

ABSTRACT

Background: In the South African mining sector, cardiorespiratory autopsy examinations are conducted on deceased mineworkers to determine eligibility for compensation, irrespective of the cause of death. An autopsy examination is a right under the Occupational Diseases in Mines and Works Act, Act No. 78 of 1973 (ODMWA) except for mineworkers who received maximum compensation awarded for occupational lung diseases in second degree category during life. Compensation awards to the deceased mineworkers' dependants can contribute to short- or medium-term poverty alleviation. In spite of the possible benefits, ODMWA autopsy utilisation by black mineworkers' families is incomplete. Increased utilisation has the potential to assist in alleviating poverty. It is imperative to understand what contributes to autopsy utilisation or non-utilisation by black mineworkers, as this will guide public health policy intervention regarding ODMWA autopsy.

Aims: The study set out to quantify the monetary contribution of ODMWA autopsy to mineworkers' families, to estimate the loss of potential financial benefits due to autopsy non-utilisation; define the characteristics of those deceased mineworkers who did not use the autopsy service (to tentatively formulate reasons for not using autopsy); and to describe the barriers and enablers that contribute to ODMWA autopsy utilisation.

Methods: The study was primarily qualitative; however quantitative investigations were undertaken using data from the National Institute for Occupational Health (NIOH), the Medical Bureau for Occupational Diseases (MBOD), and The Employment Bureau of Africa (TEBA). First, a descriptive study was undertaken to determine autopsy utilisation and establish the amount of compensation paid to dependants of deceased mineworkers over a ten-year period (2001- 2010) following autopsy examination; and to estimate the loss of financial benefits from autopsy non-utilisation. Also, the characteristics of those deceased

mineworkers recorded by MBOD in 2001-2008 but who did not undergo autopsy examination were investigated using data in the subjects' MBOD files. The characteristics investigated included previous submissions to MBOD or date of last submission; age of the deceased at death and place and date of death; labour history, the last date of work; cause of death and medical information.

Second, in-depth interviews on perceptions of autopsy were carried out with participants. The key participants were former and in-service mineworkers, relatives and widows of deceased mineworkers and others (traditional healers, occupational health practitioners, community and organised labour leaders). These categories of participants were selected because of the particular perspective that they were likely to bring to the study. A semi-structured questionnaire was used to guide the in-depth interviews. All interview data were transcribed into English. Key ideas generated were noted at the end of each interview. The notes were examined for overall depth and meaning. The notes for each respondent were uploaded in their groups onto 2003 MAXqda PC (2003) and coded into segments and grouped into categories. Emerging themes were identified using a conceptual framework and meaning interpreted.

Results

Autopsy utilisation: 71% of in-service mineworkers over the 10-year period were employed by mines affiliated with TEBA. Using the annual TEBA-reported deaths as the denominator and ODMWA autopsies as the numerator, it was estimated that during 2000-2010, autopsy utilisation by black miners who died in service ranged from 30-46%. It is argued that these figures were an over-estimate as they did not include former mineworkers or in-service mineworkers working for TEBA non-affiliated mines. The results suggest that the

majority of autopsy examinations were of TEBA registered mineworkers. Following autopsy examinations over ten years, 311 deceased mineworkers not compensated in life were certified by MBOD to suffer occupational lung disease in the first degree and 2 426 in the second degree categories respectively following autopsy examination.

Autopsy non-utilisation: From the TEBA recorded deaths and ODMWA autopsies performed by NIOH, there were 15 064 mineworkers who did not undergo autopsy examination during 2001-2012. It is estimated that 355 mineworkers would have been certified in the first degree category, and 2 769 in the second degree category had they come to autopsy.

Contribution of ODMWA autopsy to compensation: Each family of the 311 deceased mineworkers certified with occupational lung disease in the first degree category would have received an average lump sum payment of \$8 750. Similarly each family of the 2 426 mineworkers certified with occupational lung disease in the second degree category would have received an average lump sum payment of \$12 907. Additionally, each family of the 59 cases upgraded from first to second degree category following autopsy examination would have received an average lump sum payment of \$5 250. If assumptions were made that Stewart (2007)'s findings on financial spending on basic needs such as food person per family of seven members were similar to that of mineworkers compensated following ODMWA autopsy; households that received \$8 750 in compensation would have had sufficient money to buy food for 29-47 months. Similarly those who received \$12 907.79 and \$5 250 could have managed to buy food for 49-80 and 20-33 months respectively.

Characteristics of deceased mineworkers: Tentative reasons of no autopsy examination were dying at home, recent MBOD submission, age of the mineworker, previous and current TB infection certified by MBOD. Ninety six percent of them died at home and four percent

died in district public hospitals. Sixty four percent were recently submitted to MBOD and of these mineworkers, 70% had pulmonary tuberculosis. The majority were fairly young i.e. 52% died before the age of 50 years and a further 12% before the age of 60 years.

Barriers and enablers of ODMWA autopsy: Barriers and enablers of ODMWA autopsy consent and utilisation were found to be diverse, complex, and multifaceted such that a multipronged intervention strategy would be required to increase utilisation. The barriers and enablers of ODMWA autopsy were in individual/family; socio-cultural and institutional perspectives. The respondents could rationalise their acceptance or rejection of autopsy within their own individual cultural or religious belief system and these varied according to the individual's experiences, family beliefs and societal practices.

Enablers regarding consent to ODMWA autopsy were dissociation of the body from the soul, matrilineal relations to the deceased mineworker, communication with ancestors while the mineworker was healthy, deaths described as bad by participants. Key to autopsy consent facilitation was the mineworkers communicating their acceptance of ODMWA autopsy examination to their families and by communicating this intention to their ancestors -where this was consistent with their belief system.

Foremost among the barriers to ODMWA autopsy utilisation was the requirement of formal consent within a biomedical framework, which clashed with certain socio-cultural beliefs. These cultural barriers were associated with patriarchal relations to the deceased mineworkers, beliefs that being buried without cardiorespiratory organs was synonymous to burying an empty box, health workers' attitudes, mistrust, commodification of body parts,

community traditional norms and practices and unequal power relations on decision making which led to exclusion of potential beneficiaries (widows and children).

Conclusion: The study documented that a large number of in-service black mineworkers did not utilise ODMWA autopsy in spite of the potential financial benefits demonstrated. Additionally, former mineworkers who did not utilise autopsy were under fifty years of age, died of PTB within twelve months of leaving mines at their homes. The study found cultural beliefs that were barriers to autopsy utilisation, but also those that may enable these barriers to be overcome. The finding that the cultural beliefs were not static or uniform suggested that increasing autopsy consent would require comprehensive communication and awareness intervention strategies aimed at individual, family and community levels. The intervention strategies should not be once-off, but long-term and should address the cultural beliefs. The enablers of autopsy utilisation could be used in the awareness messages.

Further research is required to investigate the attitude of health care providers (nurses, traditional healers, medical practitioners etc) to ODMWA autopsy utilisation, investigate the process of decentralising the autopsy examination and the impact this will have on appeals, standardisation and resources; and to examine the legal framework which would make ODMWA autopsy permissible without the current consent requirements, possibly under similar conditions to forensic medicine. Revising consent requirements is important to alleviate the conflict felt by spouses, mineworkers and relatives who have to satisfy cultural imperatives which are at odds with giving consent to permanent removal of cardiorespiratory organs. ODMWA should remain in place until exposures resulting in occupational lung diseases have been reduced to non-disease-causing levels or no new occupational diseases are found at autopsy. The enablers and barriers to ODMWA autopsy

found in this study may be generalisable to similar socio-cultural environments outside South Africa.

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ABBREVIATIONS

CCOD= Compensation Commissioner for Occupational Diseases

DMR = Department of Mineral Resources

HIV = Human Immunodeficiency Virus

ILO =International Labour Organisation

ISBN= International Standard Book Number

MBOD = Medical Bureau for Occupational Disease

MHSA = Mine Health and Safety Act

MHSC=Mine Health and Safety Council

NCD= No compensable disease

NHA=National Health Act

NIOH = National Institute for Occupational Health

OAD=Obstructive airways disease

ODMWA = Occupational Disease in Mines and Works Act

O.L.D = Occupational Lung Diseases

PATHAUT = The Pathology Automation System (PATHAUT) is an electronic database of approximately 100 000 autopsies of deceased miners, dating back to 1975.

PTB = Pulmonary tuberculosis

RCS = Respirable Crystalline Silica

SAMI = South African Mining Industry

SAQA=South African Qualifications Authority

STATSA = Statistics South Africa

TEBA = The Employment Bureau of Africa

GP=Gauteng Province

NW=North West Province

LP=Limpopo Province

MP=Mpumalanga Province

KZN=Kwa-Zulu Natal Province

EC= Eastern Cape Province

WC= Western Cape Province

NC= Northern Cape Province

NIOSH=National Institute of Occupational Safety and Health

FS= Free State Province

RSA=Republic of South Africa

OPERATIONAL DEFINITIONS (Also refer to Appendix 14)

Arrangements for post-mortem examinations and services: The Minister of Health may with the concurrence of the Minister of Finance enter into such agreement or make such other arrangements with any institution, hospital or organisation as the Minister may consider necessary for the performance of any post-mortem examinations or post-mortem services required under this Act.

Benefit medical examination: Medical examination of in-service and former mine workers for certification by MBOD.

Certification: It is the process used by the MBOD certification committee to determine the presence or absence of occupational lung disease. The certification only occurs at the MBOD in Johannesburg.

Certification Committee: the Minister of Health appoints the medical certification committee for O.L.D and members. Committee members are medical doctors representing organised labour, employers, and government. It excludes medical doctors by the MBOD.

Clinical autopsy: An autopsy performed for any reason other than forensic or for ODMWA.

Compensable OLD under ODMWA:

1. Pneumoconiosis, which includes silicosis, asbestosis- interstitial or pleural plaques, or a combination of both, Coal Workers' Pneumoconiosis.
2. Mesothelioma attributable to risk work

3. Joint condition of pneumoconiosis and PTB
4. PTB
5. PTB which, in the opinion of the certification committee, was contracted when the person concerned was performing risk work, or was still affected within the 12-month period immediately following the last risk work
6. Obstructive Airways Disease (OAD)

OAD in mineworkers with a history of crystalline silica exposure of more than 10 years.

Cost of medical examinations: The cost of any medical examination under this Act, and the cost incurred to keep a person under observation in accordance with any provision of this Act, shall-

- in the case of a person who works at a mine or whom the owner of a mine or works intends to employ, be borne by the owner of the mine and
- in the case of any other person, be paid by the Director-General from moneys appropriated by Parliament for that purpose.

Dependants: Spouses and children of the deceased mineworkers or persons less than 18 years of age who were financially dependent on the miner

Director of the MBOD's responsibilities to submit certain medical and post-mortem reports to Certification Committee:

When the director has obtained or has received from any medical practitioner any report or communication on the medical or post-mortem examination in terms of this Act of any person-

- who has not previously been found by the committee to be suffering from a compensatable disease and who is on the ground of such examination considered or suspected to be suffering from such a disease or to have been suspected or suffering from such a disease at the time of his death; or
- who has previously been found by the committee to be suffering from a compensatable disease and who is on the ground of such medical examination considered or suspected to be suffering from a compensatable disease in a more advanced degree,

the director shall as soon as practicable submit to the certification committee a full report on such examination, and, at the request of the said committee, cause such further examinations, tests or observation to be performed as that committee may require.

MBOD ODMWA certification categories: Three degrees of impairment, each of which results in a category of compensation.

1. NCD = <10% cardiorespiratory impairment. The category also includes presence of diseases other than occupational lung diseases.
2. 1st degree category = cardiorespiratory impairment of $\geq 10\% \leq 40\%$ disability
3. 2nd degree = cardiorespiratory impairment of >40% disability
4. TB current or TB can antedate= Active PTB or PTB contracted within 12 months of leaving the mines. The mineworker is compensated 75% of earnings lost during the course of PTB treatment

Mine Health and Safety Council Dust Milestones

- a) By December 2008, 95% of all individual exposure measurement readings would be below the occupational exposure limit for respirable crystalline silica of $0.1\text{mg}/\text{m}^3$ and after December 2013,

- b) Using present diagnostic techniques, no new cases of silicosis would occur amongst those who were unexposed from 2008.

ODMWA autopsy: It is the permanent removal of cardiorespiratory organs for pathology examination.

Occupational Lung Disease (OLD): Respiratory disease acquired by a mineworker during exposure to risk work.

Rand dollar exchange rate used=Eight rands equals one dollar

Risk: 'risk' in relation to a mine or a works, means the risk of contracting a compensatable disease, to which persons who perform risk work in or at or in connection with that mine or works are exposed, or the risk determined by the risk committee in respect of that mine.

Risk work: Any work performed at a mine at a place, which is a 'dusty atmosphere' in terms of the definition of the act, shall be deemed, until the Minister by notice in the Gazette declares otherwise, declared risk work under this section. The Minister shall declare work be risk work if he or she is satisfied, after consultation with the risk committee and after consideration of such representations (if any) as may have been made to him or her by the owner of the mine in question, or by any organisation acting on behalf of such owner or on behalf of persons employed at that mine or works, that any person performing the work in question is exposed to:

- *dust of which the composition and concentration is such that it is in the opinion of the Minister harmful or potentially harmful; or*

- *gases, vapours or chemical substances, or factors or working conditions, which, in the opinion of the Minister, are harmful or potentially harmful.*

Section 34 of the ODMWA: Duties of a medical practitioner with regard to ODMWA autopsy examination in South Africa with consent:

1. The MBOD director may authorise or in writing direct any medical practitioner in the Republic of South Africa to perform a post-mortem examination or other post-mortem service under this Act of a nature determined by the director. A medical practitioner so authorised or directed who has performed a post-mortem examination or other post-mortem service in accordance with such authorisation or direction, shall forthwith submit to the director a detailed report on the result of the examination or service performed by him.
2. A medical practitioner in the Republic who attended a deceased person at the time of or immediately before his death, or has opened the body of a deceased person, and who knows or has reason to believe that such person worked at a mine or works, shall remove the cardiorespiratory organs and any other prescribed organs or parts of the body of the deceased and shall send such organs and parts of the body to the prescribed place. If no place has been prescribed, to the MBOD or to any other place specified by the director, in accordance with the prescribed procedure or, if no procedure has been prescribed, in accordance with such instructions as may be issued by the director.
3. 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.

The National Health Act guide - ISBN 978-1920025-25-0 (2008)

The post-mortem examination of a deceased person are conducted if the deceased consented to it in life, if the spouse, partner, major child, parent, guardian, major brother, or major sister of the deceased (in the specific order mentioned) gave consent, or if such an examination is deemed necessary to determine the cause of death. A post-mortem examination may not take place unless the medical practitioner in charge of clinical services has authorised it. In the absence of such a person, the person in charge of such a hospital or institution must give written authorisation to a medical practitioner. The Act also covers for the removal of tissues before burial with consent. This guide mobilises the public to demand full utilisation of their rights under the National Health Act

Work declared risk in terms of ODMWA (Act 78 of 1993): means any work place, not being a mine or part of a mine, where any of the following operations and any operation necessary therefore or incidental thereto is carried out and constitutes the main operation at such place. For the purpose of determining whether a person is entitled to a benefit under this Act—

- work performed at a controlled mine or a controlled works before the date on which that mine or works became a controlled mine or a controlled works prior to 1996; or
- work performed at a mine or works which, in the opinion of the Chief Inspector of Mines as contemplated in the Mine Health and Safety Act, 1996, would have been declared a controlled mine or a controlled works had it not closed down.

These works are:

- a) the moving, transfer or handling of stone, rock, ore, coal or other minerals, including any loading operation at subsidiary sidings;
- b) the crushing, screening, washing, classifying or concentration of any mineral;
- c) the treating of any mineral, in the form obtained from a mine, for the production of coke or for the production of a base metal in any shape or form, including ingots, billets and rolled sections;
- d) the working or treating of mine tailings deposits or mine dumps for the recovery of any valuable content thereof;
- e) the extracting of any precious metal from any mineral or concentrate;
- f) the refining of any precious metal;
- g) the drying or calcining of any source material as defined in the Nuclear Energy Act, 1993 (Act 131 of 1993);
- h) the making, repairing, reopening or closing of any subterranean tunnel

PREFACE

Over 25 years, as a mine medical officer, as Director of the MBOD and as Health Programme Manager for the Mine Health and Safety Council, I have observed the impact of the amendments to the Occupational Disease in Mines and Works Act (ODMWA), Act 103 of 1973. The amendments removed racial discrimination regarding compensation and decentralised the MBOD benefit medical examinations to all South African provinces, improving access and allowing former black mineworkers to be examined biannually (paid for by the MBOD). During these years, meetings were conducted with former mineworkers, families of mineworkers, community leaders, district health managers, and general practitioners at their villages and the Department of Health district offices to brief them on the objectives, processes, and benefits of ODMWA and the role of the MBOD, the CCOD, and the National Health Department. I expected to see many former mineworkers utilising ODMWA services biannually for possible compensable diseases. Following the meetings and discussions that created awareness on the possible ODMWA benefits, I also expected to see an increased number of ODMWA autopsy examinations. None of these expectations was met. As the director of MBOD, I also observed that former white mineworkers would utilise autopsy services more than black mineworkers would. On rare occasions in which former white mineworkers died outside South Africa, families enquired on the process required to send organs to the MBOD. In some cases, pathology reports, medical records (old and recent) carried out after the mineworker left the mines, chest x-rays and other medical results would be received by MBOD and the certification committee would evaluate these records during medical certification

Trapido et al (1998) estimated that there were millions of former mineworkers with no opportunity at that time to benefit from ODMWA. Between 1997 and 2001, as Director of

the MBOD, and with the support of the National Department of Health, Provincial Governments, and local leaders, I travelled to many of the villages in rural South Africa from which mineworkers migrated to work in the mines. These visits created an awareness of ODMWA and established partnerships with the stakeholders involved in mineworkers' benefit examinations. TEBA provided the researcher with the lists of villages from which the mineworkers came. The strategy used at each visit was to attract and invite former mineworkers, community leaders, activists for the mineworkers, local health service providers (public and private), and representatives of the local mortuaries to the meetings or workshops to discuss the ODMWA benefits and share information on the processes involved.

Many of the former mineworkers who attended the meetings and workshops became field workers. They had the task of enlisting other former mineworkers known to them and of documenting their labour histories. The MBOD paid the fieldworkers a subsistence fee. The names of the former mineworkers were sent to the nearest medical doctor or hospital, where they could be offered a benefit medical examination at an agreed fee. The field workers informed the former mineworkers about the facilities and the doctors who could provide the benefit medical examination.

The number of benefit examinations rose during the first three years, but declined thereafter. I was particularly interested in the autopsy figures of former black mineworkers, which declined from the initial improvements. From the observed declining autopsy numbers of black miners, grew the idea to research on the sociological explanation for the declining autopsy utilisation from the mineworkers and the families of deceased mineworkers.

The study adopted a mixture of quantitative and qualitative data collection. The study has ten chapters. The first chapter is the introduction and it sets the scene of the thesis. The second chapter is the literature review which provides a narrative of what was established relating to autopsy and clinical autopsy in general. The third chapter outlines the theoretical framework and the fourth chapter the conceptual framework. Chapter five outlines the methods and chapter six, the quantitative results. Chapter seven outlines the qualitative results, chapter eight general discussions, chapter nine study limitations and strengths; and ten recommendations, which, could result in improvements in autopsy utilisation and therefore benefits more dependants.

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CHAPTER 1: INTRODUCTION

'Bread is for eating, wine is for drinking. Necropsy is a means of instruction, a mechanism for correction, a pathway to discovery, a source for investigation, a storehouse of useful supplies and an avenue for technical opportunity and handmaiden of the law' Edward E Gall 1967

1.1. Background

In the South African mining sector, mineworkers undergo cardiorespiratory autopsy examinations under the Occupational Diseases in Mines and Works Act (ODMWA, act 78 of 1973) to determine eligibility for compensation, irrespective of the cause of death. ODMWA authorises a medical practitioner, following the death of a mineworker, to remove the cardiorespiratory organs with consent from close relatives and forward them to the Medical Bureau for Occupational Diseases (MBOD) or the National Institute for Occupational Health (NIOH), for an autopsy pathology examination. Similarly, a pathologist who performs a routine autopsy on such a person must follow the same organ-forwarding procedure. However, low levels of autopsy utilisation undermine the value of the service.

Murray and Hnizdo (2005) argued that more than 80% of white gold mineworkers who died either in employment or while retired utilised ODMWA autopsy services. In a retrospective cohort of 1950 HIV with known dates of HIV seroconversion and 6164 HIV negative black mineworkers who worked in a gold mine and were followed-up over a decade, Murray et al (2007) found that 70% of deaths occurring on that mine were followed by autopsy, compared with 7% occurring elsewhere. The authors attributed the low autopsy utilisation by

mineworkers who died after leaving the mines to lack of ODMWA autopsy resources. Approximately 80% of autopsy examinations were on mineworkers who worked in the gold mines and their employment history ranged from one month to several decades (Nelson et al., 2009). There was dearth of published information on ODMWA autopsy utilisation by other eligible mineworkers from other commodities both in-service or after leaving the mines.

The differentiation of mineworkers into in-service or former in the NIOH PATHAUT database commenced only in 2007 (Ndlovu et al., 2007). Table 1 shows the number of in-service and former mineworkers who had autopsy by race for the years 2007-2010 (unpublished data and obtained from Ndlovu, 2012).

Table 1: Number and proportion of current and ex-mineworkers coming to autopsy by race for 2007-2010

Year	Current mineworkers				Ex-mineworkers			
	Black		White		Black		White	
	N	%	N	%	N	%	N	%
2007	903	78.9	104	19.3	203	17.7	397	73.7
2008	843	71.1	63	11.3	264	22.3	439	79.0
2009	951	83.6	64	12.8	162	14.2	409	81.8
2010	725	75.5	47	9.0	204	21.3	459	88.1

The majority of mineworkers' autopsy examinations on in-service mineworkers were on black mineworkers, while those of former mineworkers were on white mineworkers as illustrated in Table 1. According to Ndlovu (2012), over the four years, a minimum of 0.5 percent and a maximum of 3.7 percent of overall total annual autopsies was not be classified by employment status as it was not recorded, and considered too small to influence the utilisation numbers. No published studies were found on the underlying reasons for overall autopsy utilisation by

former white and black mineworkers, however, inaccessibility to autopsy services have been partly attributed to low utilisation by black mineworker (Murray et al., 2007) and lack of ODMWA awareness (Roberts, 2009).

Although Table 1 illustrates that the majority of ODMWA autopsy examinations are on in-service black mineworkers, the underlying factors that are either enablers or barriers to ODMWA autopsy examination have never been investigated, a gap that is explored in this study.

A literature search was conducted to establish whether autopsy underutilisation existed, explore its underlying causes, investigate the existing body of knowledge on autopsy utilisation, and identify the gaps in the knowledge of barriers to utilisation. The literature search established that there was an international body of knowledge on factors, which influenced clinical autopsy utilisation. However, a gap in the literature reviewed on the autopsy examinations routinely performed following consent, irrespective of the cause of death, for compensating dependants that was similar to ODMWA autopsy process was identified. There was also a dearth of information locally on hospital autopsies.

1.2 Statement of the problem

Clinical autopsy is declining globally (Burton, 2007); however, there was an added significance in the decline of ODMWA autopsy. ODMWA autopsy provides a last opportunity to diagnose occupational lung disease that would secure compensation for the miner's family. The NIOH annual data revealed that between 1975 and 2010 the number of autopsies for black mineworkers that exceeded that of the previous year was recorded only 10

times (1976,1980,1982,1985,1986, 1987, 1990, 1995, 2000) as illustrated in figure 1. Similarly, among white mineworkers, the number of autopsies that exceeded that of the previous year was recorded nine times.

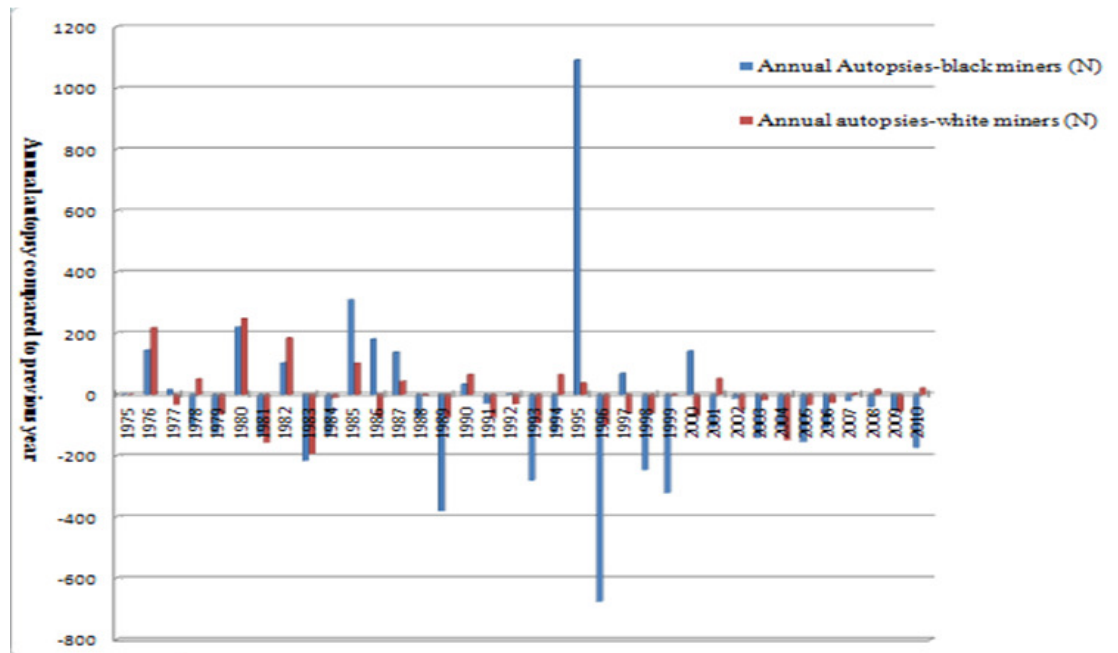


Figure 1: Annual autopsies (1975-2010). Source National Institute for Occupational Health

During 1975-2010, the overall number of deceased mineworkers undergoing autopsy examinations was less than that of previous years for both black and white mineworkers. Autopsy examination peaks are observed during 1985 and 1995, and dips during 1989, 1993, 1996, and 1999. The reasons for the peaks and dips are unknown. However, it is notable that the decline has persisted, despite the awareness programmes implemented by the Director of the MBOD between 1997 and 2001 and the NIOH awareness programmes which commenced in 2006 (Ndlovu et al., 2009). The programmes were to improve awareness and knowledge

about ODMWA processes and benefits among mine occupational health units on the mines, union representatives, mineworkers, undertakers, state hospitals, and forensic laboratories.

Roberts (2009) partly attributed the falling number of ODMWA autopsy examinations on black mineworkers to insufficient knowledge of ODMWA provisions by them, their relatives, and health personnel in rural hospitals. With the exception of mineworkers above the age of seventy years, younger mineworkers responded to ODMWA autopsy positively or their perceptions changed from negative to positive with an explanation of its possible benefits, as compared to those who considered ODMWA autopsy unacceptable (Roberts, 2009). The focus of the study was on health systems surveillance and accessibility, MBOD certification and compensation, disability, social exclusion and equity; and did not explore other enablers or barriers to of ODMWA autopsy utilisation.

In Figure 2, the annual decline in the number of ODMWA autopsy examination on the black mineworkers during 2000-2010 is further illustrated (NIOH, 2010).

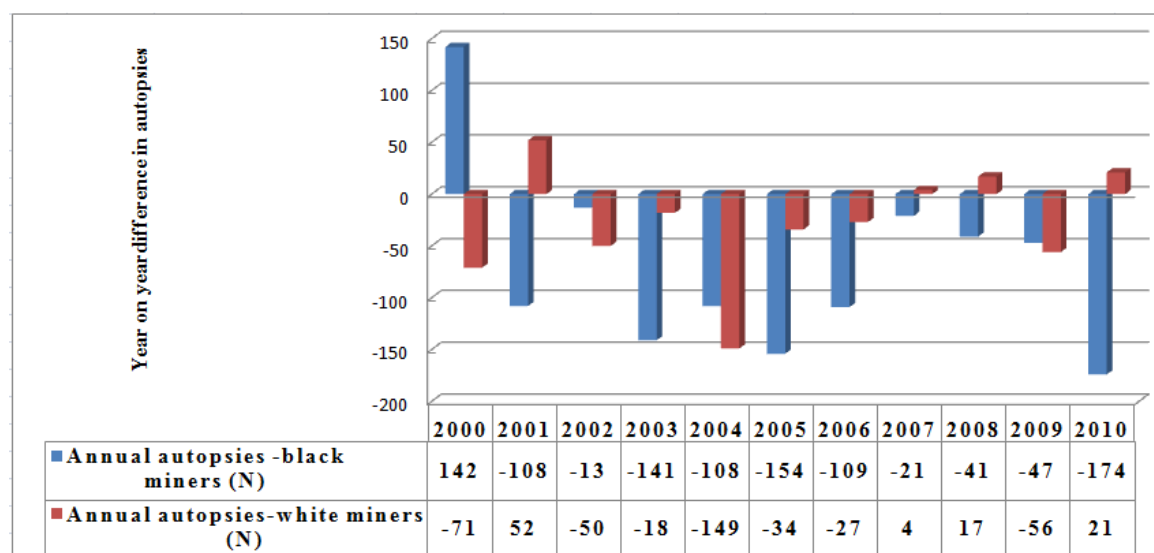


Figure 2: Year on year difference in autopsy among black and white mineworkers 2000-2010. Source National Institute for Occupational Health

Although there was decline on the number of autopsy examinations on white mineworkers, the literature reviewed asserted that white mineworkers utilised autopsy services (Hnizdo et al., 2005; Murray et al, 2007). It was important to investigate whether the decreasing number of autopsies examinations on black mineworkers was a result of non-utilisation or declining number of ODMWA autopsy eligible mineworkers.

1.3 Significance of the study

ODMWA autopsy has the potential to benefit the deceased mineworkers' families. The majority of black mineworkers' families are poor, live in rural South Africa, and are dependent on the deceased miner who may be the sole breadwinner. The low number of ODMWA autopsy utilisation in the context of the real possibility of compensation implies that there might be possible barriers to ODMWA autopsy examination among black mineworkers and their families. The meaning that black mineworkers and their families attached to autopsy and the body requires investigation.

The study will contribute knowledge to public health professionals and policy makers on the significance of compensation following autopsy examination illustrate possible missed compensation opportunities, define the characteristics of mineworkers who did not undergo autopsy examination to tentatively identify reasons for failure to utilise autopsy and explore enablers or barriers of ODMWA autopsy utilisation. The outcome of the study has implications on ODMWA autopsy processes, which could be associated with human interaction among the mineworkers, their families and communities, health practitioners and legislators. This study straddles public health and social science.

1.4 Aims and objectives of the study

The overall aim of the study is to explore the factors that could contribute to autopsy utilisation. The core objectives are:

- i. To quantify monetary contribution of autopsy to mineworkers' families;
- ii. To estimate the loss of financial benefits to mineworkers' families due to non-utilisation of autopsy;
- iii. To define the characteristics of those deceased mineworkers who did not use the autopsy service (to tentatively formulate reasons for not using autopsy services);
- iv. To describe the barriers and enablers of ODMWA autopsy utilisation by mineworkers.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

Due to the complexity of the topic, the approach to the literature review broadly considered many facets of autopsy, including biomedical, sociological, psychological, and anthropological sciences. A literature search for topics with the following key words: burden of diseases in the South African mining industry, conditions in mining conducive to higher disease rate among mineworkers in South Africa, autopsy utilisation, clinical autopsy, rate of clinical autopsy, autopsy for compensation, human post-mortem, death and dying, attitudes to or perceptions of autopsy, the body and autopsy, religion or culture and autopsy, modernity and attitudes to autopsy, consent to autopsy, ODMWA and autopsy; autopsy and occupational lung disease, consent to autopsy, traditional healing and autopsy, cultural or religious beliefs and autopsy. PUBMED, PROQUEST, SAGENET and GOOGLE scholar search engines were used. Books and journals relating to the key words were also selected from libraries or purchased.

The body of literature found to be relevant to the topic is outlined in the following sections, providing insights that assisted in the development of conceptual frameworks and guided the collection of data.

The literature reviewed deemed significant on the various facets of autopsy is presented in five sections. In the first section, the burden of occupational lung disease is presented with emphasis on silicosis and PTB. The following section discusses the legislative overview of clinical autopsy. The third part of the literature review is on resources as an enabler or a barrier to clinical autopsy services.

The fourth section of the literature review is on attitudes and perceptions of autopsy by those who are expected to utilise the services. Included in the fourth section are people who could give consent (mineworkers on their loved ones; and on themselves by communicating to their families their intention in advance), the health practitioners who are expected to request consent for autopsy from bereaving families, explain autopsy process or perform the autopsy, and the traditional healers because they provide services that would include, but are not limited to, treatment of the bereaved families or the performance of rituals at their request. The last section is on organ donation because of the similarity of this process to that of an ODMWA autopsy, the deceased being buried in a different physical form as at death because organs were harvested.

2.2 The occupational lung diseases burden in South African mining

In this section, silicosis and PTB are used to demonstrate the burden of occupational lung disease in South African mining.

‘The most important accomplishment of these preventive measures is that silicosis is becoming a negligible factor, and that in the future it will largely be stamped out’ Wrabitz V, 1939 cited in: Wagner (1995), the inexcusable persistence of silicosis. Many decades later, the optimistic views of Wrabitz (1939) are negated by the reality that the prevalence of silicosis discussed in this chapter remains high.

Conditions in mining have long been associated with higher disease rates than in non-mining populations (Basu et al., 2009). According to the Chief Inspector of Mines, respiratory diseases caused more deaths than mine accidents in 2003-2009, as illustrated in Figure 3 (DMR, 2010).

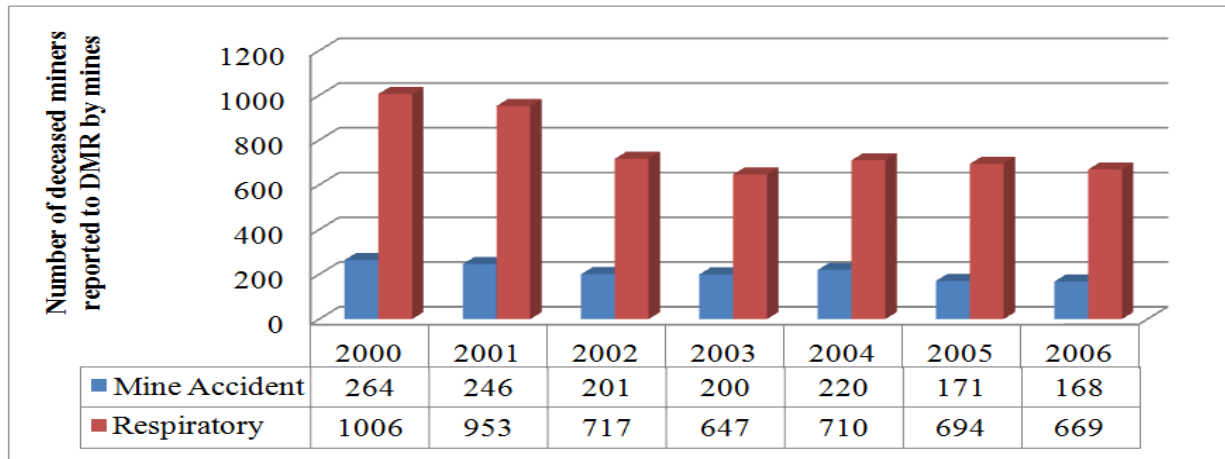


Figure 3: Causes of deaths in the South African mining industry-all commodities.

Source Department of Mineral Resources (2010)

There is a body of knowledge that have shown that PTB and silicosis illustrate the high burden of occupational lung diseases among in-service and former mineworkers exposed to occupational respirable crystalline silica dust in South Africa (Trapido et al., 1998; Churchyard et al., 2004; Girdler-Brown et al., 2008; Field et al., 2011).

2.2.1 Pulmonary pulmonary tuberculosis (PTB)

Basu et al (2009) found that mineworkers in southern Africa had incidence rates of PTB up to ten times greater than the general population. During 2003-2007, the annual number of occupational TB cases reported by the mines to the DMR was higher than all other occupational lung diseases combined as illustrated in Table 2, (DMR, 2010).

Table 2: Number of cases reported to DMR. Source DMR (2010)

Year	Silicosis	PTB	Silicosis + PTB	Coal workers pneumoconiosis	Asbestosis	Other occupational lung diseases
2003	342	3385	235	8	14	38
2004	322	3732	537	11	10	102
2005	207	3233	272	14	32	262
2006	527	3152	411	13	10	89
2007	489	2427	363	48	11	85
2008	1778	4639	995	0	0	87
2009	1706	4479	207	28	0	474
2010	1742	3253	249	80	20	406
Total	7113	28300	3269	202	97	1543

During 2003-2010, 40 524 (Table 2) out of the 3 771 337 in-service mineworkers (DMR, 2010) were diagnosed with occupational diseases were reported to the DMR (i.e. 11 per thousand workers). According to this report, the number of in-service mineworkers with silicosis increased from 342 in 2003 to 1 742 in 2010 (20% increase). In addition, the occupational lung diseases classified as ‘other’ reported to DMR increased by 24% during the same period. The category ‘other’ included asbestos related malignancy, obstructive airways disease (OAD), and combination of OAD with silicosis, PTB, and coal workers pneumoconiosis.

The large number of occupational lung diseases reported including PTB cases makes dust control strategies even more urgent considering the association between silica dust exposure and PTB as well as HIV and TB. The increasing occupational lung diseases reported to DMR suggests that ODMWA autopsy will continue to be an important process in the compensation of occupational lung diseases to mineworkers’ dependents.

2.2.2 Silicosis

The body of knowledge on the prevalence of silicosis and PTB in respirable silica-exposed mineworkers is summarised in Table 3.

Table 3: Studies of silicosis among current gold mineworkers in South Africa

Authors	Study context	Occupational lung disease	Outcome
Churchyard et al (2004)	Prevalence of silicosis and silica exposure-response relations among black South African migrant goldminers in one gold mine. A cross sectional study from November 2000 to March 2001 (N= 520, aged 37 years and more)	Silicosis	The prevalence of silicosis was found to be 18.3–19.9% depending on reader, with significant trends between the prevalence of silicosis and the length of service and cumulative exposure.
Murray et al (1994)	Prevalence of silicosis and pulmonary PTB in black South African gold mineworkers who died from unnatural causes from 1975 to 1991 (N=16,454)	Silicosis and PTB	The prevalence of PTB increased from 0.9% in 1975 to 3.9% in 1991 while that of silicosis increased from 9.3% to 12.8%. The prevalence of both diseases increased with age and duration of service and silicosis was the most significant predictor of PTB (odds ratio [OR] = 1.78, confidence limits [CL] = 1.27 to 2.30).
Nelson et al (2007)	Trends in silicosis in South African gold mineworkers at autopsy from 1975 to 2007, and quantification of the contributions of age at autopsy and employment duration to these trends (N=66781)	Silicosis	The proportion of mineworkers with silicosis increased from 0.03 to 0.32 for black mineworkers. However, the study concluded that the age of the miner and duration of employment partly explains this increase.
te WaterNaude et al (2004)	To examine the effect of silica exposure, in the absence of silicosis, on the prevalence of PTB, which is epidemic among South African gold mineworkers (N=520)	Silicosis and TB	Silica dust was found to increase the risk of PTB even in the absence of silicosis.

Based on a cross sectional prevalence study of 304 former Botswana mineworkers from Thamaga village, who worked in the South African mines, Steen et al (1997) established a history of PTB infection in 26.6% of the them, pneumoconiosis of profusion as classified by the International Labour Organisation of more than 1/0 in 26.6% -31% and progressive massive fibrosis in 6.8% of the mineworkers. Also, in a random sample of 238 ex-mineworkers from Libode, a rural district of Eastern Cape Province, South Africa, Trapido et al (1998) found that the prevalence of pneumoconiosis with ILO classification of equal or more than 1/0 was 22% and 36% (variation by reader).

The afore mentioned studies were conducted in post apartheid South Africa and after the enactment of the Mine Health and Safety Act in 1997. Marks (2003) argued that the high prevalence of silicosis in the majority of former mineworkers from remote villages was a silent disease that remained under-diagnosed beyond the state's complex epidemiological and compensation machinery. The author's arguments suggested that the medical surveillance system (hygiene and medical) stipulated in the MHSA (1997) had not achieved engineering controls completely and were challenged in extending the surveillance programmes beyond employment.

These aforementioned studies preceded the 2003 tripartite Mine Health and Safety Council milestones to eliminate silicosis by 2013 by means of limiting the occupational exposure for respirable crystalline silica to below $0.1\text{mg}/\text{m}^3$. However, the best predictor of silicosis is cumulative exposure, followed by the duration of exposure and average exposure intensity (Hnizdo et al., 1993, Steenland et al., 1995, Chen et al., 2001, Churchyard et al., 2004). Hnizdo et al (1993) demonstrated that with respirable silica dust exposure at $0.1\text{mg}/\text{m}^3$ over 10 years, up to 10% of mineworkers will develop silicosis. In addition, Churchyard et al (2004) found that 1.6% of mineworkers exposed to respirable crystalline silica of $0.1\text{mg}/\text{m}^3$ developed silicosis within 15 years of exposure. NIOSH publication (2011) demonstrated that there was an increased risk of developing silicosis with prolonged exposure to respirable crystalline silica and in an occupational environment where respirable silica dust was equal to or higher than $0.05\text{mg}/\text{m}^3$.

The reviewed literature suggests that even if the mining sector achieved the 2008 and 2013 MHSC set tripartite respirable crystalline dust exposure milestones, the complete elimination

of occupational lung diseases will be unachievable. The aforementioned studies affirm that cumulative exposure to respirable crystalline silica of $0.5 \text{ mg/m}^3 - 0.1 \text{ mg/m}^3$ does not protect the mineworker from developing silicosis. This implies that new cases of silicosis are expected for many years to come and strategies to identify and diagnosed affected mineworkers in-service, in retirement and at death need to be implemented successfully and efficiently.

Lifetime occupational lung disease surveillance of mineworkers including ODMWA autopsy will continue to be important. None of the provinces with mining commodities with potential to expose workers to crystalline silica achieved the 2003 Mine Health and Safety Council Tripartite milestones on respirable crystalline silica exposure of $<0.01 \text{ mg/m}^3$ (DMR, 2010), as illustrated in Figure 4.

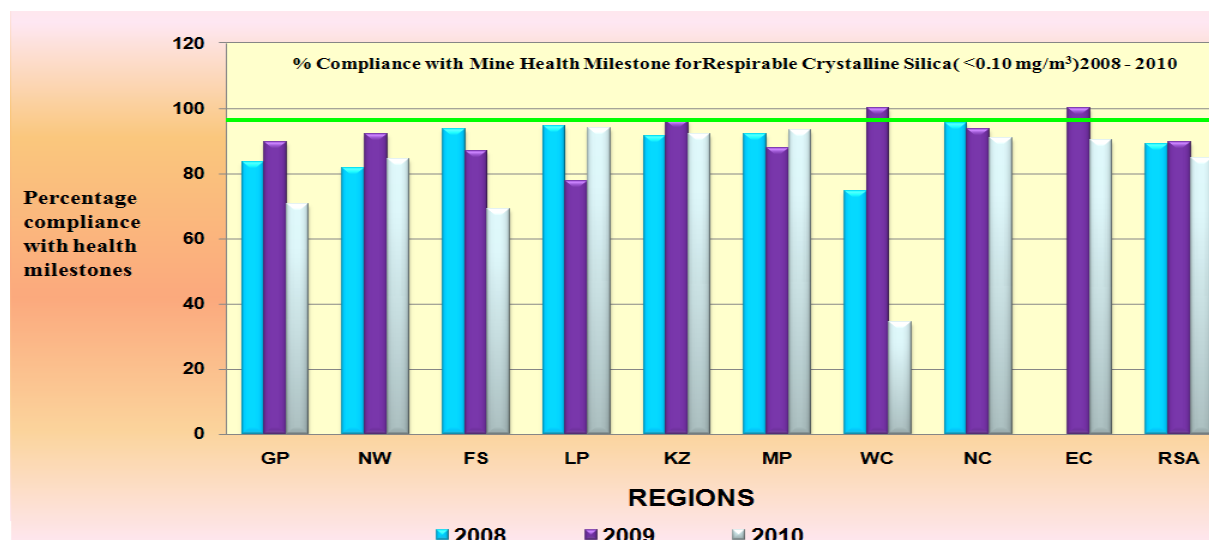


Figure 4: South African mining industry compliance with the 2003 industry milestone.
Source DMR (2010)

According to the DMR, the accuracy of the percentage compliance by mines to the set MHSC milestones was an underestimate since it represented only 18% of the mines' hygiene and health data (DMR, 2010).

2.2.3 Other problem areas associated with mining

In mines with occupational respirable silica exposure, the increased risk of TB infection exacerbates disease burden (Corbett et al., 2004) and the interaction between HIV, silica and TB (Churchyard et al., 2004).

Gilgen et al (2001) reported high prevalence of HIV and TB in communities surrounding mines, while Beinart (2001) argued that South Africa, like many other industrialised countries, migrant labour oscillation between town and countryside was a feature that signified a transition from rural to urban life. However, Rees et al (2009) maintained that while industrialisation had its benefits, oscillating migrant mine labour had unintended consequences in that the burden of silicosis, PTB, and HIV infection were increased and PTB and HIV infection were extended beyond the miner to his/her family and the community. According to Basu et al (2009), the effects on mineworkers of circular migration to and from their home communities posed an increased risk of HIV and associated TB infections. The reviewed literature on other problem areas implied that the latency of occupational lung diseases burden would be borne by communities of mineworkers.

Therefore, the importance of giving information to create awareness and knowledge on the benefits and adverse health effects of mining at a community level was necessary. While the body of knowledge draws attention to the disease burden for mineworkers, their families, and

communities, the importance of effective disease surveillance programmes also required emphasis.

