compensation by the attitudes of staff of this hospital. The low uptake recorded by this facility could have been significantly improved by the inclusion of this category of miners.

The attitude and behaviour of a healthcare practitioner plays an important role in the reception of healthcare services and the advancement of public health objectives. A positive correlation was found between healthcare workers with high emotional intelligence (EI) and hospital services utilization (Vandewaa et al., 2016). This is significant and seemed to have been understood by a prosector from the hospital, which had high rates of autopsies, who employed the concept in achieving high results. The role of this prosector in advancing the aforementioned importance of attitude was recognized by the management of the hospital and this earned him the accolade as the pillar upon which autopsy services in the hospital rested. His attitude could partly be the reason for the high autopsy uptake (100% in 2011) that was consistently reported by Hospital C.

A doctor of this same hospital demonstrated a negative attitude towards the seeking of autopsy consent. However, this doctor's attitude did not affect the autopsy process as this hospital had a high autopsy uptake. This is in contrast with other literature which points to organisational culture (often influenced by the attitudes of leaders) as being important as well, for example, in the high autopsy rate study at a University of Texas Medical Center (Haque et al., 1996). In this study, it showed that attitudes of those directly involved may have been more important than those more distal to the process.

The general attitude of the research nurse was an enabling factor for consent to be obtained. She was culturally sensitive in that she always tried to explain the autopsy procedure and its value in a very private setting. Her empathic approach towards the family of the deceased won her the admiration of the entire community. As such, after showing empathy to the family of the deceased by expressing her condolences, she would normally be given consent by the family if she asked for their consent to perform an autopsy.

A positive attitude to autopsies of their own and their relatives was shown by most interviewees in this study. All those participants who had been exposed to mining work were willing to be autopsied after death and confirmed that they have discussed their decisions to be autopsied with their families.

4.5 Study Limitations

There were several potential sources of bias in the study, which the researcher sought to limit as much as possible.

The first potential for bias was social desirability. Some of the key respondents interviewed knew the researcher from her visits conducted while working for the NIOH through an outreach programme which included presentations for autopsy compensation, training of prosectors in mining hospitals and arranging collections of lung boxes. This could have affected the quality and sincerity of responses during the in-depth interviews. Some respondents could have given false or partially false responses in order to impress the interviewer because she had trained them in the past and as a result of previous training expected outcomes.

There could have also been recall bias. The study reviewed current perceptions of people involved in autopsy compensation and related matters. Human capital in institutions is unstable at specific roles. This study recognises that, in the five years under review there was a possibility of staff reshuffling or transfers. The effect of these on this study is that study participants whose opinions and perceptions were assessed during the study might not have been in that role during the study period. Hence, some responses could have fallen short of factors that affected autopsy over the study period. Institutional circumstances could have also changed which ultimately could have affected participant's responses in this study positively or negatively.

There was also selection bias when sampling, given the socio-political context. Even though mine unrest occurred in 2012, the situation on the mines was still volatile post 2012. This volatility resulted in management and staff being overly conscious about the security repercussions that could follow after the mine unrest. Therefore, information in relation to mine safety and health was quite closely guarded. This unrest also made it difficult for the researcher to get permission to sample other mine hospitals. This study was conducted in only three mining hospitals instead of six that were initially targeted.

Another source of selection bias was the method used to select mining hospitals for the study. Selection of mines was not random thus one cannot generalize; purposive sampling was used. The bias of purposive sampling is that subjects selected for the sample are chosen by the judgment of the researcher. However, purposive selection was an advantage to this study in that only those mining hospitals identified as either having a high or a low autopsy uptake were approached to participate in the study.

This study did not explore autopsy uptake of ex-miners. This could be considered as a limitation given the fact that most ex-miners are seldom autopsied because they die away from the mining hospitals. If they had been included, uptake would probably have been very Low. However, this study focused on active miners.

In addition, this study did not explore data on refusals to consent which would have enabled the determination of whether low uptake was due to refusal to consent or no offer of autopsies.

CHAPTER FIVE - CONCLUSION

5.1 Conclusion

This study found that autopsy uptake is a multi-stage as well as multi-level process influenced by history, politics, institutions and procedures and the perceptions of individuals involved in offering and consenting to autopsy.

At the public policy level, this study found that the requirements of the ODMWA on obtaining consent were too laborious to the extent that it became unfavorable to obtain consent for autopsy purposes. Another finding from this study was that autopsies of active miners who die from unnatural causes and those who die away from employment are not done by mining hospitals. This could be because autopsies at forensic mortuaries are done before the next of kin is available to give. Autopsies for miners dying away from their employment were not done because of the shortage of autopsy facilities especially in rural areas.

At institution level, the findings of this study showed that discretionary determination of suitability by some institutions is a barrier to consent as different institutions interpreted and applied the Act in their own way to determine suitability for an autopsy. Because of this, some families were not given an opportunity to exercise their rights to consent or refuse after losing their relatives. This study also revealed that feedback on the part of the MBOD to those offering autopsies was poor. This had a backlash effect on the decision to offer autopsies, and ultimately on autopsy rates.

At the individual level in the institutions, it was found that those who offer autopsies were not fully aware of the provisions of the Act. This led some individuals to introduce suitability clauses contrary to the Act. Lack of awareness was not only limited to the service providers: if mining communities and families were aware of their rights to autopsies, they would have demanded that their relatives are autopsied even when not offered. In cases where autopsy consent was sought, factors that were thought to influence obtaining consent from the next of kin were language, personnel perceptions, as well as cultural and religious beliefs. This study found that the communication approaches and strategies used by people involved in offering autopsy consent were some of the factors that influenced the autopsy consent process.

Other important factors which do not fall within the themes above, included communication approach, cultural, religious beliefs and practices

5.2 Recommendations

The conclusion of this study is presented in the form of a three-tier ecological model summarized under public policy, institutional and individual level factors that were found to affect consent. In line with the above, the recommendations made by this study will be based on the same ecological levels for purposes of simplicity and will later suggest some management and behaviour change approaches that maybe useful to bring in change in the institutions involved in autopsy service.

5.2.1 Public policy level

One issue of poor autopsy uptake was inaccessibility to autopsy facilities by active miners who die naturally while on leave or away from the mine and those who die unnaturally but do not get autopsied. A few options have been tried in getting to use the state facilities for miner's autopsies in the poor resourced areas but has been unsuccessful. In 2011 the NIOH made a submission to the NDoH proposing the use forensic mortuary facilities for the removal of the cardio-respiratory organs of deceased mine workers (Murray, J., personal communication, March 20th, 2017). To date, the NDoH has not responded to the submission that was made. The shortage of autopsy facilities in poor resourced areas has contributed to some deceased miners not getting autopsied especially ex-miners who die at home. This study suggests that autopsy service be institutionalized.

However, intra and inter-institutional problems at the MBOD and CCOD levels are also impacting on the decision to offer consent in the mining hospital environment. A barrier to hospital staff seeking consent was issues at the MBOD certification or CCOD payout levels that acted as deterrents. Poor responsiveness or lack of payouts, which fell outside of their immediate control, need to be addressed in the respective institutions. This study recommends that mine workers' unions should mobilize their members to demand better service delivery from the MBOD and CCOD. Union representatives

could work as advocates for change in compensation service delivery. This could take the form of a peaceful protest by miners led by the union representatives and compensation activists to the MBOD and CCOD to submit a list of service demands. A peaceful march is allowed in South Africa under The Regulation of Gatherings Act 205 of 1993 (Memeza, 2006). This strategy will enforce the MBOD and CCOD to speed up the compensation process; response to autopsy service providers and families of deceased miners and finally fast-track the compensation payout process. This will as well encourage law and policymakers to consider changes in the management of the two institutions which can improve the turn-around time in their service delivery. Beyond advocacy, the initiation of a law suit in pursuit of group rights is another tier of demanding for fairness and the full implementation of all laws related to autopsy compensation. This is supported by the latest judgement in which a group of mineworkers initiated a class action against 32 gold mining companies. In this decided case, mineworkers sought the intervention of the South Gauteng High-Court to pass judgement in their favour against the 32 respondents who had failed to provide health and safety in work and living places in the mines. An extension of their plea to the court included compensation for families of deceased miners who contracted TB and silicosis (High-Court, 2016). On the basis of the above judgement, it is recommended that, in future, miners should consider resorting to the court using this case as legal precedent to secure their rights to autopsy compensation.