The emphasis on mineworkers' disease burden borne by their families and communities was illustrated in a sample of 205 former mineworkers from Eastern Cape who had a TB rate exceedingly higher than other community members and 51.7% of them diagnosed shortly after leaving the mines (Roberts, 2009). The author found that the improvements on ODMWA benefit medical surveillance systems of former mineworkers that were initiated in the late 1990s subsequent to the Libode study were no longer in operation. Girdler-Brown et al (2008) also established that among 624 former Basotho mineworkers, 24.6% had developed silicosis after leaving the mines, 26% confirmed to have previous PTB and 6.2% current PTB 18 months after cessation of work.

The burden of mine-acquired TB was argued to fuel the transmission of disease in labour-sending regions through oscillating migration (Crush et al., 2005, Rees et al., 2009), and according to Crush et al (2005) the rapid dissemination of HIV/AIDS was inexplicable without reference to human mobility inherent in the mining sector. Between 2005 and 2008, 1.3% of South Africans aged between 15-49 years were newly infected with HIV compared to 2% in the years 2002-2005 (Rehele et al., 2010). The mines draw labour from the communities or from labour sending areas with increased HIV infection, partly more because of oscillating migrant labour (Basu et al., 2009; Marks, 2003). Disease burden increases for those with exposure to respirable crystalline silica because exposure to this mineral increases the risk of TB (te WaterNaude et al., 2005; Corbett et al., 2004). The oscillating migration systems has unintended health implications for the mines, families and communities as mines

draw labour from the communities and the labour oscillate between their homes in rural areas and mines. Combining controlling respirable dust at source improved personal protective measures, real-time hygiene data and medical surveillance should be comprehensive and linked as part of the mitigation strategy to minimise occupational lung disease. The strategy thus requires a multi-disciplinary approach.

Corbett et al (2004) argued that HIV and silicosis were potent risk factors for mycobacterial disease in the South African Mining Industry. Corbett et al (2004) established an HIV prevalence of 27% among 1,773 systematically recruited mineworkers and that TB incidence was much more strongly associated with HIV infection. Murray et al (2007) confirmed that PTB was the leading cause of death in HIV-positive and negative mineworkers who died from natural causes. Nonetheless, the fact that there was also an increased risk of TB infection among respirable crystalline silica-exposed workers without silicosis implied that PTB was an occupational lung disease in silica-exposed mineworkers (Churchyard et al., 2004).

There are challenges found in diagnosing PTB in mineworkers. Using the TB Process-Based Performance Review (TB-PBPR) tool developed to identify "missed opportunities" for timely and accurate diagnosis of TB, Field et al (2011) established that TB was missed in life in 52% of cases and was wrongly attributed as the cause of death in 16% at one hospital where ODMWA autopsy was done routinely. The findings imply that ODMWA autopsy is necessary for both diagnostic quality assurance and compensation. Compensation was crucial for disabled workers following occupational accidents, especially where alternative forms of social security are limited or absent. Unlike other countries, ODMWA authorises autopsy of a

mineworker with consent of family members and this has a potential for compensation to dependants.

The literature reviewed on occupational lung diseases echoes the requirement of an overarching strategy for disease control and elimination. Wagner (1995) argued that what was outstanding in the eradication of occupational lung disease (silicosis) included the social will to act since the disease manifestations have been scientifically addressed. Wagner (1995) maintained that based on lifetime risk of silicosis, it will require more than a permissible exposure limit alone or a combined comprehensive workplace standard for silicosis control and stringent adherence to exposure limits.

In summary, the literature shows that the number of occupationally related respiratory deaths reported by the DMR was higher than deaths due to mine accidents and occupational TB was the most common of the ODMWA compensated lung diseases. The control of respirable crystalline silica dust would reduce both silicosis and TB infections but its achievement is likely to take time. Therefore, until effective dust control measures, pre in-service medical surveillance, and advanced diagnostic systems (professionals and technologies) are in place, for many mineworkers (in-service and former) the probability of dying without undergoing benefit medical examinations in life was very high. This implied that ODMWA autopsy examinations remained an important diagnostic tool for occupational lung diseases in South Africa.

2.3 Legislative framework

Many countries globally regulated autopsy services and this generally included the rights of the deceased and their families. Health practitioners who request consent for mandatory

forensic autopsy (Nemetz et al., 1987) should observe the respect of family's religious and cultural beliefs. The authors affirmed that legislations regulate the circumstances under which autopsies can be performed, the handling of the body and the burial, and the manner in which the tissues must be managed and disposed of. Sherwood et al (1995) contended that the trends of forensic autopsy, unlike that of the clinical autopsy were stable due to the mandatory nature because consent was not generally required as it is performed in adherence to a statute, except in cases of religious objection.

There was a body of knowledge on changes in legislation and policy that occurred at different periods for countries and it pertained to mandatory requisition of clinical autopsy consent from the deceased's relatives by health practitioners (Nemetz et al., 1987; Sherwood et al., 1995; Lindström et al., 1997). According to authors, the changes can be attributed to the commencement of decline in clinical autopsy examinations

Nemetz et al (1987) established that changes in legislation and policy occurred in the Scandinavian countries around 1987 and maintained that previously an autopsy could be performed following any death in hospital, unless the family signed a declining form within 12 hours of death. According to Lindström et al (1997), mandatory consent to clinical autopsy was introduced during 1997 in the Swedish Autopsy Act of 1997 and relatives of the deceased have an option to refuse clinical autopsy in all cases, except in cases of unknown cause of death.

The legislation relevant to ODMWA autopsy pertains to compensation of occupational lung diseases and is similar to that provided for workers in other western countries (Australia,

United States, and United Kingdom) but differs in that ODMWA autopsy is mandatory to all eligible mineworkers irrespective of the cause of death provided consent is given. In other countries, autopsy for occupational lung diseases would be mandatory if the cause of death is suspected to result from occupational exposure. Compensation of occupational injuries and diseases legislation may vary across countries and jurisdiction; however, the key commonality was the recognition of failed preventative systems. Bachman (1990) argued that the funders who paid for the compensation influenced compensation legislation for occupational injuries and diseases, and this in turn was affected by political considerations, including the influence of unions and the concern of the public and the state. In many instances, the compensation award might seem paltry; however, for poor communities this money could alleviate poverty.

In South Africa, the first Mineworkers' Phthisis Act was enacted in 1911, and white mineworkers only. Since then, the act was updated over the years, with the passing of the Silicosis Act (1946), the Pneumoconiosis Act (1956), the Pneumoconiosis Compensation Act (1962), and the Occupational Diseases in Mines and Works, Act 78 of 1973 (ODMWA). The 1973 ODMWA act was amended in 1993 to remove racial discrimination and again in 2002 to increase the period between state-funded benefit medical examinations from one to two years. However, two particular legislative changes that had consequences for ODMWA processes and specifically for ODMWA autopsy were the promulgation of the Mine Health and Safety Act, No. 29 of 1996 (MHSA) and the National Health Act, No 61 of 2003 (NHA).

The enactment of the MHSA, which is self-regulatory, promoted occupational health and safety in the mines through risk determination and strategies to mitigate the identified risks,

one of which was dust. The impact of MHSA on ODMWA was fragmenting the administration of risk-based medical surveillance from benefit medical examination, and duplication on occupational lung disease reporting. MHSA mandates the provision of risk-based occupational health services by the mines aimed at preventing ill health due to exposure, diagnosis and reporting thereof. DMR administers the MHSA. ODMWA requires the submission of mineworkers' medical records suspected of occupational lung disease to MBOD and offer state-funded biannual benefit medical examination including ODMWA autopsy examination to former mineworkers. The Department of Health administers ODMWA through the MBOD. Mines reports occupational lung diseases to both the DMR and the MBOD. The doctor attending to an in-service mineworker dying of an unsuspected occupational disease may neither be employed by the mine or could be someone who does not know the occupational exposure history and the importance of discussing ODMWA autopsy examination and requesting consent from family members. This legislative fragmentation signifies the reliance on the mineworker to know his/her legislative rights and be able to communicate all the benefits of legislations (MHSA and ODMWA) to his/her family. There was dearth of information on the knowledge of mineworkers and their families on these legislative rights that could explain the potential of missed opportunities from non-utilisation of ODMWA autopsy services.

The NHA licenses private health care facilities and regulates medical aid schemes. Historically, large mines provided comprehensive health care services with in-house medical aid schemes. Because of the enactment of the NHA in 2003, mines scaled down their health care facilities, introduced medical aid registration of their employees to access health care in other facilities, and concentrated their efforts on occupational health care compliance in line

with MHSA. The Department of Health administers the NHA. Many ex-mineworkers are dependent on public health services that function within the jurisdiction of NHA; however, Roberts (2009) found that benefit medical examinations were undermined. The requirement by NHA that autopsy for natural deaths or communicable diseases is performed to establish the cause has a significant influence ODMWA autopsy. Although NHA does not supersede the ODMWA's stipulation that ODMWA autopsies should be performed on every miner who has a history of occupational exposure to mining airborne pollutants, it does influence the decision to request consent, particularly for mineworkers who die in public hospitals where it (ODMWA autopsy) was not included in hospital policies and budgets.

There was a disconnect between the NHA and MHSA with regard to opportunities for ODMWA autopsy examination when compared to mine accident deaths and forensic examinations that may result in ODMWA autopsy neglect. Additionally, the NHA stipulates the consent processes regarding donation of deceased human bodies and tissues, which allows for an oral statement of consent made by the person prior to death, in the presence of at least two competent witnesses. However, ODMWA was silent on oral statement of consent by the deceased.

2.4 Resources

Infrastructural, human, and financial resources play a vital role in the provision of autopsy services. The implications of resources on clinical autopsy in multifaceted and could vary on a case-to-case basis. The lack of direct reimbursement to the health professionals who perform clinical autopsies, the inadequate numbers of facilities that offer them and fear of malpractice litigation were among the factors established to contribute largely to the decline in clinical autopsy (Burton, 2002; Burton et al., 2008, Rokoske et al., 2008). Lugli et al

(2006) found that a policy that included autopsy-related activities as part of the diagnostic investigations to be reimbursed improved clinical autopsy uptake since it offered incentives to the physicians and other professional components of autopsy services. In addition, Steigman (2002) maintained that clinical autopsy would continue to decline in the absence of its integration into effective and realistic health care quality assurance programmes, which should be included in the facilities' budgets with built-in reimbursement for pathologists. Although the MBOD reimburse the facility for ODMWA benefit medical examinations, the money does not go the facility but to the provincial health department. This may partly explain autopsy non-utilisation by former mineworkers; however, an investigation is required to establish the impact of district public hospitals' income allocation (i.e. hospital facilities not receiving payments for services rendered) to autopsy examination.

Conversely, Rokoske et al (2008) argued that an increased focus on cost control within both the public and private health care sectors gives clinical autopsy a low priority in comparison to general health care needs due to the economic environment. Clinical diagnostic errors, in particular misdiagnosis were established at autopsy examinations (Anderson et al., 1990). Nemetz et al (2006) established that although the underlying causes in autopsy decline were multifaceted, the debatable perception by some clinicians was that advanced medical and surgical diagnostic technologies were efficient enough to render clinical autopsy redundant. In contrast to the arguments that advanced diagnostic technology was efficient, ODMWA autopsy examination, continue to diagnose new occupational lung diseases in South Africa (Ndlovu, et al).

The decline in clinical autopsy over the years while that of forensic autopsy remained constant was attributed to a lack of perceived purpose for clinical autopsy because of lack of funds and disinterest that was associated with lagging behind the fight for funds more than the interest in the procedure (Wood et al, 2001). The authors affirmed the importance of clinical autopsy as included in the guidelines of the College of American Pathologists such as to establish a cause of death, determine the manner of death, compare pre-mortem and post-mortem diagnoses, produce vital statistics, and to monitor the health of the public were as significant to medicine today as in the past. According to Rankin et al (2000), other human resources crucial when discussing autopsy were bereavement counselling. The authors argued that a dedicated bereavement counselling services in a hospital could help bereaved parents to consent for an autopsy on their babies, particularly for those who wanted to know the cause of death. However, the authors did not explore whether these services could influence positively to clinical autopsy requests for consent.

The diverse opinions for clinical autopsy suggest that the causes of decline in different settings were different. While some of the clinical autopsy resource implications found from the literature reviewed could be similar to that of ODMWA autopsy setting, ODMWA was mandatory and funds were allocated by Department of Health to MBOD to ensure that former mineworkers access benefit medical examinations. Mines were also obliged to offer free surveillance medical examinations to in-service mineworkers. The free services to mineworkers and their families include removal and transportation of cardiorespiratory organs to the National Institute for Occupational Health and MBOD. In spite of the free services, a lack of accessibility to ODMWA benefit examinations by former mineworkers was found (Trapido et al., 1998; Steen et al., 1997; White et al., 2001). In addition, Clark et al

(2007) asserted that the under-resourced health facilities in mine labour-sending areas limited access by oscillating migrant mineworkers returning home with occupational lung diseases such that the diseases will not be detected, to the socioeconomic detriment of them and their families. Additionally, Roberts (2009) purported that the provincial public health facilities were under resourced to offer ODMWA benefit medical examination for former mineworkers. Although ODMWA does not prescribe to the facility that offers benefit medical examination to the mineworker, the purported lack of resources occurred while ODMWA prescribed that the facility and MBOD should agree on a cost of the services. However, the fee offered by the MBOD might unacceptable to the facility.

To address the human resources in forensic autopsy, the South African Qualification Authority had one registered unit standard 243 631, developed to assist the law, military science and security professional bodies with post-mortem examinations (SAQA, 2008). However, the drawback of this standard for ODMWA autopsy was that the individuals credited with this unit standard were only able to prepare the body for an autopsy, assist the health practitioner with the autopsy. The actual dissection of the deceased body still requires a medical professional.

In conclusion, regardless of the mandatory requirements to reimburse facilities for ODMWA autopsy costs on former mineworkers, no studies have been conducted on the influence of resources to the decline in ODMWA autopsy.

2.5 People's attitudes and perceptions of autopsy

The reasons attributed to the decline in adult clinical autopsy are varied and complex. Other than legislation, Nemetz et al (2006) argued that clinical autopsy rate was influenced, both

directly and indirectly by a range of groups that include physicians, pathologists, coroners and medical examiners, hospital administrators, the deceased (through in-life directives) and their relatives, as well as nursing home operators and funeral home directors. Authors argued that some aspects on clinical autopsy utilisation are associated with the public's attitudes, views, impressions, and understanding of the process, while others are connected to the attitudes and perceptions of the medical personnel who are expected to carry out the procedure. While the attitudes of these groups to clinical autopsy have been studied, very little was found from literature reviewed on their attitudes to ODMWA autopsy examination, which would have provided a fundamental understanding of enablers, and barriers to its utilisation, a focus of this study.

2.5.1 Public perceptions

Attitudes and beliefs in the manner in which the deceased's body should be handled are complex and these could be barriers or enablers to autopsy utilisation. There was a body of knowledge associating fear that the body will be mutilated during autopsy, belief that the body should be maintained in the best condition possible, lack of knowledge about the procedure, feeling by some relatives that the deceased has suffered enough, the costs incurred thus far, lack of rapport with the treating physician, lack of consensus with other relatives regarding the procedure, concerns relating to delays in the funeral as a result of autopsy, or simply preferring to preserve the dignity of the deceased over knowing the cause of death with refusal by relatives to give consent to clinical autopsy (Renteln, 2001; Lishimpi et al., 2007; Oluwasola et al., 2009). Although these various beliefs on the body and clinical autopsy could be similar to those associated with ODMWA autopsy examination, an

investigation specific to ODMWA autopsy utilisation was required to assist on tailored interventions.

Public views on clinical autopsy were purported to originate from secular (emotional), cultural or religious considerations, or a combination of both (Lugli et al., 1999; Burton et al., 2007; Oluwasola et al., 2009). While Burton et al (2007) found in industrialised countries, that those with secular attitude were more amenable to be influenced by the clinical desirability of an autopsy, Oluwasola et al (2009) maintained that most relatives in their Nigerian study granted permission for an autopsy if it was requested by the clinician in cases of death before the age of 50 years, because the cause of death was being sought. Also, Oluwasola et al (2009) found that individuals agreed to autopsy process in principle, but would not consent to the procedure on their own relatives. The acceptance of autopsy on others than family or self implied that acceptance did not mean consent. Therefore, in seeking to increase autopsy utilisation, the strategies used should close the gap between acceptance and consent.

Christian religion or schooling of 12 years and more influenced autopsy consent, and the decision was at an individual level as opposed to the family (Oluwasola et al., 2009). However, Oluwasola et al (2009) did not explore how religion influenced the participants' view of the body with regard to the body and the soul, except that it was found that those who refused autopsy strongly believed that their religion forbade it. Lishimpi et al (2001) asserted that the majority of parents of African children who had died of natural causes would not consent to clinical autopsy because they believed that it was a waste of time, as diagnosis should have been made before death, cited traditional or ancestral beliefs or requirement for

permission by other relatives not present during the request. In addition, Lishimpi et al (2001) maintained that religious beliefs were not a major cause of refusing consent. In this African study, unlike that of Sherwood (1995) in industrialised societies that predominantly associated autopsy decline to physicians' attitude, there was an expectation that technology and clinicians should enable diagnosis, thus rendering autopsy unnecessary. In contrast, Perkins et al (1993) maintained that among some Hispanic Americans, there was a belief that discussing autopsy prior to the death of an ill individual would hasten his or her death, while others felt that the treating clinicians were abandoning the individual before he/she died. There was dearth of information on similar studies of mineworkers and their relatives when faced with the choice of discussing autopsy and how their religious or cultural beliefs influenced their decision.

Clinical autopsy, including ODMWA autopsy, can only be performed with consent from immediate relatives listed as spouses, adult children, parents in that order. In Western cultures, a spouse is a person who in law is approached first for consent. In other traditional cultures, however, the wife did not have such powers of decision-making. Evidence suggested that in some cultures, certain decisions, including those relating to health or death, were more of a family matter and not the choice of an individual (Oluwasola et al., 2009). Death was considered by some Zulus as a *'highly intensified form of pollution that emanates from a body itself and from a chief mourner (a person closely associated with the deceased), in case of a married woman, and to a lesser extent all other relatives, necessitating some form of ritual cleansing'* (Williams, 2005). This belief implied that during the time of mourning, the widow is not allowed to be involved in planning and discussions on funeral arrangements, including matters relating to autopsy with other family members. The question

explored in this study is how these cultural beliefs influenced consent for an autopsy, specifically ODMWA autopsy.

Beliefs on the role and physical being of the deceased body in afterlife can influence decisions to give consent to autopsy as found in the body of knowledge on African beliefs associated with soul after death (Hammond-Tooke, 1974; Toynbee et al., 1976; Kalish, 1980; Mutwa, 1998). The authors concluded that there were variations across beliefs and these were on whether the soul was spiritual or had weight/mass. The authors argued that where a soul was considered to have weight, dissection, or removal of body parts could be unacceptable as opposed to a belief that the soul was spiritual. There was a dearth of information on how ancestral beliefs influenced the acceptance or rejection of ODMWA autopsy and it was necessary to have this information to assist in developing intervention policies that could accommodate such beliefs, where applicable.

In the Christian religion, there was only a belief in existence of a soul in afterlife. In contrast, scholars argued that in African religions there was a belief in a dualism between the body and soul in afterlife, which was perceived as the beginning of communication between the visible and invisible worlds, as well as the beginning of a person's deeper relationship with all of creation (Hammond-Tooke, 1974; Toynbee & Koestler, 1976; Kalish, 1980; Mutwa, 1998; Kometsi et al., 1999). According to Kometsi et al (1999), some black South Africans believed that burial with some body parts missing or receiving an organ transplant ('foreign') prohibited the individual's transition to the realm of the ancestors. However, Kometsi et al (1999) argued that the belief in prohibition to ancestry did not apply when someone other than a family member gave consent for organ donation. The interpretation of the body or soul

or a combination of both in afterlife could be either an enabler or a barrier to autopsy consent depending on the individual or family beliefs (Dickenson et al., 2004).

Although there was dearth of information on the influence of religion on ODMWA autopsy utilisation, there was a body of knowledge on the influence of religion on clinical autopsy examination. Rispler-Chaim (1993) found that autopsy presented several ethical questions acknowledged in monotheistic religious faiths. Autopsy and the harvesting of organs for organ donation were considered to damage the person's dignity and was perceived as a major sin and a violation of the body and removal of any body part from a body was forbidden in certain religions which led relatives to object on autopsy or certain medical interventions such as blood transfusion (Sheik, 1998; Campbell, 1998; Gatrads, 2001, Rashid, 2001). In Islam, there is a belief in predestination, which considers the body sacred, and to belong to God, investigators found that autopsy and dissection of body parts for research is believed to inflict pain and thus forbidden (Gatrads, 1994; Rispler-Chaim, 2001). Gordijn et al (2007) established that Hindu religion forbade autopsy because of the belief in reincarnation. Sheikh (1998) determined that Catholic religion and most Protestant religions accepted all forms of autopsy with consent from the deceased's family, with the proviso that the body is treated with respect. In the Judaic and Muslim religions, the family of the deceased could give consent to autopsy if it would benefit the family by establishing the cause of death or autopsy will save others' lives (Sheikh, 1998).

Similar to the argument of the form of existence as either spirit or mass in afterlife, a belief in afterlife continuity could be an enabler or barrier to autopsy. Gordijn et al (2007) argued that a belief in the continuity or survival of the individual's body or soul after death helped

believers make sense and meaning of death in major African traditional and Christian religions, and assisted in the process of mourning. In contrast to the arguments that religious or traditional beliefs could either be a barrier to or enable autopsy, Connel et al. (1994) maintained that educational interventions involving relatives in advance of autopsy planning improved autopsy uptake. The author argued that these interventions should include counselling on the purpose, process, and procedures of autopsy, and facilitating communication skills and awareness of autopsy services and policies among physicians. However, the author's view did not take into consideration that religious and cultural beliefs extend beyond education.

In conclusion, the diverse cultural and religious beliefs on the body and soul at death and in life-after by various people suggest that in order to comprehend beliefs associated with ODMWA autopsy, one would have to investigate such beliefs within this specific setting. The public perceptions from the literature reviewed guided the questionnaire and conceptual framework development.

2.5.2 Medical perceptions and attitudes to clinical autopsy

McManus et al (1992) found that a lack of the treating clinicians' involvement by pathologists, divergent pathologists-clinicians perceptions on autopsy, which included the time it took the pathologists to produce pathology reports for the treating doctors, the presentation of the information and its usefulness contributed negatively to clinical autopsy. Other studies found that physicians blamed themselves for the failure to cure patients and considered clinical autopsy to be of less value (Anderson et al., 1990; McManus et al., 1992). Start & McCulloch (1994) established that the decline in hospital autopsies was partly due to

the disapproving attitude and perceptions of physicians, pathologists, and other health personnel involved in the management of dying patients and their relatives.

Studies attributed lack of training for the uneasiness and despondency that some doctors felt when confronted with a scene to request clinical autopsy or contemplating one themselves; a viewpoint that was similar to that of the rest of the public (Sinard, 2001; Oluwasola et al., 2009; Perkins, 1991; Oppewal et al., 2001). However, training alone was found insufficient to contribute positively to autopsy since other scholars determined that a lack of autopsy examination experience among many junior medical doctors attributed to their discomfort in discussing the procedure with the deceased's relatives (Hooper et al., 2007; Ekanem et al., 2007; De Villiers et al., 2005). Although any trained medical practitioner can remove the cardiorespiratory organs with consent of relatives under ODMWA, there was dearth of information on medical perceptions on ODMWA autopsy.

Some scholars believed that exposure of medical students to autopsy examination and its contribution to diagnosis and quality assurance contributed positively later in their careers to their attitude to autopsy (Ruhaya et al., 2003; Sanner, 1995). According to the authors, exposing medical students to autopsy examination during training, both at the undergraduate and postgraduate levels influenced how they requested permission from the deceased's family.

In addition, apathy and poor communication among doctors about the dying patients and the necessity for an autopsy were determined to contribute to the decline in hospital autopsies

(Wood et al., 2001; Burton et al., 2003; Oluwasola et al., 2009). Some clinicians were discouraged from requesting autopsy examination by administrative bottlenecks, subsequent delays in obtaining the pathological report, time-consumed by requesting consent for clinical autopsy from distraught and grieving relatives (Burton et al., 2003). According to McDermott (2003), the age of the deceased influenced the attitude of both the clinician requesting an autopsy and the family granting permission for the procedure. The older the person, the less the likelihood that the treating clinician will request an autopsy or that the family will grant consent, as compared to the case of a younger person. According to McDermott (2003), discussing the retention of organs with parents, especially in paediatric autopsies, and the arrangements for returning them when requested have been found daunting for many doctors.

According to Loughery (2000), from a clinician's perspective, core to the autopsy decline was the difficulty in obtaining consent from relatives, especially those who believed in the effectiveness of advanced modern diagnostic techniques. Also, recent media publication of the British scandal on the retention of deceased children's organs following clinical autopsy were blamed for the apathy of health practitioners to seek consent for autopsy (Loughery, 2000).

While some of these factors may be applicable to ODMWA autopsy, they have not been previously investigated. According to Naidoo et al (2005), mineworkers who have been fully compensated while alive are less likely to have their bodies submitted for an autopsy, especially those of former Black mineworkers as compared to white mineworkers whose families are more aware of financial benefits. Naidoo et al (2005) findings hold true since those fully compensated are automatically excluded from the ODMWA benefit system because no further compensation is due. The assumption that families of black mineworkers

do not utilise ODMWA autopsy due to lack of awareness regarding ODMWA financial benefits is a historically unsupported view as no studies have been conducted among the families of mineworkers.

Bottlenecks in there afore identified from the literature sources could be similar to those of ODMWA autopsy, considering that the deceased mineworkers' treating doctors were remotely placed at a peripheral public or private health facility from the pathologists who were centralised in Johannesburg. Additionally, only the outcome of the certification by the MBOD excluding the pathology report is sent to the mine in the case of a miner who died in employment or to the family or hospital in a case of the deceased former mineworker. The completion of the ODMWA certification process could vary from months to a year. There was dearth of information on the attitude of health practitioners on autopsy in general, and ODMWA autopsy specifically, and an investigation was required to establish their perspectives.

2.5.3 Traditional healers' perceptions of and attitudes to autopsy

Traditional healers play an important role and are recognised as allied health providers in African medicine, and may be the most accessible in the community (WHO, 2008). They could be the first or last to be consulted by ailing persons or their relatives, and might be involved in the burial rites. They could also be consulted at any given time during the person's illness, and this might be prior to consulting western medical practitioners, during the course of treatment, or thereafter. In view of the traditional healers' status and their importance in maintaining African traditions, almost all national health departments in Africa have established forums to work with them (WHO, 2008).

Walaza (2005) argued that the majority of black mineworkers in South Africa attributed death to witchcraft or some supernatural power and not to the western medical perspective of disease. The author asserted that black mineworkers attributed deaths to misfortunes, which they believed were aggravated by a lack of attention paid to cultural rituals both by mine management and by other mineworkers when a mineworker died accidentally underground. The findings implied that mineworkers consider rituals to be a necessity during accidents and the involvement of the traditional healers during this period imperative. While traditional healers are consulted for a variety of good reasons, some make in news headlines associated with muti killings or removal and selling of body parts from the body allegedly for traditional medicines in South Africa (Steyn, 2005). Although in southern Africa ritual, killing was not common, according to Steyn (2005), the human body was seen as being very powerful and its parts sometimes used for medicinal (muti) purposes and these acts were publicised in the media. Muti murder referred to killing with the purpose of harvesting body parts for use as traditional medicine or 'muti', and Muti murder was seen in several countries across Africa with ethnographic evidence going back to the early nineteenth century documenting the existence of the practise in southern Africa (Vincent, 2008). According to Vincent (2008), more than 300 people were allegedly murdered for their body parts in the last decade in South Africa with one investigation reporting 250 Muti killings in the country's Limpopo Province alone in a single year.

While muti killings could impact negatively on ODMWA autopsy utilisation, there was dearth of information on the consequences of these acts and the media broadcasts. There was dearth of information on the attitude of traditional healers towards autopsy examination.

Therefore, the inclusion of traditional healers as key informants could bring their perspective on autopsy examination.

2.6 Organ donation

Organ donation and ODMWA autopsy were similar in that the deceased is buried without all the organs that were present at the time of death. In organ donation, organs and tissue are harvested to save the lives of transplant recipients, while in ODMWA autopsy the cardiorespiratory organs are removed for pathology examination, both to assist the dependant's family financially (by diagnosing occupational lung disease) and to monitor the success of risk assessment and of preventative dust controls.

Thomas (2000) identified four groups of barriers to organ and tissue donation, and transplantation among African-Americans as illustrated in Table 4. According to the author, these were lack of transplant awareness by the donors and their families, religious beliefs, distrust of the medical community by the donors and families, and racism.

Table 4: Barriers to organ and tissue donation among African-Americans Source: Thomas, 2000

Barriers to organ donation	Authors
Lack of transplant awareness	Callender (1982); Creecy et al (1990); Gutoski (1995); Roberts (1988); Rubens (1996); Schutte et al (1997); Yancey (1996)
Religious related issues including myth, misperceptions	Callender (1982); Davidson et al (1991); Gutoski (1995); Yancey (1996); Sanders-Thompson (1993)
Distrust of medical community	Callender (1982); Creecy et al (1990); Davidson et al (1991); Gutoski (1995); Roberts (1988); Rubens (1996); Sanders-Thompson (1993); Schutte et al (1997); Yancey (1996); Yuen et al (1998)
Racism defined as declining to donate organs to another race	Gutoski (1995), Yancey (1996)

From the literature reviewed, a lack of awareness and religious beliefs as barriers to give consent were similar for both organ donation and clinical autopsy. However, the distrust of the medical community was unique to organ donation and was associated with the perception that a drive to harvest the organs could override that of providing optimum health care to cure the patients. Similarly, refusal by the family of the deceased to consent to an organ or tissue transplant in cases where the recipient was of different ethnic race was unique to organ donation. Kometsi et al (1999) found consent to organ donation among some black people in South Africa to be easier if the person had committed suicide, as compared to a natural death, because the ancestral realm did not include individuals who committed suicide. The literature reviewed on organ donation was found to be of little relevance to the study because it was neither mandatory nor of a person who had disease.

Very little work has been done on factors influencing autopsy utilisation for compensation despite the abundance of historical literature on occupational lung diseases including silicosis and PTB and the value of autopsy. Also, ODMWA autopsy was unique to South Africa and had the potential to alleviate household poverty. The factors influencing clinical autopsy uptake at any given time were complex, operating at institutional, professional and individual levels.

In conclusion, the qualitative data collection enquiry on enablers and barrier to ODMWA autopsy used the findings from the existing literature for guidance. Notably, there is a dearth of information on local perceptions and attitudes of medical personnel to hospital autopsy.

The literature identified some of the complex factors contributing to the decline in clinical autopsy. The following sections discuss sociological factors found to be of relevance for this study.

CHAPTER 3: THEORETICAL FRAMEWORK

3.1 Sociological framework

This study drew on the sociological framework of rational choice as described by Wallace et al (1991) which stated that human beings made decisions based on their rational assessment of all the available options. This theory was selected because consent of relatives who can make a choice to either agree or reject autopsy based on the value they attach to the outcome of the procedure was required. Johnson (2008) argued that each individual exercise of concept of free choice's based on own interpretation of the situation because people were capable of making unique and independent choices and could not simply be constrained or influenced to choices or decisions. According to Johnson (2008), human beings act because of their biological capacity to choose and act on their culture-based capacity to reason.

The reviewed literature showed religious and traditional beliefs on the body and afterlife influence autopsy utilisation negatively or positively. The beliefs date back more than thousand years ago when St. Thomas Aquinas argued that the soul had a life separate from that of the body and could subsist without the body because it was not made up of matter or form that could be destroyed in any natural process (Stark, 1951). According to Stark (1951), Aristotle believed that the soul was inseparable from the body, rather than being simply a ghostly occupant of the body. The author argued that human beings had calculating, scientific parts that were rational (used for making decisions) and vegetative parts that were irrational and responsible for identifying individual needs. These different scholarly historic propositions and arguments about the body, the soul, and the afterlife echo many of the beliefs on the body and soul in the afterlife discussion from reviewed literature.

Taking a contemporary view, Mollernkamp (2005) asserted that human beings became engaged in value-rational and instrumental calculations, which took into account the efficiency, and future consequences of their own actions. There were also scholarly affirmations that with modernisation people had become more rational and were moving away from traditional beliefs that were grounded in superstition, religion and long-standing customs (Abercrombie et al., 2006).

If these arguments were true, it would suggest that in the twenty-first century, people who were rational would support the ODMWA autopsy process because of the increased probability of determining occupational lung diseases and securing a compensation award. The acceptance of autopsy would therefore depend on how people associated the deceased body with the soul, and the rationale behind such an association. This aspect was explored using qualitative data collection questionnaire.

The following section discusses the cultural and sociological perspectives influencing the rationale and choices for ODMWA autopsy or variables identified in the literature reviewed.

3.2 Social action perspectives

Haralambous et al (2004) argued that an action was social if the acting individual took account of the behaviour of others, thereby orienting them to follow the same course as human beings define situations and give meaning to their actions and those of others, which in turn directs their actions. The ODMWA autopsy process operates both at the individual and social levels and both levels can influence the individual's choice for or against autopsy, choices are considered. If social argument is followed, families that believed in the association with the physical body ended with the pronouncement of death ODMWA autopsy

would then become acceptable, similarly, where there was a belief on maintaining the physical form of the body at death for afterlife existence, ODMWA autopsy will be rejected.

3.3 Power

ODMWA places the power for autopsy consent on the spouse and adult children. ODMWA legislators assumed that these individuals had decision making power over the affairs of the deceased. However, Basu et al (2009) maintained that mining in South Africa was historically a male-dominated industry, as it still is, particularly with the entrenched labour migration system that left households to be managed by the mineworkers' parents and wives, all living together. This was an African family unit and within this hierarchical tradition, males were dominant figures with the decision-making powers, as compared to the female spouse. According to Haralambous et al. (2004), such power relations were present in every aspect of communication, emotional, economic, or institutional, and could be fixed in such a way that they were perpetually asymmetrical and allowed only for a limited margin of freedom. For these reasons, the study explored the influence of gendered power relations that could influence ODMWA autopsy utilisation.

Both clinical and ODMWA autopsy consent were influenced by the Human Tissue Act with the medical profession following its prescript and the families exercising their rights. Human Tissue Act uses a model of consent to address religious or cultural issues surrounding autopsy, and thus allowing the families of the deceased to consent or reject autopsy. It was the responsibility of the doctor whom the deceased consulted to request consent from the family by discussing with them autopsy objectives, how the autopsy will be done, who will do it, and the benefit for the family or others. In the ODMWA autopsy, while the role of the doctor was mandated, this was still within the biomedical clinical consent model, weakening

the doctor's power and strengthening the role of the family who needed to give consent to autopsy. To establish the possible ODMWA benefits to the dependants (female spouse and children) depends on those that have decision power to give consent. In the traditional African hierarchical family, the dependants of the miner did not have decision making power to give consent to autopsy. The study explored these hierarchical power dynamics and their role in the current consent model.

3.4 Culture

The way we live, view things or communicate broadly define culture. The way we live (for example, our work, family structures or relationships) and the way we view things (our religion, beliefs, values, perceptions, or attitudes) influence our choices. Religion was a cultural system of commonly shared beliefs and rituals that gave a sense of meaning and purpose by creating an idea of reality that was sacred, all-encompassing and supernatural (Giddens, 2006). According to Giddens (2006) culture cannot be adopted or abandoned at will, since it was learnt and internalised over time, within a specific social and environmental context, and in black African society, as in many other societies, the culture surrounding death involved the observation of a system of cultural rituals (Harries (1994). Due to the centrality of culture, this study explored how culture among mineworkers and their families influenced their choice on ODMWA autopsy utilisation.

Understanding how African religion and culture influence the meaning attached to the body in afterlife and their impact on the decision for autopsy consent called for investigation. Secular, religious and culture, together with professional attitude and beliefs (technical and non-technical), affect the utilisation of autopsy services; however, these had not been researched in South Africa in relation to ODMWA benefits. This study therefore explores the

influence that culture might have on ODMWA autopsy utilisation by mineworkers and their families. Chapter four presents the methods used to investigate the study objectives

CHAPTER 4: CONCEPTUAL FRAMEWORK

In the absence of adequate literature on enablers and barriers of ODMWA autopsy examination for compensation, the literature on general clinical autopsy examinations was used to formulate a conceptual framework for the study (Figure 5).

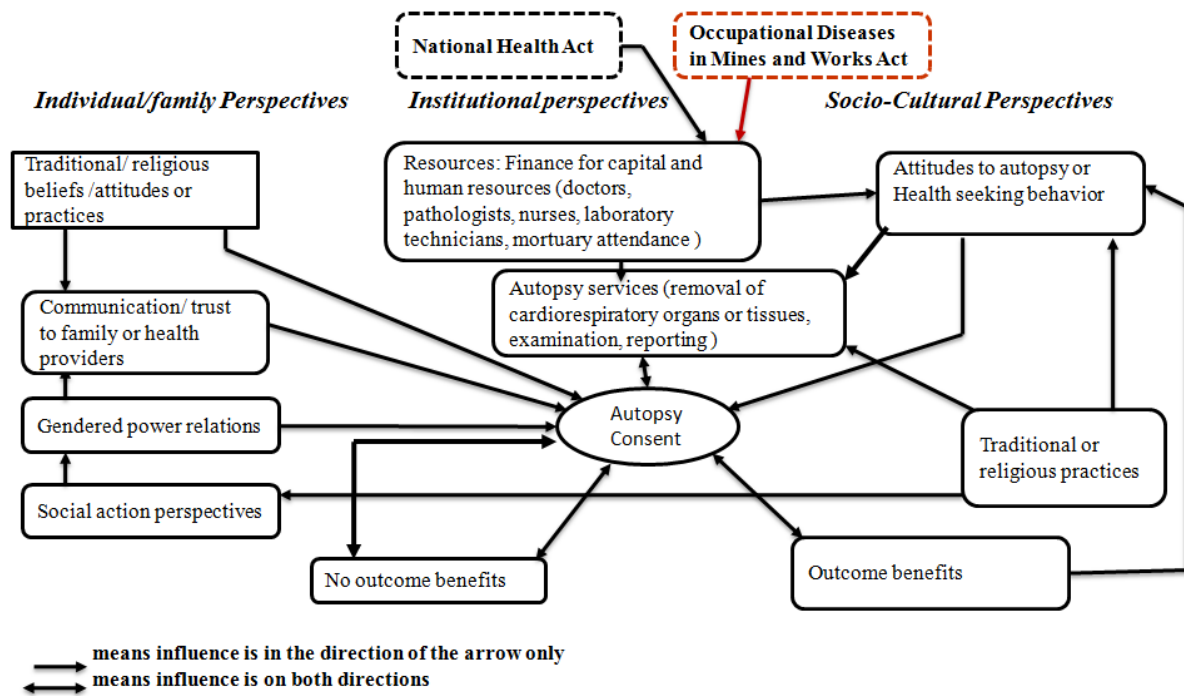


Figure 5: Conceptual framework of factors influencing clinical autopsy utilisation

The framework was adapted from an influence diagram developed by Morgan et al. (2002). An influence diagram defines decisions/actions that trigger or shape processes/outcomes and be able to the story of the 'risk' to be addressed in a non-technical but comprehensive way. Legislation and institutional factors largely drives forensic autopsy and the cultural and religious beliefs of the family respected.

However, clinical autopsy was largely dependent on the individual mineworker expressing his/her views and intentions on autopsy while still alive, or the family requesting or granting

consent and to a lesser extent on the health practitioner who should discuss the objectives of the autopsy and consent. In clinical autopsy, the legislative framework protects family and the individual while the institutional factors serve as vehicle for the performance of an autopsy upon request. In ODMWA autopsy, both scenarios are equally important and have the same weighting.

The identified potential topics found from the literature reviewed to play a role in clinical autopsy utilisation were at an individual, institutional, and community/societal levels. Topics at individual and socio-cultural levels were used to develop the semi-structured questionnaire used to guide the interviews and the thematic analysis of the transcripts.

CHAPTER 5: METHODOLOGY

5.1 Background

This study used two methods for data collection. The first one was descriptive (quantitative) and the second qualitative. Mixed methods in research inquiry combining both qualitative and quantitative forms of research in a manner that the overall strength of the study was greater than either the qualitative or quantitative research alone, particularly for inquiries that were in the domain of psychological and social aspects of human behaviour (Creswell, 2009) was selected. According to Creswell (2009), the two approaches should not be viewed as polar opposites or dichotomies, but rather as different ends of a continuum, with a study tending more to the qualitative than the quantitative or vice versa.

The first method was descriptive (quantitative) and examined ODMWA autopsy utilisation by black mineworkers, using available data from TEBA, MBOD, NIOH and DMR. From these data, compensation for occupational lung diseases following autopsy utilisation or missed compensation from non-utilisation was calculated.

The second method was in-depth interviews with four groups of participants to explore meanings attached to ODMWA autopsy in order to understand enablers or barriers to its utilisation. The use of this method was fundamental to this study because discussion of autopsy and death could evoke profound psychological and emotional responses and this required a one on one interview in an environment that was private yet familiar to the participants. In addition, qualitative studies provide an understanding of complex psychosocial issues understood through quantitative methods only (Marshall, 1996). Frankels and Denvers (2000a) maintained that the value of a qualitative research design was an opportunity of exploring meaning in both individual and group settings.

According to Burton (2003) in inductive phenomenology, the enquirer seeks insights into the meaning(s) attached to events by individuals, placing less emphasis on generalisations and seeking disparate views, rather than looking to determine the most commonly held view. Seeking disparate views was important because flexibility during data collection allowed for the grounding of an investigation on the emerging data (Burton, 2003; Neumann, 2006).

The following sections describe each quantitative and qualitative method separately.

5.2 Quantitative approach of the study

To quantify the monetary contribution of ODMWA autopsy to mineworkers' families, estimate the loss of financial benefits to their families due to autopsy non-utilisation and define the characteristics of those deceased mineworkers who did not use the autopsy service (to tentatively formulate reasons for not using autopsy). To achieve these objectives, the 2000-2010 data from TEBA, NIOH, MBOD, and DMR were used. Additionally, data from the 2009/2010 and 2010/2011 DMR annual reports were also used. The data sources, the period of selection, and the number of cases used to quantify compensation as shown in Figure 6.

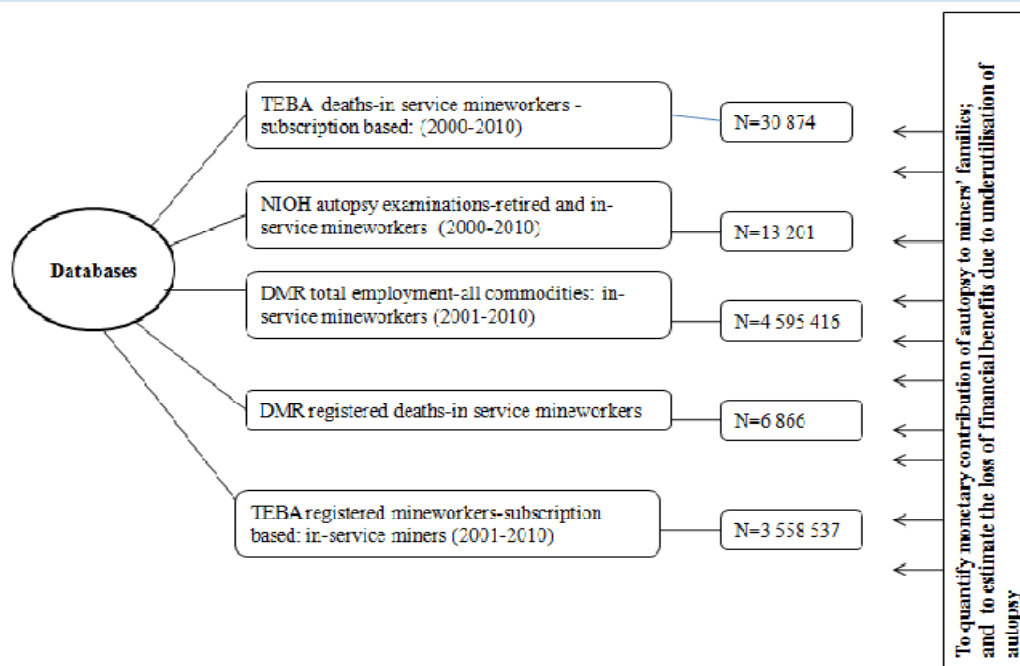


Figure 6: Data to quantify monetary contribution of autopsy and estimate loss of financial benefits from autopsy non-utilisation.

Figure 6 illustrates the total number of cases in each database. To establish compensation following autopsy examination, estimate missed compensation from non-utilisation, and formulate tentative reasons for not using autopsy services, data from these organisations were purposely selected. The organisations gathered these data for their own purposes.

5.2.1 Quantitative sampling design for database records

5.2.1.1 Sampling methods for deceased mineworkers from Nongoma

A purposive non-probability sampling technique was used for the selection of deceased mineworkers from Nongoma in Kwa-Zulu Natal who worked for mines affiliated with TEBA and died during 2004-2006. The list of subjects was sent through to MBOD to determine whether they had autopsy examination or previous MBOD submission and certification. The

specific objectives of the Nongoma data illustrated in Figure 6 were to establish their status on autopsy, MBOD submissions and to trace their families to request their participation in the qualitative study.

5.2.1.2 Sampling of deceased mineworkers who had ODMWA autopsy

All cardiorespiratory organs of in-service and former mineworkers in South Africa are examined at NIOH and pathology reports submitted to MBOD for certification. For this study, records of all deceased mineworkers examined by NIOH during 2001 to 2010 were requested from the MBOD to establish the outcome of MBOD certification following autopsy examination. The MBOD certifications were used to calculate the contribution of autopsy to monetary compensation and estimate missed compensation award.

Similarly, an annual list of all in-service mineworkers of TEBA affiliated mines for 2001-2010 was obtained from TEBA. TEBA annual number of in-service mineworkers was used as a denominator in calculating missed compensation following autopsy non-utilisation. The 10-year period was convenient to provide enough sample used to calculate compensation award following autopsy and estimate the amount lost through non-utilisation of autopsy services. In addition, compensation lost through non-utilisation of ODMWA was a contemporary issue. Therefore, the 10-year period was selected to show that the issues being investigated were not an aberration of one or two years, but systematic.

5.2.1.3 Quantitative sampling design of deceased mineworkers without autopsy

During 2001-2006, MBOD recorded 669 cases of deceased mineworkers whose families were applying for compensation following their deaths. The mineworkers did not undergo

autopsy examinations. A random sampling of one in every five of the 669 cases was carried to explore the characteristics of the deceased mineworkers to investigate tentative reasons for failure to use ODMWA autopsy. Figure 7 depicts the process used to get to the final sample.

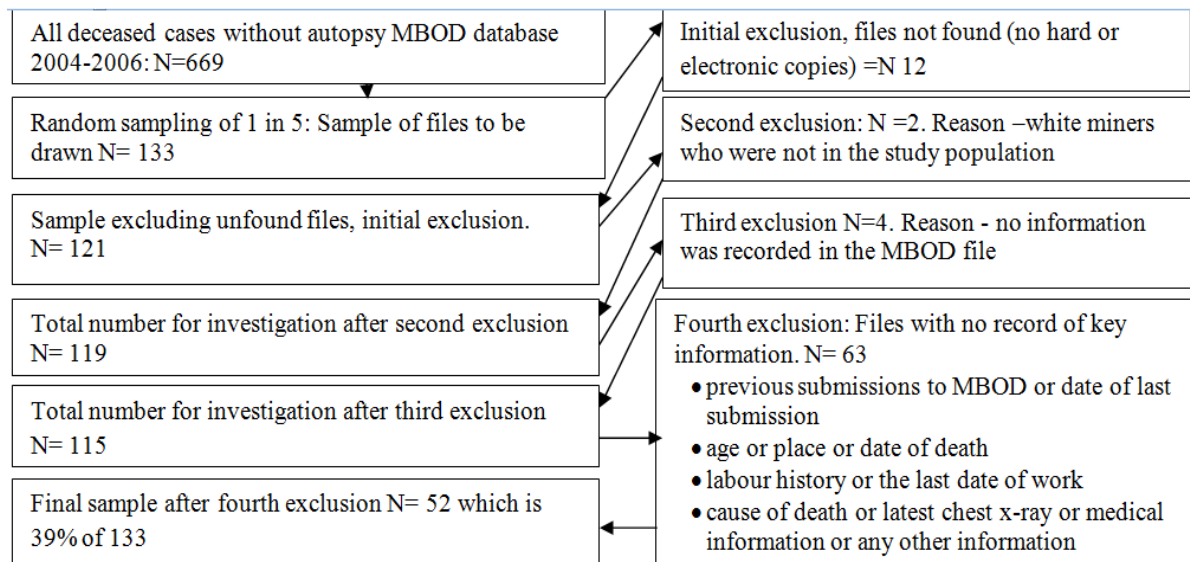


Figure 7: Record review recruitment and exclusion criteria of deceased mineworkers without autopsy (Source: MBOD)

The initial random sample of 133 cases of the 669 MBOD recorded cases was drawn. When the 133 files were requested, two cases were excluded because, even though they had been manually registered as documents for benefit application, the physical or electronic documents could not be retrieved or found. The remaining 121 physical records were drawn. Of these, two were excluded because they were white mineworkers (Note: the population of the study is black mineworkers and their families). A further four cases were excluded from the remaining 119 because only a handwritten death note (not a death certificate) with no other information was found in their files. A further 63 cases were excluded from the remaining 115 of the cases because overall it was impossible to establish whether they had been exposed to mining; and in each case there was no record of a previous

submission to MBOD, a date of last submission, a labour history, or a last date of work. The records lacked information on whether the men had actually died; there was no information on the date or place of death (rural or mine hospitals), cause of death, a latest chest x-ray or any other medical information.

The final characterisation of the deceased mineworkers, needed to assess the certification of these cases, focused on the remaining 52 records (39% of the original random sample). This included the frequency of previous submissions to MBOD, the originator of the last submission, the age of the mineworker at death, the place of death, his employment and labour history, the last date of mining work, the date of death, the recorded cause of death, the latest chest x-ray in the file and its originator, new medical information that resulted in the file being opened, and any other information which could offer insights on the certification and the deceased.

5.2.3 Quantitative data capture

Two data capture tools using Microsoft Excel 2007 were developed see Appendices 1a and 1b. Appendix 1a captured the characteristics data, while Appendix 1b recorded data of the deceased mineworkers from Nongoma registered with TEBA. The information consisted of the age of the miner at death, the place of death, the possible cause of death, the labour history, and previous submission to MBOD, date of finding, the finding itself, and the date last worked for tentative reasons for failure to use ODMWA autopsy.

5.2.4 Quantitative data analysis

Summary statistics used to present the findings of analysed data include frequencies and percentages of cross-tabulations.

5.3 Qualitative study

5.3.1 Background

To obtain in-depth information from participants on autopsy and the meaning attached to the body and the influence of cultural beliefs a qualitative survey was used. According to Marshall (1996), a key participant was an expert source whose formal role exposed him or her to the kind of meaningful information being sought by the researcher. In qualitative research, non-numerical data are collected from a sample judged large enough to clarify the aspect being investigated (Creswell, 2009).

5.3.2 Study population

The participants were former mineworkers, relatives, and widows of deceased miners, in-service miners and others (traditional healers and occupational health practitioners) and selected because of particular perspective they brought to the study. Miners and their families have a direct influence on autopsy utilisation, and traditional healers were able to offer a shared cultural perspective on attitudes to autopsy and may be in a position to influence behaviour.

Occupational health practitioners were considered able to offer a shared experience on the mineworkers' attitudes to autopsy as they had contact with miners and families during illness and at death. In the main, informants were selected because of their availability and

accessibility. Individual informants were identified through community workers, other mineworkers, and representatives of organised labour, with the exception of traditional healers. The traditional healers selected were popular among mineworkers and communities and each represented a different cultural tradition. Health practitioners worked for gold mines and privately in the communities of mineworkers.

The majority of former mineworkers, relatives, and widows were from Nongoma, a district of KwaZulu-Natal Province that has a high density of mineworkers (TEBA, 2008). Additionally, former mineworkers living in five urban townships around Free State Province gold mines and in-service mineworkers from a Randfontein gold mine west of Johannesburg was selected because of convenience, being relatively close to the base of the researchers.

According to TEBA (2008), Kwa-Zulu Natal was one of the four highest mine labour-sending areas, together with the Eastern Cape, Lesotho and Mozambique. Historically, a large number of South African mineworkers came from the Eastern Cape Province, which was the recruitment hub for migrant mining labour, followed by Kwa-Zulu Natal (KZN). Nongoma was selected for this study, as it had the highest number of migrant mineworkers in KZN. The Eastern Cape Province was excluded because at the time of the study discussions were taking place at a provincial level with ex-mineworkers, the beneficiaries of the mineworkers and other concerned members of the public about problems relating to outstanding compensation benefits and monthly pensions which should have been awarded. A list¹ of 4300 beneficiaries published in August 2009 by the Minister of Health in the Government Gazette. Because of these compensation issues, the study did not include

¹ National Gazette number 32452 of 7 August 2009, Volume 530 (Part 1 of 3).

Eastern Cape, as this would have created confusion and expectations among the participants, particularly if they were not in the published list but believed they should receive compensation particularly families of mineworkers who had died believing that they had contracted occupational lung disease prior to death. All these factors could have evoked unexpected negative emotions, which could have introduced biased responses.

Relatives of deceased mineworkers from Nongoma who were available during the qualitative phase were included in the interviews. The study excluded widows and relatives who experienced death within two years of the study to reduce psychological and emotional reactions invoked by discussing the death of their loved one. A consent form allowed the participant to withdraw at any time during the interview.

5.3.3 Data collection methods for qualitative study

The study used similar assertion by Tjale et al (2004) that in-depth interview approach explores individual or group meaning and experiences because human phenomena such as psychosocial responses embedded in cultural patterns and the inter-relationships among its components complex necessitating a flexible enquiry that allowed concepts to emerge from the data collected. The lack of familiarity with some of the questions in the questionnaire, and the possibility of lower literacy levels among some of the potential participants with the exception of health practitioners and traditional healers ruled out a self-administered questionnaire. The widows and relatives of deceased mineworkers were viewed as a vulnerable group and although focus group discussion was considered, it was excluded because interaction amongst the groups was not considered relevant to the topics beings explored. One-on-one interview was selected, rather than focus group discussion, since the

type of autopsy discussed in the study was the removal of cardiorespiratory organs and was contemporary, and needed to be treated sensitively and empathetically, given that it could easily trigger strong psychological and emotional reactions. The interview set-up ensured privacy between the interviewer and participant, permitted clarity of questions and allowed new responses to be followed-up. A focus group approach would have been inappropriate in this context.

The English semi-structured questionnaires (Appendices 2 and 3) translated to Sotho (Appendix 4) and Zulu (Appendix 5) were used to guide the interviews, allowing the same questions to be asked by the researcher of all the participants in the group. The semi-structured questionnaires derived from the literature were used as a framework to guide the in-depth interviews and to ensure exploration in detail of sociological perspectives identified in the literature review. The questions were open-ended, allowing the researcher to probe deeper and elaborate on initial responses. To test the consistency of the responses, double-barrelled questions were used; alternatively, the questions were repeated using different phrasing. The questionnaires were translated from English to Sotho (Appendix 4) and Zulu (Appendix 5) identified as the vernacular languages most commonly used and understood. During interviews there was upfront discussion of the optional recording of the interviews (Appendix 6), the participant's information document (Appendix 7) and the consent form (Appendix 8) with each participant. Prior to signing the consent form to participate, the right to withdraw anytime was discussed and permission to record the interview obtained. The interviews were in the participants' own vernacular languages which researcher also spoke. The English questionnaire version was shortened (Appendix 9) and translated to Zulu (Appendix 10).

Each interview covered the following broad areas in the questionnaire:

- Introduction to establish atmosphere of relaxation
- Gather demographic information about each participant and background details, for example on where the participant was born and grew up, and whether this area was the same in which the parents or the grandparents lived.
- Gather information relating to the labour history of the miner to ascertain exposure to risk work as defined by the ODMWA. This included the period during which the miner had been former from mining, the surrounding circumstances, and any information communicated to the miner at an exit medical examination or at any other time during engagement or medical surveillance.
- Establish whether the participants were informed and knowledgeable about ODMWA, its aims and benefits, and the processes involved in life and at death.
- Gather participants' knowledge, perception and attitudes to autopsy and the deceased body in relation to burial in the case of ODMWA autopsy.
- Discuss traditional religious, cultural beliefs and autopsy, dying, death and the deceased to establish associations.

5.3.4 Qualitative study sites and selection of the participants

The minimum number of participants, though not limited, was set at sixty or when saturation was reached. MBOD and TEBA provided the researcher with a list of contacts from communities of mineworkers who assisted with finding mineworkers and relatives of deceased mineworkers. The researcher discussed the consent form (Appendix 11) with discussed. Four strategies were used in the selection of the participants. In each strategy, the

researcher first telephoned the contact to request his or her assistance in finding the participants.

In the first approach, using the list of TEBA recorded deceased mineworkers from Nongoma, a community leader who was living in Nongoma and involved in several community initiatives and an occupational nurse practitioner stationed in Nongoma hospital were requested to trace the deceased mineworkers' families. The community leader had attended various outreach programmes by the MBOD to increase ODMWA medical examinations of former mineworkers and had a good rapport with other local leaders and the community.

Nongoma is predominantly a rural municipality in the north-eastern part of Kwa-Zulu Natal Province. It encompasses 363 settlements, only one of which (Nongoma) has some urban characteristics. 98.34% of the population lives in rural areas. Although there are twelve clinics serving the three tribal authority areas of Nongoma, a number of people did not have access to these clinics because of poor road conditions or limited access to roads, as was discovered during the fieldwork. In some areas, there were no clinics and the people depend on mobile clinics.

The second approach was to request the Nongoma community leader to brief the local indunas about the study and seek access to the participants. The community leader's brief was also to find all the mineworkers, relatives, and widows in Nongoma who were willing to take part in the study.

The third approach was through the National Union of Mineworkers, for which a regional leader in Randfontein was a contact. He briefed others about the study at the union's meetings. The regional leaders then briefed their shop stewards, who in turn briefed the mineworkers about the study. The in-service mineworkers were working for the gold mines and staying with their families at a township in Mohlakeng, Randfontein.

The fourth approach was to select former urban mineworkers. In making the selection, due consideration was given to exclude those who lived around Gauteng because the researcher had worked in the local gold mines and had run a private practice in the community between 1993 and 2004. The increased risk of subjectivity by the researcher and expectations by the participants could distract from a complete focus on the study were considered.

This scenario could arise, for example, in a situation in which the mineworker died prematurely due to non-occupational medical reasons. The interview guide and asking the same questions to all participants minimised the potential for subjectivity and bias.

Former mineworkers living in Welkom, Odendaalsrus, Henneman, Allanridge and Virginia were targeted. A contact found through the Medical Bureau for Occupational Diseases worked at a centre, which offered benefit medical examinations for both in-service and former mineworkers assisted with Free State former mineworkers. The contact and the key management personnel met with the researcher and who briefed them on the study during the piloting of the semi-structured research tool with three former mineworkers. Once management had approved the request to involve the contact in finding participants, she gave the researcher the dates that former mineworkers came to the centre for benefit medical examinations. At the initial request to participate in the study, the contact discussed with the

mineworkers who were willing to participate their preferred place of interview (the participant's home or the local hospital) and their availability. This information was given to the researcher and interview dates were scheduled. The interviews commenced in Welkom followed by Nongoma and concluded in Randfontein, and were carried out over a period of six months.

The total number of participants interviewed in each of the four groups consisted of twenty-four former mineworkers, eleven in-service mineworkers, twenty-two widows, ten relatives of deceased mineworkers, and ten key informants.

Three of the twenty-four former mineworkers participated in the pilot the questionnaire and excluded from the main study. Of the eleven in-service mineworkers, one refused to participate, citing his position as a shift boss, his ethnicity (coloured) and his belief that the study was not for him. Two other in-service mineworkers withdrew from the study, citing other engagements as reasons.

Of the ten key informants, one mine medical occupational health practitioner withdrew, saying that she had never discussed autopsy with mineworkers and that any information she gave would be speculative. She further said that her beliefs would not be representative of the participants' communities as she was Indian.

5.3.5 Pilot study for the qualitative study

The main study followed a pilot study done to test the questionnaire, establish the relevance of the questions being asked, the extent to which the information received could satisfy the

study objectives, the degree of sensitivity with which the questions should be phrased, and to estimate the duration of each interview. Six MBOD staff participated in the pilot.

During the pilot study, it emerged that the questionnaire was too long and repetitive, especially when translated from English into Zulu or Sotho. In addition, three former mineworkers from Thabong participated in Zulu and Sotho shortened versions of the questions.

It also emerged that certain African idioms needed to be included in the English version, as they had far more meaning in an African language than in an English sentence or paragraph, for example *‘Lenstwe la mohu ga le tselwe,’* translated into English as *‘A dead man’s words/instructions in life can’t be changed when he’s dead’*.

The findings of the pilot survey revealed that the questionnaire needed shortening, while the protracted version used as a reference to guide and focus the interviews without restricting the questionnaire.

5.3.6 Field study

The interviews in Welkom occurred in an unused office at an Occupational Health Centre. The researcher made three separate visits to the centre to interview participants. The third visit took place after completing Nongoma interviews. Deviation occurred with the inclusion of three widows during the interviews with the former mineworkers in Welkom. Two of the widows were from Lesotho, while the third was from Thabong. They had come to the centre to enquire about the outcome of the benefit examinations relating to their deceased husbands.

Although they were not from Nongoma, it was felt that their inclusion would enrich the data collected from the widows. The interviews ceased when no more participants were found and the time allotted for the study had expired.

The researcher was based in Vryheid, Kwa-Zulu Natal, for two weeks, travelling from there to wherever the participants chose to be interviewed, accompanied by the contact. The contact had established that Vryheid Hospital of AbaQulusi Municipal District offered MBOD benefit medical examinations to former mineworkers through its occupational health service department. The centers conducting medical benefit examination forward their medical to MBOD for certification. The former mineworkers travelled to the hospital. The researcher spent the first day establishing relationships with the occupational health nurse and the other two days interviewing the mineworkers who had come to be examined and had agreed to participate.

Ex-mineworkers from the Nongoma and other Zululand districts also travelled to the Vryheid Hospital because it was the only one offering such services. At the time of the study, Nongoma Provincial Hospital was in the process of forming an occupational health department that would offer the MBOD benefit medical examinations to ex-mineworkers.

Widows and former mineworkers from Stanele and Nkondolani in the AbaQulusi Municipal District were interviewed under a tree near the village dealership shop, except for three families who agreed to be interviewed in their homes. The participants from the Nongoma district were interviewed in the Qwuasha, Vuna, and Engolotshe villages, either in their homes or under the trees. This was a closely knit community whose female members support

each other while their men folk work in mines. In Engolotshe, village six former mineworkers were interviewed. The interviews took place under a tree in the grazing fields opposite a village dealership shop.

5.3.7 Data collection procedures

All the interviews were recorded with the consent of the participants in their vernacular languages. Notes were made during the interviews, with a summary at the end of each interview. Each night, the researcher reflected on the interviews done during the day and made notes on the highlights. The interviews were later transcribed into English.

5.3.8 Data analysis of the qualitative study

The central task during data analysis was to identify common themes in the people's descriptions of their experiences. From the literature reviewed, the conclusions drawn by the authors of data that were collected on attitudes and perceptions to autopsy by health practitioners, bereaved parents and relatives were discussed, gaps identified and areas for further exploration in the study emphasized. Most importantly for the study, the survey data from target groups in section 5.3.2 were transcribed into Office Word 2007 within 3 days of the interviews since it was recognised that recollection of the discussions was imperative. Hand written notes taken during the interviews were included with the interviewees' notes. Interviews were transcribed from Tsonga, Zulu and Sotho to English and once the interviews were transcribed and typed, the notes were read through and the key ideas generated noted at the end of each interview.

The notes were examined for overall depth and meaning. The notes for each of the participants were uploaded in their groups onto the 2003 MAXqda PC programme, which was followed by coding. According to Rossman et al (1998), coding is a method of systematically arranging the data into sections of texts prior to generating meaning to the information that emerges. Once the texts were coded into segments and grouped into categories that reflected various aspects of the phenomenon as it was experienced; themes were identified and their meaning interpreted and at the same time, divergent perspectives were also sought.

5.4 Ethical considerations

During the conceptualisation of the study, TEBA, NIOH, and MBOD were approached to discuss the availability of data that could assist in the study. Management responsible for the databases pledged support in writing, and this was submitted along with the research protocol and ethics application.

Though all the participants were adults, the questions put to them, the process that was followed to protect their identity, the handling of confidentiality and the presentation of information, including the plan to collect the data and secure signed approval by the individuals in charge of the MBOD, NIOH and TEBA, were presented to the Faculty of Humanities' Human Research Ethics Committee (non-medical) in 2007 for ethical clearance. The faculty granted approval in June 2007, with study clearance certificate, HO70618 (Appendix 11). During the interviews with widows and family members, questions were phrased sensitively. In some situations, the atmosphere was stressful as participants' expressed anger regarding the system. In order to accommodate them, I would listen and sometimes offer to contact or even contact the individuals that I worked with at the MBOD.

Although the interviews would take longer, the empathy that I showed, and my knowledge of the legislations and contacts, tended to bring the interviews back to the objectives of the study.

CHAPTER 6: QUANTITATIVE RESULTS AND DISCUSSION

In this chapter, the findings on the following three core objectives are shown and discussed:

- i. Quantification of the monetary contribution of autopsy to mineworkers' families
- ii. Estimation of the loss of financial benefits to mineworkers' families due to non-utilisation of autopsy and
- iii. Definition of the characteristics of those deceased mineworkers who did not use autopsy services (to tentatively formulate reasons for not using autopsy).

The chapter is in two sections. In the first section, the quantitative study findings are presented and discussed in the second section.

6.1 TEBA Data

The percentage of in-service mineworkers represented by TEBA was calculated using the total number of mineworkers obtained from the DMR. There was lack of comprehensive data on mineworkers who died in-service due to natural causes.

In the following sections, the number of workers registered with TEBA as a percentage of the total mining employment in South Africa is presented. DMR and TEBA crude death rates per thousand mineworkers are also presented.

6.1.2 Mineworkers employed by TEBA affiliated mines in South Africa (2001-2010)

During 2001-2010, the annual percentage of in-service mineworkers registered with TEBA was 71% that of DMR, as shown in Table 5. (Note: the TEBA mine labour numbers were obtained from TEBA records of mineworkers who worked at its affiliated members.)

Table 5: 2001-2010 percentage of TEBA registered in-service mineworkers to overall in-service mineworkers in South Africa (DMR, 2010)

Year	DMR total employment	TEBA registered mine labour	% of TEBA registered mineworkers to total industry compliment	Mineworkers not registered with TEBA	% of non-TEBA registered mineworkers
2001	407 154	314 346	77	92 808	23
2002	416 925	314 333	75	102 592	25
2003	434 859	319 322	73	115 537	27
2004	448 909	323 862	72	125 047	28
2005	444 132	325 124	73	119 008	27
2006	456 337	323 050	71	133 287	29
2007	495 150	327 817	66	167 333	34
2008	518 519	336 287	65	182 232	35
2009	491 922	335 921	68	156 001	32
2010	481 509	320 536	67	160 973	33
Mean/year	459 542	324 060	71	135 482	29

6.6.1 Crude death rates of in-service mineworkers employed by TEBA affiliated mines in South Africa during 2001-2010

The annual crude death rate per 1000 TEBA-registered in-service mineworkers was 8.7 per 1000 over a period of ten years (Table 6). Due to lack of data from non-TEBA members, their crude death rate could not be calculated.

Table 6: 2001-2010 Crude death rate per 1000 TEBA-registered in-service mineworkers

Year	TEBA registered mine labour	TEBA recorded deaths	Annual crude death rate
2001	314 346	2 983	9.5
2002	314 333	2 993	9.5
2003	319 322	2 146	6.7
2004	323 862	2 973	9.2
2005	325 124	2 861	8.8
2006	323 050	2 833	8.8
2007	327 817	3 432	10.5
2008	336 287	3 054	8.2
2009	335 921	2 754	8.2
2010	320 536	2 232	7
Mean/year	324 069	2 826	8.7

During 2003-2009 the crude death rate/1000 for all in-service mineworkers due to respiratory diseases and mine accidents combined as reported by mines to DMR in South Africa was 2.1/1000 and that of TEBA registered in-service mineworkers 7.4/1000 during the same period. DMR data excluded deaths due to non mining accidents and diseases; and were only available from 2003-2009.

Table 7: 2003-2009 Crude death rate per 1000 of overall in-service mineworkers, all commodities

Year	Number of mineworkers	Deaths reported to DMR by mines due to mine accidents and respiratory diseases	Crude death rate per 1000
2003	434 859	1 270	2.9
2004	448 909	1 199	2.7
2005	444 132	918	2.1
2006	456 337	847	1.9
2007	495 150	930	1.9
2008	518 519	865	1.7
2009	491 922	837	1.7
Mean/year	328 983	687	2.1

6.7 Autopsy utilisation

Using the annual TEBA-reported deaths (all causes) as the denominator and ODMWA autopsies as the numerator, Table 8 shows that utilisation of ODMWA autopsy examination of deceased mineworkers decreased from 57% in 2000 to 43% in 2010.

Table 8: 2001-2010 annual ODMWA autopsy examinations as a percentage of TEBA registered deaths (in-service mineworkers)

Year	Total TEBA registered deaths	Total ODMWA performed autopsies by NIOH	Annual percentage utilisation	Annual percentage non-utilisation
2001	2 983	1 690	57	43
2002	2 993	1 677	56	44
2003	2 146	1 536	72	28
2004	2 973	1 428	48	52
2005	2 861	1 274	45	55
2006	2 833	1 165	41	59
2007	3 432	1 144	33	67
2008	3 054	1 185	39	61
2009	2 754	1 138	41	59
2010	2 232	964	43	57
Mean/year	2 826	1 320	46.7	53.3

Overall, ODMWA autopsy utilisation by mineworkers who died in-service was 46.7% of TEBA registered deaths over 10 years. This is an over-estimate of utilisation because TEBA deaths were only 71% of the in-service mineworkers (Table 5), whereas ODMWA autopsies were on all mineworkers (in-service and former). If 71% of the autopsies were on the TEBA registered mineworkers, then there were 9 373 autopsies on TEBA members ($13\ 201 \times 0.71$). An estimate of utilisation for TEBA registered mineworkers would be an estimated TEBA registered mineworkers' autopsy examinations divided by TEBA recorded deaths which is 33.2%. Utilisation may therefore have ranged from about 33.2% to 46.7% for the 10-year period.

Based on TEBA registered deaths, during 2007-2010, ODMWA autopsy non-utilisation by in-service mineworkers was 70% as shown in Table 9. The in-service autopsy data were unpublished and obtained from Ndlovu (2010).

Table 9: Percentage of ODMWA autopsies on in-service mineworkers for 2007-2010

Year	TEBA recorded deaths: mine affiliated in-service mineworkers	Autopsy examination on all in-service mineworkers	Percentage autopsy utilisation	Percentage autopsy non-utilisation
2007	3 432	903	26	74
2008	3 054	843	28	72
2009	2 754	951	35	65
2010	2 232	725	32	68
Total	11 472	3 422	30	70

If 71% of autopsy examinations were on TEBA registered mineworkers, then 2 430 ($3\,422 \times 0.71$) of the 3 422 autopsy examinations during 2007-2010 were on TEBA members. Therefore an estimated 21% ($2\,430/11\,472$) of TEBA registered mineworkers who died in-service had an autopsy.

6.8 New cases of occupational lung diseases following autopsy examinations

To establish new occupational lung diseases identified by autopsy examination, MBOD certification records of deceased mineworkers who had autopsy examination were obtained from MBOD. New diseases that were certified by MBOD following autopsy examination in first and second degree categories were used to calculate autopsy contribution to compensation and to estimate the financial loss of non-utilisation. (Note: cases that were certified TB only but not in the first or second degree were excluded from the financial calculations as they are compensated for loss of wages during the course of treatment using various formulae. Also TB cases must be submitted for re-evaluation on treatment completion.)

Of the 13 127 cases certified by the MBOD over the 10-year period, the number of deceased mineworkers certified in the second degree TB category during 2001- 2010 was 1 574 which was larger than any other disease category as shown in Table 10. Overall, 67% of the cases were not eligible for compensation (i.e. no compensable disease category, TB not attributable

to risk and certifications categorised as before), 3% were TB cases eligible to be compensated for loss of wages while on TB treatment, 2% were deferred for further information.

Table 10: 2001-2010 annual certifications by MBOD following autopsy examinations

Year	No compensable disease	TB as before	TB only	TB cannot be attributed to risk work	First degree occupational lung disease	First degree occupational lung disease as before	Second degree occupational lung disease other than TB	Second degree TB	Deferrals for more information
2001	1388	40	0	18	60	0	90	80	14
2002	1177	57	30	27	54	45	153	126	8
2003	1201	13	17	0	0	23	18	0	14
2004	420	0	65	32	41	0	142	270	64
2005	1350	0	57	11	33	0	51	90	8
2006	0	0	0	0	0	47	0	0	0
2007	1734	180	60	29	0	95	0	0	0
2008	565	173	100	36	40	293	106	367	27
2009	100	20	21	31	44	293	185	403	44
2010	240	13	40	0	39	79	166	238	32
Total	8175	496	390	184	311	875	911	1574	211

The first degree occupational lung disease as before category implies that the disease did not progress to the second degree category. Table 10 includes 59 cases that were upgraded from first to second degree category (included in the second degree column).

In summary, excluding the 211 (1.6%) cases deferral over the ten years, of the remaining 12 916 cases, 22% inclusive of both first and second degree occupational lung disease categories and upgrades were certified by MBOD following autopsy examinations. Therefore, it can be assumed that all of the families of these cases were eligible for compensation.

6.9 Contribution of ODMWA autopsy to compensation

Monetary compensation amounts are calculated based on a mineworker's salary using a formula but includes a minimum and maximum salary to derive minimum and maximum permissible compensation amounts for first and second degree occupational lung disease

categories. Periodically, the Minister of Health determines the minimum and maximum salaries that are to be used in calculating compensation, therefore regulating the minimum and maximum amount of compensation to be awarded to mineworkers.

6.9.1 Compensation for first-degree certification

Following ODMWA autopsy examination in 2001-2010, a total of 311 deceased mineworkers were newly certified with occupational lung disease in the first degree by the MBOD (Table 11).

Table 11: Cases newly certified in the first degree category of occupational lung diseases following ODMWA autopsy examination: 2001-2010

Year	ODMWA autopsies performed	First degree certification
2001	1 690	60
2002	1 677	54
2003	1 536	0
2004	1 428	41
2005	1 274	33
2006	1 165	0
2007	1 144	0
2008	1 185	40
2009	1 138	44
2010	964	39
Total	13 201	311

Using the minimum and maximum annual salaries of \$3 340.54 and \$4 912.50 used in the ODMWA formula to calculate compensation, it is estimated that the 311 families were eligible for compensation of \$1 038 896-\$1 527 788 over ten years following ODMWA autopsy examination. The lump sum award that each family could receive ranged between \$5 000-\$7 5000.

6.9.2 Compensation for second-degree certification

Following ODMWA autopsy examination in 2001-2010, 2 426 deceased mineworkers had second degree occupational lung diseases category certified by the MBOD, as shown in Table 12.

Table 12: Cases newly certified in the second degree category of occupational lung diseases following ODMWA autopsy examination: 2001-2010

Year	NIOH performed autopsies	Second degree occupational lung diseases other than TB	Second degree PTB
2001	1 690	82	80
2002	1 677	153	126
2003	1 536	16	0
2004	1 428	139	270
2005	1 274	43	90
2006	1 165	0	0
2007	1 144	0	0
2008	1 185	95	367
2009	1 138	162	403
2010	964	162	238
Total	13 201	911*	1 574

*911 as shown in table 12 minus the 59 upgraded cases

Using minimum and maximum salaries of \$7 438.25 and \$10 938.75, used in the ODMWA formula to calculate compensation, it is estimated that the 2 426 families were eligible for \$18 045 195 to \$26 537 408 in compensation over the ten years following ODMWA autopsy examination. The average lump sum award that each family could receive was \$12 907.63.

The compensation award for an upgrade from first to second degree was between \$5 000 to \$5 500 as the compensation previously awarded in the first degree is deducted. Between \$260 000 to \$286 000 could have been paid to the families of 59 mineworkers.

6.10 Estimated loss of financial benefits following autopsy non-utilisation

From the TEBA registered deaths and the ODMWA autopsy examinations performed by NIOH, there were 15 064 mineworkers who did not undergo autopsy examination as shown in Table 13.

Table 13: Annual and total number of TEBA registered deceased mineworkers who did not undergo autopsy in 2001-2010

Year	TEBA registered deaths	ODMWA performed autopsies	Difference
2001	2 983	1 690	1 293
2002	2 993	1 677	1 316
2003	2 146	1 536	610
2004	2 973	1 428	1 545
2005	2 861	1 274	1 587
2006	2 833	1 165	1 668
2007	3 432	1 144	2 288
2008	3 054	1 185	1 869
2009	2 754	1 138	1 616
2010	2 232	964	1 268
Total	28 261	13 201	15 064

Three hundred and eleven first degree category occupational lung diseases were certified out of a total of 13 201 autopsies i.e. 2% and 2 426 in the second degree i.e. 18% over the 10-year period. Assuming these 10-year average proportions of certifications would have applied to those who did not come to autopsy over the same period, it is estimated that 15 064 x 2% (i.e. 355 mineworkers) would have been certified in the first degree category, and 15 064 x 18% (i.e. 2 769 mineworkers) in the second degree category. Therefore, the estimated compensation award on missed first degree category certification that could have been awarded to the 355 families is \$1 185 869.63-\$1 743 926, with each family receiving between \$5 000-\$7 500. Also, an estimated compensation award on missed second degree category certification that could have been awarded to the 2 769 families is \$20 596 514.25-\$30 289 398.75, with each family receiving between \$7 438.25-\$10 938.75.

Using TEBA registered deaths of in-service mineworkers, it should be noted that the estimated financial loss due to non-utilisation of autopsy is an under-estimate because the number of deaths in former mineworkers was unknown and were not included in the calculations.

6.11 Characteristics of deceased mineworkers who did not undergo autopsy examination

The characteristics of the 52 mineworkers who had not undergone autopsy are outlined in the following sections.

6.11.1 Duration of service and longevity after leaving mines

Fifty four percent of the deceased mineworkers in whom service history was recorded had mining service of more than five years (Table 14). Labour history was not recorded in 36%.

Table 14: Labour histories of deceased mineworkers who did not undergo autopsy: N=52

Years	N	Percentage
≤5	5	10
≥5	28	54
Unknown	19	36
Total	52	100

The majority of the 52 mineworkers, i.e. 63.5%, died within a year of leaving the mines as shown in Table 15, with 71.2% dying in less than five years after leaving the mines.

Table 15: Longevity of the miner after leaving the mine: N=52

	n (%)
% of those who died within 1 year after leaving the mines	63.5
% of those who died after 2- 5 years of leaving the mines	7.7
% of those who died more than 5 years after leaving mines	21.2
% missing information	7.7

As shown in Table 16, 63.5% of the 52 mineworkers were submitted to the MBOD while still alive and 36.5% were not.

Table 16: Record of previous submissions to MBOD other than after death: N=52

Number of previous MBOD submissions	% of previous submissions
Once	48.1
Twice or more	15.4
Never	36.5

Seventy percent of those who were submitted to the MBOD were certified to suffer from occupational PTB and could have possibly been still on treatment. However, all of them were entitled to medical check-up and resubmission to the MBOD for a certification review upon treatment completion. Three percent were certified to have first degree TB, six percent silicosis, six percent second degree PTB and silicosis and nine percent second degree TB occupational lung disease categories. Six percent had no compensable disease. With the exception of those certified with second degree occupational lung disease category (11%) the remaining 89% were eligible for autopsy examination.

6.11.2 Age of the mineworker at death

Fifty four percent of the mineworkers died before the age of 60 years (Table 17). The age at death was not recorded in 46% of the records. The majority of the mineworkers (42%) died before the age of 50 years.

Table 17: Age at death of mineworkers who did not undergo autopsy examination

Age of deceased mineworker at death	n	%
30-39	13	25
40-49	9	17
>50<60	6	12
Unknown	24	46

6.11.3 Place of death

The majority of the miners (96%) were recorded to have died at their homes while 4% died in hospital.

6.11.4 MBOD certifications and the recorded cause of death

In Table 18, the MBOD certification and the cause of death written on the death certificates are shown for 32 mineworkers with this information.

Table 18: MBOD certification and the recorded cause of death: n=32

Last submission year	Disease category	Cause of death registered in the death certificate	Last submission year	Disease category	Cause of death registered in the death certificate
1986	Silicosis & TB	Respiratory distress	1988	TB	TB
1991	TB	Notrecorded	1991	Silicosis	Notrecorded
1991	No compensable disease	Chest pains	1995	TB	TB
1995	Silicosis	Notrecorded	1995	TB	TB
1998	TB	Respiratory Tract Infection	1996	TB	TB
1999	TB	Chest pains	1997	TB	Chronic ulcer
1997	TB	Chest pains	1999	TB	TB
1999	TB	Notrecorded	1999	TB	TB
1999	No compensable disease	Headache and chest pains	1999	TB	TB
2000	TB	TB	2000	TB	TB
2000	1st degree TB	Painful feet	2000	TB	TB
2001	TB	TB	2001	TB	Liver attack
2001	TB	TB	2002	TB	TB
2003	TB	TB	2002	TB	TB
2003	TB	TB	2003	Silicosis & TB	Notrecorded
2004	TB	Notrecorded	2004	TB	Chest pains

A high proportion (81.3%) of the 32 deceased mineworkers with a record of previous MBOD certification was recorded to have suffered from occupational PTB. According to their records, 65% died of PTB.

6.12 Discussion

6.12.1 In-service mineworkers employed by TEBA affiliated mines

Seventy one percent of in-service mineworkers over the 10-year period were employed by mines affiliated with TEBA. The crude death rate per 1000 TEBA registered mineworkers was 7.4. The crude death rate per 1000 DMR recorded mineworkers 2.1. The higher crude death rate per 1000 TEBA registered mineworkers could be partly explained by a record of all deaths while that of DMR was limited to occupationally related deaths. The TEBA recorded deaths were thus a more useful source of numbers used to calculate utilisation and compensation awards.

6.12.2 Autopsy utilisation

The study found that not all TEBA registered in-service mineworkers utilised autopsy examinations. Also, figures in non-TEBA registered mines were unknown. ODMWA autopsy provisions are important as a large number of former mineworkers are not compensated in life (Trapido et al., 1998; Steen et al., 1997; Girdler-Brown., 2008) and others are found to have occupational lung diseases at autopsy (Ndlovu et al., 2010). Of particular poignancy in the South African context of impoverished rural communities is that despite the potential financial benefits for families of deceased mineworkers, the study found that there was non-utilisation of the autopsy service by black mineworkers.

It is noted was that autopsy can only be performed at the consent of the family. However, during 2001-2010, using TEBA recorded deaths; autopsy utilisation of in-service mineworkers was estimated to range between 30-46%. It is argued that these figures were an over-estimate as they did not include former mineworkers or in-service

mineworkers working for TEBA non-affiliated mines. Although not all TEBA registered mineworkers utilised autopsy, the results suggest that the majority of autopsy examinations were of TEBA registered mineworkers.

From the low numbers of in-service mineworkers utilising ODMWA autopsy, it can be argued that ODMWA utilisation by other mineworkers (not registered with TEBA and former) could be tripled. The 30-46% autopsy examination of in-service mineworkers found in this study was less than found in other studies. In a retrospective cohort of 1 950 HIV positive and 6 164 HIV negative gold mineworkers Murray et al (2007) found that 70% of in-service mineworkers who died in one gold had an ODMWA autopsy examination. According to Nelson et al (2009), autopsy service was utilised by of in-service mineworkers and by many former white mineworkers and few former black mineworkers. The reasons for the differences in utilisation of autopsy in this study and these two other studies are unclear. It argued that based on this study's results, that although the utilisation figure was high in the HIV study it could not explain the low utilisation found. One possible explanation for the difference could be the use of TEBA registered deaths to estimate in-service non-utilisation of autopsy which showed that the number of NIOH autopsies has declined steadily over the 10 years; and that this must be consistent non-utilisation because every year, the number of NIOH autopsies is less than the number of TEBA deaths. The underutilisation shown by TEBA deaths is an over-estimate because TEBA deaths do not include former mineworkers and non-TEBA deaths.

The non-utilisation implies that either the obligation of ODMWA on health practitioners to request consent from families was not being carried out or the families declined to consent. It

could also imply that the health practitioners and families of mineworkers were unaware of their obligations regarding ODMWA autopsy. No published literature that could explain the non-utilisation of autopsy by in-service mineworkers eligible for ODMWA autopsy in all commodities was found.

Further research is required to establish factors contributing to non-utilisation of ODMWA autopsy examinations by in-service mineworkers and the perceptions of mining health practitioners, organised labour and management to ODMWA autopsy.

6.12.3 Contribution of ODMWA autopsy to compensation

Following autopsy examination, 311 new cases of occupational lung diseases in the first degree category were diagnosed during 2001-2010. Similarly, 2 426 new cases of occupational lung diseases in the second degree category were diagnosed. The study found that during 2001-2010, each family of the 311 mineworkers found to have occupational lung disease in the first degree would have received an average of \$8 750. Similarly each family of the 2 426 mineworkers found to have occupational lung disease in the second degree categories would have received an average of \$12 907.79. Additionally, each family of the 59 cases who were upgraded from first to second degree category following autopsy examination would have received an average of \$5 250.

The ODWMA provisions have the potential to contribute to short term poverty alleviation. Short-term poverty alleviation following compensation of occupational lung diseases has been reported (Stewart, 2007). According to Stewart (2007), an average-sized household of seven with an income of \$250 per month was able to survive on food expenditure of \$161-

\$262 per month. These families were claimants from the Asbestos Relief Trust and compensation assisted them with immediate short-term relief from hunger (Stewart, 2007). The author argued that the relief was short-lived due to the extent of their poverty.

If assumptions were made that Stewart's (2007)' findings on financial spending on basic needs such as food person per family of seven members were similar to that of mineworkers compensated following ODMWA autopsy; households that received \$8 750 in compensation would have had sufficient money to buy food for 29-47 months. Similarly those who received \$12 907.79 and \$5 250 could have managed to buy food for 49-80 and 20-33 months respectively.

Further research to quantify and establish the contribution of ODMWA compensation to poverty alleviation by recipients and their families is required.

6.12.4 Estimated loss of financial benefits due autopsy non-utilisation

The estimated loss of financial benefits due to autopsy non-utilisation were calculated using new occupational diseases diagnosed during 2001-2012, assuming that the proportion of mineworkers found with occupational lung disease would remain unchanged following autopsy. During 2001-2010, an additional 355 and 2 769 families would have been eligible for an average compensation of \$1 185 891.70-\$1 743 937.50 in the first and \$20 596 514.45-\$30 389 398.78 in second degree categories respectively if autopsy examinations had been performed.

If similar assumptions that were made for those who were compensated following ODMWA autopsy compensation and the cost of food requirements, each of the 355 families of the mineworkers who did not undergo autopsy missed \$8 750 in compensation for occupational lung disease in the first degree category and 29-47 months of food supplies. Similarly, due to non-utilisation, each of the 2 769 families missed \$12 908 in compensation for occupational lung disease in the second degree category and 49-80 months of food supplies.

These calculations under-estimate the true losses because the number of deaths in non-TEBA registered (in-service mineworkers) and former mineworkers are unknown and are not included in the calculations.

Although money is only one aspect of defining poverty, the compensation award can be to eleven times that of the mineworkers' monthly salaries (Hlekiso et al., 2010), and the awards have been shown to offer short-term financial relief to families of deceased mineworkers, for example, settling debt (Stewart, 2007). According to Stewart (2007), compensation also raised households' medium to long-term living standards by contributing to the purchase of house appliances, for an example, furniture, and long-term improved standards of living by investing in education and livestock.

However, compensation does provide for loss of long-term household income following premature retirement or death, hence effective dust control strategies are required.

6.12.5 Characteristics of deceased mineworkers (N=52)

Characteristics of deceased mineworkers who did not have autopsy were described to tentatively identify factors which could have inhibited autopsy utilisation. Of note, 96% of these mineworkers died at home compared to only four percent who died in hospital; and 63.5% were previously submitted to MBOD. The majority (70%) of those who were previously submitted were certified as suffering from current (active) PTB which was considered by the MBOD to be contracted within 12 months. This certification meant that they were either on treatment or waiting to be resubmitted to MBOD for re-evaluation. PTB was also recorded in the death certificates of those who were previously certified TB only (65%) by the MBOD. Unlike other studies which found that mineworkers were diagnosed with PTB after leaving the mines (Girdler-Brown et al., 2008; Roberts, 2009), this study found that mineworkers left the mines while either on PTB treatment or before they could be submitted to the MBOD for re-evaluation. It is not known why mineworkers were not re-submitted to the MBOD, but for whatever the underlying factors, poor awareness of ODMWA benefits by mineworkers, their families and health practitioners is probably one explanation.

Dying at home could also have may have impeded access to autopsy services by families because of the distance between the place of death and the closest hospital or forensic institute. Other studies found that dying at a place other than a health facility impacted clinical autopsy utilisation negatively (Waldhoer et al., 2003). According to Waldhoer et al (2003), autopsy rates decreased as distance to the autopsy facility increased, even when adjusted for other important variables such as age, sex, cause of death and family status. A possible explanation was the cost of transporting those who died in private residences or nursing homes, especially chronically ill patients, and the required pathologist's

reimbursement (Lindström et al., 1997, Charlton, 2005). Reimbursement of pathologists may not be relevant to mineworkers dying at home because a provision in ODMWA was made for the MBOD to pay for the services of the pathologists and for transportation of the body for the examination. There have been no studies on the impact that dying at home has on ODMWA autopsy. Further research is required to investigate impact that dying away from hospital has on ODMWA autopsy for appropriate intervention that could increase utilisation by mineworkers and their families.

The study also found that many of the deceased mineworkers died before the age of 50 years (52%) and a further 12% before the age of 60 years. Twenty five percent of these cases were less than 30 years of age, which was younger than the mean age of mineworkers at ODMWA autopsy, while 17% was between 40 and 49 years, which were similar to the age of mineworkers who had autopsy examination (Ndlovu et al., 2008). In 2008, the mean age of black men at ODMWA autopsy was 48 years, as compared to the previous four years when it was around 44 years (Ndlovu et al., 2008).

While it could not be established from the records that the age of the miner at death may have inhibited autopsy utilisation, other studies have argued that if death occurred before 50 years of age, most relatives will give consent to an autopsy if it was requested by the clinician. However, autopsy consent will not be granted if the deceased was considered to have suffered enough (Oluwasola et al., 2009).

Deceased mineworkers in whom service history was recorded (64%) had mining service of at least a year yet none of them utilised autopsy even though ODMWA stipulated that any

mineworker with a mining service record of twelve months or more is eligible for ODMWA autopsy. The reasons for not using autopsy could not be deduced from the quantitative findings. However, cultural beliefs that the body will be mutilated during autopsy, lack of knowledge about the procedure and beliefs by some relatives that the deceased had suffered enough were associated with refusal by relatives to give consent (Renteln, 2001; Lishimpi et al., 2007; Oluwasola et al., 2009). The reasons for dying within a short period of leaving the mines could not be deduced from the records. However, part of the explanation could be that they left the mines because they terminally ill.