5.2.2 Hospital level

Several institutions are involved in consent. This study focused on hospitals that render autopsy service to families of deceased miners. A number of issues that require interventions came up at this level. As a result, this study makes recommendations based on these different issues sub-headed below as follows:

5.2.2.1 Correct interpretation of the Act

Several health professionals misunderstood ODMWA. There is a need to improve understanding of the Act among health workers and H&S staff and officials involved in offering autopsies. The MBOD as custodians of ODMWA through NIOH should build the capacity of health professionals involved in autopsy provision by conducting workshops as well as peer evaluation activities so as to clarify misunderstandings that exist in the interpretation of the Act and ensure strict adherence to provisions of the Act.

Increase self-efficacy

This study demonstrated that officials rendering autopsy service do not have confidence in communicating removal of organs to families of the deceased. This is probably because of the sensitivity around the issue of removing organs, the lack of training on how to request consent and their inability to convince families to consent to autopsies. We need to build confidence of these officials to believe in themselves that they can talk openly about autopsies and successfully convince families to agree to autopsies. Self-efficacy or confidence in doing something is defined by (Bandura, 1994) as *"belief in one's capabilities to organize and execute the courses of action required to manage prospective situations."* The sense of self-efficacy plays a major role in how these officials offer autopsies and the challenges they encounter with mourning families.

Self-efficacy to increase autopsy consent among service providers should be addressed by reinstating the NIOH outreach programme, specifically the training of health care workers involved in autopsies and union H&S officers. These outreach program should organize a workshop for those hospitals who have high autopsy uptake together with those who struggle with their uptake rates. The groups that has high autopsy uptake rates can share their approaches and experiences in offering autopsies. It is envisaged that by seeing people similar to them succeeding in openly

talking about autopsies and influencing families to give consent for autopsies, would make them to believe that they too can do the same and probably even better (Bandura, 1994). Bandura and Walters (1977) in the social learning theory, hypothesized that people learn from one another by observation, imitation, and modeling. During these workshops, officers will be guided by their peers and can practice in front of a person experienced in communicating with miners' families. This will enhance their confidence in executing their duties. Self-efficacy will also be enhanced if higher-level deterrents (policy) are addressed.

Top-down and bottom-up approaches

A blend of top-down and bottom up approaches have been shown to be most effective at increasing knowledge (Crisp et al., 2000). This study revealed that there is lack of support for officials offering autopsies from mine management. There are no internal structures in place to guide the procedure on who should be autopsied and who should not. These officials are left to use their own discretion to offer or not to offer autopsies when a miner dies. This could be because management is also lacking guidance on the interpretation and application of the Act. Top-down and bottom up approaches are ineffective when used separately**;** however, when blended together, they allow people to take a fresh approach to solving problems and improving performance (Sabatier, 1986). A top-down approach creates the focus and the required conditions for transformational change, whereas, the bottom up approach is meant to provide skills to staff (Crisp et al., 2000). So, a change can be initiated top-down and sustained bottom-up.

This study recommends blending top-down and bottom-up capacity building approaches. Top management can get clarity of the Act from the custodians, MBOD, and make policies that will guide officials involved in autopsy offering who would then create sustainable programs and strategies to correctly interpret and implement the Act. The NIOH outreach program can develop workshops that would empower and guide these officials to have a clear understanding and interpretation of the Act. In that way, it is anticipated that officials will correctly interpret, apply the Act and thereby, offer autopsies to all families of deceased miners irrespective of their clinical cause of death.

5.2.2.2 Improved feedback

This study revealed that there is poor motivation for hospital officials to offer autopsies because of lack of feedback from the compensation institutions, which has led to a myth among families and union representatives that autopsy compensation payouts are being squandered by service providers. Mine officials involved in autopsies also were frustrated by the poor service at the MBOD and CCOD.

There is a need to improve administration at the two compensation institutions. Sound administration guides the procedure. If there are clear guidelines that employees can follow with stipulated timelines, prompt feedback to autopsy providers will improve. MBOD and CCOD should restructure their communication handling procedures and processes to improve their provision of prompt feedback as delayed communication deepens mistrust among service providers and families. The NIOH pathology service staffing needs to be expanded and their roles redefined to include the revival of the defunct outreach programme in order to support the two compensation institutions.

One programme that was designed to improve provider-client relationship is Health Workers for Change (HWFC) (Haaland and Vlassoff, 2001). According to Fonn and Xaba (2001), this type of intervention allows people not only to explore the problem and issues but also to create solutions to the problems. Methods that have been proven to work in workshops for healthcare workers such as, role plays and poems by the healthcare workers as was reported by (Fonn and Xaba, 2001) can be a valuable exercise when used in workshops to improve service delivery at the MBOD and CCOD. It is anticipated that employees at the MBOD would see the need to change their ways of approaching their tasks and take pride in serving the mining community with dignity and showing a sense of urgency.