In conclusion, tentative reasons of no autopsy examination appear to be associated with dying at home, recent MBOD submission, age of the mineworker, and previous and current TB infection. Further research is required to explore the influence of a miner who has been submitted to MBOD, previous TB, the age of miner at death and dying at home have on ODMWA autopsy.

CHAPTER 7: ANALYSIS OF QUALITATIVE FINDINGS

7.1 Introduction

The analysis of the qualitative data on enablers and barriers to ODMWA autopsy consent from the five groups i.e. in-service and former mineworkers, widows, relatives of deceased mineworkers and other participants are presented in the context of the themes that emerged.

Twenty one former mineworkers, eight in-service mineworkers, 21 widows and 10 relatives of deceased mineworkers were interviewed as illustrated in Figure 8. Additionally, 10 other participants comprising of three traditional healers, occupational health practitioners, one community and one labour leader were interviewed.

During the data analysis, it was important to differentiate the participants in terms of their ethnicity; distinguish whether they were urban or rural, male or female, widows or relatives, living with their families in urban or oscillating migrant workers in order to assess the effect of these factors and their associations with the emerging themes. Figure 8 presents this information.

Former Mineworkers (21)	Relatives (10)	Widows (21)	In-service mineworkers (8)	Other participants (10)
• Urban (8) • Lesotho (3) • Eastern Cape (2) • Mozambique(1) • Free State (2) • Rural (13) • Nongoma	• Nongoma (9) • Mothers (5) • Daughters (3) • Partemal aunt (1) • Virginia • Sister in law (1)	• Nongoma (18) • Lesotho (2) • Welkom (1)	• Males (6) • Urban • From Mozambique (1) • Urban (1) • Migrant • Eastern Cape (3) • Kwa-Zulu Natal(1) • Females • Urban (2)	• Traditional healers (3) • Mine health practitioners (5) • Community leader (1) • Organised labour (1)

Figure 8: Participants by category and number

Of the 21 former mineworkers, 13 were from Nongoma, which was defined as rural, and were Zulu speaking. Eight were defined as urban because they settled with their families in local townships that were close to the mines in Welkom, Virginia and Allanridge in the Free State. However, of these eight, some were Sotho speaking who were originally from Lesotho (3); others were Xhosa speaking from the Eastern Cape (2), Tsonga speaking from Mozambique (1), and Sotho speaking who relocated from other areas of the Free State (2).

Nine of the 10 mine relatives were Zulu speaking from Nongoma, one was Sotho speaking from Virginia; she was a deceased mineworker's sister. It emerged that, of the nine relatives from Nongoma, four were mothers of deceased mineworkers, while the others included three adult daughters, one paternal aunt and one sister-in-law. Widows included 18 from Nongoma and Zulu speaking, two Sotho speaking from Lesotho and one Sotho speaking from Welkom. An interview with one widow from Nongoma was prematurely aborted because she could not respond despite having signed consent to participate.

Of the eight in-service mineworkers interviewed, two Sotho-speaking women who lived with their families in Mohlakeng Township in Randfontein. The remaining six in-service mineworkers were male and spoke mixture African languages which were Tsonga (one) from Mozambique, now living in Mohlakeng, Xhosa (three) from the Eastern Cape, Zulu (one) from Kwa-Zulu Natal, and Sotho (one) from Mohlakeng. The participants were from diverse backgrounds (Figure 8)

Almost all of the mineworkers, their relatives and widows were unaware of the benefits and processes of ODMWA autopsy examination as illustrated in Table 20.

Table 19: Awareness of ODMWA autopsy

	ODMWA autopsy unknown: n (%)	ODMWA autopsy known: n (%)
In-service mineworkers	6 (75)	2 (25)
Relatives	3 (30)	7 (70)
Retired mineworkers	15 (71)	6 (29)
Widows	19 (90)	2 (10)

The themes that emerged from the study on the barriers and enablers to autopsy utilisation could be categorised into individual/family, institutional and socio-cultural perspectives as illustrated in Table 21.

Table 20: Summary of barriers and enablers of ODMWA autopsy utilisation by category and theme

Category	Theme	Which key informant	Summary of key findings	Categorise as Enabler/ Barrier/ Neutral
Individual/ family Perspectives	Dissociation of the body and soul	Mineworkers	The soul in afterlife was independent from the body irrespective of the status at death.	Enabler
	Gendered power relations	Mineworkers/ widows/ health workers	Barrier: In a cultural family hierarchical system, a widow lacks decision making power. Enabler: Gendered supremacy of the collective over the widow was reversed in the absence of the mineworkers' family of origin. Matrilineal power-households with women as heads of household gave them decision making power.	Barrier/enabler
	Unintended consequences of ODMWA autopsy	Mineworkers/ widows/ relatives	Misfortunes are caused by angry ancestors and the deceased against those who disturbs the body, for an example, give ODMWA autopsy consent.	Barrier
	Cardiorespiratory organs as a symbol of afterlife prosperity	Mineworkers/ widows/ relatives	ODMWA autopsy removes the 'engine' required for afterlife prosperity. Missing the 'engine' synonymous with 'empty box'.	Barrier
	Commodification of the body parts	Mineworkers/ widows/ relatives	ODMWA autopsy to receive compensation award is synonymous with selling of these organs.	Barrier
	Mistrust	Mineworkers/ widows/ relatives	Women were killers and witches and would not be given any information by their husbands.	Barrier
	Communication with ancestors	Mineworkers/ widows/ relatives	Ritual ancestral communication of ODMWA autopsy when the mineworker was healthy could appease ancestors	Enabler
	Mortuary services	Mineworkers/ widows/ relatives	Body from mortuary required various sacrifices for it be acceptable to ancestors and its soul to rest in peace, therefore where possible, mortuary services would not be used.	Barrier
	Age at death	Mineworkers/ widows/ relatives	The protracted illness and dying young motivated widows to consent	Enabler
Institutional Perspectives	Attitude of health practitioners	Health practitioners	To talk about autopsy removes hope from families and mineworker. To discuss autopsy when family is grieving is uncomfortable	Barrier
Socio-Cultural Perspectives	The body and the ancestral realm	Traditional healers	Barrier: Burial without cardiorespiratory organs is culturally unacceptable by ancestors Enabler: Communicating individual requests to ancestors well in advance may appease their ancestors	Barrier/Enabler

In the category “individual/family perspectives” the themes that emerged were the dissociation of the body and soul, gendered power relations, unintended consequences of ODMWA autopsy, cardiorespiratory organs as a symbol of afterlife prosperity, commodification of the body parts, age of the deceased, mistrust, communication with ancestors and mortuary services. In the category “institutional perspectives” the attitude of health practitioners to autopsy emerged as a theme. In the category socio-cultural perspectives; the theme that emerged was the body and the ancestral realm in afterlife and corroborated by traditional healers. The qualitative study findings are presented under these categories.

For easy reference, female as a gender differentiator will only be mentioned if the respondent was female with the exception of aunts, widow and mothers. Male mineworkers will be cited as in-service or former without gender reference.

7.2 Individual/family perspectives category

7.2.1 Theme: Dissociation of the body and soul

Participants who accepted autopsy believed that the soul dissociated from the body at death and became independent of the body. (The words soul and spirit were used interchangeably to denote a similar meaning). The soul was believed to be capable of conducting its functions without the body; including the protection of the living members of its family against misfortunes and playing an advisory role when consulted by them. They argued that the spirit became a good ancestor and could be reincarnated irrespective of the status of the body at death or burial. The theme emerged as an enabler to ODMWA autopsy. The following excerpts illustrate the dissociation of body and body.

An in-service mineworker from Eastern Cape (Cakata) expressed:

‘I don’t believe that being buried without lungs affects the position of an individual to be an ancestor (‘indlhozi’). The flesh rots, however, the spirit of that person remains alive and comes back to give the light to the family. The person can also appear during family dreams as a complete person and that body is no longer the flesh that was buried.’

Former mineworker from Nongoma (Qwabi) said:

‘The soul will always be complete, irrespective of whether the body is buried complete or not... It is the body that is dead... If a person is dead his spirit lives forever, that is why we

don't forget him. We often perform traditional ceremonies for him. At a certain time we even go to his grave, knowing that the body is dead tissues which have disintegrated. ...ancestors are a spirit and not flesh.....'

Some participants perceived burial in the 21st century to be modern and for them being buried with missing body parts was a norm. They described their past experiences of burying relatives soon after death and the current practices of bodies being preserved in mortuaries before burial for as long as the family could afford to keep them. According to them, the modern way of treating the body was different from olden days, and to them, autopsy was one of the modern occurrences similar to mortuary services. They argued that the modern way of managing the body could never affect the person's transition to ancestry.

Urbanised former mineworker from Virginia, Free State (Bikeni) verbalised:

'When you are dead you are dead. In our modern times, burial without organs is the same as being buried with full organs. We used to bury our deceased without going into the mortuary. This is a modern thing. Traditionally, our elders will not agree because it's unusual'.

Urbanised in-service mineworker from Mohlakeng (David) expressed:

'I don't have any problems, as long as I have stopped breathing and the spirit was out. The body no longer has any use, whether it is buried complete or with some parts missing.... being buried without the body parts like limbs is the same as being buried without cardiorespiratory organs. I don't believe that my belief is against my tradition. It does

happen that these days that we live in, due to medical advancements, a person may miss parts of the body at death. It is what you believe in.'

The dissociation of body and soul was described as a disruption of the normal integration of experiences that included consciousness, memory, identity, or perception of the environment and was a critical trait in dissociative disorders (Fisher, 2001). According to Fisher (2001), dissociation was a very contentious theme in the field of mental health because it was routinely associated with Dissociative Identity Disorder. The author argued that all human beings dissociated, with resultant adaptive, as well as pathological consequences.

The results of this study found that the dissociation of the body and soul was outside the realm of mental health illness for adaptation. The theme was in the sphere of Christian biblical scriptures which preached that the body was returned to the earth/soil at death, while the soul/spirit of the person lived forever, irrespective of the physical state of the body at death. The study found that those participants who believed in the dissociation of the body and soul were neither influenced by Christianity nor by traditional African religions. It was associated with individual beliefs shaped by their view of the body, the meaning they attached to the body and the soul, and their rational thinking.

In-service migrant mineworker (Blaai) from the Eastern Cape articulated:

'I personally believe that 'flesh' is soil. Once spirit (umoya) leaves the flesh, the flesh has nowhere to go other than back to the soil. The soul of an ancestor does not go with flesh... The ancestors are a soul/spirit. To me this same spirit is similar to that which is religiously preached..... It does not mean that when the flesh is incomplete, so is the spirit. The flesh is

dead, there is nothing much that will be done by the flesh, it is dead and stone dead, it will never come back and what remains is to bury it.'

Key to dissociation of body and soul was the belief by participants that once the soul/spirit departed or was separated from the body and the person was pronounced dead, the body and its parts were of no value in relation to afterlife. The literature reviewed on clinical and forensic autopsy did not identify the dissociation of the body and soul as enabler or barrier to clinical autopsy utilisation.

The belief by some participants that the soul had supernatural powers to control and resurrect and protects the family in afterlife implied that if the believers were in the majority among mineworkers and their families, ODMWA autopsy utilisation could be increased by awareness programmes only. In contrast, awareness campaigns (Ndlovu et al., 2010) did not increase autopsy utilisation as seen from the study results that 30-46% of in-service had autopsy examination during 2000-2010.

The belief to self resurrect found in the study was in contrast with that of the literature reviewed in which the ability to self-resurrect was lacking in some religious or cultural Hindu, Islamic and African beliefs, as these beliefs promoted the body to be sacred and was not to be dissected (Gatrad, 1994; Sheik, 1998; Campbell, 1998; Gatrad, 2001; Rashid, 2001). Also, the study findings were in contrast to those found in Christian belief and preaching in which ancestral beliefs were not promoted.

There was acknowledgement by some participants acknowledged that upon their deaths; a final decision to consent would be a collective from their families, and this decision dependent on the attitudes and beliefs of the members collectively, as illustrated by the following two quotes. The contrasting views highlighted the complexity and the challenges on ODMWA autopsy utilisation that should be considered when intervention strategies are formulated. In certain cases where the dissociation occurred, it was found that there was a rational belief that for those who lived in peace with their families, there should not be a problem in giving consent to autopsy.

Former mineworker (Sukazi) in Nongoma explained:

'The soul will always be complete, irrespective of whether the body is buried complete or not. When a person dies with incomplete issues and problems with his departed ancestors or his parents died unhappy about him or he left bad issues with the surviving relatives (unhappy children, parents), he can leave a complete body, but his soul fights with the souls of those who went ahead of him. His soul is troubled, then he comes back to trouble those he left behind. It is because he is not rested from issues of his life and not because of missing body parts...The bad luck that others talk about on the person buried incomplete, I disagree. This is about one's belief system in life. I live my own life within the family culture and values, we are unique. When I die my family will do things their way within what they learnt, know and believe in. They may decline because it is their belief and superstition. I don't have any superstition myself. When people do not know or understand, they fall back into superstition....'

Former mineworker (Qwabi) in Nongoma expressed:

‘I can consent to autopsy because the body rots and is buried. My family may disagree. The soul is complete, even if someone is maimed one way or the other. This has never changed in culture; it has always been known that once the person dies and the soul leaves the body, the soul can’t draw back the flesh (body) and vice versa. This is not modern; it is a traditional concept which is based on knowledge, understanding and one’s belief system. It is a belief rooted on my traditional values more than the born-again Christian concept which may vary. I am not a born again. For an example, you die beheaded, you can’t glue the pieces together, but the spirit is complete, not beheaded (issue of completeness, tradition)’

The ODMWA and the National Health Act (NHA) require of the family to request autopsy examination on their loved ones or to consent if requested by clinicians. The decision to give consent for autopsy dependent on the hierarchy of family structures and power dynamics, beliefs and attitudes of the members. According to participants, ODMWA autopsy was still dependent on the individual’s attitude to the procedure and where there was conflict among the members, the procedure would not be carried out unless it was written down prior to death. Participants believed that relatives would carry out the deceased’s wishes made in life as illustrated in the following quote.

In-service urban mineworker (David) from Mohlakeng Randfontein said:

‘You see my parents are dead....they are my ancestors, should they have wished that their organs be removed whilst still alive, we would have granted their wish and they will still remain our ancestors.’

The dissociation of body and soul was found to be an individual choice, shaped by social action, in which the individual defined the situation, in this case ODWMA autopsy, and gave meaning to it. This theme did not emerge from interviews with the widows, relatives or other informants (health workers, traditional healers, community and organised labour leaders). This could be partly explained by the fact that they were not eligible for ODMWA autopsy; hence the dissociation would not be an anticipated experience.

In conclusion, the dissociation of body and soul was an enabler for ODMWA autopsy utilisation, however, to minimise the possibility of consent being rejected by ‘the collective family’ because it clashed with their own beliefs, the mineworker would need to communicate his/her intention to the family and ancestors in advance.

7.2.2 Theme: Cardiorespiratory organs as a symbol of afterlife prosperity.

There were participants who did not believe that the body and soul were dissociated at death. According to them, the cardiorespiratory organs were an engine required for prosperity in afterlife, reincarnation and resurrection and therefore rejected ODMWA autopsy. They argued that being buried or burying someone without cardiorespiratory organs was similar to burying an ‘empty box’. The respondents argued that other organs were incomparable to cardiorespiratory organs which they affirmed to be critical for life after death as illustrated by the following excerpt.

A former mineworker in Nongoma (Mgolothe) explained:

‘Let me give you an example of a car. If you remove an engine, it can’t move even if it has wheels. The limbs are small things compared to the cardiorespiratory. These organs are the

engine of the person (emphasis). I don't like this autopsy and will not agree to it. I believe when a person is dead, is asleep and autopsy is disturbing his/her peace. It is troubling the person.'

In contrast to the findings of this study which cardiorespiratory organs were specified as vital for transition to ancestry, the prohibition to ancestry from the literature reviewed did not specify the missing organs associated with prohibition to ancestry (Kometsi et al., 1999, Kalish, 1980; Mutwa, 1998).

They also argued that it was only religious people who believed that the soul can survive in afterlife without the body and expressed that burial without cardiorespiratory organs precludes a person to be accepted by ancestors or become a good ancestor. The association of the cardiorespiratory organs with resurrection into a new body in afterlife was a barrier to ODMWA autopsy as illustrated by the following quotations.

A former mineworker in Nongoma (Masondo P) reiterated:

'The soul is cardiorespiratory and without these organs, the soul is no more. The body should be complete at burial which relates to the whole soul....Those who are religious believe in soul outside the body. They are concerned about soul not the body; they can do anything about the body. Religion motivates one to take care of the soul more than the body, and rationalise that it is ok for this autopsy. Only modern people (young people) agree to autopsy.'

A widow in Nongoma (Nene) stated: *'I will not agree that he gets buried without heart and lungs....It is difficult... Money can't motivate me..... Mine is cultural and a belief that it is not correct to bury without these organs. I believe that it is sin to God. It is a sin that when God comes back to this family and He finds that he was buried without organs. The body should be complete. Amputation done in life is better; this one is not related to money.'* The belief was associated with resurrection and the need of the person's old physical body and his/her cardiorespiratory organs. This dual (cultural and Christian) belief is in contrast to Christian belief that the old body with its imperfections will be replaced by a new one.

Some participants recalled deaths of family members who were mineworkers and described how their surgical wounds would be explained by mines. They explained that following the mines' explanation, they would communicate with their ancestors using rituals to announce the surgical wounds and offered sacrifices to appease them. However, they still rejected ODMWA autopsy because of the 'empty box' symbol they attached to it and believed that in this case, rituals would not appease ancestors.

A former mineworker in Nongoma (Ndwandwe) reported:

'In western religions there was acceptance that when a person is dead, he left an empty box behind and his spirit lives. I believe that as long as I am incomplete because my heart and lungs are left behind, there will be a problem. We used to get our relatives from mines that have been operated on and incomplete. At that time we would be told and we would then sacrifice a cow to close the wounds.....'

A former mineworker in Welkom (Thaele) said:

'Many people did not use autopsy because they did not know. Our comprehension is not the same. Burial without these organs excludes you from being an ancestor. You don't have these machines (cardiorespiratory) to aid in afterlife and this is unacceptable. You will not communicate with the family in their dreams. This ODMWA autopsy is different for legs and limbs are not machines and they are far from the machine and are not the engine itself.'

Some participants argued that the cardiorespiratory organs were used to define the physical person both in life and in afterlife and their omission at burial made ODMWA autopsy unacceptable. Participants believed that each individual had a purpose in afterlife and as such must retain his/her earthly physical form and of his/her 'engine'. The omission of the 'engine' at burial was believed to give 'birth' to a callous ancestor. The following quotations exemplify on-site ODMWA autopsy examination.

A former mineworker (Mawisa) from Virginia, in the Free State, expressed:

I don't agree with the autopsy...a person is these organs. I can be checked where I died.....why send them away.....my cardiorespiratory can't be sent away....because as people we have our cultural laws and beliefs. When we have our culture and you are buried apart, the ancestors will not like it. Even if I can agree, the family won't agree that I am buried without these organs.... I can be checked at death but to be buried without organs is not correct. If the family consents when the person has died, he can come and haunt them and cause them misfortune while looking for his scattered parts. Traditionally we suffer from these decisions.... If someone dies of a serious accident in my family culture, the body is not

allowed to get into the family yard because getting inside the family yard will result in misfortunes for the family. All services/funeral proceedings/rituals happen outside and are taken to the graveyard for burial.' Autopsy could be done on-site and the cardiorespiratory organs returned to the body for burial. The acceptance of autopsy examination on site presents an opportunity to increase ODMWA autopsy examination and should be considered when intervention strategies are developed.

Some respondents believed that removing the cardiorespiratory organs would disturb a peaceful deep sleep.

Urbanised in-service mineworker from Mohlakeng and originally from Mozambique (Moyani) said:

'My belief is that this (resurrection) will not be possible as this person was buried without complete parts.... these organs are the engine of the person. I don't like this autopsy and will not agree to when a person is dead, is asleep and autopsy is disturbing his/her peace.... it is troubling the person and I will therefore not agree to this.'

The 'empty box' and associated aftermath beliefs were corroborated by the traditional healers who also observed that misfortunes often led families to consult them. There was a dearth of information on the perceptions or attitudes of traditional healers to autopsy from the literature reviewed. Traditional healers perceived autopsy examination to be a western model of finding the cause of death which they believed did not assist the families. The traditional healers corroborated beliefs that the physical form of the deceased was reunited with the soul in afterlife in order to serve the family. During consultation by the families who were

encountering misfortunes, traditional healers asserted that the cause of the families' misfortunes were unhappy ancestors and were able to assist them by following a ritual dialogue with the ancestors. The following extract illustrates the attitude and beliefs of the traditional healers to autopsy.

A traditional healer (urban) reiterated:

'Autopsy is not in our vocabulary as people. We believe that when a person dies, there should be no organs/parts removed. The person should be buried whole, so that when we reunite his body with his spirit, the body should be complete. We believe that when a person dies, he will wake up. If he appears in a picture, he must be complete. Now if he has no lungs, I have a serious problem! You see, I have been involved many times with families, either in thanksgiving rituals or communications with their ancestors. The serious problem and 'block' is when there is a complaint by the ancestor whose organs were removed or who was buried in a site not requested in life. In other words, the family may not even know that their loved one's organs were removed. However, as we do our work and communicate with the 'departed', we are able to pick up that the old man or woman is unsettled because of missing body parts.'

Traditional healers believed that all people should communicate their intentions to their families and ancestors in advance to minimise the efforts put in understanding messages from their ancestors. The traditional healers explained that many families suffer from unscrupulous traditional healers who could misinterpret the ancestral message and thus fail to address the ancestors' requests, causing the family more harm.

A traditional healer (rural and urban) re-iterated:

It is useless not to talk about death and state our positions because there is not any one of us that does not know that death will occur. People should use every available opportunity to communicate their wishes so that their families don't suffer trying to address the missed messages through the inyangas and traditional healers. There is a possibility that a person who suffers misfortunes will get a wrong nyanga who tells him/her wrong things and thus prolongs the suffering. Meanwhile, when the desires that should be carried out when death occurs are communicated during life, for example, where the grave should be and the position of the body, it saves all concerned from mishaps trying to find out what should have been done correctly. It should be noted that there are no jokes on matters of how one wants to be treated at death and burial. Autopsy for a mineworker is unacceptable. Yes, those who believe that are modern people. There those who accept cremation and indicate to their families that when they die, they should be cremated. These are the same people who could accept autopsy. I believe this can cause a problem. Yes, whichever way you look at it, it causes problems. You see, a deceased person is still the same whole person he was during life. He may be not breathing; however, he is still the same person. It is the same as troubling him. It is not right to cut him.'

The organised labour leader also corroborated the 'empty box' belief which was associated with cultural beliefs. Additionally, the lack of awareness and difficulty in accepting the process was believed to be worsened by the lack of compensation guarantee as illustrated by the following citation.

Organised labour leader and former mineworker:

'I have heard about autopsy in ODMWA and that it is done through consent. I personally believe that the ODMWA constraints are related to lack of education from both the employer and trade unions that do not provide awareness among the mineworkers, so that the mineworkers know about this and are in a position to inform their families if they wish to do so. Secondly, I believe it is a cultural thing. For example, as a Xhosa man, I find the concept of being buried without my heart and lungs difficult to agree to. What is worse about this process is that there is no guarantee that the organs will be put back into the body to be buried.....culturally, people are buried with all organs that are present at death'.

While the 'empty' box and associated aftermath beliefs were barriers to autopsy, enabling conditions around them existed, creating opportunities to increase acceptance of autopsy examination among believers. Firstly, communicating the intention for autopsy examination by mineworkers to their families and ancestors in advance was believed by some participants and corroborated by traditional healers and organised labour leader to appease ancestors. Secondly, examining the organs on site and return them for burial was more acceptable compared to permanent organ removal. In contrast to dissociation of body and soul which was limited to mineworkers (in-service and former), the belief in 'empty box' was emerged from most participants in the four groups excluding the 'others'.

7.2.3 Theme: Gendered power relations

Participants expressed the gendered power relations in their families in which they said that wives lacked decision making power to give autopsy consent. According to them, during the bereavement period, widows observed a period of mourning and would be excluded from

funeral and burial rituals and decision making. During this period of mourning, a widow's communication and contact with other family members would be limited until a pre-determined period and the person would be ritually cleansed. Some female respondents argued that even if they agreed to an autopsy examination, an opportunity to consent would have been missed because of the cultural restrictions and taboos surrounding mourning. They articulated that a man's body belonged to his birth family and not to his wife or adult children. This implied that a man's patrilineal relations were stronger than his wife's. In the literature reviewed, gendered relations did not emerge as issues that contributed to clinical autopsy utilisation.

ODMWA autopsy, in line with forensic autopsy legislation both locally and globally, required consent from immediate adult family members. This might include extended adult family members, for example, brothers and uncles, who legally have rights over the body. There is a disconnect between ODMWA autopsy benefits and the requirement of consent. It is argued that the traditional family cultures and gender dynamics were ignored. These cultures and gender issues founded on paternal power, inhibited women (wives) who related to the deceased through marriage from giving their consent to an autopsy. Consequently, this lack of decision making power in certain instances gave rise to fears by widows of their husbands' ancestors as illustrated by the following quotes.

A widow (Makhatini) in Nongoma said:

'Autopsy, I will agree to find the cause of death... however, in my situation, he belongs to his family who has a final say..... I had no power around the death and burial. You are only shown his body after the elder family women dressed him and they only show you his face. You are told not to look at face for long....you are in mourning. You will know what is

happening or get updates only if you have someone who really loves you..... You still don't have any power to question anything. My husband died in hospital and I took him there (silence)..... He died the following day and I was sent home to mourn him...yes as a wife you mourn.....'

The complexity of gender dynamics during mourning implied that in patrilineal relations, the requirement for autopsy consent excluded the very dependants (wife and children) who were expected to benefit from it. Women said that they would be inducted into the husband's family culture including ancestral expectations, roles and rules including communication when they got married as exemplified in the following citation.

A widow (Magwaza) in Nongoma said:

'In my culture we believe in ancestors. I was also brought up that way. My father would not consent to any organ transplant because he believed that those had disease, especially in modern times. When we get married, we are told what the ancestors of that home do not agree with. This will be one of them'

The lack of decision power also extended to mothers, further affirming the paternal power superiority on matters such as death. The following excerpt illustrates this view.

The mother of a deceased mineworker in Nongoma who was a bachelor (Jiyane) explained:

'He was my son. I didn't have decision power over his body. His ancestors will demand the body parts. They will not agree to this. Even when the individual has lost a finger or undergoes an operation, a ritual is performed to announce these occurrences to ancestors. I

am glad I do not have a child who will work in the mine that I have to make this decision. He was my last son.'

A widow (Ntuli) from Nongoma said:

'I do understand that the person has passed on and the lungs may be diseased...however, in my situation, he belongs to his family who has a final say and their answer will then become final.'

While the wives did not have decision making power to give consent, patrilineal powers extended to paternal aunts who were also privileged to communicate with ancestors as shown by the following citation.

A paternal aunt of the deceased mineworker in Nongoma (Mabaso) articulated:

'My brother's son died at the age of 31 years leaving a small child. He came back ill..... If I had knowledge about the autopsy, I will consent..... If I know where the parts autopsy went, I would have agreed....I will inform him and the ancestors through the sacrificial killing. I will consent because of the purpose and there is possibility that his kids, who are currently suffering financially, get a chance of compensation..... It is now the issue of the person not discussing the laws with the family and the doctors not talking. It is the current myth of young ones to believe that they will live longer than ugogo (grandparents)..... They do not communicate'.

The study found that wives who stated that they had decision powers to give consent to ODMWA autopsy were those whose in-laws, including uncles and siblings, were deceased or

lived outside South Africa. In such cases, the wife assumed responsibility and decision powers to manage the funeral as shown by the following quotes.

A widow in Nongoma (Magaiya) said: *'I had the power to consent because he was living with me. I don't know if his family was around.'*

In certain cases where the mineworker's parents were deceased and the couple had been living as modern nuclear family and the following passages illustrate this.

A widow in Nongoma (Shandu) said: *'I will consent. You see, I am alone and his parents died earlier. If it is to help me and my kids and really understand that his disease does not relate to mining.'*

Another widow (Dlamini) commented: *'I had the power to consent because he was living with me. I hoped to find the cause of death. I had the power to consent because my in-laws were dead.'*

The study found that some widows in a traditional African family unit did not have decision making power over their husbands' estates, including that of decision making over their funerals and this was corroborated by health practitioners. Additionally, the concept of consent within the African tradition as experienced by some of the health practitioners was perceived to be different from that of western culture. Based on their experience, they described how some adult patients would never give consent to a surgical procedure or

medical treatment (for an example, blood transfusion) before consulting with their families, as reflected in the following quotations.

Occupational health practitioner and manager at a mine expressed:

‘You won’t understand, but even with a life-saving surgical procedure, an adult black person may not consent immediately, but will request to consult with family prior to consenting. This is so in many black cultures. Western medicine will never understand this... Some believe their body parts are being sold. It is the same as consent for an operation. Unless there is a knowledgeable someone in the family who they trust and can explain the processes.’

A community health nurse practitioner said: *‘I find that even now, when information is given to the patients, they still want to consult the elders first before making a decision.’*

The statement supported what was recorded by the participants that communication in the African tradition extended beyond the individual to include other family members and the ancestors through rituals.

The literature reviewed did not discuss how descent through the male or female line influenced autopsy utilisation. In this study, participants argued decision making by a wife was considered by the family to be a minor and this view was supported by the experience of health practitioners.

Occupational health practitioner and manager at a mine (female):

'Wives are still subordinate. They must sit on a mat, be covered, while the elders make the decision. Usually it's brothers, uncles who have the final words. The wife is never heard. In my experience, I have not come across a situation in which the mother of the deceased has decision power on her son's burial arrangements....'

The traditional healers corroborated patrilineal power relations described by participants. According to them all African traditional practices were similar yet differentiated by the manner in which they were practiced and the sacrificial systems applied. According to them, gendered power dynamics were not regarded as subordination because women had defined roles. They rationalised that a man had different role as the head of the family from that of his wife and his mother because links to paternal relations, as illustrated by the following citations.

A traditional healer (urban) stated:

'You must remember that a woman was 'nwananyana'(a girl) before she became 'mosadi'(woman) and later on 'mme'(mother). The word N'wa'(a title before maiden surname) means you belong or are a child from another family married to your new family and you have your own power as a wife. For an example, the fact that you are called mma-kgathabo---, means you have been given the power over certain decisions because you gave birth of Thabo. If I die my family tradition and what is required is known by my family, they can inform my wife. They (my family) know which songs must be sung, the messages to be said to my ancestors (sic communication) and the rituals that must be performed in line with the family tradition and culture. The wife will not be able to sing this song for me, as she will not know the song. My wife would join after my family has completed the task. There are

certain lines that must be toed, there is an aunt (father's sister) who is female, the uncle (father's brother). Rakgadi is the sister and an aunt to my children...and knows the family tradition (not of the family she married into).

Another traditional healer (urban) stated:

'In our culture, when a women is married, we pay through 'cows' and do not mention money. The cow's synonym relates to dowry that is to unite the two families' ancestors. When we require her services as an aunt (paternal), we follow the normal channels of formally requesting her from her marital family. If her new family declines, we will accept and we will not force them. At this new family she is the mother of that family who builds the new family through procreation (tswala). She remains the paternal aunt (mikgadi) of her birth family and the mother to the new family (marital). Wife (Mosadi) has her power, which she has been given in this new family and proclaimed publicly. Please note that a woman has a bigger role to play in a family and in society....For an example, when I die my wife knows what should be done and where I should be buried because we have been communicating and she knows. She will discuss this with the family elders.Now in modern times....' The citation emphasises the supremacy of patrilineal power relations yet recognises the importance of communicating one's intentions in advance.

Some respondents explained how their mother in-laws assumed decision power in the absence of their father in-laws and uncles. According to them, the mother in-law (ugogo) ran the household with her remaining adult sons in second command. This implied that decision power was dynamic and could change depending on the family circumstances. The followings excerpt illustrates this.

A widow from Nongoma (Ntshaba) said:

'I would consent to autopsy if I had power and if there was need and necessity..... I did not have any decision powers at funeral arrangements. The decision power was with his mother (ugogo) and brother. They would make decisions and I would hear from them whether I like it or not. I stole a view him (seeing) when they dressed him...I was not allowed to see his body...Ugogo continues to be in charge... I and my children live with her '

The emphasis on cultural induction of women was corroborated by the community leader from Nongoma who expressed the following:

'Traditionally, the wife does not have any power.... The power is with the men more than the mother.... If the man refuses, there is nothing the wife can do.... even if he is dead, if the in-laws refuse she has to toe the line. If I refuse, a dispute arises..... If you do something that they or he did not tell you or hid information something bad can happen to you.....anything from losing a limb to almost one of her children dying. Even if you perform sacrifices, they will not work until she confesses whatever she did without permission (she consented to autopsy).... Even if she confesses, the price that she will pay is higher..... for an example, a specific cow as compared to a goat.... for she did not listen to the family's traditional laws.'

Patrilineal relations were found not to be conducive to ODMWA autopsy examination because consent could be withheld by the family of the deceased mineworker if their beliefs clashed it and the decision makers were uncles as opposed to paternal aunts. Matrilineal relations in the absence of paternal relatives on the contrary were found conducive to autopsy examination. Also, the absence of the deceased mineworker's family created an opportunity

for the widow to give consent. This theme emerged only from the widows and relatives of the deceased mineworkers who were all women and was corroborated by traditional healers and health practitioners. The importance of communication by the mineworkers to their spouses on their intentions was asserted by traditional healers to be a vehicle to ensure that their expectations are met when they died.

7.2.4 Bad death

Some participants believed that ODMWA autopsy would assist them to find the cause of death and bring closure to what they considered a bad death. They defined bad death as dying during one's prime productive life (before the retirement age of 60 years) after a protracted period of ill health and leaving behind young children and a spouse. Another element of bad death as described by participants was dying after being discharged by the mines on the grounds of ill health. They described their expectation and hope that the mineworker would be cured and be able to resume working, either at the mines or in other industries. Bad death was also described by some participants as death occurred after a short severe illness which they believed that the person suffered immensely. The following extracts capture the participants' notion of bad death:

A widow from Lesotho (Molupe) stated:

'My husband worked 28 years at the mines.... The MBOD certified him TB only, but he said he never had TB. He became stronger, but later got worse.... He had been working for a long time being sick. We did not know what was wrong. He never told me what was wrong, until recently when he died and I was told of TB...If I was requested, I would have agreed to

establish what was eating him or what was wrong and compensable. Now they (mine) are saying that the disease he suffered from was not compensable.....'

A widow from Welkom (Mofokeng) said:

My husband was submitted to MBOD and was certified to have PTB only. He at the mines for 21 years but retired due to ill health..... I still don't know the cause of death, as I was never told anything....and we never discussed his sickness.... I would have agreed. We still do not know what was wrong; I would want to find out what was wrong if autopsy would have helped...'

A widow (Ndaba) in Nongoma explained: *'My husband died in 2003 of what I was told was TB. He has been sick for a long time, 'drying out' slowly to a point of being dry when he died..... We went up and down consulting doctors. He ultimately died on his way to hospital and he was still employed. When I asked what was 'drying him up' he said he did not know, sometimes complaining of his joints, or headache. I am always asking myself what killed him. In the olden days autopsy was done on people working in the mines without us being asked. We were told it was the law and it must be done.... He was taking TB treatment at the time of his death. I would have agreed to autopsy because I want to know what ate him. His children also want to know. He died looking for compensation from the mines... It may be a modern thing, but the cause of death remains important.'* The description by some participants revealed a picture of mineworkers who returned home due to ill health and required further care by their spouses and families.

Participants argued that although compensation was not guaranteed, they would find closure by establishing the cause of death as expressed in the following passages.

A widow in Nongoma (Makhatini):

'I will agree to find the cause of death. I still do not know why he died. I will agree not necessarily for the possibility of compensation but to find the cause of death. I will not have a problem of burial without organs. I have heard about the ancestors' thing during a death, I don't believe in it. He died in hospital.... I took him....the following day he was gone (died) and I was sent home to mourn.'

A widow in Nongoma (Xulu):

'I knew about ODMWA autopsy because I worked in the mines. I discussed the autopsy with family (in-laws) but they refused. I did not have the power. The family asked me what I was going to do, should I find the cause of death. It was not for money but to find out what was the cause of his death. He was a miner from 1971 until his death in 1979. The hospital staff told me that he had TB. I asked the hospital where he could have contracted the TB.....even now I still worry. The last child in 1979 just before he died still wants to know....'

Another mother (Jiyane) said:

'My son worked in the gold mine until he died in 2004 at the age of thirty-one. In his death it was noted that he died of TB. There had not been any discussion about compensation. I know the first time he was cured of TB, but the second time it killed him. You know, men will never tell you everything. I will consent to autopsy because I will want to find the cause of death

BUT the organs must be returned for burial. Even if my son wrote down his wish, I will not believe it that he wanted me to allow him to be buried without his organs.'

The theme emerged from widows and relatives only and was associated with the mineworker returning home ill and deteriorated while being cared for by the family until demise. Bad death was also associated with TB as the cause of death and yet according to the participants was not compensable. According to Clark et al (2007) an increasing number of migrant workers of working age became ill and returned home from urban areas where they worked, therefore shifting the burden of care for their terminal illnesses to their families and the rural public healthcare system.

Although widows and mothers of deceased mineworkers were deprived of decision making powers to give autopsy consent they accepted ODMWA autopsy to elicit the cause of death.

7.2.5 Theme: Unintended consequences of ODMWA autopsy

Another theme which emerged from the interviews was that of the unintended consequences of ODMWA autopsy. This theme was contrary to the ODMWA intent which presupposes that those that are affected would view its compensation benefits and accede to consent by virtue of lack of policy that guides those that might be apprehensive about the procedure. This theme was in contrast to the ODMWA autopsy examination's intent to award compensation benefits to the beneficiaries of those certified with occupational lung disease. There was no policy to guide those who might be apprehensive about the procedure. Notably, is the recognition by the legislators that benefit medical examinations of a miner in life may not be sufficient to diagnose occupational lung disease through mandating with consent from

family members autopsy of deceased miners under ODMWA who were occupationally exposed to dust miners irrespective of the cause of their deaths for compensation to be awarded to their dependants. It was found that the mandatory intent had unintended consequences, as was perceived by a majority of participants (n=34). These consequences were fear, afterlife destructiveness, including misfortunes, ODMWA autopsy as a careless, selfish or scary process, ODMWA autopsy- mortuary.

From the participants' description of these unintended consequences, five sub-themes that emerged were fear, afterlife destructiveness including misfortunes and ODMWA autopsy as a careless/selfish (yamabomu) act.

7.2.5.1 Fear

Some respondents explained that they feared thinking and discussing ODMWA autopsy when the mineworker was alive and more so at his/her death. Some were even fearful to discuss their own beliefs on autopsy because they believed that this could result in their own deaths or the death of someone in their own families. Respondents were also fearful of the vengeance of the deceased and of ancestors. The study found fear among those who were expected to have autopsy dialogue with the health practitioner, and to give consent for autopsy and explain the procedure to other members of the family, as illustrated in the following quotations from interviews:

An in-service mineworker from Nongoma and a traditional healer (Masondo C) said:
‘Talking about death is not a usual or a common thing, however ...even if it is a common occurrence..... The body should be complete at burial which relates to the whole soul. What

was done in the family for ancestors is no longer done. If my family agrees on mine, it will be their woe. If autopsy is done without family consent I won't know of misfortunes, maybe that is why many families will forever have unexplained misfortunes.'

It is evident from what this miner said that his family would be afraid to give consent to autopsy, even if they knew the benefits because of the anticipated wrath. His circle of influence indicated that his beliefs and attitudes towards ODMWA autopsy rejection have a wider influence in his community.

Although participants indicated a reluctance to give consent, they did not attribute misfortunes to ODMWA autopsy when the procedure was performed without the family's consent. There was a dread of giving consent to ODMWA autopsy services in cases where there was a belief that the ancestors or the deceased would demand that they returned the removed organs. The fear of giving consent was also related to the belief that the deceased's soul would not rest in peace until such time that the cardiorespiratory organs had been returned for burial with the rest of the body. Most of the participants feared that they could meet the demand by the ancestors and the deceased to return the organs because they would not know where the organs had been taken to and believed this could anger them causing severe misfortunes to them and their families. This finding contrasts with those in the literature reviewed in which fear was associated with the perception that the body would be mutilated (Lishimpi et al., 2007; Oluwasola et al., 2009).

A widow (Masondo C) in Nongoma said:

'This autopsy is not right. The person can trouble the family saying that I want the organs you left behind. He can come back looking for his organs. He can bring bad luck to the family.'

A widow from Lesotho (Lekoro) commented:

'I am afraid, the family will be afraid. He will be angry to leave his organs behind, he will not rest. It is not ok unless his organs are returned for burial. It is said that without his cardiorespiratory, he can't be an ancestor.'

Some would actually prefer quality medical examinations that would ensure that benefits were awarded in life, as maintained by a former mineworker from Nongoma (Mbatha): *'Even if I were to consent to this autopsy, my family will never agree..... It is better to get the money when still alive. If the family consents, that person will come to haunt them. He will kill them all, saying that he is not complete and causing to suffer, instructing them to go and collect his parts wherever they are.'*

However, there were some participants who believed that the anger from ancestors could be minimised if the mineworker communicated his intention for autopsy examination to his ancestors.

Former mineworker from Nongoma (Ntshakala) verbalised:

'In my family culture, I believe this may not be acceptable because they (ancestors) know the person to be complete at death, and now he is buried being tormented (autopsy). They will not recognise him. The scenario changes if he agreed in life because he will have

communicated his intention to the ancestor in a proper way known to the ancestors. The ancestors will not disagree with him because they will be consulted about it. However, if I am ripped open without my consent, it will be a violation of my rights. I will come and harass them (whoever gave consent) and also remove their organs. A cow will not work, because I did not agree. However, the doctors can open me to check the cause of death and return my organs back, and then it will be acceptable.'

Fear of the deceased spouse and the ancestors was also espoused by the family's defined by taboos, roles and responsibilities of women during funeral activities as summed up by the following excerpt by a rural community leader from Nongoma.

'In some Zulu family traditions, a wife can't go to the mortuary to wash him or accompany those who collect the body from the mortuary. I must be covered by a blanket from head to toe and sit in the same room with his coffin. When the family wash him and perform rituals... I am not expected to look..... There is a belief that if the widow looked at him, he could see her and thereafter will follow her after that (burial). This implied that you could follow him soon.'

The fear of giving consent to ODMWA autopsy was associated with the traditional norms of the family around decision making on funeral arrangements. Those with patrilineal links to the deceased had more power of decision over the deceased, including communication with ancestors irrespective of gender than those linked through maternal relations. They believed that their ancestors would sanction any request made to them including the rite of passage because of their privileged ability to communicate with them and this removed their fear.

The patrilineal power was verbalised by a paternal aunt in Nongoma (Mabaso):

‘If I knew about this autopsy, I would have communicated this to the ancestors because I have the power to do so. You will trouble others if you did not prepare your rite to passage with your ancestors, and communicate everything you are expected to do culturally.’

The patrilineal power associated with decision making emerged from all the groups and were corroborated by traditional healers and health practitioners were similar to those argued by van Niekerk (2000), who maintained that *‘patriarchy should be interpreted differently in western and African traditions, arguably because it was the imposition of western patriarchal colonial systems in Africa which undermined the traditional socio-cultural structures that empowered women in traditional African societies, for an example, women who acted as mediators between the ancestors and the group in ancestor cult which existed amongst some tribes.’*

7.2.5.2 Afterlife destructiveness by ancestors or the deceased’s soul

A further sub-theme that emerged was the belief that the deceased and their ancestors could inflict suffering including misfortunes to those who give consent for an autopsy examination and the retention of cardiorespiratory organs. The participants expressed that their failure to comply with returning the organs for burial could give rise to ancestors who were evil. It could also result in restless souls that would be destructive to them and their families. There was a belief among the participants that the families of mineworkers who had given consent to the procedure were experiencing misfortunes. This belief hinders acceptance of autopsy and again revealed that ODMWA autopsy procedure of cardiorespiratory organ retention required review.

Respondents expressed their fear of discussing or accepting autopsy because of their apprehension of misfortunes as they believed that the ancestors and the soul of the deceased considered the cardiorespiratory organs priceless. Some perceived ODWMA autopsy process as tormenting and deforming the body and this could cause the deceased be to be disowned by his/her ancestors because they would not recognise him/her. The anticipated revenge caused and placed the responsibility for communicating the request for autopsy from ancestors with the mineworker. In Western culture, this could be seen as planning one's rite of passage, except that in this case it was deemed appropriate if it was communicated when the individual was healthy.

A former mineworker (Mgolothe) from Nongoma said:

'He will kill them all, saying that he is not complete and has been caused to suffer, instructing them to go and collect his parts wherever they are. It is better if he himself agreed in life and instructed them or requested them to agree. It is different if the person has amputated body parts, which he agreed to and this is done in life and everyone can see. There won't be any misfortune as he will prevent them since he has given consent.'

A former mineworker (Mbatha) from Nongoma stated:

'An incomplete person at death can't be an ancestor, but a killer. The family will forever work hard to satisfy him. This is different from an accident. The post-mortem in this case is done where the body is examined and body parts are returned for burial thereafter.'

The belief that an individual whose organs are taken away could become vengeful caused the participants to reject autopsy to be performed based on their understanding of its intended value.

A widow from Lesotho (Lekoro) said: *‘I am afraid, the family will be afraid. He will be angry to leave his organs behind, he will not rest. It is not ok unless his organs are returned for burial. It is said that without his cardiorespiratory, he can’t be an ancestor.’* This statement illustrates the value that individuals attach to the organs and the fear of misfortunes that can be caused by those who were rejected by ancestors because of missing organs.

The beliefs articulated by participants that the process was a risk to them and their families because the ancestors knew that the deceased’s body was interfered with after death was a barrier to ODMWA autopsy. The theme emerged from the four groups and was corroborated by the traditional healers.

7.2.5.3 ODMWA autopsy as an act of carelessness/selfishness

ODMWA autopsy as an act of carelessness or selfishness emerged as sub-theme from the interviews and was found to be a barrier to autopsy. Some respondents believed that ODMWA autopsy was not of good assistance, but an act of carelessness/ act of selfishness (*‘into ya mabomu’*) by those requesting consent and those who gave consent. Respondents perceived medical doctors to be capable of making the correct occupational lung disease diagnosis when the mineworker was still alive. Respondents described their experiences of losing a member of their families in accidents and explained how they dealt with the dismembered body. However, they argued that ODMWA autopsy was not an accident and

the request for ODMWA autopsy consent immediately after the mineworker died was considered more selfish.

A former mineworker (Mawisa) from Virginia, if the Free State explained: *‘Autopsy is unacceptable. It happens that a person dies and organs are removed, you deal with the person’s remains like those for an example who died in exile. Bones are now returned home. This autopsy is considered a selfish act that will result in family misfortunes. The communication must take place long before the person is too ill and dying.’*

There was dearth of information on reviewed literature regarding unintended consequences of clinical autopsy as described by respondents in this study.

7.2.6 Theme: Commodification of the body parts

Some participants perceived ODMWA autopsy process to be a commodification of the body parts. The theme was not found in the literature reviewed on clinical autopsy. Commodification of body parts originated from organ donation. According to Sharp (2000), the human body and its parts were targets for commodification within a myriad of cultural settings, from slavery and other oppressive labour practices, to female reproduction, the realms of sorcery and endocannibalism, and more recently to biomedicine.

The participants rejected ODMWA autopsy because they perceived to be synonymous with selling of the body parts because organs were retained and there was potential for compensation to be awarded. For some, the struggle of searching for the missing organs demotivated them as reflected in the following excerpt.

A widow in Nongoma (Sikhakhane) stated: *'I believe in God and in ancestors. If I consent to autopsy, when the person comes back, I will struggle with finding where these organs went to. I will also struggle with consenting to something unknown in the family life. My Christian life complements my ancestral belief. It is a belief system. I will never consent to autopsy for money, even now that I am poor; it is like 'dicing' body parts.'* In this statement ODMWA autopsy's objective of identifying occupational lung disease and awarding compensation was associated with the concept of commodification of body parts which would be required for resurrection. Reflected in the statement was the dualism belief in ancestors and Christian. According to William-Jones (1999) Cartesian dualism influenced the development of western medicine by 'conceiving of the person as separable into mind and body which demythologised the body and made it a morally neutral secular object.' This divide permitted the objectification and commodification the body, allowing its parts to be treated like property or assets (William-Jones, 1999), a factor rejected by the participants who believed in dualism in afterlife as consisting of the body parts and soul. The words dice, gamble and sell were used interchangeably by respondents.

A widow from Nongoma (Madala) said: *'Even if I knew I will not consent to it..... It will be like I am dicing the body..... I will not do it, even if it was for the money..... Money gets finished. I will not do it because I love and respect his body. I believe the soul can take care for itself. I take care of the body. Burying him without lungs and heart will be like burying an empty box.'*

A former mineworker from Nongoma (Masondo P) explained: *Autopsy is not correct, whether it is for compensation or not. It is like selling your parts for money. I would not be motivated by money. Money finishes. It is like I sold my family, my child, never! The body will be buried complete. The doctor can explain why autopsy should be done, to find the cause of death and so what.*

The association of the cardiorespiratory organs with a resurrected body confirmed ODMWA autopsy rejection in its current process, as a mother from Nongoma (Fakazile) explained: *‘I can’t gamble with my organs because I would want to be complete at the time of resurrection. If these organs are removed and taken away, what will I use to go to God?’*

The health practitioners corroborated media publications that the body parts being stolen by mortuary attendants whom they believed could influence people’s perception to autopsy negatively. They attributed the negative media stories on the sale of body parts to apathy to discuss ODMWA autopsy with mineworkers or their relatives. The mentioned that some families agreed to give consent to ODMWA autopsy only if the cardiorespiratory organs were returned for burial. Participants found incinerating the body parts after examination unacceptable. The following extracts from the interviews with the health practitioners highlight these findings.

A clinical and ward nurse manager at a mine hospital remarked: *‘What is compounding the issue (ODMWA autopsy) is that the mortuary workers have been found and arrested for selling body parts to hoax traditional healers.’*

The scandal on the sale of body parts which usually make headlines (Appendix 12) has been attributed to the negative attitudes to autopsy utilisation. The autopsy scandal on the organ retention that was covered by media in the United Kingdom was attributed to the doctors' discomfort about requesting autopsy from parents (McDermott, 2003).

The study findings were similar to other studies that concluded that consent to autopsy could only be given if the organs were going to be returned to the family before the funeral (Lishimpi *et al.*, 2007). The authors argued that families could decline giving autopsy consent because funeral delays could occur. The following citation illustrates the belief by participants to wait for the body parts.

A community health nurse practitioner stated: *'I found during my focus group that the majority of Xhosas were strong in their refusal to be buried without their lungs. One even said that he is willing to tell his family to hold the funeral for up to four weeks whilst waiting for the return of the organs.'*

From an occupational health practitioner and manager: *'Those few that I see, I do tell them. This is difficult, and an individualistic belief, however, mixed with that of the family. You should understand that even if the person agrees, the family has a final decision. He may agree, but the family will refuse because parts are being sold. I have seen this in my career.'*

A traditional healer (urban): *'You are saying, the heart and lungs are removed and taken somewhere for examination so that where necessary, the family receive compensation. We are unable to do 'commercial businesses' with people's body parts. It is not a black culture or tradition to 'benefit financially' using relatives' body parts. Those who use this for*

business know that this is not traditionally acceptable. As I have said, the spirit does unite with the body and hence the body should be complete (not disturbed at death). A person's death is not the death of a business transaction. When a person dies, we are interested in burying the person and not in how much the body parts can bring us. Even in a transplant, you need to talk to the ancestors.' The last sentence suggests recognition of organ transplant, but only once it has been accepted through communication with ancestors.

The traditional healers said that it was a conviction in contemporary societies that the body belongs to the soil and the spirit is the one that lives forever:

A traditional healer (urban): *The belief that body parts are not relevant in afterlife is a modern belief. It is not a traditional belief. It is not our culture, where we come from. God created a person as a whole. When the person dies, and we bury him completely we don't say we are returning flesh to flesh, we say we placing him at his place of rest. We are placing him; we are not 'throwing' him away. We are not burying him or her as defined in western culture; we are depositing him or her ('deposit' is boloka in Sotho). This is similar to treasure deposit. We know we will find the person any time we visit the site.'*

Rural community leader: *There is a belief that body parts are sold and that is why people are not reincarnated like before the time of body dissection by doctors. Nowadays, organs are removed, that is why many people do not wake up alive. To join the ancestors, a sacrificial goat must be slaughtered to say we have now returned your missing parts back so that the ancestors should not be surprised to see a person without these organs. Even if it is a leg,*

arm etc to return the missing limbs so that the person should be able to wake up as a soul/ancestor and be able to walk and function normally.'

7.2.7 Theme: Mistrust

Another theme which emerged was a belief that women were murderers and witches within the context of a spouse's death. Mineworkers who believed that women were murderers said that they hid the information on their health or money from their wives. They reported that their wives will never be given decision power to request or consent to ODMWA autopsy. While communication was found to be of utmost importance for ODMWA autopsy to be acceptable to ancestors, a culture of mistrust could impede its effectiveness. Mistrust by donors who believed that doctors would accelerate their death in order to harvest their organs was associated with organ donation (Thomas, 2000). There was dearth of information on mistrust of medical doctors associated to autopsy. Mistrust as a theme is illustrated by the following statements.

Urbanised in-service mineworker from Mohlakeng and originally from Mozambique (Moyani) explained:

'I will never pass my secrets to my wife. I have a will that includes only my children. My wife was born and grew up around here, while I come from one of the neighbouring countries. We live here together as a family and are happy together. I believe that if she knew about my finances, something bad could happen to me. I find that this (omitting financial truth) is the right way to go.'

A former mineworker from Nongoma (Mthethwa) articulated:

'I do not believe that being buried without the cardiorespiratory is similar to burying an empty body. I also do not believe a good ancestor is being buried complete... However, my family can know about it (autopsy) but not my wife... It is a problem. This law can also be told to the magistrate who can then implement it.... I know of a friend of mine whose son died of stomach ulcers, do stomach ulcers kill? I believe the wife poisoned him so that she can get the money. Women will finish the men and consent to autopsy if they know that there is going to be possible compensation. In my culture, women do not have power to decide on this, only men have power for decisions.' In spite of the mineworker's belief on the dissociation of body and soul, mistrust to his wife and other women reversed its positive impact to autopsy utilisation. In this case, the wife could be afraid to request autopsy even if she knew because she might already be accused of killing her husband by his family.

A former mineworker (Mpatsoe) from Welkom said:

'I believe that women are witches and that should they know that you have consented to ODMWA autopsy which has potential compensation, they can do anything sinister. You see, even when I was working... and now that I have retired due to ill health, I have never discussed anything with women, including money issues..... I am the breadwinner and her role is to receive any money I give her.'

An in-service urban mineworker (David) stated:

'Yes, women are killers. However, this cannot be generalised. There is a wife who can be influenced by friends to do bad things. The wife's love and commitment must be of such a nature that despite many influences she will not murder. It may happen that a woman does

hear about the autopsy process and compensation, and assumes it is a given that disease will be found because the husband worked for 10 years, and takes him out.'

The belief by male mineworkers that women were killers was corroborated by female mineworkers and health practitioners, as illustrated by the following passages.

An in-service female mineworker (Sonti) from Mohlakeng, Randfontein explained:

'The notion that a female spouse is a murderer does not surprise me. I had often heard even outside mining that when a man dies, it is always a woman who killed him. This is an old belief which I have not and still do not understand. What happens if I as the wife die, who will have killed me? This is the problem. I believe this myth has its roots in gender, it is a gender issue and it is not correct.'

Some women experienced withholding of pertinent information as illustrated by the following excerpt.

A fiancé living in Nongoma (Nokulunga) stated: *'My fiancé died at the age of 34 years after six years of mining. He was retrenched on ill health. He had paid lobola, but I was not staying with him. I only came when he was too sick and stayed until he died. He never told me anything; however, he had requested the birth certificates of the kids before returning home from the mines. He never told me what they were for. He always believed he'd get better and go back to work.'*

The health practitioners corroborated the study findings that wives were not trusted by their husbands and in some families, were suspected or even accused of killing their husbands.

According to them, this tendency was associated with beliefs inherent in some African communities. They observed that widows came back to the mines after mourning to seek information about their husbands which was recorded to have been discussed. They believed that lack of trust prevented lack of information sharing between couples.

All health practitioners were aware of ODMWA autopsy process, but said that they were uncomfortable to discuss it with greaving families and families of terminally ill patients. They were also uncomfortable to discuss autopsy with terminally ill patients.

The health practitioner and manager (female) at a mine said: *'Traditionally, it is believed that a woman kills. The wife is always sidelined, while he gives the information to those he trusts. Even if the man does not have brothers, the uncles are those with power. It does not matter who is alive on the husband's side, distant relatives will always be sought to come and take charge of the funeral.....sideline the wife and put her in her submissive role of mourning.....she has no decision power. I have seen this in my career.'*

A clinical and hospital nurse manager (male) at a mine said: *'The belief that a wife killer is individualistic and relates to mistrust. Some men die without telling their wives anything relating to money issues. I know that some of the Basoths believe in this, as I am a Sotho. It is a Basotho thing, I don't know about the other cultures. We had an incident the other week at the hospital. The relatives of a deceased miner came to the hospital to complain that his wife, who was a school teacher, should not be given the money due to her. We told the extended family that we treat the patients and do not get involved with their estates and referred them to the mine office.....'*

According to health practitioners, mineworkers who showed interest in ODMWA autopsy examination became despondent when they learnt that compensation was not guaranteed. They noted that in-service mineworkers questioned the value of ODMWA autopsy.

A community health nurse practitioner (female) said: *‘When you tell them that not everyone gets compensated, they get despondent. When it came to the burial, they stick to their cultural rituals, even those who showed interest. Even after the information is given, they still want to consult the clan/elders. During the focus group meetings, mineworkers asked me why must they be diagnosed and compensated after they are dead.’*

The traditional healers (males) corroborated their experiences in the communities that wives were sometimes blamed for the deaths of their husbands. The perception of traditional healers on mistrust of women differed as illustrated by the following citations.

Thus, from a traditional healer (urban): *‘We come across this in our walk in life, we do come across this, and it is true.’*

However, another traditional healer (rural and urban) disagreed: *Of course some men do believe that or even believe that their wives’ relatives do, but this is not the truth.’*

7.2.8 Theme: Communication

Respondents reported that the gendered power relations, family, traditional and religious fears to consent may be mitigated through proper and timeous communication with ancestors. They viewed advance communication with ancestors would appease them where they were such beliefs thus increase ODMWA autopsy acceptance. According to the respondents,

communication would address the “empty box” concern, deceased’s anger and rejection by ancestors of an incomplete body and the suffering inflicted by the process could be minimised as illustrated in the following passage.

A grandmother of the diseased mineworker from Nongoma (Mabaso):

‘If I know, I can consent, and I will also remind the ancestors and him through the sacrificial killing....’ The statement affirmed that the grandmother assumed decision making powers and responsibility of taking care of her grandchildren in the absence of the father. The assumed power leveraged her ability and acceptance by the ancestors to appease them.

Trust and communication among family members were viewed as very important for ODMWA autopsy as illustrated by the following passage.

In-service mineworker (Blaai) from Eastern Cape:

‘This autopsy is unusual... culturally; it is believed that discussing it openly, one is challenging it. There are many people who miss this compensation. It was in our culture that discussing matters relating to death was not a good thing as one could be calling it... There is no need not to tell your wife because if she knows, she will make informed decisions. Also if the family knows, they will perform the necessary burial rituals. This can’t be communicated when the person is dead because the ancestors will only know when the person is dead.’ This statement illustrates the fear that discussing death would attract it. The findings were not unique of the study; the literature revealed that for some people discussing autopsy with an ill person was a form of abandonment by the treating clinician (Perkins et al., 1993). Also, Chigidi (2009) argued that taboos control, guide and regulate the behaviour of the people

following them was associated with failure to plan and communicate what must be done when the individual dies.

Among most African traditions, euphemism would be often used in talking about death and many other things that would be considered offensive or harsh; for example, the phrase used to announce the death of someone would be translated as '*He or she has left us or has gone away*'(Chigidi, 2009).

Participants believed that communication between mineworkers and their spouses about objectives of ODMWA autopsy examination and their intention could assist their spouses to give consent. The study findings were similar to the Western culture of a will, except that it involved rituals communication with the ancestors. The following quote illustrates the belief that the intention by the mineworker about ODMWA autopsy examination could be treated the same way as the Western culture about the living testimony.

An in-service mineworker (Andile) from Randfontein said:

'If this autopsy is not communicated during times of good health, it can be difficult, it will be difficult for her to request autopsy at death. If we discussed during my life it will be easier because I would have communicated my intention to my family. If I died today without having informed my family in advance, no one will consent and no autopsy will be done and an opportunity for possible compensation would have been missed.'

An in-service female mineworker (Sonti) from Mohlakeng, Randfontein said:

I don't believe that family members might not speak up about my wish to have this ODMWA autopsy when I am dead. My personal wishes should be respected if communicated in

advance (during life) to members of the family. There can't be any problems. I believe that the lack of consent to this autopsy was lack of knowledge which could empower us mineworkers to discuss ODMWA and its benefits with our families when we are well.

Respondents explained how an entrenched traditional belief in carrying out the deceased person's wishes will override that of the living persons provided that the communication to the ancestors had been properly carried out, as illustrated by the following quotes:

An in-service mineworker (Nyandeni) from Mohlakeng, Randfontein explained:

'I will consent to autopsy. I told my family that when I die, my wife must inform the mine that my organs can be examined to check for occupational diseases and the other organs to be donated if they are healthy to help those alive. If my relative wrote in a will that he/she consents to autopsy or how he/she wants to be buried, I will carry it out because they were their wish. I would not want to disagree with his spirit and soul. His beliefs might not be the same as mine. I would not want to disagree with his soul as an ancestor.'

An in-service mineworker (Ntshakeni) from Eastern Cape said:

'In my family culture, I believe this autopsy may not be acceptable because the ancestors know the person should be complete at death..... However, the autopsy would be acceptable if he agreed to it while still alive and communicated his intention in a proper way to his ancestors. The ancestors will not disagree with him and they will know when it is done.'

A former mineworker (Mashiane) from Welkom, Free State said:

'In discussion with my family in advance, they would be able to consult with the ancestors and manage with the process in that the way the ancestors require so that they do not at any stage get angry. This should be discussed when you are still alive, long before you get sick'. My body parts should be signed off by my family and they should be told where the organs are taken for future tracking and the process should be paid for.' There was an expectation by some that part of the communication should include how the organs in ODMWA autopsy could be traced and also returned to the family for burial. Some expected their family to be compensated for 'temporarily' accepting the procedure. According to them, the ODMWA autopsy process was similar to putting a non-refundable deposit for an item/asset that one intends using with a proviso that it should be returned when it had fulfilled the job. Unfortunately, in ODMWA autopsy, the cardiorespiratory organs are not returned.

From a rural community leader:

'When a treating doctor requests the family to give consent for removal of cardiorespiratory organs when a person is dying does not sound right..... It feels like the doctor wants to remove from a living person. That is why we are afraid and say we do not consent.' The statement illustrated the fear of discussing autopsy when the mineworker is alive yet ill.

The health practitioners had diverse perceptions on ODMWA autopsy which related either to their personal views of the procedure or to those of the mineworkers, as seen in the following extract. Discussing autopsy when a patient was dying was uncomfortable and considered bad timing as illustrated in the following statement.

A clinical and hospital nurse manager at a mine (male) said: *'To date, I have been working in the mining hospitals the past 25 years, initially, in the TB ward. I never informed the workers, in spite of the fact that I was aware of the act and autopsy, because it is not easy. From the hospital side we can only reinforce it. It is not easy to talk about death when the person is dying. It is like wishing them off from the face of earth and removing their last hope of survival. That is why I say it should be done at an engagement centre and during induction when they are healthy. I don't think it is right to do it when they are sick. I don't believe that it is right to talk about this when they are sick or dying. It needs to be done when you are healthy and of clear mind' It must be documented with knowledge that the person can change their minds. This should be enforced annually with knowledge that the family reserves a right to consent, because people can change their minds. It should also be reinforced during annual medicals and recorded, even when the person changes his month. We are here to treat the patient; the autopsy is with the mortuary.'*

The discussion of death was also found to be unnerving with regard to organ donation, as noted by a community public health nurse practitioner (female): *'I had visits around mines in the Gauteng province to discuss ODMWA autopsy and spoke to occupational health nurses at the occupational health centres. I also held three focus group meetings with mineworkers and health and safety representatives. I found that very few occupational health nurses communicate ODMWA autopsy, except at exit examinations of the mineworkers. I don't see any reason not to give ODMWA information at exit.... Death talk was uncomfortable'.*

The belief in the body being mutilated was not limited to the mineworkers and their families. Some health practitioners also believed that autopsy mutilates the deceased body, for

example, a clinical and ward nurse manager at a mine remarked: *My brother committed suicide after 10 years as a surface miner and only worked underground for a month. I refused to consent, for his death was not mine-related and I don't believe he could have contracted the disease in a month. My family believes that if I die, my body should not be mutilated.*' The study noted that understanding the health practitioners' cultural beliefs and sensitivities required further investigation since they play a role in influencing ODMWA autopsy request for consent.

7.2.9 Theme: Mortuary services

Mortuary services emerged a barrier to autopsy. Dying at home in certain remote villages prevented families from using the mortuary services because participant believed that a body from mortuary was unacceptable to the ancestors and the soul of the deceased. They articulated that ritual cleansing was required to cleanse 'ice' from refrigeration. According them burial within 3 days at most to avoid refrigeration was preferred to curb ritual cleansing to remove the ice and appease the ancestors. There was also perception that bodies from mortuaries were incomplete. The following excerpts highlight the beliefs on mortuary services.

A mother of a deceased miner (Makhatini) from Nongoma: *'Traditionally, a person was buried whole without going to hospital. Hospital meant modernisation and also came mortuaries. In other remote areas, people still die without reaching any hospital and get buried in 2 days, whole, without reaching mortuary.'*

A widow from Nongoma (Makhosi) explained:

'My husband died in 2004 at the age of 54 years. The family washed his body (ritual cleansing. We wash all cases from mortuary to remove the ice to prevent him/her from feeling cold in afterlife.

Widow from Nongoma (Madala): *'My husband died in 2006 (45 years). A goat was killed for a ritual of washing his body to remove ice and pave a path for him to be accepted by ancestors and for his comfort.'*

The belief that mortuary service was unacceptable and could be a barrier to autopsy was corroborated by the community leader from Nongoma as illustrated in the following extract:

'In the olden days, there were no mortuaries; a child was buried same day and an adult the following day. The mortuary is cold and it is believed that the deceased would be unable to be restored in afterlife. The mortuary causes the person not to wake up because of ice and also the coffin. The other thing was that there is a belief that the organs are removed'

Mother of the deceased mineworker (Makhatini) from Nongoma: *Traditionally, a person was buried whole without going to hospital. Hospital meant modernisation and also came mortuaries. In other remote areas, people still die without reaching any hospital and get buried in 2 days, whole, without reaching mortuary.*

A widow (Mabaso) from Nongoma: *'They were catholic, but they followed the rituals of washing the body to rid of cold ice'*. This statement illustrate that the mortuary beliefs were not influenced by Christian religion.

The belief that mortuary is a barrier to ancestral well being was corroborated by the community leader as illustrated in the following extract: *'In the olden days, there were no mortuaries; a child was buried same day and an adult the following day. The mortuary cold and it is believed that the deceased is unable to be revived in afterlife. The mortuary causes the person not to wake up because of ice and also the coffin. The other thing is that there is a belief that the organs are removed.'*

7.3 Socio-cultural category

7.3.2 Theme: Traditional healers' perspectives on autopsy

While ODMWA autopsy targets the mineworker and his/her family, their interactions with the rest of the community potentially influenced their world views on it. The roles that health workers and traditional healers play in the community and their attitude to autopsy could influence ODMWA autopsy examination.

The traditional healers viewed autopsy examination negatively. Some of the negative views were on the western diagnostic methods of diseases which were unacceptable to them. According to them the body should be left undisturbed as illustrated by the following quote.

On tradition and autopsy: *'Traditionally, when a person dies, he has died. If he is killed by a gun or motor vehicle accident, we would accept that these were the cause of death. In the olden days, whatever the cause of death was, the body was buried without inflicting further suffering. Western doctors like cutting people and it not that they want to help anyone because the person is dead and all the family want is to do is bury their loved one. The cause of death was already traumatic. Post-mortem is for the Western doctors to satisfy themselves*

and further try to establish the extent of internal damage and continue to inflict suffering on the body.'

The study finding that the body should be left intact for cultural reasons was not unique. According to Renteln (2002) Mexican Americans believe that soul resides in or near the body for up to several days after death and can feel pain; therefore it is believed that if autopsy is performed, the soul suffers either physical pain from cutting the flesh (if the soul is in the body) or psychological pain from observing the violation of the body (if the soul resides outside the body).

The study found that body parts were missing at burial because of surgical operations and accidental deaths, rituals were performed to appease ancestors. Also, traditional healers argued that rituals would be futile for the ODMWA autopsy, as the procedure was unacceptable:

Tradition and western surgical intervention (urban): *'Yes, traditionally there are 'means and rituals' that are performed for missing body parts because other than medical, it can also happen in an accident. If you are injured, these are done in life so that when a person dies, his body is 'reunited' with the parts missed in life. Should this not be done, there will be problems as the person's spirit will be troublesome later on'.* This statement epitomises the belief by the traditional healers and some of the participants on the unintended consequences of autopsy, following the removal of the cardiorespiratory organs and subsequent burial without them.

A traditional healer (urban) said: *‘There are many things that happen in the person’s life that when the families seek help from the traditional healers, it is found that the deceased person through his spirit talks to the family. Your ancestor who is called a Modimo in Sotho is troubled and wants his/her parts. This is where we, the traditional healers, then get involved, where we agree in terms of introducing the medically amputated parts or post-mortem (not this autopsy). This process is followed so that the person does not become restless.*

Sitho, it is an African belief system. Within that system, for example, different cultures come through in practice. Shangaans have a specific cultural way to practice tradition. However, the tradition remains similar. We don’t practice using the same means of expression; however, African tradition is the same. It is for this reason that the practice is cross-cultural, without any ethnical boundaries. Yes, it is true the only difference is in practice. One family practices its traditions differently from another. The problem arises when we want to satisfy our individual family traditions through the practice of another family in pursuit of satisfying whoever we are trying to, other than the family.’

According to traditional beliefs corroborated by traditional healers the deceased was destined to be an ancestor and can become a scorned callous ancestor when cardiorespiratory organs are removed and disposed of separately and this was believed to be the findings by traditional healers when family experience consulted them.

However, they recognised the roles that mineworkers could play on alleviation of family misfortunes by communicating with their families and ancestors about their autopsy intentions. This implies that the strategy to increase utilisation ODMWA autopsy utilisation

could be achieved through extensive awareness and communication of ODMWA autopsy programme to mineworkers, their families and communities.

7.4 Conclusion

The qualitative findings confirmed that the factors influencing ODMWA autopsy utilisation are complex and multifaceted. A range of socio-cultural barriers to consent for an autopsy examination were identified. However, these barriers were also found to present intervention opportunities which could increase utilisation. The prominent socio-cultural perspectives were beliefs in continuity or survival of the individual's body with its soul, commodification of heart and lungs, fear of misfortunes caused by the deceased or ancestors of those who gave consent, belief in reincarnation, a rejection by ancestors or not becoming a good ancestor because of permanent removal of cardiorespiratory organs and gendered power relations. The interventions had a the potential to address the cultural perspectives found to be ritual ancestry communication of the intention for autopsy examination when the mineworkers is healthy and their families and community were communicated with, to increase awareness. The findings drew attention to issues that must be included in mitigation strategies aimed at assisting the mineworkers and their families to consider regarding ODMWA autopsy. While the existing body of knowledge on clinical autopsy facilitated an understanding of relevant aspects to be investigated, the study found new cultural dimensions that should be considered when dealing with ODWMA autopsy.

Additionally, the study found that the rational choice of accepting autopsy was not based on knowledge and understanding of autopsy. Instead, it was more concerned with the question of the dissociation of the body from soul in afterlife. This belief was found not to be rooted in religion or culture, but in the individual's attitude towards the deceased body. The concept of

dissociation of the body from the soul was found to be a new contribution to knowledge as an enabler to ODMWA autopsy. Though the dissociation was enabling for ODMWA autopsy, the participants who had this perception acknowledged that the final decision to consent depended on the family members' beliefs and perceptions. Consent was therefore still a gulf to be bridged. The majority of widows and relatives maintained that their spouses or sons did not discuss their wellbeing or their finances with them, citing a lack of communication due to trust issues. This would imply that ODMWA autopsy was a barrier to the very people it was meant to assist, especially where the wife has accepted the process. The trust issues were corroborated by some mineworkers, who reiterated that they would not communicate matters that had financial implications to their spouses, including their health. It was further corroborated by the health practitioners at mines, on the basis of their experience of interacting with the widows. Family paternal bonds as a source of power were found to govern decision making with regard to death, as compared to maternal relationships. Those who were related to the deceased on the father's side had power, as opposed to those on the mother's side, irrespective of gender. This was corroborated by the traditional healers who defined these roles within the African traditional culture and the communication with ancestors.

These findings work against ODMWA autopsy, which requires consent by the immediate family before the procedure could be carried out. Such consent was perceived as an act of selfishness because of the fear of the wrath of the ancestors or the deceased. The participants associated the removal of cardiorespiratory organs with the commodification of such organs, resulting in an 'empty box' unsuitable for afterlife or for acceptance by the ancestors, and limiting the deceased's chance to be a good ancestor which in turn would lead to misfortunes.

This finding worked against the current ODMWA autopsy process of centralized pathology examinations. The concept of an empty box as a hindrance to ODMWA autopsy is a key contribution to knowledge. The study also noted that health practitioners may share the same cultural beliefs that reject ODMWA autopsy procedure with some of the mineworkers and their families and further investigation was required to assist on policy formulation to address this issue.

The study also noted that the current ODMWA autopsy procedure of organ retention works against the African traditional and religious belief in the dualism of the body and soul in afterlife, seen as a means to the ancestral realm and to resurrection. Additionally, the study found that mortuary services were believed to be a barrier to ancestral well being. This finding suggests that those who believed in mortuary as a barrier would be unlikely to use it if the deceased died at home. This can be aggravated by lack of financial resources for an undertaker. This works against the strategies to promote ODMWA autopsy awareness with undertakers in rural areas.

CHAPTER 8: GENERAL DISCUSSION

8.1 Introduction

South African mineworkers have a high burden of occupational lung diseases (Churchyard et al., 2004; Girdler-Brown et al., 2008; Trapido et al., 1998; Steen et al., 1997) but many do not receive occupational compensation in life; consequently, the ODMWA autopsy provision is important. Yet non-utilisation of autopsy is substantial. The aims of this study were to quantify the monetary contribution of autopsy to mineworkers families, estimate financial benefits missed due to autopsy non-utilisation, define the characteristics of deceased mineworkers who did not use the autopsy service (to tentatively formulate reasons for not using autopsy); to describe the factors that contribute to ODMWA autopsy utilisation (i.e. barriers and enablers); and to explore factors contributing to the low ODMWA autopsy utilisation by black mineworkers and their families. These factors are necessary to understand facets of effective interventions that can improve utilisation.

In the following sections, the quantitative findings will be discussed first, followed by each area from the qualitative study found to be an enabler or a barrier to autopsy.

8.2 Quantitative study findings

Seventy one percent of in-service mineworkers over the 10-year period were employed by mines affiliated with TEBA. During 2001-2010, using TEBA recorded deaths, autopsy utilisation of in-service mineworkers was estimated to range between 30-46%. It is argued that these figures were an over-estimate as they did not include former mineworkers and in-service mineworkers working for TEBA non-affiliated mines. In terms of ODMWA (Act 78 of 1973), these mineworkers were eligible for autopsy examinations. ODMWA authorises a medical practitioner following a death of a miner to

remove the cardiorespiratory organs, provided consent from the family is obtained, and to forward them to NIOH for pathology examination. ODMWA authorises a family member who believes that the deceased miner suffered from an occupational lung disease to request an autopsy examination irrespective of the cause of death. The autopsy process requires the family to make a request (implying consent) or the health practitioner to request consent from the family (inferring communication). The study found inconstancy between TEBA registered deaths and the autopsy examinations performed.

ODMWA compensation award to families has a potential to provide short-term poverty relief. If assumptions were made that Stewart's (2007) findings on financial spending on basic needs such as food person per family of seven members were similar to that of mineworkers compensated following ODMWA autopsy; households that received compensation for first degree occupational lung disease category would have had sufficient money to buy food for 29-47 months. Similarly those who received compensation for second occupational lung disease category could have managed to buy food for 49-80 months.

The study found that the tentative reasons for ODMWA autopsy non-utilisation were associated with dying at home, recent MBOD submission, age of the mineworker, and previous and current TB infection.

Although the contribution of autopsy to new occupational lung diseases, and the potential compensation to mineworkers' families was shown, the factors influencing ODMWA utilisation could not be deduced from the quantitative study.

The conclusions drawn from the quantitative study were that further research is needed to quantify and establish the contribution of ODMWA compensation to poverty alleviation by recipients; to explore the influence of MBOD submission, previous PTB, the age of mineworker at death and dying at home have on ODMWA autopsy; and to identify the underlying factors for the disparate number of autopsies performed and the in-service deaths.

8.3 Qualitative study findings

8.3.1 Introduction

The study explored individual/family, institutional and socio-cultural perspectives in the conceptual framework in Figure 5, which is reproduced in this section for reference and to draw attention on the complexity of the factors that contributes to ODMWA autopsy utilisation.

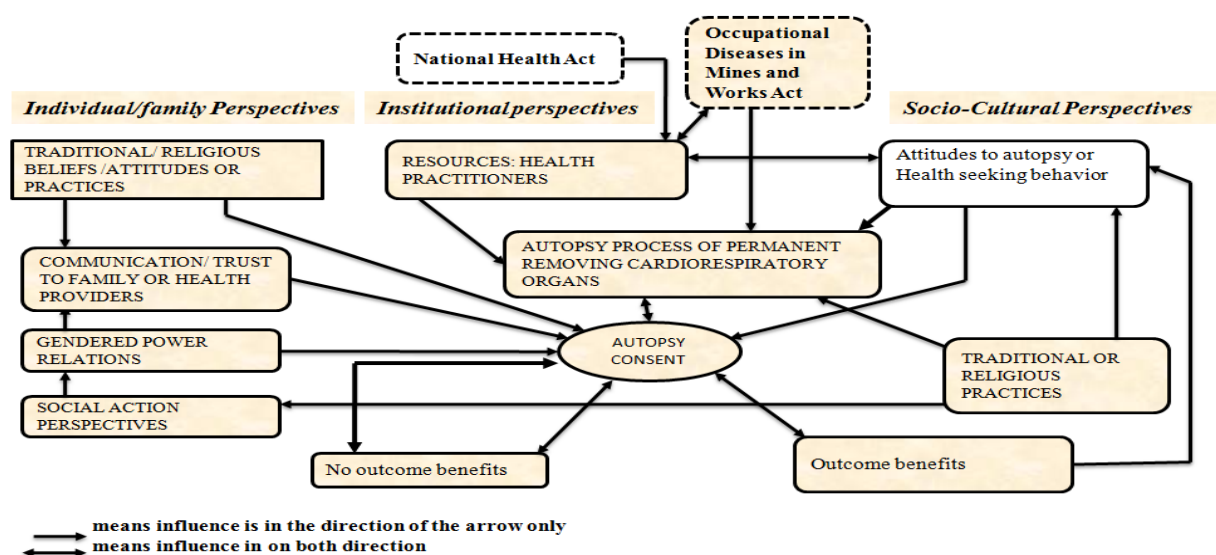


Figure 5: Conceptual framework of factors influencing clinical autopsy utilisation

Factors influencing ODMWA autopsy consent and utilisation were found to be diverse, complex, and multifaceted and these were entrenched in cultural, religious or societal domains.

The barriers and enablers of ODMWA autopsy were under individual/family; socio-cultural and institutional perspectives and are highlighted in Figure 5 (reproduced). These factors were on religious and cultural beliefs regarding ODMWA autopsy process, gendered power relations, communication, resources (health practitioners) and socio-cultural perspectives (traditional practices) and will be discussed as either enablers or barriers of ODMWA autopsy, in the following sections. The study found participants whose cultural and religious beliefs were grounds upon which they accepted autopsy. The respondents could rationalise their acceptance or rejection of autopsy within their own individual cultural or religious belief system

8.3.2 Enablers of autopsy utilisation

8.3.2.1 Dissociation of the body from the soul and autopsy consent

In clinical autopsy, the family consents to dissection of the body, examination of organs and the taking of tissue or non-tissue samples for pathological examination. In ODMWA autopsy process, the family consents to the dissection of the body and the permanent removal of the cardiorespiratory organs for examination.

Participants argued that the soul/spirit were independent of the body and capable of conducting all functions including protecting the family against misfortunes when consulted. They believed that the spirit can be reincarnated irrespective of the status of the body at death

or burial and become a good ancestor. The ability for the soul to self-resurrect irrespective of the status of the body including autopsy examination was lacking in other studies (Gatrad, 1994; Sheik, 1998; Campbell, 1998; Gatrad, 2001; Rashid, 2001) and prohibited in other religious and traditional beliefs (Hindu, Islamic, African) which promoted the body to be sacred and not to be dissected.

The dissociation of body and soul by believers present an opportunity to policy makers and implementers to increase ODMWA autopsy utilisation through awareness and communication strategies and build knowledge among the believers.

8.3.2.2 Gendered power relations: Matrilineal relations

Gender and authority did not emerge from literature reviewed as a factor contributing to clinical autopsy utilisation. The qualitative study found that gendered power relations played a role in ODMWA autopsy consent. While most respondents belonged to patriarchal families in which men were dominant and those with patrilineal relations had decision making powers on the deceased, there those in which matrilineal relations existed. In matrilineal relations, the women (mothers/grandmothers) had the power to give consent autopsy examination. Decision making power by women also existed in the absence of the mineworkers' family of origin and for those who live in a modern nuclear family structure.

8.3.2.3 Communication with ancestors

Almost all of the participants, with the exception of one former mineworker, practiced dual beliefs (Christian and African tradition), and believed in individual afterlife and ancestral communication. They believed that foremost, ODMWA autopsy process and the potential

compensation benefits needed to be empathetically communicated in advance to all mineworkers, their families and communities in order to alleviate cultural barriers to consent. The study found that trust in the ODMWA process must be gained from the mineworkers, their families and the society, and that the purpose and the potential benefits must be understood by all of them. According to ODMWA respondents, central to building public and family trust; communication, awareness and knowledge should occur when mineworkers are healthy.

This perception presents an opportunity for policy makers and the mines to develop and implement an intervention awareness and communication strategy. The communication should target mineworkers at engagement, during periodical examination and at exit. Similar messages should be communicated with families and the communities. The respondents believed that this strategy would enable them to perform rituals and reduce the potential for a wife to be accused by the family and community of the murder of her husband.

The findings reflect some aspects of the gendered ideology in a patriarchal society, which according to Hussein (2004) is created and reflected in multiple ways, with communication and tradition playing a great role in creating and reflecting it.

The conclusion drawn from the results was that the communication factors required to achieve ODWMA autopsy consent were complex and required good rapport with the recipients, comprehension of the subject and the recipients, their beliefs and myths on the subject matter. There was belief that mineworkers should take the responsibility of informing their families and ancestors. It is argued that the communication strategy could consider the beliefs (enablers and barriers) found in this study.

8.3.2.4 The age of the deceased

The majority of widows stressed that they would give consent for autopsy to establish the cause of death because their husbands had died young, as did other relatives. They also articulated that they would grant permission for autopsy if required by the clinician. However, they stated that lack of decision making power and withholding of information by their spouses and in the case of mothers, their children, could supersede their intention to give consent. The stated young age was found to be similar to that of mineworkers who did not undergo autopsy examination. It can be argued that the lack of decision making power and of information could tentatively explain the non-utilisation of ODMWA autopsy by the mineworkers whose records were reviewed.

The influence of age on autopsy examination and acceptance of the procedure if it is requested by clinicians was similar to that of other studies. Most relatives would only grant permission for an autopsy if it was requested by the clinician in cases of death before the age of 50 years because they sought the cause of death (Oluwasola et al., 2009). Rankin et al (2002) concluded in their study of bereaved parents that autopsy was found to be a useful and necessary tool in helping them discover the underlying cause of death, a finding similar to this study.

Health practitioners at both the mines and public health facilities can influence the utilisation of autopsy by explaining the potential adverse effects of occupational exposures and taking a good labour history.

8.3.2.5 Bad death

The study found that death defined as bad by participants was an enabler of ODMWA autopsy. Death was defined as bad if it occurred during a person's productive work life, leaving behind young children and a spouse after a protracted period of ill health. Death was also as bad if it occurred soon after being discharged from mines due to ill health. Death was also considered bad if it occurred after a short illness of a young person with dependants. The quest to find closure on the cause of death by some widows and relatives became an enabler of ODMWA autopsy. Therefore, intensifying the rights of mineworkers under the MHSA and ODMWA through empathetic communication to them and their families when they leave mines on ill-health is required. Measures should be kept in place for transferring them out to nearby hospitals/ clinics.

8.4 Barriers to autopsy

Boglioli et al (1991) observed that in contrast to forensic autopsy, one key impediment to non-forensic autopsy examination was the requirement of consent. The study found ODMWA autopsy consent was rejected by participants in a variety of cultural circumstances, however, some of these barriers could be minimised by awareness and communication strategies to mineworkers, their families and their communities.

8.4.1 Gendered power relations: Patriarchal relations

ODMWA autopsy, in line with forensic autopsy legislation both locally and globally, requires consent from immediate adult relatives and this may include extended-family adult relatives who legally have rights over the body. This alignment by ODMWA autopsy was found to be an oversight, as it ignored traditional family cultures and gender issues of most

mineworkers and their communities. These cultural and gender issues were founded on paternal power and inhibited wives from giving their consent for autopsy.

The theme was a dominant one within the realm of a patriarchal society. According to Coetzee (2001), *‘the concept "patriarch", as ‘the father and ruler of the family and tribe’, was first used during Biblical times and refers specifically to the sons of Jacob’*. According to Hussein (2004), in patriarchal societies there is a deliberate social construction of masculinity and femininity which cuts across all the other cultural and socio-economic structures of every nation. Widows described the cultural taboos which were directed to them to be limiting them to make decisions.

The study found that awareness and communication strategies aimed at mineworkers, their families and communities has potential to minimise gendered power relations, improve trust, enable ancestral communication and thus increase autopsy utilisation. There was a belief by the majority of participants across the four groups (former and in-service mineworkers, widows and family members) that communication should be extended to the ancestors through family rituals unique to each family.

8.4.2 Empty box beliefs

The belief that cardiorespiratory organs were the ‘engine’ required for afterlife and being buried without them was synonymous with burying an empty box was a barrier to autopsy.

“Empty box” was influenced by both cultural and religious beliefs in after life. This finding contrasted with that from other cultures and religions where dissection of the body was completely forbidden (Gatrad, 1994; Sheik, 1998; Campbell, 1998; Gatrad, 2001., Rashid,

2001). Examination of the cardiorespiratory organs on-site and returning them to the body for burial was considered more acceptable by those who associated burial without them to an 'empty box'.

8.4.3 Health workers and ODMWA autopsy

The theme that attitude of health workers was a barrier to autopsy was found. They were reluctant to discuss autopsy with ill mineworkers or their families. Health practitioners' reluctance to ask grieving families for consent was found to be a potential barrier in this study, similar to other studies (Sanner, 1995; Sinard, 2001; Burton et al., 2007; Oppewal et al., 2001). The literature revealed that for some people discussing autopsy with an ill person was a form of abandonment (Perkins et al., 1993). While taboos controlled, guided and regulated the behaviour of the people following them, the fear of discussing death results was argued to be a failure to plan and communicate what must be done when the individual dies (Chigidi, 2009). Among most African traditions, the researcher knows that euphemism is used in talking about death and many other things that would be considered offensive or harsh; for example, the phrase used to announce the death of someone could be translated as *'He or she has left us or has gone away'*. These cultural practices require that sensitive wording should be considered when a communication strategy is planned.

As in other studies, apathy and reluctance to discuss autopsy with the dying patients were found among health practitioners who were caring for the patient and this was associated with notion of giving up too soon (Alderson et al., 1998). According to Alderson et al (1998), the understanding of consent varied among different professions, and was too multifaceted to be contained in a single theoretical model. Alderson et al (1998) recognised the *positivist*

model, which presumes that consent is a factual exchange of medico-legal information, the *constructionist* model, which holds that consent is a complex and ambiguous process, and the *functionalist* model, which sees consent as a formality. From the study findings, it could be argued that ODMWA autopsy fits all of these models and each one of them could either be a barrier or an enabler, depending on who explained the procedure, who receives the information, who was to undergo the autopsy, and the circumstances under which a particular the person died.

Similar to gendered power relations and ‘empty box’ ODMWA autopsy association, ODMWA autopsy awareness could be part of pre-employment, periodical and exit medical examinations. Awareness campaigns should be extended to districts and form part of DMR’s communication about dust and occupational lung disease preventative and surveillance programmes as stated by the health practitioners and community leader.

8.4.4 Mistrust

Wives were mistrusted and information withheld. The mistrust of women is not unique to the mining environments but inherent in communities as corroborated by health practitioners and traditional healers.

Fewer in-service mineworkers utilised autopsy examination; the majority of mineworkers died shortly after leaving the mines; the majority of windows stressed that their husbands died a bad death and did not know the cause of death; and the mineworkers stressed that they hid information associated with money. Although, mistrust may not completely be associated with these findings, it is argued that their inter-relatedness renders it partly relevant, assuming

that the mineworker was given an exit medical examination card as required by the MHSA and alluded to by the health practitioners at mines.

Mistrust associated with autopsy between spouses was unique to this study. From the literature reviewed, mistrust was found in organ donation and was directed to medical doctors by family members who believed death could they would stop care prematurely so that organs were haversted (Thomas, 2000).

8.4.5 Commodification of body parts

ODMWA autopsy process of organ retention and compensation was analogous to selling the body parts, in the context of the organs not being returned for burial with the body. This perception deterred these participants from accepting ODMWA autopsy. The respondents believed in dualism of the body and soul in afterlife and used the words dice, gamble and sell interchangeably.

Commodification of body parts from literature reviewed on autopsy was not found, but it was found in organ donation (Sharp, 2000).

8.4.6 Traditional norms of the community

According to WHO (2008), traditional healers could be the only accessible allied health providers to most rural communities in Africa. The study found that traditional healers were consulted by families in their communities to assist in ancestral rituals and expressed their experiences on death and misfortunes. Their perception of autopsy revealed that while they

did not agree with autopsy on themselves; they acknowledged that consulting ancestors in advance would assist mineworkers and their families to avert misfortunes.

CHAPTER 9: STUDY LIMITATIONS AND STRENGTHS

The study limitations are categorised under each methodology used to gather data.

9.1 Quantitative

The quantitative study limitations can be categorised into misrepresentation and misclassification. The research design was descriptive and hence left very little scope for analysis deviance. Despite the limitations considered below, the biases introduced are unlikely to have been large enough to impact on study findings or conclusions.