5.2.3 Individual level

This study found that personnel perceptions as well as cultural and religious beliefs of persons involved in communicating with families affected outcomes of consent

requests. Persuasive communication induces change or stimulates action. People tend to influence or be influenced by others through persuasive communication (Perloff, 2010). Therefore, this study recommends tailor-made communication strategies to be designed by occupational health specialists for frontline autopsy service providers to enable them to use persuasive communication when they engage with families of deceased miners. The NIOH as part of their outreach program should train hospital staff involved in offering autopsies on how to deal with religion and culture sensitivities.

In addition, mine workers' unions should encourage their members to sign a living will clearly giving consent for autopsy and that should be considered and be respected as the wish of the deceased to have organs removed for autopsy after death.(Bandura and Walters, 1963)

5.3 Other Recommendations

During the study the researcher made observations that were not key objectives of the study, but which nevertheless are important and may facilitate the improvement of autopsy uptake levels. Recommendations from these observations are stated in this section.

The researcher was aware of health education and promotion materials which were developed by the Mine Health and Safety Council (MHSC) for distribution to mineworkers. This material was meant to encourage mineworkers to talk about mine related diseases and compensation to their families and to improve self-efficacy. However, during this study, the researcher observed that these materials never got to the intended people, the mineworkers, for whom they were developed. Possible barriers to distributing these materials were not discussed. It is recommended that checks and balances should be put in place by the MHSC to ensure that such important educational tools reach mineworkers and minimize the loss of operating capital in investments that do not yield their intended outcomes. It is further recommended that immediate steps be taken by the MHSC to get mine workers' unions to distribute such materials to the beneficiaries.

5.4 Further Studies

A few areas have been identified as knowledge gaps in this study and further investigation or research will help to unravel possible solutions. Two of these areas that further research is required are listed below.

- A qualitative study to identify best practice in requesting consent for autopsies from families of deceased mineworkers.
- A qualitative study of peer-led autopsy education approaches that increase the chances of obtaining autopsy consent (Kumar et al., 2010)

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APPENDIX 1 Plagiarism Declaration Report

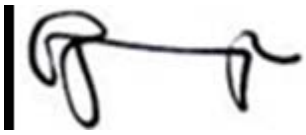
PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

SENATE PLAGIARISM POLICY: APPENDIX ONE

I, **Julian Qedizaba Mthombeni** (Student number: **678721**) am a student registered for the degree of **Masters in Public Health (MPH)** in the academic year **2017**.

I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.
- I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.

Signature:  Date: 7th April 2017

APPENDIX 2 Clearance Certificate no. M130820

R14/49 Ms Julian Mthombeni

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M130820

NAME: (Principal Investigator)	Ms Julian Mthombeni
DEPARTMENT:	School of Public Health Medical School
PROJECT TITLE:	Exploration of Factors Influencing the Uptake of Autopsy Compensation for Miners in South Africa
DATE CONSIDERED:	30/08/2013
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Mrs N Ndlovu & Mrs S Nieuwoudt
APPROVED BY:	Professor PE Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	27/09/2013

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**.

Principal Investigator Signature Date 30 October 2015

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX 3 Data Collection Checklist

Data collection checklist

Exploration of factors affecting the uptake of autopsy compensation for miners in South Africa

Item	Available Yes/ No	Comments
Is there a documented Procedure?		
Are documented procedures followed?		
Is there a private comfortable place for mourning families to discuss autopsy compensation available?		
Are autopsy compensation procedures explained to families?		
Are autopsy compensation benefits explained to the families?		
Death register available? No. of deaths per year 2008 2009 2010 2011 2012		
Autopsy register available or noted? Lungs removed per year 2008 2009 2010 2011 2012		
Is there anything else that you would like to mention that is explained to the families?		