9.2 Annual disease certification misrepresentation

The data for the study were from the MBOD, NIOH and TEBA and were collected for the organisations' own purposes with differing collection periods of data collection. There is a time lag from the time a miner dies to the autopsy examination report and finally to a MBOD certification. This limitation may have lowered the annual number of MBOD certifications in a particular year or increased the preceding year's actual number of cases certified during that year but decreased that of the following year. The results of the annual actual number of diseases certified should be interpreted with caution, given this limitation. However, annually, all the mineworkers certified with new first or second degree occupational diseases and upgrades from first to second degree by the MBOD receive compensation award, and in the event that they had died, their family does. Therefore, the monetary value of compensation for families and the amount missed due to underutilisation would not have been affected.

The missed compensation may have been underestimated or overestimated, on the assumption that the uncertified mineworkers would have suffered similar occupational lung

diseases as those certified by the MBOD during the same period. Therefore, it is possible that, though the calculations were based on an assumption, the reality could be higher than estimated. It is recommended that the effect of missed compensation be investigated further using statistical modelling with samples from both TEBA- and non-TEBA-registered deceased mineworkers.

TEBA deaths representing 71% of employed black mineworkers in the South African mining industry during 2001-2010 were used to calculate autopsy underutilisation among black mineworkers. The data are limited to in-service mineworkers and the vital status of mineworkers in retirement was limited. During 2007-2010, a higher proportion of autopsy examination in black mineworkers was on mineworkers who died in employment (for example, 75.5% of them died in employment in 2010 compared to 21.3% who were retired). Further research is required to determine the utilisation of mineworkers who die in retirement.

The sample for the record review was selected from all the records of mineworkers who did not undergo autopsy during 2004-2006. The limitations identified were associated with the quality of data. Also, some descriptive characteristics were missing in some records. Many records missed data required to characterise the mineworkers. Of the original sample of 133 only 52 (39%) records could be used. It is unknown to what extent the 52 represented the 133. Therefore, the generalisation of the findings to other deceased mineworkers who did not undergo autopsy is restricted. The results provided tentative reasons for not utilising autopsy (dying at home, age at death, pulmonary tuberculosis as cause of death linked to recent MBOD submission) and this requires further investigation.

9.2.1 Misclassification of disease

Pulmonary tuberculosis was a common cause of death in the death certificates of the 52 deceased mineworkers who did not undergo autopsy. However, there might have been misclassification of disease, especially since 96% of them died at home. Studies have found poor correlation on the clinical cause of death and autopsy cause of death and in some series the differences were found to decline with improved diagnostic technology and training. By analysing the results of 53 distinct autopsy series over a 40-year period, Shojania et al (2003) showed a statistically significant decrease over time for major errors which were defined as clinically missed diagnoses involving a principal underlying disease that was a primary cause of death and only detected at autopsy; and concluded that by contrast, individual studies from different periods that compared rates of autopsy-detected diagnostic errors and found strikingly unchanged error rates reflected inadequate statistical power as a result of diagnostic improvements over time and increased clinical selection as autopsy rates decrease.

Three hundred and eleven new cases were certified in the first degree category and 2 426 in the second degree category. There may have been misclassification of diseases into first or second degree category and this would have affected the calculations of monetary value following autopsy examination. However, bias on the certification of occupational lung diseases at autopsy is minimised by the set standards for pathology autopsy examination and disease categorisation of ODMWA. The standardised report by the pathologist is used by the certification committee as outlined in Schedule 44 of ODMWA as illustrated in Appendix 10. Bias is further minimised by ODMWA requirement of a quorum of four medical doctors, one of whom is a chairperson for the Certification Committee meeting. ODMWA also has a reviewing committee that must convene to consider cases which are disputed by the

mineworkers and their families. The reviewing committee also considers cases that the Certification Committee did not reach consensus.. It would be important, however, to investigate in future studies quality controls at both certification and pathology reporting.

9.3 Qualitative

The qualitative study limitations can be categorised into inherent interviewer bias, participants' bias, selection bias and gender. However, it is not believed that biases in the findings were sufficient to invalidate the major findings.

9.3.1 Inherent interviewer bias

A potential interviewer bias was identified as a potential limitation, as there was a potential for subjectivity with regards to the researcher's own perceptions of the topic. To reduce this bias, a standardised interviewing guide was used for all the interviews.

9.3.2 Participants' bias

It was recognised that that answers given by some participants could be limited by their belief that they pleased the researcher without being relevant to the question. This was reduced by introducing the topic from the summarised questionnaire's page by the interviewer prior to the interview commencing, using the participant's language and probing each response. Also, some questions in the questionnaire were repeated but phrased differently to check for consistency. The participants' responses were also summarised at the end of each interview to make sure that they captured the participant's contribution on the questions asked.

Another limitation identified was the impact that those who gave consent to participate may have had different views from those who did not. This was minimised by including a diverse group of five i.e. mineworkers (former and in-service), widows, relatives of deceased mineworkers and other (traditional healers, health practitioners, community and organised labour leaders). The participants represented diverse groups (Zulu, Shangaan, Sotho and Xhosa, Venda) men and women.

9.3.3 Selection bias

Although the participants volunteered to participate in the study, the request to participate in the study was done by someone they knew and trusted. They may have told what they believed would please their contact and the researcher. While this bias could be real, the traditional healers, health practitioners, community and organised labour leaders corroborated the responses from the participants and this suggests that the responses were genuine.

9.3.4 Gender biases

Gender was recognised as a potential limitation which would result in unwarranted generalisation of research findings on the barriers and enablers of autopsy utilisation. The findings would have been biased towards male or female if participants did not include both. This was reduced by including both genders in the interviews, asking them the same questions and by grouping them after transcribing the interviews and during data analysis., to reduce the limitation, cross checking of responses across groups was done to identify themes unique to groups and corroborated by others (traditional healers, health practitioners, community and organised labour leaders).

9.4 Strengths of the study

Despite the limitations, the study has strengths. The study is the first to estimate the percentage of deceased mineworkers who do not utilise autopsy in South Africa. The study showed that the number of autopsies of current mineworkers who undergo autopsy is far less than anticipated. It is also the first study to estimate the potential compensation award that was missed due to autopsy not being undertaken. The study made use of key databases, namely NIOH, MBOD and TEBA, and showed that combining the data from these databases can be used to produce important public health information. This is also the first study to examine the characteristics of deceased mineworkers who did not have an autopsy so that tentative reasons for not using the service could be identified.

The study was able to establish that there are complex concerns surrounding autopsy utilisation by mineworkers and their families that would not be addressed by a single strategy. There was genuine concern that was echoed by many participants that related to burial without the cardio-respiratory organs which is a prerequisite for ODMWA autopsy; this was a barrier to ancestry, ancestry acceptance and afterlife. The study is the first to highlight that paternal relations gave decision making power over the deceased's body as compared to maternal relations regardless of the gender and this affect ODMWA autopsy consent. The study was able to establish that autopsy consent in some family situations would not be discussed even if it was known because of lack of trust. Also, for those who believed in traditional medicines and culture, it was highly unlikely that autopsy consent will be given, considering the corroborated findings by the traditional healers and health practitioners (who could relate to case studies they could recall). The majority of these mineworkers were certified TB only by MBOD and subsequently died of it as recorded in their death certificates. This suggests that the submission to MBOD and longevity post

submission was a barrier to autopsy which led the mineworkers to miss autopsy. This is the key strength to the body of knowledge on the broad factors influencing negatively on autopsy utilisation that should be taken into consideration in strategies geared to increase utilisation.

The combination of quantitative and qualitative approaches complemented each other and was a strength of the study. The inclusion of various participants affected by ODMWA autopsy and key informants in the qualitative study were added strengths. The differentiation of former mineworkers into urban (Free State) and rural (Nongoma in Kwa-Zulu Natal) strengthened the study. Additionally, randomly selection of in-service mineworkers at a mine without pre-determining their home of origin and including key participants (urban and rural traditional healers, health practitioners, union leaders) to explore corroboration of key findings were further strengths of the study. While the researcher may have been open to interviewer bias, she also brought personal strengths to the study with regards to understanding how the ODMWA autopsy systems should function in an ideal setting, as well as experience of other legislation for occupational health and safety in South Africa. The triangulation of the findings and information across both studies was a strength

CHAPTER 10 CONCLUSION, RECOMMENDATION AND FUTURE RESEARCH RECOMMENDATIONS

10.1 Conclusion

The study set out to quantify monetary contribution of autopsy to compensation, estimate the loss of financial benefits due to underutilisation, define the characteristics of those deceased mineworkers who did not use the autopsy service and describe the factors that contribute to ODMWA autopsy utilisation.

The study has shown that ODMWA autopsy makes a substantial contribution to compensation and that the estimated financial loss of underutilisation is large. Tentative reasons for not utilising autopsy are complex. The conclusion of the study calls for interventions on the current ODMWA autopsy process that will ensure that the barriers that the mineworkers and their families face are addressed.

The study found barriers to autopsy, but also cultural beliefs that may enable these barriers to be overcome. The barriers and enablers of autopsy were found to be complex and could be classified under individual/family, institutional and socio-cultural perspectives. Drawing on the rational choice theory the study found a clash of cultures and rationalities that result when compensation was seen as poverty alleviation from one perspective and as a body commodification from another and as upsetting the ancestors. Additionally the decision making power to give consent was found not to be clearly defined, with patriarchal relations to the deceased taking an upper hand in one setting, yet in another one matrilineal relations were superior. The study showed that gender, age, and location within the family could complicate

the standard patriarchal arguments that limited women's power . These findings may be generalisable to similar socio-cultural environments outside South Africa.

Most important among the barriers was the requirement to obtain formal consent for autopsy within a biomedical framework, which clashed with certain socio-cultural beliefs. However, respondents reported that consent could be facilitated, for example by living mineworkers making their agreement to autopsy clear to their families and by communicating this intention to ancestors -where this was consistent with their belief system.

Although autopsy is intended to provide the last chance for those eligible for compensation, many saw the process as failing them for they believed that diagnosis and compensation should occur in life.

To turn around the current situation of poor autopsy utilisations, ODMWA autopsy processes require re-evaluation. The ODMWA compensation system also requires re-evaluation regarding linkage to the Mine Health and Safety Act, and creation of knowledge and awareness to its beneficiaries and their communities. This is important because occupational lung diseases have a long latent period and may develop long after the mineworker has retired from mining; and some mineworkers continue to be exposed to respirable crystalline silica dust $\geq 0.1 \text{ mg/m}^3$ (DMR, 2010).

10.2 Recommendations

10.2.1 Policy implications

The cultural beliefs of people can only be influenced; they cannot be forced. Democratic laws are made both to govern people and to protect their rights. It is the right of the miner to retire from mining unharmed. However, it is recognised that systems might fail the miner, including, for example, medical surveillance. In the meantime, it has been shown that autopsy remains an important tool in the quest to remedy some of the financial insecurities of the mineworkers' families.

10.2.2 Recommendations:

From the discussion and the conclusions drawn, it is recommended that:

1. Communication strategy

First, the study findings that cultural beliefs influence ODWMA autopsy consent - and within the culture itself there are various interpretations- provide an opportunity to ensure that mineworkers, their families and the communities they come from or live in understand the purpose of autopsy. The high burden of un-diagnosable occupational lung diseases in life warrants this intervention and should be considered as a method to secure informed consent.

Foremost, the ODMWA autopsy process and the potential compensation benefits need to be empathetically communicated. There is a need to develop a communication strategy for mineworkers and their families and communities to increase knowledge and awareness and thus increase utilisation. The messages in the communication should address the findings by this study, although not limited to them. The communication

strategies should be geared towards building trust by mineworkers, family and public on ODMWA autopsy process.

2. Decentralisation of ODMWA autopsy to district level

Decentralisation of autopsy examination, so that organs can be examined and replaced before burial, thus removing the ‘empty box’ barrier warrants consideration. However, replacing the organs for burial would remove the opportunity for re-examination during an appeal by families and this issue needs consideration if decentralisation of autopsy is to be advocated. Also, centralisation allows a uniform and standardised pathological assessment of disease and extent of disease. Additionally, the ODMWA autopsies data are comprehensive and have been the resource for both mineworkers’ occupational lung disease surveillance and research over many decades. Steps to preserve the advantages of a centralised pathological assessment and ODMWA autopsy database should decentralisation occur would have to be put in place.

3. ODMWA amendment

Amendment of ODMWA so that its consent requirements are similar to forensic autopsy examination requires investigation, while respecting individual cultural beliefs.

4. Additionally, monitoring and evaluation of the control measures must be linked to exposure and the medical surveillance of the miner. Such surveillance should continue until the death of the mineworker.
5. Also, a development and testing of a comprehensive set of communication tools for use in different settings to promote the use of ODMWA autopsy is required.

6. The provisions allowing for ODMWA autopsy must be maintained until it is clear that autopsy is not necessary. This can be proven by affordable and diagnostic technologies that surpass those of autopsy.

10.3 The following areas require further research or investigation:

1. Underlying factors that contributes to the decline of autopsy utilisation among mineworkers dying in-service in the South African Mining industry.
2. The effect of missed compensation be investigated further using statistical modelling with samples from both TEBA and non-TEBA-registered deceased mineworkers.
3. The impact ODMWA autopsy utilisation by mineworkers who die at home, the cost of transporting the body to the facility and the cost of mortuary services.
4. Resource requirements for decentralising ODMWA autopsy.
5. A survey on skills requirements and capacity required for promoting autopsy awareness and communication.
6. A study to quantify the impact of compensation payments for occupational lung diseases on households. The research should include the burden that ill health adds to a household.
7. A survey on the impact that public district and private hospitals' income allocation and policies have on ODMWA autopsy examination.
8. The perceptions and attitudes of mining health practitioners, organised labour and management to ODMWA autopsy;
9. The impact that submission to MBOD by mines of mineworkers on ill health termination programmes at the mines have on further benefit medical examination including autopsy beyond mining.

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APPENDICES

Appendix 1: Data collection tools for record review of deceased mineworkers who did not undergo 1(a) autopsy and for TEBA registered Nongoma deceased mineworkers 1(b)

Appendix 1 (a): Data collection for record review of deceased mineworkers without autopsy

MBOD number /Case number	Number of previous submissions	Date of last submission	Previous certification finding	Labour history	Date last worked	Age at death	Date of death	Place of death	Death Certificate - cause of death	Last CXR	Last CXR originator	New medical records

Appendix 1(b): Data collection tool for TEBA Nongoma deceased mineworkers

Case number	Previous MBOD certification	Year of submission	Labour history	Date last worked	Date of death	Age at death	Place of death	Suspected cause	Current certification

Appendix 2: Semi-structured questionnaire for in-service and retired mineworkers

AV Banyini-Student no: 3708309A

Opening

My name is Audrey Banyini, I am a student doing a post graduate study on autopsy and compensation. I thought that it would be a good idea to interview you as work at a mine (active) or you have worked previously at a mine (retired). Your identity and residence will be kept anonymous in the report. The interview should take around 60 minutes. Are you available to commence the interview now? I will use a tape recorder, summarise how I understand your input, and allow you to amend anything you or I have said to avoid misunderstanding. We will conduct the interview in your home language. What is your home language?

Introduction

Demographics

As I have introduced myself, this section is important for me to know you so that I am able to ask relevant questions.

1. Please tell me your name
2. Where do you live?
3. How long have you lived at this address?
4. Is this the same area were you born?
5. Were your parents or grandparents born in this area also?

Work in the mines

The questions help with knowing the person, the duration of risk exposure, link it to the amended act in the era of the rights to information.

a. In case of active mineworker

1. Where are you working now (i.e. coal or gold)?
2. What do you do?

b. In case of retired mineworker

1. When did you stop working?
2. What were the reasons for the termination?
3. What information if any were you given when you left work?
4. With regards to any law or exposure, were you health ever discussed with you?
5. What aspects of your health were discussed you?
6. Which law was discussed with you
7. Who discussed these with you?

c. For both active and retired mineworkers

1. How many year of schooling did you have a chance to finish?
2. What was your salary when you retire or now in case of active worker? NB: This will enable approximation of possible compensation.
3. What was your first job at the mines?
4. How old were you?
5. What motivated you to join the mining industry?

Compensation legislations

For the relatives to be eligible for compensation under the Occupational Diseases in Mines and Works Act, the deceased's cardio-respiratory organs should be removed at a place of death arrangements have to be made with the Medical Bureau for Occupational Disease (MBOD) or National Institute for Occupational Health (NIOH). The cost of organ removal and transportation is borne by MBOD and NIOH examines them to exclude or confirm occupational lung diseases and forward the report to MBOD for evaluation. The questions in this section seek to establish knowledge, understanding and attitude on this process and compensation.

1. What kind of compensation are you aware of?
2. What compensation law can you remember?
3. Who informed you?
4. When?
5. How were you informed?
6. How much do you understand about compensation of lung disease for a mineworker who dies?
7. Will there be a difference if the mineworker dies at home as compared to dying while in employment?
8. Why would there a difference if any if not why?
9. What should be in case of death to benefit the compensation laws?
10. By the employer?
11. Is there a role for family in these laws?
12. What are they?
13. Have you heard of the MBOD?
14. Who are they?
15. Who informed you?
 - If unknown, researcher to explain it
16. Have you heard of NIOH?
17. Who are they?
18. Who informed you?
 - If unknown, researcher to explain it
19. Are you aware of the Occupational Diseases in Mines and Works Act?

If yes what is it?

- How did you know it?

If not researcher to explain

20. Are there any other act you are aware that relates to mining?

- *If not ignore*
- If yes seek to understand how they link to ODMWA and provide explanation if necessary. This is important for autopsy process clarification in case of confusion

21. Would you say that the act and the processes benefit the mine-worker?

- If so, how does the mineworker benefit?
- What are the benefits?
- Do you know of anyone who's benefited from the act and its processes?
- Who are they?

If no benefits are received, what could be the reasons?

- What do you think should be done to make them beneficial?
- Who should do it?

Autopsy

The autopsy process in this study refers to the removal of heart and lung at site of death and sending them to NIOH for pathological examination. The body is buried without organs. The autopsy process is said to be more sensitive and can pick compensatable diseases that have been missed with a chest x-ray taken during life. The questions in this section seek to establish knowledge, understanding and attitude on autopsy, autopsy process and decision making. NB: some questions are repeated purposeful to gain consistency of information provided.

What do you think of this process?

22. Were you aware about these services prior to this meeting?
23. How did you know about them?
24. What do you know of the removal of cardiorespiratory?
25. Where are the organs sent to?
26. Do they get returned for burial?
27. What will happen to the family should the person be buried without the organs?
28. What will happen to the deceased should burial occur without the organs?

29. Who gives permission for the removal of organs?

- In the case of the mineworker dying in mine hospital?
- In the case of mineworker dying in public hospital?
- In the case of mineworker dying in at home?

30. Are you aware of someone who had autopsy without knowledge of family?

- What happened?

31. Are you aware of families who used the autopsy services or mineworkers who agreed during life that the organs be removed?

- Are they from your same village?
- What happened to them?
- Did their families benefit?

In Sotho there is a saying that ‘Lenstwe la mohu ga le tselwe’ translated to English ‘a dead man’s words/instructions in life can’t be changed when he’s dead’.

32. What do you think of this?

33. What would make a family honour or not honour the words of the deceased, and decline autopsy?

34. What do you see as the role of a wife or mother in autopsy decision making?

- Explain, what is autopsy in your understanding?

I know that family consent/permission should be sought before the lungs are removed

35. What happens if no permission is acquired?

36. What is compensation?

37. What could be the possibility of the family refusing the procedure?

38. Are you aware of someone who’s had the procedure?

39. Are you aware of the benefit the family received?

40. How do you view this procedure from a personal perspective?

In Sotho there is a saying ‘Lenstwe la mohu ga le tselwe’ which in .” translated to English ‘a dead man’s words/instructions in life can’t be changed when he’s dead’.

1. What do you think of this?

2. What would make a family not honour the words of the deceased?

3. What do you see as the role of a wife or mother in autopsy decision making?

4. What decision would you make if you were requested to consent to autopsy?

- For a family member?

- For yourself during life?

If accepted, what will be the reasons?

If not, what will be the reasons?

Social action

There is a modern belief that people in general have moved away from traditional beliefs grounded in superstition, religion and long standing customs and have become rational. An example can be made that those that are rational will believe in autopsy process because of the possibility of receiving compensation

1. What are your comments on this?
2. Is there a possibility that even if someone still follow African tradition, they will consent to autopsy because of monetary gain?

Power

Power can be referred as a capacity of people or groups to control or influence the actions of others with or without their cooperation. Power can be an enabler or disabler on human action. The autopsy process is has been already established and stipulated in ODMWA as discussed in the previous sections.

1. What are your comments with regards to the autopsy process and the ODMWA?
2. Does the act has powers to achieve what it set out to, which is to empower the families of deceased to benefit from possible compensation? Please elaborate on your comments
3. If there was anything that should be improved on the act and processes if any, what would that be?
4. What are your comments with regards to organs be sent to Johannesburg?
5. Does the MBOD as the directorate for health possess any powers to achieve what it set out to, which is to empower the families of the deceased to benefit from possible compensation? Please elaborate on your comments
6. Would you say the process does achieve its goals of picking up those missed in life and hence provide good compensation? Please elaborate
7. If there was anything that required improvement on MBOD process what would that be?

8. What are your comments with regards to family power and the autopsy process?
9. Are the families having power with regards to autopsy?
10. What power is it and why?
11. Is declining consenting to autopsy some form of power to you? Please elaborate
12. What power form of power will this be?
13. How can this power ensure that the family get compensation where it was necessary?
14. Who should make decision on the procedure?

- The wife?

Why should this be the case?

- Family elder?

Why should this be the case?

Religion

Religion can be defined as a set of beliefs and practices generally held by a community, involving adherence to codified and the study of ancestral or cultural writings, history, and, as well as personal

1. What are your comments on this statement?
 2. What are your comments on this with regard to organ removal and burial of the body without them?
 3. Can religion be a barrier or enabler for organ removal?
 4. Please explain why and how
 5. What will be the effect of an individual breaking away from the religion?
 6. Please explain why and how
- Does one's religion changes when they move to urban areas?
 - Will the effects if any be the same?
 - Please explain why and how

Death and dying

There are cultural beliefs that may translate to the management of the dying and death, the questions seeks to find out the issues and how they maybe a link with the autopsy and compensation

I read recently that as human beings, we are ‘death denying’, i.e. discussing and planning our death in life and when we or our loved ones are terminally ill is not easy for various reasons.

1. What do you think maybe the possible reasons?
2. How can autopsy and compensation be discussed with a dying person and or his family?
3. What should happen in discussing death or autopsy by a husband with a wife?
4. Who should make decision on the procedure?

Culture and mourning

There are cultural beliefs that may translate to the management of mourning the dead and possible relationship with afterlife and ancestral spirits. The questions seek to find out how these issues maybe influencing autopsy and compensation

I heard that there are different African cultures surrounding mourning but in general there are similarity on mourning and burial.

1. What is meant by culture during mourning period?
2. Does this influence the discussion on whether to remove or not to remove the organs?
3. How does this organ removal influence the mourning process
4. What are the cultural relevance to autopsy and compensation?
5. What would happen if these are ignored?
6. What would happen if the wife ignores this due possibility of receiving compensation?

Conclusion

Well, it has been a good experience interviewing you. I should have all the information.

I appreciate the time you took for this interview. Let me briefly summarise key themes that I observed during our interview

- Is there anything else you think would be helpful for me to know so that I can successfully understand issues surrounding autopsy and compensation?

- Thanks again

Appendix 3: Semi-Structure questionnaire: Family members of deceased mineworkers

AV Banyini-Student no: 3708309A

Opening

My name is Audrey Banyini; I am a student doing a post graduate study on autopsy and compensation. I thought that it would be a good idea to interview you as I believe that you lost a loved one who worked in the mines. Your identity and residence will be kept anonymous in the report. The interview should take around 60 minutes. Are you available to commence the interview now?

(In cases in which consent) I will use a tape recorder, summarise how I understand your input, and allow you to amend anything you or I have said to avoid misunderstanding. We will conduct the interview in your home language. What is your home language?

Introduction

Demographics

1. As I have introduced myself, this section is important for me to know you so that I am able to ask relevant questions.
2. Please tell me your name is
3. Where do you live?
4. How long have you lived at this address?
5. Is this the same area where you born?
6. Were your parents or grandparents born in this area also?
7. How are you related to the deceased?

Work in the mines of your relative

1. What was your relative' job at the mines?
2. The next section seeks to establish knowledge by the relative on the deceased's labour history at the mines and death including notification process. It also seeks to establish knowledge on monies due which could death benefits as well as pending compensation of occupational diseases or injuries
3. How old was he when he died?
4. How did he die?
5. Who was the next of kin, in terms of family relations who was first contacted about it?
6. Who informed you?
7. How were you informed?
8. What was the cause of death?
9. Who informed you about the cause of death?
10. What other information were you given?
11. With regard to monies, compensation, autopsies

If death occurred at home

The section seeks to gain understanding from the relative of knowledge on causes of death that may be directly or indirectly linked to occupational exposure which could have possibly been communicated to the worker, the processes to be followed which can be linked to autopsy and whether relatives go through the documentation of the deceased to establish all factors that may relate to money (death benefits, insurance claims, compensation etc). Some questions are purposefully repeated in a different format to establish content consistency.

1. When did he stop working?
2. Was he terminated from working in the mines?
3. What were the reasons for his termination?
4. Who informed you of his termination?
5. What else were you informed of? (e.g. termination of service due to ill health relating to TB, silicosis, injury, medical condition, no more work or dismissed)
6. From your observation was he too ill or did his condition improve so he could go back to work?
7. Was there any other information he discussed with you prior to his demise?
8. With regard to his health while at the mines?
9. What was it?

With regards to his demise

1. What is the illness he died from?
2. Did he die at home? if yes
3. Who certified him dead and who removed the body from home?
4. Did the person who certified him discuss rights of mineworkers with regards to law? (NB for researcher to be explored further later). What were they?
5. If no, where did he die? If other than hospital, the questions follow those above
6. If hospital
 - Who informed you of his death?
 - Was the information about his illness in keeping with your observation of his health?
 - Did the health workers in discuss rights of mineworkers with regards to law? (NB for researchers to be explored further later)
 - What were they?
 - Do you think that the cause of death is related to your relative's death? Why or why not

If death occurred during employment

The questions seeks understand the relative's knowledge on the autopsy processes under ODWMA.

1. Who informed you on the death of your relative?
2. How were you informed of the death?
3. Were you the first one to be contacted about it?
4. Who was the other next of kin contacted about it?
5. Can you recall what happened thereafter; until you loved one was buried?
6. Can you recall what else you were told e.g.? That autopsy is obligatory to claim posthumous compensation?
7. Who told you?
8. What was your reaction to this information?
9. Did you concert to the autopsy?

If yes

1. What was the motivation behind the acceptance?
2. Did you travel to the mine and who paid for the travel? (NB: to establish whether relative was with the deceased at time of death)
3. Did you have the power to concert to autopsy or consulted with you and other family members first?
4. If you did consult, did you inform them later or chose to keep it a secret from them? If autopsy kept secret, any reasons for it?

If no, what was the motivation behind the refusal?

5. Did another family member concert to the autopsy?

If yes

6. What was the motivation behind the acceptance?
7. Did they travel to the mines? (NB: to establish whether relative was with the deceased at time of death or works at mines i.e. readily available)
8. Did this family member have the power to concert to autopsy or consulted with you and other family members first?

- If no, what was the motivation behind the refusal

Compensation legislation

For the relatives to be eligible for compensation under the Occupational Diseases in Mines and Works Act, the deceased's cardio-respiratory organs should be removed at a place of death arrangements have to be made with the Medical Bureau for Occupational Disease (MBOD) or National Institute for Occupational Health (NIOH). The cost of organ removal and transportation is borne by MBOD and NIOH examines them to exclude or confirm occupational lung diseases and forward the report to MBOD for evaluation. The questions in this section seeks to establish knowledge, understanding and attitude on this process and compensation

1. What kind of compensation are you aware of?
2. Who informed you of the laws?
3. How were you informed of them?
4. How much do you understand about compensation of lung disease for a relative or spouse who have worked in the mining industry?
5. What should be done to benefit from the compensation laws?

By family?

1. What processes should be followed?
2. Before your relative's death, were you aware of occupational lung disease?
3. What are they?
4. Who informed you?
5. How were you informed?
6. Were you told what one should do?
7. Have you heard of the MBOD
8. Who are they?
9. Who informed you?

If unknown, researcher to explain it

1. Have you heard of NIOH
2. Who are they?
3. Who informed you?

If unknown, researcher to explain it

1. Are you aware of the Occupational Diseases in Mines and Works Act?
2. If yes what is it?
3. How did you know it
4. If not researcher to explain
5. Are there any other act you are aware that relates to mining

If not ignore

If yes seek to understand how they link to ODMWA and provide explanation if necessary.

This is important for autopsy process clarification in case of confusion

1. In your view does ODMWA and the processes discussed help the mine-workers or their families?
2. Note to researcher: The questions here seek to establish whether ODMWA, MBOD and NIOH are seen as of benefit. More it is hoped that concepts may arise that may relate to barriers or enablers to autopsy services.
 - If so, how are they helpful?
 - Do you know of anyone who's benefited from it?
 - What were the benefits
 - How did you come to know about the benefits
 - If no, what could be the reasons
 - What do you think should be done to make them beneficial
 - What do you think should be done to make them beneficial
 - Who should do it

Autopsy

The autopsy process in this study refers to the removal of heart and lung at site of death and sending them to NIOH for pathological examination. The body is buried without organs. The autopsy process is said to be more sensitive and can pick compensatable diseases that have been missed with a chest x-ray taken during life. The questions in this section seek to establish knowledge, understanding and attitude on autopsy, autopsy process and decision making. NB: some questions are repeated purposeful to gain consistency of information provided.

1. What do you think of this process?
2. Were you aware about these services prior to this meeting?
3. How did you know about them?

4. What do you know of the removal of cardiorespiratory?
5. Where are the organs sent to?
6. Do they get returned for burial?
7. What will happen to the family should the person be buried without the organs?
8. What will happen to the deceased should burial occur without the organs?
9. Who gives permission for the removal of organs?
10. In the case of the mineworker dying in mine hospital?
11. In the case of mineworker dying in public hospital?
12. In the case of mineworker dying in at home?
13. Are you aware of someone who had autopsy without knowledge of family?
14. What happened?
15. Are you aware of families who used the autopsy services or mineworkers who agreed during life that the organs be removed?
16. Are they from your same village?
17. What happened to them?
18. Did their families benefit?
19. In Sotho there is a saying that 'Lenstwe la mohu ga le tselwe' translated to English 'a dead man's words/instructions in life can't be changed when he's dead'.
20. What do you think of this?
21. What would make a family honour or not honour the words of the deceased, and decline autopsy?
22. What do you see as the role of a wife or mother in autopsy decision making?
23. Explain, what is autopsy in your understanding?
24. I know that family consent/permission should be sought before the lungs are removed
25. What happens if no permission is acquired?
26. To the possibility of compensation?
27. What could be the possibility of the family refusing the procedure?
28. Are you aware of someone who's had the procedure?
29. Are you aware of the benefit the family received?
30. How do you view this procedure from a personal perspective?
31. In Sotho there is a saying 'Lenstwe la mohu ga le tselwe' which in ." translated to English 'a dead man's words/instructions in life can't be changed when he's dead'.

- What do you think of this?
- What would make a family not honour the words of the deceased?
- What do you see as the role of a wife or mother in autopsy decision making?
- What decision would you make if you were requested to consent to autopsy?
- For a family member?
- For yourself during life?
- If accepted, what will be the reasons?
- If not, what will be the reasons?

Social action

There is a modern belief that people in general have moved away from traditional beliefs grounded in superstition, religion and long standing customs and have become rational. An example can be made that those that are rational will believe in autopsy process because of the possibility of receiving compensation

1. What are your comments on this?
2. Is there a possibility that even if someone still follow African tradition, they will consent to autopsy because of monetary gain?

Power

Power can be referred as a capacity of people or groups to control or influence the actions of others with or without their cooperation. Power can be an enabler or disabler on human action. The autopsy process is has been already established and stipulated in ODWMA as discussed in the previous sections.

1. What are your comments with regards to the autopsy process and the ODMWA?
2. Does the act has powers to achieve what it set out to, which is to empower the families of deceased to benefit from possible compensation? Please elaborate on your comments

If there was anything that should be improved on the act and processes if any, what would that be?

1. What are your comments with regards to organs be sent to Johannesburg
2. Does the MBOD as the directorate for health possess any powers to achieve what it set out to, which is to empower the families of the deceased to benefit from possible compensation? Please elaborate on your comments

3. Would you say the process does achieve its goals of picking up those missed in life and hence provide good compensation? Please elaborate
4. If there was anything that required improvement on MBOD process what would that be?
5. What are your comments with regards to family power and the autopsy process?
6. Are the families having power with regards to autopsy?
7. What power is it and why?
8. Is declining consenting to autopsy some form of power to you? Please elaborate
9. What power form of power will this be?
10. How can this power ensure that the families get compensation where it was necessary?
11. Who should make decision on the procedure?
12. The wife?
13. Why should this be the case?
14. Family elder?
15. Why should this be the case?

Religion

Religion can be defined as a set of beliefs and practices generally held by a community, involving adherence to codified and the study of ancestral or cultural writings, history, and, as well as personal

1. What are your comments on this statement?
2. What are your comments on this with regard to organ removal and burial of the body without them?
3. Can religion be a barrier or enabler for organ removal?
 - Please explain why and how
 - What will be the effect of an individual breaking away from the religion Please explain why and how
 - Does one's religion changes when they move to urban areas
 - Will the effects if any be the same
 - Please explain why and how

Death and dying

There are cultural beliefs that may translate to the management of the dying and death, the questions seeks to find out the issues and how they maybe a link with the autopsy and compensation

I read recently that as human beings, we are ‘death denying’, i.e. discussing and planning our death in life and when we or our loved ones are terminally ill is not easy for various reasons.

1. What do you think maybe the possible reasons?
2. How can autopsy and compensation be discussed with a dying person and or his family?
3. What should happen in discussing death or autopsy between a husband and wife?

Culture and mourning

There are cultural beliefs that may translate to the management of mourning the dead and possible relationship with afterlife and ancestral spirits. The questions seek to find out how these issues maybe influencing autopsy and compensation

I heard that there are different African cultures surrounding mourning but in general there are similarity on mourning and burial.

1. What is meant by culture during mourning period?
2. Does this influence the discussion on whether to remove or not to remove the organs?
3. How does this organ removal influence the mourning process
4. What are the cultural relevance to autopsy and compensation?
5. What would happen if these are ignored?
6. What would happen if the wife ignores this due possibility of receiving compensation?

Conclusion

Well, it has been a good experience interviewing you. I should have all the information. I appreciate the time you took for this interview. Let me briefly summarise key themes that I observed during our interview

- Is there anything else you think would be helpful for me to know so that I can successfully understand issues surrounding autopsy and compensation?

Appendix 4: Sotho translation of questionnaire

AV Banyini-Nomoro ya Moithuti: 3708309A

Pulo

Lebitso la ka ke Audrey Banyini; Ke moithuti wa Thuto ya dikeri tsa bobedi mme boithuto ba ka bo itshetlehile ho ho ngola thesise e buang ka tsa ho sehwa ha mofu ho fumana sesosa sa lefu le ho fumana moropotso. Ke nahana hore ke mohopolo o motle ho o botsa dipotso jwalo ka mosebeletsi (ya ntseng a sebetsa) kapa ya kileng a sebetsa morafong pele mme a beha meja fatshe. Boitsebiso ba hao le sebaka seo o dulang ho sona se tla bolokwa e le lekunutu repotong ena. Dipotso di tla nka feela metsotso e 60. Na o a ka ba le nako bakeng sa ho o botsa dipotso hona jwale? Ke tla sebedisa motjhini o hatisang lentswe, mm eke tla etsa kgutsufatso ya ka moo ke utlwisisang ditaba tseo o buileng ka tsona, mme ke tla o dumella le hore o ka lokisa moo re sa utlwanang hantle teng le wena hore re ke re utlwisisane hantle. Re tla o botsa dipotso ka puo ya hao ya lapeng. Puo ya hao ya lapeng ke efe?

1. Selelekela

Dintlha tsa bohlokwa

1. Jwalo ka ha ke se ke ipoletse, karolo ena ke ya bohlokwa haholo ho nna ho tseba e le hore ke tle ke botse dipotso tse tshwanetseng.
2. Lebitso la hao o mang?
3. dula hokae?
4. na le nako e kae o dula atereseng ena?
5. tswaletswe hona sebakeng sena?
6. Na le batswadi ba hao kpa baholo ba hao le bona ba tswaletswe hona sebakeng sena?

2 Ho sebetsa morafong.

Dipotso di re thusa ho tseba haholwanyane ka motho, nako eo motho a ka bang kotsing ka yona, ho e amahanya le molawana o itseng wa nako eo ho latela dintlha tse amanang le ditokelo tsa mosebetsi.

Maamong a mosebeletsi ya ntseng a sebetsa.

1. sebetsa kae hajwale (khr morafong wa mashala kapa wa gauta)?
2. sebetsang moo?

Maamong a mosebeletsi wa morafo ya seng a beile meja fatshe?

1. kgaoditse ho sebetsa neng?
2. iii. Mabaka a ho tlohela mosebetsi e ne e le afe?
3. Ke dintlha dife tseo o ileng wa di bolellwa ha o ne o tlohela mosebetsi?
4. Ho latela melawana e itseng na o ile wa botswa le ho buisana ka maemo a hao a bophelo?

5. iv. Ke dintlha dife tse amanang le bophelo ba hao tseo ho ileng ha buisanwa ka tsona?
6. v. Ke molawana ofe oo ho ileng ha buisanwa ka ona le wena?
7. vi. Ke mang ya neng a buisana le wena ka dintlha tsena?

c. Bakeng sa a mosebeletsi ya ntseng a sebetsa le ya beileng meja fatshe

1. Ke dilemo tse kae tseo o di nkileng sekolong hore o fumane monyetla wa ho qeta?
2. ne o fumana moputso wa bokae ha o ne o beha meja fatshe kapa ha o ntse o le mosebeletsi wa ka dinako tsohle? ELA HLOKO: Sena se ama bonyane ba moropotso oo o tlang ho o fumana.
3. Mosebetsi wa hao wa pele morafong e bile ofe?
4. ne o le dilemo di kae?
5. ile wa kgahlwa ke eng ho sebetsa morafong?

3. Molawana wa Ditlhapiso

Bakeng sa hore ba leloko ba ka fumaneha bakeng sa moropotso tlasa Mafu a fumanwang ha motho a sebetsa Morafong le Melawana wa Mosebetsi, ditho tsohle tsa tshebetso ya pelo di tshwanela ho ntshuwa sebakeng seo mofu a hlakahaletseng ho sona mme ho tshwanela ho etswa ditokisetso tsa lepato tlasa tsamaiso ya Mokgatlo wa Mafu a fumanwang Mosebetsing (MBOD) kapa tlasa Mokgatlo wa Naha wa tsa Bophelo bo Botle wa Basebetsi (NIOH). Ditjeho ke tsa ho ntsha setho sa mme bakeng sa ho romelwa sebakeng se seng ditjeho ke tsa MBOD le NIOH e a di hlahloba e le ho hanana kapa ho dumellana le hore lefu le bakilwe ke bohloko ba matshwafo ebe ba romela repoto ho MBOD hore e e hlahlobe. Dipotso tse karolong ena di batla tsebo le kutwisiso le maikutlo mabapi le mokgwa wa tsamaiso le moropotso.

1. Ke ditlhapiso tsa mofuta ofe tseo o di tsebang?
 2. Ke mang ya o boleletseng ka melawana ena?
 3. e boleletswe ke mang? Neng?
 4. ile wa tsebiswa melawana ena ka mokgwa ofe?
 5. utlwisisa hakae ka ditlhapiso tseo motho wa leloko ya sebetsang morafong a di fumanang ha a tshwerwe ke bohloko ba matshwafo?
 6. Na ho ka ba le phapang ha mosebeletsi wa morafo a hlokahalla lapeng ha ho bapiswa le ha a hlokahalla mosebetsing?
- Phapang e ka ba hokae haeba a hlokahalla lapeng kapa mosebetsing?

7. Ho ka etsahala eng maemong ao lefu le bang molemong wa melawana e laolang ditlhapiso

- Ka monga mosebetsi
- Na ho na le karolo e bapalwang ke lelapa melawaneng ena?
- Ke efe?
- Na o kile wa utlwela ka MBOD
- Ke bomang?
- ba tsebisitswe ke mang?

Haeba o sa tsebe ka bona, mofuputsi o tla hlalosa

8. Na o kile wa utlwela ka NIOH

- Ke bomang?
- ba tsebisitswe ke mang?
- Haeba o sa ba tsebe, mofuputsi o tla hlalosa

9. Na o tseba ka ha Mahloko ao motho a a fumanang ha a sebetsa morafong le Melawana ya Tshebetso?

10. Haeba karabo e le E hlalosa hore ke afe?

11. a tsebile jwang?

12. Haeba o sa tsebe mofuputsi o tla hlalosa

13. Na ho na le melawana e meng eo o e tsebang e sebediswang merafong

- Haeba o sa e tsebe o se ikgathatse ka yona
- Haeba karabo e le E sheba hore e amana jwang le ODMWA mme o fane ka tlhaloso haeba ho hloka hala. Sena se bohlokwa bakeng sa tlhalosetso ya mokgwa wa thsabetso wa ha ho sehwa mofu haeba ho na le pherekano.
- Ho ya ka wena na melawana ena ya tsamaiso e hlalositsweng ka hodimo e ka thusa ba malapa a basebeletsi ba merafong?
- Haeba ho le jwalo, mosebeletsi wa morafo o fumana molemo ofe?
- Melemo ke efe?
- Na ho na le batho bao o ba tsebang ba kileng ba fumana molemo ho tswa melawaneng ena?
- Ke bomang?

14. Haeba ho se na melemo e fumanwang, mabaka e ka ba afe?

- Ha o nahana ho ka etsuwa jwang hore e be le molemo?

- Ke mang ya tshwanelang ho etsa sena?

Ho sehwa ha mofu

Ho sehwa ha motho ya hlokaletseng thutong ena ke tshebetso ya ho ntsha pelo le matshwafo sebakeng seo mofu a hlokaletseng ho sona le ho romela ditho tsena ho NIOH bakeng sa ho ya hlahlojwa. Setopo se bolokwa ntle le ditho tsena. Mosebetsi wa ho sehwa ke o hlokolotsi haholo mme o ka bontsha mafu a lokelang ho fumantshwa moropotso a ileng a se ke a bonwa ka x-ray ya sefubeng e ileng ya nkuwa nakong eo motho a sa phela. Dipotso karolong ena di hloka ho bontsha tsebo, kutlwisiso le maikutlo mabapi le mosebetsi wa ho sehwa, motjha o tshwanelang ho latelwa le ho etsa diqeto. ELA HLOKO dipotso tse ding di phetilwe ka sepheo ho fumana dintlha tse nepahetseng.

15. Maikutlo a hao ke afe mabapi le mokgwa ona wa tshebetso?
16. Na o ne o tseba ka ditsheletso tsena pele o tla kopanong ena?
17. tseba eng ka ho ntshuwa ha pelo le matshwafo?
18. Ditho di romelwa kae?
 - Na di a kgutliswa hore di tla bolokwa le setopo?
 - Ho tla etsahalang ho ba lelapa ha setopo se ka bolokwa se hloka ditho?
 - Ho tla etsahalang ka mofu ha lepato le ka etswa ditho di le siyo?
19. Ke mang ya fanang ka tumello yah ore ho ntshuwe ditho?
 - Maamong ao mosebeletsi wa morafo a hloka hallang sepetlele sa morafo?
 - Maamong ao mosebeletsi wa morafo a hloka hallang sepetlele sa mmuso?
 - Maamong ao mosebeletsi wa morafo a hloka hallang lapeng?
 - Na ho na le motho eo o motsebang ya kileng a sehwa a ntshuwa pelo le matshwafo ntle le ho tsebisa ba leloko la hae?
 - Ho ile ha etsahala jwang?

Na ho na le malapa ao o a tsebang ao ba malapa a bona a kileng a a sehwa kapa batho ba sebetsang morafong ba kileng ba dumela ba sa phela hore ditho tsa bona tsa mmele di tle di ntshuwe ha ba se ba hloka hetsa?

- 20 Na ba tswa motseng oo o dulang ho ona?
- 21 Ho ile ha etsahala jwang ka bona?
- 22 Na ba malapa a bona ba ile ba fumana molemo o itseng?

Ka Sesotho ho na le polelo e reng 'Lentswe la mofu le ahelwa lesaka, se bolelang hore seo mofu a se boletseng se ke ke sa fetolwa ha a se a hlokahetse.'

20 Maikutlo a hao ke afe ka taba ena?

21 Ke sefe se ka etsang hore ba lelapa ba se ke ba sekehela lentswe la mofu tsebe mme ba hanane le taba ya ho sehwa?

22 bona boikarabelo ba mosadi kapa ba mme e le bofe bakeng sa ho etsa diqeto tsa hore mofu a sehwe?

23 Hlalosa, ka mantswa a hao hore ho sehwa ha mofu ho bolelang

24 Ke tseba hore tumellano ya lelapa e tshwanela ho etswa pele matshwafo a ka ntshuwa.

25 Ho etsahala eng ha ho sa etswa tumellano?

- Mabapi le ditlhapiso?
- Kgonahalo ya hore lelapa le ka hana ho fana ka tumellano e ka ba efe?
- Na o a hlokomela hore ho na le e mong ya seng a kile a etsa sena?

Na o hlokomela hore hore ho na le melemo eo lelapa le tla e fumana?

20 Maikutlo a hao ke afe tabeng ena?

21 Ka Sesotho ho na le polelo e reng 'Lentswe la mofu le ahelwa lesaka e bolelang hore seo mofu a se boletseng ha a sa phela se ke ke sa fetolwa ha a se a hlokahetse.'

22 O reng ka taba ena?

- Ha o sheba o bona mosadi kapa mme a bapala karolo efe bakeng sa ho etsa diqeto mabapi le ho sehwa ha mofu?
- Wena o ne o tla etsa diqeto dife haeba o ne o kopuwa ho fana ka tumello ya ho hore mofu a sehwe?
- Bakeng sa e mong wa ditho tsa lelapa?
- Ha e ne e le wena o sa phela?
- Ha o ne o dumela mabaka e ne e tla ba afe?
- Haeba o ne o sa dumele, mabaka e ne e tla ba afe?

Boemo ba phedisano

Ho na le maikutlo a hore batho ba se ba suthile mekgweng ya ditumelo tsa bona tsa kgale tsa ho dumela mafeela, tumelong le ho itshwarella ka tsa botjhaba mme ba se ba hlabolohile.

Mohlala o ka etswang ke wa hore batho bas eng ba hlabolohile ke bona ba ka dumellanang le taba ya ho sehwa ka lebaka Lahore bat la fumantshwa moropotso.

- Maikutlo a hao ke afe mabapi le taba ena?
- Na ho na le kgonahalo ya hore le ha e le hore motho o ntse a dumela ditumelong tsa kgale tsa SeAforika, ba ka dumellana le taba ya ho sehwa ha mofu ka lebaka la tjhelete e lefuwang?

Boemo ba dilemo

Ho bile le ngangisano ya hore motho ka mong kapa dihlopha tse itseng tsa batho di kgethollwa ho latela boemo ba tsona ba dilemo le hore sena se ka boela sa laolwa ke boemo ba thuto eo motho a nang le yona, moputso oo a o fumanang le bokgoni booa nang le bona. Maamong a basebeletsi ba merafo ba tswang dinaheng tse ka ntle, ho nnile ha ngangisanwa ka hore hobane batho ba batsho ba bangata ban e ba sa amohelwe e le karolo ya basebeletsi ba ka nkuwang e le basebeletsi ba ka dinako tsohle, sena se ile sa etsa hore ho se be le ho dumellana ha hore mofu a sehuwe hore ho tle ho be le moputso o lefuwang.

1. Maikutlo a hao ke afe mabapi le taba ena?
2. Na boemo ba dilemo bo ka ba le tshwaetso e itseng mabapi le ho sehwa ha mofu kapa ho hananan le hona?
 - Hobaneng ho ka ba jwalo?
 - Ke maemo afe a lelapa a ka ka bang le tshwaetso mabapi le ho sehwa ha mofu kapa ho ho hanana le maikutlo a jwalo ho latela boemo ba dilemo?
3. Na ho ka ba le mabaka a mong a amanang le boemo ba dilemo a ka kgothaletsang kapa a nyahamisa maikutlo a ho fana ka tumello ya ho sehwa?
4. Ha jwale mmuso o kgothaletsa mmenyetla e lekanang morafong bakeng sa banna le basadi. O nahana hore ho tla ba le phapang ho basebeletsi ba merafo ba batjha le ho moloko o motjha wa ba batsho wa ka nako e tlang le ba malapa a bona mabapi le ho dumellana le ho sehwa ha setopo kgahlalong le moloko wa kgale?
5. Ke hobaneng ha ba dumellana le ho sehwa kapa ba hanana le hona?
 - Ha o nahana ho hanana le ho sehwa kapa ho dumellana le hona ho na le kamano efe le boleng ba botjhaba ba Maaforika? Jwang?
 - Ha o nahana ke hobaneng batjha ba sejwalejwale(batjha ba ya merafong, ba reka matlo,ba dula le malapa a bona) ho ka ba le tshwaetso ho buuweng ha mofu le moropotso?

Matla

Ha ho sehwa ka matla ho bolelwa bokgoni ba batho kapa sehlopha se itseng se laolang kapa se ka bang le tshwaetso diketsong tsa ba bang ka/ntle le ho ba kenyeletsa. Matla e ka ba bokgoni kapa ho hloka bokgoni diketsong tsa motho. Ketso ya ho sehwa e se e qadilwe le ho hlaloswa ke ODWMA jwalo ka ha e hlalositswe dikarolong tse fetileng.

1. Maikutlo a hao ke afe mabapi le mokgwa oo ho sehwa ho etswang kateng le ODMWA?
- Na ketso ena e na le matla a ho fumana se lebeleletsweng, e leng ho matlafatsa malapa a ba hlokaletsweng ke ba malapa a bona e le hore ba fumane moropotso? O kopuwa ho hlalosa karabong ya hao.
- Haeba ho ne ho na le ho hong ho tshwanelang ho matlafatswa molawaneng o itseng le mokgwa wa tsamaiso o sebediswang, e ne e ka ba ofe?
2. Maikutlo a hao ke afe mabapi le hore ditho di romelwe Johannesburg?
3. Na MBOD ke molaodi wa tsa bophelo ya nang le matla a ho fumana se lebeleletsweng, e leng ho matlafatsa malapa a ba hlokaletsweng ke ditho tsa lelapa ho fumana molemo o itseng wa moropotso? O kopuwa ho hlalosa karabong ya hao.
4. Na o ka re mokgwa ona wa tshebetso o fihlelletse ditlhoko tsa ona tsa ho thusa ba lahlehetsweng ke ba malapa a bona ka ho ba fumantsa moropotso? O kopuwa ho hlalosa.
5. Haeba ho ne ho na le ho hong ho hlokaletsweng ho matlafatswa mabapi le MBOD e ne e ka ba eng?
6. Maikutlo a hao ke afe mabapi le matla ao lelapa le nang le ona le ka moo mosebetsi wa ho sehwa o etswang ka teng?
7. Na malapa a na le matla mabapi le ho sehwa ha mofu?
8. Ke matla afe le hore hobaneng?
9. Na ho hana ho fana ka tumello mabapi le ho sehwa ha mofu ho fana ka matla a itseng ho wena? O kopuwa ho hlalosa.
10. E ka ba matla a mofuta ofe?
11. Na matla ana a ka nnetefatsa hore lelapa le fumana moropotso moo ho hlokehang?
12. Ke mang ya tshwanelang ho etsa qeto mabapi le tsamaiso?

- Mosadi wa mofu?
- Hobaneng ho le jwalo?
- E moholo ka lapeng?
- a.Hobaneng ho le jwalo?

Boemo ba tekano

Kelohloko ho mofuputsi: Mona ke mabapi le ba dumellanang le hore ho sehwa ho na le melemo e itseng. Ho bile le dingangisano mabapi le hore ditshebeletso tsa bophelo bo botle le ba ikarabellang ho ditaba tsa phekolo ba tshwanela ho etsa tekolo ya bosetjhaba ya mekgwa ya puisano, maikutlo a ho kenyeletsa mekgatlo ya tsa phedisano (ya motho ka mong) le ka moo sena se ka hlaloswang ke teng ke motho ka mong.

1. Na o ka hlalosa ka moo le ileng la hlalosetswa ka teng mabapi le ho sehwa ha mofu nakong eo le ntseng le le bofifing? Haeba karabo e le E, tswela pele.
2. Na o ka re mekgwa o sebediswang o ileng wa hlaloswa ka teng mabapi le ho fana ka tumello o ne o le kgahlanong le botjhaba le ditumelo tsa lelapa nakong eo le leng bofifing? Hlalosa.
3. Na ho na le ho hong ho qhomang ka kelellong ya hao ha o ntse o nahana ka moo le hlaloseditsweng mekgwa oo mofu a sehlang kateng?
4. Haeba ho na le molaetsa o mong o o ka batlang ho o fetisa o ka ntlafatsang menyetla ya tekolo ya boemo ba botjhaba ya bophelo le ditshebeletso tsa phekolo, e ne e tla ba ofe?

Tumelo

Tumela e ka hlaloswa e le ditlwaelo tsa setjhaba, tse kenyeletsang ho tsitlallela ditumelong tsa botjhaba le badimo kapa dingolwa tsa botjhaba, hisitori ha mmoho le tumelo ya motho ka mong.

1. Maikutlo a hao ke afe mabapi le polelo ena?
2. Maikutlo a hao ke afe mabapi le ho ntshuwa ha ditho tsa mofu le ho patwa ha setopo se se nang ditho tse ding?
3. Na tumelo e ka ba tshita kapa ya ba yona e kginang ho ntshuwa ha ditho tsa mofu?
 - O kopuwa ho hlalosa hore hobaneng le hore na jwang
4. Tshitiso e ka ba efe ha motho a behella tumelo ya hae thoko?
 - O kopuwa ho hlalosa hore hobaneng le hore na jwang

5. Na tumelo ya motho e a fetoha ha a tloha sebakeng sa mahaeng a fallela sebakeng sa ditoropong.
6. Na ho tla ba le phapang haeba dintho di dula di ntse di le jwalo?
 - kopuwa ho hlalosa hore hobaneng le hore na jwang

Ho shwa le lefu

Ho na le ditumelo tsa bosetjhaba tse laolang ho shwa le lefu, dipotso di batla ho fumana dintlha le hore di ka ba le kamano jwang le ho sehwa le moropotso.

1. Ke badile lesedinyana le leng morao tjena le hlalosang hore, re “batho ba itimeletsang lefu” khr ho sehwa ka lefu le ho etsa ditlhophiso tsa lefu re ntse re phela mme ha re/ kapa bao re ba ratang ba kula ha ho na mabaka a bonolo a mangata a fapaneng.
2. Ha o nahana e ka ba ka mabaka afe?
3. Na ho sehwa ha mofu le moropotso ho ka buisanwa ka tsona le motho ya hlokahalang kapa le ba lelapa?
 - i.Ho etsahalang ka monna ya nang le mosadi?
 - ii.Ke mang ya tshwanelang ho etsa diqeto tsa hore ho sebetswe jwang?

Botjhaba le ho ba bofifing

Ho na le ditumelo tsa botjhaba tse ka hlaloswang ke ba tsamaiso ya ditaba tsa batho ba lilelang wa habo bona ya seng a hlokahetse le kamano e teng ya ya hlokahetseng le meya ya badimo ba hae.Dipotso di batla ho fumana hore dintlha tsena di na le kamano efe le ho sehwa ha mofu le moropotso.

Ke utlwetse hore ho na le ditumelo tse fapaneng tsa botjhaba bo fapaneng ba Maaforika ho latela mekgwa eo ba ilang ka teng empa ka kakaretso ho na le tshwano e itseng mabapi le ho ila le ho boloka mofu.

1. Ho bolelwang ka botjhaba mabapi le nako ya ho ilela mofu?
 - Sena se ka ama puisano mabapi le ho ntshuwa/ho se ntshuwe ha ditho tsa ya hlokahetseng?
2. Botebo ba maikutlo a bona bo hokae ho latela ho sehwa ha mofu le moropotso, khr na di ke ke tsa elwa hloko?
 - Ho ka etsahalang ha di ke ke tsa tsa elwa hloko?

3. Ho ke etsahalang ha mosadi wa mofu a ka se dumele mabapi le ho fumana moropotso?

Qetelo

1. Ke hantle ha ke o botsitse dipotso. E re ke etse feela kakaretso ya dihlooho tsa ditaba tseo ke di etseng hloko ha re ntse re buisana.
2. Selekela se kenyeletsang tsebo eo o nang le yona ho latela bohloko ba matshwafo le mokgwa o sebediswang ho buwa mofu.
3. Melawana e laolang moropotso le mekgwa ya ho sehwa ha mofu. Ho sehwa ha mofu ho letela dintlha tse latelang

- .Tumello ka kakaretso
- Seabo sa mosadi ho mosadi
- Lefu le ho shwa
- Botjhaba le ho ba bofifing
- Botjhaba le boleng tse amanang le lepato le ditho tsohle.
- Boemo ba phedisano
- Boemo ba dilemo
- Matla
- Tumelo

Ke leboha nako eo o nkadimileng yona mabapi le ho o botsa dipotso. Na ho na le se seng seo o nahanang hore se ka re thusa bakeng sa ho tseba tse ding tsa dintlha tse amanang le ho sehwa ha mofu le moropotso?

Ke nahana hore ke fumane dintlha tsohle tseo ke neng ke di hloka.

Ke a leboha.

Sehlomathiso sa 4- Kgutsufatso ya sekejule sa dipotso bakeng sa ho bokella dintlha.

Dintlha tsa bohlokwa

1. Lebitso, dilemo, kamano le mosebeletsi wa merafo boemong ditho tsa leloko
2. Sebaka moo o tswaletsweng teng
3. Lehae moo o dulang teng
4. Tatelano ya ba lelapa

Ho sebetsa morafong

Dipotso di re thusa ho tseba haholwanyane ka motho, nako eo motho a ka bang kotsing ka yona, ho e amahanya le molawana o itseng wa nako eo ho latela dintlha tse amanang le ditokelo tsa mosebetsi.

1. Hisitori mabapi le mosebeletsi wa morafong.
2. Maemong a mosebeletsi wa morafong ya seng a beile meja fatshe

Ke dintlha dife tseo o di fumaneng ha o ne o tlohela ho sebetsa morafong ho kenyeletsa le melawana e laolang merafo, ho sebetsa morafong, maemo a bophelo le dintlha tse amanang le phekolo.

1. Bakeng sa mosebeletsi wa morafong le mosebeletsi ya seng a beile meja fatshe-
Dilemo tseo a keneng sekolo ka tsona le moputso oo a o fumanang le oo a o fumaneng nakong eo a neng a beha meja fatshe.

Melawana ya meropotso

Bakeng sa hore ba leloko ba ka fumaneha bakeng sa moropotso tlasa Mafu a fumanwang ha motho a sebetsa Morafong le Melawana wa Mosebetsi, ditho tsohle tsa tshebetso ya pelo di tshwanela ho ntshuwa sebakeng seo mofu a hlakahaletseng ho sona mme ho tshwanela ho etswa ditokisetso tsa lepato tlasa tsamaiso ya Mokgatlo wa Mafu a fumanwang Mosebetsing (MBOD) kapa tlasa Mokgatlo wa Naha wa tsa Bophelo bo Botle wa Basebetsi (NIOH). Ditjeho ke tsa ho ntsha setho sa mme bakeng sa ho romelwa sebakeng se seng ditjeho ke tsa MBOD le NIOH e a di hlahloba e le ho hanana kapa ho dumellana le hore lefu le bakilwe ke bohloko ba matshwafo ebe ba romela repoto ho MBOD hore e e hlahlobe. Dipotso tse karolong ena di batla tsebo le kutwisiso le maikutlo mabapi le mokgwa wa tsamaiso le moropotso.

Ho sehwa

Ho sehwa ha motho ya hlokaletseng thutong ena ke tshebetso ya ho ntsha pelo le matshwafo sebakeng seo mofu a hlokaletseng ho sona le ho romela ditho tsena ho NIOH bakeng sa ho ya hlahlojwa. Setopo se bolokwa ntle le ditho tsena. Mosebetsi wa ho sehwa ke o hlokolotsi haholo mme o ka bontsha mafu a lokelang ho fumantshwa moropotso a ileng a se ke a bonwa ka x-ray ya sefubeng e ileng ya nkuwa nakong eo motho a sa phela. Dipotso karolong ena di hloka ho bontsha tsebo, kutlwisiso le maikutlo mabapi le mosebetsi wa ho sehwa, motjha o tshwanelang ho latelwa le ho etsa diqeto. ELA HLOKO dipotso tse ding di phetilwe ka sepheo ho fumana dintlha tse nepahetseng.

2. Maikutlo a hao ke afe mabapi le mokgwa ona wa tshebetso?
3. Na o ne o tseba ka ditsholetso tsena pele o tla kopanong ena?
4. tseba eng ka ho ntshuwa ha pelo le matshwafo ha mosebeletsi wa merafong?
5. Na ho na le motho eo o motsebang ya kileng a sehwa a ntsuwa pelo le matshwafo ntle le ho tsebisa ba leloko la hae?
6. Na ho na le malapa ao o a tsebang ao ba malapa a bona a kileng a sehwa kapa batho ba sebetsang morafong ba kileng ba dumela ba sa phela hore ditho tsa bona tsa mmele di tle di ntshuwe ha ba se ba hlokaletse?
7. Ka Sesotho ho na le polelo e reng 'Lentswe la mofu le ahelwa lesaka, se bolelang hore seo mofu a se boletseng se k eke sa fetolwa ha a se a hlokaletse.'

Tsebo ya melemo ya ho sehwa

- Ka Sesotho ho na le polelo e reng 'Lentswe la mofu le ahelwa lesaka e bolelang hore seo mofu a se boletseng ha a sa phela se ke ke sa fetolwa ha a se a hlokaletse.' Maikutlo a hao ke afe ka taba ena?

5Boemo ba phedisano

Ho na le maikutlo a hore batho ba se ba suthile mekgweng ya ditumelo tsa bona tsa kgale tsa ho dumela mafeela, tumelong le ho itshwarella ka tsa botjhaba mme ba se ba hlabolohile. Mohlala o ka etswang ke wa hore batho ba seng ba hlabolohile ke bona ba ka dumellanang le taba ya ho sehwa ka lebaka la hore ba tla fumantshwa moropotso.

Na ho na le kgonahalo ya hore le ha motho e mong a sa ntse a latela ditumelo tsa kgale tsa SeAforika, ba ka dumellana le taba ya ho sehwa hobane feela ba tla iphumanela tjhelete?

6.Boemo ba dilemo

Ho bile le ngangisano ya hore motho ka mong kapa dihlopha tse itseng tsa batho di kgethollwa ho latela boemo ba tsona ba dilemo le hore sena se ka boela sa laolwa ke boemo ba thuto eo motho a nang le yona, moputso oo a o fumanang le bokgoni boo a nang le bona. Maamong a basebeletsi ba merafo ba tswang dinaheng tse ka ntle, ho nnile ha ngangisanwa ka hore hobane batho ba batsho ba bangata ba ne ba sa amohelwe e le karolo ya basebeletsi ba ka nkuwang e le basebeletsi ba ka dinako tsohle, sena se ile sa etsa hore ho se be le ho dumellana ha hore mofu a sewe hore ho tle ho be le moputso o lefuwang.

1. Maikutlo a hao ke afe mabapi le taba ena?
2. Na boemo ba dilemo bo ka ba le tshwaetso e itseng mabapi le ho sehwa ha mofu kapa ho hananan le hona?
3. Hobaneng ho ka ba jwalo?
4. Ke maemo afe a lelapa a ka bang le tshwaetso mabapi le ho sehwa ha mofu kapa ho hanana le maikutlo a jwalo ho latela boemo ba dilemo?
5. Ha jwale mmuso o kgothaletsa menyetla e lekanang morafong bakeng sa banna le basadi.O nahana hore ho tla ba le phapang ho basebeletsi ba merafo ba batjha le ho moloko o motjha wa ba batsho wa ka nako e tlang le ba malapa a bona mabapi le ho dumellana le ho sehwa ha setopo kgahlalong le moloko wa kgale?
6. Ke hobaneng ha ba dumellana le ho sehwa kapa ba hanana le hona?
7. Ha o nahana ho hanana le ho sehwa kapa ho dumellana le hona ho na le kamano efe le boleng ba botjhaba ba Maaforika? Jwang?
8. Ha o nahana ke hobaneng batjha ba sekwalekwale(batjha ba ya merafong, ba reka matlo,ba dula le malapa a bona) ho ka ba le tshwaetso ho buuweng ha mofu le moropotso?

Matla

Ka matla a ho sehwa ho bolelwa bokgoni ba batho kapa sehlopha se itseng se laolang kapa se ka bang le tshwaetso diketsong tsa ba bang ka/ntle le ho ba kenyeletsa. Matla e ka ba bokgoni kapa ho hloka bokgoni diketsong tsa motho.Ketso ya ho sehwa e se e qadilwe le ho hlaloswa ke ODWMA jwalo ka ha e hlalositse dikarolong tse fetileng.

1. Maikutlo a hao ke afe mabapi le mokgwa oo ho sehwa ho etswang kateng le ODMWA?

2. Haeba ho ne ho na le ho hong ho tshwanelang ho matlafatswa molawaneng o itseng le mokgwa wa tsamaiso o sebediswang, e ne e ka ba ofe?
- Maikutlo a hao ke afe mabapi le hore ditho tsa mmele tsa mofu di romelwa Johannesburg
- Haeba ho na le ho hong ho tshwanelang ho ntlafatswa mabapi le MBOD e ka ba hofe?
- Maikutlo a hao ke afe mabapi le matla ao lelapa le nang le ona mabapi le tshebetso ena ya ho sehwa?

Na malapa a na le matla mabapi le ho sehwa ha mofu?

- Na o na le matla a ho hana hore wa leloko a buuwe? O kopuwa ho hlalosa.
- Ke mang ya tshwanelang ho etsa qeto mabapi le ho sehwa ha mofu?

Tumelo

Ho na le ditumelo tse ngata tsa botjhaba tse ka hlalosetswang ba ka sehloohong ba tsamaiso mabapi le ho hlokahala le lefu, dipotso di hloka ho fumana dintlha le hore di ka amahangwa jwang le ho sehwa le moropotso o fumanwang.

1. Ke badile lesedinyana le leng morao tjena le hlalosang hore, re “batho ba itimeletsang lefu” khr ho sehwa le ho etsa ditlhophiso tsa lefu re ntse re phela mme ha re/ kapa bao re ba ratang ba kula ha ho na mabaka a bonolo a mangata a fapaneng.
2. Ha o nahana e ka ba ka mabaka afe?
3. Na ho sehwa ha mofu le moropotso ho ka buisanwa ka tsona le motho ya hlokahalang kapa le ba lelapa?
- Ho etsahalang ka monna ya nang le mosadi?
- Ke mang ya tshwanelang ho etsa diqeto tsa hore ho sebetswe jwang?

Tumelo e ka hlaloswa e le ditlwaelo tsa setjhaba, tse kenyeletsang ho tsitlallela ditumelong tsa botjhaba le badimo kapa dingolwa tsa botjhaba, hisitori ha mmoho le tumelo ya motho ka mong.

1. Maikutlo a hao ke afe mabapi le polelo ena?
2. Maikutlo a hao ke afe mabapi le ho ntshuwa ha ditho tsa mofu le ho patwa ha setopo se se nang ditho tse ding?
3. Na tumelo e ka ba tshita kapa ya ba yona e kginang ho ntshuwa ha ditho tsa mofu?
4. Tshitiso e ka ba efe ha motho a behella tumelo ya hae thoko?

5. Na tumelo ya motho e a fetoha ha a tloha sebakeng sa mahaeng a fallela sebakeng sa ditoropong.

Ho shwa le lefu

Ho na le ditumelo tsa bosetjhaba tse laolang ho shwa le lefu, dipotso di batla ho fumana dintlha le hore di ka ba le kamano jwang le ho sehwa le moropotso. Ke badile lesedinyana le leng morao tjena le hlalosang hore, re “batho ba itimeletsang lefu” khr ho sehwa le ho etsa ditlhophiso tsa lefu re ntse re phela mme ha re kapa bao re ba ratang ba kula ha ho na mabaka a bonolo a mangata a fapaneng.

1. Ha o nahana e ka ba ka mabaka afe?
2. Na ho sehwa ha mofu le moropotso ho ka buisanwa ka tsona le motho ya hlokahalang kapa le ba lelapa?
3. Ho etsahalang ka monna ya nang le mosadi?
4. Ke mang ya tshwanelang ho etsa diqeto tsa hore ho sebetswe jwang?

Botjhaba le ho ba bofifing

Ho na le ditumelo tsa botjhaba tse ka hlaloswang ke ba tsamaiso ya ditaba tsa batho ba lilelang wa habo bona ya seng a hlokahetse le kamano e teng ya hlokahetseng le meya ya badimo ba hae. Dipotso di batla ho fumana hore dintlha tsena di na le kamano efe le ho sehwa ha mofu le moropotso.

1. Ke utlwetse hore ho na le ditumelo tse fapaneng tsa botjhaba bo fapaneng ba Maaforika ho latela mekgwa eo ba ilang ka teng empa ka kakaretso ho na le tshwano e itseng mabapi le ho ila le ho boloka mofu.
2. Ho bolelwang ka botjhaba mabapi le nako ya ho ilela mofu?
3. Sena se ka ama puisano mabapi le ho ntshuwa/ho se ntshuwe ha ditho tsa ya hlokahetseng? Ho ka etsahalang ha di ke ke tsa tsa elwa hloko?
4. Ho ke etsahalang ha mosadi wa mofu a ka se dumele mabapi le ho fumana moropotso?

Qetelo

Ke hantle ha ke o botsitse dipotso. E re ke etse feela kakaretso ya dihlooho tsa ditaba tseo ke di etseng hloko ha re ntse re buisana.

1. Selelekela se kenyeletsang tsebo eo o nang le yona ho latela bohloko ba matshwafo le mokgwa o sebediswang ho sehwa mofu.

2. Melawana e laolang moropotso le mekgwa ya ho sehwa mofu
3. Ho sehwa ha mofu ho letela dintlha tse latelang
 - Tumello ka kakaretso
 - Seabo sa mosadi ho mosadi
 - Lefu le ho shwa
 - Botjhaba le ho ba bofifing
 - Botjhaba le boleng tse amanang le lepato le ditho tsohle.
 - Boemo ba phedisano
 - Boemo ba dilemo
 - Matla
 - Tumelo

Ke nahana hore ke fumane dintlha tsohle tseo ke neng ke di hloka.

Ke a leboha.

Appendix 5: Zulu translation Isithasiselo 2(b): Uhlelo lokuxoxisana: Amalungu omndeni abasebenzi basezimayini abashonile

AV Banyini – Inombolo yomfundi: 3708309A

Ukuvula

Igama lami ngingu-Audrey Banyini. Ngingumfundi wasenyuvesi ofundela iziqu zebanga eliphakeme ezicwaninga ngokuhlinzwa kwezidumbu ukuthola imbangela yokufa kanye nesinxephezelo esitholakalayo. Ngiye ngabona ukuthi kuyoba ngumbono omuhle ukuba ngixoxisane nawe njengoa ngizwe kuthiwa ulahlekelwe ngumuntu omthandayo obesebenza ezimayini. Ukuthi ungubani kanye nekheli lakho akuzukuvezwa embikweni ozokwenziwa.

Ingxoxo kumele ithathe imizuzu ethi ayibe ngama-60. Uyatholakala ukuzoqala manje ngengxoxo?

Ngizosebenzisa isiqophamazwi (itheyiphu), ngifingqe ukuthi ngikuzwisisa kanjani okushoyo, futhi ngikuvumele ukuthi ulungise noma yini eshiwo nguwe noma yimi ukugwema amaphutha okungazwisisani.

Ingxoxo izokwenziwa ngolwimi lwakho lwasekhaya. Ukhuluma luphi ulimi ekhaya?

Isingeniso: *Imininingwane ethintene nokwazi ngomuntu nendawo akuyo*

1. Njengoba sengizazisile , lesi siqephu sibalulekile ukuze ngazi ngawe khona ngizokwazi ukubuza imibuzo efanelekile.
2. Igama lakho ungu?
3. Uhlalaphi?
4. Usunesikhathi esingakanani uhlala kuleli kheli?
5. Lena yiyona ndawo owazalelwa kuyo?
6. Abazali noma omkhulu bakho nabo bazalelwa kule ndawo?
7. Uhlobene kanjani nomufi?

Ukusebenza ezimayini kwesihlobo sakho

Umsebenzi wesihlobo sakho ezimayini ubukade uyini?

Isiqephu esilandelayo sihlose ukuthola ulwazi isihlobo esinalo ngomlando wokusebenza kukamufi ezimayini nangokushona kwakhe, kufaka phakathi nenqubo elandelwe yokwaziswa ngako. Sihlose nokuthola ulwazi ngezimali ezamukelwayo ezingaba izimali ezitholwa lapho kushone umuntu kanye nesinxephezelo esisalindelwe esikhokhwa ngenxa yezifo noma ukulimala okwenzeka ngenxa yomsebenzi.

1. Ubeneminyaka emingaki uma eshona?
2. Ushone kanjani?
3. Ngubani obesondelene naye, ngokobuhlobo bomndeni ngubani owaba ngowokuqala ukuthintwa ngako?
4. Ngubani owakwazisa?

5. Waziswa kanjani?
6. Kwakuyini imbangela yokufa?
7. Ngubani owakwazisa ngembangela yokufa?
8. Yinmiphi eminye imininingwane owanikwa yona?
9. Mayelana nezimali, isinxephezelo, ukuqhaqhwa kwesidumbu ukuthola imbangela yokufa

Uma ukushona kwenzeke ekhaya

Lesi siqephu sihlose ukuzuza ukuzwisisa ngokusebenzisa ulwazi isihlobo esinalo ngezimbangela zokushona ezingahle zibe zixhumene ngokuqondene ngqo noma ngokungaqondene kulokho ohlangabezana nako emsebenzini okungahle kwenzeke ukuthi umuntu lowo oyisisebenzi wayazisiwe ngazo, izinqubo okufanele zilandelwe ezingahle zixhunyaniswe nokuqhaqhwa komzimba ukuthola imbangela yokufa, kanye nokuthi ngabe izihlobo ziyayifunda yini imibhalo kamufi ukuthola wonke amaphuzu angahle ahambelane nemali (imali etholakala ngokushona komuntu, izimali ezikhokhwa ngumshuwalense, isinxephezelo, njll.). Eminye imibuzo iphindwa ngenhloso ibekwe ngenye indlela ukuze kuqinisekise ukufanana kwalokho okushiwo.

1. Wagcina nini ukusebenza?
2. Ubeyekisiwe yini ukusebenza ezimayini?
3. Zazi yiny izizathu zokuyekiswa kwakhe?
4. Ngubani owakwazisa ngokuyekiswa kwakhe?

Yini enye owawutshelwe ngayo? isib.: ukuyekiswa umsebenzi ngenxa yokugula okuphathelene nesifo sofuba (i-TB), isifo esihlasela amaphaphu ngenxa yezinto ezakungena ezinjengothuli (i-silicosis), isimo sempilo engeyinhle, ukuphela komsebenzi noma ukuxoshwa)

1. Ngokubona kwakho ngabe ubegula kakhulu noma ngabe isimo sakhe saba ngcono waze wakwazi ukubuyela emsebenzini?
2. Ngabe kukhona eminye imininingwane axoxa ngayo nawe ngaphambi kokushona kwakhe?
3. Mayelana nempilo yakhe esesezimayini?
4. Kwakuyini?
5. Mayelana nokushona kwakhe.
6. Yisiphi isifo esimbulele?

7. Ngabe washonela ekhaya? Uma uthi yebo.
8. Ngubani owaqinisekisa ukuthi ushonile ngempela futhi ngubani owasusa isidumbu ekhaya?
9. Ngabe umuntu owaqinisekisa ukuthi ushonile waxoxa yini nawe ngamalungelo abasebenzi basezimayini mayelana nomthetho? (NB for researcher to be explored further later? Kwakuyimaphi lawo malungelo?
10. Uma ngabe uthi qha, washonela kuphi? Uma ngabe washonela kwenye indawo engesona isibhedlela, imibuzo mayilandele leyo engenhla.
11. Uma ashonela esibhedlela
12. Ngubani owakwazisa ngokushona kwakhe?
13. Ngabe imininingwane yokugula kwakhe ibihambelana nalokho obukubona ngempilo yakhe?

Ngabe abasebenzi bezempilo baxoxa nawe ngamalungelo abasebenzi basezimayini mayela nomthetho? (NB for researcher to be explored further later)

1. Kwawuyimaphi lawo malingelo?
2. Ngabe ucabanga ukuthi imbangela yokufa ithintene yini nokushona kwesihlobo sakho? Kungani ucabanga ukuthi kunjalo noma akunjalo?

Uma ukufa kwenzeka ngesikhathi esasebenza

Imibuzo kuhloswe ngayo ukuzwisisa ulwazi isihlobo esinalo ngenqubo yokuqhaqhwa kwesidumbu ukuthola imbangela yokufa ngaphansi kwe-ODWMA.

1. Ngubani owakwazisa ngokufa kwesihlobo sakho?
2. Waziswa kanjani ngokushona lokho?
3. Waba ngowokuqala yini ukuthintwa ngako?
4. Ngubani omunye oyesihlobo owathintwa ngako?
5. Ungakhumbula yini ukuthi kwenzakalani ngemuva kwalokho; kuze kube yilapho kungcwatshwa lowo omthandayo?
6. Ungakhumbula ukuthi yini enye owayitshelwa? isib.: ukuthi ukuqhaqhwa kwesidumbu ukuthola imbangela yokufa, kuphoqelekile, ukuze ukwazi ukufaka isicelo sesinxephezelo esitholakala umuntu eseshonile?
7. Ngubani owakutshela?

8. Waphatheka kanjani ngalo mbiko?
9. Wavuma yini ukuthi kuqhaqhwe isidumbu ukuthola imbangela yokufa?
10. Uma uthi yebo
11. Yini eyayikukhuthaza ukuthi uvume?
12. Waba nohambo oluya emayini yini, futhi ngubani owakhokhela uhambo? (NB: to establish whether relative was with the deceased at time of death - qiniseka ukuthi ngabe isihlobo sasikanye nomufi yini ngesikhathi sokufa)
13. Wawunawo yini amandla okuvuma kuqhaqhwe isidumbu ukuze kutholakale imbangela yokufa noma kwaboniswana nawe namanye amalunga omndeni kuqala?
14. Uma ngabe wabonisana nabanye, wabazisa emuva kwesikhashana noma wakhetha ukukugcina kuyimfihlo? Uma ngabe ukuqhaqhwa kwesidumbu ukuze kutholakale imbangela yesifo kwagcinwa kwaba yimfihlo, kwakunaziphi izizathu zalokho?
15. Uma uthi qha, yini eyakhuthaza ukwenqaba lokho?
16. Ngabe elinye ilungu lomndeni lakuvumela ukuqhaqhwa kwesidumbu ukuthola imbangela yokufa?
17. Uma ethi yebo
18. Yini eyakhuthaza ukuvuma lokho?

Baba nohambo oluya ezimayini? (NB: to establish whether relative was with the deceased at time of death or works at mines, i.e readily available - qiniseka ukuthi ngabe isihlobo sasikanye nomufi yini ngesikhathi sokufa.noma ngabe sisebenza ezimayini, okusho ukuthi sasitholakala kalula)

1. Ngabe leli lungu lomndeni lalinawo amandla okuvuma ukuqhaqhwa kwesidumbu ukuthola imbangela yokufa noma labonisana nawe namanye amalunga omndeni kuqala?
2. Uma uthi qha, yini eyakhuthaza ukwenqaba lokho?

Umthetho wezinxephezelo

Ukuze izihlobo zikwazi ukuthola isinxephezelo ngaphansi koMthetho Wezifo Ezivela Ngenxa Yomsebenzi Ezimayini Nasemisebenzini (i- Occupational Diseases in Mines and Works Act (i-ODMWA)), izitho zikamufi zenhliziyo nezokuphefumula kufanele zisuswe lapho eshonele khona. Kufanele kwenziwe amalungiselelo ne-Medical Bureau for Occupational Disease (i-MBOD) noma ne-National Institute for Occupational Health (i-

NIOH). Izindleko zokususwa kwezitho nokuhanjiswa kwazo zithwalwa yi-MBOD kuthi i-NIOH izihlole ukuze isho ukuthi izifo zamaphaphu ezibangwa ngumsebenzi azikho noma zikhona bese idlulisela umbiko kwi-MBOD ukuze uyohlolisiswa. Imibuzo ekulesi siqephu ihlose ukuthola ukwazi, ukuqondisisa kanye nendlela izinto ezibukwa ngayo ngale nqubo eyenziwayo nangesinxephezelo.

1. Nhloboni yesincephezelo oyaziyo?
2. Ngubani owakwazisa ngemithetho?
3. Waziswa kanjani ngayo?
4. Wazi kangakanani ngesincephezelo esikhokhwa ngenxa yesifo samaphaphu esinikezwa ngesihlobo noma okushadwe naye osebenze ezimayini?
5. Kufanele kwenziweni ukuze kuzuzwe kumthetho wezincephezelo?
6. Ngumndeni?
7. Yiziphi izindlela okufanele zilandelwe?
8. Ngaphambi kokushona kwesihlobo sakho, ubukade wazi ngesifo samaphaphu esivela ngenxa yomsebenzi owenziwayo?
9. Yiziphi?
10. Ngubani owakwazisa?
11. Waziswa kanjani?
12. Wawutsheliwe yini ukuthi umuntu kumele enzeni?
13. Ubusuke wezwa nge-MBOD?
14. Ingobani?
15. Ngubani okwazisile?
16. Uma ingaziwa, umcwaningi makayichaze
17. Ubusuke wezwa nge-NIOH
18. Ingobani?
19. Ngubani owakwazisa?
20. Uma ingaziwa, umcwaningi makayichaze
21. Ngabe uyazi yini ngoMthetho Wezifo Ezivela Ngenxa Yomsebenzi Ezimayini Nasemisebenzini (i- Occupational Diseases in Mines and Works Act)?
22. Uma uthi yebo, uyini?
23. Uwaze kanjani?
24. Uma uthi qha umcwaningi makachaze

25. Ikhona eminye imithetho oyaziyo ehambelana nezimayini?

26. Uma kungenjalo yishaye indiva

Uma uthi yebo funa ukuqonda ukuthi ixhumana kanjani ne-ODMWA futhi unike incazelo uma kudingeka. Lokhu kubalulekile ukuze kucaciswe ngenqubo elandelwayo ngokuqhaqhwa komzimba ukuz ekutholakale imbangela yokufa uma kwenzeka kuba nokudideka.

1. Ngokubana kwakho i-ODMWA nezinqubo okuxoxwe ngazo ziyabasiza yini abasebenzi basemayini noma imindeneni yabo?

Ukuqaphelisa umcwanjngi: Imibuzo lapha ifuna ukuqonda uma ngabe i-ODMWQ, i-MBOD ne-NIOH zibonakala njengezilusizo yini. Ngaphezu kwalokho kwethenjwa ukuthi kungahle kuvele imiqondo engahle ihambisane nezithikamezo noma izinsiza eziqondene nensizakalo yokuqhaqhwa kwesidumbu ukuthola imbangela yokufa.

2. Uma kunjalo, zilusizo kanjani?
3. Ukhona omaziyo owasizakala ngazo?.
4. Lwaluyini usizo lolo?
5. Waze kanjani ngosizo lolo?
6. Uma uthi qha, kungenxa yazihi izizathu?
7. Ucabanga ukuthi kungenziwani ukuzenza zibe lusizo.?
8. Yini ocabanga ukuthi ingenziwa ukuzenza zibe lusizo?
9. Ngubani ofanele akwenze lokho?

Inqubo yokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa?

Inqubo yokuqhaqhwa komzimba ekulolu cwaningo ibhekise ekhukhishweni kwenhliziyo namaphaphu endaweni yokufa zithunyelwe ku-NIOH ukuze ziyohlolwa ngokuphathelene nesayensi yezifo. Umzimba ungawatshwa ngaphandle kwezitho lezo. Imibuzo ekulesi siqephu ifuna ukuthola ukuthi kukhona ulwazi yini, ukuqondisisa nendlela yokubuka izinto maqondana nokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa, inqubo elandelwayo ngokuqhaqhwa lokho nokuthathwa kwezinqumo.

Inqubo yokuqhaqhwa komzimba ukuthola imbangela yokufa ihlanganisa ukukhishwa kwenhliziyo namaphaphu nokungawatshwa komuntu ngaphandle kwamaphaphu.

1. Ucabangani ngale nqubo?

2. Ngokuqonda kwakho iyini?
3. Ngabe ubuwazi ngalokhu okwenziwayo ngaphambi kokufa kewsihlobo sakho?
4. Ungasho ukuthi lokhu okwenziwayo kungaba lusizo emindenini yabasenzi basezimayini?
5. Kungaba lusizo kanjani noma kungabi lusizo kanjani emndenini?
6. Wazini ngokukhiswa kwenhliziyo namaphaphu?
7. Zithunyelwaphi izitho?
8. Ziyabuyiswa ukuze zingcwatshwe?
9. Kuzokwenzakalani emndenini uma umuntu engangcwatshwa ngaphandle kwezitho?
10. Kuzokwenzakalani kumufi uma umngcwabo ungaba khona ngaphandle kwezitho?
11. Ngubani onikeza imvume ngokukhishwa kwezitho?
12. Kumuntu oshonele esibhedlela sazezimayini?
13. Kumuntu oshonele esibhedlela sika wonkewonke?
14. Kumuntu oshonele ekhaya?
15. Ukhona omaziyo owaqhaqhwa umzimba ukuze kutholakale imbangela yokufa ngaphandle kokwaziswa komndeni?
16. Kwenzakalani?
17. Ukhona imindenini oyaziyo eyasebenzisa insizakalo yokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa?
18. Ivela kuso isigodi sangakini?
19. Kwenzakalani kuyo?
 - Yasizakala?

NgesiSuthu kunesho esithi 'lentswe la mohu ga le tselwe' uma liguqulelwa esiZulwini lithi 'amagama kamufi awanakuguqulwa lapho eseshonile'.

1. Ucabangani ngalokhu?
2. Yini enganza umndenini uhloniphe noma ungahloniphi amazwi kamufi, futhi wenqabe ukuqhaqhwa komzimba ukuze kutholakale imbangela yokufa?
3. Yini oyibona njengendima kankosikazi noma umama ekuthatheni isinqumo ngokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa?

Okwenzeka ekuhlalisaneni kwabantu

Kunenkolelo yesimanje yokuthi abantu ngokubanzi sebeqhelile kumasiko abo enkolelo yesintu asekelwe ekukholelweni emandleni angaphezu kwalawo umuntu anawo, enkolweni kanye nasezinkambisweni ekukudala zikhona futhi sebekwazi ukubuka izinto ngeso elikwazi ukucubungula izinto. Isibonelo singenzeka sokuthi labo ababuka izinto ngeso elikwazi ukucubungula bazokholelwa kwinqubo yokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa ngenxa yokuthi kungenzeka bathole isinxephezelo.

1. Uphawula uthini ngalokhu?
2. Kungenzeka yini ukuthi noma ngabe umuntu esawalandela amasiko esintu, uzokuvumela ukuqhaqhwa komzimba ukuze kutholakale imbangela yokufa, ngoba efuna ukuzuza imali?

Amazinga akhona ekuhlalisaneni kwabantu

Sekuke kwaphikiswana ngokuthi abantu noma amaqembu ehlukani noma ngokwamazinga okuhlaliswana ngawo futhi lokhu kunganqunywa ngokwemfundo, imali engenayo nengcebo. Ohlelweni lwabantu abahamba bayosebenza ezimayini, kuye kwaphinda kwashiwo ukuthi ngenxa yokuthi abasebenzi abaningi babengakaze bemukelwe njengezinga labantu abasebenza isikhathi esingenakunqamuka, lokhu kungahle kube kuqhamuke nomphumela wokungemukeleki kokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa ukuze kunikezwe isinxephezelo.

1. Uphawula uthini ngalokhu?
2. Ngabe izinga umuntu akulo kwezokuhlalisana lingaba nomthelela ekwemukelweni noma ekwenqatshweni kokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa?
3. Kungani lokhu kungaba njalo?
4. Yini engenza isimo sezimali somndeni womuntu sibe nomthelela ekuvumeni noma ekwenqabeni ukuqhaqhwa komzimba ukuze kutholakale imbangela yokufa uma siqhathaniswa nesikhundla umuntu anaso ngokwezinga abekwa kulo kwezokuhlalisana emphakathini?
5. Kungaba nezinye izizathu ezikhona yini ohlelweni lokubekw akwabantu ngokwamazinga ezingabanga noma zingabangi ukuvuma ukuqhaqhwa komzimba ukuze kutholakale imbangela yokufa?

Njengamanje uhulumeni uphakamisa amathuba alinganayo asezimayini kubo bonke abasha besilisa nabesifazane. Ucabanga ukuthi kuzoba khona umehluko kulusha nakuzizukulwane ezinsundu zesikhathi esizayo zabasebenzi basezimayini nemindeni yabo ekwamukeleni inqubo yokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa uma kuqhathaniswa nesizukulwane esidala?

1. Kungani bengavuma noma bengenqaba inqubo yokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa?
2. Ucabanga ukuthi ukwenqaba noma ukuvuma kunobudlelwane noma yibuphi namagugu namasiko esintu? Kanjani?
3. Ngabe ucabangani ukuthi ukuphendukela kwezesimanje (abantu abasha bangena ezimayini, bathenga izindlu, bahlala nemindeni yabo) kuzoba nomthelela muni kwinqubo yokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa nasenhlawulweni?

Amandla

Amandla angachazwa njengekhono labantu noma lamaqembu lokulawula noma lokuba nomthelela ezezweni zabanye ngokuthola ukubambisana nabo noma ngaphandle kwako. Amandla angaba yinsiza noma yisithikamezo kokwenziwa ngabantu. Inqubo yokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa isisunguliwe futhi yachazwa ku-ODMWA njengoba kuchaziwe eziqeshini ezingenhla.

1. Uyini umbono wakho mayelana nenqubo yokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa nange-ODMWA?
2. Ngabe umthetho unamandla okufeza lokho obukuhlosile, okungukunikeza imindeni yabashonile ukusizakala okungavela esinxephezelweni esingaba khona? Uyacelwa ukuthi uchaze wenabe ngemibono yakho.
3. Uma bekukhona obekungahle kwenziwe ngcono kumthetho nakuzinqubo, uma kukhona, kungaba yini?
4. Ungaphawula uthini mayelana nokuthunyelwa kwezitho eJohannesburg?

Ngabe i-MBOD njengeziphathimandla zolwazi kwezempilo inamandla noma yimaphi okufeza ebikuhlosile, okungukunikeza imindeni yabashonile ukusizakala okungavela okungavela esinxephezelweni esingaba khona? Uyacelwa ukuthi uchaze wenabe ngemibono yakho.