APPENDIX 4 Interview and Focus Group Guide

IN DEPTH INTERVIEW GUIDE FOR All KIs

A. Preparation Checklist

The following preparations should be completed before each IDI:

- ☐ 1 extra copy of study information sheets
- ☐ 1 extra copy of consent forms
- ☐ 2 copies of audio-recording consent forms
- ☐ Digital audio-recording equipment (tested for working condition)
- ☐ Backup batteries for audio recorder(s)
- ☐ Notebooks for interviewer
- ☐ Private room
- ☐ Food and drinks for interviewee

Name and Signature of Study Staff: _____ *Date:* _____

B. Checklist for Facilitator and Note taker

The IDI shall only progress once the following are confirmed:

- ☐ Study ***consent form has been signed*** and ***copy given to interviewee***
- ☐ Interviewee has ***signed audio-recording consent form***

Name and Signature of Study Staff: _____ *Date:* _____

C. Introduction Exercise

Note: Start recording

Once the consent process is complete, to build rapport, have the interviewee introduce a little bit about her/himself without using her name, e.g. age and period in current job

Note: Check that recorder is working before proceeding

1

D. Interview guide

1. Could you tell me a little bit about your involvement in when a mineworker passes away.

    a. How do you know about the autopsy compensation?
    b. How do you get to know about a death of a mineworker?

2. What are the procedures with regards to contacting the family of the deceased and making arrangements when a mineworker who worked at this mine dies?

    a. Could you take me through the steps of the procedure followed after the death of a miner?
    b. What do you think about the steps / procedures followed after the death of a mineworker? Why?

3. How the family is made aware of the right to autopsy compensation?

    a. How do you feel about telling the family about the removal of the organs of deceased?
    b. How do you feel about asking the family to have the organs of their loved one removed?
    c. What has been the family's response when you offer them this autopsy?
    d. Where do you normally talk to the family when offering the autopsy?
    e. Roughly, how long does it take you to talk to the family?

4. Has there been any significant change in the way that autopsies are offered to families of deceased person recently? [If so, please describe]

5. If you could make changes in the way autopsies are offered, what would you change?

6. How would you advise families that do not want autopsy compensation for their deceased relative?

7. If your own relative had died, would you give consent to autopsy compensation, why?

Thank you for participating in the study, your contribution is appreciated.

APPENDIX 5 Interview Consent

INFORMED CONSENT:
I hereby confirm that I have been informed by the study staff (_____) about the nature, conduct, benefits and risks of the Exploring factors influencing the uptake of autopsy compensation for miners in South Africa Study.

- I have also received, read and understood the above written information
- I am aware that the results of the study, including any personal details such as those regarding my age will be anonymously processed into a study report.
- In view of the requirements of research, I agree that the data collected during this study can be processed in a computerized system by the researchers or on their behalf.
- I may, at any stage, without prejudice, withdraw my consent and participation in the study.
- I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.

PARTICIPANT:

_____

Printed Name and Time | Signature / Mark or Thumbprint | Date

I, _____ herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

STUDY STAFF:

_____

Printed Name Time | Signature | Date and

4

APPENDIX 6 Audio-recording Consent

Audio-recording Consent Form - Interview

The reason for audio-recording the interview has been explained to me.

I am aware that I may choose whether to participate or not to participate in the interview and to be recorded.

I am aware that I may stop the interview at any point.

The researcher will take measures to make sure that the recording is kept confidential and safe.

I consent to having the interview audio recorded.

Interviewee:

Name: _____

Signature: _____

Date: _____

Researcher

Name: _____

Signature: _____

Date: _____

APPENDIX 7 NIOH Autopsy Consent Form

NATIONAL INSTITUTE FOR OCCUPATIONAL HEALTH

25 Hospital Street, Constitution Hill, Johannesburg
PO Box 4788 Johannesburg 2000, South Africa
Tel: (011) 712 6400 • Fax: (011) 712 6450
Autopsy enquiries
(011) 712 6444 • (011) 712 6434 • (011) 7126465

CONSENT FOR A POST-MORTEM EXAMINATION

I _____

The *spouse/major child/ parent/ guardian/ major brother/ major sister/

(* Delete whichever is not applicable)

Of the late (name) _____

Age_____ **Sex**_____

Hereby consent to a post-mortem examination and the removal of such tissues as may be considered necessary for the purpose of the requirements of the Occupational Diseases in the Mines and Works Act (No.78 of 1973)* and for diagnostic, medical education, research and scientific purposes

Signature _____

Witness _____

Witness 2 _____

Place _____

Date _____ **Time** _____

NATIONAL HEALTH LABORATORY SERVICE
NATIONAL INSTITUTE FOR OCCUPATIONAL HEALTH