1. Ungasho ukuthi le nqubo iyazifeza izinhloso zayo zokufukula labo abasele ngemuva empilweni futhi ngenxa yalokho inikeze isinxephezelo esihle? Uyacelwa ukuthi uchaze.
2. Uma kungaba khona noma yini edinga ukwenziwa ngcono kwinqubo ye-MBOD kungaba yini?
3. Ungaphawula uthini mayelana namandla abomdeni nenqubo yokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa?
4. Abomndeni banawo yini amandla mayelana nokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa?
5. Mandla mani futhi kungani benawo?
6. Ngabe kwenqaba ukuvuma ukuqhaqhwa komzimba ukuze kutholakale imbangela yokufa?
7. Kungaba hlobo luni lwamandla lolu?
8. Lawa mandla angaqiniseka kanjani ukuthi abomndeni bathole isinxephezelo lapho bekufanele khona?
9. Ngubani ofanele ukuthatha isinqumo ngenqubo elandelwayo?

Ngunkosikazi?

- Kungani lokhu kufanele kube njalo?
- Omkhulu wabomndeni?
- Kungani lokhu kufanele kube njalo?

Ukuhambisana kwezokuhlalisana

Ukuqaphelisa umcwaningi: Lokhu ngokwalabo abemukela ukuqhaqhwa komzimba ukuze kutholakale imbangela yokufa. Kuye kwashiwo ukuthi izinsiza kwezempilo nezokwelashwa kufanele zibhekisise ukuhlolwa kwamasiko okuphathelene nezindlela zokuxhumana, indlela okubukwa ngayo indawo ekhona kubandakanya nokuthi umuntu uphila kanjani nabanye ngokwezokuhlalisana (ikhasimende) nokuthi lokhu kuchazwa kanjani yilowo muntu.

1. Ungakhumbula ukuthi ingxoxo yokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa yenziwa kanjani ngesikhathi sokushonelwa kwakho? Uma ethi yebo, qhubeka.
2. Ungasho yini ngemuva kokuba sekwenzekile ukuthi indlela inqubo eyachazwa ngayo nesicelo semvume kwakuhambelana namasiko nezinkolelo zakho eziyigugu ngesikhathi sokushonelwa? Chaza
3. Kukhona okunye okufika emqondweni wakho mayelana nenqubo yonke ofuna ukuxoxa ngako?
4. Uma ngabe ukhona noma yimuphi umlayezo ufuna ukuwudlulisa ongahle uphucule isimo sokuhlolwa kwezamasiko nezokwelashwa, ungaba yimuphi?

Ezenkolo

Kunenkolelo kumasiko engaguqukelwa ekuphathweni kwamashonayo nokufa. Imibuzo ihlose ukubuza ngezingqinamba nokuthi mhlawumbe zingaxhumana kanjani nokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa nokunxeshezwa. Ngisanda kufunda ukuthi njengabantu, 'singabaphikisi bokufa', okusho ukuthi ukuxoxa nokuhlela ukufa kwethu nalaho thina noma labo esibathandayo begulela ukufa akulula ngenxa yezizathu ezahlukahlukene.

1. Ucabanga ukuthi yiziphi izizathu ezingahle zibe khona?
2. Ngabe ukuqhaqhwa komzimba ukuze kutholakale imbangela yokufa nesinxephezelo kuyakwazi ukudingidwa nomuntu oshonayo kanye/noma nomndeni wakhe?
3. Kwenzakalani ngendoda enonkosikazi?
4. Ngubani okufanele athathe isinqumo ngenqubo elandelwayo?

Ukufa nokushona

Kukholelwa ekuthini ukuba mbaxambili okuphakathi komzimba nomphefumulo njengenkolelo yokuba khona kwempilo ngemuva kokufa kuyavunywa ukuthi kuyemukelwa ngamanye amasiko nezinkolelo zabansundu baseNingizimu Afrika.

1. Imibono yakho ngesitatimente. Ngabe ukukhiswa kwesitho somzimba kungaba nomthelela ekubeni mbaxambili komuntu?
2. Yini engahle yenzeke uma izitho zikhishwe ngaphandle kokwazi noma yikuphi komndeni?

3. Maqaondana nomqondo wokuba mbaxambili komuntu:Ngabe kulesi simo isinxephezelo sizokwenqatshwa? Kungani?

Amasiko nokuzila

Kukhona izinkolelo zamasiko ezingahle ziguqulelwe ekulawulweni kokuzilela abashonile kanye nobudlelwane obungahle bube khona ngempilo elandela ukushona kanye nemimoya yabashonile. Imibuzo ihlose ukuthola ukuthi ngabe zonke lezi zingqinamba zingahle ziba namthelela muni ekuqhaqhweni komzimba ukuze kutholakale imbangela yokufa nasekunxeshezeleni.Ngiye ngezwa ukuthi kukhona amasiko esintu ahlukene dngamele ukuzila kodwa ngokubanzi kunokufanayo ekuzileni nasekungcwabeni.

1. Kuqondweni ngesiko ngaleso sikhathi sokuzila?
2. Lokhu kungaba nomthelela kanjani engxoxweni emayelana nokuthi zingasuswa noma zingasuswa izitho?
3. Ngabe ayini amandla okufaneleka kwawo mayelana nokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa nesinxephezelo?
4. Kungenzakalani uma lokhu kunganakwa?
5. Kungenzakalani uma unkosikazi engakunaki lokhu okufanele kwenzeke ngenxa yokuthi angahle athole isinxephezelo?

Isiphetho

Hhayi-ke, kubonenwe kwaxoxwa nawe. Mangifingqe ngamafuphi izindikimba engizibonile ngesikhathi sengxoxo yethu.Isingeniso esifaka ulwazi ngokuhlangana nothuli okumayelana nesifo samaphaphu esivela ngenxa yomsebenzi nenqubo yokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa.Imithetho ekhishwayo ngezinxephezelo nezinqubo zokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa.

1. Inqubo yokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa mayelana nalokhu
2. Ukuvuma ngokubanzi
3. Indima kankosikazi
4. Ukufa nokushona
5. Isiko nokuzila
6. ‘Amagugu’ amasiko axhumene nokuthi umuntu angcwatshwe nazo zonke izitho.

7. Amazinga akhona ekuhlalisaneni kwabantu
8. Okwenziwayo ekuhlalisaneni kwabantu
9. Amandla
10. Inkolo

Ngiyabonga ngesikhathi osithathile sale ngxoxo. Ngokucabanga kwakho kukhona okunye okungaba lusizo kimi engifanele ngikwazi khona ngizophumelela ekuzwisiseni izingqinamba ezimayelana nokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa nezinxephezelo?

Kufanele ukuthi ngiyitholile yonke imininingwane engiyidingayo

Ngiyabonga kakhulu

Appendix 6: Recording consent form

Title: Utilisation of autopsy services for posthumous monetary compensation among black mine workers in South Africa. From the participatory information discussed, I am requesting to record and take notes of the interview and discussions. The reasons for recording and or note taking are to enable me to summarise and enhance the quality of our interview and discussion later on. The report and summary to the University will be codified to protect your identity. The recorded tapes will only be for my use to write the study and I will only use the recordings ones for this purpose. Upon the University accepting my thesis, I will destroy the tapes. You are under no obligation to agree to the discussion being recorded and can decline to be recorded. We will proceed with the interview and I will take notes should you agree.

If you agree to the recording before the tape is switched on, may we now go straight to the first part of the introduction on the interview schedule, followed then by codenaming you using your initials, thereafter switching on the tape to recode our interview?

I, agree voluntarily to be recorded during this interview

Signed.....

Name.....

Date.....

Appendix 7: Participant information statement

I,, agree to voluntarily participate in the research project

Title: Utilisation of autopsy services for posthumous monetary compensation among black mine workers in South Africa

In giving my consent I acknowledge that:

The information on the research, the process and procedures including the time involved for participation have been explained and discussed with me and on the information sheet.

The participant information statement has been explained to me, and I have had the opportunity to discuss the information and my involvement in the project with the researcher.

I also read the participant information statement (), tick if it is the case.

I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher, now or in the future.

I understand that I can withdraw from the study at any time, without affecting my relationship with organisations managing the benefit medical examination and compensation.

I understand that my involvement is strictly confidential and no information about me or my relatives, living or dead will be used in any way that reveals my identity or theirs

Signed.....

Name.....

Date.....

Appendix 8: Participant consent form

Introduction:

Thank you for agreeing to spend some few minutes while I explain the study to you. My name is Audrey Banyini.

Title of my study is: Utilisation of autopsy services for posthumous monetary compensation among black mine workers in South Africa.

Who is carrying out the study?

The study is being conducted by myself, Audrey Banyini, currently employed by the Mine Health and Safety Council for the past 2 years, as a programme manager of the Occupational Health Technical Advisory Committee (OHTAC), that oversee the occupational and health research in the mining industry. My professional background is being a mine medical doctor for 15 years, and the director for the Medical Bureau for Occupational Diseases for 4 years. However, the purpose of this study is for Study with the University of the Witwatersrand under the supervision of Prof Leah Gilbert.

What is the study about?

In terms of the Occupational Diseases in Mines and Works' Act (ODMWA), anyone who suspects that the deceased had occupational lung disease, even if death was not caused by it, can request an autopsy examination. This involves taking the cardiorespiratory and sending them to Johannesburg. For the past 30 years, the number autopsy utilisation among black mine workers is declining. The study concerns finding out barriers or acceptance on autopsy examination for the purpose of compensation. You have been selected as a participant because of (i) **your background on having been a employed as a mineworker,** (ii) **you are currently working as a mine worker or** (iii) **you have lost a family member who was a mineworker.** (Selection will be ticked with the right participant at the time.

What does study involve?

We will use your language of communication because I can speak all local South African languages. The study involves in-depth interviews using a questionnaire and the discussions will be taped recorded using a tape recorder for the purpose of capturing the discussion as this will ensure that what was discussed is referenced to correctly. Where necessary, notes may be taken to aid in listening to the tape.

How much time it will take?

The interview will take approximately 1 hour to complete. The total time allocated to complete all the study interviews is 3 months.

Can you withdraw from study?

Your participation in this study is completely voluntary and you are therefore under no obligation to consent. You can also withdraw at any time during the interview.

Will anyone else know the results?

All aspects of the study including results will be strictly confidential and on anonymous, and only myself and my supervisor will have access to the information on the participants. However, anonymity will be kept when results are published.

Who will benefit from the study?

The study will benefit me to obtain my Study.

Can you tell other people about the study?

Yes, anyone you think is affected or has been affected by autopsy examination services. If they are interested in participating in the study, they should contact me at 082 7851095.

What if you require further information?

If you would like to know more at any stage, please feel free to contact me at 011-656 1797 or 082 785 1095.

What if you have a complaint or concerns?

If you have any concerns or complaints about the conduct of this research, please contact the senior ethics Officer, University of the Witwatersrand 011- 717 1234

Appendix 9: Shortened -data collection interview schedule

1. Demographics
2. Name, age, relationship with the mineworker in cases of relatives
3. Place of birth
4. Current home
5. Family structure

Work in the mines

The questions help with knowing the person, the duration of risk exposure, link it to the amended act in the era of the rights to information

1. Labour history in case of mineworker
2. In case of retired mineworker
3. What information if any were you given when on leaving the mines including areas relating to law, exposures, adverse health impact and further medical surveillance
4. For both active and retired mineworkers-Years of schooling and salary on retirement or currently.

Compensation legislations

For the relatives to be eligible for compensation under the Occupational Diseases in Mines and Works Act, the deceased's cardio-respiratory organs should be removed at a place of death arrangements have to be made with the Medical Bureau for Occupational Disease (MBOD) or National Institute for Occupational Health (NIOH). The cost of organ removal and transportation is borne by MBOD and NIOH examines them to exclude or confirm occupational lung diseases and forward the report to MBOD for evaluation. The questions in this section seek to establish knowledge, understanding and attitude on this process and compensation.

Autopsy

The autopsy process in this study refers to the removal of heart and lung at site of death and sending them to NIOH for pathological examination. The body is buried without organs. The autopsy process is said to be more sensitive and can pick compensable diseases that have been missed with a chest x-ray taken during life. The questions in this section seek to establish knowledge, understanding and attitude on autopsy, autopsy process and decision making. NB: some questions are repeated purposeful to gain consistency of information provided.

1. What do you think of this process?
2. Were you aware about these services prior to this meeting?
3. What do you know of the removal of cardiorespiratory?
4. Are you aware of someone who had autopsy without knowledge of family?
5. Are you aware of families who used the autopsy services or mineworkers who agreed during life that the organs be removed?
6. In Sotho there is a saying that 'Lenstwe la mohu ga le tselwe' translated to English 'a dead man's words/instructions in life can't be changed when he's dead'.
7. Knowledge of autopsy benefits
8. In Sotho there is a saying 'Lenstwe la mohu ga le tselwe' which in ." translated to English 'a dead man's words/instructions in life can't be changed when he's dead'.
What do you think of this?

Social action

There is a modern belief that people in general have moved away from traditional beliefs grounded in superstition, religion and long standing customs and have become rational. An

example can be made that those that are rational will believe in autopsy process because of the possibility of receiving compensation-Is there a possibility that even if someone still follow African tradition, they will consent to autopsy because of monetary gain?

Power

Power can be referred as a capacity of people or groups to control or influence the actions of others with or without their cooperation. Power can be an enabler or disabler on human action. The autopsy process is has been already established and stipulated in ODMWA as discussed in the previous sections.

1. What are your comments with regards to the autopsy process and the ODMWA?
2. If there was anything that should be improved on the act and processes if any, what would that be?
3. What are your comments with regards to organs be sent to Johannesburg
4. If there was anything that required improvement on MBOD process what would that be?
5. What are your comments with regards to family power and the autopsy process?
6. Are the families having power with regards to autopsy?
7. Is declining consenting to autopsy some form of power to you? Please elaborate
8. Who should make decision on the procedure?

Religion

Religion can be defined as a set of beliefs and practices generally held by a community, involving adherence to codified and the study of ancestral or cultural writings, history, and, as well as personal

1. What are your comments on this statement?
2. What are your comments on this with regard to organ removal and burial of the body without them?
3. Can religion be a barrier or enabler for organ removal?
4. What will be the effect of an individual breaking away from the religion
5. Does one's religion changes when they move to urban areas

Death and dying

There are cultural beliefs that may translate to the management of the dying and death, the questions seeks to find out the issues and how they maybe a link with the autopsy and compensation. I read recently that as human beings, we are 'death denying', i.e. discussing and planning our death in life and when we or our loved ones are terminally ill is not easy for various reasons.

1. What do you think maybe the possible reasons?
2. Can an autopsy and compensation be discussed with a dying person and or his family?
3. What happens in a case of a man with a wife?
4. Who should make decision on the procedure?

Culture and mourning

There are cultural beliefs that may translate to the management of mourning the dead and possible relationship with afterlife and ancestral spirits. The questions seek to find out how these issues maybe influencing autopsy and compensation. I heard that there are different African cultures surrounding mourning but in general there are similarity on mourning and burial.

1. What is meant by culture during mourning period? How can this influence the discussion on whether to remove or not to remove the organs?
2. What would happen if these are ignored?
3. What would happen if the wife ignores this due possibility of receiving compensation?

Conclusion

Well, it has been interviewing you. Let me briefly summarise the themes that I observed during our interview. I appreciate the time you took for this interview. Is there anything else you think would be helpful for me to know so that I can successfully understand issues surrounding autopsy and compensation? I should have all the information I need.

Thanks again

Appendix 10: Isithasiselo 4 – Isifinqo – Uhlelo lokuxoxisana olufingqiwe lokuqoqa imininingwaneImininingwane ethintene nokwazi ngomuntu nendawo akuyo

1. Igama, iminyaka, ubudlelwane nomuntu osebenza ezimayini uma kunezihlobo

2. Indawo yokuzalwa
3. Ikhaya okuhlalwa kulo manje
4. Ukwakheka komndeni

Ukusebenza ezimayini

Imibuzo isiza ekwazini umuntu, isikhathi esedlula ehlangene nokungaba yingozi, kukuhlanganise nomthetho osuguquliwe esikhathini samalungelo okunikezwa ulwazi.

Umlando womsebenzi uma kwenzeka kubasebenzi basezimayini.

Uma kwenzeka kumuntu osethathe umhlalaphansi osethathe umhlalaphansi.

Yimiphi imininingwane uma ubukade uyinikwe lapho ushiya ezimayini kanye nezingenxenye eziphathelele nomthetho, ukuhlangana nezinto ezithile, umphumela ongemuhle ngokwezempilo kanye nokunye ukuhlolwa okuye kwenziwa kwezokwelashwa Okwabo bobabili abasebenzi abasasebenza nasebathatha umhlalaphansi ezimayini – Iminyaka abayifundile esikhleni kanye neholo lapho bethatha umhlalaphansi noma manje.

Imithetho ekhishiwe ngezinxephezelo

Ukuze izihlobo zikwazi ukuthola isinxephezelo ngaphansi koMthetho Wezifo Ezivela Ngenxa Yomsebenzi Ezimayini Nasemisebenzini (i- Occupational Diseases in Mines and Works Act (i-ODMWA)), izitho zikamufi zenhliziyi nezokuphefumula kufanele zisuswe lapho eshonele khona. Kufanele kwenziwe amalungiselelo ne-Medical Bureau for Occupational Disease (i-MBOD) noma ne-National Institute for Occupational Health (i-NIOH). Izindleko zokususwa kwezitho nokuhanjiswa kwazo zithwalwa yi-MBOD kuthi i-NIOH izihlole ukuze isho ukuthi izifo zamaphaphu ezibangwa ngumsebenzi azikho noma zikhona bese idlulisela umbiko kwi-MBOD ukuze uyohlolisiswa. Imibuzo ekulesi siqephu ihlose ukuthola ukwazi, ukuqondisisa kanye nendlela izinto ezibukwa ngayo ngale nqubo eyenziwayo nangesinxephezelo.

Ukuqhaqhwa komzimba ukuze kutholakale imbangela yokufa

Inqubo yokuqhaqhwa komzimba ekulolu cwaningo ibhekise ekhukhishweni kwenhliziyi namaphaphu endaweni yokufa zithunyelwe ku-NIOH ukuze ziyohlolwa ngokuphathelele nesayensi yezifo. Umzimba ungawatshwa ngaphandle kwezitho lezo. Inqubo yokuqhaqhwa komzimba lokho kuthiwa iyezwela kakhudlwana futhi iyakwazi ukubona izifo ezibonelelwa

ngokunikezwa isinxephezelo okungenzeka ukuthi azibonakalanga ku-xray yesifuba ngesikhathi umuntu esaphia. Imibuzo ekulesi siqephu ifuna ukuthola ukuthi kukhona ulwazi yini, ukuqondisisa nendlela yokubuka izinto maqondana nokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa, inqubo elandelwayo ngokuqhaqhwa lokho nokuthathwa kwezinqumo. QAPHELA: eminye imibuzo iphindwe ngenhloso ukuze kube nokufana eminingwaneni enikeziwe.

1. Ngabe ucabangani ngale nqubo?
2. Ubuwazi yini ngalolu sizo ngaphambi kwalo mhlango?
3. Wazini ngokususwa kwenhliziyo namaphaphu?
4. Ngabe kukhona omaziyo owaqhaqhwa umzimba ukuze kutholakale imbangela yokufa ngaphandle kokwaziswa komndeni wakhe?
5. Uyazi yini ngemindeni esebenzise insizakalo yokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa noma abasebenzi basemayini abavuma besaphila ukuthi kukhishwe izitho zabo?
6. NgesiSuthu kunesho esithi 'lentswe la mohu ga le tselwe' uma liguqulelwa esiZulwini lithi 'amagama kamufi awanakuguqulwa lapho eseshonile'.
7. Ulwazi ngosizo olutholakala ngokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa.
8. NgesiSuthu kunesho esithi 'lentswe la mohu ga le tselwe' uma liguqulelwa esiZulwini lithi 'amagama kamufi awanakuguqulwa lapho eseshonile'.

Okwenziwayo ekuhlaisaneni kwabantu

Kunenkololo yesimanje yokuthi abantu ngokubanzi sebeqhelile kumasiko abo enkololo yesintu asekelwe ekukholelweni emandleni angaphezu kwalawo umuntu anawo, enkolweni kanye nasezinkambisweni ekukudala zikhona futhi sebekwazi ukubuka izinto ngeso elikwazi ukucubungula izinto. Isibonelo singenzeka sokuthi labo ababuka izinto ngeso elikwazi ukucubungula bazokholelwa kwinqubo yokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa ngenxa yokuthi kungenzeka bathole isinxephezelo

Okwenzeka ekuhlalisaneni kwabantu

Kunenkolelo yesimanje yokuthi abantu ngokubanzi sebeqhelile kumasiko abo enkolelo yesintu asekelwe ekukholelweni emandleni angaphezu kwalawo umuntu anawo, enkolweni kanye nasezinkambisweni ekukudala zikhona futhi sebekwazi ukubuka izinto ngeso elikwazi ukucubungula izinto. Isibonelo singenzeka sokuthi labo ababuka izinto ngeso elikwazi ukucubungula bazokholelwa kwinqubo yokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa ngenxa yokuthi kungenzeka bathole isinxephezelo.

1. Uphawula uthini ngalokhu?
2. Ngabe izinga umuntu akulo kwezokuhlalisana lingaba nomthelela ekwemukelweni noma ekwenqatshweni kokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa?
3. Kungani lokhu kungaba njalo?
4. Yini engenza isimo sezimali somndeni womuntu sibe nomthelela ekuvumeni noma ekwenqabeni ukuqhaqhwa komzimba ukuze kutholakale imbangela yokufa uma siqhathaniswa nesikhundla umuntu anaso ngokwezinga abekwa kulo kwezokuhlalisana emphakathini?

Njengamanje uhulumeni uphakamisa amathuba alinganayo asezimayini kubo bonke abasha besilisa nabesifazane. Ucabanga ukuthi kuzoba khona umehluko kulusha nakuzizukulwane ezinsundu zesikhathi esizayo zabasebenzi basezimayini nemindeni yabo ekwamukeleni inqubo yokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa uma kuqhathaniswa nesizukulwane esidala?

1. Kungani bengavuma noma bengenqaba inqubo yokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa?
2. Ucabanga ukuthi ukwenqaba noma ukuvuma kunobudlelwane noma yibuphi namagugu namasiko esintu? Kanjani?
3. Ngabe ucabangani ukuthi ukuphendukela kwezesimanje (abantu abasha bangena ezimayin, bathenga izindlu, bahlala nemindeni yabo) kuzoba nomthelela muni kwinqubo yokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa nasenhlawulweni?

Amandla

Amandla angachazwa njengekhono labantu noma lamaqembu lokulawula noma lokuba nomthelela ezeznweni zabanye ngokuthola ukubambisana nabo noma ngaphandle kwako. Amandla angaba yinsiza noma yisithikamezo kokwenziwa ngabantu. Inqubo yokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa isisunguliwe futhi yachazwa ku-ODWMA njengoba kuchaziwe eziqeshini ezingenhla.

1. Uyini umbono wakho mayelana nenqubo yokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa nange-ODMWA?
2. Uma bekukhona obekungahle kwenziwe ngcono kumthetho nakuzinqubo, uma kukhona, kungaba yini?
3. Ungaphawula uthini mayelana nokuthunyelwa kwezitho eJohannesburg?
4. Uma kungaba khona noma yini edinga ukwenziwa ngcono kwinqubo ye-MBOD kungaba yini?
5. Ungaphawula uthini mayelana namandla abomdeni nenqubo yokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa?
6. Abomndeni banawo yini amandla mayelana nokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa?
7. Ngabe ukwenqaba ukuvuma ukuqhaqhwa komzimba ukuze kutholakale imbangela yokufa?
8. Ngubani ofanele ukuthatha isinqumo ngenqubo elandelwayo?

Ezenkolo

Ezenkolo zingachazwa njengeqoqo lezinkolelo nezinkambiso ezilandelwa kabanzi ngumphakathi, ezibandakanya ukulandela imibhalo eyenziwe kanye nokucwaningwa kwemibhalo yezamadlozi noma yezamasiko, umlando kanye nokubhekene nomuntu uqobo.

1. Ungaphawula uthini ngalesi sitatimende?
2. Ungaphawula uthini ngalokhu mayelana nokukhishwa kwezitho nokungcwatshwa kwesidumbu ngaphandle kwazo?
3. Ngabe ezenkolo zingaba umsizi noma yisithikamezo ekususweni kwezitho?
4. Uyoba yini umphumela wokuthi umuntu aqembuke enkolweni yakhe?
5. Ngabe inkolo yomuntu iyaguquka yini lapho efudukela ezindaweni ezisemadolobheni? **Ukufa nokushona**

Kunenkolelo kumasiko engaguqukela ekuphathweni kwamashonayo nokufa. Imibuzo ihlose ukubuza ngezingqinamba nokuthi mhlawumbe zingaxhumana kanjani nokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa nokunxeshezela. Ngisanda kufunda ukuthi njengabantu, ‘singabaphikisi bokufa’, okusho ukuthi ukuxoxa nokuhlela ukufa kwethu nalaho thina noma labo esibathandayo begulela ukufa akulula ngenxa yezizathu ezahlukahlukene.

1. Ucabanga ukuthi yiziphi izizathu ezingahle zibe khona?
2. Ngabe ukuqhaqhwa komzimba ukuze kutholakale imbangela yokufa nesinxephezelo kuyakwazi ukudingidwa nomuntu oshonayo kanye/noma nomndeni wakhe?
3. Kwenzekani esimweni sowesilisa ononkosikazi?
4. Ngubani okufanele enze isinqumo ngenqubo elandelwayo?

Isiko nokuzila

Kukhona izinkolelo zamasiko ezingahle ziguqulelwe ekulawulweni kokuzilela abashonile kanye nobudlelwane obungahle bube khona ngempilo elandela ukushona kanye nemimoya yabashonile. Imibuzo ihlose ukuthola ukuthi ngabe zonke lezi zingqinamba zingahle ziba namthelela muni ekuqhaqhweni komzimba ukuze kutholakale imbangela yokufa nasekunxeshezeleni. Ngiye ngezwa ukuthi kukhona amasiko esintu ahlukene dngamele ukuzila kodwa ngokubanzi kunokufanayo ekuzileni nasekungcwabeni.

1. Kuqondweni ngesiko ngaleso sikhathi sokuzila? Lokhu kungaba nomthelela kanjani engxoxweni emayelana nokuthi zingasuswa noma zingasuswa izitho?
2. Kungenzakalani uma lokhu kunganakwa?
3. Kungenzakalani uma unkosikazi engakunaki lokhu okufanele kwenzeke ngenxa yokuthi angahle athole isinxephezelo?

Isiphetho

Hhayi-ke, kubonenwe kwaxoxwa nawe. Mangifingqe ngamafuphi izindikimba engizibonile ngesikhathi sengxoxo yethu. Isingeniso esifaka ulwazi ngokuhlangana nothuli okumayelana nesifo samaphaphu esivela ngenxa yomsebenzi nenqubo yokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa. Imithetho ekhishwayo ngezinxephezelo nezinqubo zokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa. Inqubo yokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa mayelana nalokhu

1. Ukuvuma ngokubanzi
2. Indima kankosikazi
3. Ukufa nokushona
4. Isiko nokuzila
5. 'Amagugu' amasiko axhumene nokuthi umuntu angcwatshwe nazo zonke izitho.
6. Amazinga akhona ekuhlalisaneni kwabantu
7. Okwenziwayo ekuhlalisaneni kwabantu
8. Amandla
9. Inkolo

Ngiyabonga ngesikhathi osithathile sale ngxoxo. Ngokucabanga kwakho kukhona okunye okungaba lusizo kimi engifanele ngikwazi khona ngizophumelela ekuzwisiseni izingqinamba ezimayelana nokuqhaqhwa komzimba ukuze kutholakale imbangela yokufa nezinxephezelo? Kufanele ukuthi ngiyitholile yonke imininingwane engiyidingayo

Ngisabonga futhi

Appendix 11: Ethics approval

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (NON-MEDICAL)

R14/49/1 Banyini

CLEARANCE CERTIFICATE

PROTOCOL NUMBER H070618

PROJECT

A sociological examination of factors influencing the utilisation of Autopsy services for posthumous monetary compensation for occupational lung disease among Black mine workers in South Africa

INVESTIGATORS

Ms AV Banyini

DEPARTMENT

Sociology

DATE CONSIDERED

07.06.15

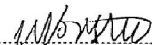
DECISION OF THE COMMITTEE*

Approved Unconditionally

NOTE:

This ethical clearance is valid for 2 years and may be renewed upon application

DATE

CHAIRPERSON..... 
(Professor M Vorster)

cc: Supervisor: Prof S Buhlungu
Sociology

DECLARATION OF INVESTIGATOR(S)

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

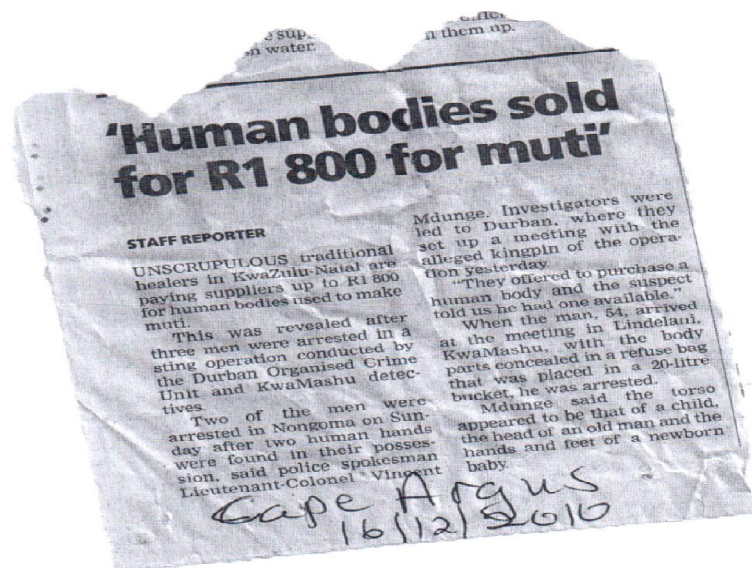
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. I agree to a completion of a yearly progress report.

Signature

This ethical clearance is valid for two years from date of approval.

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix 12: Media publication on muti killings



Appendix 13: Occupational Diseases in Mines and Works Act, 1973 (ACT No. 78 of 1973)

Definitions

‘benefit’ means money which has been awarded or which is required to be awarded or money which has been paid or which is required to be paid or the payment of money or a claim for the payment of money, as the context may require, to or in respect of a person or to or in respect of the dependants of a person, on the ground that such person was under the previous Act found to be suffering from pneumoconiosis or pulmonary pulmonary tuberculosis, or has under this Act been found to be suffering from a compensable disease, but does not include money awarded under the previous Act or this Act to a person in the form of a special grant or in the form of assistance in connection with the training of any person;

‘cardiorespiratory organs’ means all or any one of the following organs, namely larynx, trachea, bronchial tree, lung parenchyma, pleurae, lymphatic system of the lungs, vascular system of the lungs, nerve supply of the lungs, diaphragm and nerve supply to diaphragm, heart, pericardium and large intrathoracic bloodvessels;

‘Certification committee’ means the Medical Certification Committee for Occupational Diseases established under section 39;

‘Commissioner’ means the Compensation Commissioner for Occupational Diseases appointed under section 54 (a);

‘Compensable disease’ means- (a) pneumoconiosis;

(b) the joint condition of pneumoconiosis and pulmonary pulmonary tuberculosis which, in the opinion of the certification committee, was contracted while the person concerned was performing risk work,

or with which the person concerned was in the opinion of the certification committee already affected at any time within the twelve months immediately following the date on which that person performed such work for the last time;

(d) permanent obstruction of the airways which, in the opinion of the certification committee, is attributable to the performance of risk work;

*[Para. (d) substituted by s. 1(a) of Act 30 of 1978.]*e) any other permanent disease of the cardiorespiratory organs which in the opinion of the certification committee is attributable to the performance of risk work; or

(eA) progressive systemic sclerosis which, in the opinion of the certification committee, is attributable to the performance of risk work; or

[Para. (eA) inserted by s. 1 of Act 27 of 1974.]

(f) any other disease which the Minister, acting on the advice of a committee consisting of the director and not fewer than three other medical practitioners designated by the Minister, has, subject to the provisions of subsection (2), by notice in the Gazette declared to be a compensable disease and which, in the opinion of the certification committee, is attributable to the performance of risk work at a mine or works;

[Para. (f) substituted by s. 2 of Act 45 of 1975.]

[The Minister has in G.N. 1209 of June 1989 declared platinum salt sensitivity (platinosis) to be a compensable disease, with effect from 10 May 1989.]

‘Director’ means the Director of the Medical Bureau for Occupational Diseases appointed under section 3(1) (a);

‘Medical practitioner’ means a person who is registered as a medical practitioner under the Medical, Dental and Supplementary Health Service Professions Act, 1974 (Act 56 of 1974);*[Definition of ‘medical practitioner’ substituted by s. 1(i) of Act 208 of 1993.]*

‘Minister’ means the Minister for National Health and Welfare;

[Definition of ‘Minister’ substituted by s. 7(b) of Act 89 of 1988 and by s.1 (k) of Act 208 of 1993.]

‘pneumoconiosis’ means a permanent lesion, excluding a calcified lesion, of the cardio-respiratory organs caused by the inhalation of dust in the course of the performance of risk work;

[Definition of ‘pneumoconiosis’ substituted by s. 1(b) of Act 30 of 1978.]

‘previous Act’ means the Pneumoconiosis Compensation Act, 1962 (Act 64 of

1962), including the other laws repealed by section 136 of any laws relating to the payment of compensation to or in respect of persons in respect of miner's phthisis or silicosis or pneumoconiosis or pulmonary tuberculosis contracted in the employment of mines or as a result of employment at mines, which receded the Pneumoconiosis Compensation Act, 1962;

'risk' in relation to a mine or a works, means the risk of contracting a compensable disease, to which persons who perform risk work in or at or in connection with that mine or works are exposed, or the risk determined by the risk committee under section 20 or 21 in respect of that mine or works, as the context may require;

Ss 13(1)The Minister may by notice in the Gazette declare to be risk work any particular work or all work performed in or at or in connection with any mine or works or part of a mine or works, or at a particular place or under particular circumstances in or at or in connection with any mine or works.

(2) The Minister shall under subsection (1) declare any such work as is referred to in that subsection to be risk work if he is satisfied, after consultation with the risk committee and after consideration of such representations (if any) as may have been made to him by the owner of the mine or works in question or by any organisation acting on behalf of such owner or on behalf of persons employed at that mine or works, that any person performing the work in question is exposed to-

(a) dust of which the composition and concentration is such that it is of the opinion of the Minister harmful or potentially harmful; or

(b) gases, vapours or chemical substances, or factors or working conditions, which, in the opinion of the Minister, are harmful or potentially harmful.

S34

Duties of medical practitioner in regard to post-mortem examination or service

(1) The director may authorise or in writing direct any medical practitioner in the Republic to perform a post-mortem examination or other post-mortem service under this Act of a nature determined by the director, and a medical practitioner so authorised or directed who has performed a post-mortem examination or other post-mortem service in accordance with

such authorisation or direction, shall forthwith submit to the director a detailed report on the result of the examination or service performed by him.

(2) A medical practitioner in the Republic who attended a deceased person at the time of or immediately before his death, or has opened the body of a deceased person, and who knows or has reason to believe that such person worked at a mine or works, shall remove the cardiorespiratory organs and any other prescribed organs or parts of the body of the deceased and shall send such organs and parts of the body to the prescribed place or, if no place has been prescribed, to the bureau or to any other place specified by the director, in accordance with the prescribed procedure or, if no procedure has been prescribed, in accordance with such instructions as may be issued by the director.

(3) 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.

Chapter IV

Certification of compensable diseases

S39

Establishment and constitution of certification committee

(1) There shall be established a committee, to be called the Medical Certification Committee for Occupational Diseases, which shall exercise the powers and perform the functions conferred upon or assigned to it by this Act.

(2) The certification committee shall consist of the director and not less than three or more than five other members to be appointed by the Minister, who shall be medical practitioners and of whom, subject to the provisions of subsection (4)-

(a) one shall be a medical practitioner whose name has been submitted to the Minister in terms of that subsection by the owners of controlled mines and controlled works or by an organisation or organisations qualified, in the opinion of the Minister, to act on behalf of such owners; and

(b) one shall be a medical practitioner whose name has been so submitted by an organisation or organisations qualified, in the opinion of the minister, to act on behalf of persons who

perform risk work at controlled mines or controlled works.

S44

Degrees of compensable diseases

(1) For the purpose of this Act a person shall be deemed to be suffering from a compensable disease in the first degree-

(a) in the case of pneumoconiosis, if the certification committee has found that he is suffering from pneumoconiosis, whether or not it has impaired his cardiorespiratory functions, and the certification committee has found a resultant permanent disability of more than 10 per cent but not more than 40 per cent;

(b) in the case of a compensable disease referred to in paragraph (d) of the definition of “compensable disease” in section 1 (in this section referred to as “the definition”), if the certification committee has found that he is suffering from such a disease and the certification committee has found a resultant permanent disability of more than 10 per cent but not more than 40 per cent; (c) in the case of a compensable disease referred to in paragraph (c), (e), (eA) or (f) of the definition, if the certification committee has found that he is suffering from such a disease which has permanently impaired his ability to perform his ordinary work by more than 10 per cent but by not more than 40 per cent;

[Sub-s. (1) substituted by S. 14(a) of Act 208 of 1993]

(2) For the purposes of this Act a person shall be deemed to be suffering from a compensable disease in the second degree-

(a) if the certification committee has found that he is suffering from more than one compensable disease simultaneously which together have permanently impaired his ability to perform his ordinary work by more than forty percent, or that he is suffering from pulmonary tuberculosis and another compensable disease simultaneously

(b) in the case of pneumoconiosis, if the certification committee has found that he is suffering from pneumoconiosis which has permanently impaired his cardiorespiratory functions by more than 40 per cent;

(c) in the case of a compensable disease referred to in paragraph (d) of the definition, if the certification committee has found that he is suffering from such a disease which has permanently impaired his cardiorespiratory functions by more than 40 per cent

(d) in the case of a compensable disease referred to in paragraph (e) of the definition, if the certification committee has found that he is suffering from such a disease which has

permanently impaired his ability to perform his ordinary work by more than 40 per cent
(e) in the case of a compensable disease referred to in paragraph (f) of the definition, if the certification committee has found that he is suffering from such a disease which has permanently impaired his ability to perform his ordinary work by more than 40 per cent
(f) in the case of a compensable disease referred to in paragraph (c) or (eA) of the definition, if the certification committee has found that he is suffering from such a disease which has permanently impaired his ability to perform his ordinary work by more than 40 per cent

Appendix 14: Pathology standards for autopsy examination and compensation in terms of the occupational diseases in mines and works act 1998

Identification of the specimen must be checked by comparing names and numbers on the booklet, aluminium tags and plastic bags.

Sections for microscopic examination as follows:

- | | |
|-----------------------|--------------------|
| 1. Main bronchus | 5. Right lower |
| 2. Hilar lymph glands | 6. Left upper lobe |
| 3. Right upper lobe | 7. Left mid zone. |

4. Right middle lobe 8. Left lower

Heart (including both myocardium and coronary artery) can be included.

**ALL CASES OF CANCER OF LUNG, TRACHEA, LARYNX AND
MESOTHELIOMA (ANY SITE):**

- 1) Additional sections of normal lung (in 1 cassette) and tumour (in a separate cassette).
- 2) Tissue for electron microscopic asbestos fibre typing and counting - from the upper, mid and lower zones of the uninvolved lung - 3cu cms., to include the pleura. This to be submitted to the EM unit with the name, MBOD no, P no, date of examination and pathologist.

Histologic stains:

1. Bronchus - alcian blue, aldehyde HE Glands - aldehyde HE
2. Lungs - aldehyde HE, alcian blue
3. Zn and Grocott's, Reticulin where indicated
4. Mesothelioma - immunohistochemical confirmation

SILICOSIS

1. Alveolar proteinosis. Other causes to be excluded.
2. Dust reticulation with/without collagenisation is recorded but not quantified.
3. Nodular silicosis - a nodular interstitial lesion which is distributed around small blood vessels and respiratory bronchioles. There is concentric collagenisation. Silicotic plaques can be found in relation to the pleura and islets may also be present in parenchymal lymph glands.

Quantify islets as follows:

- occasional 1 - 4
- few 5 - 14
- moderate 15 - 30
- large number >30

Nodules (islets), pleural plaques and silicotic parenchymal lymph nodes are all counted and added together.

Silicotic lesions in the regional lymphglands are not accepted as indicating pneumoconiosis.

Massive fibrosis - coalescent silicotic islets forming a focus of fibrosis 2cm or more in diameter. Zones of diffuse fibrosis and active/inactive pulmonary tuberculosis may be present in the lesion. The maximum diameter of the lesion/s and location must be recorded.

CERTIFICATION

1st degree - moderate / large number of islets

- massive fibrosis where the sum of the lesions is >5cms

2nd degree - alveolar proteinosis

MIXED DUST PNEUMOCONIOSIS

Is distinguished from silicotic islets by the extension of the fibrosis into the alveolar walls. The collagenisation need not be concentric.

COAL WORKERS PNEUMOCONIOSIS

1. Simple coal worker's pneumoconiosis (macules) - an interstitial lesion distributed around respiratory bronchioles composed of coal dust and collagen, with or without focal emphysema
2. Massive fibrosis - black masses of coal dust 2cm or more in diameter. Collagen need not be present. The maximum diameter and location of the lesion/s must be recorded in the additional comments section.
3. Rheumatoid coal pneumoconiosis - interstitial nodules (0.5 to 2cm diameter) showing concentric layering of coal dust. Quantify as for silicosis.

ASBESTOS RELATED DISEASE

Asbestosis - asbestos bodies associated with interstitial fibrosis.

Quantify:

1. Slight - fibrosis confined to the respiratory bronchioles and adjacent alveoli.
2. Moderate - extension of the fibrosis

3. Marked - widespread fibrosis with only a few recognisable alveoli.

Asbestotic plaques

Circumscribed areas of dense acellular collagen with a basket weave appearance. Plaques may be present on the parietal or visceral pleura, diaphragm and pericardium. The diameter of the largest plaque - as greater or less than 5cm - must be recorded. Also record if the plaques are densely calcified.

1. Diffuse pleural fibrosis - cellular fibrosis involving the parietal pleura, visceral pleura or interlobar fissures which measures 5cm or more in diameter. This finding must be recorded in the additional comments section.
2. Lung, laryngeal and tracheal cancer - histological types: squamous, adeno, small cell, large cell, bronchioloalveolar.
3. Mesothelioma - pleural, peritoneal, pericardial. The histological subtype must be recorded.

Certification

1. 1st degree - moderate asbestosis
 - Asbestotic plaques in sum >5cm which are not heavily calcified
 - diffuse pleural fibrosis >10mm thick and in sum > half the pleural surface
2. 2nd degree - marked asbestosis:
 - (i) diffuse pleural fibrosis >10mm thick and in sum > half the pleural surface with the opposite lung showing some evidence of asbestos associated pathology
 - (iii) Lung, laryngeal, tracheal cancer with a history of asbestos exposure
 - (iv) Mesothelioma (any site) with a history of asbestos exposure.

EMPHYSEMA

Emphysema may be panacinar, centrilobular, focal, and irregular. The severity is assessed visually or by gridcounting of a whole lung section if available.

Quantify:

1. Insignificant degree: less than 35%
2. Moderate degree: between 35% and 65%
3. Marked degree: over 65%

Certification:

1. 1st degree - moderate

2. 2nd degree - marked

The results of lung function tests within 2 year of death take precedence over the pathology findings. There must be at least 10 years high dust service and at least 20 years low dust service. Certification is only considered within 10 years of leaving service.

CHRONIC BRONCHITIS & CHRONIC BRONCHIOLITIS

Because of great problems with tissue preservation, and because clinico-pathological studies have shown that the pathological assessment of these diseases does not contribute over and above emphysema this and will no longer be used for certification. These items should however still be recorded in the booklet.

ACTIVE PULMONARY PULMONARY TUBERCULOSIS

Granulomatous inflammation with caseous necrosis, epithelioid histiocytes and Langhans giant cells, with or without acid fast bacilli. In some circumstances not all of the above features may be present. Applies to lesions in the lung parenchyma and bronchi, wall of a cavity, pleura, pericardium and hilar lymph glands. The presence of fibro-caseous and miliary disease, tuberculous bronchopneumonia and cavities is recorded. The extent of disease must be recorded. Record presence of acid fast bacilli if ZN stain positive.

Pulmonary pulmonary tuberculosis quantified as follows:

1. insignificant - focal lesion involving <10% of lung
2. moderate - lesion involving 10-40% of lung
3. marked - >40% of lung volume obliterated

2nd degree certification:

1. moderate and marked pulmonary pulmonary tuberculosis
2. miliary and bronchopneumonic pulmonary pulmonary tuberculosis
3. tuberculous pericarditis
4. pulmonary pulmonary tuberculosis of any severity in the lungs and lymph nodes **plus** any other certifiable disease (eg emphysema, silicosis in the 1st degree)

NB severe chronic pulmonary pulmonary tuberculosis: those cases where there is extensive destruction of the lung (ie a cause of death) but where activity may not be

found. Record such cases on an individual basis.

Where certifiable pulmonary tuberculosis is the only disease present then compensation is only awarded if risk work was > 1 year duration (in shifts) and if deceased died within one year of ceasing risk work. If there is pulmonary tuberculosis with any other certifiable disease there are no time limits.

Additional comments

Booklet amendments:

1. Pleura: to silicotic pleural plaques
2. Lungs: the pigmented zones are fibrotic and are aggregated in
3. Pulmonary tuberculosis: change insignificant to focal
4. Add in a section on certification findings
5. Review CWP

Basis for compensation:

5. <10% disability = NCD ie presence of disease is recorded but no compensation
6. 10 - 40% disability = 1st degree
7. >40% disability = 2nd degree
8. Massive fibrosis: in life <1/3 vs >1/3 of lung tissue affected. Detail extent of involvement. Heart: it is important to note right ventricular hypertrophy as this indicates to the committee an increased disability and may be used to upgrade compensation.

Asbestosis: it is important not to overdiagnose. Diffuse pleural thickening: not simply adhesions! Tuberculous pericarditis: a section of heart must be taken if this is mentioned clinically. Other pneumoconioses: eg mica, are dealt with on an individual basis